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80% OF CHILDREN WITH PDD-NOS HAVE SEVERAL CO-MORBID PSYCHIATRIC DISORDERS

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INTRODUCTION

A diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) applies when an individual fails to meet specific criteria for autistic disorder or another explicitly defined pervasive developmental disorder (PDD), but has similar difficulties in social interaction, reciprocal communication, and/or stereotypical behavior (APA, 1994). These difficulties may be milder or of different quality than those seen in autistic disorder (Towbin, 1997). Like children with autistic disorder, children with PDD-NOS may have stereotyped interests, preoccupations, or limitations in imaginative play, although such features may also be mild or even absent. And also in contrast with autistic disorder, PDD-NOS does not have to be associated with a language deficit (Towbin, 1997).

DSM-IV (APA, 1994) provides 12 explicit criteria for autistic disorder, divided over the domains of social interaction, communication, and stereotyped interests and repetitive behaviors. A child must display at least six criteria for a diagnosis of autistic disorder to be assigned. For a DSM-IV diagnosis of PDD-NOS, criteria are not explicit and are somewhat ambiguous. No specific items or scoring algorithms are provided. As a consequence, children with PDD-NOS may have different combinations of symptoms (Walker et al., 2004) and therefore constitute of a very heterogeneous group. Buitelaar, Van der Gaag, Klin, and Volkmar (1999) developed more standardized research criteria for PDD-NOS that differentiated reliably between PDD-NOS and non-PDD children. These explicit criteria are used in the current study.

Studies that provide information on the prevalence rates of PDD-NOS often fall short of strict diagnostic criteria, and assessment procedures differ per study and change over time, which makes prevalence rates difficult to compare (Fombonne, 1999). As Wing and Potter (2002) pointed out, prevalence rates of all types of PDDs in recent studies seem considerably higher than in older studies. Recently, Chakrabarti and Fombonne (2001) suggested that PDD-NOS is at least twice as common as autistic disorder in the general population and that this substantial group may have similar treatment needs as the autistic group (Fombonne, 1999). The paradox is that, although PDD-NOS may be much more common, the disorder is much less frequently studied than autistic disorder (Volkmar & Lord, 1998).

Despite the high prevalence, knowledge about psychiatric co-morbidity patterns associated with PDD-NOS is hardly available. Knowledge about specific types of co-morbidity that occur frequently with PDD-NOS would be useful to efficiently focus clinical assessment. Such additional symptoms may cause considerable distress, interfere markedly with daily functioning, and may respond favorably to treatment. For instance, pharmacotherapy can play a role in treatment of co-morbid attention and hyperactivity problems, may be helpful in reducing anxiety, aggression and obsessive preoccupations (e.g., Keen & Ward, 2004; Santosh & Baird, 2001), but has a limited effect on improving social communication deficits in PDDs (Tanguay, 2000). Medication is also beneficial for reducing these interfering co-morbid symptoms, and may subsequently facilitate effective application of treatments, such as behavioral intervention (McDougle, Stigler, & Posey, 2003). Early use of behavioral interventions in children with PDD may lead to reductions of aggression, tantrums, and self-injurious behavior up to 80-90% (e.g., Horner, Carr, Strain, Todd, & Reed, 2002; Iwata et al., 1994).

Knowledge of co-morbidity patterns in PDD-NOS may also enhance further research regarding subtypes of PDD-NOS. For instance, PDD-NOS that is associated with specific types of co-morbidity, such as anxiety or mood disorders, may have different genetic or neurobiological correlates, may differ with respect to prognosis, or may warrant different treatment approaches than, for instance, PDD-NOS with co-morbid disruptive behavior disorders.

Some studies investigated co-morbidity between PDD-NOS and symptoms of Attention-Deficit/-Hyperactivity Disorder (ADHD) in school-aged children. However, exact data on rates of ADHD in children with PDD-NOS are not available. This may be partly related to the priority rules of DSM-IV, which only permit the use of a co-morbid ADHD classification when the symptoms do not occur during the course of any PDD (APA, 1994). Therefore, it seems nearly impossible to simultaneously apply a classification of both PDD-NOS and ADHD. Luteijn, Serra et al. (2000) compared 5 to 12 year old children with PDD-NOS (*n* = 190) and with ADHD (*n* = 152), from an outpatients' clinic for child and adolescent psychiatry. Classifications of PDD-NOS and ADHD were based on DSM-IV criteria (APA, 1994). Parents filled out the

Child Behavior Checklist 4-18 (CBCL; Achenbach, 1991). It was found that average scores of the PDD-NOS group on the CBCL Attention Problems scale equaled those of the ADHD group. Hence, this study indicated that co-morbid attention problems seemed to occur frequently in children with PDD-NOS.

To the present authors' knowledge no data are available about the co-morbidity of PDD-NOS and other externalizing disorders such as Oppositional-Defiant Disorder (ODD) or Conduct Disorder (CD). Gilmour, Hill, Place, and Skuse (2004) showed a substantial co-morbidity of PDD in children with CD, but no conclusions could be drawn about the reverse: rates of co-morbid CD in children with PDD-NOS.

Muris, Steerneman, Merkelbach, Holdrinet, and Meesters (1998) investigated the prevalence of co-morbid anxiety disorders in children with autistic disorder (n = 15) and PDD-NOS (n = 29), aged between 5 and 14 years. Classification of PDD-NOS or autistic disorder was based on DSM-III-R criteria (APA, 1987). All children had undergone extensive psychological and psychiatric screening, and a multidisciplinary team of professionals of the Center of Autism assigned the diagnoses. Co-morbid anxiety disorders were investigated using the Diagnostic Interview Schedule for Children-Parent version 2.3 (DISC-P; Shaffer et al., 1996). Results indicated that 84.1% of the children met diagnostic criteria for at least one anxiety disorder. The most common anxiety disorder was simple phobia (63.3%), and the least frequent anxiety disorder was panic disorder (9.1%), although panic attacks occurred regularly (56.8%). Furthermore, 11.4% of the children met diagnostic criteria for obsessive compulsive disorder (OCD). Some anxiety disorders (e.g., simple phobia, separation anxiety disorder, avoidant disorder, and overanxious disorder) were significantly more prevalent among children with PDD-NOS than among children with autistic disorder. The sample size of this study was small, which limits its generalizability. Further, diagnosis of PDD-NOS was not based on standardized assessment.

Further information regarding the co-morbidity of psychiatric disorders in children with PDD-NOS would be very useful for clinical and research purposes. Therefore the aim of this study was to investigate psychiatric co-morbidity patterns in school-aged children with PDD-NOS.

METHOD

Participants

Participants were 94 children, 6 to 12 year old, who fulfilled PDD-NOS research criteria (age range 6; 5 – 12; 11 years, M = 8.5, SD = 1.9, 88.3% boys; n = 83, and 11.7% girls; n = 11). All patients visited the outpatients' department of child and adolescent psychiatry, Erasmus Medical Center Rotterdam, the Netherlands. Co-morbidity was assessed with the DISC-IV-P (Shaffer, Fisher, & Lucas, 1998). Subsequently, subgroups of PDD-NOS children with different co-morbid disorders were compared on measures of severity of PDD related social contact and communication problems (i.e., Autism Diagnostic Observation Schedule-Generic [ADOS-G]; Lord, Rutter, DiLavore, & Risi, 1999; Children's Social Behavior Questionnaire [CSBQ]; Luteijn, Jackson, Volkmar, & Minderaa, 1998; Luteijn, Minderaa, & Jackson, 2002).

All consecutive referrals between July 2002 and September 2004 (n = 503) were screened for the presence or absence of a PDD-NOS research diagnosis. One hundred and eight children met sufficient criteria for a research diagnosis of PDD-NOS and were therefore eligible to participate in the study. Two of them were excluded due to parental language difficulties. A further nine parents refused to take part in the DISC-IV-P assessment, and three children were excluded because of severe neurological or physical problems (e.g., blindness). This yielded 94 children with a research diagnosis of PDD-NOS for whom reliable DISC-IV-P data were available.

Assessment

PDD-NOS research criteria

In the current study, a diagnosis of PDD-NOS was based on explicit research criteria. Buitelaar et al. (1999) compared children with clinical diagnoses of autistic disorder (n = 205), PDD-NOS (n = 80), and non-PDD diagnoses such as mental retardation and language disorders (n = 174) on the 12 criteria for autistic disorder. Both ICD-10 (WHO, 1993) and DSM-IV (APA, 1994) classification systems were used. They found that a short set of seven criteria, derived from the 12 original criteria for autistic disorder, discriminated best between the PDD-NOS group and the group of non-PDD children. These seven items were divided over the domains of social interaction (four items), communication (two items), and stereotyped interests and repetitive behavior (one item). To diagnose PDD-NOS, at least three items had to be present including at least one social interaction item, and the child should not meet criteria for autistic disorder or other types of PDD.

Child psychiatrists, registrars, and psychologists supervised by child psychiatrists rated the research criteria. Twenty-four different raters were involved. Rating was based on assessment of early development through current level of social, communicative, and adaptive functioning, obtained from semi-structured interviews carried out with the parent(s) or caretaker(s) as well as psychiatric observation of the

child in a one-to-one situation. School and relevant medical information was obtained, as well as psychological assessment information. Immediately after all diagnostic procedures were finished, a multidisciplinary team obtained consensus with regard to the final DSM-IV (APA, 1994) classification, and PDD-NOS research criteria were rated subsequently.

We carried out an interrater reliability study on 30 randomly selected children (32%). Two clinicians independently rated all the PDD-NOS research criteria. Agreement between the raters on the presence or absence of a PDD-NOS diagnosis was moderate to good (κ = .62, 80.77% agreement). Further, we computed a score for the total number of PDD-NOS criteria rated positive by each rater for each child. The correlation between these scores by the two raters was high (Spearman's rho = .79), indicating excellent agreement (Cichetti & Sparrow, 1981).

DISC-IV

The Dutch version of the DISC-IV (Ferdinand & Van der Ende, 1998; Shaffer et al., 1998) is a highly structured respondent based interview to assess DSM-IV Axis I psychiatric disorders in the past year, in children and adolescents. The DISC-IV has a parent version (DISC-IV-P) for parents of children aged 6 to 17, and a child version (DISC-IV-C) to be administered to children aged 11 to 17. In this study, the DISC-IV-P was used to assess anxiety disorders, mood disorders, schizophrenia, and disruptive behavior disorders. DISC-IV diagnoses are solely based on parent reports about the presence or absence of symptoms. Clinical observations of the interviewer are not used.

The complete Dutch DISC-IV (Ferdinand & Van der Ende, 1998) contains just fewer than 3000 questions of which around 10% are considered 'stem' questions that are always asked. The stem questions are concerned with broad symptom descriptions and are designed to lead to false-positive answers. Subsequently, there are many 'contingent' questions that are asked if a stem question is answered positively. Contingent questions assess whether symptoms meet the intensity, frequency, and duration criteria as specified by DSM or ICD classification systems. Thus, the contingent questions improve the accuracy of the stem questions (Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000). To obtain a Dutch version of the DISC-IV, the original American version was translated into Dutch, and then translated back by an independent translator. Subsequently, the original version and the back translation were compared by the developers of the original version at Columbia University New York, as well as by the Dutch translators, after which the translation was adapted.

Studies of earlier versions of the DISC-P have shown good test-retest and interrater reliability (Schwab-Stone et al., 1993; Shaffer et al., 1993; Shaffer et al., 1996). The DISC-IV showed moderate to good reliability (Shaffer et al., 2000). Psychometric properties of the Dutch DISC-IV are not available yet.

In this study, psychologists, research assistants, and psychology undergraduate students (supervised by psychologists) had all been trained by the authors of the Dutch DISC-IV (Ferdinand & Van der Ende, 1998) who, in turn, had been trained as trainers at Columbia University New York by the authors of the original DISC. The interviewers were blind to any other diagnostic information about the child. In 69.1% (n = 65) of the cases the mother of the child has been interviewed, in 5.3% (n = 5) the father, in 24.5% (n = 23) both parents, and in 1.1% (n = 1) a different caretaker has been interviewed.

WISC-R

The Dutch version of the Wechsler Intelligence Scale for Children-Revised (WISC-R; Van Haasen et al., 1986; Wechsler, 1974) was administered. As the original version, the Dutch version has shown sufficient reliability and validity. The WISC-R generates a Full Scale Intelligence Quotient (FSIQ), a Verbal Intelligence Quotient (VIQ), and a Performance Intelligence Quotient (PIQ) (M = 100, SD = 15). For 95.7% (n = 90) of the children WISC-R data were available. FSIQ varied between 55 and 120 (M = 91.22, SD = 17.43). PIQ varied between 49 and 129 (M = 92.84, SD = 18.90), and VIQ varied between 51 and 122 (M = 91.57, SD = 16.60). For four children WISC-R could not be administered due to mental retardation (n = 2), hearing problems (n = 1), and insufficient knowledge of the Dutch language (n = 1).

ADOS-G

The ADOS-G (Lord et al., 1999) provides a standardized context to observe PDD related behaviors in the domains of social interaction, communication, and stereotyped behavior. In this study, subgroups of PDD-NOS children with different co-morbid disorders were compared on the subscales Reciprocal Social Interaction (i.e., eye contact) and Communication (i.e., stereotyped language) of the ADOS-G. These two subscales have shown high reliability and validity. The diagnostic algorithm of the ADOS-G allows classification of participants as having autistic disorder or ASD. The distinction between the categories depends on symptom severity. For 93.6% (n = 88) of the children in this study ADOS-G data were available. An ADOS-G classification of autistic disorder was assigned in 10.2% (n = 9) of the cases, and a further 47.7% (n = 42) had an ADOS-G classification of ASD. The remaining 42.1% (n = 37) received

scores that were below the threshold for an ASD classification. Six children were unable (i.e., severe communication deficits) or unwilling to take part in the ADOS-G assessment.

CSBQ

The CSBQ (Luteijn et al., 1998; Luteijn et al., 2002) is a 49-item parent questionnaire that covers a wide range of PDD features of a child in the past two months. The items refer to problem behaviors seen in children with milder variants of PDD (Luteijn, Luteijn, Jackson, Volkmar, & Minderaa, 2000). The score format is 'does not apply' (score 0), 'sometimes or somewhat applies' (score 1), or 'clearly or often applies' (score 2). The items are divided over six subscales, referring to Behaviors not tuned to situation (e.g., Doesn't know when to stop), Withdrawn (e.g., Acts as if others are not there), Orientation problems in time, place, or activity (e.g., Easily gets lost), Difficulties understanding social information (e.g., Does not understand jokes), Stereotyped behavior (e.g., Flaps arms/hands when excited), and Fear of and resistance to changes (e.g., Opposes change).

Psychometric properties of the CSBQ have been studied in a large Dutch sample (n = 3407) (Hartman, Luteijn, Serra, & Minderaa, in press). Three types of reliability were studied. Cronbach's α (based on n = 3407), that reflects internal consistency was good (α = .94 for total score, and between .76 and .90 for the subscales). Intraclass Correlation Coefficients (ICC), reflecting interrater reliability (mother versus father information) was good (ICC = .86 for total score, and between .75 and .89 for the subscales). Further, test-retest reliability (interval of approximately four weeks) was good as well (r = .90 for total score, and between .80 and .88 for the subscales) (Hartman et al., in press).

For 97.9% (n = 92) of the children in this study, CSBQ data were available. For two children, CSBQ data were not available due to refusal of the parent(s) to fill out the questionnaire. In the current sample Crohnbach's α was good; alphas were between .81 and .88 for the six subscales, and .94 for the total score.

Data analysis

To determine which co-morbid psychiatric disorders were present in children with PDD-NOS, rates and 95%-confidence intervals were calculated for each co-morbid diagnosis.

To compare four different co-morbidity groups in the total sample of PDD-NOS children, on IQ, ADOS-G, and CSBQ data, analysis of variance (ANOVA) and multivariate analysis of variance (MANOVA) were used. To further compare the four groups on number of PDD-NOS criteria that were present, non-parametric statistics were used. For these additional analyses, mood and anxiety disorders were summed as internalizing disorders.

Ethics

Parent(s) or caretaker(s) of the children had all signed informed consent forms prior to participation in the study. Children who were 12 years old signed the consent forms themselves too. The Medical Ethics Committee of the Erasmus Medical Center has approved the study.

RESULTS

PDD-NOS research criteria

In Table 1 the percentage of children who were scored positively on each research criterion for PDD-NOS is listed. Although all 94 children were assigned a research diagnosis of PDD-NOS, not necessarily every criterion was present in each child. Criterion 1a (marked impairment in the use of multiple non-verbal behaviors to regulate social interaction) and criterion 1b (failure to develop peer relationships appropriate to developmental level) received the highest percentages of positive scores (77.7% and 92.5% respectively).

Insert Table 1 about here

Co-morbidity

Table 2 shows rates of co-morbid DISC-IV-P diagnoses. Overall, 80.9% (n = 76) of the children had at least one co-morbid psychiatric disorder, and 54.3% (n = 51) had two or more co-morbid psychiatric disorders.

In 61.7% (n = 58) of the children with PDD-NOS, criteria for at least one disruptive behavior disorder (ADHD, ODD, and/or CD) were met. ADHD was present in 44.7% (n = 42) of the children, ODD in 37.2% (n = 35), and CD in 9.6% (n = 9) of the children. In 14.9% (n = 14) of the children, the criteria for the inattentive type of ADHD were met, whereas the criteria for the hyperactive-impulsive type were met in

8.5% (n = 8) of the children, and the criteria for the combined type were met in 21.3% (n = 20) of the children.

After disruptive behavior disorders, anxiety disorders were the most prevalent. In 55.3% (n = 52) of the children, at least one anxiety disorder was present. The highest rates were for simple phobia (38.3%, n = 36). Simple phobias were mostly related to fear of the dark (n = 11), fear of insects (n = 3), and fear of needles and injections (n = 3). Social phobia was present in 11.7 % (n = 11) of the children, followed by separation anxiety disorder (8.5%, n = 8), agoraphobia (6.4%, n = 6), OCD (6.4%, n = 6), and generalized anxiety disorder (5.3%, n = 5).

With regard to mood disorders, 13.8% (n = 13) of the children with PDD-NOS had at least one mood disorder according to the DISC-IV-P, of which major depression occurred most frequently (10.6%, n = 10).

It can also be seen in Table 2 that none of the children fulfilled sufficient criteria for a diagnosis of schizophrenia. However, when psychotic symptoms such as delusions or hallucinations were investigated separately, it appeared that in 5.4% (n = 5) of the children hallucinations were present, followed by delusions (3.2%, n = 3).

Insert Table 2 about here

Groups of co-morbidity

When the children with one or more co-morbid anxiety disorder (n = 52) and one or more disruptive behavior disorder (n = 58) were further investigated, it was found that a high degree of overlap occurred. In Figure 1 it can be seen that in 19.1% (n = 18) of the children, no co-morbid disorders were present. In 19.1% (n = 18) of the cases only co-morbid internalizing disorders (sum of mood and anxiety disorders) were present, in 21.3% (n = 20) only co-morbid disruptive behavior disorders were present, and in the majority of the cases (40.5%, n = 38) internalizing and disruptive behavior disorders occurred simultaneously.

Insert Figure 1 about here

ANOVA showed no significant difference on FSIQ between the four groups (p > .05), and MANOVA showed no significant difference on VIQ or PIQ between the four groups (p > .05). MANOVA indicated that the groups did not differ significantly on scores on the Reciprocal Social Interaction or the Communication domain of the ADOS-G (p > .05). And non-parametric statistics showed that the groups did not differ in the number of PDD-NOS symptoms that were present (p > .05).

Furthermore, ANOVA indicated a significant difference in total CSBQ score between the four groups (F(3, 88) = 5.879, p < .01). Hochberg's GT2 post hoc analyses subsequently revealed that the total CSBQ score in the PDD-NOS group with internalizing and disruptive behavior disorders was higher than in the PDD-NOS group without co-morbid disorders (p < .01), and higher than in the PDD-NOS group with co-morbid internalizing disorders (p < .05). MANOVA showed that CSBQ subscale scores differed significantly between the four groups (F(18, 255) = 3.219, p < .001). Hochberg's GT2 post hoc analyses indicated that the group with co-morbid internalizing and disruptive behavior disorders had significantly higher scores on the CSBQ subscale Behaviors not tuned to situation, than the other three groups (p < .001, p < .001, and p < .05). Further, on the subscales Orientation problems in time, place, or activity and Stereotyped behavior, the scores of the group with co-morbid internalizing and disruptive behavior disorders were higher than the scores of the group with internalizing disorders (p < .05), and higher than the scores of the group without co-morbid disorders (p < .05).

DISCUSSION

To our knowledge this was the largest study thus far that investigated rates of co-morbid anxiety, mood, and disruptive behavior disorders, and schizophrenia, in school-aged children with PDD-NOS, in which PDD-NOS was classified by using explicit standardized criteria. Previous studies focused more on medical or sometimes psychiatric conditions associated with autistic disorder, used smaller samples, or did not use explicit criteria for PDD-NOS. At least one co-morbid psychiatric disorder was present in 80.9% of the children. In general, disruptive behavior disorders were most prevalent, followed by anxiety disorders, and mood disorders.

Co-morbid disruptive behavior disorders were present in 61.7% of the children, of which ADHD occurred in 44.7% (divided over three types of ADHD), and ODD occurred in 37.2% of the children. Rates for disruptive behavior disorders in the present study's sample were very high, compared to for instance ADHD prevalence rates of 2% to 11% in the general population (e.g., Shaywitz, Fletcher, & Shaywitz, 1994; Szatmari, Offord, & Boyle, 1989).

Luteijn, Serra et al. (2000) showed that children with ADHD and children with PDD-NOS both had severe problems in executing appropriate social behavior, and that attention problems did not differ between the groups. This indicated a high degree of overlap between features of PDD and ADHD but frequencies of ADHD in PDD-NOS children were not provided, all the more because DSM-IV does not permit this combination (APA, 1994). Barkley (1990) reported that children with PDD-NOS are often first diagnosed with ADHD. Possibly, differences between ADHD and PDD-NOS children become more evident at higher ages (Roeyers, Keymeulen, & Buysse, 1998). For treatment purposes it is important to be aware of the high rate of ADHD in PDD-NOS, because the associated symptoms of inattention or impulsiveness may be responsive to pharmacological treatment (Keen & Ward, 2004; Santosh & Baird, 2001), whereas the deficits in social interaction and communication are not (Tanguay, 2000). This also applies to co-morbid ODD and CD symptoms, since additional symptoms such as aggression and tantrums can be greatly reduced with early behavior interventions (Horner et al., 2002). Optimal management of aggression in children with PDD involves both behavioral and pharmacological treatment (McDougle et al., 2003). An overlap between features of ODD, CD and PDD has been demonstrated before (Gilmour et al., 2004; Moffitt, Caspi, Rutter, & Silva, 2001), but these studies focused more on the social and communication deficits in children with CD, and the exact rates of co-morbid ODD or CD in children with PDD-NOS have not been studied before.

Besides disruptive behavior disorders, anxiety disorders also occurred frequently. At least one co-morbid anxiety disorder was present in 55.3% of the children. Muris et al. (1998) previously demonstrated a high occurrence of anxiety disorders in children with PDD-NOS, significantly more than in children with autistic disorder, but the sample was very small, PDD-NOS was not classified by using explicit research criteria, and the overlap with disruptive behavior disorders was not assessed. Currently, DSM-IV guidelines do not permit the co-morbid diagnoses of generalized or separation anxiety disorder, or social phobia with a PDD. Anxiety symptoms, similarly to attention problems, may not be the core symptoms of PDD, but comprehensive guidelines for pharmacotherapy and behavioral interventions on how to treat these symptoms in children with PDD are available (e.g., Horner et al., 2002; Posey & McDougle, 2000; Santosh & Baird, 2001). It is thus important to be aware of the high rates of anxiety disorders in children with PDD-NOS, because besides being treatable, these additional symptoms may result in extra burden. Additional anxiety symptoms might inhibit the potential of mastering educational or daily life skills.

With regard to mood disorders, findings of a previous study in autistic disorder were not confirmed in the current sample of children with PDD-NOS. Ghaziuddin, Ghaziuddin, and Greden (2002) described depression as possibly the most common psychiatric disorder in autistic disorder. In the current sample, mood disorders were present, but to a much lesser extent than disruptive behavior or anxiety disorders. Ghaziuddin et al. (2002) mentioned that the rate of depression in autistic disorder and related disorders may rise with age, whereas attention and aggressive symptoms could be more prevalent at younger ages. Possibly this applied to the current sample of school-aged children as well.

No children in this study met the criteria for schizophrenia, which is not very surprising as the majority of cases of schizophrenia have their onset in late adolescence or adulthood (Rosenbaum Asarnow, Tompson, & McGrath, 2004). However, a small part of the current sample of children with PDD-NOS showed isolated symptoms of delusions and/or hallucinations. These symptoms may be a forerunner of future psychotic episodes and they may therefore be very important to identify. For instance, Poulton et al. (2000) showed that the presence of psychotic symptoms at age 11 predicted a schizophreniform disorder in adulthood.

Most previous studies focused on co-morbidity of one group of disorders (e.g., PDD and anxiety disorders), whereas in the current study the high degree of overlap of co-morbid disorders was remarkable. Co-morbid internalizing and disruptive behavior disorders were present simultaneously in 40.5% of the children with PDD-NOS. This group with double co-morbid disorders did not differ from the other co-morbidity groups, or the group without co-morbid disorders, on deficits in social contact or communication as rated by clinicians (e.g., ADOS-G, number of PDD-NOS criteria). According to the parents (e.g., CSBQ) however, the PDD-NOS children with double co-morbidity showed more PDD related behaviors (e.g., stereotyped behaviors). Thus, apparently, a child with PDD-NOS and more co-morbid disorders is experienced by the parent as more severely disturbed in social contact and communication, than a child with PDD-NOS without co-morbid disorders.

To conclude, the way a diagnosis of PDD-NOS was obtained in this study should be taken into consideration when interpreting the findings, as well as the fact that standardized criteria for PDD-NOS, as used in this study, are generally not used in clinical or research settings. PDD-NOS diagnoses are often not based on clear and standardized criteria, but on the fact that a child does not meet the severity, intensity or number of criteria for a diagnosis of autistic disorder, whereas nevertheless, problems in social interaction and communication are present. Hence, it is unknown to which extent the findings of the present study apply to children who receive a diagnosis of PDD-NOS in regular clinical practice. This underscores the need for application of standardized criteria by clinicians, which is further underlined by other difficulties classification of PDD-NOS suffers from. PDD-NOS is often regarded as the most complex

diagnosis to make in the autistic spectrum and is difficult to differentiate from autism (e.g., Allen et al., 2001; Buitelaar et al., 1999; Prior et al., 1998; Volkmar et al., 1994; Volkmar & Wiesner, 2004). Interrater reliability of diagnosing PDD-NOS within the autistic spectrum is low (e.g., Mahoney et al., 1998; Towbin, 1997; Volkmar, Klin, & Cohen, 1997). This was also illustrated by the finding in the present study that, although raters agreed on the number of PDD-NOS criteria that were present ($r = .79$), kappa reflecting agreement between raters on the presence of a PDD-NOS diagnosis was only moderate ($\kappa = .62$), and the association between PDD-NOS and ADOS-G classifications was far from perfect.

Limitations

Children from only one outpatients' department were included which may have limited the generalizability of the results. Also, a university outpatients' department of child and adolescent psychiatry is generally not the first mental health service that children with psychiatric problems are referred to. Less severe cases may visit community mental health centers first. Therefore, the current study sample may not represent the target population of all children with PDD-NOS. It is possible that less severe cases display less signs of co-morbid disorders and that estimates of co-morbidity in the present study are higher than average. Future multi-center and epidemiological studies in possibly more representative samples are needed to test the present study's findings.

To the present authors' knowledge this study in a separate group of school-aged children with PDD-NOS was the largest study that used standardized assessments thus far, but nevertheless confidence intervals were still relatively broad.

Clinical implications

High rates of co-morbid psychiatric disorders in school-aged children with PDD-NOS were found. This is important when it comes to treatment planning. No single treatment is effective for all children with PDD-NOS. This is due to the large variety of symptoms and deficits demonstrated by these children. No cure seems to be available yet to treat the core deficits in PDD-NOS of social contact and communication deficits, but behavioral interventions and pharmacological treatment decisions are often based on the presence of associated symptoms, such as hyperactivity, inattention, or anxiety. The present study underscores that assessment of these associated symptoms is important.

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0006

WELLBEING IN THE CURRICULUM: HELPING STUDENTS HELP THOSE WHO HELP THEM

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Introduction

This presentation will be of interest to professionals who are engaged in the development of educational processes for higher functioning students. We will be using filmed examples of our work over a four year period as well as interviews with students.

Trends in social inclusion led to a number of students with a late diagnosis of asc - either high functioning autism or Aspergers being referred to our centre. These students had struggled to make sense of the relevance of their education and to fit in with their peer group in a mainstream setting. The curriculum that was well established for students with a more classic profile (Kanner's type autism) within the centre proved to be unsuccessful with this new group of students.

These students were difficult to educate and appeared to be oppositional in the classroom situation. Our hypothesis was that this implied a lack of self identity and reflected their feeling of having little sustainable control over their environment. We needed to find ways of creating a meaningful life for them by helping them acknowledge neurological impairments and creating the adaptations necessary for success.

We know that in typical people, the lack of control over the immediate environment can subsequently lead to a loss of personal wellbeing. We saw this behaviour in our new students, who demonstrated a lack of trust in themselves and their teachers. Over many years they had developed patterns of unacceptable behaviours when experiencing stressful situations.

Wellbeing had always been the driver for our education of students with autism but now we were redefining that concept by moving to a programme that provided students with sustainable tools for self-reliance. Wellbeing now entailed aspects of comfort, personal happiness and security, having your thoughts, feelings and interests acknowledged. The key was helping these young people define 'what kind of person am I'?

Background to developing a New Teaching Style

The senior management team discussed with clinical and educational psychologists how to develop a best fit model, based on small group teaching with a maximum size of eight students.

From these discussions emerged themes that were real and reoccurring issues for both staff and students. These were used to develop a framework in which we could further consider how best to provide support for staff and students. We needed a way of describing an approach where adults worked alongside students preparing them to develop a clearer understanding of the successful strategies that would help them fit into the world around them. This was a process that needed to relate to the future as well as the present. This style became talked about as a 'Plan to Learn'. Our task was to support with guidance and safe rules.

Re-occurring themes from staff observation and discussion

- **Interpreting Emotional Literacy**

Students displayed emotionally charged behaviours ranging from apprehension about situations to out of control mood swings. These high energy emotions were allied with a lack of body awareness. These students lived in a chronic state of fight or flight. Staff were shocked by the level of aggression displayed by students. Students could also be shocked by the damage they had caused to people and the environment and sometimes to themselves.

- **Disorganisation**

Students struggled to plan and organise the many aspects of their daily routine; they appeared attracted to the forbidden. Students did not have a profile of themselves as being able to organise their feelings or thoughts into a pattern that could be communicated and understood by an adult.

- **Confusion**

Staff realised that they unintentionally created an environment that could be confusing for the student when they were not included as part of the thought process. If we wanted students to have a strong disposition to organised thought, it became clear that staff needed to demonstrate these internal processes in an external form. Students need to see and hear not just the product of adult thinking but how that thinking becomes action. A system of predictability was needed that allowed discussion on what are the tasks to be completed and what are the alternatives. We had to make this explicit in terms of each individual thinker. Thinking was displayed in comic strip conversations, cartoons, mind-maps. Each activity was planned as a presentation of: 'this is what we are doing', 'this is what I am thinking'.

- **Reflective thinking**

Learning from experience was not a skill that was successful for many students. If we wanted to encourage students to maintain a consistent pattern of appropriate behaviour we needed to recognise and describe that behaviour explicitly. The process acknowledged the understanding that both students and staff had a fundamental difficulty in identifying the specifically important aspects of a skill. Failure needed to be seen in the context of a stage in thinking; 'something went wrong, how can we fix it for next time'

- **Self-belief**

Students were aware that some aspects of their lives were very difficult. But when things were difficult both students and staff could not easily recall the positive memories of past achievements. These needed to be created in text or graphic form in order to remind students of what they had previously achieved. It was important to change the mind set of adults into believing that there was something to respect and like about these individuals.

Creating a style called BERIS to support wellbeing

Being able to make appropriate choices to sustain wellbeing depended on teaching the students that there are specific types of thinking for particular situations. We made a 'book of knowledge' for each student, containing strategies that could enable students to create a profile of themselves. We wanted to encourage students to become familiar with the thinking and ideas that allowed them to search for solutions to difficulties. These books were variously called planners, organisers, day books, according to the preference of the individual. In using this system we started to help students convert observed information and experience into a format that became accessible for them. This involved selecting relevant information, storing the information, remembering and imagining what to do next. The premise being that from a state of calmness, clearer thought was possible. The acronym we used to refer to this simple 5 part framework is BERIS (Body Basics, Environment, Relatedness, Insight and Self belief)

The successful teacher was able to use this acronym as a framework to provide students with a supportive strategy which reflected them as positive thinkers, able to choose the appropriate response in difficult situations. The student's planner reflected their personal history, feelings or prejudices, a narrative that reflected the challenges of their daily life at school. The elements of BERIS were formalised into individual plans that staff and students constructed together:-

Body Basics progressed to Plans to Calm

The Body Basics curriculum provided a specific range of actions that could help reduce the body's reactions to feelings and emotions. The premise was that we couldn't rely on students to relieve anxiety by merely talking about it. We needed to teach recognition of the physical signs and triggers of their own anxieties and then to prepare a plan that addressed how to respond appropriately.

Environment progressed to Plans to Organise

The environmental element of the curriculum ensured that we reduced confusion regarding unplanned or altered activities. We developed strategies to help with the procedure of change and to promote the students ability to accept activities imposed on them.

Relatedness progressed to Plans to be with Others

The relatedness element of the curriculum helped to develop an understanding of how adults could be a point of reference for assistance. By making plans and rehearsing, it became possible to reduce the fears around interactions.

Insight progressed to Plans to Think

A consistent routine was established for debriefing after both positive and negative experiences. The purpose was to help students and staff recognise the elements that either went well or not, and to make a plan for the next occasion. This was an extension to thinking that allowed both parties to recognise the value of different ideas. The adult can present in response to the student the possibility of 'how else could we have helped?' and 'how can we help next time.'

Self-belief progressed to Plans to Succeed

Students were supported to monitor 'self talk' to restrict negative messages about fear of failure. This involved acknowledging talents and abilities and supporting a strong sense of personal responsibility. The recognition that we all have a choice in almost all situations strengthened the notion that choosing strategies, and making predictive plans is key. The ultimate aim was for the student to be at the centre of their learning in a more self reliant manner.

What students told us

Plans to Calm

Our temptation was to increase the range of strategies and variations on strategies that existed; students told us that they were able to identify a specific strategy that worked for them. They needed staff that remembered and modelled this in a consistent manner. Three elements became particularly apparent

- Touch and massage for relaxing

- Breathing for calming

- Gestures for thinking

In order that massage could be made a real life strategy for our students as adults, we developed a wellbeing clinic. Vocational students could make appointments to attend a wellbeing clinic and voiced the desire to continue with this strategy once they had left school.

Plans to organise

We provided students with a range of planners and organisers relating to age and ability. Although there was an initial resistance by students to using what appeared to be a controlling influence, this altered when students were able to change the content from a prescribed social story format into their own words. The provision of cameras progressed these to more personal photo stories.

Plans to be with others

We acknowledged the students feelings that life could often be unpredictable and confusing. Students had developed a long standing and sceptical view of how adults perceived them. Because students found it difficult to monitor their tone of voice and posture they were often interpreted as oppositional rather than confused. Mantras provided students with a script of appropriate words and postures to use in times of anxious social interaction.

Plans to think

Students varied in their ability to talk about what they knew to influence their states of wellbeing. Many students have been able to identify their stressors, their physical responses and the strategies that work for them. This has been a very exciting development. With this knowledge students can make plans to use wellbeing strategies by asking others to help them access this information.

Plans to succeed

Our students told us it was possible to keep an angry mood going by talking or thinking about it. They showed us that innate emotional patterns of response could be changed with the right experiences. The ability to bring 'out of control' emotions back into control became the first step in developing self-awareness. Self-awareness allowed students to manage their feelings and to recover from bad moods more quickly. Through self awareness students learnt to give ongoing attention to their internal states, to know what they were feeling, why they were feeling it, and to further identify the events that caused upsets and emotional hijackings, and use progressive strategies to bring their feelings back under control.

Staff training in response to students comments

The notion of a school as a caring community was a difficult concept for students to understand, especially those who had experienced exclusion as a response to their unacceptable behaviours. In calm moments

we learnt that students often desired to be in an environment where adults kept firm boundaries and maintained a role of being in charge.

Where disorganised and apparently oppositional students are driven to dominate their teachers, training staff to respond positively with appropriate strategies was a key issue. The emotion in the student's voice, rather than words being said, which when recognised, provided a basis for mutual advancement. This could allow adults to respond flexibly whilst maintaining class and group functioning rules.

Students would request the help of trusted adults to remind staff who did not follow these programmes. The work that we had previously done in structuring the environment would not be successful unless staff were able to observe and rethink from the perspective of the young person. Staff had to develop the ability to deal with negative emotions resultant from unsuccessful interventions, learning to say confidently 'I didn't understand'.

Developing a relationship of mutual trust would enable staff to confirm to students that they wanted them to be:

- Responsible for their own actions

- In control of their own emotions

- In charge of their potential for learning

Changing Perspectives

Teaching wellbeing is about making explicit the body - brain awareness link. This is the link of identifying physical reactions in our body and recognising these as belonging to ourselves in response to situations or thoughts. Unfortunately the link that we make between arousal and our emotional interpretation becomes seamless limiting our awareness to the emotional responses.

In order to deliver high level nurturing, staff had to be able to adjust and 'tune-in' to each individual. We observed that staff needed a high level of personal wellbeing; they too needed to be balanced and in-touch with themselves, physically and emotionally. Most typically developing people have a sense of their bodies. They are able to talk about sensations and perceptions in order that they can make sense of them, they know what their body feels like. Immaturity of the limbic brain prevents children with asc from responding to these feelings and creating their own survival stories, possibly resulting in more conflict. Some are hypersensitive, others hyposensitive, meaning that they do not have a 'felt' sense of a 'self reliant me' because their nervous system is out of balance.

Training opportunities included Tai-Chi, Yoga, Brain-Gym and Massage helped us to learn how the body and brain are connected. We became aware of how the brain reads the body's reaction and tells itself that 'things are out of control'. WE developed an awareness of how when under stress the 'working memory' becomes impaired, meaning that both child and adult may find it difficult to remember a previous strategy for handling a difficult situation.

All staff were offered training in Touch Talks© - a 3 day touch-massage course developed as a peer massage programme for students. Initial resistance gave way to relief as staff developed an awareness of the tension within their own bodies resulting from their own anxieties. Head and shoulder massage became part of the routine of staff meetings. Staff created massage stories for individual students using calming self statements to change the student's ability to handle stress. Students responded positively to stories where they were the central character. Students became less touch defensive and opportunities for peer massage at the end of PE lessons, music and drama sessions allowed students to receive nurturing touch throughout the day.

Understanding that under stress the involuntary nervous system, which controls heart rate and breathing becomes emotionally charged making student responses erratic led to the development of mantras for explaining actions. We were able to say 'when your heart pounds, it's hard to breathe' or 'the brain wants more oxygen when your body feels edgy'. Equally students could say 'my heart's pounding, I need a breather'. Breathe and Blow became a key message whenever staff felt overwhelmed. We taught staff to blow into the palm of their hand in order to lengthen the breath. The mantra 'when your heart is beating fast, you need to breathe and blow' was introduced into work sessions.

We then added self nurturing gestures taken from a yoga programme. Self touch or natural gestures are recognised as promoting wellbeing by releasing the hormone called Oxytocin. The physiology of touch was used with students.

- 'Putting your hand on your head brings oxygen to the brain, you need oxygen to think'.

- 'Putting your hand on your chest makes your lungs take a deeper breath'.

- 'Hands folded in your lap or on your tummy, make you feel more relaxed'.

- 'I'm impressed by the way you are using touch to calm down'.

Staff modelled using the gestures whenever they needed to think, be calm or take a calming breath. This led to further development

- 'At work it's important to look the part. I liked the way you hold your hands. I can see you are in control'.

- 'Can you see I'm taking a break to think, I'm not sure of the answer'.

In a strategy that models what adults often do in their everyday life where we make excuses to go for a toilet break of a breath of fresh air, students were taught to go to places to calm down. Safe Havens were created where students could sit and think without being disturbed. Contrary to initial perception, students rarely abused this thinking space, returning to a work session at an agreed time. We also explored the use of aroma in creating an optimistic environment. Students made their own aroma sprays for the gym, wellbeing room or as presents to take home.

We discovered that wellbeing is an essential component of the curriculum that was critical for growth and development. Touch, breathing and positive affirmations stimulate the nervous system into a state of relaxation. Although children with asc are thought to be innately averse to touch, we found they responded positively to being massaged.

Conclusion

The BERIS style allowed us to support students to make the connection between their experiences. It enabled us to rethink traditional approaches and find a flow between the ways to teach impulse control, perspective taking and self awareness. The kit we created with the students provided them with a rounded profile of themselves. When students have a sense of agency they are more able to deal with the ups and downs of their autism. We learnt that unless we helped students create their own strategies we cannot really claim to be teaching them to become independent life long learners.

0007

A PUZZLE WITHIN THE PUZZLE: IMAGINATION AND AUTISM

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Imagination: a puzzling concept

An impairment in imagination is put forward as a basic characteristic of autism in almost every article or textbook. However, what exactly this impairment is and what its consequences are for the well known symptoms of autism often remain unclear and are left to the reader's imagination… Autism is often called a puzzling disorder, but it seems that imagination is a kind of a puzzle within the autism puzzle.

Based on a large population study Wing and Gould described in 1979 the basic symptoms of autism as a triad of impairments: an impairment of social interaction, communication and *imagination*. This triad has since then received ample support and is now considered to be the golden standard in the description of the core symptoms of autism. It is obvious that, besides the impairments of social interaction and communication, the impairment of imagination is a basic characteristic of autism. It is remarkable, however, to see that this self-evidence is not reflected in the diagnostic criteria for autism, as described in the classification systems of DSM and ICD. Wing's and Gould's triad has been replaced by another 'triad': social interaction, communication and *restricted or repetitive repertoire of activities and interests*. It is strange to see how the characteristic that Wing and Gould considered to be a *result* of the impairment of imagination has become in the diagnostic criteria the third heading in the three groups of characteristics. Imagination has more or less disappeared and got somewhat lost under the heading of qualitative impairments in communication, where the criteria mention *"a lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level"*. This lack of make-believe play can hardly be considered as a synonym for an impairment of imagination since, as we will describe further, imagination is much more than make-believe play.

Imagination is mentioned a second time in the diagnostic criteria. These state that there should be "Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) *symbolic or imaginative play*." This criterion reflects the original triad, but, again, the impairment of imagination is narrowed down to its expression in play, while other aspects of imagination, such as social imagination, remain unmentioned.

Even more surprising is the fact that an impairment in imagination is completely lacking in the criteria for Asperger syndrome, although difficulties in imagination are seen as characteristic for all autism spectrum disorders. The criteria for Asperger syndrome match those for Autistic Disorder, except for the fact that the criteria for qualitative impairments of communication have been left out. The criterion of a delay or abnormal functioning in the three areas (social interaction, communication and symbolic of imaginative play) with onset prior to the age of three years, is absent as well when it comes to Asperger syndrome. As a consequence, the impairment of imagination is completely absent in the diagnostic criteria for Asperger syndrome. This is highly remarkable, since nobody doubts the presence of this impairment, even in so called high-functioning people or people with Asperger syndrome.

There seems to some controversy among scientists and researchers about the role of imagination in autism. Some consider the impairment in imaginative and symbolic abilities as an explicit and pronounced characteristic of autism (e.g. Wing, 1996), while other researchers don't see the lack of imagination as a distinct characteristic, because people with autism seem to be able to mentally rotate objects, which is proof of imaginative abilities (Baron-Cohen, 2002, personal communication).

Apparently, imagination seems to be a difficult and confusing term. This is reflected in the different words, synonyms and definitions used for it: imagination - fantasy - symbolic or representational ability – mental imagery. The word has several meanings within everyday language, which are matched by an equal range of usages within psychology (e.g. pretence, social imagination, counterfactual thinking). Throughout history, imagination has been a tough and cumbersome topic for philosophers and psychologists. This made it difficult to qualify it. Some considered imagination as a supremely valuable source of creativity and inventiveness, while others thought of imagination as dangerously, a source of sin or aberration (imagination as the opposite of reason).

Imagination: the ability to represent things

The concept of imagination in folk psychology is largely influenced by the Romantic conception of it, focussing on the aspects of creativity, originality and the imaginary or fantasy. Most people associate imagination with the ability of creating stories, science fiction, fairy tales, fantasy creatures, art, new products, original solutions to a problem and so on. To be short, imagination is seen as the capacity to

create highly novel or original ideas and products. However, imagination is also much more down to earth. What is the colour of your neighbour's car? How many chairs are there in your kitchen? How many suit cases fit in the trunk of your car? To answer these questions, you have to picture yourself things in your mind that are hardly fantasy or science fiction. They are very realistic. Yet, they require imagination.

A basic definition of imagination is: the ability to form mental images of something that is not present to the senses (Thomas, 1999). Imagination is, to put it simply, the ability to represent things in the mind, or to "see in the mind's eye" (although imagination occurs in all sensory modes, most literature and research in philosophy, psychology and cognitive science has concentrated solely on the visual mode). According to Thomas, mental imagery is quite similar to perception, but it occurs in the absence of perceptual stimuli. Thomas (1999) defines imagination as a "quasi-perceptual experience". As such, it might be more associated with prototypically cognitive functions such as memory, perception and thought, than with those aspects that prevail in the folk psychology definition of imagination, namely fantasy and the imaginary. Imagination is quite similar to *representation*.

There is no doubt about the existence of a human ability to form mental images, however, there is quite some discussion about how it works. This debate is well known as the analog- propositional debate, which is basically a discussion about the nature of mental images and parallel to the so called sense-datum debate of perception. To put it simply, the analog approach or 'picture theory' claims that mental images are a kind of 'pictures in the head', similar to computer graphic files. According to the propositional or 'description theory', mental representations are not picture-like but rather a kind of descriptions in the brain's language. We will not describe the whole debate, which remains largely unresolved today, but the controversy about the nature of mental representations has made it clear that mental images are not always and not necessarily visual or 'pictures in the head'. There are probably different forms of representation within the brain, some of them being pictorial, other ones more 'abstract'. To illustrate this, the following example. When asked about the colours of the Belgian flag, you will probably activate some sort of 'picture' in your mind. However, when asked to imagine Belgium as a republic (instead of a kingdom), no pictures or mental 'images' need to be involved.

Imagination in autism: concrete and pictorial

Both research as practice have shown that it is clear that there is no complete lack of imagination in autism. People with autism can see things in their mind, particularly when it concerns concrete things, such as objects. We assume that the imagination or mental representation of people, behaviour and scenes is equally intact in autism, especially for behaviours or situations that have been seen or experienced before. On the contrary, it might well be that, when it comes to the imagination of concrete items, people with an autism spectrum disorder perform even better than neurotypicals due their sometimes eidetic of photographic memory. Temple Grandin, a well known high functioning woman with autism, is an excellent example. She has an astonishing ability to visualize things in her mind: she can run three-dimensional simulations of two-dimensional blueprints of live stock facilities in her head. "My imagination works like the computer graphics programs that created the lifelike dinosaurs in Jurassic Park. When I do an equipment simulation in my imagination or work on an engineering problem, it is like seeing it on a videotape in my mind. I can view it from any angle, placing myself above or below the equipment and rotating it at the same time. I don't need a fancy graphics program that can produce three-dimensional design simulations. I can do it better and faster in my head." (Grandin, 2006). Livestock facilities (just as any other building) and, by extension, objects, people and situations are concrete and, hence, can be visualized. As long as they can be represented in a concrete and visual way, imagining things is not necessarily a problem for people with autism. However, it seems to be more difficult for them to represent things that are less concrete or visual, such as mental states (feelings, thoughts, ideas) and social concepts (such as honesty or friendship). Despite her high intelligence and her dazzling capacities in imagining buildings or even an animal's perspective, Temple finds it very hard to imagine for instance feelings. And if she tries to imagine emotional and social concepts, she will try to – literally –make pictures of it. When asked by Oliver Sacks (1995) "How do you imagine falling in love?", Temple answers: "I don't know. Maybe it is something like fainting – if it isn't that, then I don't know." In imagining abstract concepts such as 'love', Temple cannot proceed beyond literal and concrete representations.

Even in the mental representation of visual and concrete things, difficulties can arise. It is remarkable that people with autism often need more time when instructed to imagine something. Someone with autism told that this is a consequence of having to construct the mental images in a piecemeal way. Since imagination is closely related to perception, we can assume that the fragmentary and hyper detailed way of perceiving also is reflected in the way people with autism build up mental representations. Due to their exact eye for details and their hyper realistic way of perceiving, people with autism can also form representations that are too concrete or too detailed. When, during a course for high functioning people with autism, I asked the participants to think of a bicycle, a woman with autism replied that she could impossibly do so. She said she could think of her own bicycle but that she was unable to think of 'a bicycle': "What bicycle do I have to think of, then?" she asked me.

It seems that autistic imagination has the same three characteristics as the autistic perception:

- detail focus / hyper specificity
- eidetic / photographic
- concrete.

Imagination and concept formation: rules and exemplars

Imagination, as the ability to represent, plays an important role in the formation of cognitive schemata and concepts. If the ability to represent reality is too much detail focused or too concrete in autism, the concepts formed in an autistic brain will consequently be qualitatively different.

Concepts are what we use to navigate through and make sense of the world around us, enabling us to classify and interpret new situations in terms of previous similar ones. They can be concrete, like 'chair', or abstract, like 'beauty'. There are different theories about how concepts are formed. The older, now generally rejected theory (e.g. see Smith & Medin, 1981 for an overview), says that concepts are formed on the basis of a set of rules, defining the necessary and sufficient defining properties. Rules work fine for so called nominal kinds, such as cousin, triangle or felony, but for more natural categories such as animal, flower or tree we don't just use rules to recognize or classify them. The two newer theories hypothesize that concepts are not formed on the basis of rules but on the basis of similarities. One theory assumes that concepts are formed on the basis of exemplars: we represent a concept or category by storing many or all known exemplars of the category (Nosofsky 1988). The opposing theory claims that concepts are formed on the basis of prototypes (Rosch, 1983). That prototype may be a real exemplar or a combination of features from different exemplars. A prototype can be defined as the most representative member of a category and is like a summary of the most important features. Both models have been contrasted extensively during the past decades and it seems that we use both concrete ways of categorization (using exemplars) and abstract ways (using the more abstract prototypes).

For brain 'economical' reasons, i.e. in order to prevent a working memory overload, we tend to use prototypes for the rapid recognition and categorization of objects and scenes. By generating and storing prototypical images, we do not need to memorize all the exemplars or instances of a category or concept. For instance, we can understand the bird concept and understand the meaning of the word 'bird' without having to imagine one or more concrete birds, just as we can understand a story without having to store every single word or sentence in our memory. We don't necessarily need detailed images, definitions, rules or descriptions to understand the "birdness" of birds because in most situations we can rely on some sort of general, skeletal and prototypical 'mental image'.

Klinger and Dawson (1995, 2001) studied the categorization abilities of children with autism and concluded that people with autism may not abstract a summary representation (a prototype) during category learning but, instead, may form categories by memorizing a list of rules. However, in their experiment children with Down syndrome equally showed impaired prototype learning abilities, which raises the question of whether the impairment in prototype learning is specific to autism. Moreover, in their study, Molesworth, Bowler and Hampton (2005) did not find evidence of a reduced or absent prototype effect in autism, but several methodological differences could account for the discrepancies between the results of the two studies.

Temple Grandin (2000) describes her difficulties in creating prototypes. She seems to be unable to generate an abstract, prototypical concept of, for instance, a dog. Instead, she has in her brain a huge collection of pictures of all the dogs she has ever seen. Grandin calls her mind a "web browser"; she can browse through all these picture memory files in her mind, can stop at any one picture and study it. Grandin can develop categories, but in an exemplar rather than in a prototypical way, and with more reliance on specific details: "My mind seeks these categories amidst an array of little details" (Grandin, 2000). Grandin's accounts clearly demonstrate that more able people with autism can develop more abstract concepts, but these will still contain more concrete and visual details than the concepts of neurotypical people. Autistic concepts in the autistic imagination are, in line with the autistic perception, more detail based.

Because they are more abstract, prototypes have the advantage of flexibility: they facilitate the generalization of concepts because the concept is stripped off of all kind of redundant details. Problems with the imagination of more prototypical images could account for the generalization problems in autism. If your concept of an birthday party contains a lot of details and one of them is missing in a certain situation, chances are you will not recognize the situation as a birthday party or you will be confused.

In autism, there doesn't seem to be a general impairment in imagination but rather a specific deficit, a qualitative impairment, or – in a more positive wording – a different style, with assets and deficits.

Strengths in the autistic imagination	Weaknesses in the autistic imagination
Representation of concrete issues	Representation of abstract issues
Imagination based on exemplars	Imagination based on prototypes
Visual representations	Conceptual, non-visual representations

Imagination: seeing possibility, not only reality

What we described until now only concerns imagination as 'seeing' without an input from the sensory system, i.e. imagination separately from perception. But imagination also plays a role *in* perception and cannot be seen completely independent from it. Imagination does not only refer to the ability to represent reality with the mind's eye, but also to the ability to see what could possible be a reality. White (1990) describes imagination as the ability 'to *think of* [something] as possibly being so' (p. 184).

For too long, perception has been seen as a passive process of receiving information from the senses. It is currently well known that perception is a very active process: the brain does not receive information from the outside world, it reaches out towards the world very actively. As opposed to the more classical views of perception and imagination (the quasi-pictorial and the description theory described above), in the view of perception as an active process, the so called perceptual activity theory, "no end-product of perception, no inner picture or description is ever created. No thing in the brain is the percept or image. Rather, perceptual experience consists in the ongoing activity of schema-guided perceptual exploration of the environment" (Thomas, 1999, p. 218). In this way, imagination can be seen as the drive behind our search for meaning in perception. The definition of imagination (as 'seeing' without an input from the senses) could also be reversed: perception is imagination with feedback from the senses. Imagination takes the role of a researcher that tests all kind of hypotheses about the world around us in order to make sense of it. Imagination is "the interpretative aspect of perception, as what makes mere mechanical sensation into perception of something meaningful" (Thomas, 1997, p. 100). "Seeing as" refers to the capacity of "going beyond the information given" (Bruner, 1957). In this regard, two aspects of imagination need to be mentioned: filling in the gaps and seeing possibilities.

Filling in the gaps

Thanks to your imagination, the next sentence can be understood and becomes meaningful, despite a lot of letters missing in it.

Imagi tion is th abil ty to f ll in th g ps in your per ept on.

Thanks to your imagination you see "a news anchor telling the news" and not "the upper half of a human body making sounds". Thanks to your imagination you will recognize and find back your mobile phone, almost completely hidden under the newspaper on your desk. This seemingly obvious and unconscious process of filling in the gaps does not always occur spontaneously in autism. During an outing in the country side, an adult with autism did not recognize a horse, of which only the head could be seen because it was standing in a stable with the lower part of the door closed. He needed to be reassured that the rest of the horse was also there, so that there was no horse head 'hanging' there. It seems that in autism quite often things do not exist if they literally cannot be seen.

Seeing possibilities

When we see a book, we see more than just the object called a book. Immediately, our imagination adds a lot of information that cannot be perceived. We intuitively know that we can take the book without having fear that it will bite us; that, when we open it, it won't melt; that we can read in it but also that we can use it to kill that annoying fly in the room; that the book won't fall in love with us; that it is inedible; etc. etc. All these meanings are not available in the mere presentation of the book (its colour, size, shape etc.), they are the product and result of our imagination. Imagination lifts the impressions coming from our senses up to the level of a meaningful perception. Imagination is not only helpful for recognizing what we perceive, but it also helps us to know how we should react to what we see, hear, smell or feel. Imagination as 'seeing possibilities' gives us a manual for the world. We hypothesize that this aspect of imagination is impaired in autism. Seeing possibilities is synonym to supposing and basically comes down to 'pretending'. Although we normally use a book to read, when we intuitively know that we can equally use it to give the annoying fly a smack, we pretend that the book is a fly swatter. The difficulties with pretence, especially pretence play, are a well documented characteristic in autism. Imagination as 'supposing' is also crucial for counterfactual reasoning, i.e. reasoning about what isn't so. Counterfactual reasoning does not only involve logical thinking but also imagining. In normal children, counterfactual reasoning is facilitated when they are prompted to use their imagination. However, this does not seem to occur in children with autism:

although abstract counterfactual reasoning appears to be intact in children with autism, their counterfactual reasoning is not facilitated by pretence in the normal way (Scott, Baron-Cohen & Leslie, 1999).

Autism as WYSIWYG-perception

Seeing possibilities lies at the core of the process of giving meaning. However, seeing possibilities seems to be difficult for people with autism. They have difficulties to go beyond what is presented directly to the senses. As one high functioning man with autism described it: "I am my senses!". It seems as if the autistic perception works according a "what you see is what you get" principle. We say people with autism are hyper realistic, because they see reality rather than possibility. They can imagine what is and what has been, but imagining what could be is more difficult for them. In his e-mail conversation with a Dutch woman (*Double click*, Landschip & Modderman, 2004), a high functioning man writes: "I find it terribly difficult to imagine situations that I haven't experienced before…". He gives a nice illustration of his difficulties imagining something that is not present: 'I have this annoying problem: twice a week somebody goes shopping for me. I have to give that person my shopping list by telephone. If I have one banana left on the kitchen table, then I think about putting bananas on my shopping list, but when there are no bananas left, I cannot think about bananas, I cannot imagine me eating a banana without seeing a banana and so, I forget to put them on my list. It seems as if I forget the existence of bananas, even if they are my favourite fruit. This is not only so for bananas but for almost everything. One day I will only order tomatoes, because I never run out of them….' (p. 164). This example clearly demonstrates how difficult it can be for people with autism to imagine things out of nothing and without sensory input. This difficulty adds another item to the list of characteristics of imagination in autism:

Strengths in the autistic imagination	Weaknesses in the autistic imagination
Imagining "what is" and "what has been"	Imagining "what could be"; supposing

Imagination, pretend play and creativity

A lot of children with autism seem to be able to engage in pretend play, and many high functioning children with autism engage in fantasy play or enjoy fantasy materials. Some of them can even make up stories, imaginary words or imaginary play friends. This observation seems to contradict the assumption of an impairment in imagination. The confusion seems to be a result of the romantic interpretation of imagination that associates imagination with creativity and fantasy. Fantasy and creativity require the ability to imagine, but are far from synonyms of imagination. It is clear that people with autism can, up to a certain point, imagine things and make mental representations. The impairment in imagination should not be interpreted as an inability to see things with the minds eye. It is more a qualitative impairment, with the above mentioned strengths and weaknesses. These are reflected in the pretend play, the use of fantasy and the creativity in autism. For instance, a lot of pretend play seen in children with autism is copied from other children or from television, rather than self generated. It has been shown that children with autism have a marked difficulty in spontaneously producing pretend play in free play situations, but that this difficulty is reduced by providing substantial structure to the play situation (Jarrold, 2003). Possibly, the external cueing overcomes the internal difficulties in generating possible new or imaginative meanings for play materials. It is also possible that a child with autism engages in pretend play, without pretending. Pretend play requires the person to be conscious of the fact that the pretended reality is played and that the real meaning differs from the meaning in the play situation. It can happen that a child with autism imitates a symbolic act seen in another child (e.g. a sibling) and holds, for instance, a banana as a telephone, but without conscious knowledge of the new, symbolic meaning of the banana (See the difference between 'acting-as-is' and 'acting-as-if' in Perner, 1991).

According to Allan Leslie (1987) there are three levels of symbolic play: object substitution (e.g. pretending a banana is a telephone), attribution of pretend properties (e.g. pretending that a doll's face is dirty) and inventing imaginary objects (e.g. pretending that there is a cup of tea when there isn't one). Research (e.g. Libby, 1998) has shown that some children with autism are capable of object substitution, but attribution of pretend properties and, especially, creating a meaning out of nothing (inventing imaginary objects) are quite difficult for them. Symbolic play without (visual) input from reality is impaired in autism. On that level, we are talking about imagination in its purest form: no input from the senses.

Some studies examined imagination and creativity in children with autism and gave evidence for an impairment in imagination. Craig and Baron-Cohen (1999), for instance, report on three studies suggesting impoverished creativity in children with autism. According to these studies, children with autism can be creative up to a certain level. They could, for instance generate novel changes to an object, though fewer than children from the control group. However, the changes generated by the children with autism were all reality-based, rather than imaginative. The results of this study are in line with our hypothesis that

imagining 'what is' is less impaired in autism than imagining 'what could be', resulting in imaginative creativity being more difficult than reality-based creativity.

Research on the drawing abilities in autism confirm the hypothesis of an impairment in the imagination of non-reality based meanings. Craig, Baron-Cohen and Scott (1998) found that children with autism did not differ from control children in their drawings of existing objects, but that they were less able (but not unable) to make drawings of impossible things, e.g. a man with two heads or a house with a door in the roof. Surprisingly, the children with autism could point out what was real or unreal when given drawings of unreal things. It seems that people with autism have a concept of what is unreal, impossible or fantasy, but that they have difficulties spontaneously generating imaginary ideas.

This is far from saying that there is a lack of creativity in autism. Autistic artists, like Gilles Trehin, Jessy Park or Stephen Wiltshire are proof of the contrary. It is remarkable, however, that the art of people with autism is mainly based on reality, quite often objects such as buildings or vehicles. In line with our hypothesis that the autistic imagination reflects the characteristics of the autistic perception, the drawings of artists like Trehin, Park or Wiltshire are often amazingly realistic and impressively detailed. In contrast, conceptual art is rare amongst artists with autism. The art works of people with autism are in line with our assumption that the representation of concrete and visual issues is not impaired in autism, but the representation of non-reality based and more abstract, conceptual issues is. There is more object-creativity in autism than concept-creativity, because the latter depends on aspects of imagination that we hypothesize to be impaired: the imagination without concrete, visual cues.

This does not eliminate the possibility of complete imaginary art. Take, for instance, the drawings of Gilles Trehin. Gilles developed a complete imaginary city, named Urville (see www.urville.com), including an imaginary historical, geographical, cultural and economic description of it. Gilles' drawings are impressive. His creation, however, has it roots in reality and is more concrete than conceptual. On his website he describes how Urville was created in his head. It all started with a (visual) fascination for the skyscrapers of New York, when he lived there as a child. Gilles, on his website: "At this time, I decided to build skyscrapers in Lego, *but I never had a precise objective*." Only a couple of years later, he decided to make drawings of his city, rather than building them in Lego. The inspiration for his earlier drawings came from illustrated books on real cities.

People with autism appear to be able to create novel things and to invent imaginary things, but it seems that they are impaired in creating something new 'out of nothing', when there is no concrete or visual input. Creating novel meanings and combining things into something new, two abilities commonly associated with creativity, do not necessarily demand high levels of imagination. Inventing novel combinations of, for example, a mouse, a telephone book and a frying pan (e.g. a mouse frying a telephone book in a pan) probably requires less imaginative abilities than, for instance, imagining how you should react in a situation you never experienced before. As a matter of fact, people with autism might even outperform neurotypicals in finding new combinations, because of their well developed systemizing abilities (Baron-Cohen, 2006). With their analytical mind and the typical autistic persistence, people with autism can, given a certain input, probably repeat the same operation (e.g. making a combination of mouse, telephone book and frying pan) over and over again, until the output gives no new combination anymore. But a systemizing brain is probably lost when there is no input or no suggestion for operations to be performed on this input.

Imagination and the current psychological theories on autism

The three main psychological theories on autism hypothesize a deficit/delay in Theory of Mind, Executive Functions and Central Coherence. None of these hypotheses fulfils all the criteria for a good psychological theory and each hypothesis has been challenged by several studies. However, they do help us to understand autism and they try to provide the bridge between the behavioural and the neurological findings on autism. These three theories should not necessarily be seen as rivals; it is possible that autism is the consequence of a combination of the acclaimed deficits or that there is another, underlying deficit, unifying the three theories. We will argue that imagination plays an important role in theory of mind, executive functioning as well as central coherence. We don't claim imagination as the unifying concept, nor do we offer a new theory on autism. Rather, we argue that an impairment in imagination is fundamental in autism and, in our opinion, any (new) theory on autism should incorporate the qualitative impairments in imagination and offer a plausible explanation for them. We will describe the link between imagination and central coherence, theory of mind and executive function only briefly here. A more detailed description can be found in the original, Dutch version of the current text (Vermeulen, 2005/2006).

Imagination and central coherence

In the revised edition of '*Autism: explaining the enigma*', Frith (2003) puts forward the hypothesis of a 'bottle neck problem' in autism. In perception, both bottom-up as top-down processes play a role. Bottom-up refers to the incoming information from the senses, while top-down refers to the influence of our knowledge about the world and our expectations on the interpretation of the input coming from our senses. Top-down refers to the schema-guided perceptual exploration of the environment in active vision. In this

'active vision' (Thomas, 1999), perception is guided by imagination through the 'filling the gaps' and 'seeing possibilities' principles described above. In this way, a lack of imagination and a lack of top-down modulation (Frith, 2004; Hill & Frith, 2003) can be seen as related to each other. Frith (2004) sees the lack of top-down modulation as compatible with the weak central coherence hypothesis. When there is insufficient top-down control, when perception is not guided by the conceptual knowledge and our imagination, bottom-up processes are unusually strong, resulting in a WYSIWYG-type perception: things are what they are and their meaning is not influenced by imagination of other possible, non perceptible meanings. Another consequence is that there is a tendency to focus on local, rather than global aspects of the object or situation perceived. Central coherence is the tendency to pull together information for higher-level meaning, meaning that is not present to the senses, but that is the product of our imagination.

According to Frith (2003, p. 158), "A drive for coherence and the ability to make use of context are one and the same thing". It is well known that contextual information guides our visual attention (see e.g. Chun, 2000). Visual attention is guided by context. We distinguish (Vermeulen, in preparation) two kinds of context: the context that is present to the senses (the scenery around the target of attention) and the context not present to the senses (our knowledge about the world, our concepts). In autism, there is evidence for a tendency towards local processing, i.e. the processing of details regardless of their context. Recent research has shown that, in autism, there may not necessarily be a deficit in the ability to process information on a global level, but rather a bias towards local processing (see a.o. the concept of enhanced perceptual functioning in Mottron et al., 2006). So, it seems that people with autism are able, when cued, to process context. However, this relates only to the context 'given', the context present to the senses. We assume that people with autism experience difficulties in contextual processing especially when it concerns the context that has to be imagined, such as other people's mental states, alternatives in choices, or possible solutions to a problem. It is especially the implicit contextual issues, those that are the product of our imagination, that are a problem in autism (Vermeulen, in preparation).

Imagination and executive functions

The term executive function (EF) describes a set of high-level cognitive abilities that control and regulate other abilities and behaviours. Executive functions are necessary for goal-directed behaviour. EF is a kind of umbrella term and encompasses a variety of abilities such as the ability to initiate and stop actions, to inhibit prepotent but inappropriate reactions, to plan and monitor behaviour and to change it if necessary. Because EF refers to quite different cognitive abilities, research into a possible deficit in EF in autism had shown mixed results (Hill, 2004): the hypothesized deficit in EF does not seem to be universal in autism, although several aspects of EF seem to be impaired in autism. Other neurodevelopmental disorders, such as attention hyperactivity disorder and Tourette's syndrome, also involve EF deficits. However, the EF deficits in autism seem to be different from those seen in these other disorders. Compared with children with attention deficit and hyperactivity disorder, children with autism do not have so many problems with inhibition and impulse control but mainly with those EF aspects that concern flexibility and planning (Geurts et al., 2004; Kenworthy et al., 2005; Kleinhans, Akshoomoff & Delis, 2005). Flexibility and, especially, planning are two aspects of EF that involve imagination, more in specific the ability to see 'possibilities' and to suppose. Flexibility and planning are those aspects of EF that are related to creativity. Flexibility is associated with the ability to generalize skills and actions beyond well known routines and situations and to think of 'new' possibilities. Construction workers and craftsmen, for instance, are quite flexible in their use of all kind of tools to open up bottles of beer. When they want to open a bottle, they do not necessarily need a bottle-opener, because they can 'see' in numerous objects (such as a key-ring, coins, screwdrivers, the edge of a table or even human teeth) a possibility of removing the capsules of beer bottles. This is the result of imagination (seeing what could be, seeing possibilities). Planning equally involves the ability to disengage from the current situation, from what is literally given, and to open up in one's imagination possible alternatives for the current situation. Wing (1996, p. 99) writes: "The worth of real imagination and creativity lies in the ability to associate past and present experiences and making plans for the future, both every day plans for tomorrow as the big plans for the rest of life". Simulation and anticipation are essential in planning and both take place in our imagination. In their study of creativity and imagination in autism, Craig and Baron-Cohen (1999) found that children with autism spectrum disorders were capable of generating realistic novel changes to an object, but that they were especially impaired in generating imaginative changes. This result can be better explained by a deficit in imagination than by a deficit in EF. According to the EF hypothesis, generating both kinds of solutions should be impaired, as a consequence of an impairment in generating novel reactions. Craig and Baron-Cohen conclude that their results point to the importance of imagination in creativity.

Imagination and theory of mind

The link between imagination and theory of mind has been well documented in the literature, for instance the relationship between pretence and the ability of metarepresentation (Leslie, 1987, but see also Jarrold et al., 1994). Mental states (such as feelings, desires and thoughts) are invisible and, hence, need to be imagined. You can see a tear on someone's face, but the sadness that you 'see' behind the tear, is a product of your imagination. Mentalizing is a form of imagining. Or, as Craig and Baron-Cohen formulate it (1999, p. 325): "…the deficits in social understanding and communication, which have been linked to a

theory of mind abnormality, may turn out to also be connected to the problems in imagination and creativity."

Theory of mind abilities are essential to what is commonly known as 'folk psychology'. Folk psychology refers to everyday human psychological competence, that is the knowledge, skills and resources that underpin our everyday capacity to predict and explain the behaviour of ourselves and others. In explaining folk psychology, two theories have been put forward. The 'theory theory' (Lewis, 1972) claims that folk psychology should be considered as a 'theory', which – as any other theory - organizes mental events taxonomically, makes generalizations ("laws"), and makes predictions about the future. In recent years, increasing attention has been given to the alternative account, known as simulation theory (Gordon, 1986). This theory suggests that mind reading involves making a simulation of the other person's experience and coming, based on that simulation, to predictions and explanations. Using our "mirror" system in the brain (Gallese and Goldman, 1998) and our imagination we put ourselves in the shoes of someone else. According to the simulation theory, imagination lies at the heart of mind reading. In simulation, we 'pretend' being the other person and we try to see the world through his or her eyes. It is no coincidence that people, when they try to be empathic towards another person, often react with expressions in the line of "I can *imagine* how hard, sad (etc.) that must be…".

Studies (see a.o. Abell, Happé & Frith, 2000; Castelli et al., 2002; Klin, 2000) have shown that the human brain spontaneously adds social meaning (mental states or personality traits) to ambiguous or even non-social stimuli (such as moving triangles). The attribution of mental states to animated shapes is a product of our imagination. According to these studies, people with autism are less able to attribute mental states to animated shapes. The imaginative power that enables us to see more than there is to be literally seen, lets us evolve from pure behaviourists to mentalizers or empathizers.

Conclusion

In line with Wing's original description of the triad of impairments, an impairment in imagination seems to be an essential characteristic of autism spectrum disorders. This impairment should not be seen as a lack of imagination, but rather as a qualitative impairment. People with autism seem capable of imagining certain things, and might even outperform non-autistic people in the creation of visual mental images, but they have difficulties imagining things that are not concrete or non-pictorial. Their imagination shares the same characteristics as their perception: it is primarily detail focused and concepts in the autistic 'mental world' seem to be more exemplar based than prototypical. Reality based imagination might well be intact in autism, but we hypothesize that especially the imagination of realities that '*could be*', the imagination of *possibilities*, is impaired. In summary, not the ability to "see with the mind's eye" as such is impaired in autism, but the ability to "see *as* with the mind's eye". This leads to a qualitative impairment in creativity, especially the creativity to generate novel and imaginary (in contrast with reality based) meanings without a clear input. Imagination also seems to play a role in the three prevailing psychological theories on autism. Without imagination it becomes difficult to read other people's minds. Without imagination things are what they are and consequently, flexibility in attributing meaning and planning behavioural reactions will be limited. Imagination is also crucial in the top-down control of the sensory input and the contextual attribution of meaning. An evidence-based description of the specific impairments in imagination in autism is for the most part still lacking, the neurological basis of an impairment in imagination is unknown and it remains unclear what exactly the role is of imagination in cognitive abilities such as mind reading, central coherence or executive function. Future research is needed to help us to understand the role of imagination in autism.

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0008

PRIMARY HEALTH CARE PROFESSIONALS: WHAT DO THEY NEED TO KNOW ABOUT THE AUTISM SPECTRUM?

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Introduction

This paper is based on work commissioned by NHS Education for Scotland (NES) and carried out by the Autism Team within the School of Education at the University of Birmingham. The brief was to produce a web-based resource on the autism spectrum for use by primary health care practitioners and to write a series of short leaflets as guides for those assessing and working with children and adults with a known or suspected autism spectrum disorder (ASD). The list of primary health care practitioners includes dentists, General Practitioners (GPs), dieticians, hospital doctors, health visitors, nurses, occupational therapists, physiotherapists and speech and language therapists. Each member of the Autism Team at the University of Birmingham has had practical experience of working with individuals across the lifespan with ASD and with their families and professionals. This has included work at all ages (early years to adults) and at all levels of intellectual ability. In addition, the Team has experience of developing training materials and resources for a wide range of professionals working in different settings. Of particular relevance to this proposed resource, was the web-based, accredited autism course for professionals and parents developed by the Autism Team. This involved designing and creating easily navigable web pages and web resources for students (URL: www.webautism.bham.ac.uk). An evaluation of how user-friendly the Webautism programme is, has been built in from the start and many changes have been made during its four year life to the present. Web-based delivery of materials is in its relative infancy and there is much skill and expertise in setting up sites which make information easy to access and understand.

Need for the resource

Both research and practice and reports from families often show that primary health care professionals often have limited knowledge of ASD (NIASA, 2003; Howlin, 2003). This is not surprising given that most are generic workers and have to deal with individuals with a wide range of disorders and conditions. Increasingly, posts are being created where a health professional has dedicated time (either full or part-time) to focus on those with ASD, but this is still the exception. The initial training for dentists, doctors, nurses and therapists may have very little on ASD, and knowledge and understanding of ASD continues to develop and change, so this knowledge needs to be continually updated. There are post- qualification courses specific to ASD, some of which are accredited, but funding and opportunities to access these again may be limited. Studies on the age at diagnosis show that although this is decreasing (Howlin & Moore, 1997), there are still many children and adults with ASD who are misdiagnosed or not diagnosed until they are in the secondary phase of education or into adulthood (Murray, 2005).

With increased awareness of ASD and improved identification, prevalence is rising (Medical Research Council, 2001) and so the numbers of children and adults with a diagnosed ASD whom healthcare professionals will meet is also rising. There are important implications for the assessment, treatment and management of individuals with ASD relating particularly to communication, sensory perception and responses, anxiety, fears and social understanding. Having knowledge and understanding of these may be crucial to obtaining a correct diagnosis and to the success of treatment, and is likely to enhance the health care experience of the individual with ASD and families and carers generally.

Possible scenarios for the primary health care practitioner in relation to ASD

It may be the case that the practitioner knows in advance that the person referred has an ASD. In these situations, there is the opportunity to alter the environment, the approach taken by staff, the waiting time and other aspects of the appointment which may be to the advantage of all concerned. In some cases, a practitioner may only be told that the person has an ASD on arrival at the clinic, centre or hospital. There is then less opportunity to take appropriate action, but still time to modify the actions of key personnel and to ask the parents or carers for advice. There will be many times when the practitioner does not know that the individual has an ASD (and the diagnosis might also be unknown to the individual and the family). In these situations, there may be confusion over symptoms and reported behaviours leading to misdiagnosis or inappropriate management of the assessment or treatment plan. It might occur to the practitioner that the person has an ASD, and then decisions need to be made as to how that suspected diagnosis may be explored. Finally, the prime reason for the visit may be that the individual or parent suspects ASD. Again, this would lead to a different set of actions and knowledge by the practitioner. The Website and leaflets are designed to enable practitioners to respond appropriately and effectively in each of the above scenarios either during the diagnostic assessment or in the course of treatment for related or unrelated conditions.

Possible experiences in a health care setting for a person with ASD

There are a number of possible events and actions which might occur for the person with ASD in visiting a health care setting for assessment or treatment, as follows:

- o   Making an appointment

- o   Having to wait to be seen

- o   Completion of written forms

- o   Giving a medical history

- o   Undergoing a physical examination or treatment

- o   Being prescribed medication

- o   Admissions to hospital

- o   Visits at home

For children and young people with ASD, the parent or carer is likely to make the arrangements for the appointment. For adults with ASD who live independently, it may be very difficult to recognise they have a need to visit a health care practitioner or to make the necessary arrangements to do so. Burlton (1999) describes the increasingly challenging behaviour of a young adult with ASD who was usually fairly calm. Detailed behavioural analyses by staff threw no light on the underlying causes of this. It was only when he collapsed on the floor in agony, that it was discovered that his intestine was impacted, having eaten a large quantity of plastic carrier bags over time. He needed emergency surgery.

Using the telephone or visiting a health centre may be difficult or impossible without support. Once an appointment is made, the individual has to be able to manage and tolerate the physical, sensory and social aspects of a health care setting, all of which may pose significant problems. Reading and understanding forms which may need to be completed is likely to require more time and explanation and health care staff may not appreciate the need for support in doing this, even when asked, if the person appears to have fluent spoken language and good vocabulary.

Once with the practitioner, it is usually necessary to describe the nature of the concern. Again, it is known that many with ASD have difficulty in explaining and indicating the source of pain or distress. Practitioners need to appreciate the literal thinking of those with ASD when phrasing questions and interpreting responses, to ensure they do get an accurate assessment and analysis of the presenting problems. Many have written of the sensory problems experienced by those with ASD and so a physical examination or treatment involving touch, removal of clothes, bright lights, or machine noise may pose significant problems for some individuals (Bogdashina, 2003; Myles Smith et al., 2001; Williams, 1998). Where a parent or carer is present, then information on the nature of the examination and the likely response is often essential beforehand. Yet, many parents have said when they have offered such advice, this has been ignored, to the detriment of all concerned. Practitioners may feel that it is not appropriate within the rules of privacy and confidentiality for parents or carers to be present during a consultation, but the guide here needs to be what is appropriate to the person and what is in their best interests, rather than what is age appropriate.

There are case studies which report on the unusual and atypical responses of individuals with ASD to medication which is prescribed for the general population (Gringras, 2000). So practitioners need to be aware of this possibility and monitor the person closely to check for this. Sedatives, for example, have led to hyperactivity in some. Adults with ASD may misunderstand how and when they should take or use medication. For example, an able woman with ASD described how she increased the frequency with which she applied the ointment to her eye, as the condition was not improving and she took the view that more ointment must be better. Her eye condition seriously worsened. Where hospital admission is required, many individuals with ASD can manage such change if well prepared for what is going to happen and when they are given some idea of when they will return back home, where possible. In terms of home visits, some may find it easier if the practitioner visits them at home rather than the clinic; others would not want their private space to be invaded by strangers. Consultation with the person or the parent or carer is therefore important.

Leaflets developed for primary health care practitioners

It was decided to create four leaflets on separate aspects of ASD, and that these would be linked and delivered on a one per month basis over four months. Their titles are as follows:

o   Has my next patient for an ASD?

o   ASD and additional conditions

o   Supporting your patient with ASD

o   Supporting the family with a child or adult with ASD

Has my next patient got an ASD?

This covers the key signs or alerting symptoms that a child or adult might have an ASD. It gives advice on ways to explore a possible diagnosis and details of diagnostic instruments and procedures, as recommended by NIASA (2003). In addition, there is a short section which considers the potential benefits of diagnosis.

ASD and additional conditions

It is of course possible for a person to have other disorders or conditions in addition to ASD (eg visual or hearing impairments, learning disabilities, Down syndrome, cerebral palsy), and there are some which appear to occur more frequently than in the general population (eg epilepsy) (Gillberg & Coleman, 2002). Some children and adults will develop mental health disorders (Ghazuiddin, 2005), particularly anxiety disorders and depression, which may be initiated and maintained by inappropriate living, educational or working environments. Many report or experience sleeping difficulties and dietary problems and some have been misdiagnosed as schizophrenic (Lawson, 1998) or as having an obsessive compulsive disorder as symptoms have been misinterpreted. Cognitive behaviour therapy has been reported as being helpful for some with Asperger syndrome (Hare,1997) and relaxation techniques and peer support can be helpful in addressing mental health issues.

Supporting your patient with ASD

This leaflet describes a number of ways in which the practitioner who knows the person has an ASD, can enhance the consultation and assessment process. Suggestions are made as to how the physical and sensory environment might be altered and on the ways in which information can be given and explained to the person

Supporting the family with a child or adult with ASD

This is written to stress the importance of involving the parents or carers in the process, irrespective of the intellectual ability or age of the person concerned and to take their concerns seriously. In addition, it is advised that good literature is provided on the diagnosis and the treatment recommendations, wherever possible. As the situation of families and individuals with ASD is often exacerbated by other social, financial and housing factors for example, it is suggested that the individual or the family is referred on to other agencies who might offer support and advice.

Structure of the website

There are four main sections, each covering a different topic. The user can access the different sections in the order they find most useful. There is no predetermined route. A site index will allow searches for particular subjects. The four topics covered are the person with a known ASD; practical strategies; health issues in ASD; and diagnostic issues, each of which is divided into three or four parts. A number of case studies have been written on children and adults to illustrate different points, and links have been created in the relevant parts of the site (see *Appendix 1* for an example of a case study). The section on the patient with ASD covers the potential effects of ASD on the child or adult, sensory issues, and understanding behaviours seen and reported. The section on practical strategies covers routine medical management; recognising and managing stress and encouraging communication. The third section on health issues covers daily living and relationships, emotional issues, mood disorders and idiosyncratic reactions to illness. The final section covers diagnostic issues concerned with identification, screening, diagnostic instruments and protocols, and co-occurring conditions. It also has a section on what follows diagnosis, making the point that advice on interventions needs to be linked to diagnosis, otherwise individuals and families are left feeling unsupported.

Potential barriers to the use of the website resource and the leaflets

Information overload is a problem for many primary health care professionals. The amount of post received each day and the ever increasing lists of electronic information and electronic resources (eg e-books; e-journals; websites) can mean that new resources are buried or lost and not accessed by the intended audience. The NES deliberately commissioned a resource in two forms – written and web-site, to increase the likelihood of uptake. Many working in health are generic workers and ASD is just one of many priorities. With the rising interest and media headlines in ASD over the last 5 years, some may feel that ASD as been given too much emphasis, at the expense of other disorders and conditions.

Evaluation of the website resource and the leaflets

At the time of writing the paper, the website has not been officially launched, although this is planned for November 2006. It is planned to record the number of visits to the site and to build in a method of feedback. The leaflets have been distributed and anecdotally there have been positive reports on these and requests for more copies to be sent out. Once the Website has been launched, it is intended to interview users about its value, contents and navigability. Most resources are created by people who know about ASD. It is important to evaluate what sense the information makes to those who know little about ASD, so a range of people will be interviewed in terms of prior knowledge of ASD.

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Appendix 1: Example of a case study given on the website

Peter is a forty-five year old man with autism who is articulate and literate and who lives alone without support. For many years, he was employed as a hospital porter. This was a full-time post and was his main contact with people. However, three years ago he was made redundant and this dramatic change in circumstance affected him greatly. With the end of his employment, Peter not only lost contact with colleagues, but also many of his regular routines. His job was also his motivation to care for his

appearance and to go into the world outside his flat. With this motivation gone, Peter began to neglect himself and spent whole days alone. He became increasingly depressed and de-skilled.

His mother and GP arranged an appointment for him to see a psychiatrist, to address his depression. This took place on a Monday morning. Peter had no expectations of the appointment and answered questions in his typical, literal way, giving exactly the information asked of him and no more.

For example, when asked by the psychiatrist if he was eating and sleeping OK, Peter replied that he was. His mother intervened at this point to ask exactly what food and sleep Peter had taken in the preceding weekend. In a matter-of-fact voice, Peter explained that he had stayed in bed all weekend, and had eaten two crumpets on the Friday and nothing since.

Peter did not perceive this as a problem, since this is what he had felt like doing, and so it had been his choice. He was not able to make a connection between this behaviour and his general mood, nor place it in context and identify that it was an unusual behaviour for him, or an undesirable behaviour for his general health. Without the intervention and help of a person who knew Peter well, the psychiatrist may not have been able to get this important information from Peter, and so may not have been able to help his recovery (which was a combination of treatment for depression and practical support to re-introduce constructive routines and community links).

0009

AUTISM ACCREDITATION – THE RECOGNITION AND DEVELOPMENT OF HIGH QUALITY AUTISM SPECIFIC PROVISION IN THE UK

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Quality assurance, Accreditation and Service quality are topical issues worldwide and the trend to focus on quality, standards and accountability is ever increasing. Specialist service providers agree that quality is important and evidence of this is essential to satisfy purchasers, yet many find that traditional quality assurance systems are not appropriate tools to measure autism specific services.

The National Autistic Society (NAS), United Kingdom took cognisance of this and since 1992, has operated an autism specific quality assurance programme which aims at improving the quality of service provision for people with an autistic spectrum disorder. Autism Accreditation provides a systematic framework for continuous review and development by ensuring that services registered meet established criteria.

Autism Accreditation has been extremely successful in raising quality and standards in specialist and generic services for both children and adults in the United Kingdom and this paper will cover the evolution of the programme since 1992 focusing on an overview of the process, the standards used, role of the Standards Body and Panels. This paper will also address these issues regarding autism specific quality assurance from both the programme providers and the 'clients and consumers' point of view and include data collected from a survey of participants as to the effectiveness of the programme and the outcomes in terms of quality, marketing, benchmarking and service development planning and conclude with ideas for the future.

The Autism Accreditation quality assurance process.

What is quality? Behind this question lies the fundamental issue of the purpose of education and care. Is it about what is wanted or needed, and if so, who defines these wants and needs? There are many competing views on what the nature of quality is. Some view it as implicit and indefinable 'you know it when you see it.' The opposing view is that quality should be viewed in terms of 'measurement' i.e. according to satisfactory conformance to some predetermined standard. Others claim that quality is simply a matter of reputation. In the commercial sector quality is often viewed in terms of meeting or exceeding contract requirements, in the service industry it can be defined as whether or how well the duties were performed or how well the customers' needs were met.

In education, the debate on quality often focuses on standards of attainment in examinations whereas it is believed in many other circles that there is necessity for a shift in focus from the quality of outcomes to the quality of the processes. Grey in Preedy (1993, p 27) is cautious about Local Education Authorities (LEA's) insisting that school's in the UK publish their exam results as a measure of quality as he believes that we run the risk of rewarding schools for the 'quality' of their intakes and not what they do with them.

The dictionary describes 'quality' as 'a degree of excellence'. Further definitions relating to quality focus on conformity with the requirements. A working definition for a quality service for people with an autistic spectrum disorder can be expressed as:

- The service is responsive to the current and changing needs of its clients

- The service is fit for its stated purpose.

- The service is operating to agreed standards

- The service is committed to the achievement of high quality

Quality and Standards

Much of the literature on quality in education focuses on quality as an ideal, an intangible and intellectually complex concept. There is a difference between 'quality' and 'standards.' 'Quality' is about consistently meeting expectations whereas the 'standard' refers to the expectations themselves. The consistency and rigour with which processes and procedures are carried out is 'quality' and the degree to excellence of the propounded processes and procedures is a 'standard'. Autism Accreditation describes itself as a quality assurance programme that involves the service undergoing a self-audit with prescribed standards and an external review leading to accreditation.

A quality audit is a systematic and independent examination to determine whether quality activities and related outcomes comply with planned achievement of agreed standards, and to evaluate the need for improvement and the focus of development. Teams having no direct responsibility for the service being audited, but preferably working in similar or related situations, carry out the quality audits. An audit should not be confused with an inspection performed for the purpose of quality control.

Quality Assurance

Quality assurance attempts to assure the quality of the output before it occurs and does this by focusing on the production or service process. Quality Assurance involves prevention through more accurate specification and managerial support would be provided to enable staff to meet these required standards. Basically, quality control tells if a service is going wrong whereas quality assurance aims at preventing it going wrong. Munroe-Faure and Munroe-Faure (1992, p.6-7) describe quality assurance as:

"…a management system designed to control activities at all stages … to prevent quality problems and ensure only conforming products reach the customer. The key factors of an effective quality assurance system are:

      (i)   an effective quality management system

      (ii)   periodic audit of the operation of the system

      (iii)   periodic review of the system to ensure it meets changing requirements

Quality Assurance usually involves the audit of an organisation's management system by an outside agency and the formal process of external validation by appropriate quality certifying body such as Autism Accreditation. Examples of quality assurance systems that include a system of 'accreditation' from an outside agency are Investors in People, British Standards 5750, The European Quality Award (E.Q.A.) and Autism Accreditation. All these programmes have prescribed criteria used as a checklist to rate the structures and functions of the organisation as a means of assessing quality.

History and Development of Autism Accreditation.

The NAS who owns and manages Autism Accreditation was started by a group of parents in 1962 and has grown into the UK's foremost organisation for people with autism and those who care for them. The NAS runs six residential schools and children's homes and eighteen adult day and residential services.

Providing quality requires a system of evaluation, accountability, and improvement that meets its specific needs and has models of management and evaluation that recognise the dynamic of the process. The tools traditionally used to measure quality in education and care proved frustrating to providers of autism specific services and it was difficult to produce evidence of autism specific quality. This lack of objective or quantifiable evidence of 'what is different about quality services for people with autism' led to issues with funding authorities, decreasing credibility and loss of competitive edge.

The NAS recognised this and in order to address this issue and meet the UK Government requirements of 'standards, choice, accountability and value for money' plus ensure the feasibility of specialist services within the voluntary sector, a programme of quality audit and service review leading to 'accreditation' was introduced aimed specifically at schools and adult services for people with an autistic spectrum disorder.

The NAS was the initial catalyst but the Autism Accreditation programme was developed by the NAS in partnership with the affiliated network of local autistic societies. The initial standards for accreditation were developed by the members of the programme and led by the Children's Services and Adult Services Committees. Start up costs were assisted by a two-year grant from the Department of Health, but subsidized by the NAS.

The original issues addressed by the development of an autism specific quality audit system were:

- the need to identify what constituted quality in autism specific services

- the need to quantify the specialist content of services

- the sharing of good practice

- the need to demonstrate 'value for money' or 'value added' as is currently required

- the need to promote continuity and consistency in the quality of services across the UK.

Other benefits identified for services enrolled in the programme were:

- the establishment of the credibility of autism specific services

- the value of participation in an objective external assessment programme

- the sharing and development of specialist knowledge and skills

- the reviewing and developing of the accreditation quality assurance framework

- being able to demonstrate through accreditation that the organisations formally identified its commitment and ability to provide services addressing the specialist needs of people with an autistic spectrum disorder.

In recent years with the introduction of 'best value' and increasing competitiveness between services due to the limited budgets held by the funding authorities, many services believe that the enrolment in the programme and achievement of accredited status has become a marketing tool and has helped services achieve a business advantage over those not enrolled in autism accreditation.

What is Autism Accreditation?

Quality assurance is an internal process of service review and development of the organisational structure, responsibilities, processes, resources and outcomes for implementing and developing quality service. It is a process that requires the involvement and commitment of all and focuses on consistency and continuity in all levels of performance and operation.

Autism Accreditation is an autism specific quality assurance programme that consists of a continuous cycle of review and development, the aim being to provide a systematic framework for the development of quality in services providing education and care to people with an autistic spectrum disorder. This is achieved by way of a peer review using standards developed for each particular type of service being reviewed. The standards consist of core standards, accompanied by a set of specialist standards appropriate for that particular service for example, an adult day centre, residential school or supported living provision. These standards and the structured format of the review provide the consistency and continuity in evidence collection by which to measure the practice and ethos of an establishment and objectivity when recording and reporting.

After enrolment, an Advisor is assigned to support the service to interpret the standards and develop their practice to the standard required to achieve accredited status. The first review will occur within the first three years of enrolment. After a service has achieved accredited status, annual reviews will be conducted based on the services' previous review report, an area for development selected by the panel, an area of their choice and a random standard selected by Accreditation.

Via the review teams and self audit documentation, evidence is collected on the 'autism specific' elements of a service via a set framework of standards. Evidence is acquired in written format prior to the visit through a self audit and during the review by process of observation, discussion and data collection with the use of indicators and standards to focus the consistency of the decisions made. Evidence is evaluated using autism specific criteria applied to each area of the service reviewed.

In order to achieve accredited status the school or service must demonstrate evidence of:

- a specialist knowledge and understanding of autism.

- that the knowledge and understanding of autism consistently informs the organisation, the resources and management of the service

- that the knowledge and understanding of autism consistently informs the individual assessment and support plans for all service users

- evidence that the knowledge and understanding of consistently informs all aspects of practice.

The Standards Body are responsible for developing and updating the standards that services are assessed against in order to find evidence of autism specific practice. Core standards that all services are assessed against cover a wide range of issues and include:

Recruitment and Induction	Continuity and consistency	Social understanding and ability
Professional development	Assessment, reporting and reporting	Flexibility of thought to cope with change
Staff information resource	Individual plans	Service Development Plan
Consistent understanding of autism	Behaviour support	Operational policies
Communication	Family and support links	

To ensure that Autism Accreditation is an autonomous and unbiased system, a range of procedures have been set up to ensure impartiality and independent decision making. Although owned by the NAS, Autism Accreditation is independent of the NAS management structure, reporting directly to the Chief Executive and the Board. The decision-making in respect of the awarding of accredited status is the responsibility of an accreditation panel, led by the Lead panel member (a member of the Standards Body and representative of the NAS). Accreditation panels consist of practitioners with a professional qualification and experience in autism specific education, research or care and they are selected to serve on panels which are hearing reviews on services which match their particular expertise. After considering the review report and in consultation with the review team leader, the panels make the recommendation to award, defer or deny accredited status. This decision is ratified by the Director through discussion with the Lead panel member to ensure that correct procedures were followed and the standards and criteria for accreditation have been consistently interpreted and the certificate of accreditation is awarded by the Board. Appeals are dealt with by the Director.

An evaluation of Autism Accreditation as a Total Quality Management system

It could be argued that considering Autism Accreditation was developed as a quality assurance system, the fact that its focus is on 'fitness for purpose' and strives to meet its specific customer's requirements; it could be viewed as a Total Quality Management system. The significant dimensions required to achieve total quality i.e. a focus on customers, vision, values and people is the foundation on which Autism Accreditation was based. The entire programme has been developed to meet the specific needs of people with an autistic spectrum disorder. Total quality management systems should be adapted and developed to allow a service to be itself and express its full potential, and Autism Accreditation embraces this concept totally. All services within the programme are individual and adapted to function to meet the needs of their specific client group but all strive to meet the overarching quality standards that are accepted 'good practice' in this specialist field.

Autism Accreditation satisfaction survey

The aim of Autism Accreditation is to improve the quality of life for as many people with autism and their families by improving and maintaining quality standards and in addition to this, increase the visibility, credibility and influence of specialist autism service providers. This survey completed in 2003 aimed to assess whether Autism Accreditation had achieved these stated aims and to evaluate the satisfaction of participants in the programme and informal follow-ups have since been undertaken.

Motivation to participate in Autism Accreditation

The rationale for joining Autism Accreditation appears to have changed over the 12 years it has been in existence. Initially participants represented the autistic societies and the majority joined to improve quality and to obtain some form of recognition, or validation, that they were centres of excellence and leaders in the field of service provision for people with an autistic spectrum disorder. It was only from about 1997 onwards, when Autism Accreditation began to attract wider consumer interest, that services started realizing its value as a marketing tool. In a specialist field such as autism, quality is extremely marketable and with increased competition in the UK, the concept of added value has exacerbated this. This trend started to increase sharply in 2001 and may account for the large number of national health service and private providers who enrolled at that point with the aim of improving both quality and marketability.

Overall the motivation to join Autism Accreditation prior to 2000 was well balanced between quality issues and marketing. 98% joined to increase quality and 82% were motivated by the marketing benefits. The fact that 97% were motivated by the opportunity to validate their service and thus increase credibility would suggest that the majority were motivated to join the programme due to a commitment to increase quality and an awareness of the power of quality as a marketing tool.

Since 2005 there has been a change in new membership with a large increase of private providers and Local Education Authority and Social Service provisions enrolling. In a very competitive, entrepreneurial

and economically driven environment, the 'kite mark' appears for many to be the most influential factor for joining with a focus on the marketing opportunities the credibility, kudos and the 'financial viability' the 'accredited status stamp' brings.

Increased quality as a result of Autism Accreditation

The survey found that 100% of schools and 98% of adult services reported joining the programme to increase quality and 100% of accredited schools and 73% of non-accredited schools and 92% of accredited adult services and 82% non-accredited adult services report that participation in Autism Accreditation has increased quality.

100% of accredited schools and 82% of non-accredited schools, and 87.5% of adult services had evidence of increased staff awareness in autistic spectrum disorders which has a positive impact on the quality of the provision. The survey also found that 64% of schools, 87% of accredited adult services and 88% of non-accredited services reported an increase of activities for their pupils/clients and 75% of schools reported an increase in pupil progress and targets being met with 63% of adult services reporting an increase in client's targets being met and 70% had evidence of increased progress. Incidents of challenging behaviour were reported to have decreased by 53% of adult services. This was not significant in schools.

Accredited schools appear to be more committed to quality with all using a range of quality assurance systems in addition to Autism accreditation. There appears to be a correlation between schools and services that join Autism Accreditation and benefit most from it and the use of other quality assurance methods. Accredited schools use an average of 3.2 other quality assurance systems whereas non-accredited schools use 2.5. In the Adult sector, accredited services use 1.5 and non-accredited services 1.4. No accredited schools and only 3% of non-accredited schools do not use any other quality assurance system systems but 22% of accredited adult services and 21% of non-accredited services use no other systems. The commitment to quality and the use of a range of systems to improve quality appears to be more prevalent in schools than adult services and these schools also used a range of internal systems, intrinsically focusing on quality as a core part of their practice and not something 'added on' for external validation. This, according to Bowring-Carr and West-Burnham (1994) is where real quality in education lies.

> " Quality cannot be imposed from outside. Quality, the drive for quality, the obsession with quality, comes from within, or it cannot be achieved at all." (p.53)

Since 2002 and additional benefit of participation in Autism Accreditation has become predominant and that is the staff development and training aspect of leading or contributing to a review team or as a panel member. The services that encourage their staff to participate in these activities report the excellent benefits it has on individual staff development plus the development of the quality practice in the service. In 2006, services owned by autism specific charities represent only 13% of the membership and yet it is interesting to note that schools and services that have maintained accredited status over a significant period of time are predominantly from this sector and they are also the services whose staff contribute most to the process. This shows a strong commitment to improving the lives of people with autism by the charities and has also resulted in an increase in quality through greater expertise and experience and this is backed up by studies that have found that staff development opportunities increase the retention of high quality staff.

Increased marketability as a result of Autism Accreditation

The closer the match between who the customer is, what is offered and how it is presented, the greater the chance of 'fitness for purpose' and therefore quality. It is on this premise that Autism Accreditation was developed. A viable service needs to decide on a strategy to position and promote itself within the community to whom it wishes to provide its services and autism specific quality is the most appropriate one for these services and this can be demonstrated through achievement of accredited status. All participants in Autism Accreditation believed that it was a strong marketing tool and that the marketing of autism specific quality is very powerful.

All schools surveyed and 95% of accredited and 89% non-accredited adult services believed that participation in Autism Accreditation would validate their practice and increase their credibility leading to increased marketing opportunities such as requests for training and consultancy. 64% of accredited schools report an increase in requests for training as did 63% of accredited adult services. The response from non-accredited schools was as high with 73% of non-accredited schools reporting an increase in requests for training. Most of these schools were LEA schools in areas where they the only provision or seen as experts in their field.

The survey also found that 82% of schools had evidence of increased parent and purchaser satisfaction. 77% of adult services had evidence of increased parent and 80% increased purchaser satisfaction. The level of complains received had only reduced by 37% in accredited schools and adult services and 38% in non-accredited services. Many omitted to answer this question stating that they had remained constant if not insignificant.

Schools and services are accountable to market forces as unless they are able to attract and retain sufficient customers they will not receive adequate funding to ensure viability.

" Schools and Colleges are both faced with a situation where their survival ultimately depends on attracting sufficient numbers of pupils and students. This has encouraged a marketing orientation. " Coleman and Bush (1994, p.68)

This has become a very serious issue in the UK since the governments focus on inclusion. Capitalising on the fact that a good reputation is the deciding factor for many parents, and a means by which they can try to persuade funding authorities to name the school of their choice and not be forced into accepting the school named by the authority, evidence of autism specific quality is essential. Accredited status is the strongest means by which they can judge specialist quality.

While 53% of accredited schools and services reported an increase in referrals, 50% of non-accredited services also did. This would indicate that enrolment in the programme assumes a commitment to the development of quality, an assumption this survey found sometimes to be untrue. It also indicates to the NAS that a national marketing exercise is required to increase the awareness of purchasing authorities of the value of Accreditation and the need for services to have evidence of autism specific practice that is accredited to be named on their preferred provider lists.

It was interesting to note though, despite the introduction of the government's policy on inclusion, in 2003, 57% of accredited schools and services still reported a decrease in vacancies and only 14% of non accredited services did. This statistic has changed dramatically over the past 3 years with a much larger percentage of schools, in particular independent residential schools, having evidence of a change in referral patterns, decreased referrals and increased vacancies by 2006.

A service with a quality reputation is also attractive to staff and it was hypothesised with the 'kite mark' of Accredited status and the additional training benefits being part of the programme brings; recruitment and retention of staff would increase. The survey found that only 24% of accredited schools and services and 40% of non-accredited schools and services reported a reduction in staff turnover and 27% of accredited schools and services and 29% of non-accredited schools and services reported a reduction in staff absenteeism. Literature suggests that services who participate in quality assurance systems retain and recruit more staff than those who do not. This result may not be entirely down to Autism Accreditation but also due to social and economic trends in the UK.

'Value added' benefits of Autism Accreditation

Other motivators that came out strongly in were Autism Accreditation's value as a development tool by 98% of all services, and 74% of schools use the Autism Accreditation standards as a means of preparation for other inspections whereas only 64% of adult services did. 13% of non-accredited schools and 31% non-accredited adult services did not use accreditation as a benchmarking tool. 83% of accredited services did. The development of Quality Action Groups was found to be 'patchy' with more adult services than schools having these.

Conclusion – Customer satisfaction

It would appear that the overwhelming majority of participants in Autism Accreditation are extremely satisfied with the results of their participation in the programme. In 2006 participants also rate the bi-annual 'Best autism practice' forums as valuable and the networking opportunities a contributing factor to their job satisfaction. There is overall satisfaction with the support they receive from the Accreditation Advisors, and services that have had reviews led by the Advisors are very satisfied.

The majority found the Autism Accreditation review process supportive and developmental and the opportunities to contribute to the process through participation in teams and panels was not only seen as a means to improve their own professional practice and the quality of their services but also a positive and 'value added' aspect of their professional careers which motivated them to increase their commitment to autism and improve their knowledge.

Autism Accreditation can be described as successful and effective as it has achieved its aim in improving the quality of service provision for the clients in its schools and services and in doing this has also made them more successful in terms of competitiveness, security of tenure and proactive in terms of growth and development. There is strong evidence that by participation in the programme the service's quality

improves, and yet it appears that it is the enrolment in the programme and not accredited status that results in an increase in marketability, an issue for the NAS and Autism Accreditation to address in the future.

Autism Accreditation– the management of quality assurance

Quality has to part of the culture of an organisation to be successful and effective and therefore it is essential that the Autism Accreditation itself demonstrates a commitment to quality such as the participants in the programme do. Consequently Autism Accreditation is a founder member of the United Kingdom Accreditation Forum and in 2001 voluntarily participated in a self-assessment pilot and peer review using the International Standards for Healthcare Accreditation Bodies (ISQua) with very positive results. Autism Accreditation's commitment to improve quality standards is acknowledged

"The Autism Accreditation programme is an extremely authoritative and well structured quality system which promotes continuous improvement to create the highest care standards." Chairman. UK Accreditation Forum and ISQua, UK.

The continuous development of Autism Accreditation specialist standards

The quality and value of Autism Accreditation rests with initially the standards and secondly, how these are interpreted. Team leaders, team members and panel members undertake rigorous annual training in the interpretation of the standards and use of indicators, guidance in making fair and sound judgements and how to report and present their findings to the panel but unless the standards themselves are appropriate, fit for purpose and meet the needs of the individual services, the programme will not be effective. In the complex world of supporting people with an autistic spectrum disorder we can only measure quality by measuring the right things and not that which is most easy to measure and for this reason we need highly specific criteria to judge against.

Only with continuous improvement can Autism Accreditation create the highest care and education standards and it has met this challenge over the past 13 years. Autism Accreditation grew from 12 adult services and 6 schools in 1993 to 128 adult services and 37 schools in 2002. The largest percentage increase in membership has been from non-autistic society provisions such as Health Trusts, privately owned services and those run by LEA's and Social Service Departments. Until 2000 all services were assessed against the Core standards and either school or adult service standards.

Since 2000 there has been a large increase in membership and the profile has changed greatly. By 2002, 33% of members were from the NAS and affiliated charities and 24 % were from other charities. 24 % of members came from private providers, 14 % from LEA's or Social Service Departments and 6 % from the NHS. The autism specific voluntary sector still made up 33% of the membership (as opposed to 100% membership in 1993) but there was a sharp increase in membership from generic charities who provide support to people with autism in provisions for people with learning disabilities.

This profile has further changed and membership has doubled over the past four years. In 2006 there are 277 services registered; 187 adult services and 90 schools. Only 13% of membership is now from the NAS and affiliated charities and 13 % from generic charities. The big increase has been in the private and government sector; 51 % of members private providers and 25 % LEA's/Social Services.

The original charities that were part of the development of Autism Accreditation are now in the minority and the level of autism specific expertise in services enrolling now days cannot be assumed to be the same as it was in the past. The membership profile has changed so considerably, this has led to the development of a range of specialist standards developed to meet these provider's needs and in anticipation of future potential need. The following specialist standards are available for services to be assessed against in addition to the core standards and Care of the Aging is currently being developed

Children's Services / Education	Adult Services
Pre-schools	Residential Services
Day Schools	Day Services
Residential Schools	Secure Accommodation
Colleges and Further Education	Employment Services
Educational Outreach Services	Community Outreach Services
Foster Care Agencies	Supported Living Services

Respite Care Services for children	Respite Care Services for adults

The change in the membership profile could be put down to a number of factors and as the research project in 2002 predicted, economic factors including marketing, inclusion, obtaining a competitive edge and financial constraints of local authorities have made an impact plus the increasing entrepreneurial climate within the world of providing services for people with autism.

The future of Autism Accreditation

The development of Autism Accreditation arose out of a desire to ensure consistently high standards of provision throughout, initially, the affiliated network and subsequently, all providers of autism specific services whether they be within the voluntary, private or public sector. This has not changed in fact it is possibly more important now and in the future as is the need to be able to demonstrate quality, effectiveness and value for money. A number of highly specialised schools and services have been Accredited since the programmes' inception and yet feel that they may be losing their 'cutting edge' status do to the increased number of Accredited services. After achieving Accredited status for three consecutive years, services are awarded 'Plaque status' and are may be offered a 'gap year' by the panel followed by a full review but as yet, there is no real means of distinguishing between 'bronze, silver and gold status'. To address this issue, Autism Accreditation is considering introducing 'excellence standards' which the panel will invite 'exceptional' services to consider being assessed against. Excellence standards will require a full audit every two years. To be considered for the Excellence standards, 90% of observations must be rated as good, none less than satisfactory and panels will need to possess the skills required to moderate decisions and benchmark services.

Many generic services are increasingly offering support to people with an autistic spectrum disorder within learning disability services and the Autism Accreditation standards will ensure that these people receive a service 'fit for purpose'. In addition to this, there may be some private providers who enter this field for economic more than humanitarian reasons and LEA's who re-designate schools to decrease expenditure rather than increase educational opportunities for children with autism. To promote the rights of people with autism to receive appropriate and high quality services, an objective means to assess the autism specific quality of a provision is even more important today.

There are greater numbers of services for people with autism in the UK and this has increased the competitiveness of the market and the need for recognised reputation, credibility and thus viability. A number of strategies are discussed in literature on the marketing of schools, a specialist provision would probably opt for an 'enhanced niche' model, (Murgatroyd and Morgan 1992, p.29) which requires a school to provide a service mix that gives emphasis to some particular aspect of the service it provides such as specialising in a particular field of education. A school pursuing this strategy seeks to create a very distinctive position for itself as it aims to carve a unique role in the market for schooling by becoming 'leading edge'. In achieving 'leading edge' or ' centre of excellence' status this school would need to compare itself with other schools offering the same specialism and a number of strategies including quality management, marketing, benchmarking and involvement with an externally accredited quality assurance system such as Autism Accreditation are means to achieving this.

Inclusion has had a great impact on specialist schools for children with an autistic spectrum disorder and many have experienced decreasing pupil numbers. The reality of the situation is that few mainstream schools offer children with an autistic spectrum disorder 'inclusion' but rather 'integration' where the child has to adapt to the existing school environment and not the other way around. Schools aiming to include children with an autistic spectrum disorder could enrol in Autism Accreditation to develop this practice and embark on joint initiatives with accredited schools each providing what is appropriate for the child, a partnership to the benefit of the child.

There is need for and an economic incentive to develop new services for people with an autistic spectrum disorder and the Autism Accreditation standards can provide the framework to develop new services. It will provide an excellent tool to design and cost prospective services plus a tool for staff training. This is a feature of the programme which has not yet been fully utilised and has massive potential for service providers as the framework will be supported by advice and guidance from the Accreditation advisors.

The recognition and development of high quality autism specific provision in the UK

Autism Accreditation provides participants in the programme with membership of the only autism accreditation programme in the world to our knowledge. It has been very successful in the recognition, promotion and development of high quality autism specific provision in the UK and a number of countries in the European Union are showing interest. As it is not prescriptive and focuses on the specific needs of people with an autistic spectrum disorder, it is able to be translated internationally.

In 2001 Autism Accreditation was supporting and developing good practice which affected just over 4,000 people in the UK with an autistic spectrum disorder and this figure has doubled in 2006. There is no doubt that Autism Accreditation has put 'autism specific quality' on the UK service providers agenda and the hope for the future is that it will also influence decision making in terms of purchasers, funding bodies and developers.

As with most things in life, what you put into something is what you get out of it and Autism Accreditation is no different. The final word on Autism Accreditation will be left to a participant in the programme, Principal: specialist school for children with an autistic spectrum disorder in London.

" OFSTED, Care Standards, Investors in People, British Standards 5750, The European Quality Award etc and peer review systems all help a school improve standards and quality but only Autism Accreditation keeps us focused on the most important aspect of our work, the quality education and care of the pupils with autism. Autism Accreditation also helps us interpret and apply other quality assurance, inspection and regulation programmes within a framework of autism specificity and underpinned with a sound knowledge of autism."

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0011

WHAT IF PARENTS DIE? QUALITY OF LIFE FOR OUR PERSONS WITH AUTISM…EXPLORING NEW TERRITORIES

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Quality of Life is more than good food and medical care. It is a concept that goes beyond work and free time skills taken care of by special services.

Each person has a right to a place in this world, and so do persons with autism.

A very important value is 'belonging'. If our child with autism has had good services during childhood and adolescence, he/she should have had an 'Individualized Educational Programme'. This IEP should go together with an 'INDIVIDUALIZED PLAN FOR LIFE ' containing ideas about how to reassure quality of life for his future.

The more the participation of the Person with Autism in the development of his own Plan for Life, the bigger the chance that his wishes, desires and interests will steer the directions of his personal life.

It goes without saying that Parents, Siblings and people who love the individiual with Autism will have the highest contribution in this Plan for Life. This contribution should continue during the whole life of the person with autism, also after the death of the parents…

People with autism should not only be considered as 'consumers'. They need to be respected, they have strenghts, they need to be able to participate in public life and to be included in ordinay places, they can have a contribution in society, they belong to society, to US.

Good services and motivated professionals will always be extremely important. On the other hand, we have to reflect in a very deep way upon ALL aspects (positive and negative) of the idea of "appropriate services from the cradle to the grave".

Aren't we closing doors that possible can stay open ? The more professionals around someone with autism, the more parents and siblings often step aside and the more the social network around the person with autism shrinks. It is a pity that in many cases the ONLY relationship in the life of a person with a handicap is often a 'professional relationship'.

People with autism will not be cured but they'll live healthier if their quality of life grows. Lots of institutions provide a life far away from society, hidden somewhere in the middle of nowhere, with a beautiful garden, clean and safe, providing food, medical care and occupation. A perfect mini-world, a society in miniature where professionals come and go and where the indivual stays…probably for the rest of his/her life.

We need institutions, but we needn't build a society or a world in miniature. Society and the world already exist. Insitutions needn't become the world for their clients.

Why is our neurotypical culture so afraid of changes and of differences ?

Some difficulties will remain, but while we are still alive, we have to make plans for our children. Society is NOT going to do this, it will be up to US.

Services should try to find the strength of the individual and try to create chances for development of the individual within society. They should support clients in the creation of a social network and give the necessary individualized help.

Family, neighbours, friends, professionals, devoted people who care have to become aware of differences among people and of the vulnerability and the strengths of special people. They can belong to the very important social network of a person with autism. In this way we could come to a concept as "SAFEGUARDING".

If services and society gradually change and develop this way together there could be a very positive mutual influence.

Lots of work will have to be done to change existing cultural patterns, especially for people with autism, belonging to a different culture.

There is a difficult balance to keep in mind : not giving too little, not giving too much. A balance between the right to have a life of its own and the right to get adequate and maximal support in order to live this life.

During this lecture ideas and concrete examples will be given how to create a social network and how to develop ideas for 'a plan for life'.

Let's not create a world apart, let them live with us, and within the existing world, let's try to discover new possibilities, new territories…

0012

ISSUE SPECIFIC BEHAVIOUR TRAINING: AN INNOVATIVE APPROACH TO PARENT TRAINING & FAMILY SUPPORT IN RURAL MISSOURI, USA

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Introduction

The mission of the Judevine Center for Autism is to make a real difference in the quality of lives of children and adults with autism, where ever they may live. To reach this mission, we have developed a highly effective, mission-driven service delivery system that stems from a core training for parents, professionals, and staff from all backgrounds. Judevine has always recognized competency-based parent and professional training as the most effective way to empower families and professionals to succeed.

We live in the United States of America (USA), which is in North America. There are 50 states that make up the United States. We are from the state of Missouri, which is considered to be a midwestern state, located right in the center of the country. There are 113 counties (regions) in Missouri, covering a total of 68,886 square miles.

The Judevine Center for Autism's main office has been located in St. Louis, Missouri since its inception in 1971. While St. Louis is the main location for Judevine services, in 1991 the need for services for rural families was identified. Thus, Judevine began expanding services to rural areas. Judevine now has offices in Central, Southeast, and Southwest Missouri, which are known as the Missouri Autism Projects.

While parent training is the cornerstone of the Judevine Center's services, many different support services are offered, such as assessments and evaluations, crisis intervention, public education, school inservices, Individualized Education Program (IEP) Advocacy, community integration, sib shops, specialized therapies (Music Therapy, Occupational Therapy, Speech Therapy and Discrete Trial Training). In addition, Judevine offers a 24 hour transitional treatment program in which an individual attends school and is placed in residential programming at the Judevine Center.

Judevine Thinking Set:

The Judevine program is unique in a number of ways, but our Thinking Set is what truly sets us apart from other providers. A recent visitor from Australia reviewed our programs along with many others in the United States. He summed up his experience by sharing that there was just something different about Judevine, and he couldn't put his finger on what it was, just a feeling he got from staff and the way he observed staff interacting with the consumers. He commented that they were so positive and respectful in their interactions, yet they were also very successful in supporting the children through whatever they were doing. This review illustrates some of the main components of Judevine's "Thinking Set" or philosophy. The thinking set is something we introduce in every form of training we provide. It allows participants to communicate about the issues of autism and behaviour and to come at these things from the same direction. What visitors are frequently impressed by is that regardless of which Judevine employee they speak to, when they ask a question, they get a very similar response that takes into account the hallmarks of the thinking set. The thinking set provides for a common language and approach to use in intervention.

One premise of the thinking set is that Judevine views autism as a communication disorder, not a behaviour disorder. Behavioural issues are frequently seen in children on the spectrum, but it is important to realize that most of the behavioural issues stem from difficulty with communication. Knowing that communication is the primary issue, it is not surprising that many of the most effective strategies to support an individual with autism are language-based. Another important premise of the thinking set is that the children we work with must be viewed as a "person-first". This means that we do not define a child by their behaviour or use their behaviour to describe them. We view the child as normal and recognize that they have areas where they need specific support in order to cope, behave, and communicate in ways that result in a win-win outcome for both the parent (or teacher) and themselves. Win-win outcomes are such that both parties to the exchange are reinforced by the interaction and therefore seek to participate in those interactions again. In our drive to use a positive approach in all of our programs, we address these guidelines during the thinking set workshop. We teach trainees to use positive language in all situations. Specifically, this means that while most adults would say things such as, "No!", "Stop it", or "Don't" to redirect a child's inappropriate behaviour, we provide instantaneous feedback through coaching to shape the trainee's language to instead state the behaviour they would like the child to exhibit. While this may seem easy, in action it is quite difficult to retrain someone's way of speaking. The reasoning behind this approach is that stating the desired behaviour sets the child up for success and provides a verbal rehearsal of what the child *should* do versus paying verbal attention to a negative behaviour we don't want

the child to display. An example would be if a child were throwing blocks or running down the hall, most adults would be inclined to say- "Don't throw those blocks" or "Stop running!". Stating the desired behaviour such as "Blocks are for building", "The blocks need to stay on the table" or "You need to walk in the hall" all help to create the win-win outcome of the child behaving appropriately and subsequently being reinforced for their ideal behaviours, while maladaptive behaviours receive no attention. Consequently, the adult is also reinforced by their interaction being more positive and at the same time effective.

With all behaviour principles, it is crucial to recognize that behaviour principles are laws that are operational and in effect at all times; you can no more ignore the principles of reinforcement as you could the law of gravity. They are enduring and they apply regardless of the situation or the people. The training program teaches parents and professionals to apply principles consistently regardless of environment and setting events. Where Judevine is unique in their approach of applying behaviour principles to the problems of the child in the context of social exchange. We look at the behaviour that is occurring from both parties to the exchange and analyze what is occurring at the most basic level of the interaction.

Judevine Center for Autism Services:

The three week intensive training is Judevine's original training model and continues to be the core model in which all other training programs are developed around. Because this training program is based on a modular system, it allows for flexibility within structured presentations that can be individualized depending upon the need of the trainee or the intensity level of the training program being delivered. A variety of workshops are presented to trainees in a sequential order that allows the trainee to gain more in-depth knowledge as the workshops progress. There are two types of three week training programs offered, parent training and professional training.

The three week intensive parent training is center-based in which the family comes to the Judevine Center (or a designated facility) for three weeks and brings their child with them. During this process, the trainee will work individually with a Judevine staff to set goals regarding their child's behaviour and skills and then observe while a Judevine staff works with the child to address those goals. Data is tracked throughout the training to measure progress as well as efficacy of interventions. Parents undergo baseline sessions on the first day of training with their child and these sessions, as well as the goal setting practicum guide the trainer as to what skills will be targeted during the three weeks. Parents attend the training daily from 8:30 a.m. to 5:00 p.m., Monday through Friday for the three weeks, totalling 120 contact hours. Each day of training is filled with a number of different workshops that are presented in a lecture format, and then are augmented with guided observation and written practice of the targeted topics. Demonstration of the particular strategies takes place in the daily sessions the Judevine staff conducts with the child. Throughout the training process, as the trainee gains knowledge through lectures about behavioural principles, theories of behaviour, and behaviour development strategies, the trainee also observes the Judevine staff apply these concepts in a social exchange format with the trainee's child from a remote viewing location. Gradually, the trainee is brought into the treatment room where the Judevine staff is working with the child. At first, the trainee's assignment is to take data on a specific goal, which familiarizes the trainee to the room and allows the trainee to practice relative theories. Following, the trainee takes over conducting the exchange sessions, while the Judevine staff coaches the trainee from a remote location. The trainee has the opportunity to obtain six graduate credit hours for mastery of this training model.

Key Elements of Training:

Key elements of the Judevine Center's trainings are present in every training regardless of the type of program. The key elements give the family a framework of practical knowledge that involves both theory and practice through a series of workshops, as well as verbal and written feedback. In order to apply the concepts and theories that are specific to the Judevine approach of working with individuals with autism, the trainee must first have a working knowledge of the theories behind the Judevine approach. Therefore, a number of different workshops are presented in lecture format, which is then augmented by guided observation and written practice of the targeted topics. Demonstration of the particular strategies take place in the daily exchange sessions the Judevine staff conducts with the child. Competency measures of the material presented are taken through the completion of homework and practicum applications.

Hands-on coaching experiences allow the trainee to learn, practice, and apply skills to their own child while receiving simultaneous feedback through a microphone/earpiece device. This technology allows the Judevine staff to provide feedback in the moment to ensure that parents implement the strategies properly the first time and expedite the learning process. Verbal and written feedback then follows each training session. These various components to the training program allow us to measure the competency of the parents across a number of criteria. Competency-based means the trainee is able to apply the training in novel and unique training scenarios and they demonstrate mastery. One parent trainee commented that after leaving the Judevine training, she had the "quickest mental reflexes on the block" and that she could "in a moment, run through in her mind a number of different ways to handle a particular situation and then

decide which one of those would be the most effective". This kind of application is critical to being competent in a skill. It's been said that you can have all of the "book" knowledge in the world, but if you can't *DO* it, that knowledge does no good. We strongly believe that the participant has to be actively involved in the learning process throughout the training to gain true competency. Parents frequently report that following the training they are empowered to implement programs with their child, to effectively advocate for their child's needs, and experience a reduced level of stress in the home as a result of the training. Following training, a summary staffing is conducted which entails going over the trainee's goals for their child for the future, as well as the progress the child has made since the beginning of training.

The Start of the Missouri Autism Projects:

In the beginning rural families were left to navigate the world of autism on their own with no direction or feedback as to how to support their child. Basically, autism education and intervention in the rural communities was relatively bleak and parents had no one to turn to. Parents reported feeling lonely, as if they were the only ones on earth who were dealing with the issue of autism. Parents were tired of facing the daily struggles alone and without help and knew they needed the following: 1) parent training and hands-on strategies that could be used in all environments; 2) services close to home that were flexible and responsive 3) services directed and individualized by each family.

In 1990, a small group of family members of individuals with autism joined together in a grassroots effort to approach legislators about the need for autism services in rural areas. Parents educated legislators about the struggles of having a child with autism and their desperation for services. The parents' effort to educate legislators about the need for autism services was realized and a line item was assigned to the Department of Mental Health (DMH) budget. Legislators supported it in their legislative session. Following, the Governor signed the budget, which included the new autism funding line item. "Never doubt that a small group of committed people can change the world. Indeed, it is the only thing that ever has"...

Following, a Parent Advisory Committee (PAC) was formed (similar to a Board of Directors). The PAC was made up of six parents who were appointed by DMH as the stewards of the Autism Project funding. It was up to PAC members to find a provider that could deliver the autism services identified by rural families. After interviewing other providers, the PAC chose the Judevine Center as the contracted service provider and the Missouri Autism Projects were established.

All Missouri families referred to the Judevine Autism Project by DMH receive services for free. The parents, PAC, and Judevine Center got together and formed a menu of services for families to choose from, with the main focus being parent training and functional hands-on strategies to address specific issues. This menu allowed families to individualize services based on their specific needs.

In order for families to access services, their child must meet eligibility for Autism Project services. An evaluation is completed on the child, only to determine eligibility, as Judevine does not diagnose. If the child has autism, or is suspected of having an Autism Spectrum Disorder, then the family is found eligible to receive Autism Project Services.

Rural families wanted the intensive three week training model as part of the menu of service for the Autism Project funding. However, due to certain monetary and distal constraints, this model was not feasible to deliver to all families. Since this training is primarily center-based, it would be difficult for families who lived long distances from the training site to attend everyday for a three week period. Secondly, taking a leave of absence from work could be financially stressful to lower income and single parent families, as well as those families who own farms. Also, since fiscal year 2001, the Autism Projects had been given additional funding each year for their programs. Since then, we have been faced with a "flat budget", that is, no additional funding, despite continued new referrals. Our challenge was to devise a way to continue serving families across 92 counties currently receiving support from us, as well as serving new families who also needed support, given the same amount of funding.

In the beginning, the Autism Projects provided a therapy model where we sent Judevine staff into homes to conduct exchange sessions with individuals with autism, we did not specifically focus on parent training. However, our concern with the therapy model was that the treatment plan was successful when the Judevine staff was present in the home, however, the parents did not understand how to generalize the techniques to their child, which resulted in the Judevine staff being in the home for extended periods of time, up to 1 to 2 years or more. This lack of parent training produced even longer waiting lists. Judevine knew something had to be done and developed a different model of implementation.

Our response to this challenge was to change our in-home service delivery model from a therapy-based service to a parent training model. This generated a variety of models of implementation, such as eight day training and introductory workshops, but the best format to meet the unique needs of rural families had yet to be discovered. The answer was Issue Specific Behaviour Training (ISBT), which is a culmination of previous training programs. We customized components of our current three-week parent training program

to be delivered in the family's home. This responded to the needs of families who were unable to attend the center-based training programs. During this program, families work with Judevine staff to identify a particular issue they are facing with their child with autism. Our staff provide them a foundation of knowledge about autism issues through a series of workshops delivered to the family in their home, at their convenience. As well, the family completes a variety of homework and practicum to enhance their skills and reinforce their learning. During each visit, the Judevine staff also work with the individual with autism, modeling strategies the family learns in workshops. Eventually, the parent takes on the role of therapist, and works with their own child, employing the techniques they have learned, and addressing the specific issue they identified in the beginning of the program. During their sessions, the parent is coached by the Judevine staff through a remote ear piece, receiving feedback on strategies and teaching techniques to use in the moment.

Critical elements of this ISBT program had to be identified, such as how to teach staff to deliver the training, which modules to use, how in-depth the information should be, and a few other logistical elements. In order to effectively serve more families through ISBT, the three week training workshops had to be condensed to mini-workshops, without losing the effectiveness and core knowledge of the lengthier versions. This was the main consideration when we designed the ISBT notebook. Some of the mini-workshops include topics such as Introduction to Autism, Behaviour Development, and Teaching Strategies. In addition, parents are taught how to objectively observe and analyze social exchanges, and how to restructure maladaptive exchanges into ideal exchanges, all while applying the techniques learned to the specific issue identified by the family.

The responsibilities of the parents' had to be identified for ISBT to be effective and completed in a timely manner. Therefore, we had to determine out how to make families accountable for keeping appointments and participating in the training. The parents sign a contract which outlines expectations, such as the No Call/No Show/Cancellation Policy, completion of homework, active participation during practicum and observing exchange sessions. The parent is also responsible for conducting a baseline session which serves as a pre-treatment measure of the child's behaviour prior to the Judevine staff working with the individual. After exchange session procedures have been modeled by Judevine staff, the parent takes on the role of therapist. The parent works with their own child, employing the techniques they have learned, and addressing the specific issue they identified in the beginning of the program. During their sessions, the parent is coached by the Judevine staff.

The final step was figuring out how to implement this new training program into an already existing service model. First of all, parents had to be educated about their choices and how a shift was going to be made from a therapy model to a training model for all families. Secondly, decisions had to be made as to how many families each Judevine staff could serve simultaneously. Presently, Judevine staff work with 8 families at a time during ISBT, depending on the amount of travel involved. Once ISBT is finished, the Judevine staff rotates in new families, while still engaging in follow-along for 6 months or more.

Since developing this training, families have reported a higher level of satisfaction with their services, and the Autism Projects have been able to reach a far greater number of families. For example, in fiscal year 1998, the Southwest Missouri Autism Project served 222 families. In fiscal year 2002, with the ISBT program, the Project served 607 families. By using this program and given a limited budget, 42 staff are able to effectively serve approximately 1827 families across 56,961 square miles of rural Missouri. This innovative new approach has allowed the Judevine Outreach Services Autism Projects to live their mission, providing a higher quality of services and supports to families across Missouri, while maximizing current, limited funding dollars and staff resources.

Autism Project Facts

	Central MO Autism Project	Southeast MO Autism Project	Southwest MO Autism Project
Location	Columbia	Poplar Bluff & Cape Girardeau	Springfield & Joplin
Counties Served	49	19	24
Number of Staff	21	9	12
Current DMH Allocation			

| | 886,189 | 355,668 | 509, 819 |
| Total Families Referred | 1488 | 594 | 1154 |

Total Number of Referrals

	Central MO Autism Project	Southeast MO Autism Project	Southwest MO Autism Project
Fiscal Year '91	42		
Fiscal Year '92	90		
Fiscal Year '93	227	57	
Fiscal Year '94	307	95	
Fiscal Year '95	357	125	141
Fiscal Year '96	437	161	226
Fiscal Year '97	530	192	279
Fiscal Year '98	621	230	356
Fiscal Year '99	747	279	471
Fiscal Year '00	854	316	564
Fiscal Year '01	948	347	688
Fiscal Year '02	1048	433	818
Fiscal Year '03	1177	470	908
Fiscal Year '04	1317	520	1017
Fiscal Year '05	1488	594	1154

Number of Families Served

	Central MO Autism Project	Southeast MO Autism Project	Southwest MO Autism Project
Fiscal Year '91	20		
Fiscal Year '92	60		
Fiscal Year '93	163	13	
Fiscal Year '94	130	55	1
Fiscal Year '95	160	108	65
Fiscal Year '96	181	155	134
Fiscal Year '97	284	155	192

Fiscal Year '98	329	136	222
Fiscal Year '99	463	200	263
Fiscal Year '00	424	255	474
Fiscal Year '01	501	265	557
Fiscal Year '02	620	304	607
Fiscal Year '03	632	307	648
Fiscal Year '04	751	295	704
Fiscal Year '05	738	295	794

0013

THE SOCIAL AND FAMILY INTEGRATION OF A PERSON WITH AUTISM

I Bayonas

Spanish Parents Association for People with Autism, Spain

The family of an autistic person is exactly the same as that of any other family, and I say this because it achieves nothing looking for something to blame. The parents of an autistic child go through the same challenges of raising a child just like any other "norma!" parents: nobody showed us the way, there is no university nor academy where they prepare you to be parents, and much less so for parents of autistic children.

What happens when a child is born? The normal feeling is that of happiness, in that you are living the most marvelous experience of your life. You devote every minute of the day to them. When you see your child so healthy and, why not say it, so beautiful!, you can't imagine that in a few months you will start to notice strange behaviours which you don't understand and find hard to accept, but in the back of your mind you will know something is happening to your child.

When it is obvious that something strange is happening, the pilgrimage starts from pediatrician to pediatrician and none of them are able to explain to you what is happening to your child. After, psychiatrists, psychologists, schools. My child has been in seven schools and they have rejected him from five of those. They were private schools for special education, but they assured me that he would not be able to adapto In addition to al! of this, you also suffer the anguish, family and marriage tensions, which the situation can generate.

Families should know that it is logical and completely natural that problems and tensions will exist. The tranquility and calm are altered, and the plans and illusions that we would have made and created suffer a breakdown which translates to reproaches, incomprehension, depression, etc. In spite of this, we must fight so that all the family, parents and children included, understand the problem and are involved in the education and caring of the autistic child. We must manage our expectations to be realistic and short term, we must not hope for miracles, but also not abandon the fight. We must not feel sorry for ourselves, as this achieves nothing. The path in front of us is a long one.

In the family in general, communication and dialogue is always very important. This is absolutely vital in the family of an autistic child. It is necessary to share problems, speak with any siblings and explain to them the situation, ask for their collaboration, and explain that above all they must treat the autistic child with respect and in a way that is as normal as possible. If the sibling is younger then they can show the autistic child how to play, interact and imitate. If older then we must make sure that they do not overprotect, and also that they try to integrate the autistic child with their friends, encouraging communication so that the autistic child develops an interest for things going on around them. The siblings need to be involved but without overloading them with excessive responsibility. We have no right to mortgage their lives. We must be conscious that we are asking them to confront a situation, which will be difficult for them. Possibly, many siblings at one time or another in their development have wished to be autistic in arder to receive more attention from their parents. A normal relaxed family environment is fundamental for an autistic child, but also necessary for the other family members.

Also it is important to involve the autistic child in household chores. A program of activities can be devised such as making the bed, making the table, taking out the rubbish, drying the dishes, going to buy bread or the paper accompanied by someone ... We need to give them a lot of encouragement through, for example, kisses and loving hugs, even though it seems that they are not aware or don't care, deep inside they like it. They appreciate it when they are treated like any other member of the family. In my case, with my 35 year cid son David, we always try that he participates (in his own way) in everything that happens in the family. We have achieved that now he doesn't inflict self-injury, his hyperactivity has decreased, and now he is more sociable and cultured. Unfortunately, his capabilities are still low, but he is integrating with his family, which for me is the most important thing, and also with the environment in which we !ive. Everyone who knows him loves him and accepts him the way that he is.

I started his integration 20 years ago (I acted in advance of the Law for the Integration of Handicapped People) in my neighbourhood. My "business card" was:

"Hello, my name is María Isabel Bayonas, I am David's mother. My child is autistic and I would like to ask that you help me as I am canying out a program with him so that he leams to do errands. I will tell him to come for some bread, please, when he comes to your shop prompt him by asking him what he wants". They helped me. That was the way that I did it, shop by shop: in the kiosk, in the supermarket ... I also spoke with the gang of children in the neighbourhood, and asked them to integrate David into their games (this I couldn't achieve as David didn't know how to play, but I did achieve that these children carne to know what autism was, and leamed how to better help and understand people with autism). As time passed, I had accomplished that the entire neighbourhood loved him and, more importantly, that they felt that they had participated in the evolution of David. Now they tell me: "Mrs. Bayonas, My! How David has improved. We are really achieving something aren't we?". It's beautiful isn't it?

Another important achievement for me is the love and respect that his siblings feel for him. They talk with their friends about him, the problem, and tell anecdotes about him. They feel proud of him. David has always had a big dependency on me, but three or four years ago he was more dependent on his father: he imitated him, and idolised him. His behaviour has become much more normal which has confirmed to me that we should not put limits on ourselves as each day they can learn something new.

What we should all do, on the contrary, is try to understand their world. We live our lives trying to make them understand and adapt to our world, but do we do anything to know and understand theirs?

An autistic person is both special and different, but with their virtues and defects they can provide lots of happiness and satisfaction just like any other. We should remember, even though apparently they don't demonstrate it, that an autistic person needs and loves us, as their family is the most important thing for them. We need to work everyday to achieve that they are as self-sufficient as possible (keeping in mind that they will always have a dependency on us) and, above all, the most important thing is that they are happy. I have worked together with my family all these years to achieve that my son is happy, and now, it is my son that is making all of us happy.

0014

MAKING A START: DEVELOPING A SEXUALITY EDUCATION PROGRAMME FOR LEARNERS WITH AUTISM

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Making a Start: Developing a sexuality education programme for learners with Autism

Introduction

> *'People with ASD have sexual feelings just like anyone else but they understand them less well '.[i]*

As sexual development has such a strong social and emotional component it is hardly surprising that many young people with ASD struggle to process their sexual feelings and manage the bewildering range of social expectations and conventions related to sexuality[ii]. It follows that sexuality education needs to be part of their school education and yet it is an area that is not easily taken up. On the one hand this difficulty may reflect past negative attitudes toward the sexuality of young people with ASD e.g. they are asexual, they cannot understand, and that trying to talk about it will only lead to greater behavioural problems. On the other hand the different perception of young people with ASD means that getting the message across presents us with a genuine challenge.

In this paper I will reflect on the experience of introducing a sexuality education programme at Vera School (for learners on the ASD spectrum), in the Western Cape, South Africa, over a period of two years. This includes an overview of the themes approached, how we worked with different abilities and the perceptions of teachers involved[iii].

Background

One effective approach to deliver sexuality education is to use group work[iv]. Group work presents a time to practice social skills, to learn from each other and the opportunity to establish values and expectations related to social behavior and relationships. This approach is particularly important to learners with intellectual disability who have fewer opportunities for social and incidental learning connected to their sexuality[v]. These learners need even more help understanding difficult and relative social concepts and interpreting the often confusing and contradictory messages they receive from the media and family or care givers[vi].

I worked with learners with intellectual disabilities in a number of ELSEN schools (Education for Learners with Special Educational Needs) and was invited to introduce a programme at Vera School. Up until this point there was no formal sexuality education programme in the school, issues related to sexuality were responded to on an incidental and individual basis as the need arose:

> *"Before the programme the principle was to answer honestly if questions were asked, not sweep it under the carpet – and at the appropriate age to give basic information when the need arose". (Principal Vera School, Aug 06)*

Up until this point I had no direct experience of learners with ASD. Before I began I assumed it impossible to work with learners with ASD as a group. I assumed all learners at the school would find group work painful and confusing. I imagined every young person with difficult behavior and feared that attempting sexuality education in a group would result in chaos.

This showed how I had absorbed some of the pervasive myths of autism[vii]: that all young people with ASD were socially withdrawn locked away in a world of their own and did not want to relate to others, that difficult behaviour was the norm and that communication would be mostly impossible. I doubted the enthusiasm of the school psychologist who invited me to work in the school and felt the programme would most probably be short lived.

However through the experience of working with learners with ASD and their teachers I reached another conclusion; that sexuality education is possible with groups of young people with ASD and although many learners may also need an individual programme most benefit from and enjoy group work immensely. The group is an appropriate approach to sexuality education because learning related to sexuality is brought into the open and becomes a shared class experience and a shared frame of reference for learners and teachers alike:

"The programme means a more organised and structured approach, we can be more proactive than reactive, starting at a younger age". (Principal Vera School Aug 06)

Over the last two years I have worked with nine class groups of different ages and abilities. Each programme took place over two to three terms for each group working once a week for ¾ hr to 1hr. Initially groups took place in the hostel lounge. Holding the session in a different space from the class room was beneficial as this signaled the session as different and gave us more privacy from classroom interruptions. However this was not always possible or practical and at a later stage some programmes took place in class rooms. The most important factor in choosing a venue was that it remained consistent for each group along with the time and day on which the session took place. The learners sat in a circle on chairs with their teacher and assistant or assistants as part of the group.

What follows is a summary of work in relation to two broad categories of learners: firstly low ability groups who experience profound difficulty communicating and who may be non- verbal or minimally verbal and secondly groups who are more able to communicate verbally, many of whom work on academic skills.

Groups with profound communication difficulties

"My children need to be exposed to everything. If I can't talk I can still communicate, and having access to all programmes in the school says a lot about the personal dignity of these children, that they have rights". (Helen, Teacher of a group of 10 -12 year old boys)

This is the area of work that I found the most challenging and different to my previous work with groups with intellectual disability including more severe intellectual disability. The main difference was the difficulties experienced by the learners in relation to meaning and communication, occasionally combined with behavioral difficulties. Most of these learners could not communicate easily or could not communicate verbally at all. I aimed to:

- help the learners understand they could make choices,

- establish age appropriate boundaries around touching others and touching oneself

- give information relevant to their age and stage of sexual development.

Content summary

"With my kids it can seem as if they are not taking stuff in, but it often filters through. Days, sometimes weeks later, they show understanding or carry out the task .I find it is going in and having an impact. I feel cross when they are sidelined……" (Helen, Teacher of a group of 10 -12 year old boys)

We worked as concretely as possible on social interaction skills and appropriate behaviour in relation to sexual development. Learners could choose to be tickled with a duster or sprayed with a water spray. They could choose how to greet other members of the group by choosing cards showing a hug, a high five or shaking hands. They learned to recognize and name body parts using large body outlines of a man or woman and cut out body parts. They matched pictures of different places such as the toilet, bathroom, bedroom or sitting room to behaviour appropriate to those places.

Starting the session

It was important that the session was enjoyable and not stressful. It helped to repeat activities each week. This meant learners became familiar with games and the kind of visual resources used and gained the confidence to increase their participation over the weeks. I found it important to keep activities reasonably short and to be aware of variety in the session.

Each session started with a name game using a cushion. Each learner took turns to hold the cushion and say their own name or gesture to themselves. This activity signaled the beginning of the session and was a way of welcoming and acknowledging all the participants. All the learners were able to throw the cushion to another person, but for some the task of saying their own name was consistently difficult and they would repeat my name or the name of the last person who had a turn. This difficulty is not surprising for learners with ASD considering their difficulties with language and meaning especially in connection to personal pronouns and the likely use of echolalia[viii]. To help the learners we gave them a photo of themselves to hold up as they held the cushion.

Another activity related to greeting as well as giving the opportunity to make a choice, was the greetings game:

"Rebecca introduced cards illustrating a hug, a handshake, a high five and a shoulder hug. By prompting the learners to ask and wait for permission before doing the action, Robin who has a problem asking and accepting permission or a decline for a hug has shown improvement. He does not run up to people to hug them anymore. He uses the handshake more. He also is starting to ask for a hug and to accept a decline" (Beulah, teacher of a mixed group of 15yr olds, 21st Aug 07).

Lionel was extraordinarily motivated with this (greetings) game. Especially compared to how he participated in the session in 2005, he was jumping up to have a turn. He made different choices of greetings and of people. (Session sheet[ix] 29.5.06)

I have more recently introduced smaller individual versions of these greetings cards to the learners' communication books.

It was important to include some activities in the session that did not make overly difficult communicative demands on the learners usually at the beginning and at the end of the session. One activity was playing with a balloon filled with a few lentils. The balloon could be shaken or hit across the circle to another member of the group:

Balloon on cloth and ball on cloth. Feel it is good to find group activities that are involving and fun -- that aim to relax – that it doesn't matter what the response is.(Session sheet, January 05).

We rolled a ball to each other or bounced a balloon or ball on a large piece of cloth held between us. Younger learners took turns to lie under a cloth whilst the rest of the group held it over them and moved it up and down to make a breeze. These activities aimed to engage the learners in a more open ended way but still encouraged social interaction and turn taking.

Making choices

'They are more vulnerable more susceptible to be violated, we need to try and equip them, and with Autism you never know (what they may understand) it is always worth going there' (Kim,Teacher of older boys, Aug 06)

The skill of decision making and making choices are central to sexuality education. Learners cannot protect themselves from abusive touch unless they know they have the right to say no. It is possible to work on this concept with learners with severe intellectual disabilities who can relate meaningfully to the words 'Yes, I want something' or 'No, I do not want something'. However, I soon realized that many learners with ASD found this very difficult. When asked to make a choice many learners would echo back the phrase 'yes or no'? I realized that yes and no are used in endlessly different contexts and are therefore very complex concepts for learners with ASD. Yet I wanted the learners to realize that they could control something happening or not happening by saying yes or no.

We attempted to make the concept clearer. The teacher introduced small cards showing 'a tickle' and a yes and no card and a stop card. The learners were encouraged to take the card that indicated their choice and verbalize their choice if possible. Some learners began to recognize the yes card and would choose appropriately and consistently. We would ask the learner if they wanted a tickle, or a spray of water or occasionally a sweet. When tickled or sprayed we encouraged the learners to hold up the stop card and say stop or sign stop.

Using pictures

'Many people with autism are visual thinkers. I think in pictures. I do not think in language. All my thoughts are like videotapes running in my imagination. Pictures are my first language, and words my second language.' (Temple Grandin[x].)

Learners with intellectual disabilities can often show their understanding, by moving a picture to a category even if they can not express their understanding with words. This approach related well to learners with ASD who are visual thinkers. When we worked in the hostel learners were given my photo to signal that it was time to go to sexuality education. The learners carried the transition card to the hostel and handed it to me on arrival.

The visual aids used were drawings that I had made and developed for learners with intellectual disabilities. These included a variety of cut out people painted on both sides and depicting young men and women, clothed, in underwear and naked. We also used a drawing of a lounge, dining table with chairs, a bathroom and a toilet with a door that could open and close, and a bed with covers that lifted up.

For some learners a photo of the real object or place would be a more meaningful resource however, because we were working in a group it was not possible to use photos of the learners own lounge,

bathroom etc. This could be done in the future if working with individual learners on a specific issue. Most learners could relate to the pictures of different places and could match the person with the appropriate place; for example 'the man wants to have a bath', 'eat his dinner', 'go to the toilet', etc. The learners were then encouraged to physically place the cut out person in the correct place and if appropriate close the door of the toilet or bathroom.

We also used the pictures of people to point to different body parts and told a story of the boy or girl washing in the bath, using this as an opportunity to reinforce body part names:

> *I felt there is potential in this (bathing story) the group engaged- possible to revise body parts and the exercise of what body part is he (the cut out boy) touching now- worked well and has the potential to lead into work on masturbation. (Session sheet, 1.2.05)*

Probably the most successful visual resource was two large laminated body outlines of a man and woman with cut out body parts. It worked well for the learners with ASD to use cut out body parts and cut out clothes which they placed on the appropriate part of the body. As the learners did this we used the correct names for the body parts. When the exercise was completed we asked the learners to point to named body parts with a small stick. Most groups were predominately boys and worked on their own gender. When the group was mixed we worked in single sex groups each group working on their own gender.

> *Some of the group are not able to recognize the body parts or place in correct place. Some are able to place body part in the correct place every time.(Session sheet 1.2.05)*

Masturbation

Our attitude towards masturbation will vary depending on our upbringing, and values related to sexuality. Many people now recognise that masturbation is a normal and healthy sexual expression (if done at the appropriate time and place) and may be, for many adults with ASD, their only real sexual outlet. If we are to help the young adult to feel good about their sexual feelings we need to respond to the issue of masturbation from childhood, and throughout adolescence, in a way that is positive not punitive, and which sets clear boundaries and limits in terms of time and place.

We worked on masturbation with a group of young men aged 15yrs to 16yrs. Once the group was familiar with the body parts on the outline and had repeated a lot of work on matching the people to appropriate places clothed and unclothed, we began work on masturbation. We added a cut out hard penis to the body parts and affirmed that a mans penis sometimes goes hard. We used the cut out people and asked the learners to discriminate which man had a soft penis and which had a hard penis.

I introduced fake body fluids, (apple juice for urine, water for sweat and tears, and hair conditioner for semen). Over the weeks we named and placed the body fluids on the appropriate body part on the outline. I made a clay penis with a syringe inside which demonstrated ejaculation using the fake semen. We then showed the learners a sequence of pictures showing a boy masturbating ending in a repeat of the demonstration of ejaculation. We then matched different pictures to appropriate places and asked the learners to place a picture of a boy masturbating in the bathroom shutting the door, in the bedroom under the covers or in the toilet with the door shut. At a later stage we re-assessed whether the learner could place the picture of the masturbating boy in the appropriate place. Some consistently placed the picture correctly.

More able groups

This area of work was more familiar to me as I previously facilitated sexuality education programmes with people with mild to moderate intellectual disability. However I realized that I needed to think more carefully about breaking concepts down and not taking the learners use of language as a definite indication of their understanding. I aimed to:

- help the learners practice social skills such as decision making and giving or refusing permission especially in relation to touch

- encourage positive self esteem in relation to growing up and becoming a young adult

- give information relevant to their age and stage of sexual development.

Content Summary

> *The biggest challenge for our learners is getting them at a level of being at ease with the topics. (Kim, Teacher 7(14 -16 yr olds, Aug 06)*

We played many of the games used with the less verbal groups and likewise worked as concretely as possible using the visual resources described above. However, these learners were able to understand the programme in relation to an overall concept such as 'growing up and becoming a young man or woman'. The learners could (with the help of their teacher) reflect on why we played different games, why the skills we practiced, such as listening or respecting each other, were important. They could reflect on other situations in which behaviour would be appropriate or inappropriate e.g. in relation to hugging someone or touching private body parts and they were able to use more complex and visual resources such as drawings of good and bad touch[xi].

Starting the session

These groups were able to understand and needed rules for the session. The rules clarified how to behave in the session and reinforced social skills such as turn taking, listening and not interrupting. The rules were developed with the group in the second session and a poster of drawings and words was made as a visual reminder.

At the start of each session we played a name game with the cushion or the balloon. This welcomed the group and provided a familiar signal that we were beginning the session. We included the permission games and greeting games used with the lower ability groups. Permission games such as "Can I tickle you?" emphasized social qualities such as listening and respecting one another, as well as emphasizing that we have the right to say yes or no to any sort of touch. Learners, who did not play in accordance with the rules, repeated their turn and those who managed a difficult social interaction appropriately were praised. Although the learners would often request a greeting from their teacher the game also showed warm friendships between peers:

> *The group did very well, asking choosing and listening – Andrew tends to hug so hard he lifts people up – but could give a gently hug when asked. (Session sheet 7.3.06 mixed ability group of 10- 12yrolds)*

Generally these games aimed to be brief, fun and easy for the learners to engage with. It was important the learners felt relaxed and familiar with how we worked together before we moved onto more sensitive subjects:

> *"Initially I thought for their level the group was too easy, but as we went along and I saw the enjoyment it was good to start low and slow and they built a relationship with you, and towards the end when we did more advanced stuff I thought it was amazing the words that stuck, the new vocabulary they had learned" (Ella, Teacher 12- 14yr olds, Aug 14th 07)*

Using pictures and sorting activities to generate discussion

> *It is easier to work with the more verbal learners in terms of getting through, but comprehension is still a problem, this makes the visual very important, we still need that visual aspect in the programme.(Kim, Teacher 14 -16yr olds, 7 Aug 06)*

Many of the activities in the session used pictures or cards with statements written on them. These maintained the visual aspect of the programme and helped to focus each activity very specifically. The group was asked to sort the pictures or statements in relation to one or two criteria. For example, true or false in relation to body changes at puberty; a yes decision or a no decision for teenage characters in relation to different issues such as peer pressure or sexual abuse, behaviour appropriate to teenagers or behaviour appropriate to small children, pictures depicting people touching 'did they both say yes, or is one person saying no stop? The learners would take turns to pick a card or picture and place it in a category to demonstrate their understanding or view. The teacher would then facilitate a discussion where appropriate. The categories were indicated using pictures or objects and the learner would physically place the card or picture as well as verbalizing their answer.

In one sense these activities are individual ones because each learner takes their separate turn and their understanding can be assessed, and yet the activity raises vocabulary, concepts and values that the whole group is then aware of. These can be referred to at other times by the teacher:

> *"What was interesting when my learners chose to use it (the words) in class, it was private to them – quite unusual – they weren't using (the word) masturbation in other places. The words weren't something they just used, words were used when we spoke about the topic, I could relate a lot of the things we did to the term 'young men' we used that word a lot, that helped them in their whole attitude".(Ella,Teacher 11-13yr olds Aug 14th 06)*

The Concept of 'Private'

The concept of private is complex and relative: we can be private alone, with another person, or in a group! There are private body parts, possessions, property, conversations, places, rooms, information, documents. The many associations and meanings of private makes it potentially very confusing for learners with ASD. Working with these learners made me aware of the need to use the word in its context rather than using the word generally e.g. rather than saying 'that's private' saying 'that's a private body part'. We made lists of everything that was private and the learners made up short role plays or scenes to show different meanings of the word, e.g. One group made a scene about looking through a key hole when someone was on the toilet and trying to open the door without knocking.

We used a sorting activity to work on the difference between a private thought that should be kept to oneself and a secret or a worry that needs to be told to a trusted adult. The group identified someone in their lives whom they trust and could talk to if they were worried. We then sorted statements into three categories. Firstly, something that can be told to everyone such as 'we went to the beach yesterday' (categorized by a group of cut out people representing friends). Secondly, something that is a private thought that does not need to be shared such as 'I have just had a huge poo!' (categorized by placing the statement out of sight under a cushion), and thirdly something that needs help from a trusted adult, particularly in relation to bullying, illness or sexual abuse such as 'My uncle wants me to touch his private parts, he says it is our secret' (categorized by a male and female cut out representing a trusted adult). We emphasized that it was always important to talk to a trusted adult if worried or uncertain.

Sexual development

It is important to establish the correct names for private body parts from the beginning of childhood. This ensures the adolescent with ASD will not have to learn a whole new set of words for body parts or become stuck using words that are childish and age inappropriate. Unfortunately language connected to sexuality is even more confusing for learners with ASD as sex or sexuality is often spoken about indirectly, using slang terms, or jokes.

Many learners were initially embarrassed and resistant to learning about private body parts. They would use words like 'disgusting' and 'its rude' and laugh. It is important to remember these responses are an indication that these learners have absorbed the social convention that it is not polite to talk about private body parts either with slang words or the correct terms. Yet this response is not helpful in terms of the young person with ASD being able to ask questions or get help concerning their sexual development. It also means that the young person with ASD is perhaps more vulnerable in terms of sexual abuse or inappropriate touching if they feel it is a topic that should never be discussed. It is vitally important to convey to learners with ASD that there are certain contexts in which it is appropriate to talk, learn or ask questions about sexual development or private matters. We stressed that the session was a time when we learned about these things and if they had questions or worries it was important to discuss these with an adult whom they trusted, such as the class teacher or family member.

To help the group accept that it was permissible to learn about private body parts we added a rule that it was okay to say private body part words because we were learning about becoming young men and women:

> *- very reluctant to say correct private body part words – prefer to use butt, bottom and winky. Sam saying that it is disgusting -- I added we can say private body parts to the rules. (Session sheet, 21.2.06, mixed ability group aged 10 12yrs)*

We introduced private body part words through a team game using clothes. Each team searched for one item of clothing and named all the body parts that it covered. This activity assessed how comfortable the learners were in naming private body parts and introduced them to the idea that it was okay to say those words in the session. Some groups managed this activity very quickly and competitively and other groups (usually younger learners) would struggle initially to name the body parts rather than the clothes.

Once the group was able to say and hear the private body words we drew body parts on large male and female laminated outlines. A pen was passed around the circle and when the music stopped whoever had the pen drew on a body part. When the drawing was complete we assessed the learner's vocabulary and understanding by asking them to point to named body parts with a small stick:

> *No proper names for body parts – titties/ winky/ and pee – pee – told them penis and breasts and nipples. Andrew and Sam found it very difficult to say or point to private body part names – needed the permission and so the rules helped' (Session sheet, 28.2.06 mixed ability group aged 10-12yrs).*

We then used the cut out body parts described above and placed them on the body outlines recapping vocabulary for all body parts and if appropriate pointing out the difference between a boy and a man and a girl and a woman.

The work in the single sex groups focused on giving more detailed information about sexual development at puberty. This work was only begun once the learners were able to name and recognize private body parts. This work aimed to give the learners information relevant to their own stage of development and gender.

The boys or young men's work started with the concept of erections using the cut out body parts on the male outline. The boys were asked to distinguish between a soft and hard penis and to understand that a mans penis can be both. The word erection was new for many of the learners. Once the boys understood this we showed them a picture sequence of a young boy asleep who has an erection and a wet dream[xii]. The boys were asked questions about the picture sequence and to notice whether the boy was asleep or awake:

> *Wet dream story: none of them knew / or seemed to know about semen or wet dreams (Session sheet 30.8.05 boys group aged 11 to 14yrs)*

This activity was repeated to allow the boys to practice the vocabulary and become familiar with the concept. Once the boys were familiar with the concept of wet dreams and body fluids it was then possible to work on the concept of masturbation.

> *Showed the wet dream sequence and stressed the boy is asleep and then showed the masturbation sequence and stressed the boy is awake and it feels nice (he is in a private place and at an appropriate time (Session sheet 2.11.05 boys group aged 11 to 14yrs)*

We introduced fake body fluids urine, semen, sweat and tears which were placed on the male body outline corresponding to the appropriate body part. This helped the boys to distinguish between urine and semen. We then showed the boys the picture sequence of a young man masturbating. Some groups could learn the term masturbation and other groups used the phrase the boy is rubbing or playing with his penis. We asked the group where the boy could do this and most were clear that the boy could masturbate in his bedroom with the door closed, or in the bathroom or toilet with the door closed. Some groups would then be asked to match the masturbation picture with a picture of an appropriate place.

In the young women's group we introduced the concept of female genitals being private and hidden from view. In the mixed group we had referred to the woman's pubic hair as her private parts or her vagina. In the single sex group we showed the young women a drawing of a woman's genitals and named the parts where body fluids came out, the vagina, the uretha and the anus. The learners practiced pointing to the different parts and hearing and saying the names. We then introduced fake body fluids including menstrual blood (tomato sauce) and vaginal discharge (lubricating gel). The learners placed the fluids on the body outlines and we discussed menstruation. The learners then practiced putting pads on panties and looked at a story sequence of a young woman managing her period[xiii]. We also showed a story sequence of a young woman masturbating[xiv] and discussed the appropriate time and place for this.

Although this work took place in single sex groups it was important that the learners understood that puberty and sexual development happens to both sexes, and that the work going on in the other group was not secret. To support this ethos each group summarized and fed back their discussions to the whole group at the end of the session. Sometimes this information would be shared by the teacher and sometimes one or two of the learners would volunteer to talk. To encourage the learners to be used to hearing and discussing sexual development in the mixed group we introduced a quiz on puberty:

> *True or false quiz worked well – I gave each person a card and they had to decide if it was true or nonsense – I included the category of get help (if you don't know the answer). New words – puberty, privacy, erection, masturbation, period, ejaculation (Session sheet 2.11.05 boys group aged 11—14yrs)*

The Teacher's Role

I found that the teacher's role in the programme was crucial. The teacher's presence, focus and involvement seemed to influence the outcome of the session more than in other special schools. This most probably relates to the intense knowledge that the class teacher holds in relation to the communication abilities and needs of each individual learner. The class teacher seemed to contain and hold the class and support their interest, almost as if they are a conductor for the learner's involvement. Compare the notes about two consecutive sessions where the teacher was present and absent:

> *Group very cohesive and co-operative. They enjoyed the games and participated enthusiasitically. Group able to wait their turn – although some learners did lose focus at times they were not disruptive. Group enjoyed their assistants taking part and having a turn' (Session sheet 31.1.06 Mixed ablity mixed group)*

And the next week:

A much more disruptive and unfocused session. Lyn (the teacher) was delayed with Robin who needed attention and then needed to leave early. Learners more unfocused, more irritable with each other – need their teachers support/ holds them in a way the assistant does not (Session sheet 7.2.06 Mixed ablity mixed group)

Over the programme I found that it was essential that the class teacher and assistants were present in all the sessions not only so that the learners could focus and feel comfortable, but also so they could use vocabulary introduced in the session and reinforce concepts at other times. This means that learning takes place after the session when the class teacher follows through on concepts and vocabulary raised in the session. However, this follow through is dependent on the teacher feeling at ease and confident with issues connected to sexuality. It is also important for parents to be informed of content and approach so that they can support their son or daughter and perhaps understand the unexpected comment:

Although one parent told me they were sitting in the Spur and the child said "that man has pubic hair". (Ella,Teacher 11-13yr olds Aug 14th 06)

In all programmes we held at least one parent meeting to inform them about the programme, show them the resources and activities used and allow them to ask questions and share ideas and concerns.

The aim of this programme has been an interchange of skills whereby the class teachers will eventually take on the responsibility of running their own programme with their own classes:

This experience is more empowering so that teachers are informed of appropriate techniques that are autism specific –we are looking at an autisim specific approach in which the preferred mode of learning is mostly visual and we are in the process of making our own kit for use by our teachers –The teachers are having the benefit of experiencing the presentation of learning material under the direction of an expert in the field of sexuality education (Principal, 14th Aug 06)

To this end, I am working with groups every other week. This model means that in the week in-between the class teacher repeats the session and gains experience of adapting and leading the work themselves as well as collecting the resources necessary for the session.

Evaluation and conclusion

At this stage the programme has been evaluated informally through teacher feedback meetings at the end of each term with the principal. In these meetings the teachers involved reflect and share how the programme has progressed, what has been covered, and the response of the group involved. This means the evaluation of the programme is more teacher than learner based and asks whether the teacher feels able to continue, repeat and adapt the programme to their own class group. This recognizes the importance of developing suitable resources for sexuality education that the teacher feel familiar and confident with. The latest model of delivery also focuses on the teachers taking more responsibility in the programme and running the session themselves on alternate weeks.

Personally I have seen a shift in how individuals participate in the sessions. For the less verbal learners this has been most apparent when they re- joined the programme with another teacher after participating in the previous year. Some learners participated with more intent in games such as the greeting game, and some were able to choose and present the yes card in the permission games, rather than picking up both and echoing 'yes or no'. Many of these learners were also able to recognize and place the body parts appropriately.

With the more able learners learning was more apparent within the programme through the vocabulary the learners began to use and in how they shifted from being giggly and embarrassed to matter of fact and straight forward in how they discussed sexual development. I have had three higher ability learners moving on to another group in another school and was impressed by what they had retained and could talk about in relation to the work we had completed on growing up, wet dreams and masturbation.

Through this experience I have reassessed my preconceived views of Autism and now feel that many learners with ASD *are* able to engage in group activities, that most learners *are* able to take turns and show awareness of others in the group. I have been surprised by the friendliness and warmth of many learners as well as their willingness and enthusiasm to take part in the sessions.

We are getting through in terms of being appropriate. Before the programme it was a question of giving the learners instructions about what is appropriate or not, now it is a question of asking the learner. The learner is now an active participant –"Is this appropriate? Where can we go to do this? (Kim, Teacher 14-16yr olds, 7th Aug 06)

Overall, this comment demonstrates a shift not in learner behaviour in relation to sexuality but in terms of the teacher's response to this behaviour. The teacher asks the learners to work it out for themselves,

referring back to the session. This means teachers can take pictures and words used in the session and refer to them at other times to respond to behaviour and reinforce learning. This follow-through is important as sexual development and socially appropriate behaviour needs to be addressed on many levels: in a programme as part of the curriculum, individually and with parents and carers at home or in a hostel.

Perhaps then the most important aspect of the programme is that of placing the issue of sexual development and growing up as part of the school curriculum, as something that all learners have access to. One teacher felt that sexuality education should be part of the teaching curriculum for all learners because this 'normalizes' the subject and brings it out into the open. She also felt that making sexuality education part of the curriculum would help parents engage with the issues more readily and acknowledged that parents need support.Making sexuality education part of the school curriculum also means that a teacher can be proactive and introduce themes they feel the young people need to learn about rather than responding after the event or to a crisis.

In conclusion, although learners with ASD have individualised perception and there is a strong argument for individualised programmes and intervention in relation to sexuality education, there is also a case for offering all learners input as small class groups. Group work is time efficient but also brings learning about sexuality into the open, proactively, into each classroom culture.

[1] Peeters, T (1997) Autism From theoretical understanding to educational intervention, Whurr Publishers ltd, UK p128.

[2] Jordan, R. (2001) Autism with severe learning difficulties.

[3] All teacher and learner names have been changed.

[4] Vergnaini, T & Frank, E. (1998) Sexuality Education for senior phase (Grades 7-9) Teachers, Heinemann, S.A.

[5] Caspar, L.A. & Glidden, L.M. (2001) Sexuality education for adults with developmental disabilities. Education and Training in Mental Retardation and Developmental Disabilities,36,172-177.

[6] Carter, J.K. (1999). Sexuality education for students with specific learning disabilities. Intervention in School and Clinic, 34,220-224. McConkey, R. & and Ryan, D.(2001). Experiences of staff dealing with client sexuality in sevices for teenagers and adults with intellectual disability. Journal of Intellectual Disability Research,45, 83-87.

[7] Ten Myths of Autism A parent Investigates Five to Eleven Vol 3 No9 March 2004

[8] Peeters, T (1997) Autism From theoretical understanding to educational intervention, Whurr Publishers ltd, UK p52 -53.

[9] Session sheets referred to in this paper relate to the record I kept of each programme. Each sheet recorded the activities planned for the session, comments on how the learners responded and ideas for the following week.

[10] Dr Temple Grandin, Aut Talk (Autism SA, April 2006, issue 9)

11 Good and bad touch pictures: Step- by- Step; A Sexuality and HIV/AIDS education programme for young adults with intellectual disability. A facilitators Manual, Rebecca Johns (2005) published by Western Cape Forum for Intellectual Disability, p143-154.

[12] Dixon, H.& Craft, A. (1991)Picture Yourself. Four sets of illustrative cards and photographs. London LDA. Picture Your self

[13] Talking together about growing up: a work book for parents of children with learning disabilities. Scott, L. &Lerr-Edwards, L (1999)   FPA, London p 64-65.

[14] Dixon, H.& Craft, A. (1991)Picture Yourself. Four sets of illustrative cards and photographs. London LDA. Picture Your self

0016

IS AUTISM AN IMMUNE MEDIATED INFLAMMATORY DISORDER?

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Abstract

A loss of or a failure to mature proportional control of the body's innate immune responses has a direct impact on adaptive cellular and humoral immunological function. Adverse cross talk between the immunological and neurological systems at the mucosal border, the site of extensive innate immune activity has implications for local and systemic inflammatory cytokine production.

The enteric and central nervous systems are directly affected by cytokine-, the master controllers of the immune system. The stimulation of and the continuous exposure to pro inflammatory cytokines such as IL-1 and TNFά leads to the translocation of the gene transcription factor Nuclear Factor Kappa B (NFkB) and this may account for or amplify neurodevelopmental and seizure symptoms.

Inappropriate or excessive immune responses are caused, signified, or accompanied by a dysregulation of the body's normal cytokine milieu. Functional impairment leading to both physical and psychological effects may then be induced in sensitive individuals by the same chemicals normally released for the purpose of protection against dangerous pathogenic organisms.

Dysfunction of the innate and adaptive immune systems associated with the common mucosal immune system can be caused or intensified by inadequate production of secretory immunoglobulin A and the induction and release of NFkB. This leads to a loss of mucosal tolerance, and an increased production of pro inflammatory cytokines, the same cytokines induced at the mucosa are also produced centrally and act on brain receptors.

Individuals with autism have characteristics of loss of mucosal tolerance, identified low production of secretory IgA and altered cytokine balance. The subsequent failure to mature dendritic cells and promote regulatory T cell induction of mucosal tolerance may present a clinical opportunity for symptom and condition improvement. Clinical treatment to raise SIgA and improve the intestinal microflora ecology in children diagnosed with autism has produced improvements in bowel function, social interaction, sleep and cognitive abilities.

Conclusion: Loss of mucosal tolerance and the subsequent up regulation of adaptive and innate cytokine pro inflammatory responses may induce neurodevelopmental changes in susceptible individuals. Restoration and continuous management of mucosal tolerance results in symptom reduction.

Introduction

Autism spectrum disorders (ASD) are part of a broad spectrum of neurodevelopmental disorders known as pervasive developmental disorders, which occur in childhood. They are characterised by impairments in social interaction, verbal and nonverbal communication and the presence of restricted and repetitive stereotyped behaviours.[xv] This complex mix of social and physical disabilities will combine into a unique 'person centred' combination with differing levels of intensity.

The diagnostic frequency of autism appears to be increasing not only within the UK[xvi] but also in the USA[xvii], Europe and the Middle East.[xviii] It is also apparent that certain types of common childhood health conditions such as asthma, eczema and allergies[xix] are becoming more prevalent.[xx]

So are these just perceptions[xxi,xxii] or are these based in reality[xxiii] - if they are, is there a common link, something that can provide a connective and cohesive plan or intervention? It is in this area of intervention and investigation that the science of immunology offers so many possible and plausible explanations.

It is generally understood that during infection, inflammatory cytokines induce regulated changes in the host's internal milieu to create a hostile environment to invading pathogens. Recent evidence indicates that these cytokines are also constitutively produced, and that their production is increased by environmental stressors other than microbes, and they modulate and are involved in the control not only of the immune system but also of "normal" physiological processes.[xxiv]

Cytokines are released by most cells in the body especially those with a role in our defence system. It appears that a common immunological pattern with neurodevelopmental and autism spectrum conditions

is a loss of the ability to maintain immunological control of the principle cytokines and a loss of functional neutrality within the immune system referred to as 'anergy'.

> *People tend to get the immune system the wrong way around; we're so focussed on the immune system responding to things, that we forget that 99.99% of the time, its job is NOT to respond to things.* [xxv].

If immunological anergy is lost and the subsequent cytokine disturbance promotes a persistent state of inflammation, the result can be the development of an immune mediated inflammatory disorder (IMID). Depending on the genetic make up, the environmental triggers and the level of disruption, it appears that autism and neurodevelopmental conditions may develop and evolve within individuals as a type of IMID.

IMID's are characterised as a group of diseases or disorders that involve an immune response described as inappropriate or excessive, and is caused, signified, or accompanied by dysregulation of the body's normal cytokine milieu. IMID's cause acute or chronic inflammatory injury, sometimes severe, in any organ system.

With this in mind the restoration of inflammatory and immunological anergy through the resolution of the IMID represents a potential safe and effective intervention.

Neuro Immune Abnormalities

Neuroimmune interactions start very early on during embryogenesis and persist throughout the lifetime of the individual. A successful neurodevelopment is dependant upon a normal balanced and proportional immune response. To date a variety of abnormal immune responses have been identified in individuals diagnosed with autism. These include abnormal or skewed T helper cell type 1 (T_H1)/T_H2 cytokine profiles[xxvi], decreased lymphocyte numbers[xxvii], decreased T cell mitogen response[xxviii], and the imbalance of secretory and serum immunoglobulin levels.[xxix,xxx]

Immune dysregulation of this type could result in the generation of localised or systemic inflammation and/or the release of immunomodulatory molecules (cytokines/chemokine/neurokines) which are then able to influence, alter, or modify neurodevelopment and/or neuronal function, especially at critical times of development. [xxxi,xxxii]

Abnormalities of the immune system may then be responsible for the mediation of the pathophysiology of autistic spectrum disorders. Cytokines play a pivotal role in initiating and maintaining immune responses, and have been implicated in the aetiopathogenesis of major neuropsychiatric disorders including autism. Various cytokine associated abnormalities have been detected in autistic subjects[xxxiii] such as elevated IL-2 serum levels implicating the activation of T cell subpopulations having an impact in autism.[xxxiv] Another study found that autistic subjects had elevated plasma levels of IL-12 and IFNγ whilst IL-6, TNFά and IFNά remained unaffected.[xxxv]

Abnormalities in cytokine production from B cells, Natural Killer cells and macrophages have also been reported.[xxxvi] Other findings indicate alterations in innate immune function with increased TNFά production when stimulated by cell wall fragments called lipopolysaccharides (LPS).[xxxvii] A prolonged exposure by the CNS to circulating pro inflammatory cytokines can impact upon brain development and may also cause neurotoxicity and other symptoms identified in autistic subjects.[xxxviii]

Altered gastrointestinal derived cytokine activation has been identified in children with ASD.[xxxix] Whilst there appears to be a complex pattern of cytokine production in children with autism, it is one that does not fit the traditional T_H1/T_H2 paradigm;[xl,xli] this may however, be a reflection of the different patient groups who have been studied. The presentation of differing groups and differing clusters of symptoms provide indications that different cytokine profiles may reflect differing autism behavioural phenotypes.

The greatest collection of immune tissue in the human body is found in the gastro intestinal tract[xlii] and there appears compelling though at times contradictory evidence that in many individuals diagnosed with autism the gastro intestinal tract is a site of dysfunction.[xliii, xliv]

Our immune system, not only that which is found in the mucosal tissues of the gastrointestinal tract, is adept at warding off or defending us against intruders, but in order this can occur without detriment to the host there must be three key elements in place; Competence, integrity and proportional response.

To work correctly the immune system must competent, functional and complete as well as being capable of delivering a response appropriate to the challenge. A system inadequate in these areas can lead to aberrant inflammatory activity with systemic effects that may manifest as conditions as diverse as, autism[xlv] inflammatory bowel disease[xlvi], irritable bowel syndrome[xlvii], neurodevelopmental disturbances[xlviii], auto immune diseases[xlix], allergy[l], asthma[li], diabetes[lii], obesity[liii] and cardiovascular[liv] problems amongst many others.

Gastrointestinal Immune Systems

The mucosal surfaces of body are principally found in the gastrointestinal tract but are also present in the respiratory and genito urinary tract which when combined make up a vast area of delicate epithelial barriers. These tissues are points of continuous, contiguous and intimate interactions between the immune system and the outside world, under constant antigenic pressure they are the site of the greatest volume of immune/neurological decision making in our bodies.[lv] Key to the integrity of the immune response at this point of contact is the presence of viable human strain bacteria beneficial to the host.[lvi]

The list of beneficial functions attributed to intestinal bacteria continues to grow and includes nutrient processing,[lvii] regulation of intestinal angiogenesis,[lviii] development of gut-associated lymphoid tissues (GALT),[lix] induction of oral tolerance,[lx] mucosal immunity,[lxi] and diversification of the pre-immune antibody repertoire.[lxii] Changes in the distribution and frequency of allergies and inflammatory bowel disease also appear to be linked to alterations in the interaction between host and bacteria.[lxiii, lxiv]

This sensitive and delicate system is the site of intense immunological activity, for not only must it mount an appropriate immune response, but also maintain a constant 'cross talk', a term which refers to the complex physiological loops in immunity between the epithelial tissues, immune, endocrine, ENS and CNS (Brain). This innate and highly active mucosal immunological barrier covers some 400m^2 and is known as the Common Mucosal Immune System (CMIS).

Parents have long reported through empirical observation that their children have gastro intestinal symptoms and that many react differently to certain food groups, depending on the food chosen would often present with loose stools and or constipation. In one study of 500 autistic children almost 50% had recognised gastrointestinal functional problems.[lxv] As a consequence these delicate tissues are then subjected to complex immunological and neurological activity.

These mucosal boundaries rely upon various secretions for protection such as mucins[lxvi] defensins[lxvii] and secretory antibodies, especially Secretory Immunoglobulin A (SIgA)[lxviii]. In addition they employ specialised epithelial physical components such as the tight junctions between the enterocytes and other components associated with apical surface coats. The majority of these common mucosal tissues have to depend upon a single layer of epithelial cells[lxix], this barrier is susceptible to challenges especially immunological ones, and have been found to be more 'leaky' - a state of increased permeability[lxx] in autistic individuals. [lxxi]

This exchange of information, the local sampling of antigens, their subsequent processing and the intricate management of this complex web of function may be perceived as the 'Immunological Brain'.[lxxii] Correct functional of the gastro intestinal immunological brain is dependant on the colonisation of the intestine with beneficial microflora, essential for the normal development on maintenance of the humoral and cellular immune responses.[lxxiii]

These interactions between the mucosal immune system and enteric microbes, presented in ever-changing and novel patterns, maintain the physiologically normal state of immunological anergy (inflammation free) or activation of gut-associated lymphoid tissue (inflammation present) throughout life. These interactions with environmental antigens then benefit and activate specific and adaptive, natural, (i.e., not deliberately stimulated) semi-specific, and aspecific elements of the mucosal immune systems.

The gut-associated lymphoid tissue (GALT) is essential to immune responsiveness and can be divided into 3 compartments, each with its own conspicuous and characteristic immune elements and reactions:

1. Peyers patches (PPs), are the organised lymphoid tissues found in the wall of the small intestine that contain B lymphoid follicles and inter follicular populations of CD^{4+} (helper) and CD^{8+} (cytotoxic)T cells, many with the propensity to re-circulate to and selectively lodge in mucosal tissue, they are also involved in oral tolerance against proteins.[lxxiv]

2. Gut lamina propria, is the meshwork of connective tissue underlying the gut epithelium that contains a broad spectrum of myeloid and lymphoid cells, especially immunoglobulin (Ig) A plasmablasts, CD4$^+$ T cells, dendritic cells, and mast cells. Lamina propria CD^{4+} T cells promote T$_H$1-like immune responses against intracellular pathogens and support T$_H$2-like humoral responses against extracellular pathogens by providing help to mucosal B cells and plasmablasts.[lxxv]

3. Intraepithelial leukocyte spaces, are the spaces between intestinal epithelial cells and above the basement membrane that are populated by a variety of small, round cells, especially Natural Killer cells and many CD8$^+$ T cell subsets.[lxxvi,lxxvii]

The ability of each of these principal components to remain active and proportional depends upon stimulation by appropriate gut microbial antigens. Disturbances in this communication network and

subsequent alterations in function can be seen in some autistic individuals when they fail to exclude a known immunological provocateur such as casein or gliadin, the subsequent immune reaction can produce a wide range of symptoms.[lxxviii]

For the body to assess the need for and to judge the level of response a process of immunological sampling must occur, both within the gut lumen and across the epithelial barrier to specialised immune receptors.[lxxix] Here the mucosal tissues operate a unique approach to handling the contact with commensals and pathogens. Bacteria are efficiently killed when taken up by macrophages, but most commensals are retained alive when collected by professional antigen presenting cells called dendritic cells. These cells then migrate to the mesenteric lymph nodes, via various routes and induce a localised SIgA response, which in turn limits further bacterial penetration and aids luminal colonisation.[lxxx]

The majority of the foreign antigens in the gastrointestinal tract are derived from two sources; food, of which some estimates suggest up to 50 tons are swallowed within a lifetime, and the abundant commensal microbial flora, both of which require an evolving and constant level of tolerance to be achieved, to avoid inappropriate responses.

Thus a major role of the CMIS is a down regulation or the induction of a non responsive state within in its armamentarium this function is referred to as 'oral tolerance'[lxxxi] and represents one of the least understood but most interesting components of the 'immunological brain'[lxxxii]. Oral tolerance failure may be invoked by a failure to achieve a suitable post natal maturation of the immune system due to inadequate or excessive priming of the mucosal tissues by bacteria and antibodies, then pro inflammatory cytokines may be induced from loss of tolerance to antigens. The subsequent immunological deviation may itself then be recognised as a 'stressor' leading to increased output of cortisol. The increased cortisol may also be a problem as the pro inflammatory cytokines IL-1 and TNFά blunt the normal cortisol feedback receptors and encourage a prolonged increase of circulating cortisol and increase the risk of illness from hypercortisolaemia.[lxxxiii]

The suggestion that the immune system may play a role in the aetiology of certain psychiatric disorders is an old one, first suggested by Wagner-Jauregg in 1887, and one of a number for which he won the Nobel Prize in 1927.[lxxxiv] The more contemporaneous scientific views on the mechanisms by which peripherally released cytokines can act on the brain and induce behavioral effects have been profoundly modified by the more recent understanding that cytokine receptors are clearly expressed in the brain,[lxxxv] and that administration of cytokine receptor antagonists annuls the central effects of peripherally administered cytokines.[lxxxvi]

These findings have been further complemented by the demonstration of the existence of a central cytokine compartment, inducible by peripheral cytokines,[lxxxvii] the presence of these receptors and their influence on behaviour appears to be significant. In animals, experiments have shown that increased cortisol and cytokine activity in early post natal development may be an important determinant for the future management of stressors throughout life.[lxxxviii,lxxxix]

Much of the CMIS is developed during gestation and at full term requires the priming of the mucosal tissues from birth canal bacteria and immunoglobulins to ensure eventual production of SIgA and a balanced T helper cell response[xc]. It does however remain plastic in its nature and through its exposure to differing strains and quantities of bacteria it is able to evolve and develop at any point in the lifespan of the host.[xci,xcii] This developmental capacity provides the ability to reprogramme the dysfunctional or sub optimal 'immunological brain' to achieve improvement in health and function, within the autistic individual with altered immune status.

Gastrointestinal Commensals

The lumen of the gastrointestinal tract is uniquely designed to meet and manage its exceptional environmental challenges. A highly diversified community of micro organisms live in our intestines with densities approaching 10^{12} microbes per millilitre of lumen contents in the distal gut.[xciii] The composition of this community of between 10 and 100 trillion organisms varies within the gastrointestinal tract and between each person.[xciv]

This microbiota is composed of between 500-1000 different bacterial species, with an aggregate biomass of 1.5kg.[xcv] It is clear that there are substantial variations in this microbial biome even among members of the same family, and certain types of bacteria's do seem more provocative than others in autism, such as clostridia species.[xcvi,xcvii]

There is also a substantive population of viruses in the gastro intestinal tract, in 2003 the viral DNA from faecal material was analysed revealing a population of over 1200 viruses of which less than 2% were understood. Their interaction and communication with bacteria where they may be acting as phages in the

gastrointestinal tract represents a significant area of exploration.[xcviii]. The effects and roles of viral agents in the promotion and progression of autism have also been attracting research investigation.[xcix]

These differential species of over 1900 organisms residing in the human gastrointestinal tract have a collective genome equivalent or greater than our own. This unique microbiome gives an opportunity to mine it for its clinical use in manipulating the eco/immunological environment and to provide a variety of biomedical applications.

Not only is the gastrointestinal tract the most immunologically active tissue, it is also the most metabolically active tissue, it's epithelium sheds up to 3 billion cells per hour in the small intestine and about one tenth of this in the large intestine[c]. In addition the mucosum must manage peristalsis and associated food and fluids and also provide a viable home to this wide variety of microbial species which in turn must be managed to act in a symbiotic manner with us[ci].

In order that these vulnerable species bind and then form and maintain an intestinal ecosystem many variables must be overcome. Whilst this is an area of expanding knowledge, the polysaccharide rich mucus paste overlying the gut epithelium appears to be essential in maintaining this biofilm community. Biofilms are dense cohesive communities of microbes that embed themselves whilst resisting the shear forces of peristalsis[cii].

Secretory Immunoglobulin A (SIgA)

Recent evidence suggests a dynamic interplay between the microbiota, the mucosal immune system and the biofilm; one of the key components to the function of the CMIS and the eco-immune system is the production of SIgA. Although the importance of mucosal IgA-mediated protection is unquestionable, the role of intestinal IgA in regulation of the gut flora and how dysregulation of gut bacteria affects the immune system are only partially understood.

What is known is that hypermutated mucosal IgA's are critical for regulation of bacterial composition and represent the main element of the immune system involved in maintenance of gut flora homeostasis.[ciii] Increased production of SIgA where SIgA deficiency has been identified can be achieved with the use of a yeast species called Saccharomyces Boulardii[civ] and the use of human strain bacteria.[cv]

Saccharomyces Boulardii, a symbiotic but non commensal species used in conjunction with other essential nutrients such as zinc, glutamine, lysine, cysteine and other amino acids, essential fatty acids, short chain fatty acids, minerals, fibre and antioxidants and specialised bacterial species has profound effects on the CMIS. When delivered appropriately they will beneficially impact inflammatory/immunological and ecological activity so improving the 'immunological brain' function to the benefit of the host. This includes the function of the higher order brain tissues, due to a reduction in circulating pro inflammatory cytokines.[cvi,cvii]

Reduction in the production of SIgA levels is also associated with increased absorption of food protein antigens so allowing greater allergenic potential and inappropriate protein transfer across the mucosal barrier and a reduced level of resistance to mucosal membrane infection[cviii]. By increasing SIgA production food intolerance and some allergy can be resolved, as well as adverse overgrowth of commensal yeast such as Candida albicans as SIgA competitively inhibits the transmigration of the opportunistic Candida albicans.[cix]

The first line of restitution in this matter is to look for and identify the presence of pathogens, absence of normal bacteria and the ability of the mucosal plasmablasts to produce SIgA. The use of correctly administered probiotics can have a profound effect by promoting plasma cell production of SIgA, decreasing the inflammatory and immune response, providing nutrients for the intestinal cells, suppressing gut pathogens, helping to maintain the effectiveness of the mucous barrier, assisting in the detoxification of gut derived toxins and lastly offering protection against reactive oxygen species or 'free radicals'.[cx]

The application of bacteria for the purpose of immune regulation is called immunobiotics[cxi] these organisms are arguably the largest detoxification component of the body and the endogenous enteric bacteria represent an enormous health and function orientated reservoir, which can be constantly and safely replenished.[cxii]

Observation

An observational longitudinal analysis of children and adults diagnosed with ASD has revealed a consistent alteration in the production of SIgA. Most individuals present with a disparate range of symptoms, consistent with the highly variable genotypical manifestation of autism. However, the collection of salivary samples from these individuals (>200) has revealed a consistent low level of SIgA in > 85% (less than 110ug/ml) a normal level in 10% +- 1% (between 100ug/ml and 471ug/ml) and a raised level of SIgA in 5%+- 1% (greater than 471 ug/ml).

Modifying the plasma cell production of SIgA to reflect a more age related and proportional level of SIgA has produced a number of benefits to the affected autistic individuals, with 5 principle benefits being reported by parents and carers:

1   Improved gastrointestinal function

2   Improved sleep patterns and duration

3   Improved language

4   Improved sociability

5   Improved eye contact

Enteric Nervous System

The enteric nerve tissue mass is enormous, the total number of neurons in the bowel probably exceeds that in the spinal cord and the aggregate of all of the other (non-enteric) neurons of the peripheral nervous system (PNS) combined. Its structure and chemical responsiveness makes the ENS like a 'second brain',[cxiii] with every class of neurotransmitter found in the brain also found in the ENS.

Once the ENS goes array, whether through infection, immune insult, malnutrition, toxicity or poor dietetic practices the complexity of correction becomes a maze like metabolic hall of mirrors. As the role of bacterial communication within the gut (bacterial-epithelial cross-talk) is further clarified, physicians will be able to more predictably modulate gut immune responses, by the use of specialised probiotics, nutrients and non commensals. [cxiv,cxv]

As a human's intestinal eco system is constantly shaped by interactions between its microbes (both intra and inter species communications), epithelium, mucosal immune system, microvasculature and enteric nervous system,[cxvi] and because of the tremendous plasticity of this area the gastrointestinal tissues represent the largest area of intervention options with greatest benefit to risk.

Nuclear Factor Kappa B (NF-ĸB)

NF-ĸB is a transcription factor residing in the cytoplasm of every cell and translocates to the nucleus when activated. Its activation is induced by a wide variety of agents including stress, cigarette smoke, viruses, bacteria, inflammatory stimuli, cytokines, free radicals, carcinogens, tumor promoters, and endotoxins.

On activation, NF-ĸB regulates the expression of almost 400 different genes, which include enzymes (e.g., cyclooxygenase (COX-2), 5 Lipoxygenase (5-LOX), and Inducible Nitric Oxide (iNOS), cytokines (such as TNFa, IL-1, IL-6, IL-8, and chemokines), adhesion molecules, cell cycle regulatory molecules, viral proteins, and angiogenic factors. The constitutive activation of NF-ĸB has been linked with a wide variety of human diseases, including depression, asthma, atherosclerosis, AIDS, rheumatoid arthritis, diabetes, osteoporosis, Alzheimer's disease, and cancer. [cxvii] In addition brain tolerance is also considered to be adversely affected by the induction and promotion of NF-ĸB leading to increased risk of seizures and neuronal damage.[cxviii,cxix,cxx]

NF-ĸB activation induces the expression of many molecules that mediate the recruitment and activation of immune cells, but also protects cells from cytokine-induced death by inducing the expression of anti-apoptotic proteins. This bidirectional element of NFĸB makes it a complex molecule for therapeutic induction or suppression.

In a recent experiment; NF-ĸB inhibition prevented the expression of pro-inflammatory cytokines, chemokines and the adhesion molecule VCAM-1 from CNS-resident cells. NF-ĸB-dependent gene expression in non–microglial cells of the CNS provides a permissive pro-inflammatory milieu that is critical for CNS inflammation and tissue damage and may represent a possible cause or aggravator of autism. [cxxi]

As NF-ĸB is one of the pivotal regulators of pro-inflammatory gene expression,[cxxii,cxxiii] it plays crucial roles in the nervous system, including potential roles in long-term responses to synaptic plasticity, pro-or anti-apoptotic (or programmed cell death) effects during developmental cell death, and neurodegenerative disorders.[cxxiv] NF-ĸB production is associated with excititotoxicity induced neuronal cell death in animal models, and whilst its role in neuronal health is bi directional, inappropriate and persistent upregulation of NF-ĸB represents an unwanted risk factor for neuronal health.[cxxv] Because of the strong link of NF-ĸB with different stress signals, it has been called a "smoke-sensor" of the body. In the management of conditions

of mood and function the management and control of increased but inappropriate NF-κB production represents a therapeutic window.

Several agents are known to suppress NF-κB activation, including T$_H$2 cytokines (IL-4, IL-13, and IL-10), interferons, endocrine hormones, phytochemicals, corticosteroids, and immunosuppressive agents.

Within the CMIS the epithelia of the intestinal tract characteristically maintain inflammatory hypo responsiveness toward the normal microflora. Experiments using non virulent enteric organisms (non virulent *Salmonella* strains) can limit the synthesis of inflammatory molecules induced by a variety of promoters. This immunosuppressive effect involves inhibition of NF-κB.[cxxvi] By managing the microbial milieu especially where there is evidence of altered microbial ecology, through utilising specialised bacterial messengers the inappropriate promotion of NF-κB can be limited to appropriate response levels.

Probiotics As Immune Modulators

Initially sterile, once outside of the womb the human gut goes through dramatic changes in its gut microflora until it reaches its 'climax community' which in turn remains permanently modifiable by environmental, drug, nutrient, bacterial and host gene factors.[cxxvii]

Our extended evolutionary journey in which humans and bacteria have co-evolved to become a hybrid of bacteria and human, this relationship has resulted in a state of mutualism or cooperation and as such these species are recognised by the gastro intestinal immune system as harmless "old friends" because otherwise a persistent defensive response would be required and this would merely lead to immunopathology.

Therefore, rather than priming aggressive immune responses, these organisms prime immunoregulation. They do it by inducing an unusual pattern of maturation of specialised immune priming cells called dendritic cells[cxxviii,cxxix] in such a way that these retain the ability to drive immune anergic inducing regulatory T cells (T$_{reg}$)[cxxx]. This effect requires the gastro intestinal immune system to operate in an effective and proportional manner and in turn maintain mucosal tolerance.

Whilst the 'hygiene theory' of immune activation and control has gained some significant followers,[cxxxi] it now seems probable that an extension of the microbial exposure strategies referred to as the "old friends" mechanism is more feasible. This model suggests that in an environment that less actively primes regulatory T cell activity, immunoregulatory disorders will occur first in those individuals whose gastro intestinal immune systems are least efficient at developing good stable regulatory T cells.[cxxxii] A simple example is in the restoration of tolerance to cow's milk allergy that can be achieved when regulatory T cells are allowed to mature correctly.[cxxxiii]

Conclusion

The body must achieve a state of immunological tolerance or anergy to achieve and maintain health, a loss of this balance results in an increased expression of pro inflammatory cytokines, which if not brought under control have the potential to create an immune mediated inflammatory disorder or disease.

Mutualism between commensal bacteria and their host is established by the competence of the host mucosal immune system to restrict the penetration of commensals to low levels. This allows a productive mucosal immune response without inducing unnecessary systemic immunity to these organisms. Provided the mesenteric lymph nodes are intact, the result of repeated intestinal commensal priming is to induce IgA selectively and locally, forming one of the layers of the mucosal barrier that limits bacterial penetration.

Autistic and neurodevelopmental subjects have evidence of altered cytokine balance, and a history of gastrointestinal problems, both of which are known promoters of and the conclusion of loss of immunological tolerance.

ASD subjects are also known to be low in the main gastro intestinal immunological mediator, Secretory Immunoglobulin A and as such are more prone to immune discord.

The correction and maturation of the gastro intestinal tract immune system and the subsequent reduction of circulating pro inflammatory cytokines has had consistent improvement in the function of children with ASD, their bowels, emotion and language.[cxxxiv]

The further investigation and understanding of this system of intervention which represents a safe and potentially effective treatment for people with ASD is justified.

AUTISM AND THE SEROTONIN TRANSPORTER: A GENETIC STUDY IN SOUTH AFRICAN INDIVIDUALS

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Abstract:

Autism is a pervasive developmental disorder (PDD) affecting 1/1000 individuals with a male to female prevalence ratio of 4:1. Genetic and non-genetic factors have been implicated in autism. Unusual serotonin synthesis and hyperserotonemeia in 25-33% of individuals affected by autism has been reported. The serotonin transporter gene (5-hydroxytryptamine transporter; 5-HTT/SERT) consisting of a 44bp ins/del polymorphism has been strongly implicated in autism based on its differential expression. It codes for the serotonin transporter a transmembrane protein that controls serotonin (5-hydroxytryptamine; 5-HT) signaling and availability. Selective serotonin reuptake inhibitors (SSRIs) aimed at increasing 5-HT levels in the synapse has been successful in treating autistic symptoms. Because of this strong association of the SERT with autism we conducted a pilot study on 40 individuals affected by autism and 80 normal individuals in the South African population to determine whether the serotonin transporter promoter length polymorphism (5-hydroxytryptamine transporter length polymorphism; 5-HTTLPR) is associated with autism. All patients were genotyped and the allele frequency conforming to the Hardy-Weinberg equation was determined. It was discovered that the S allele was present in 25% of individuals with autism compared to 11% in unaffected individuals. A high frequency of the L allele was also observed in the South African population, which is in line with the frequency observed in European populations, while the opposite is true in some Asian populations.

1. Introduction:

Autism, first discovered by Leo Kanner in 1943, is a developmental disorder characterized by three main features, namely, a lack of social interaction, problems and impairment with communication and routine/repetitive behaviors. Majority of children affected by autism show symptoms by age three, however 30% of affected children have a regressive onset (Miles and McCathren 2005). Autism generally affects 1/1000 but when the broader spectrum is also taken into account a prevalence rate of 1/300 to 1/500 individuals are affected worldwide and the affected ratio of males to females is 4:1 (Sutcliffe et al. 2005). Population studies on the incidence of autism reported 1 in 158 individuals are affected by autism worldwide however incidence rates of autism varies from country to country (http://taap.info/incidence_and_cost_of_autism.htm). Honda et al. (2005) reported an increase in the incidence of autism from 47.6 per 10 000 in 1988 to 117.2 per 10 000 in 1996 while in Australia it was found to be 5.5 per 10 000 in 1999-2000 (Williams et al. 2005). Autism is caused by both genetic and non-genetic factors and involves numerous susceptibility genes. Whole-genome screens of families suggest that there are at least ten genes interacting with each other that possibly cause autism (Muhle et al. 2005). Genetic studies revealed a 2-8% recurrence rate of autism between affected siblings and a 60% concordance for classic autism in monozygotic (MZ) twins compared to 0% in di-zygotic (DZ) twins (Muhle et al. 2005). When less stringent criteria is used to evaluate autism a concordance rate of 60-92% is found in the case of MZ twins and 0-10% in DZ twins (Wassink et al. 2004, Muhle et al. 2005, and James et al. 2005). This suggests that environmental and epigenetic factors affect the variability of symptoms found in this spectrum disorder.

Autism is a psychiatric disorder and evidence suggests that there's an imbalance of neurotransmitters, for example, serotonin, dopamine, reelin, in the brains of individuals affected by autism. Numerous studies have also reported an elevated level of serotonin (hyperserotonemeia) in the urine and blood in 25-33% of individuals with autism (Tordjman et al. 2001, Coutinho et al. 2004, and Sugie et al. 2005) and abnormal rates of serotonin synthesis in patients affected with autism (Bartlett et al. 2005). Individuals affected by autism show symptoms like sleep disorders (11%), anxiety and fear (17-74%), and poor attention (60%) all of which overlaps with other psychiatric disorders like depression (Tsai 1999).

Treatment for psychiatric disorders like autism has been developed in the form of drugs. These drugs act as antagonists of neurotransmitters by either activating receptors or competing for binding to transporters with other neurotransmitters. The most effective drugs used to treat symptoms of individuals suffering from autism include the SSRIs fluoxetine, fluvoxamine, sertraline, citalopram and paroxetine (Yu et al. 2002; Sugie et al. 2005 and White et al. 2005). SSRIs bind to serotonin transporters thereby blocking the reuptake of serotonin, which leads to an increase in serotonin levels in the synapse. After treatment with antidepressants symptoms like anxiety and sleep disorders were alleviated and improvement in language ability was also noticed in individuals with autism. Based on the efficiency of SSRIs numerous genetic studies, focusing on the serotonin transporter (SERT), have been undertaken.

The efficiency of serotonin signaling is controlled by the serotonin transporter (SERT) a Na^+ and Cl^- dependent transmembrane transporter protein. The SERT has high affinity for serotonin and actively clears it from the synaptic spaces transporting it back into the axonal terminal where it is recycled. The serotonin transporter gene is found on chromosome 17q11 where it spans a 31kb region and consists of 14 exons which codes for a 630 amino acid protein (Bartlett et al. 2005). Polymorphisms occurring in the non-coding regions that affect its transcription efficiency include: the 5-hydroxytryptamine transporter length polymorphism (5-HTTLPR); a 17bp variable number of tandem repeat (VNTR) in intron 2; a ~380bp deletion occurring between the 5-HTTLPR and the start codon; and a G to T single nucleotide polymorphism (SNP) in the putative adenylation site at the 3' untranslated region (UTR) (Murphy et al. 2004, Bartlett et al. 2005, and Guhathakurta et al. 2006). The first two exons, exon 1a and 1b, are also reported to be alternatively transcribed (Ramoz et al. 2006). In the promoter region of the SERT a 44bp insertion/deletion polymorphism (5-HTTLPR) is found roughly 1kb from the start codon. The two variants of this gene are called the long (L) and the short (S) variant respectively. The long variant of 5-HTT has a two to three fold increase in basal activity, seen when fused to a reporter gene after it was cloned and expressed in human placental choriocarcinoma cells (Klauck et al. 1997 and Bartlett et al. 2005). In this study, we determined the genotype of individuals with autism vs. unaffected individuals for the serotonin transporter gene and its allele frequency in these two populations.

2. Materials and Methods:

Sample collection:

Ethical clearance was obtained from the University of the Western Cape ethics committee, the Western Cape Education department and written consent was obtained from parents of the children after explaining the project and procedures to be used. A total of 40 patients with autism from a school for individuals with autism participated. Control samples (40 males and 40 females) were collected from normal schools in Cape Town, Western Cape. Swabs of patients partaking in this study were taken by rubbing the swab against the inside cheek for 1 minute. This was done for both the left and right cheek. The tips of the swabs were placed into a 2ml eppendorf tube to which 400ul of 1x PBS pH 7.4 (0.14M NaCl; 0.0027M KCl; 0.0101M Na_2HPO_4; 0.0018M KH_2PO_4) was added.

DNA extraction:

DNA was extracted from the swabs using either the Cell To DNA (CTD) kit (Genecare Molecular Genetics (Pty) Ltd.) or a modified protocol using the Qiagen kit (Southern Cross Biotechnology (Pty) Ltd).

Steps 1-4 were modified as follows:

1. Vortex the swabs in the PBS until the solution becomes milky

2. Transfer 300ul to a clean 1.5ml eppendorf tube

3. Centrifuge at 12K for 5 min and remove the supernatant

4. Add 300ul Buffer FG1 to the cell pellet and mix by pipetting to resuspend the cells

PCR of Samples:

The concentration of DNA was determined by using the NanoDrop 1000 (NanoDrop Technologies). Primers used were the same used by Klauck et al. 1997 (Forward: GGCGTTGCCGCTCTGAATGC; Reverse: GAGGGACTGAGCTGGACAACCAC). The PCR reactions contained the following in a final volume of 25ul: 0.4ng/ul BSA (10ng/ul); 4pM Forward primer (5pM/ul); 4pM Reverse primer (5pM/ul); 1x Buffer (10x); 100uM dNTPs (2mM); 1.5mM $MgCl_2$ (50mM); 1U BioTaq (5U/ul); 150-200ng DNA; and deionized autoclaved dH_2O. PCR conditions used were as follows: initial denaturation 95^oC for 5min; 35 cycles of denaturation 95^oC for 30s, annealing 63^oC for 30s, elongation 72^oC for 1min; final extension 72^oC for 10min; and hold 4^oC.

Gel Electrophoresis:

A total of 20*ul* of PCR product of the samples were loaded on a 1.2% Agarose gel along with a 100bp DNA ladder (Fermentas O' GeneRuler[TM] DNA Ladder Mix) and was electrophoresed at 75V for 90 minutes. Gels were stained with EtBr and viewed using an Alpha Imager (Alpha Innotech Corporation).
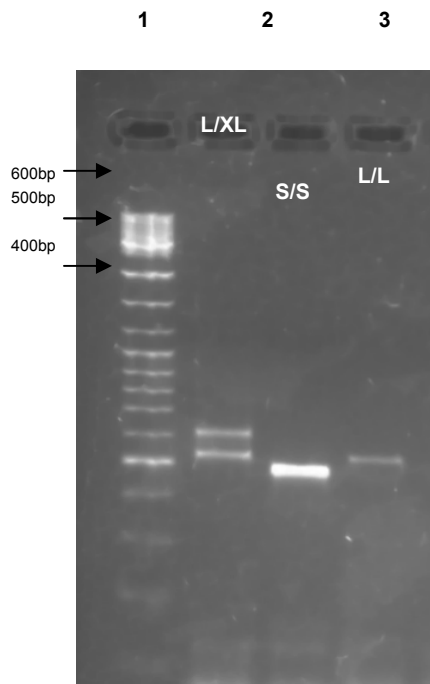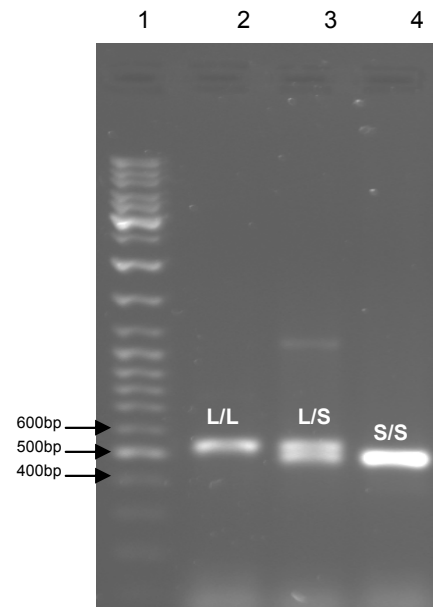

Fig.1: Genotype determination via gel electrophoresis on a 1.2% agrose gel. Lane 1 contains 100bp DNA ladder and lanes 2-4 represent L/XL, S/S and L/L genotypes respectively.

Fig.2: Genotype determination via gel electrophoresis on a 1.2% agrose gel. Lane 1 contains 100bp DNA ladder and lanes 2-4 represent L/L, L/S, and S/S genotypes respectively.

Statistical Analysis:

The allele frequencies were determined using the Hardy-Weinberg equation (fig. 4). Chi-square significance tests were performed on the affected and unaffected groups (table 3).

3. Results:

The genotype of the 5-HTTLPR as well as the allele frequency, using the Hardy-Weinberg equation, was obtained for 40 individuals affected with autism and 80 unaffected individuals (40 males and 40 females) (tables 1 and 2; figs 3 and 4). Four different genotypes were observed viz., L/L, L/S, S/S and L/XL (figs 1 and 2). The L/XL variant was found in the affected group, not shown in the tables. Comparison of allele frequency of affected and unaffected individuals only shows a slight difference in the frequency of the L variant. However, a frequency for the S allele is approximately double in the affected population compared to the unaffected population (fig. 4). The chi-square test revealed that the frequency of the S allele is significantly high ($p<0.05$) in the affected group than compared to the unaffected group.

Table 1: Genotype and Allele Frequency of 5-HTTLPR in South African Population affected with Autism
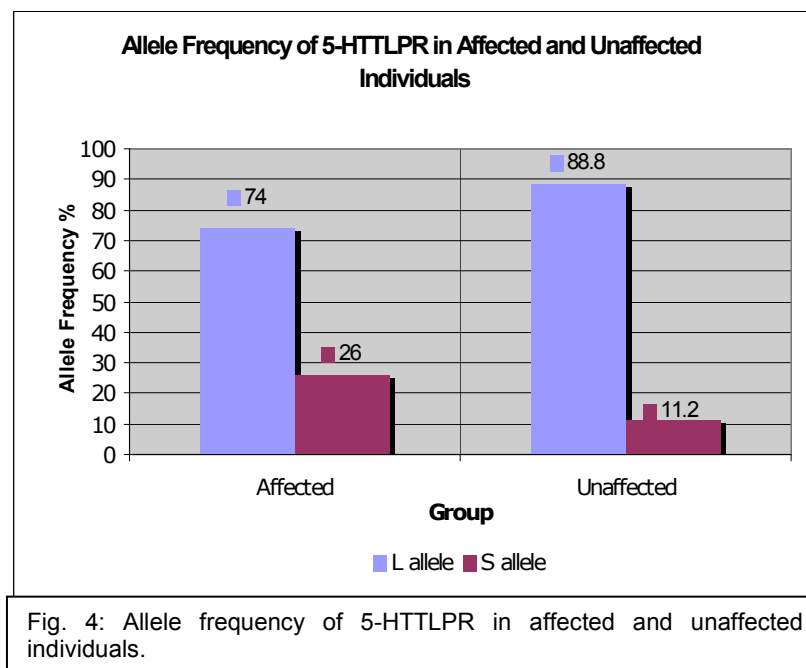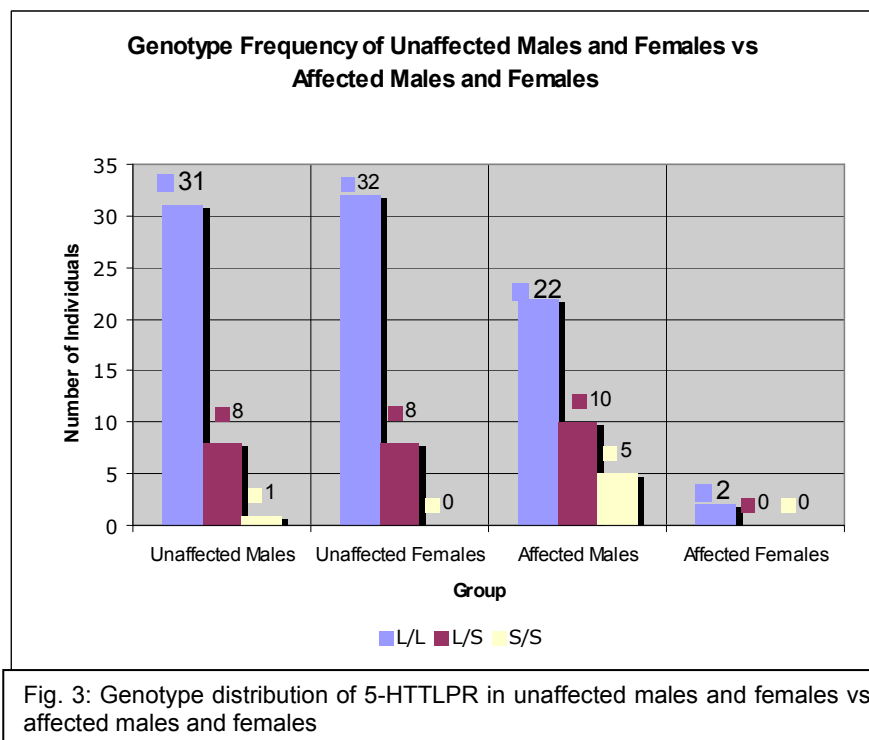
Group	5-HTTLPR Genotype			Total	Allele Frequency %	
	L/L	L/S	S/S		L	S
Groups A,B,C (3-17)	24	10	5	39	74	26
Group A (ages 3-7)	11	3	2	16	78	22
Group B (ages 8-11)	12	4	2	18	78	22
Group C (ages 12-17)	1	3	1	5	50	50
Males	22	10	5	37	73	27
Females	2	0	0	2	100	0

Table 2: 5-HTTLPR Genotype and Allele Frequency in the Normal South African Population

Group	5-HTTLPR Genotype			Total	Allele Frequency %	
	L/L	L/S	S/S		L	S
Group ABC	63	16	1	80	88.8	11.2
Group A (ages 3-7)	20	6	0	26	90	10
Group B (ages 8-11)	21	4	1	26	90	10
Group C (ages 12-17)	22	6	0	28	90	10
hMales	31	8	1	40	87	12
Females	32	8	0	40	90	10

Table 3: Chi-square calculation of 5-HTTLPR Genotype in Affected and Unaffected Individuals

Genotype	Affected	Unaffected	x^2
L/L	24	63	1.062
L/S	10	16	0.389
S/S	5	1	6.993
Total	39	80	8.444

Fig. 3: Genotype distribution of 5-HTTLPR in unaffected males and females vs affected males and females

Fig. 4: Allele frequency of 5-HTTLPR in affected and unaffected individuals.

4. Discussion:

In this pilot study, the genotype and the allele frequency of the 5-HTTLPR was determined for 40 individuals affected with autism and 80 unaffected individuals (40 males and 40 females). The affected population consisted mostly of males due to two possible reasons: firstly, because of the affected 4:1 prevalence of autism in males vs. females a higher ratio of males to females in our group was expected; and secondly, a lack of consent by parents of females with autism which was beyond our control. Many studies based on 5-HTTLPR genotyping have either found contrasting results or nothing significant at all. Yu et al. (2002) found 13 out of 121 Chinese patients suffering from depression with the L/L genotype and 72 with the S/S genotype respectively, while in a Korean population 5 out of 120 patients were L/L

homozygotes (Yu et al. 2002). In the Japanese population the L/L genotype frequency is between 5.5-9.6% on the other hand in populations including the French, Germans and Indians a L/L genotype frequency in the range of 33.1-37.5% is present (table 4). Conflicting results were reported by Klauck et al. (1997) who found preferential transmission of the L allele as opposed to the S allele reported by Cook et al. (1997).

Table 4: Genotype Frequencies of 5-HTTLPR in Autistic Populations

Population group	Genotype Frequency %			Sample #	Author
	L/L	L/S	S/S		
Jewish/Israeli	39.4	45.5	15.2	33	Yirmiya et al., (2001)
German	33.1	48.4	18.5	130	Klauck et al., (1997)
Japanese	9.6	32.7	57.5	104	Koishi et al., (2006)
Japanese	5.5	38.9	55.6	18	Sugie et al., (2005)
Portugese and Azorean	28.8	49	22.2	104	Coutinho et al., (2004)
Indian Northeastern population	37.5	50	12.5	16	Guhathakurta et al., (2006)
Indian Eastern population	34.9	53.9	9.6	63	Guhathakurta et al., (2006)
Caucasian, Hispanic, Hispanic-Caucasian	44.4	43.1	12.5	72	Zhong et al., (1999)
French	36.6	49.3	14.1	71	Tordjman et al., (2001)
Our study (South African)	62.5	25	12.5	40	

Patients with different 5-HTTLPR genotypes were found to respond differently to drug treatment. Pollock et al. (2000) reported an improvement in depressed individuals with the L/L genotype compared to those with a S/S genotype. Smeraldi was the first to report an improved response to fluvoxamine in L variant carriers compared to S/S homozygotes (Yu et al. 2002). Sugie et al. (2005) reported that fluvoxamine was more effective in patients with the L allele than those with the S allele. Individuals with the L/S genotype falls between the L/L and S/S genotype range with respect to drug response (Yu et al. 2002). SSRIs function to increase the serotonin levels in the synapse. In S/S homozygotes a lower level of the SERT is present leading to an increase in 5-HT in the synapse. Patents with the L/L genotype have increased SERT expression and therefore have less 5-HT in their synapse. In a human postmortem study SERT mRNA levels in the brains of individuals with the L/S and the S/S genotype were found to be lower than that found in individuals bearing the L/L genotype (Little et al. 1998). It was noticed that patients treated with SSRIs show no immediate improvement in symptoms which implies that SSRIs influence a regulatory mechanism leading to this delay in symptom improvement (White et al. 2005). Studies on SERT regulation after chronic antidepressant treatment reported a down-regulation of SERT in humans and rats. It was found that in rats treated with paroxetine or sertraline a 80% decrease in SERT binding sites occurred in the hippocampus CA3 region even though there was no long term changes to SERT mRNA levels (White et al. 2005). Gould et al. (2003) reported a 75-80% reduction in SERT binding sites in the dentate gyrus, dorsal raphe and lateral nucleus of the amygdala of rats treated for 6 weeks with paroxetine. When 17 healthy humans were treated with 40mg of citalopram per day, the SERT binding in the diencephalons and brainstem decreased after 8 days of treatment. No further reduction of SERT binding occurred when patients were treated for another 8 days (White et al. 2005). Patients with the S allele have an increased serotonin level in the synapse and treatment with SSRIs seems to make symptoms worse. It could be possible that in these patients with an S allele the serotonin signaling functions at its maximum potential while in those with the L allele it is impaired. This is what accounts for the improvement in symptoms in L allele patients compared to S allele patients. From this it can be concluded that other mutations or receptors in the serotonin pathway could be regulating the availability and function of serotonin and that the serotonin pathway is not the only pathway affected by genetic and/or other factors playing a role in the etiology of autism.

The results of the present study are limited because of the limited sample size. Inclusion of more individuals in both affected and unaffected groups will improve the overall significance of the study. The

study concluded that individuals with autism have a higher frequency of the S allele in their genotype, which points towards higher level of serotonin in the synapse of these individuals. This conclusion opens the way for detailed analysis at a pharmacogenetics level as the individuals who are homozygous for the S allele cannot be prescribed with SSRIs. The present study also highlights that more SNPs should also be investigated to obtain a clear picture of drug uptake in individuals with different genetic make-up. This is a major issue that should be addressed in detail in future studies.

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0019

A RANDOMISED PLACEBO-CONTROLLED TRIAL INVESTIGATING POLYUNSATURATED FATTY ACID (PUFA) SUPPLEMENTATION IN CHILDREN DIAGNOSED WITH AUTISTIC SPECTRUM DISORDERS (ASD): STUDY RATIONALE AND DESIGN

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Abbreviations: gastrointestinal (GI), polyunsaturated fatty acids (PUFA); autistic spectrum disorder(s) (ASD); red blood cells (RBCs); omega-3 (ω-3); omega-6 (ω-6); phospholipase A2 (PLA2); eicosapentaenoic acid (EPA); docosahexaenoic acid (DHA); gamma-linolenic acid (GLA); attention-deficit hyperactivity disorder (ADHD).

Abstract

Current UK cohort data from the past decade to date suggests a significant increase in cases of autistic spectrum disorders that cannot be simply explained by improvements in diagnostic practice. Several environmental factors have been implicated including the effect of diet. Biochemical and clinical evidence suggests a pattern of alterations in fatty acid metabolism in several childhood neuro-developmental disorders, including autistic spectrum disorder (ASD). Certain polyunsaturated fatty acids (PUFA) are crucial for both the structural integrity of neuronal membranes and neuronal signalling. Data derived from the analysis of red blood cells (RBCs) demonstrates a reduced concentration of PUFA in children with ASD, linked to an increase in phospholipase A2 (PLA2) activity. The positive effects of dietary supplementation with eicosapentaenoic acid (EPA)-rich oils in ASD children with increased PLA2 activity has been reported in an open-label study, where parents observed improvements in cognitive and motor skills, increased sociability and reductions in aggression. More recently the first published randomised placebo controlled trial of 13 children with autism given omega-3 (ω-3) PUFA supplementation showed significant reductions in hyperactivity and stereotypy. Larger placebo-controlled supplementation trials of children with related neuro-developmental disorders have demonstrated significant improvements in learning and behaviour following supplementation with a combination of ω-3 and omega-6 (ω-6) PUFA. Therefore a 6-month randomised placebo-controlled trial of 81 children (aged 4-11 years) with a diagnosis of ASD was carried out, giving daily capsules of ω-3 and ω-6 PUFA (0.56g/day EPA, 0.17g/day docosahexaenoic acid and 0.06g/day gamma-linolenic acid), or a placebo. Urinary samples were taken at baseline, 3 and 6 months, following previous laboratory observations based on liquid chromatographic methods suggestive of changes in urinary patterns and content following the use of such supplements. Other psychometric and behavioural outcome measures included assessments of receptive language ability, behaviour and motor skills. Results of the biochemical analysis from this trial may throw some light upon the nature of the mechanisms that underlie behavioural or cognitive changes. This paper presents the extensive methodology of the trial in advance of a future publication which will include full analysis of the data.

Introduction

Parents, health professionals and educationalists have identified increasing numbers of children diagnosed with autistic spectrum disorders (ASD). Baird and colleagues [1] recently reported data on the prevalence of ASD in a total cohort of 56,946 children aged 9 – 10 years in the South Thames region (UK) finding a total figure equivalent to 116.1 per 10,000 - significantly higher than previously acknowledged. There has been much discussion regarding the potential cause/s for the increase in cases of ASD reported in the last decade, with several environmental factors put forward including the influence of diet.

Biochemical data has previously indicated the presence of abnormal levels of various compounds detected in biofluids from people with ASD; some of these compounds detected in urine were thought to be biologically-active peptide species derived from dietary sources. This subsequently led to the use of diets devoid of foods containing casein (the main protein found in mammalian dairy produce) and gluten (derived from barley, rye and wheat) as potential ameliorative tools for the condition. Whilst many anecdotal reports and open trials have reported success with using such a dietary approach, controlled trials have thus far shown only inconclusive findings, due to various methodological challenges in ensuring compliance and controlling for other potential confounders [2]. Complimentary biochemical studies have likewise highlighted deficiencies of particular nutrients including amino acids, vitamins and minerals in children with autism [3,4]. Whether these deficiencies are due to an underlying malabsorptive state,

atypical feeding behaviour common to neuro-developmental conditions or other potential metabolic abnormalities associated with gastrointestinal (GI) barrier function is not known at the current time.

The potential for a role for essential fatty acids in the aetiology and treatment of autism is a more recent proposal. Biochemical data from the Victoria Hospital Glasgow showed an increase in phospholipase A2 (PLA2) in blood cells of participants with autistic spectrum disorder (ASD), compared with controls [5]. Excessive levels of PLA2 are known to be capable of releasing polyunsaturated fatty acids from cell membranes, leading to membrane damage and inflammation. Such findings could help explain the cognitive and behavioural difficulties common in autism, as well as the higher incidence of atopic and/or auto-immune somatic conditions such as asthma and eczema. An abnormality in fatty acid metabolism may also explain why a larger number of males are affected, along with observed increases in pregnancy/birth complications seen in ASDs [6].

Analyses of blood lipid samples from individuals on the autistic spectrum have also shown significantly lower levels of ω-3 polyunsaturated fatty acids compared with controls [5,7,8]. Additional data suggestive of accelerated loss of certain ω-3 polyunsaturated fatty acids (eicosapentaenoic acid and docosahexaenoic acid) from blood samples during storage in ASD compared to controls is also relevant [8].

Autism shares a number of developmental features with other conditions including dyslexia, dyspraxia and attention deficit hyperactivity disorder (ADHD), that have similarly been associated with fatty acid deficiency. The enzyme PLA2 appeared at higher levels in study participants with dyslexia [9]; blood samples from children and young adults with ADHD have also shown lower levels of certain ω-3 fatty acids (EPA and DHA) compared with controls [10]. Due to the important role that polyunsaturated fatty acids play in the central nervous system it is possible that biochemical deficiencies, implicated across a range of neurodevelopmental conditions, could be responsible for some of their shared cognitive, perceptual and behavioural features.

A small open-label pilot study of children diagnosed with ASD supplemented with EPA-rich fish oil at varying daily doses (2-4g), for a period of 6 months, previously reported corrected deficiencies in ω-3 polyunsaturated fatty acids in red blood cells of children with diagnosed with regressive autism and Asperger syndrome [5]. In this study, anecdotal reports from parents showed subsequent improvements in participant's cognitive and motor skills, as well as increased sociability and reduced aggression. More recently, a randomised placebo controlled trial has been published with a sample of 13 children with autism, given 1.5g per day of ω-3 PUFA for a period of 6 weeks [11]. The findings showed the significant advantages of ω-3 fatty acids over placebo, with a reduction in hyperactive and stereotypic behaviours. These findings are consistent with larger-scale trials of supplementation with children with other neuro-developmental conditions displaying the symptoms of ADHD [12,13].

Based on this collective evidence, a double-blind randomised placebo-controlled trial was carried out to determine the biochemical and clinical effects of a specific dietary change using ω-3 and -6 polyunsaturated fatty acid supplementation with a large group of primary-aged schoolchildren with ASD.

Design and Methodology

Design

This was a randomised double-blind placebo-controlled trial lasting 6 months, with a one-way cross-over from placebo to fatty acid supplementation after 3 months. A flow chart of recruitment through to intervention is shown in Figure 1. The trial protocol was approved by the University of Sunderland's Ethics Committee and Sunderland NHS Primary Care Trust Ethics Advisory Committee. The trial commenced in April 2005.

Hypothesis

Children aged 4-11 years diagnosed with autism spectrum disorder (ASD) after taking daily supplements of ω-3 and ω-6 fatty acids for 3 months, will show changes in urinary metabolites, compared to children who are taking a placebo for the same period. Cognitive and behaviour measures before and after supplementation will reflect these differences. Children switching from placebo to fatty acid supplementation at 3 months will show similar patterns of change to children who took the active treatment from baseline, suggesting a therapeutic effect of PUFA supplementation on the features of ASD.

Subjects

The parents of 81 primary-aged schoolchildren (aged 4-11 years) identified with ASD volunteered from 23 schools (22 in County Durham, one in Sunderland) to take part in the trial. All children diagnosed with ASD were included in the trial to ascertain response as a function of severity of ASD symptoms. Of these

participants, two pupils already taking a fatty acid supplement prior to the trial and one prescribed dexamphetamine were excluded (several other potential children were excluded from participation prior to the trial starting on the basis of current use of pharmacotherapy for conditions such as epilepsy / seizure disorder). Full informed written consent was obtained from each of the participating children's parent or primary caregiver. Parents and children were informed at the beginning of the study that they were free to withdraw from the study at any time without any explanation being required. Each of the 78 children were allocated to a pre-randomised blinded treatment of active or placebo capsules, with assessments completed at baseline, 3 months and 6 months.

Assessments
Main outcome measures

Previous laboratory observations at the Autism Research Unit in Sunderland, suggested that certain compounds appeared in urine samples of children with ASD following ω-3 supplementation. Biochemical data was therefore gathered using a non-invasive urine sampling method. Samples were collected at baseline, 3 and 6 months, for analysis by gradient-elution High Performance Liquid Chromatography (HPLC) with UV detection at the University of Sunderland using previously published methods [14-16]. Sample analysis will be conducted using a two-stage approach (with a view to further analysis by Liquid Chromatography-Mass Spectrometry, LC-MS).
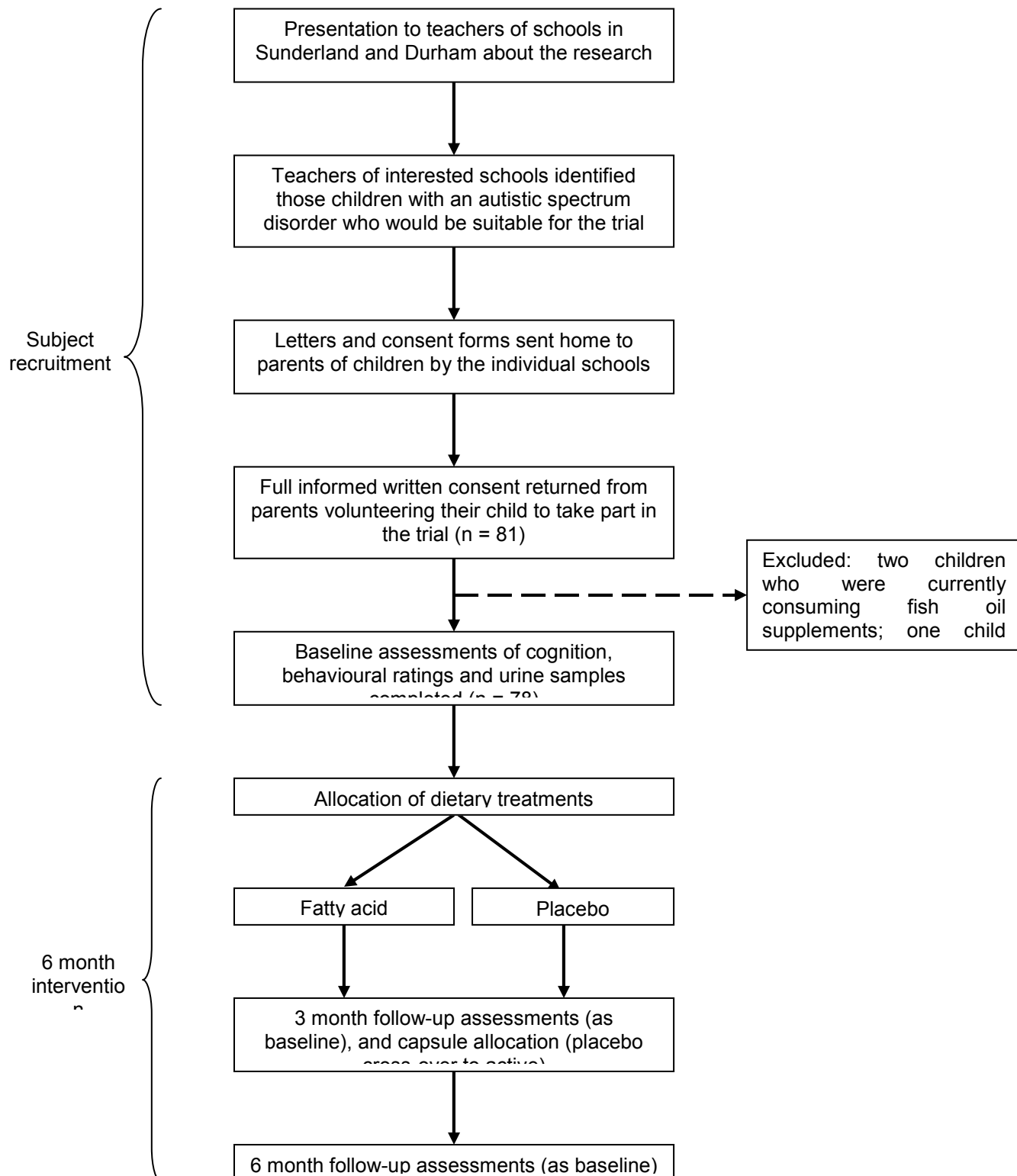
i) Solid-phase extraction sample preparation

Sample fractions are extracted by vacuum elution using an IST VacMaster using Varian 5ml 200mg C18 Bond Elut LRC solid-phase extraction (SPE) cartridges (Phenomenex, UK). SPE cartridges are preconditioned with 2ml of methanol (Sigma, UK) followed by 2ml triple distilled H_2O and 4ml 0.1% (v/v) aqueous trifluoroacetic acid (TFA) (Fisher, UK). 5ml of sample are vacuum extracted and washed with 2ml 0.1% (v/v) aqueous TFA and 1ml of 10% acetonitrile (Sigma, UK) 0.1% TFA 90% 0.1% (v/v) aq. TFA. Final sample collection is made in aliquots of 1ml of 40% acetonitrile 0.1% TFA 60% 0.1% (v/v) aq. TFA.

(ii) Reversed-phase gradient high performance liquid chromatography (RP-HPLC)

RP-HPLC is carried out on an integrated Agilent 1100 HPLC with a UV-DAD detector using a C18 Jupiter (Phemonenex, UK) column (25cm x 4.6 mm I.D., 300 Å pore diameter, 5µm particle diameter). The column temperature is internally regulated at 25˚C. Primary detection of IAcrGly is by UV absorbance (range 200-400nm, 0.1 min peak width, 4nm slit) at 215nm (reference wavelengths 360 ± 100nm). Results are reported as mAu. Mobile phase A is aq. 0.1% TFA and mobile phase B, 0.1% TFA in acetonitrile. A gradient of 5%-50% (v/v) mobile phase B over 8-40 min at a flow-rate 2 ml min⁻1 is used for analysis followed by a continued gradient of 50-80% (v/v) mobile phase B (40-55 mins) and a post-runtime (5 mins) back to original gradient conditions. Sample vials (2ml) (Agilent, UK) containing 1ml of total SPE urine sample are injected (10µl) by autosampler.

Figure 1: Flow diagram of recruitment and trial protocol

Subject recruitment

- Presentation to teachers of schools in Sunderland and Durham about the research

- Teachers of interested schools identified those children with an autistic spectrum disorder who would be suitable for the trial

- Letters and consent forms sent home to parents of children by the individual schools

- Full informed written consent returned from parents volunteering their child to take part in the trial (n = 81)

  - Excluded: two children who were currently consuming fish oil supplements; one child

- Baseline assessments of cognition, behavioural ratings and urine samples completed (n = 78)

6 month intervention

- Allocation of dietary treatments
  - Fatty acid
  - Placebo

- 3 month follow-up assessments (as baseline), and capsule allocation (placebo cross-over to active)

- 6 month follow-up assessments (as baseline)

To obtain a broad overview of the possible effects of supplementation on the behaviours associated with ASD, a range of assessments were included to measure behavioural change, memory, language and movement skills:

1. *Receptive vocabulary*

The Test for Reception of Grammar (TROG) [17] consists of 80 four-choice items which are grouped into blocks. The child is presented with 4 scenarios on each page, and the examiner would make a statement (*e.g.* 'The long pencil' or 'The cup is on the book') to which the child would be asked to respond by pointing to the picture that represents that statement. The test is scored in terms of blocks passed, and a block is only passed if all four items within it are responded to correctly. The maximum score is 20 blocks passed. The test is standardised for children aged 4 - 12 years, and the block score can be converted to a centile score.

2. Emotions and Behaviour

The Emotional and Behavioural Development Record Sheet is a teacher-rated assessment, commonly used in schools, comprising five questions in each of three categories: learning, conduct and emotional behaviour. Responses are scored from '0' (the behaviour is not at all true of the child) to '5' (the behaviour is always true of the child). The maximum score in each section is 25 and the maximum total score is 75. Higher scores indicate good behaviour.

The Conners' Rating Scales were used in the assessment of ADHD-related behaviours. The long form of both the teacher (CTRS-L) [18] and parent (CPRS-L) [19] scales were used in this study. The teacher scales consist of 59 items with four response categories from 0 (the behaviour is not at all true of the child) to 3 (the behaviour is very much true of the child). The parent scales are similar, but comprise 80 items. Scoring of responses yields scores in 6 subscales (on the teacher assessment; 7 subscales on the parent assessment) and 7 global scales, each of which can be converted to an age- and gender-standardised T score which can be compared with the population normative values. Standardised t-scores range from 38 - 90, where 50 is the mean. Scores ranging between 61 and 65 classify the child has showing 'mild' behaviour difficulties; between 66 and 69 are considered 'moderate'; and those of 70 and above are 'severe' behavioural characteristics.

3. *Motor control*

The Movement Assessment Battery for Children [20] assesses fine and gross motor coordination. The scores from 8 subtests in three categories (manual dexterity: 3 subtests; ball skills: 2 subtests; static and dynamic balance: 3 subtests) are summed to give a total impairment score. Each subtest is scored from '0' (no impairment) to '5' (severe impairment). The maximum score for the test is 40: manual dexterity – 15; ball skills – 10; static and dynamic balance – 15. The test is standardised for children aged between 4 and 12 years and total impairment scores can be converted to a centile score. Scores below the 5th centile are indicative of a definite motor problem and those between the 5th and 15th centiles are considered to indicate a degree of difficulty which is border-line.

4. *Working memory*

Digit Span is a subtest of the Wechsler Intelligence Scale for Children – Third UK Edition [21], assessing a child's short-term and working memory. Number sequencing items, forwards and backwards, give a total raw score which can be converted to an age-standardised score. The maximum raw score is 30 (16 forwards / 14 backwards), and the standard score has a mean of 10 (standard deviation: 3).

5. *Physical signs of fatty acid deficiency*

The Fatty Acid Deficiency Checklist assesses parental responses to 12 questions on a health checklist, relating to the frequency within the last year of symptoms related to fatty acid deficiency concerning their child. Scoring is on a four-point scale from '0' (the child has not displayed the symptom at all) to '3' (the child has displayed the symptoms very much), and these are summed to give a total deficiency score. Using the findings of Stevens *et al* [22], a total deficiency score of 3 or less is considered low and 4 – 12 considered high.

Fatty acid intervention

The active intervention consisted of an EPA-rich marine fish and evening primrose oil supplement, at a total dose of six capsules daily, taken as three capsules twice per day, under the supervision of either parents (during weekends and holidays) or teachers (during school-time). This provided the following daily

essential fatty acid doses (as natural triglycerides): 558mg EPA, 174 mg DHA, and 60mg GLA. In addition, the preparation also supplied 9.6 mg vitamin E daily. The placebo consisted of identically appearing capsules taken in the same way, containing a daily intake of 2.9g of refined medium-chain triglycerides derived from tropical oils such as coconut and palm oil, and included elements to mimic the appearance, taste and smell of the active capsules: 4.mg of carrot oil macerate, to colour match the capsules, and a minor element of fish oil to give a taste and smell similar to the active capsules. The latter provided a total daily intake of 16.2 mg of EPA, and 10.8 mg of DHA. This gave placebo participants an ω-3 intake equivalent to 2.9% of the EPA intake on active and 6.2% of the DHA intake.

The capsules were packaged in uniform blinded treatment pots, with a unique treatment code identifying an individual treatment. Randomisation of 90 treatment codes, to one of two treatment groups, was carried out by the capsule suppliers using a web-based random sequence generator. The children, parents, teachers and researchers were blind to treatment group status, and unblinding did not take place until after the end of the study.

Data Handling

The urinary data collected from this trial is being processed at the Autism Research Unit at the University of Sunderland. All cognitive and behavioural assessment data has been collated by the Educational Psychology Services of Durham County Council. Statistical analysis is being carried out by an independent statistician at University of Newcastle. To ensure confidentiality of data, subjects are identified by a trial code for all datasheets submitted for statistical analysis. All data collected from this study has shared ownership between the lead investigators: Dr. Madeleine Portwood of Durham County Council, and Dr. Paul Whiteley / Mr. Paul Shattock of University of Sunderland.

Baseline Data

Of the 78 children who received blinded supplements at baseline, 69 were boys and 9 were girls (a ratio of 7:1). For the whole group, the mean age was 8 years and 6 months (standard deviation: 1 yr 7 months); the youngest child was 4 years 1 month and the eldest 11 years and 5 months. Boys had an average age of 8 years 5 months (SD: 1y 7m) and girls, an average age of 8 years 9 months (SD: 1y 1m).

Of the sample 23 children (29%) were identified with severe autism, and the remaining 55 were on the milder end of the autistic spectrum, including those with a diagnosis of Asperger Syndrome.

Behaviour and Cognitive characteristics of the sample.

Figure 2 shows descriptive statistics of scores on cognitive and behavioural data at baseline. Scores on receptive language show wide variability which is to be expected in a sample of children on the autistic spectrum; behavioural ratings show mild to moderate problems in this sample according to parents and teachers, based on average scores on the Conners ADHD Index scale; motor control scores while on average are good, show that a proportion of the children had borderline difficulties with the coordination tasks.

<u>Figure 2: Descriptive statistics at baseline on cognitive and behavioural assessments.</u>

	N	Minimum	Maximum	Mean	SD
TROG centile score	78	0	99	26.9	28.1
Parent ratings on ADHD Index	46	46	90	66.4	10.3
Teacher ratings on ADHD Index	65	41	90	64.7	11.3
Behaviour Checklist total score	47	10	70	33.7	12.4
Digit Span raw score	74	0	22	9.3	3.8
ABC Total Impairment score	76	5	40	17.1	8.2

Fatty acid deficiency ratings of the sample.

Parent ratings of fatty acid deficiency signs showed that the majority of children at baseline displayed high scores (>3), based on previous categorisations of this measure [22]. See Figure 3 for a histogram of these ratings.

Figure 3: Distribution of baseline parent ratings of fatty acid deficiency signs

Fatty Acid Checklist

Mean =5.05
Std. Dev. =4.043
N =55
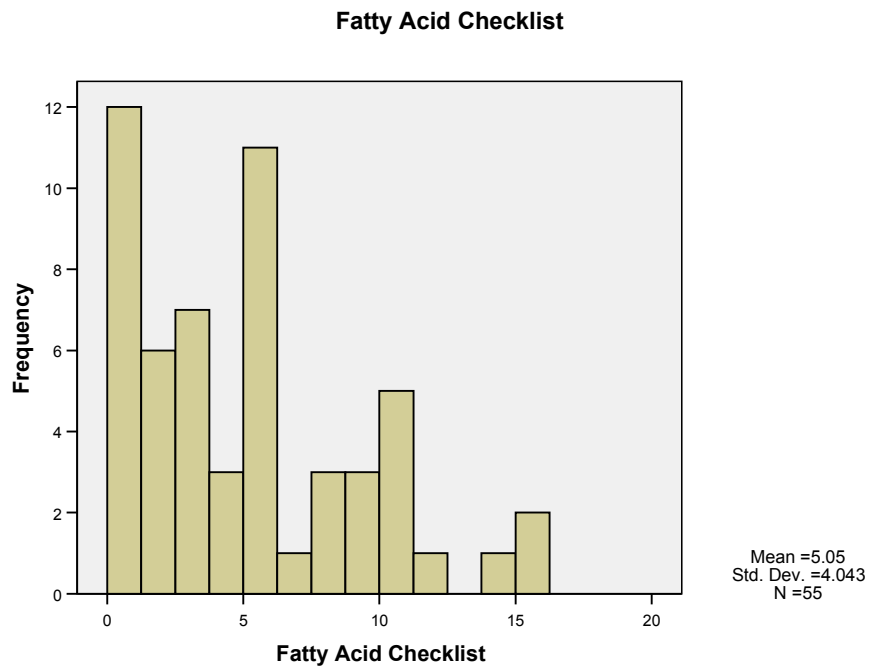
Urinary profiles of the sample:

At the time of writing data from urinary analysis has not been fully processed. All samples are stored at the Autism Research Unit at the University of Sunderland at -80°C.

Conclusion

A 2006 UK report has highlighted that diagnoses of children with autistic spectrum disorders (ASD) have seen a rapid rise in the last decade; diet being proposed as one potential contributory factor. Biochemical and clinical evidence suggests that some features of autism may be alleviated with the use of ω-3 and -6 fatty acid supplements, over a period of time, by addressing dietary deficiencies or metabolic abnormalities. This randomised placebo-controlled trial is the first of its kind to assess biochemical and clinical responses to PUFA supplementation in a sample of children with autism. The results will help to determine whether this safe nutritional intervention may be proposed as a potentially effective therapy for the symptoms associated with autism spectrum disorders.

Acknowledgments

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CHILDHOOD AUTISM: A CIRCUIT SYNDROME?

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We would like to propose that 'autism' should not be thought of as a single entity; but rather be considered the final common manifestation of altered functioning of the 'cerebellolimbic' circuit (1). In this respect, it can be compared to the 'frontal lobe syndrome', a constellation of neurobehaviors which result from any disruption of the frontal lobe circuitry.

THE CLINICAL MANIFESTATIONS OF AUTISM: ALTERATIONS OF CEREBELLOLIMBIC FUNCTIONING

Autism as a disorder was first reported by Kanner in 1943 (2) to describe a group of children who shared similar behavior patterns and had in common "extreme aloneness from the beginning of life and an anxiously obsessive desire for the preservation of sameness." Because Prescott (3) and others described similar behaviors in primates reared in maternal-social isolation, psychodynamic theories regarding the etiology of autism prevailed. Interestingly, Prescott believed this social isolation led to cerebellar maldevelopment and was the first to implicate the cerebellum as the location of the pathology in autism. Autistic behaviors are characterized by markedly abnormal or impaired development in social interaction and communication with a restricted repertoire of activity and interests (4,5). Autism has a prevalence that ranges from 2/1000 (6) to 2-5/10,000 (7), depending on the study. Cases with documented developmental regression are rare and do not necessarily implicate a post-natal exposure. Rett syndrome, one of the autistic disorders caused by a gene mutation (8), shows significant initial regression thought to be due to increasing developmental demands outgrowing the available neuronal circuitry.Autism is only rarely the sole syndrome; other problems may including seizures (9), mental retardation, (10,11,12,13) decreased visual acuity (14), defects in hearing (14), and Attention Deficit Hyperactivity Disorder (ADHD)(15).Some patients demonstrate "islets" of special abilities and these 'savant' abilities may reflect excess expression of some pathways.

LIMBIC SYSTEM

Can the clinical behaviors associated with autism be attributed to alteration of the limbic system and it's cerebellar connections? Animal models, including primates, demonstrate that lesions in the hippocampus, medial temporal lobe or amygdala can lead to behaviors similar to autism: increased passivity and tantrums, fewer social contacts, active withdrawal, emotionally expressionless faces, more self-directed behavior and motor sterotypies (16,17,18,19). This led Brothers (20) to propose that the amygdala forms part of the network of neural regions that comprise the "social brain." Hetzler and Griffin (21) have further postulated that the Kluver-Bucy syndrome seems a good animal model of autism because the behaviors of autistic children are very similar to those seen in animals or human adults following bilateral damage to the temporal lobes. This has led to the assumption that autism is a "temporal lobe syndrome."

Aggression, a common problem in autistic children, has been found to be related to serotonin levels in hippocampus and amygdala in rats (22,23). However, at least part of the limbic system may be performing well or even at a compensatory superior level. The most functional sensory system of many children with autism is the olfactory system, which is part of the limbic pathway. Also, some aspects of memory, whose pathways include the amygdala and the hippocampus, may be intact and demonstrate increased functionality, at least in 'savants.'

CEREBELLUM

Although the cerebellum is primarily concerned with the motor control of skeletal muscles, in the last 40 years basic research has demonstrated a broader function, including the control of seizures, vegetative functions, emotional behaviors, and a role in cognitive behaviors, particularly in spatial and discrimination learning (24,25). Currently there is a recognized cerebellar cognitive affective syndrome, in which adults with isolated cerebellar lesions demonstrate cognitive impairments with some similarities to autism (26,27). Children with cerebellar lesions manifest disturbances of auditory sequential memory and language processing (right cerebellar hemisphere), deficits on tests of spatial and visual sequential memory (left cerebellarhemisphere). Vermal lesions demonstrated two profiles: (1) post-surgical mutism, which later evolved into speech disorders or language disturbances similar to agrammatism; and (2) behavioral disturbances ranging from irritability to behaviors reminiscent of autism (28,29).

Autistic patients demonstrate findings on neurological examination consistent with cerebellar dysfunction including abnormalities of gait, balance, and alternating movements, as well as hypotonia, in the absence of neuromuscular, extrapyramidal, or pyramidal motor dysfunction (30). Also, patients with acquired cerebellar lesions and autistic patients are slow to reorient or shift their attention between two spatial locations or between auditory and visual information (31).

In animal models, rats with vermal lesions developed behavioral symptoms similar to autism, with disinhibition tendencies, persevering behavior, increased spontaneous motor activity, and decreased

environmental attentiveness (32) while in the GS strain guinea pig, characterized by hypoplasia of vermal lobules VI and VII, autistic-like symptoms have also been described (33).

The Neuroanatomy of Autism: Zeroing in on the CerebelloLimbic Circuit

DOES THE CEREBELLOLIMBIC PATHWAY EXIST?

We have proposed that the cerebellolimbic pathway is involved in generating autistic behavior. Is there any evidence that this circuitry exists? Animal studies have shown the existence of a direct pathway between the fastigial nucleus and the amygdala and septal nuclei and reciprocal circuitry between the fastigial nucleus and the hippocampus. This implies a role for the cerebellum in regulation of emotion and cognitive processes. Extensive cerebellar projections have been described with posterior paleocerebellar (flocculonodular lobe in particular) connections to the limbic system, structures of the frontal and temporal lobes, and hypothalamic regions (34).

There is evidence of cingulo-ponto-cerebellar connections in cats, with the paraflocculus being the receiver for the limbic input via the ventromedial pontine nuclei (35). In rats, lesions of the cerebellar fastigial nucleus resulted in significant reduction in activity, open-field exploratory behavior, and social interactions. These were not related to the motor effects of the lesion, which suggests a separate fastigial output pathway with ascending fastigial projection to the limbic structures. This may mediate fastigial influences on activity and social interaction (36). And finally, the cerebellar cortex can exert an inhibitory influence on the amygdala and hippocampus by way of the nuclei fastigii (37). Therefore, there is clear anatomical evidence that the limbic area is connected with the cerebellum.

IS THE CEREBELLOLIMBIC CIRCUITRY AFFECTED IN AUTISM?

Now that we have demonstrated that abnormalities of the limbic lobe and cerebellum can lead to autistic behaviors and that anatomically, cerebellolimbic circuits exist, are they, in fact abnormal in autism?

Neuropathology

Megalencephaly was one of the first anatomical findings associated with autism (38,39), but there have been relatively few more detailed post-mortem studies; review of the literature reveals 52 cases documenting pathological examination (40-47). In Darby's review of 33 cases (40), no consistent abnormalities were found. Two of four cases reported by Williams et al. (41) had associated disorders (phenylketonuria, and probable Rett syndrome). In one of the two idiopathic cases, pyramidal cell dendritic spine density was reduced in the mid-frontal gyrus and the number of Purkinje cells was also reduced. Coleman et al. (42) found no consistent differences in cell counts in several cortical regions from a single case and two controls except that the glia : neuron ratio was smaller in the autistic brain. The brainstem of this case was examined by Rodier at al. (48) and showed a hypoplastic facial nucleus and superior olive.

Bauman and Kemper's study of six brains is the most comprehensive post-mortem study of autism (44). In all cases, there was reduction in cerebellar Purkinje cells of variable severity. There was also reduction in the granule cell density, and neurons of the cerebellar nuclei were enlarged in the brains of two children and decreased in size and number in the adults. Inferior olivary neurons were preserved, suggesting that the Purkinje cell findings have a developmental basis (unassociated with retrograde olivary cell loss, glial cell hyperplasia, or empty baskets). In the forebrain, abnormally small densely packed neurons were noted in all areas of the hippocampus, subiculum, mammillary body, septal nuclei, and amygdala. Hippocampal pyramidal cells were measured in two cases of infantile autism (49); neurons in CA4 were significantly smaller and dendritic branching of both CA4 and CA1 neurons was less than in controls.

Anatomic abnormalities have been seen in other limbic structures (amygdala, anterior cingulate) as well as in cerebellum, and there is increasing evidence that these areas are important in memory, behavior, and learning. The decreased cell size and reduced dendritic branching are features consistent with arrested maturation, and no dysmorphic neurons were identified to suggest a malformation.

In tuberous sclerosis (TS), there has been an association between the number of cerebellar tubers with more autistic behaviors, and this observation was independent of the IQ in these subjects (50). Bolton and Griffiths (51) found that TS patients with the clinical diagnosis of autism were more likely to have temporal lobe lesions. In their study of 18 patients, there was no correlation with lateralization, cerebellar tubers, or other anatomic abnormalities.

A neuroanatomical comparison of monozygotic (MZ) twins discordant for strictly defined autism showed a markedly smaller caudate, amygdala, and hippocampal volume, together with smaller vermian lobules VI and VII in the most severely affected twin (52).

Although studies have demonstrated different patterns of neuropathology in the brains of autistic individuals, certain conclusions can be made. There is a curtailment of normal development of neurons in

the forebrain limbic system, an apparently congenital reduced number of Purkinje cells; and age related changes in cell size and number of neurons in the nucleus of the diagonal band of Broca, the cerebellar nuclei, and in the inferior olive. These abnormalities in the anterior cingulate, hippocampus, subiculum, entorhinal cortex, and mammillary body are in an interrelated forebrain circuit proposed by Papez (53) as a substrate for memory and emotion, and in the closely related septal nuclei and amygdala. We feel that these findings are consistent with alterations in the cerebellolimbic circuitry.

Neuroimaging

Because of the difficulties in obtaining autopsy tissue, much of the focus has been on utilizing neuroimaging techniques to better define anatomical differences in living subjects. Using morphometric analysis of specific brain regions, studies of autistic individuals with a wide range of functioning have documented quantitative abnormalities of the corpus callosum (54-56), medial temporal lobe, and amygdala (57). In studies examining the cerebellum, findings have ranged from hypoplasia of vermal lobules VI and VII (58), absence of differences in area of vermal lobules VI and VII on mid-sagittal MRI (59-63), and a bimodal distribution with vermal hypoplasia in 43/50 and hyperplasia in 7/50 autistic subjects (64). To confuse matters more, Schaefer at al (65) found vermal lobule VI and VII hypoplasia as a nonspecific feature of a variety of neurological disorders not associated with autism. The collective neuroimaging studies of the cerebellum in autism have used differing methodologies and produced heterogeneous results that are difficult to compare. Recently functional neuroimaging has been utilized in an attempt to better define the biochemistry of autism.

BIOCHEMISTRY OF THE CEREBELLOLIMBIC CIRCUIT

Serotonin is a major neurotransmitter involved in limbic functioning and alterations in serotonin receptors have been demonstrated in the treatment of depression (66), anxiety (67) and schizophrenia (68). There is also evidence of serotonergic abnormalities in autism. Decreased serotonergic transmission such as from tryptophan depletion causes an exacerbation of autistic symptoms (69). Serotonin transporter polymorphisms have a relatively high prevalence in autistic subjects and their families (70). Chugani et al. (71) have described developmental changes in brain serotonin synthesis capacity. Their data suggests that humans undergo a period of high serotonin production during childhood, and that this developmental process is disrupted in autism. The reduced brain serotonin before puberty may disrupt synaptic connectivity in sensory cortical regions (71). Chugani et al. (72) using positron emission tomography, reported asymmetries of serotonin synthesis in frontal cortex, thalamus, and dentate nucleus of the cerebellum in boys, but not girls, with autism. They found significant lateralization, with decreased serotonin synthesis in the left hemispheric frontal lobe and thalamus matched by an elevated synthesis in the contralateral dentate nucleus. The 5HT5A receptor is highly expressed in cerebral cortex, hippocampus, and cerebellum. 5HT5A mRNA was widely distributed in the cerebellum and highly expressed in the Purkinje cells. Since the cerebellum receives diffuse serotonergic afferents, this finding suggests that the 5HT5A receptor may have an important role in mediating the effects of 5HT on cerebellar function (73).

Of interest is the recent finding of Lopez-Alberola et al. (74) of reduced brain-derived neurotrophic factor (BDNF) in the cerebellum of autistic postmortem tissue. BDNF has been shown to promote serotonin production and is important in neuronal survival, eliciting sprouting from serotonergic neurons and increasing serotonin turnover. From animal studies, serotonin increases BDNF mRNA and protein by acting on 5-HT1A autoreceptors, causing up-regulation of BDNF, which in turn activates TrkB to promote serotenergic phenotype-specific markers (75).

Interestingly, studies of cell adhesion molecules have shown that many types are expressed in the CNS and have an important role in morphogenesis. It has been suggested that cadherins, a family of cell adhesion molecules, regulate segregation and aggregation of early neurons and neurites during development and contribute to the formation of functional units from a relatively homogeneous mass of undifferentiated cells. The expression pattern of cadherin 8 in developing mouse brain was seen in limbic cortices, septal areas, and cerebellum and again suggests functional connectivity (76). It is interesting to hypothesize that autism arises from a failure of these adherins to correctly engineer the appropriate network connections.

Other Organ Involvement in Autism: the Cerebellolimbic circuit as the Master Computer

Other organ systems have been investigated for their involvement in the etiology of autism. Can we fit these findings into our theory of a circuit syndrome? Here, we will discuss the two most studied organ systems: the GI and immune systems.

AUTISM AND THE GI SYSTEM

Many investigators have demonstrated GI abnormalities in autism (77) including esophagitis, disaccharide malabsorbtion, elevated number of Paneth's cells (78), chronic intestinal inflammation associated with immunodeficiency (79), and increased amount of vasoactive intestinal peptide (VIP) in the blood of newborns who eventually developed autism (80). Finally, there was a single case report of a child who improved after receiving secretin as part of a GI evaluation (81). These findings have led many investigators to postulate mechanisms whereby GI dysfunction could 1) be a marker for the etiology of autism, 2) be the cause of autism, or 3) lead to the cure of autism.

Findings of malabsorption, have led to the theory that a 'leaky' gut may allow 'toxins' such as gluten/casein (82,83) or mercury (84) to enter the blood stream causing autism (77,85,86). Attempts to treat autism with IV secretin (87-90) have been unsuccessful.

All of the above theories imply that the GI disturbances reflect the *primary* disorder which leads to the *symptoms* of autism. However, much more likely is that either a common abnormality can affect *both* the GI system and the CNS independently (ie, there are neuropeptides that are active in both areas) or, as we believe, a *primary* defect in the CNS may cause the GI abnormalities. There has been interest recently in the 'brain-gut' neuraxis and the concept of the "visceral brain" (91,53). This theory closely ties the limbic lobe, especially the amygdala, with the GI system and emotional behavior (92) and implies that this CNS pathway modulates the effects of stress on the GI system. Electrical stimulation and ablation of the limbic lobe has been shown to influence gastic ulcer formation (93-97) and in animal models, direct CNS infusion of some peptides induced peptic ulcers (TRH,VIP) where others prevented stress-induced ulcers (bombesin, calcitonin, CRF, Neurotensin and opioid peptides)(98). Interestingly enough, any of these peptides given peripherally had either little or no effect, indicating that although they can be found in both the CNS and in the gut, their actions in this situation were central. This might explain why secretin given peripherally has shown to be of little benefit in autism.

Finally, in an interesting review by Mayer et al. (99) the authors postulate an even closer relationship between the gut and the limbic lobe. They discuss the theory put forth by Nauta (100) and Damasio (101) that 'gut feelings' define a subconscious form of intelligence whereby previous experience can be encoded into visceral sensations and stored into a form of memory. They feel that our rational decision making is based in part by these visceral encoded sensations associated with prior positive or negative outcomes. Studies have demonstrated that autonomically regulated GI functions such as motility, secretion, and mucosal blood flow are sensitive to the emotional state of the subjects (102). Mayer et al. (99) feel that this bi-directional communication between the limbic area and the viscera plays a critical role in the generation of emotional responses and associated emotional feelings which may be critical in making decisions using 'gut instincts'. Therefore, we feel strongly that the GI disturbances which can be found in some autistic children are a *secondary* manifestations of the altered brain circuits, and strongly support the involvement of the limbic lobe.

AUTISM AND THE IMMUNE SYSTEM

There have been many published articles documenting alterations of the immune system in children with autism including abnormalities in T-cell function (103-107), reduced natural-killer cell activity (108), altered immunoglobulin levels (109), the presence of auto-antibodies to neuronal proteins (110-115), aberrant maternal-fetal immune response (116), increased number of autoimmune disorders in family members (117), and association of various HLA haplotyes (118-120). However, many of these studies can not be reproduced and other labs have provided contradictory results (109,114,121-124). Plioplysis et al. (125) demonstrated that anti-CNS antibodies were also present in control patients with the same frequency. Because of the demonstration of measles virus DNA in a group of autistic children with GI abnormalities (126), much attention has been paid to the role of the MMR vaccine in causing autism. Even now, many people refuse to abandon this theory despite numerous articles showing no such association (127-130).

Therapeutics: Rewiring the CerebelloLimbic circuits

Given evidence for serotonergic abnormalities in autism (131), the most consistent and promising results have been found with medications that affect the serotonin pathways, whether the serotonin reuptake inhibitors or atypical antipsychotics. Autistic patients have demonstrated improvement after receiving tryptophan, the metabolic precursor to serotonin (132).

Clinical data from studies of *clomipramine* (133-135), *fluoxetine* (136-139), *sertraline* (140), and *fluvoxamine* (141) show that these drugs, associated with serotonin function may be useful in reducing repetitive and compulsive behaviors, and aggression, as well as improving social relatedness in some

individuals with autism. *Buspirone*, a 5HT1A partial agonist, was found in one study to also reduce the hyperactivity and stereotypic behaviors of autistic children (142).

A new class of drugs, the atypical antipsychotics, benzisoxazole derivatives, are believed to act through dopamine type 2 and serotonin 2A receptor antagonism (143). Of these, *risperidone* has been used with success in the treatment of autism, in children as young as 23 months (144). Risperidone blocks both serotonin and dopamine receptors and is superior to placebo in reducing the overall behavioral symptoms of autism, i.e. repetitive behaviours, aggression, anxiety, depression, and irritability (145,146). It also stabilizes mood and improves communication (147). Ichikawa et al. (148) have found that risperidone's 5HT2A and D2 receptor blockade, regardless of intrinsic 5HT1 affinity, facilitate 5HT1A agonist activity.

CONCLUSION: CEREBELLOLIMBIC CIRCUITRY: THE AUTISTIC PATHWAY

In the above paper, we have attempted to review much of the research being done in the field of autism and present it based on our model of a circuit syndrome; in the case of autism, a dysfunction of the cerebellolimbic circuitry. We have demonstrated that this circuitry exists anatomically, and that lesions in these areas can lead to behaviors very similar to autism in both humans and animal models. In addition, we have shown that the characteristic abnormalities seen in patients with autism are found in these same locations and that serotonin, the neurotransmitter most associated with autism, is important to this circuitry. Interestingly, in reviewing the old literature that first discussed autistic behaviors in primates raised in social isolation, we found studies demonstrating that cerebellum, limbic system, and the whole cerebral cortex are deficient in DNA in these animals as compared to controls (149). Also, aberrant electrical discharges have been described in both the limbic system and cerebellum in Harlow wire-cage, isolation reared rhesus monkeys (150). Therefore, we have come full circle, historically, on the pathophysiology of autism. Although we by no means propose that unnurturing parents are the culprits for infantile autism, much of this early literature supports the more recent data that the cerebellum and limbic system are intimately related and the site of the pathology. As we have alluded to before, autism is not a single disease, but rather arises from a multitude of different pathologies that clinically manifest the same phenotype, i.e. the behavioral pattern of autism. We believe that all these entities share a common pathway, the cerebellolimbic circuit. Hence, it is most likely that the disruption of this circuitry produces the behavioral pattern herein described as AUTISM.

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0021

THE CHANGING PROFILE OF AUTISM IN A CLINIC FOR CHILDREN WITH DEVELOPMENTAL DELAY. A TEN YEAR SURVEY. THE MEMORIAL INSTITUTE FOR CHILD HEALTH AND DEVELOPMENT.

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Background.

Studies done in developed countries have shown an ever increasing prevalence of autism since the condition was initially described by Kanner in 1943. It is widely debated whether the increased prevalence represents a true increase in the condition or an increased awareness and knowledge amongst parents and professional workers and the development of specialist services. Widely debated. Felt that increased awareness is important but concerns that here may be an absolute increase due to environmental factors.

Paediatric services play an important role in the early identification and management of children with ASD. The wide range of other conditions associated with this condition and the uncertainty as to the underlying pathology has led to extensive investigations seeking for a single pathology. The general consensus appears to be that there is not set protocol and that investigations should be based on a thorough clinical evaluation. Opinions as to the possible yield of investigations range from 10 to 30 percent. There is more likely to be a low positive yield in the higher functioning children and a higher yield in the more disabled children[1,2]. There is increasing optimism for a positive outcome with early diagnosis and intervention and the use of screening tools such as the CHAT (Checklist for Autism in Toddlers) in paediatric services has been recommended.

Motivation for this research

The study was done in the developmental assessment clinic at The Memorial Institute for Child Health and Development (TMI). This clinic provides an assessment service for children with developmental delays as well as learning and physical disabilities. There is not a particular focus on children with psychiatric disorders in this clinic as there is a paediatric psychiatric service in the building. Children who are identified as having a psychiatric problem are preferentially referred to the psychiatric service. This study was motivated by the clinical impression that an ever increasing number of children with Autistic Spectrum Disorder are presenting to the assessment clinic..

The clinic is part of a state hospital service serving predominantly a disadvantaged and black community although children from all social classes and racial groups are seen. The medical staff are all experienced neurodevelopmental paediatricians or medical officers

The aim of this study was

- To test the hypothesis that the there is an increasing number of children presenting to the clinic with features of ASD (Autistic Spectrum Disorder).

- To compare the characteristics of the patients to those of children seen elsewhere.

- To assess the yield of medical investigations.

Methodology

This is a retrospective study and is part of a larger epidemiological study looking at all the patients seen at the clinic over the past 10 years.

A database was developed to look at:

- The presenting problems of the children attending the clinic?

- The referral agent.

- The associated physical, neurological problems, developmental and behavioural problems.

- Investigations done and the positive yield.

- The final diagnosis and what aetiology was established.

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Discussion of findings

For the purposes of this paper the children who were diagnosis as having autistic features were examined in more depth.

As it is the intention to examine all the files of all patients for the period 1996 -2005 files were examined in alphabetical order. 1218 files were analysed out of a potential 2598 this represents 47% of the cases seen. In this sample a total of 49 children were identified where the primary diagnosis was considered to be ASD i.e. about 4% of the total cohort. A breakdown of cases over the 10 years shows an increase in cases of ASD from 1996 to 2005 (see table 1). This can be at least partially attributed to an increasing prevalence in the community. The sudden rise in numbers between 2004 and 2005 could be explained by the unit being perceived to have an interest in Autism by the community.

Table 1. Total number of children seen at the clinic compared to the number of children with ASD over a 10 year period.

Year	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Total No. children	71	102	109	130	119	116	123	136	137	158
Children with ASD	1	1	2	6	1	4	5	8	7	13
Percentage	1.4	1	1.83	4.6	0.84	3.5	4.1	5.9	5.1	8.2

It is of interest to do a more detailed analysis of the children presenting with features of ASD in comparison to studies done in developed countries. As would be 58% of the ASD group were private as compared to 32% of the children coming for other reasons. This possibly indicates a lack of expertise in the private sector to deal with this type of child resulting in referral to a state clinic with a perceived greater skill level.

The percentage of children with ASD as compared to other disabilities is consistent across the different racial groups (4%). Although this is in agreement with international literature it is of interest that the recognition and presentation for help between the different racial groups in South Africa is so similar in spite of the different cultures represented[2].

Literature from developed countries indicates that at lease 50% of children with ASD are at least moderately mentally disabled. It is however pointed out that there is a recent trend for children to be less severely mentally disabled[2]. It is therefore of interest that in this study the majority of the children were referred for speech delay or behavioural problems (73%) with only 2 of the 49 presenting with a primary diagnosis of mental retardation. The most common behavioural problem describes is that of "Autistic behaviour" in 45 of the children. Hyperactivety was described in five of the children while one had numerous behaviour problems. Half the children presented at 3 and four years of age with the youngest child presenting before the age of two years. Because the children were so young it is possible that the professionals involved may have been reluctant to describe the children as mentally disabled. However it is unlikely that the children would have been severely mentally disabled. This relatively early presentation suggests a high level of awareness in the community of the condition.

The relative paucity of abnormal physical and neurological findings correlates well with other studies where it was found that the higher functioning group of children were less likely to have physical or neurological abnormalities [1]. In this group 5 children were macrocephalic, one child had seizures, two children were deaf, one was blind and one child was large (above the 97 percentile on all growth parameters).

Investigations were done on 68% of the children. these include CAT and MRI scans of the brain, chromosomes, EEG's , metabolic tests and other unspecified investigations. The investigations had a positive yield in 62% of cases, which is higher than would be suspected from studies elsewhere where a 10 to 30% yield is described [3]. An underlying aetiology was identified in 39% of the cases. In the group where an underlying cause was found a familial predisposition was the most common underlying problem. This is higher than described in other studies where a known cause was described in 25% of cases[3].

Table 2. Outcome for investigations done to determined the aetiology of ASD.

Type of investigation.	Investigation done	Positive investigation	Percentage yield
MRI Brain	2	1	50
CT scan of the brain	14	5	36
EEG	16	6	38
Chromosomes	12	1	8
Metabolic screening	4	0	0
Genetic other	5	0	0
None	12	-	-
other	2	0	0

Conclusions

It is not possible from this study to determine whether there is an increasing prevalence of children with ASD. What can be said is that there is a six fold increase in the number of children being referred to the developmental assessment clinic than occurred 10 years ago. In the geographical are drained by the service there appears to be a good awareness of the problem as manifested by early referral of relatively high functioning children. Although the profile of the children presenting to TMI is very similar to that reported in other studies the special investigations shower a greater yield than is reported in other studies. The main cause of the condition in this study as in other studies remains unknown.

Recommendations from this study.

It is recommended that a carefully designed prospective study be done which allows for more accurate categorization of the children.

This study has shown that the prevalence of identified ASD is increasing. Sadly the development of services for these children is not keeping pace with the detection. It is essential that both the Health and Social services are made aware of the situation and lobbied to develop services for these children.

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0022

10 YEARS ON; - AN INVESTIGATION INTO THE OUTCOMES FOR PUPILS WHO PREVIOUSLY ATTENDED AUTISM SPECIFIC SCHOOLS RUN BY THE NATIONAL AUTISTIC SOCIETY

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INTRODUCTION

The National Autistic Society in Britain has been providing schools for children with autism since the mid nineteen sixties, indeed The Sybil Elgar School in London was the first such school set up in the UK. Over that period a great deal of knowledge and expertise in assisting our pupils has been acquired so that we are now able to respond to individual needs and develop individual talents within a framework of consistency and structure. However we have become increasingly aware that the journeys of some of our students once they leave school may not be so successful, leading to unsatisfactory outcomes and family distress.

The need for more studies to illuminate what happens to people with autism once they become adults has been previously highlighted (Howlin and Goode, 1998), (Seltzer, Krauss, Orsmond and Vestal, 2001), (Holmes 2000). This piece of work was commissioned and supported by the NAS to find out what does happen once students leave our schools. I hoped to find;

- the relationship between level of functional skill and outcomes as an adult

- the role of parental empowerment in outcomes

- significant factors in the success or failure of transitions between school and adulthood

- points of good practice for achieving successful transitions

Information was gathered from a cohort of young people currently aged 22 to 27 who used to attend two of our schools. Data was gathered from school records, professional reports, interviews with families, and assessments of functional skills of the young adults, and an empowerment scale for parents or carers.

The work is not yet complete but these preliminary findings are offered in the hope that they will prove useful to others working and living with these issues.

SUBJECTS

It is acknowledged from the outset that the subjects used for this study were not randomly chosen. The purpose was to follow up a very discrete group of people; those on the autistic spectrum who had needs of such severity and complexity that placement in an independent specialist school had been deemed necessary. Their needs could, in part, have been to do with family circumstances but in all the cases examined the people themselves have presented significant challenges to their parents and carers both in the past and now.

It could also be reasonably argued that the families interviewed do not represent a true cross section of the population. It has long been the case that parents who familiarise themselves with special education issues, who know their way around special education legislation and who research available provision, both locally and nationally, are more likely to be effective advocates for their children and more successful in obtaining the placements of their choice. This argument applies to all the people I interviewed, but it does not appear to be a social class or education issue. From my information on the educational backgrounds and occupations of those who responded, there appears to be considerable variety, from General Practitioners to hairdressers to taxi drivers to those who are unemployed. Several were or are self employed, some having chosen this type of occupation as it gave them more flexibility in caring for their son or daughter.

All the parents and carers of people who are now aged 22 to 27 and who attended two of the NAS London based schools were contacted by letter and asked to contact me if they wished to be involved with the study. 87 letters were sent, 31 parents or carers responded, a response rate of 36%

One can hypothesise about the reasons people do not respond but below are two obvious ones;

- House moves. Letters only went to the address known to have been correct 5-10 years ago. Where possible I updated addresses as interviewees told me of other parents who had moved, but it is likely that many of letters did not reach the addressee.

- People did not wish to be involved, one e-mailed me to decline.

The information presented here is based on the 19 cases interviewed to date.

DATA GATHERING

Historical

For early information I obtained copies of as many relevant documents as possible, usually from parents. In theory it should have been possible to obtain information from the person's current placement as records should be passed on to the next place. However, in practice, this often does not happen for a number of reasons; staff may not know where the person is to go to, there is a change of plan resulting in the records being sent to the wrong place and then lost, only partial records are sent on, records are destroyed, a 'fresh start' is requested so previous records are forgotten. Fortunately most parents proved to be great hoarders and produced large filing boxes of paper containing every letter, report, newsletter, photo and picture relating to their child's time at school. This was enormously helpful to me and many hours were spent with mums and a portable photocopier on living room floors surrounded by a sea of paper while we decided what was useful. Incidentally I can recommend this technique as a non-threatening way of prompting parents so that a complete history is obtained.

I aimed to collect every Statement of Special Educational Need, Psychological report, Speech and Language Therapy report, Occupational Therapy report and Education report as well as annual review data and any relevant medical reports. As, in most cases, I didn't have access to school records, reports on behaviour were limited to what had been shared with parents and parents recall.

Interview

I chose to interview the parents who responded as this was probably the best way to elicit the individual accounts of their son's or daughter's journey towards adulthood. 'Interviewing …is essentially a conversation …but also, significantly, an instrument of data collection.' (Oakley 1999). An interview is no ordinary conversation; it has to be arranged; it rests on an often unspoken or understated 'exchange'; one person wants something and another person has to decide whether they have the information, whether they want to impart it and if so, in what way and at what cost. As it is so essential to establish 'rapport' between interviewer and interviewee to be able to conduct a satisfactory interview, I was very fortunate that all the respondents were keen to tell their stories. Being a professional staff member of the NAS gave me credibility in parent's eyes, and, as the stated aim of my research was to provide information useful to others faced with similar problems, they wanted to help.

A semi-structured interview was used as I wanted to be able to let parents tell their story in their own way while keeping the freedom and flexibility to pursue topics as they arose. Several questions were asked of all interviewees if the matter had not been covered in their narrative. I started each interview by asking parents to tell me the story of their son or daughter's life from school to college or adult placement. In most cases this resulted in a very long and detailed narrative that covered most of the relevant points. I prompted if necessary. Most parents chose to go back to the early years, describing battles to obtain diagnosis and appropriate school places.

I took notes but did not tape the interviews as I found in the three pilot interviews that this tended to hinder the conversation. After each one I added detail to my notes and reflected on my own reactions to the interview. In interviewing research it is acknowledged that the interviewer plays an important part in generating the findings by their reactions, their questioning and their feedback to the interviewee. As I was the sole interviewer there were no issues of between interviewer reliability.

Interviews were analysed for content and all the information on each topic was coded and grouped.

Functional skills

IQ has traditionally been looked upon as the best discriminator of outcome in studies of people with autism (Lord 1992) along with communication skills. However, more recent work on outcomes has concentrated adaptive functioning; the ability to cope in a variety of social and domestic settings. Correlations between adaptive functioning, as measured by the Vineland Adaptive Behaviour Scales, and outcomes have proved to be stronger than either the relationships between IQ and outcome or communication skill and outcome.

Parents helped me to complete the Expanded Form Interview Edition of the 1984 version of the Vineland Adaptive Behaviour Scales (Sparrow, Balla, and Ciccetti, 1984) for their son or daughter based on current functioning. This gives a measure of functional skill in each of three areas, Communication, Daily Living and Socialisation compared to standardised norms. Vineland results are usually expressed as centiles but as the vast majority of my results were at the <0.1 level I used age equivalents in months for comparison purposes.

I coded all the current placements depending on the degree of independence catered for,

1. Supported living in flat or house with others, support staff coming in to check once per day.

2. Living at home, day attendance at college, no additional staff support.

3. Living in at home or in residential placement, 1 staff to 2 people.

4. Residential placement, 1 staff to 1 person.

5. Residential placement, 2 staff to 1 person.

6. Residential placement, 3 staff to 1 person.

7. Secure hospital 24 hour supervision

Using the codes I compared the Vineland results with the current placements.

Parental empowerment

There is an established correlation between feelings of anxiety and feelings of empowerment. In almost any stressful situation, the more empowered you feel the lower your anxiety levels as you feel that you have the knowledge and power to make a difference. Lansdown (2002) quotes the The Disabled Children's Action Group (DICAG) who argue that there are five elements needed for parental empowerment:

1. Having mutual respect between parents and professionals which accepts that parents, like professionals, have qualities and skills.

2. Acknowledging and recognising families' needs and strengths.

3. Providing information as an essential foundation for making rational and informed choices.

4. Creating opportunities for exposure and social contacts, for example by involving parents as contributors in professional training, participation in conferences and in local, provincial and national policy making.

5. Supporting the development of economic independence of mothers through early childhood development facilities, basic adult education and training and skills development in self-employment.

In an attempt to ascertain the degree of empowerment felt by the parents I interviewed, they kindly completed the Family Empowerment Scale, Koren, DeChillo,and Friesen, 1993. This instrument is designed to gauge parents' feelings about the extent to which they have power and influence in three areas; their son or daughter, their son or daughter's services, and the development of services generally. The latter covers aspects such as influencing legislation, understanding the SEN and care systems, telling agencies and governments how services could be improved etc.

Results are given as mean responses on a 5 point scale for each of the three areas; Parents gave me two sets of responses to the scale; their current views and their views at the time their son or daughter was transferring from school to college or adult service.

RESULTS

Placements

Distribution of Subjects in Different Types of Adult Placement

Number of Subjects	Type of placement	Degree of independence

		ranked 1-7
3	Supported living in flat or house with others, support staff coming in to check once per day.	1
1	Living at home, day attendance at college, no additional staff support.	2
5	Living at home, attending a day centre, or in residential placement, 1 staff to 2 people.	3
7	Residential placement, 1 staff to 1 person.	4
1	Residential placement, 2 staff to 1 person.	5
1	Residential placement, 3 staff to 1 person.	6
1	Secure hospital 24 hour supervision	7

THE RELATIONSHIP BETWEEN FUNCTIONAL SKILL AND OUTCOMES AS AN ADULT

People with higher overall levels of **Communication skill** as measured by the Vineland were placed in settings which afforded a greater degree of independence.

People needed to have developed their **Daily Living skills** to a level above the 9 year age equivalent to be living independently, albeit with some support. Below the 9 year age equivalent there was no clear relationship between Daily Living Skill level and outcome.

Socialization skills were the strongest predictor of outcome in terms of placement, the better the person's social skills the more independent their placement.

There was one notable exception in the results above. One individual has cognitive and communication skills within the normal range and can perform most personal and domestic skills without assistance. However he has a great intolerance of other people and directs his energies to ensuring that he can live undisturbed. As his behaviour poses serious risks both to himself and to others it is not possible to allow him the degree of independence that his abilities might predict.

THE ROLE OF PARENTAL EMPOWERMENT IN OUTCOMES

(parents' comments are given in italics)

High scores, 4 to 5 out of a maximum of 5, on the Family Empowerment Scale were associated with parental satisfaction with current services, acceptance of their son's or daughter's abilities and disabilities and having made plans for the future. 11 of 19 parents reported current high empowerment ratings, 58%.

Median scores, 2 to 4, were associated with uncertainty over current placement, disappointment with frequent staff changes, and concern over lack of trained staff. 5 of 19 parents reported median empowerment ratings, 26%.

Low scores, 1 to 2, were associated with lack of knowledge of possible options, feelings of not being listened to, fear of parents views being ignored as the person was officially an adult, getting old and or infirm, other family stresses, 3 of 19 parents reported current low empowerment ratings,16%. All three had their sons or daughters at home and had been waiting for placements to be finalised for some months.

Changes in Empowerment Ratings

In 73% of cases empowerment ratings increased between the time of transition from school to the present. The 27% of cases where it remained the same or decreased were associated with ongoing uncertainty about placements.

Fluctuating scores

Several parents commented that their feelings of empowerment fluctuated widely over time depending on many factors such as the success or otherwise of the provision at the time, their child having one key member of staff with whom they had a very positive relationship, the degree to which professionals knew about autism and were prepared to listen, access to useful support groups and people doing what they said they would.

- *She gets on very well with her key worker, it has made all the difference*

- *Careers service usually do not have a clue- they wanted to interview him for 2 hours before the meeting*

Keeping informed

Most of the parents interviewed had made great efforts to keep themselves informed and arrange their lives to accommodate their son's or daughter's needs. This was more a matter of survival than choice. Those that felt they had the necessary knowledge had higher empowerment scores.

- *I did a crash course in special needs legislation and managing paperwork, not bad for a hairdresser who left school at 14 with no qualifications.*

- *I'm good at playing the system 'loud and long'*

- *I went to work for myself so that I could get to all his meetings.*

- *TEACCH is excellent for him, we went on the course and we've always used it at home.*

- *I wasn't given much information or consultation*

Professionals and Autism

Finding one professional with some authority who knew about autism proved to be the single most useful factor for some. As the parents I interviewed all lived in the Greater London area the same names kept cropping up; Dr R and Dr B, paediatricians, Mrs G and Dr W, psychologists. These people tended to figure strongly in parents' accounts of diagnosis and initial assessment but several parents had sought to maintain the link throughout their son's or daughter's life.

- *Dr R. He spotted it straight away.*

- *Find a key person, Dr R, Dr B or Dr W*

- *Relief when you find someone who knew about autism, they will recognise it.*

- *You need the label autism or ASD*

- *We've been everywhere to get help, Dr R was the answer*

Conversely some doctors still came in for criticism for disregarding parents' worries.

- *I was blanked by the paediatrician, called a 'frigid mother'*

- *The doctor did not believe me, said I was neurotic*

Even when professional staff did have knowledge of autism and some experience of interventions parents sometimes had frustrations.

- *He will say what people want him to say. I don't think the social workers understand that.*

- *My son talks to us not the staff. He tells us that he is cross about things that the staff have no knowledge of. It leads to misunderstandings.*

- *Without reference to anyone they tried to teach him Paget Gorman sign language when he had been able to use symbols successfully at school*

- *He started talking when he went to college at age 18. Just a few words and short phrases but he can make himself understood. Happened because no one knew signing there. He now has a vocabulary of 100+ single words.*

Fears for the future

Worries about the future figure highly for most parents

- *Will his brother have to look after him- he's been away at university, now has own place?*

- *It's not right to expect his brother and sister to take over looking after him. They have their own families now.*

- *If the family look after him after I've gone will they know him like I do?*

- *Our whole family functions around him; everything we do or don't do depends on him. We are dependent too.*

- *His needs can change dramatically, after an obvious event, death of his father, or for no obvious reason. People do not understand.*

- *It's not right to expect his brother and sister to take over his care.*

- *His medical needs not understood, he is very complex*

- *When I go he should go with me*

- *It's in the will. When I go, he is going to his auntie, who is younger. My daughter will look after his interests. She is executor of my will. I've set up protected trusts, went to a specialist solicitor via the local Autistic Trust.*

- *Defining moment was seeing an elderly couple walking with their adult mentally disabled son. They were totally isolated, avoided by others. Will we end up like that?*

SIGNIFICANT FACTORS IN THE SUCCESS OR FAILURE OF TRANSITIONS BETWEEN SCHOOL AND ADULTHOOD

For the cohort under investigation the success of their transition was gauged by how successful their current placement is in meeting their needs and how easy it was to achieve it. Measures used included;

➢ Parental satisfaction with the current arrangements

➢ Number of placements since leaving school or further education facility attached to school.

➢ Unplanned periods at home.

➢ Breakdown of placements including exclusions.

Most successful transfers

Not surprisingly parental satisfaction was highest in the cases where the adult placement had been planned well in advance, at least 2 years and where there had been one planned transfer with no unscheduled periods at home. This outcome represented 22% of the cases analysed so far.

- *'Always got what I wanted for her. Approached it like a military operation- worked at it. Always knew the cost to the authority, knew what they would offer, had visited the places they would recommend so knew what I liked about them and what I didn't. I knew her the best, could speak from experience.*

- *I'm now doing the same planning and organising with direct payments, I'm given the money and have to find provision.*

- *No problem getting provision, being who we are helped. We are both GPs. I'm on the board of the local autism trust.*

- *Couldn't find what we wanted so we set up the provision. It's a house for 6 young adults with Asperger Syndrome*

- *Need to plan 2/3 years ahead*

- *He could have gone to college in the north of England, paid by Education, but it was only for a couple of years. I wanted a place for him to live longer term. As we chose the adult residential place when he left school Social Services had to pay it all so there was no argument.'*

Medium successful transfers

Transfers that were less successful were characterised by funding difficulties leading to anxiety, several changes of placement, uncertainty about how long current placement will continue, being sent to look at places that were full or unsuitable and promises about future provision development that did not materialise. These represented 24% of the cases analysed so far.

- *It was a nightmare finding another place-they kept sending us to places that were full.'*

- *Staff from the school set up their own place for adults, a small living unit. Parents had great faith in it as they knew the staff. Not sure if it can last.*

- *Private organisations are all very well. They start off with the right intentions then can't keep trained staff or take more challenging people to fill the places.*

- *You never know if services will close.*

- *I found a horticulture placement for him but Social Services wouldn't pay for 1 to 1 support*

- *Policy is to cater in borough but there is no Autistic Spectrum provision. We keep being told it is developing but no sign yet.*

- *If you have Social Services and Education joint funding you have a battle for future placements. If entirely Social Services they will continue with the responsibility*

- *Parents want a long term placement*

- *He was funded by Further Education to age 20 then Social Services wouldn't pay as they never had.*

- *Need someone to go with you to look at placements, someone who knows about these things*

- *This place, that place, nothing definite.*

Least successful transfers

The least successful transfers were characterised by exclusions from specialist provisions (16% of sample), unplanned periods at home from 3 months to 3 years (38% of sample) and lack of suitable provision to date. In total the least successful transition group represented 54% of the sample

- *2 years fight to get the provision I wanted*

- *We're 'written out of the script' by Social Services*

- *My sister has to take over when I'm depressed.*

- *The agencies are no good at emergency help, when I was suddenly left as sole parent they said would have to wait for assessment.*

- *First they said he couldn't board then they wouldn't have him at all*

- *I took them to court, now promised a place in Kent, no idea when it will happen*

- *We were ignorant of what there was, it has been horrendous, have to fight all the time*

- *After the boarding school there were promises about new provision, it took months.*

- *He's been in a series of unsatisfactory places, I sued for maladministration.*

- *People said they could cope then couldn't, nothing seemed to help.*

- *His behaviour at home was always very different to school- he does what he wants at home, there is no pressure.*

- *Old habits die hard. She holds out her arm and I put the deodorant on. She could do it for herself.*

- *He could run his bath by himself at the residence, they had water temperature controls, I have to do it for him*

POINTS OF GOOD PRACTICE IN ACHIEVEING SUCCESSFUL TRANSITIONS

1. **Advanced planning**. Seeking the next placement 2 to 3 years before it is needed.

2. **Assessment.** Obtaining thorough, up to date assessments that detail functional skills and behavioural issues as well as medical needs helped to establish the right type of placement from the outset.

3. **Parental involvement.** Involving parents at all stages, listening and taking account of what they say. Even if the person is officially an adult parents and carers still have a major role to play in their lives, not the least because it is with parents that they are likely to be living if placements break down.

4. **Funding.** Sorting out the funding issues in advance.

5. **Flexibility.** Professionals being flexible, able to look at individual needs, fitting the provision to the person not the person to the provision.

6. **Long Term Needs.** Taking into account longer term needs at the time of transition placement and ensuring that the services chosen have a future.

   All parents want to know that their son or daughter will be happy and settled for life.

7. **Knowledge of Autism.** Key professionals in the transfer having a good knowledge of Autistic Spectrum Disorders. People being prepared to say they don't know but will find out.

8. **Visiting.** Only recommending visits to places that are definitely suitable and have vacancies. Providing professional advice and support during visits if needed.

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0023

THE WESTERN AUSTRALIAN AUTISM DIAGNOSTICIANS' FORUM, INC (WAADF,INC) – A COLLABORATIVE, CROSS-DISCIPLINARY AND CROSS-SECTORIAL APPROACH TO MAINTAINING DIAGNOSTIC EXCELLENCE.

SA MacDermott

Western Autralian Autism Diagnosticians' Forum, Inc, Perth, Western Australia, Australia

Introduction

This presentation will provide an overview of the assessment and diagnostic process for autism spectrum disorders in Western Australia (WA), and explore the development of the Western Australian Autism Diagnosticians' Forum, Inc (WAADF). It will discuss WAADf's development as an organization as well as its goals, challenges, current achievements and planned projects. Copies of WAADF's recently published diagnostic process will be available for review at the presentation.

Accurate assessment and diagnosis is the essential first step for all persons seeking autism spectrum disorder (ASD) related service provision in Western Australia. In particular, entrance to funded early intervention services is dependent on the outcome of this process. There is general agreement that these two aspects of service delivery are closely intertwined and require careful coordination.

The Western Australian Autism Diagnosticians' Forum Inc (WAADF) has been responsible for the documentation of agreed standards and descriptions of best practice for assessment and diagnosis in Western Australia[1]. Such agreement has been possible due to WAADF's unique position as an organization with cross-sectorial and cross-disciplinary membership. This in turn enables broad collaborative actions which are reflective of the practices of its members.

WAADF's Current Membership

WAADF's membership currently comprises 87 financial members representing ten different disciplines and areas of occupation. The majority of members are clinicians who are active diagnosticians in the field and working within government, non-government and private organizations. Representatives from intervention service provider groups, researchers, education and disability sectors, the WA Autism Association and a parent representative are also actively involved in the group. In addition, WAADF's quarterly Forum meetings are also regularly attended by students on placement in the various member organizations as well as new staff members from these groups. WAADF's elected Board has cross-sectorial and cross-disciplinary representation and, in accordance with its constitution, also includes a parent representative.

WAADF's Membership Breakdown by Discipline / Occupation

Discipline/Occupation	Current Financial Members
Paediatrics	10
Psychology/Clinical Psychology	32
Speech Pathology	31
Occupational Therapy	1
Social Work	1
Research	3
Education	3
Therapy	2
Management	3

Parent Representative	1
Total	**87**

WAADF Membership – Organizations and Sectors Represented

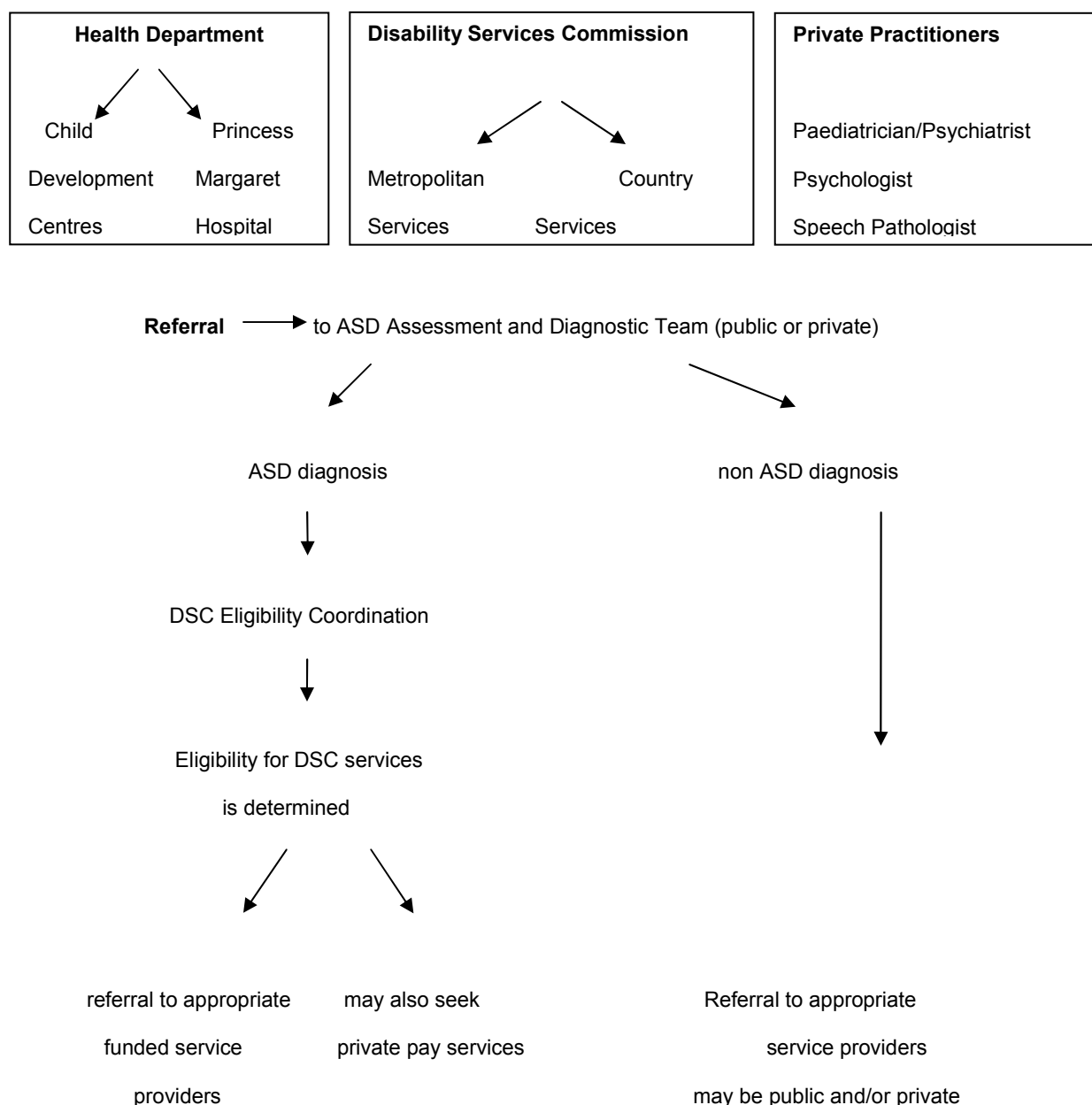| Organization/Sector |
|---|
| Disability Services Commission |
| Education |
| Public |
| Private |
| Autism Association |
| Funded intervention service providers |
| Private intervention service providers |
| Private diagnostic service providers |
| **Other** |
| Parent Representative |

Overview of the ASD Assessment and Diagnostic Process in WA

In Western Australia, an individual is diagnosed with an autism spectrum disorder if a team of experienced assessors agree on the diagnosis. For children (less than 12 years of age) this team includes a paediatrician (and a psychiatrist if mental health issues are also identified), a psychologist and a speech pathologist. Assessments for adolescents (12-17 years of age) and adults (aged 18 years and older) are carried out by a clinical psychologist, a paediatrican (for up to 17 years of age), and/or a psychiatrist. A speech pathologist is consulted as needed.

ASD assessments may be conducted within a multidisciplinary team setting (usually government agencies such as the Health Department or Disability Services Commission) or by individual professionals who work separately but collaboratively (usually private practice). Regardless of the assessment model used, once the assessments are completed, the professionals involved communicate their findings with the other members of their assessment team, and reach a joint decision regarding the most appropriate diagnosis.

In most instance, the multidisciplinary teams providing ASD assessments in WA are comprised of the three "core" disciplines described above as they represent the skills necessary to specifically address the diagnostic criteria as stated within the DSM. However, there is consensus within the professional community in WA that the area of Family Functioning is significant to the ASD diagnostic process and important in developing a complete understanding of the strengths and needs of the individual, their family/carers and their functioning within the broader community. Where ever possible, representatives from allied professions such as Social Work and Occupational Therapy participate in assessments thereby contributing to the diagnostic process and the support of the family.

Once a diagnosis of an ASD has been made, the assessing team forwards the individual's assessment results (in a written report that specifically addresses the current DSM criteria) to the Disability Services Commission's (DSC) Eligibility Officers. These officers then make a decision as to whether or not the referred person meets their eligibility criteria for services. DSC then informs the individual and/or family or carers accordingly. A member of the assessing team is also assigned to forward all appropriate information to the Western Australian Register for Autism Spectrum Disorders.

ASD Assessment and Diagnostic Service Providers and Process in WA

Health Department	**Disability Services Commission**	**Private Practitioners**
Child Princess Development Margaret Centres Hospital	Metropolitan Country Services Services	Paediatrician/Psychiatrist Psychologist Speech Pathologist

Referral ⟶ to ASD Assessment and Diagnostic Team (public or private)

ASD diagnosis   non ASD diagnosis

DSC Eligibility Coordination

Eligibility for DSC services

is determined

referral to appropriate   may also seek   Referral to appropriate

funded service   private pay services   service providers

providers   may be public and/or private

WA Assessment and Diagnostic Standards and Guidelines

WAADF published *The Diagnostic Process for Chidlren, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders: Guidelines and Standards for Service Provision in WA[1]*, in two versions, in 2005. The assessment providers' version is intended for use by assessing clinicians or other professionals in the field. The family and service providers' version is a slightly condensed version and is intended to be more accessible to non-clinicians. WAADF is currently developing an explanation of the assessment and diagnostic practice in a summary brochure form. It is intended that this version will be produced in quantity and distributed through community sources such as doctor's offices, child health clinics and early childhood facilities.

The guidelines and standards for ASD assessment and diagnostic practices described in these booklets have been achieved through collaboration and consensus amongst clinicians in the field and are acknowledged as a statement of best practice. These guidelines and standards are also recognized by major state agencies involved in the provision of ASD related services such as Disability Services Commission (DSC), WA Department of Health, WA Department of Education and Training, and the WA Autism Association. In addition, they are taken into consideration by agencies such as DSC when reviewing referral information to determine eligibility for services.

WA Register for Autism Spectrum Disorders

The WA Autism Register[2] began data collection in January 1999. It is a unique population-based register of all known individuals newly diagnosed with an ASD diagnosis in Western Australia. The Register has had close links with the Forum (which became WAADF at incorporation) since its inception. The Register's ongoing success reflects the collaborative provision of data by all assessing clinicians. To date it is estimated that approximately 90% of identified cases of ASD in this state are included in the database.

Clinicians are asked to complete a data collection form, which includes both diagnostic and demographic information, at the time of diagnosis. For confidential information (name, date of birth, postcode) to be included, consent must be obtained from the parents or persons themselves. Confidential information collected by the Register helps to eliminate double notification entries, to recognize changes in diagnoses within the same person over time, and to assist with the comparison of the numbers received at the Register with numbers diagnosed at each centre. At the end of each year the major diagnosing centres review their records for any missed cases.

Data gathered by the Register provides information about ASD diagnostic subgroups, the place of diagnosis, comorbid conditions, age at diagnosis, gender, ethnicity, country of birth, cognitive abilities, adaptive behaviour, primary language at home, and the person's language skills at the time of diagnosis. The success of the Register is dependent on the collaboration of assessors in both public and private practices and their willingness to participate in this process.

Initial funding for the Register was provided by Disability Services Commission and the Australian Rotary Health Research Fund. Since 2002 funds have been received from both the WA Department of Education and the WA Department of Health.

WAADF, Inc – Early Start to Incorporation

In the early 1990's, WA experienced a surge in autism-related assessment referrals similar to that described in international literature as having occurred during the same period in the United Kingdom, Europe and North America[3,4]. This increasing demand for services in WA was met by a dynamic and increasingly cross-disciplinary and cross-sectorial response that ultimately resulted in WAADF's formation.

Steps to Incorporation

WAADF (www.waadf.org.au) became an incorporated not-for-profit organization in 2004, however it did not start out as a planned incorporated organization, it evolved into one. This process began in 1988 with the formation of a Western Australian Ministerial Working Party. This group came about as a result of pressure from the WA Autism Association for state government funding in the area. The working party published reports in 1988 and 1989 and their recommendations highlighted the need for a consistent diagnostic process and a central diagnostic team. As a result, a Central Diagnostic Panel (CDP) was formed in 1991. Its members included representatives from the Health Department, Disability Services Commission (DSC) and the WA Autism Association thereby setting the precedent for WA's enduring collaboration in this area.

Other significant milestones in the formation of WAADF were as follows;

- Specialist autism assessor training programs began in 1994

- Cross disciplinary assessment and reporting protocols were established in 1996

- Standards for paediatric ASD assessments were formally documented in 1998

- Formation of the Autism Clinical Diagnostic Forum (ACDF) in 1998 (forerunner to WAADF)

- Standards for adult ASD assessments were established in 1999

- Standards for establishing a diagnosis of Asperger's Syndrome were reconfirmed in July 1999

- Standards for establishing a diagnosis of PDD-NOS in WA were agreed on in 1999 and reconfirmed in 2002

- WA Register for Autism Spectrum Disorders began collecting data in 1999

- Standards for the provision of ASD assessments by DSC Specialist Country Services were documented in January 2000

- Statement of Autism Assessment Standards Across DSC Autism Centre and State Child Development Centre (SCDC) were released in January 2000

- Standards for ASD assessments provided by Private Practitioners were documented in 2001

- Autism Diagnosticians' Forum was formalized with the election of inaugural office bearers in 2002

- Autism Accreditation Project Working Party was established in 2002 as a DSC funded project. Some additional funding was later provided by the Health Department.

- **WAADF, Inc became an incorporated organization May 7th, 2004**

Why incorporate?

The focus of this group has always been on the development and maintenance of best practices in the assessment and diagnosis of autism spectrum disorders. Issues that have driven the development of the group over time have included the need to;

- develop state-wide standards for diagnosis that concur with international standards

- develop criteria to be used in diagnosing ASD subgroups (Asperger Syndrome and PDD-NOS) and ensure consistent interpretation of all diagnostic criteria

- develop standards and guidelines for cross-disciplinary paediatric and adult assessment and reporting protocols and ensure they are met by all professionals making ASD diagnoses and subsequent referrals to DSC

- develop specialist autism training programs

In the fifteen years since this group began (in 1991), the practices of clinicians who work in the Autism field in Western Australia have continued to reflect the ongoing research findings and significant growth in knowledge both from within Australia and internationally. This growth was also seen in the decision by the group to establish a more formal presence and structure in order to support the ongoing development of the group and its members. As a result the Autism Diagnosticians' Forum (The Forum) was officially formed in 2002 with the election of formal office bearers. However, it was the establishment of the Autism Accreditation Project in October 2002 which was to act as the catalyst for The Forum's 2004 incorporation.

An assessor training process for speech pathologists and psychologists has been available in WA, in an evolving form, since 1994. This process has always been considered to be "informal" in nature and has always functioned as a "colleagueal" or mentored training process without any prescribed training methodology or skill acquisition criteria. The majority of speech pathologists and psychologists who are currently members of WAADF received their specialist training in this manner. Many of these clinicians have then in turn participated as peer mentors in training their disciplinary peers. This method of training is consistent with the recognition that the judgement of clinical experts is considered to be the gold standard in diagnosing autism[5].

Over time, this informal training regimen developed into a three phase process. Phase 1 requires the trainee to observe two full assessment sessions as they are conducted by experienced clinicians. In Phase

2 the trainee participates in two assessments and negotiates with their mentor which parts of the assessment they will be responsible for. The mentor provides support and feedback as needed. During Phase 3 the trainee is responsible for conducting their discipline's component of the assessment while their mentor observes and provides any necessary feedback. The training is mostly accessible through WA's disability and health agencies.

As the numbers of clinicians requesting specialist assessor training increased, there was growing interest within the Forum to determine if it was possible to refine the current training process in order to formalize the training procedures and standards. The Forum membership elected to establish the Autism Accreditation Project (AAP). A working party was established in October 2002 with the aim of investigating the requirements for developing an accredited specialist assessor training program. It was anticipated that one of the outcomes of such a program would be an increased access to high quality ASD diagnostic services for individuals and their families all across Western Australia. The AAP was initially funded through a short term grant from Disability Services Commission while additional short term funding was later provided by the Health Department.

The working party conducted an extensive review of local needs combined with an extensive literature search. Consequently they developed a project overview as well as draft protocols and training materials for the specialist training program, including a draft of the guidelines and standards for ASD assessment and diagnosis in WA.

It became apparent to The Forum that completion of the AAP would require a considerable commitment of time and funding. In addition, once the project was developed, the training program would need to be "housed" outside of any of the existing agencies in order to continue to operate independently. At the same time, earlier sources of funding ceased and The Forum accepted responsibility for completing the development of the accreditation project as well as the publication of *The Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders: Guidelines and Standards for Service Provision in Western Australia*[1]. It became apparent that incorporation had many potential benefits in support of the group's primary goal of supporting quality ASD assessment and diagnosis across the state. The establishment of not-for-profit status would also create wider avenues for pursuing funding options, thereby supporting The Forum's goals and facilitating the expansion of member services and supports. As a result, the membership voted in support of incorporation and WAADF, Inc became an incorporated group in May 2004.

WAADF's Goals

The goals of the organization are to;

The guidelines and standards for ASD assessment and diagnostic practices described in these booklets have been achieved through collaboration and consensus amongst clinicians in the field and are acknowledged as a statement of best practice. These guidelines and standards are also recognized by major state agencies involved in the provision of ASD related services such as Disability Services Commission (DSC), WA Department of Health, WA Department of Education and Training, and the WA Autism Association. In addition, they are taken into consideration by agencies such as DSC when reviewing referral information to determine eligibility for services.

- define and promote specific assessment and diagnostic guidelines and standards, and encourage state-wide consistency in the provision of ASD assessments and diagnosis

- encourage active review and sharing of assessment and intervention related resources and information by both WAADF members and other interested people and organizations

- promote the provision of objective and comprehensive information regarding ASD assessment and diagnosis to families and caregivers of people with ASDs

- act as an advocacy voice for individuals with ASD and their caregivers by promoting maximum access to high quality assessment and diagnostic services

WAADF works to meet these goals through a range of enterprises, as follows.

Assessment standards and guidelines booklets

- Assessment Providers' Version – a copy is included with initial membership; also available to purchase

- Family and Service Providers' Version – a copy is available free of charge to WA families through the sponsorship of Lotterywest and the administrative support of the WA Autism Association; it is also available to purchase.

- Copies of both versions have been purchased by individual clinicians, government departments, hospitals and schools across WA

- Purchasing enquiries have been received from inter-state and internationally

Membership support and professional development

- Quarterly WAADF meetings provide opportunities to disseminate information, share recent developments in the field, facilitate interpretation of diagnostic criteria, discuss scientific literature, participate in case discussion, share resources and benefit from peer networking.

Website

- WAADF has recently established its own website www.waadf.org.au but can still be accessed through a link at its previous host website www.autismwa.org.au

- The site is still being developed with plans to include a range of open access as well as members only sections

Specialized assessor training

- WAADF continues to support the informal training process that is currently in place

- Acquisition of adequate funding to complete the development of the Accreditation Training Program continues to be a goal for WAADF

Newsletter

- WAADF launched its quarterly "between meetings" newsletter in April 2006 to provide enhanced opportunities for information dissemination and member networking

Professional Library

- The WAADF Board has recently agreed to establish a professional resource library. Items will be accessible to members at meetings and for extended borrowing

Where to Next?

WAADF has continued to develop and mature in the two years since its incorporation and its accomplishments are considerable considering that its Board consists entirely of volunteers who have many other professional and personal commitments.

No doubt new challenges and considerations not yet considered will emerge, however at this time the following are issues identified by the Board and membership as areas of interest or need;

Assessment standards and guidelines booklets

- Review and refine the current booklet based on feedback received prior to a second edition reprinting

- Complete the simpler Family Brochure version of the assessment booklets which is currently in draft form

Membership support and professional development

- Continue to request member feedback regarding service needs and wants

- Develop strategies to identify assessing clinicians who may not yet be WAADF members in order to ensure maximum membership inclusivity

- Continue to encourage cross-disciplinary and cross-sectorial membership

- Continue to develop improved strategies for supporting assessors working in rural and remote locations

- Continue to develop strategies to encourage the widest possible participation by members in WAADF's projects thereby ensuring consideration of the widest possible range of views, enriching

the organization by accessing its memberships' diverse knowledge and skills and spreading the work load beyond the volunteer Board members

Website

- Continue to develop WAADF's website including the Members Only section

- Complete the development of the online Membership Listing

Specialised assessor training

- Continue to support the currently available 3 Phase informal assessor training process

- Pursue funding options to enable the progression of the Autism Accreditation Project

Newsletter

- Continue to develop the newsletter format and content to meet the needs of the membership, with particular consideration of the needs of clinicians living outside of the metropolitan area

Community advocacy to support the organization's goals

- Continue to build collaborative networks and relationships with agencies and service providers

- Continue to act as an advocate for individuals with ASD, their families and service providers in issues relating to ASD assessment, diagnosis and service provision

Funding

- Maintain the lowest possible membership fees in order to actively encourage maximum participation

- Develop grant applications and other mechanisms for generating funds to support WAADF's projects and membership services

Summary

Beginning in 1991, and continuing throughout its evolution to its current form, WAADF has proven to be a resilient and dynamic organization. It benefits greatly from the diversity of its membership and provides both seasoned and new practitioners in the field unique opportunities for ongoing skill development, networking and collaboration. The organization that currently exists is indebted to the many clinicians whose skill, enthusiasm, commitment, vision and tireless contributions have provided the foundation for its current and future growth. WAADF is an example of effective cross-disciplinary and cross-sectorial collaboration in the provision of high quality assessment and diagnostic services for persons with autism spectrum disorders and their families and caregivers.

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THE JUDEVINE MODEL OF PARENT TRAINING: FAMILY DRIVEN AND FAMILY SUSTAINED

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Parenting a child with autism often results in few of the natural rewards inherent in parenting. Children may not say their first word or may lack eye contact and cuddling. They often miss or experience delays in developmental milestones of same age peers. When they do develop language and social interaction, it may take far longer for the parent to experience a spontaneous "I love you" or the hug initiated or reciprocated from their child. Parents often report remorse for the stages of life that may never occur- a first kiss, a first date, being part of a team sport. In answer to these issues, parent training is a front line of intervention.

Many training models, which espouse the use of behavior principles, do so with a focus on behavior management. In attempting to control or "manage" behavior, approaches to training often miss the focus on the dynamic nature of social interaction. True behavioural change requires effort, accounts for variables such as motivation, context, conditions under which behavior is learned and maintained. Managing behavior often fails in its monolithic approach to learning in terms of control versus learning to learn. Training which is sustainable throughout a lifetime requires examination of behavior and behavior change within the framework of social interaction, or exchanges. Learning is dynamic rather than static. In human behavior, it occurs within the context of patterns of interaction through which people shape each other's behavior rather than control or manage others. With this foundation, learning to learn, grow and change in relation to others becomes the primary focus of parent training.

The Judevine Model of Parent Training is unique in its focus edifying the family's inherent expertise regarding the needs of its individual members and the family as a whole. To do so, the foundation of parent training is on behaviour development within the context of social exchanges. Focus on behaviour development, rather than behavior management is integral to the sustainability of the training as a framework for individual, family and system change as the child with autism, his family and community grow and change over time. Effective training begins with acknowledging that change, or learning is difficult and requires effort. Motivation for change must be powerful and worth the effort in terms of payoff or reward for all those involved in the process. A history of success comes from the recognition that the payoff or reward is found in the increase in skill, the reduction in effort of communication and the positive relationships that develop as a result of the process. The Judevine model of service delivery, with its core in parent training begins with these premises and serves as a lifelong foundation for individual, family and community change.

Resulting from a university affiliation in the early 1970s, research in applied behavior analysis within the context of social exchanges was initiated at the Washington University Social Exchange Lab with children with autism and their parents. Families reported for the first time, experiencing the natural reinforces inherent in parenting such as reciprocal eye contact, cooperative play and spontaneous verbal interaction. While funding for the research moved to another university, families took the skills they had begun to acquire in interaction with their children and expanded the program from the bounds of a university to start a non-profit organization to continue the research with the help of Lois J. Blackwell, lead researcher.

The tenets of the Judevine Model are multifold. First, training reviews behavior principles or laws with govern social exchanges. The understanding that people shape each other's behavior and that learning is a dynamic, lifelong process best maintained within the context of social exchanges in the central tenet to training and service design. Second, the training examines motivating variables in terms of what makes it worth the effort to learn, grow and change in relation to others, the conditions under which one is to learn and the payoff relative to the effort one exerts in the learning process. The utilization of applied behavior analysis within the context of social exchanges and the consideration of response effort and relative pay off-components of behavioural economics make the Judevine Training Model unique in its approach to lifelong growth and intervention for the child with autism.

These core components are coupled with other key elements that set the model apart from other means of intervention. First, participants in training set goals for behavior change. Next, parents and professionals work side by side in guided observation, coaching and workshops. Parents are regarded as the expert on the family member with autism. It is the family that will sustain the change and growth that occur as a result o the training-in the short and long term. Unlike other models for intervention, the family and the person with autism are the key players in intervention. People outside the family will come and go as "professionals" but no one lives 24 hours a day, 7 days a week within the framework of the family and

community from which the child with autism is born. In preparation of skills, which rely on methods and people who will come and go throughout one's lifetime, the behavior principles which acknowledge that like physical laws, laws govern behavior? Behaivoral principles operate to establish, maintain and change behavior over time as people grow. This provides the framework for growth and change within and in support of the family, the community and in the larger service delivery system. Parents take data, along side the Judevine staff. They work on objectivity and learn o collect data within the context of the family as a means by which to "baseline" behavioural change.

Use of technology from the inception of the program is another difference in the Jude vine model. Use of videotape serves many purposes in the analysis of social exchanges. First, it gives rise to over 30 years of data from which longitudinal analysis of change is possible. Self monitoring and self correction are also possible through the use of technology to replay exchanges within the context of training. The use of modelling and demonstration, too, is possible through videotape, even to remote locations for training.

With the Judevine Model of service delivery as a foundation, interventions, then, may be added to the array of treatment methodologies and tailored to each individual's needs. Interventions can also be evaluated for efficacy and maintained or discarded as newer; more refined or more appropriate interventions become available. Although training takes many forms, the use of baseline data collection, analysis of social exchanges and motivating variables is applicable not only in the context of parent/child intervention. It also serves as a foundation for group seminars and in services for professionals. It provides a basis for group problem solving in sibling support and family connections groups. Natural Support Workshops provide information at a more basic level to the neighbour, bus driver or friend from church who wants to help, but needs to learn just a little more. The language of training is the common language spoken by those who participate in the Judevine model of service delivery. Issue specific consultation allows for more in depth problem solving. Advocacy at many levels are provided to communities, government systems and groups of parents and professionals nationally and internationally.

As families began to identify service gaps from the organization's inception, new services have developed. Respite services provided a structured teaching opportunity from which children and their families get a break from their daily routine, but continue to develop language, social and self help skills. Clinical services such as occupational, speech and behaviour therapy provide more traditional interventions. A classroom provides for alternative instruction of a more intense level to thoroughly address academic, social and communication needs for adolescents with autism. Residential , recreation, Supported Employment and community based services complete the array of lifelong services developed for and by people with autism and their families as needs are identified.

Learning to be a keen observer and as objective as possible, analyzing what establishes, maintains and changes behavior are the critical skills developed in parent training. Setting social exchanges up to be "win win" is the next key skill developed. In this, learning that one has to give a little to get a little is a foundation for successful life long interaction. An examination of the relative variables which govern interaction in terms of setting, pay off, player in the interaction also transcends the context of the family and generalizes to analysis of groups, communities, cultures and systems.

There are several outcomes enjoyed by those who participate in training and access services through the Judevine model. People with autism become successful, taxpaying, contributing members of their families, communities and professions. They have friends. They go on to begin support groups and to advocate for systems change for themselves. Families are able to articulate and advocate for the needs of their children and their family as a whole. Professionals understand their role in edifying the family, but recognize the expertise the family has inherent as they parent the child with autism. They develop skills that are critical to work with the child with autism but which are good, solid principles of effective teaching and learning. Families advocate changing systems in their classroom, school, church, medical community, and within the context of the community as a whole. They learn that behaviour principles apply to all interaction, even those involving government systems. BY shaping interaction into win/win social exchanges or restructuring interaction through the analysis pf behaviour principles, change is possible within the family for a lifetime The framework for growth is integral to the family and will grow as each individual and the family as a whole changes. The mission of Judevine is "to make a real difference in the lives of people with autism and their families wherever they may live". The model of training makes it possible to do just that.

0025

VOCATIONAL TEACHING QUALIFICATIONS IN AUTISM SPECTRUM DISORDER

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The increase in the rate of diagnosis of students with Autism Spectrum Disorder (ASD) means that there are more and more students with ASD in schools. Students with ASD require specialised knowledge and teaching skills, but pre service mainstream and specialist teacher training in Victoria does not adequately equip teachers with the skills they need to effectively teach students with ASD. Research has found that teachers who are otherwise competent and accomplished in their work frequently consider themselves to be less than capable of serving the needs of the students with ASD, and there are good reasons to believe they are right. When specialised services are unavailable, or when teachers are not equipped with knowledge and appropriate intervention strategies, then the classroom containing the student/s with ASD, the individual student with ASD themselves, and their parents invariably suffer.

This paper looks at an attempt at improvement of mainstream classroom teaching of students with ASD by equipping teachers with greater understanding of the disorder and specialised intervention strategies that have been demonstrated to be effective with students with ASD. Two Australian accredited autism specific vocational courses (at Graduate Certificate and Graduate Diploma level) established by Western Autistic School (WAS), an autism specific school and training centre in Melbourne, aim to provide evidence of effective ways of assisting teachers to develop competence and confidence in teaching students with ASD. The vocational courses delivered by the Autism Teaching Institute (Western Autistic School's Registered Training Organisation (RTO)) acknowledge the teacher's need and desire for specialised on- the- job training with expert coaching to learn how to effectively teach students with ASD, and the need for theoretical material to complement what is learnt in practical classroom experiences.

This paper is presented in two parts. Part 1 provides a rationale for ASD specific competency -based teacher training courses. Part 2 provides details of the vocational ASD specific teacher training courses, delivered by the Autism Teaching Institute (ATI)[cxxxv]. The aim is to show how teachers in the course of study, are equipped with understanding of ASD and the specialised intervention strategies that have been proven to be effective with students with ASD.

Part 1

Rationale for vocational teacher training courses in ASD

I. Prevalence of ASD[cxxxvi]

The trend globally is that identified cases of autism are increasing. The need for teacher training is critical with more and more ASD students in mainstream and generic special schools.

II. The nature of autism of ASD in the mainstream classroom

Students with Autism Spectrum Disorder can pose significant problems to the functioning of the classroom. Such students have complex learning needs.[cxxxvii] There is enormous variability in severity and symptoms of the disorder. Students with ASD can have the full range of intellectual skills but their communication and interaction skills only occur in a more limited and impaired range. Areas affected include the ability to use and understand spoken language, receptive language, body, facial language and gesture to 'read' social situations. In regular classrooms, teaching of students with ASD must include the most basic forms and functions of communication, social skills training and behaviour management. The student's unique cognitive style is also problematic for teachers because knowledge of how regular students learn and of mainstream curriculum and programs does not map onto the learning profile of a student with an ASD. Such symptoms in a classroom context can cause great stress for the student, teachers and peers. Compounding the problem is the requirement of the teacher to balance the needs of all class members, and to manage the concerns of the parent community that their children are getting appropriate and fair attention.

Generic special settings too have a high percentage of students with ASD. These schools face the complex challenge of catering for the diverse range of individual needs across a broad range of disabilities. The challenge for teachers of students with autism in generic special settings is compounded by lack of adequate training.

III. The experience of teachers and students with ASD in regular schools

First hand accounts by adults with autism of their school experience, and an account of my own experience of working in regular schools makes real the difficulties for the student with ASD, and their teachers. For example Temple Grandin[cxxxviii] writes…

> I went to normal elementary school with older experienced teachers and small classes. Mother was another important person…She worked very closely with the school. She used techniques that are used today in the most successful mainstreaming programs to integrate me into the classroom [structured teaching, individualised objectives, modified language of instruction, social facilitation]. The day before I went to school, she and the teacher explained to the other children that they needed to help me… I was expelled from high school for fighting and moved to a small country boarding school for gifted children with emotional problems. In high school the people that helped me most were the creative, unconventional thinkers.

Therese Jolliffe in the same year[cxxxix] explains her experience of schooling

> '(as) a confusing, interacting mass of events, people, places, sounds and sights…. Although ordinary schooling enabled me to leave school with a dozen or so O-levels and few A-levels and then to obtain a degree, it was not worth all the misery I suffered…I hated school, I was frightened by the girls, boys and teachers and everything there. When I was at school I was kicked, hit pushed over and made fun of by other children.

The following two case studies represent what I have frequently observed in regular school classrooms. Jonathon is a Grade 4 student at his local primary school. He started school in prep and was diagnosed with Asperger Syndrome in grade 3. The school had previously contacted WAS for advice and help when Jonathon was in grade 2 because he was hiding under tables, refusing to do any class work and was anxious and fretful about everything at school. The teacher stressed that her usual responses and strategies she employs with the other children (individual explanations, praise, rewards and reprimands) were not working. She said that the only thing that she said did work was to leave him alone or allow him to sit in the book corner or at the computer. Zona is also in Grade 3 and like Jonathon she started regular school at prep age. Zona was the first child with 'savant' skills that I had met. She had prodigious scientific knowledge of the human body and genetics, and read university level medical books. Her teacher wanted help with Zona's behaviour toward other students. Zona was intolerant of her classmates. She made inappropriate social comments, for example, calling her classmates 'dumb' and 'stupid' when they got answers wrong, lecturing them on the disease spread by coughing and sneezing, questioning the accuracy of teachers' statements, calling out answers, leaving her desk and making unpredictable angry outbursts. By Grade 4 Zona was attending school part time whilst her parents tried home-schooling with her. She is now at secondary college attending some specific classes with a 'minder' part-time.

What do these case studies show? First is the importance of early intervention. Many students with high functioning ASDs like Jonathon and Zona, begin school not having had early specialised interventions so they often don't have the foundation skills for learning nor the functional expressive skills they need to be successful at school. In the early years students with ASD won't readily learn on their own or from watching others, so specialised instructional techniques in the most basic areas of learning are required (eg, Koegal and Koegal, 1995, Quill 1995). In the case of Jonathan, although he had a good vocabulary, he couldn't ask for help, ask for a break, or say that he didn't understand. He basically coped in class by running videotapes of car racing computer games in his head. In Zona's case she missed out on early learning of vital social skills, eg. working alongside and as part of a group, turn-taking, learning how to get along with others and how to make and keep friends. The second thing the case studies clearly show is that teachers need specialised knowledge of ASD and of specific strategies, before the students arrive in their classroom. Using the case studies of Zona and Jonathon, I later explore how competency based training courses attempt to equip teachers with understanding of ASD and the specialised intervention strategies that have been proven to be effective with students with ASD.

IV Inclusion, disability and law

The increase in the rate of diagnosis of ASD coincides with the international movement toward mainstreaming of students with disabilities into local schools. The policy of inclusion began with the 1975 USA Public Law 94-142 'Education for all Handicapped Children Act'. In Australia, inclusion rights are not formalised by legal mandates although states and territories have policies for inclusion and integration. In any classroom setting, students with ASD are extremely resource intensive, can be disruptive to the learning of other students, and require specialised interventions for effective classroom management. Importantly, teachers have a legal responsibility to offer reasonable care to all children in their classes, regardless of the child's disability or the adequacy or otherwise of their own training. In the absence of legal provisions for inclusion, anti-discrimination and equal opportunity law appear to be providing avenues for redress for persons with a disability and their parents (Forlin & Forlin 1998).

The U.S 'No Child Left Behind Act' (NCLB) of 2001, raises questions about the preparation of teachers in relation to special education, and for teachers of students with ASD in particular. The NCLB Act requires that all students be taught by highly qualified teachers and that by 2002-2003, Title 1 schools were to aim to meet "adequate yearly progress" (AYP) goals for their total student populations and for specified demographic subgroups, including major ethnic/racial groups, economically disadvantaged students, limited English proficient (LEP) students, and students with disabilities (US Department of Education 2002). A question arising from the NCLB Act is how the description of a 'highly qualified teacher' is to be satisfied for teachers of students with ASD. This question is also taken up in Part 2 of the paper when the teacher competencies covered in the vocational teacher training courses are discussed.

V. Issues in teacher preparation

There is a lack of accepted professional standards specific to autism in teacher preparation programs (Scheuermann et al 2003). ASD specific training where it does exist is typically an ad hoc process with great variation in the scope and depth of the training, in the content of the training, eg. whether the focus is on single or multiple intervention approaches, and with the availability and timing of the training.

Teacher effects

Research has found that teachers are the single most important variable in student learning outcomes. Up to 60%of the variance in individual learning outcomes is attributable to teacher/class differences, thus student learning is greatly influenced by how teachers teach (Cuttance 1998, 2000; Hill et al 1996). There is little formal data about the state of teacher preparation in autism. Nor is there specific research on the relationship between the teacher and the learning outcomes of students with ASD. There is however anecdotal evidence that positive learning outcomes for students with ASD are correlated with the degree of teachers' knowledge and understanding of ASD, and of the teaching practice particular to ASD. Also related to this is a teacher's perception of autism, ie. whether a teacher perceives the ASD student as having deficits rather than being different will influence how they will deal with them as a consequence of that thinking and this is a challenge for teacher preparation programs.

Political effects

Peck & Furman (1992) suggest that a fundamental problem constraining the inclusion of students with disabilities and impairments in regular classrooms is the effect of contemporary pedagogy in schools. Since the 1980's classrooms arrangements have been based on constructivist principles. Constructivism involves an inquiry approach where it is thought that full understanding occurs only when students learn for themselves from hands-on experience without direct instruction or teacher intervention. The constructivist classroom is likely to be exactly the wrong environment for the student with ASD. Given the nature of the disorder, students with ASD need explicit instruction, close attention and monitoring, predictability and structure in the educational environment as illustrated in Jonathon and Zona's experience of the classroom.

VI. Research context

There is very little research that focuses specifically on inclusion of students with ASD in mainstream schools. Mesibov et al (1996) assert that the 'philosophical movement for full inclusion has preceded systematic research on its assumptions or effectiveness…most research has looked at students with disabilities other than autism' (p.338). The literature on inclusion of students with disabilities as a group supports the claim that mainstream teachers struggle with teaching students with disabilities. Scruggs & Mastroprieri (1996) conducted a meta analysis of teachers perception of inclusion from 1958 – 1995 and found that whilst 2/3rd of the 10, 560 teachers surveyed support inclusion, only a ¼ to 1/3 reported that they had sufficient time, training or resources to implement successful inclusion.

Parents and teachers are uncertain about the outcomes of inclusion and how best to address the educational needs of students with ASD (Kasari et al, 1999; Mesibov et al, 1996). Two studies focused on the teacher's perceptions of autism and educational practice. Both used a survey study that was first conducted by Stone and Rosenblum (1998) and later followed up by Help et al (1999). Both studies found that mainstream teachers have generally poorer knowledge of autism when compared to special education teachers and mental health professionals. The Helps et al (1999) study showed that mainstream teachers tended not to understand that students with autism need more structure, explicit teaching, or predictability, nor that classroom organisation can make a difference to the behaviour of these students.

In another study, Mavropoulou & Padeliadu (2000) compared Greek special education and regular teacher's perceptions of autism and the implications for educational practice. These researchers found that the regular teachers did not recognise the implications of autism for the approach taken to achieving instructional objectives. They found that the regular teachers seemed more concerned with the social and psychological well being of the autistic child and perceived the role of the school to be comforting, sociable

and warm. A study by Miles et al (1993) found that teachers interacted less with students with ASD when with their peers. They asserted that this showed that the physical integration of students with ASD is alone not enough. Robertson et al (2003) looked at the effects of ASD students' behaviour on their relationships with their teachers and found that success of the relationships was negatively associated with behaviour problems, social exclusion and the lack of 1:1 aide support in the classroom.

The Helps et al study found that mainstream teachers had not received autism specific training and were less likely to agree with broadly established educational principles for teaching students with ASD. An Australian Senate Enquiry (2002) also found that teachers of students with ASD in mainstream schools do not receive the pre or post service training needed to adequately maintain a classroom that contains ASD students. The Senate report also found that professionals and educators in mainstream and generic special settings who are otherwise accomplished in their work frequently consider themselves to be less than capable of serving the needs of students with ASD.

VII. Perspectives of parents of students with ASD about mainstream schooling

Howlin (2004) says that parents assume an explicit treatment provider role for their children with ASD far into adulthood. Each year parents face the prospect of providing on-the-job training to schools as new staff come into contact with their child/ren. Kasari et al (1999), in a study of parental perception of inclusion, found that, compared to parents of children with Down's Syndrome, parents of autistic children were uncertain about the benefits of full inclusion and whether full inclusion was desirable for their children. Half of the parents of autistic children did not think that their child's educational needs could be addressed in an inclusive programme and that the autistic child's social and communication difficulties were the main barriers to inclusion.

VIII. Experience and research conducted by the author

In my 10 years of experience working with regular schools in the WAS outreach program (see summary of WAS 2005 outreach services in Appendix 2), it was common for schools to be reluctant to enrol students with ASD particularly where such students had a history of behavioural difficulties. I also found that in regular school classrooms, it was common for teachers who had not had autism specific training or support, to interpret the 'behaviours' exhibited by the student with ASD as deliberate acts of naughtiness. They commonly described the student as odd, withdrawn, bizarre, difficult, rude and anti-social. The 'behaviours' generally reduced and so did the use of negative descriptors of the students once staff had received information on ASD and after they were shown specific teaching strategies and techniques. In a review of the outreach services provided by WAS, in 2002 a small exploratory research project was conducted by the author to look at the efficacy of outside specialist help for mainstream classroom teachers of students with ASD (Thomson 2002). Taped phone interviews were conducted with seven classroom teachers who had previously used WAS services. The aim was to sharpen the understanding of the problems faced by educators and to investigate ways of meeting their needs. The following statements are typical responses to two of the interview questions.

'What were you looking for when seeking programs or services [for your students with ASD]?'

-"Someone who knew the school situation"

-"Guidance and understanding of the issues and strategies"

-"We were frustrated and uneducated so wanted help"

-"Help"

-"Information about autism and strategies for the classroom"

-"Needed direction, assistance and guidance with curriculum and academic issues, behaviour both emotional and physical"

-"Someone with experience of mainstream schools"

What do you/did you value most [about the WAS outreach service]?

-"Ongoing access to information and knowing we are on track"

-"Two things; knowledge gained and ability to have an expert to talk to the family"

-"Ideas and someone who knew what they were talking about"

-"Reassurance of being on the right track and further strategies"

-*"Reassurance that you're there: good to have at the back of your mind"*

-*"You're our link between parents, community you and us"*

It became clear in the course of the interviews with the teachers that there was a need to investigate how teachers in mainstream schools come to understand ASD and how they learn the unique competencies necessary to successfully teach individuals with ASD in an inclusive setting. The author is currently undertaking a research project investigating improving classrooms that contain students with ASD. The primary research method is use of pre and post surveys of teachers enrolled in the vocational ASD teacher training qualifications that are described later. The assumption underpinning those training courses is that the success of classrooms containing ASD students requires a) that teachers understand ASD and b) teacher's ability to make use of specialised educational interventions that have been demonstrated to be effective with students with ASD. In the case of regular schools it is assumed that:

-The standard general classroom is not set up to cater for the needs of students with ASD

-The nature of ASD is such that if teachers don't have appropriate ASD training, then the classrooms containing students with ASD, the individual student themselves and the their parents invariably suffer

-Standard teacher training and experience does not equip teachers to cater for a student with ASD and that competency based vocational training might

-That there is a need for research to advance understanding of inclusion policy and practice.

IX. Government Reports- Senate Report and Victorian Government Meyer Report 2002

The Victorian government commissioned Meyer Report 2001 reviewed the Program for Students with Disabilities and Impairments in terms of provision of quality teaching and support services. The Meyer report identified the risk of 'A loss of commitment to inclusive education, innovative practice and strategic planning for quality public education, where insufficient professional development for general educators has resulted in a lack of knowledge and skills to support children with disabilities in their school community (p30)'

A Senate enquiry (2002) found that professionals and educators in mainstream and generic special settings who are otherwise accomplished in their work frequently consider themselves to be less than capable of serving the needs of students with ASD. This problem is evident at a time when more and more students with ASD in particular Asperger Syndrome (AS) and Pervasive Developmental Disorder (PDDNOS) are attending mainstream schools. Students with these spectrum disorders nearly all attend mainstream schools because these categories of disorders are not recognised within the Program for Students with Disabilities as they are non-ID classifications. As a result they are usually denied PSD funding and schools are not formally required to provide individually determined learning plans for them.

The Senate report tabled in Federal Parliament in December 2002 includes the following excerpts:

'The education systems are almost totally unprepared to deal with either the early diagnosis of autism spectrum disorder or its treatment. Specialist knowledge and experience in reprogramming severe autism sufferers to the point where they benefit from mainstream schooling is very limited.

The evidence from many submissions and from witnesses who appeared before the committee gives the clear impression that quality education for students with disabilities is a scarce commodity in schools generally…. A picture has emerged of students affected by disabilities taught in many cases by teachers unskilled or lacking in confidence in their ability to involve them in full curriculum, resulting in students performing less than their full capability….

The committee received much evidence of a serious and worsening skills shortage… That teachers are not always prepared for this experience and unskilled in methods which involve teaching across a wide spectrum of abilities…Of much greater concern is the unlikelihood of most teachers already in service receiving adequate professional development in this area'.

'The committee takes the view that effective professional development requires programs to be properly structured and sustained over a period of time, involving both theoretical material and active involvement in practical 'best practice' experiences. Quality professional development comes at a cost. If the outcomes of this training result in attitudinal change in regard to inclusive education, improved teaching methods and increased levels of pedagogical and technical skills, these costs will be justified'.

Part 2

In the light of the difficulties encountered by teachers in mainstream schools in dealing with students with an ASD, this section provides details of the vocational ASD specific teacher training courses, developed by the Autism Teaching Institute [cxl](ATI). The aim is to show how teachers in the course of study, are equipped with understanding of ASD and the specialised intervention strategies that have been proven to be effective with students with ASD. The efficacy of the course is illustrated by showing how such understanding could be applied to the situations described in the case studies previously considered.

As a preliminary I explain why vocational training was chosen rather than the higher education university studies. The ASD specific teacher training courses include a Vocational Graduate Certificate in Teaching Students with ASD and a longer Vocational Graduate Diploma of Teaching Students with ASD. This is the first time that Vocational courses have been delivered at post graduate level. The choice of vocational training rather than higher education university courses is based on:

-The heterogeneous nature of ASD autism (students need an individualised and specialised educational program tailored to their specific needs)

-The absence of a full theory of the disorder itself

-The fact that assessments in vocational education reflect the competencies of the job as closely as possible

-The teachers need for frequent application of skills and knowledge, with a number of students with ASD, in different situations and with others

- Recognition that progress through the stages of professional growth from novice to competency/expert performance may take many years of relevant experience

-The transformative goal of helping understanding of ASD at the level of individual teachers and also at the school and system level

- The experience of working with other schools as previously detailed in the student case studies and the exploratory research, that led WAS to believe that staff training in the form of 'one-off' consultations, classroom visits and in-service training, whilst helpful, needed to be supplemented by active involvement in practical 'best practice' experiences with expert peer coaching in a supervised practicum experience in a specialised school setting and sustained professional development and training in specialised techniques for instructing and managing students. There is ample evidence to support this view (Senate Report 2002, Meyer report 2002).

-An investigation of the university courses of study in ASD in Australia; (there are two higher education graduate certificates in ASD at universities in Canberra and South Australia (See Appendix 3 Autism specific training programs in Australia and the UK) revealed that universities provide only limited provision for hands-on supervised practicum in classrooms specific to ASD. Additionally, assessment of teacher competency in a vocational education context may differ from assessment in other settings. Assessment in these vocational courses is the application of combined theoretical study[cxli] and the WAS staff[cxlii] applying their professional judgement against endorsed course competencies

-Capturing tacit and expressed knowledge of teaching students with ASD (from staff at WAS).

Teacher Competencies

Owing to the choice of vocational training, competency based training courses have been created, and the Victorian Institute of Teaching has recognised the Graduate Diploma level course (taken over 2 years of part time study) as a specialised qualification for teachers of students with ASD in mainstream and specialist classrooms. The units of competency in the courses stemmed from a brainstorming activity of the job profile of a teacher of ASD (see Appendix 4) by experts in the field. Students enrol first in the Vocational Graduate Certificate in Teaching Students with ASD and in each semester complete 2 units of competency as outlined below.

The Vocational Graduate Certificate in Teaching Students with ASD is nested within the Vocational Graduate Diploma of Teaching Students with ASD

Autism Teaching Institute is a Registered Training Organisation (#21709)
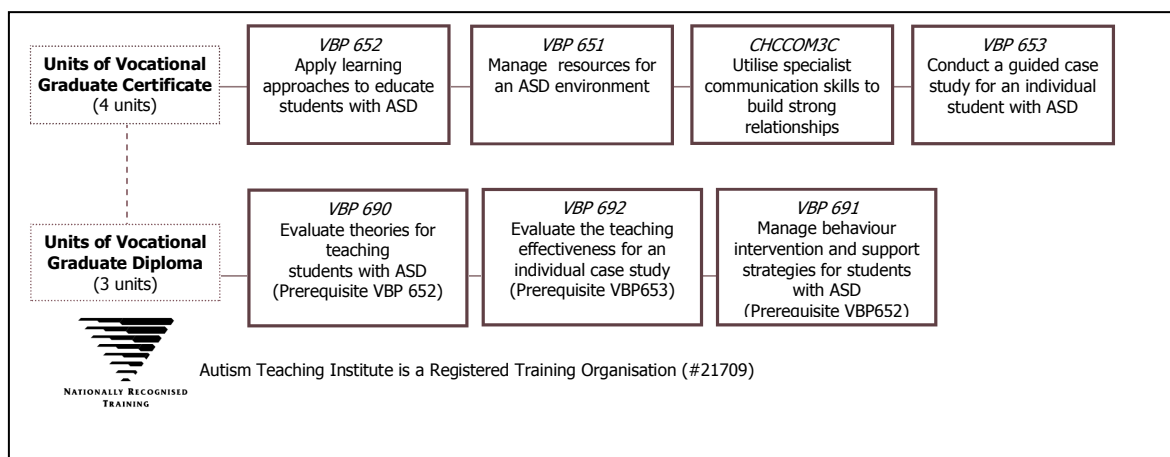
I have linked the case studies to just two of units of competency of the certificate level course (ie, *Apply Learning Approaches to Educate Students* with ASD and *Manage Resources for an ASD environment outlined in the table below*), in an attempt to show how the courses can be an effective way of assisting teachers to first understand ASD, and then how to teach students with ASD. The competencies referred to in the case studies are italicised and in bold.

Summary of Competency areas in the Vocational Graduate Certificate of Teaching Students with ASD

VBP651 Manage resources for an ASD environment	*VBP652 Apply learning approaches to educate students with ASD*	*VBP653 Conduct a guided case study for an individual student with ASD*	*CHCCOM3C Utilise specialist communication skills to build strong relationships*
Select and prioritise ASD specific teaching aides and tools *Apply visual tools (photos, Compic, Boardmaker etc)* *Structure the physical environment (suitable spaces, visual cues and prompts)* Sources (educational suppliers, websites etc) School / departmental policies and procedures Documentation (IEP, PSG minutes, school policies) Skill development programs (students) ASD specific professional development	*Assess communication and social/ emotional characteristics and needs of individual students* *Interpret ASD learning style and specific learning problems* Perception and Sensory processing characteristics recognised *Individualise the curriculum* *Modify communication and language* *Apply ASD specific strategies and structure* Sources (Speech Pathologists, OTs, readings/references) ASD specific PD	Clarify function and parameters of case study Convene multi-disciplinary team Document case study methodology Implement an intervention strategy Apply School/ departmental protocols Involve teaching staff and stakeholders Apply Teaching resources Evaluate relative effectiveness of intervention Evaluate outcomes of case study	Implement strategies to check effectiveness of communication with students and others Apply specific communication techniques to facilitate group discussion and assist in resolving conflict Specific mediation and other processes applied within organisational structure Sources (referrals) Professional development Evaluate communication strategies to promote ongoing participation of all parties Documentation

For example referring to the unit *Apply Learning Approaches to Educate Students with ASD*, the case studies reveal that teachers need to:

Modify communication and language *methods used with the student with ASD*

Jonathon's teacher used abstract, open ended language not knowing that he needed clear, unambiguous, concrete, logical and coherent information and instruction to make sense of lessons. For example, he needed verbal instructions to be supplemented with a written plan or schedule, to know what the purpose of the task was and that he certain time in which to complete it.

- *Explicitly teach communication and language skills and facilitate their use with others through* **ASD specific strategies and structures**

Zona's teacher was unaware that Zona needed modelling of alternative phrases to use with her peers, eg. rather than a verbatim medical dictionary description of the disease spread by coughing, to say to her peers "please cover your mouth when you cough- coughing spreads germs'. In addition to modelling alternative social responses for Zona to use with her peers, the teacher was unaware of the need to support Zona to apply the learnt phrases consistently. Jonathon's teacher did not know that his good vocabulary belied his pragmatic language difficulty, ie. to use language functionally to say 'I don't understand', 'I need help', 'I need a break", 'It's too noisy' etc. and that she needed to explicitly teach him to use language for a range of functions.

- **Interpret ASD learning style and specific learning problems** *including individual student's specific strengths and weaknesses with learning*

Jonathon's teacher did not know about the uneven skill profile characteristic of autism, eg. that he was unable to use his excellent memory for facts and information in a generalised way and apply the knowledge to different contexts, and that he relied on his obsessive interest with car racing to manage his anxiety with learning and group tasks. The teacher was also unaware of the positive effects on Zona's self esteem and place in the peer group if she were to nominate her as the 'Class Mentor 'for all science problems in the class.

In the unit *Manage Resources for an ASD environment* the teachers in the case studies needed to:

- **Structure the educational environment**

Jonathon's teacher didn't know how helpful it is to provide the student with ASD with a written schedule showing the beginning and end of a task and the steps in between, and to include a preferred activity at the end that he see to work toward; or that schedules help the student with ASD predict events/activities and to prepare the student for changes to the school day etc. The teacher didn't know that making a deal with Zona to have her complete set tasks at her desk, by using a visual task schedule that included at the end access to an activity she prefers, was an effective strategy.

Conclusion

With the increase in numbers of students with ASD in all school sectors and the adoption of inclusive educational policies, there is a growing demand for teachers who are able to meet the unique needs of such students. However, pre-service teacher training does not equip teachers with the skills needed to teach students with ASD. Western Autistic School, as a result of many years experience, has found ways of training teachers on –the- job and on the basis of that expertise is now, through the Autism Teaching Institute, trying to formalise and extend this process to make the training available generally. ASD specific training courses for teachers are being offered for the first time in Australia at the Autism Teaching Institute. Since this is the first year of instruction in these vocational courses (the diploma course is taken over 2 years) no definitive conclusions can yet be drawn as to their effectiveness. However, teachers undertaking the course already report that they have gained a greater understanding of the nature of ASD and the differential effects of ASD on students. There is evidence that with ongoing training, including supervised experiences with student with autism, coaching and feedback, teachers are growing in confidence that they can effectively teach students using ASD evidence based teaching strategies. As one teacher put it in a reflection exercise, "My better understanding of the underpinning issues and problems of ASD has already made me see behaviour and learning problems differently and clearer… I now know to put more emphasis on the foundations of communication, eg. to teach the child to take an object to a person to request something first and I understand that everything kids do before they talk falls into nonverbal pragmatics… and you have to focus on pragmatics before you can effectively work on speech itself". A different teacher reported that "The first semester of the Vocational Certificate has worked as a framework for reviewing, rethinking and adding to my knowledge and skills in teaching students and supporting people with ASD".

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AUTISM AND CAREERS REQUIRING EMPATHY: ARE THEY COMPATIBLE?

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Introduction & Background

"New research is suggesting that adults with Asperger Syndrome can achieve, maintain & succeed in a wide range of occupations" wrote Tony Attwood (1). Yet the 'caring professions' are barely mentioned in the growing literature on career and employment issues for individuals on the autism spectrum, not even in one of the longer lists of 62 suitable occupations, which its author states "may help you to brain stretch" (2, p240). May this paper help stimulate further 'brain stretch' …

My own interest in this topic began when, after two decades working successfully in my profession as a family doctor, I received a response from a professional body to disclosure of my own AS diagnosis. This response suggested I had made a poor career choice, since AS people have "difficulty understanding and identifying with the emotional reactions of human beings." At that time, I knew of no others with AS diagnoses working in medical or similar professions. However, in my subsequent exploring of the topic, I've now met personally, among colleagues, clients, and friends in the autism community, some 34 ACs trained or working in the caring professions, and have read accounts by a further 14. The experience of these 48, together with review of literature on autism and empathy, provides the substance of this paper, which could be regarded as (to adopt the theme of this Conference) 'a preliminary fieldtrip into unexplored territory'. I suspect there are many more out there somewhere: undiagnosed, diagnosed but not necessarily disclosing, perhaps unemployed or working in a job other than their chosen 'caring profession' career.

Terminology as used in this paper

Both *Autism* and *Autism spectrum (AS)* refer here to the whole autism spectrum, including Asperger's Syndrome (as do some quotes using the casual terms *Autie* or *Aspie*, which originally referred to those diagnosed Autism or Asperger's Syndrome respectively).

Autism community refers to the worldwide fellowship of autistic people, networking mainly by internet but also in real life. Some terms used within the autism community, and some passages in this paper, are *neurotypical (NT)* or the term coined by Roger Meyer *non-spectrum (NS),* both referring to *non-*autistic people; and *AC,* embracing both *autistic individuals* (those with a formal professional diagnosis anywhere on the autism spectrum) and *cousins* (those with autistic features but no formal diagnosis).'Cousins' may be *self-diagnosed peer-confirmed* (where their self-diagnosis has been validated by autistic adults).

Neurodiversity is an umbrella term encompassing conditions like autism and dyslexia, where the nervous system is considered atypical.

Caring professions refers here to health professionals (doctors, nurses, therapists); counselors and social workers; teaching professionals; and ministers of religion.

Autism: Relevant concepts and models

The current **biomedical model** of autism is controversial for a number of reasons, and may result in misdiagnosis, missed diagnosis, mis-understanding about the nature of autism, and therefore risk inappropriate advice, treatment and support. Major concerns include: Firstly, that it's a deficit pathology-based model, emphasizing apparent deficits while overlooking strengths, adaptive strategies etc. Secondly, that it's defined by behaviors, regardless of the underlying process: for instance whether a given behavior is a problem to be got rid of, or might be a compensatory strategy enabling that individual to function better than they would without it. Thirdly, that its emphasis on the so-called 'triad of impairments', risks overlooking other common problems like sensorimotor issues. Finally, that it's a categorical model for a multidimensional condition whose component features interact with one another, context, adaptations etc., all evolving over time.

Alternatives include the **sociological model**, which considers autism comprises differences that only become disability because of society's current response to them. From my own experience both personally living in the autism community, and clinically working with individuals of all ages and positions along the autism spectrum, I tend to agree with AC Phil Schwartz's appraisal (3, p148) that "the truth … lies between the extremes: There are both intrinsically disabling factors in autism, and aspects of atypical individuality that are disabling primarily because society devalues them or fails to accommodate them."

Literature from the field of diversity studies, gives clues about possible benefits to our world of such differences:

About diversity in general, Paul Grobstein writes (4)

"The biological process produces variants, as the only way to be prepared for unknown challenges, times when the environment changes in unpredictable ways. It's the variants that provide the basis for dealing with such challenges."

Thomas West (5), relating this to human culture, argues that neurodiversity has a 'deep survival value' for the human race, and that people with different ways of thinking may be needed for the complex problems ahead for society: "We

need many kinds of ability, and no individual can have all kinds. So we should encourage diversity not only to be civil, respectful, humane and just, but also because we have a particular stake in diversity that's [seldom acknowledged]: We want there to be people who have abilities we do not yet know we need, abilities we haven't even tried to measure. … The solution to our problem[may lie] with turning to someone who may be a bit unusual … someone who may not fit the traditional patterns of academic or career success. Sometimes the visual thinkers and 'dyslexic visionaries' may see things that others may not see. They may be ready to take actions that others, in their pride and arrogance, are not ready to take".

As autistic experience and ideas are increasingly heard, there's been a shift in perspective by some professionals: for example replacing 'deficit' and 'disorder' by '(qualitative) difference', and even suggesting (6) transforming 'the diagnostic criteria for Asperger's Disorder' into 'the discovery criteria for aspie', defined by (a triad of) strengths instead of a triad of deficits.

'The invisible end of the spectrum' (7) refers to those with so-called 'mild' or sub-clinical autism such as 'residual Asperger's Syndrome' (8 p26), who've adopted compensatory strategies so effective that their autism difficulties are easily overlooked, their autism 'invisible' to others (even some professionals). Issues these ACs face include unique dilemmas around disclosure, and the tendency for their AC oddities to be attributed by others to moral defects etc. Such 'invisibility' is common among adult, female and gifted ACs, those with comorbid conditions such as depression or anxiety, and seems likely also among ACs working in caring professions. In a benign environment and with good supports, such individuals may never be diagnosed, as Dinah Murray writes (9) "Many able people of Aspie disposition can find a welcoming niche in which they flourish. In those 'right circumstances', such people may never attract clinical attention because they do not fulfil the diagnostic criteria of social dysfunction. They may spend their lives on the right side of the official boundary because the circles in which they mix do not find them worryingly odd … [or] dysfunctional: a virtuous circle of success through confidence and confidence through success keeps them free from diagnosis-attracting calamities." But if circumstances suddenly change, such an individual may decompensate dramatically and their underlying AS become apparent. Referring to conditions at this 'invisible' end of the spectrum as 'mild' can be very misleading, as ACs & some professionals (10, 11 p27) have pointed out. Uta Frith suggests (10) that Asperger's Syndrome might better be regarded, not as "a very mild form of deficit" but as "compensatory learning in the presence of a severe deficit", a view with which many on the spectrum identify (though perhaps preferring the term difference to deficit).

Empathy and autism

What is empathy? Among both professionals and lay people, there is considerable variation and overlap in the use of terms like *empathy, sympathy,* and *compassion.* For the purposes of this paper I have adopted Dziobek & Rogers' (12) usage, where empathy "broadly refers to the reactions of one individual to the observed experiences of another person, and has two main components: *cognitive empathy*: the ability to engage in the cognitive process of adopting another person's perspective [involving *theory of mind / social cognition*] and *affective empathy*: the ability to experience emotional reactions to the observed experiences of others". Two facets of affective empathy are (12) "*empathic concern*: the tendency to experience feelings of sympathy and compassion for unfortunate others" and "*personal distress*: the tendency to experience distress and discomfort in response to extreme distress in others."

Most professional literature about autism, describes impairment of empathy as a core feature. 'Sufferers' are often depicted (12) as "cold, emotionless, and indifferent, [even] culminating in comparisons with psychopaths: '…it would appear that both Asperger syndrome and psychopathy … share some common characteristics, notably the total absence of human empathy …' (International Journal of Psychophysiology, 1998)." In stark contrast is the literature by AS individuals themselves, whose personal accounts portray rich unique inner lives, including the experience of feelings and empathy.

Research on empathic capacities in autism (for summaries see 12, 13, 14), though limited, does mostly suggest that autistics lack appropriate empathic response. Recently Dziobek & Rogers, in their study (12) designed to overcome shortcomings of previous research by separately measuring component skills and

using more naturalistic methods of assessment, found that subjects with Asperger Syndrome scored significantly lower than NT controls on cognitive empathy, significantly higher on personal distress, and equivalently on empathic concern. These researchers concluded, "Because individuals on the spectrum have problems in social cognition they appear to lack empathy. In reality they have as much empathic concern (the core aspect of empathy) as neurotypicals … Empathy is one of the most remarkable human characteristics and for the longest time autism has irresponsibly and mistakenly been depicted as an 'empathy disorder.' We would like to contribute … towards giving autistic individuals back the place on the empathic spectrum that they deserve."

Turning now to social cognition, which has been more extensively researched than empathy (12): Difficulty shown by autistic individuals in research does not necessarily mean inability to understand others' perspectives. For instance, according to Roeyers et al (14) "The available evidence suggests that able adults with PDD … clearly know that mental states exist and they seem to recognise that certain situations require them to obtain knowledge of the mental state of other people … [and] are, at least to some extent, able to 'infer' … these mental states." Nuyts and De Roeck (15) found '"that high-functioning adults with autism make normal use of mental states in one-to-one conversation". Roeyers et al called for studies to clarify whether autistic difficulties with social cognition are *"due to information-processing problems and / or, as suggested by Pierce et al (16) to an attentional problem caused by overarousal in complex social environments."*

Accounts by ACs support this idea, that apparent social cognition difficulty may indeed be due to slow processing, difficulty attending to more than one cue at a time, difficulty interpreting nonverbal / other social cues, etc; resulting in *differences or delays* in empathic understanding and response, problematic in some but by no means all situations. For instance:

> "It is difficult to analyse social encounters in a busy environment. Meeting people is more confusing than ever because I am less able to attach any meaning or to interpret what is going on correctly. Busyness makes me feel very unsure and my generally poor level of coping drops even more…. It can even be too great an effort to greet somebody, which complicates the situation even more." (17, pp32-3)

> "I develop great insights into people over time, but in the moment … It seems impossible to try to focus on my own thoughts or feelings and consider different thoughts or feelings in another person or persons at the same time especially if I am talking or actively listening to the other person talk. It takes time to process all the various components of a social interaction. I believe I spend huge amounts of time doing this, a lot of the time I spend alone goes into this." (18)

> "My slow way of apprehending people can … seem quite "penetrating" when NTs become aware of it … more a case of resonance than of penetration … They don't realise anything is happening in / with me because I am not reacting (positively) to all those ripples and they assume I am not sensitive to other people. Well, I am. But I am 'slowly' sensitive." (18)

The following ACs, all of whom work in the caring professions, go on to outline strategies they use in such situations, and how they acquire them:

> "I'm an intensely sensitive person. I'm just not always able to call up the appropriate emotion 'in the moment' without the opportunity to process it … [but have learnt that] knowing the acceptable diplomatic thing to say in the moment can be of immeasurable benefit even if one doesn't feel it just then." (19, p141)

> "Emotions are a sort of 'second' language to me. … having to 'read between the lines' confuses things. When this happens, I know that something is going on but I'm not sure what it is. I want to do something about it, but not only am I unsure of what to do, I don't know how to do it. As a result, too much energy goes into processing the situation and a shutdown occurs in the communication arena … I find it helpful if others can say exactly what they mean along with creating a feeling of safety and trust. … Some phrases that I keep in my response repertoire for these situations include "What can I do to make you feel better about this?" … While having an algorithm or method for handling these types of situation helps, it does not approach the facility others off the autism spectrum seem to have for these emotionally charged situations" (20, pp121-2)

> "Delayed reaction or temporal distortion seems to happen with my emotional reactions at times. This can be handy for keeping my cool in a disturbing situation but may create an impression of lack of empathy. If a chance arises to express my feelings a day or two later, it is often easier to do so then … I find it difficult to find the words to say to terminally ill patients and their families. I hope that giving my time, and my being there, has shown that I cared … Over time we can build a repertoire of suitable responses to help show we do care." (21)

"I am a great person to have around in the case of accidents and the like. I remain cool as a cucumber and am able to deal with everything quite effectively, because due to the visual stress, my emotions are suppressed and cannot get in the way." (22 pp9-42)

"All my social behaviours have been learnt, as I lack such insights myself…. What comes naturally to anyone else I need to capture intellectually and learn by heart. What anyone else fells intuitively I have to translate into rules, the way you try to understand maths. … The breakthrough came when I did a course in Educational Science … where social rules were discussed in great details … I developed techniques for dealing with feelings, for talking, for taking part in meetings … In order to deal with other people's feelings I need to put on my 'professional hat', otherwise I won't manage." (17, pp75-6):

Some professionals now acknowledge such AS capacities. As Glenys Jones writes (23) "We frequently read that those with autism … lack social empathy. … Perhaps because individuals with autism have to work out consciously and scientifically what is appropriate, they develop more insights than NTs who do not consciously have to pay such attention to this."

To what extent is the supposedly superior NS capacity to understand another's perspective, due to greater inherent capacity, and to what extent an illusion due to the greater ease with which anyone (NS or AS) understands someone similar to self? Some autistics thus question NS theory of mind (18) and empathy (24) as exemplified in NS-AS interactions. As Jim Sinclair writes (24) "When I am interacting with someone, that person's perspective is as foreign to me as mine is to the other person. But while I am aware of this difference and can make deliberate efforts to figure out how someone else is experiencing a situation, I generally find that other people do not notice the difference in perspectives and simply 'assume' that they understand my experience … If I know that I do not understand people and I devote all this energy and effort to figuring them out, do I have more or less empathy than people who not only do not understand me, but who do not even notice that they do not understand me?"

ACs working in caring professions

Given that some of us on the autism spectrum are already out there working in the caring professions, do we do an adequate job?

What gifts might we bring to such work?

How do we cope? What challenges & issues does this raise? The remainder of this paper will consider these questions. First, some more personal accounts to illustrate. Note that what we enjoy or excel at, goes beyond the usually-cited AS assets like being systematic or good at details!:

"I am convinced that in some respects my autism makes me an excellent care worker, leader and guide. … [via] clarity and structure [which] create feelings of safety and trust … I acknowledge them and let them believe in themselves… and always try to take them seriously. … [BUT] I have never really managed very well with colleagues. This is the reason why I keep changing my job or getting fired. Each time I got the same comments 'There are no problems with your work, but we don't know you, you're awkward, you're obstructing the team and your colleagues, nobody can get close to you, you don't anticipate, we have no idea what goes on in your mind.'" (17 pp78 & 102-3):

"Teaching elementary age school children was great fun because I so related to their naïve sense of wonder and joy in exploration and discovery of self-expression through art … but in the staffroom, I was as hopelessly inadequate as I had been during any other unstructured time in my own school career." (19 pp138-9)

"Teaching is a challenging job, especially for those of us with social and organizational issues, but it is worthwhile and interesting. For those with the inclination, I'd say go for it. After all, every failure is just another step on the road to success." (25 p81)

"Having had to acquire the [theory of mind] skill instead of being able to simply assume that I can use my own thoughts and thought processes as a model for those of other people is a huge advantage interacting with patients. … Another rather unexpected advantage of autism is better communication. … Social communications are difficult for us, because they often have as priority, not to explain something, but 'bonding' between conversational partners … In actually getting a message across NTs aren't very effective communicators. … So-called normal communication is just as defective as autistic communication. The mistakes made in 'normal' communication are simply so omnipresent that nobody notices them anymore. … I have often noticed how teachers do not listen to what students are really asking and consequently do not give an informative answer. After the lecture, I have to explain to my fellow students what the 'real' answer to their questions is. Most people don't really answer appropriately

to what has been said to them. They simply go off like alarm-bells in a completely predictable way, repeating old reaction patterns to perceived slights or attacks." (22 pp9-42)

Here are excerpts from a discussion about such careers by ACs (a teacher, a doctor, a chaplain, and an occupational therapist), as captured in "Women from another planet?" (26):

"Jean: Ava, you said something about your clients feeling listened to for the first time, then later on, something about your interest in knowing how it is that people like us, in the professions requiring lots of social contact, do it. I'd like to explore that as a thread, especially since so many of us here are in or aspiring to professions that involve people, something that on the surface seems unlikely.

Sue: … I actually empathize with the children I work with and advocate for them tooth and nail … sort of like fighting for the self that I didn't fight for. …

Ava: I've acquired the art of listening through years of listening listening listening because I couldn't participate in conversations. When one gives up trying to make oneself heard, it's more possible to focus on what the other person has to say … my difficulty with words means that firstly there are more silences, well silences can be therapeutic! For example enabling the other to suddenly say the most significant thing of all, something they maybe needed time and courage to voice that wouldn't have happened if I had plunged straight into a quick-fix answer. And the client seems to appreciate my putting time and thought into their problem, so has patience, knowing their problem is complex (attempts to solve it elsewhere having failed) and they really do want an accurate answer, unlike in social life. Secondly, even when there aren't silences, I generally get the client talking and say as little as possible myself, which elicits a fuller more accurate story than firing questions does …

Jean: My students say I'm excellent at conducting discussions on sensitive topics in such a way that they feel free to open up because they're in a safe setting. And I can be diplomatic about a lot of things in settings that aren't threatening. This is a consequence, though, of an awful lot of thinking and deliberate learning campaigns on my part.

MM: My work with persons with Alzheimer's disease is like coming home. They are people who also have a neurological difference. They are blunt and honest, no longer hiding behind cultural norms. … They don't expect greetings, they live in their own world, they are discriminated against as they lose their ability to speak. Where I have a problem is having to report and attempt to explain to NT administrators. It is an uphill climb that frustrates me to no end. I get very tired of the dehumanisation of people with dementia. Most people ask them the wrong questions, and treat them like a little child instead of the adult that they are. So they're going to get angry. I am a good chaplain because cultural norms are dropped during this time. NTs fall apart and don't know what to do. It is an area in which instinctively I do well and shine. …

Jean: I hear from my students that I do it well, and I know that my particular way is much more inclusive than that of some teachers. Because I have no capacity to put people in social categories, I take what students say seriously."

An in-depth example: AS 'GP's (general practitioners / family doctors)

An AS colleague & I, each with over 30 years' GP experience, compiled some lists from our own experience, feedback from patients, and a BMJ article by a third (anonymous) "doctor with the full-blown syndrome" (27). As there are entire books on strategies autistic people use for coping with life in general, and the workplace in particular, our main emphasis here was on specific ways we apply AS strengths and strategies in our medical work, a topic not covered elsewhere.

AS features that enhance the 'art and science of medicine' (21, 27):

Many of the 26 listed 'aspie criteria' (6) apply: for instance, taking one criterion from each of the 'triad', "listening without continual judgment or assumption"; "determination to seek the truth"; and "unique perspective in problem solving".

Cognitive features like different styles of thinking (spatial, non-linear etc (26)), along with other traits, may contribute to finding novel solutions to problems.

As for communication and social style, there may be advantages in both *innate* features (like 'that slight reserve which makes a good GP': being caring & interested but a little removed?; staying objective, focusing on content, with emotions switched off or 'on back-burner'; not biased by issues of status / 'liking' / 'being like' patient, etc) and *learnt* ones such as the ability to translate between perspectives (e.g. NS vs. AS); and being good listeners (using prompts to elicit story, pauses / silences & what may come out of those, being careful & precise e.g. "What do you mean by that?" instead of assumptions).

The above, together with a 'passion for patient care'; alertness to anxiety; thoroughness; excellent memory (for patients' lives, families, details of illnesses); taking patients seriously; awareness things can go wrong, are not always as they seem, and that it's our job to find a solution; may result in our spending more time reassuring patients, being

less dismissive of those 'minor' complaints worrying for the patient or not in the textbooks, 'going a further mile' in listening & investigating so uncovering a diagnosis earlier than might otherwise have occurred, and overall determination 'to get it right' for the patient, in diagnosis and treatment.

AS strategies to cope with challenges of medical work (21,27)

Features making *doctor-patient interactions* easier than other social encounters include their short duration, one-on-one, clear purpose and structured format / script (doctor elicits problems, then discusses possible solutions). The process is enjoyable (the diagnostic 'detective-work', and / or translating between perspectives), as is even the social experience itself! (compensating for our limited abilities & satisfaction in more complex social interactions?)

Interactions with colleagues and staff are more problematic: We may relate better not to our medical colleagues but to those in other roles, like receptionists or cleaners.

In general, for us, managing career and the rest of life go hand in hand, and involve finding a balance between relaxed acceptance & anxious self-monitoring. Other general strategies, & specific ones for organisation & planning, communication, and sensorimotor issues are important but lengthy: details of these & more, available from author on request.

AS careers in caring professions: Broader issues

The following apply to other AS careers as well, but in the caring professions they have their own particular nuances. For these issues, there are no simple strategies or solutions:

Diagnosis and disclosure ('Recognition and acknowledgment')

With a positive model, 'insider' insights and what I call 'enlightened knowledge and support' throughout assessment & adjustment,

the

process of discovering one is autistic, whether by formal professional diagnosis, or 'self-diagnosed peer-confirmed' within the autism community, is an important key to making sense of one's life. As

Jane Meyerding puts it (28) "Instead of failing to succeed at what you're not, you can start learning how to succeed at what you are."

 There are many ideas about how to do this, brainstormed within the autism community via Internet & real-life support groups, and books *by* adults on the spectrum.

For those in 'caring profession' careers, obtaining an official diagnosis may not be easy though, needing a diagnostician well versed in the subtleties and paradoxes at this end of the spectrum (7). Those with formal AS diagnoses are likely to have been diagnosed late, and though on the one hand this may have meant years of distress and confusion, on the other hand, while the deficit model and its assumptions prevail, perhaps earlier diagnosis might have barred us from these very careers we find so fulfilling? As Dominique Dumortier writes (17 pp 92-3) "I am glad that I wasn't diagnosed until much later… While I may not have had a lot of understanding or the right support, I did get many chances. … as they didn't know about it I was able to go into mainstream education and then on to study Educational Science … which I probably wouldn't have … if they had known about my autism. The course helped to turn me into the kind of person I am now."

After diagnosis comes the question of disclosure to others, an issue especially tricky at this 'invisible end of the spectrum' and in careers like these. Though disclosing the diagnosis 'should' result in better understanding and support, in reality it is commonly met with negative responses such as disbelief ('But you don't seem any different to anyone else, we all have times like that') or loss of credibility, as a teacher who disclosed her diagnosis relates (29) "I did the wrong thing by telling a so-called trusted colleague I had autism. After being praised for years for how well I did my job by parents and colleagues, I wasn't thought capable anymore so I was pushed out in a tactful way. Colleagues, family and friends didn't want to visit or communicate any more. So please keep AS hidden if you want to have a professional and happy life!" Even Liane Holliday Willey, regarded as one of the most confident and experienced at talking about her diagnosis in a positive informative way, writes (30)

No amount of self-confidence can keep away all the risks intrinsic to telling others about AS … [or] stop others from reacting in ways that might make our lives more difficult.… People who hear I'm Aspie are still wont to look at me differently, either pitying me or worrying that ultimately I'm not up for the task at hand. … Sometimes I even find people alter the way they speak to me, using slower speech or simple terms, as if my AS means I am stupid, dense or deaf. No matter how many good facts you tell when disclosing your AS, there will be others who fail to hear the good stuff, so unnatural is it for them to understand that neurological differences do not mean unable … you will run the risk of others having reservations and doubts about your abilities and maybe even your personality on the whole…. For me, the risks are worth taking, but I have a very big group of supporters who make me whole no matter how much society tires to chop me up.

There are many issues to consider, well outlined in recent literature such as the book 'Coming out Asperger' which encompasses many viewpoints and situations. As editor Dinah Murray writes (9) "Disclosure of an autism spectrum diagnosis means disclosure of the fundamentally flawed personhood implied by the diagnostic criteria. It is likely to precipitate a negative judgment of capacity involving permanent loss of credibility." On the other hand, she suggests, were we to transform *diagnosis* into *recognition*, and *disclosure* into *acknowledgement*, a completely different outcome might ensue!

In the current climate, it probably behoves ACs to postpone *full disclosure* till very confident and secure about themselves, work & workplace, diagnosis, and the issues involved. *Partial disclosure* can, however, be a good compromise: disclosing only the issue relevant to the particular situation, for instance *central auditory processing disorder* to explain why information need to be written, or *prosopagnosia* (difficulty recognizing faces) to explain that ignoring colleagues met away from the usual context (work) is a neurological issue not snobbery. As one survey respondent explains (31) "I choose not to [disclose] because of the inevitability of being treated as a 'Case'. Instead, I'm slowly opening up about my individual AS traits, without giving them a label, so that people can treat me as a 'person who is over focused and can't develop routines and has a really quirky way of looking at some things' etc., rather than 'autistic.'" Such partial disclosure can be well combined with requesting *accommodations* to help one work better. While sensory issues may be easily accepted and accommodated, the social ones are more difficult for those at the 'invisible end of the spectrum' to be convincing about, even though accommodating these may benefit others too: the whole workplace, or even society at large.. As Stephen Shore (32) suggests "It may be appropriate to say 'I work best if people are very direct with me instead of trying to mince words on a subject they might think would be upsetting to me.' In short: … clear direct communication makes for better understanding all round [for everyone]."

Once ACs do feel confident & secure, ideally with the support of *mentors, allies (3)* and if necessary *advocates,* disclosure can be of far-reaching benefit. As expressed by ACs Jane Meyerding (31) "When we do come out autistic at work, we can try to do it not only for our own advantage (or survival), but also as part of a broader current of social change, a 'neurodiversity movement' that will pave the way for other autistics to have a smoother ride as they enter the workplaces we have pried a little bit wider open" and Phil Schwartz (3) "[The social-model approach would] … advocate acceptance of our aesthetic sensibilities, cognitive patterns, emotional responses and socialization preferences as diversity issues – establishing neurological diversity as a legitimate dimension of diversity alongside religious, ethnic, racial, gender and physical-ability diversity in mainstream society."

That might require society to re-examine its definitions of 'normality' and 'social acceptability', as Dinah Murray points out (33): "The route towards social acceptability by current standards is a route towards disguise, concealment and presentation … [which] places the highest value on presentation skills. … We might see that being the sort of person who attracts an ASD diagnosis is likely to mean having an honourable and scrupulous disposition and a concern for 'getting it right' which includes a concern for truth and may confer tremendous capacity for work."

Fatigue

Social fatigue in the workplace is common for ACs, compounded by sensory and executive function issues in and beyond the workplace. Managing work plus life becomes a major challenge, as Jane Meyerding outlines (31) "Given how much interaction is required by most jobs, it can feel as if we are working two jobs simultaneously. We need to do our work but we also must expend huge amounts of energy on generating and maintaining a social interface. That's why I've been working par-time most of my life. If I try to work a full-time job, I need to spend the rest of my waking hours recuperating. Literally. … It wasn't so bad when my mother was alive; she provided a lot of support with what the therapists call 'activities of daily living.' Food, cleaning, planning … Unfortunately being employed part-time usually eliminates all access to supplemental income … [and] publicly funded support. The theory seems to be that either you are disabled and need both financial and practical support, or you can work and therefore need / deserve nothing. For many employed autistics, the result of that dichotomy is steadily accumulating stress, which, sooner or later, spills over into the job …".

This is echoed by ACs working in the caring professions:

> "I work part-time because I need a sizeable proportion of the week to 'reload'. … work itself [is not] a problem, but having to be around other people is very tiring for me." ((22 pp 9-42)

" My brain gets tired, especially when I've had to talk a lot, rather than just listen. To cope with this 'brain drain' I try to relax when possible, such as for a minute or two between patients, and to keep my arousal level around 5. And work part-time, in short bursts. When I did work all day, I needed a long lunch break at home to lie down." (21)

Social aspects of the workplace

As per accounts quoted earlier, fathoming 'workplace politics', and coping with unstructured time like tea breaks, are more difficult for ACs than relating to clients: It can seem that 'fitting' socially while doing a mediocre job (neither too good nor too bad), are the criteria for success, whereas the AS combination of social 'mis-fit' with high work ethics is a 'recipe for disaster'. ACs are easy targets for bullying and more subtle forms of sabotage (2, 25, 31). Whatever the career, these social problems do vary from worksite to worksite, depending on attitudes etc. of 'boss' & co-workers (25), and may be more prevalent when autism is 'invisible' (7). In a survey of 30 autistic people concerning work issues (31) the three most common AS-related reasons for being fired were 'lack of ability to network or socialize with co-workers', 'not liked by co-workers or supervisor', and 'seen as weird or odd'. Such discrimination, as well as the increasing emphasis (2, 25, 31) on team skills and interpersonal communication in all jobs, even IT, are also barriers when seeking a job, as survey participants detailed:

"It seems that NTs are only interested in people's personalities. They don't care about what you can actually do. Since to them I look like a nut or a zombie, they wont hire me; they judge me because of my slightly off body language." (31)

"Now on job applications, they all put 'must have interpersonal skills, must be able to work as part of a team' … It discriminates against auties, but what can we do? If the job description said 'must not be blind' or 'must be able to walk' there would be an outcry as that would be against people with those disabilities. But when it comes to AS, I do not think any companies understand." (31)

Jane Meyerding (31) compares this challenge to that 30 years ago when women were seeking access to full participation in the workplace, on their own terms rather than by being expected to "act like men (e.g. adopt stereotypically 'male' communication styles) … We need an analogous cultural change … a chance to demonstrate how relaxing the boundaries of what is considered 'normal' will benefit everyone…when society becomes able to integrate more of the marginalized into greater participation."

In fact, ACs *are* capable of excellent teamwork and interpersonal skills, in our own style, as shown by communication and collaboration within the autism community (34).

Unemployment, under-employment & their effects:

It's been estimated that among ACs who want to work and are able to, overall 90% are unemployed or under-employed (25). Just how common this is among ACs qualified in the 'caring professions', is unknown, but some tragic examples are documented (22 pp 81-4, 29, 35). For instance David Andrews describes (35) his 'bleak future as an Aspie psychologist', feeling that his diagnosis is regarded by NT professionals and public as invalidating his abilities, knowledge and hard-won qualifications.

Fitness for such work

This issue of fitness is likely to be viewed differently, according to which lens one examines it under: Through the 'biomedical deficit' lens, anyone 'diagnosed' as having Asperger or Autistic 'disorder', may be assumed inherently and permanently lacking empathy etc. Yet through the 'sociological' lens, 'discovering' & accommodating those with positive 'aspie' traits, may reveal plentiful empathy etc.

Tony Attwood (36) describes four adjustment strategies that an AS individual may adopt from an early age, upon realising they are 'different': 'imitation', 'reactive depression', 'escape into imagination', and 'denial & arrogance'. It is those adopting the last strategy, who may pose a risk in the caring professions, if unwilling to accept and learn from their differences. However, denial and arrogance as human defences are, I believe, equally prevalent among NTs. Moreover, care is needed not to falsely assume 'arrogance' in an autistic merely because of mannerisms like pedantic speech, literal insistence on rules, difficulty recognising faces etc. Perhaps whether or not an individual copes by denial & arrogance, comes down to other aspects of our common humanity. How much do we want (whether AS or NS) to learn about our strengths and weaknesses, about how to use our strengths to help compensate for our weaknesses? Once aware of the existence of other perspectives (which may indeed happen later for someone on the autism spectrum), how willingly do we (whether AS or NS) apply this in our interactions? What choices do

we make (whether AS or NS), as free human beings: to act in a safe or unsafe, responsible or irresponsible, moral or immoral, manner towards our fellow human beings? I suspect that most of us on the spectrum, who end up in careers such as these, chose our paths for humanitarian reasons, and have worked hard to understand ourselves and our fellow humans.

Summary: What hinders & helps AS 'caring profession' careers

Common barriers include

1. biomedical deficit model of autism, with associated myths & prejudices

2. AS-unfriendly social environment (worksite, boss, 'workplace politics')

3. AC's arrogance & denial (of own autism & associated issues)

4. limited knowledge about ACs in such careers → limited careers advice / support

5. 'one size fits all' emphasis on teamwork & interpersonal skills

6. 'all-or-nothing' approach to full-time work / help with ADL (activities of daily living)

7. naive disclosure

8. intolerance of difference

In contrast, key factors for success include

1. positive model of autism e.g. sociological

2. AS-friendly social environment (worksite, boss, 'workplace politics')

3. AC's insight into own strengths & weaknesses & how to work with these; self-recognition of autism (with or without official diagnosis)

4. knowledge & supports: from AS peers (strategies, culture, support, ongoing learning) and well-informed mentors, allies, advocates, careers advisors

5. creative inclusive approach to teamwork, interpersonal skills, adaptability

6. support for part-time work & / or help with ADL

7. care around disclosure: partial (initially) with essential accommodations: to protect self; full (when confident & secure) : for societal benefit

8. acceptance and celebration of neurodiversity

Conclusion

The ideas and personal accounts presented in this paper, suggest that with insight, and opportunity to work from autistic strengths and style, autistics are fully capable of empathy, compassion, responsible wise problem-solving, and of mastering, even excelling at, careers requiring these capacities: not only in the 'caring professions', but in all occupations where empathy is essential, including parenting. Further professional and societal shifts are needed, but ultimately a more creative inclusive attitude in these and all vocational niches, is likely to benefit human culture as a whole.

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0027

SELF-DETERMINATION AS A GUIDING CONCEPT IN PEDAGOGICAL INTERVENTIONS FOR PERSONS WITH AUTISM

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Introduction

One day a father of an adult man with high functioning autism called me. He was quite worried about his son and he thought that his son was leading a very dull life. The son lives by himself in a small town. He has no real job, no friends, and no contact with his neighbors. He is engaged in one big interest, that takes all his time. All this according to the story the father told me.

- What can I do to make his life worth living? the father asked me.

- Have you talked to him about your concerns?

- No, but it is obvious that he lacks quality of life.

Later on the father talked to his son about his worries, and the son was quite surprised. He is happy and satisfied with his life, and he lives that kind of life he actually wants to live.

It is quite common that some concepts central to quality of life implicitly are part of intervention programs for persons with disabilities, but it is far from very common that these concepts are included as explicit core concepts used for guiding thoughts of suitable interventions (Brown & Brown, 2003). Self-determination is one of these central concepts. Today only a few intervention programs for persons on the autism spectrum take their starting point in the individual with autism and his or her values. I will in this paper argue that self-determination is important to take into consideration when planning a pedagogical intervention for a person on the autism spectrum. It is time to put focus on the individual and the question how he or she can be supported to reach his or her highest degree of quality of life. To reach this goal, the practitioners have to pass over power to the individual with autism and see him or her as a partner and to start working in collaboration with the person involved. The individual with autism has to be given tools to be able making decisions for himself. It is, however, time for a change in how autism is conceived of as well. Without a deep understanding of autism and how this condition influences the whole personality, an intervention program risks to become a technique and by that, missing the goal of high quality of life.

Quality of life for persons on the autism spectrum

There is a growing consensus regarding the definition of quality of life for persons with intellectual disabilities and how to assess and apply it in practice (Schalock et al., 2002, Schalock, 2004). One important step towards this consensus was made in 1996, when Schalock first published a list of eight core domains: (1) emotional well-being, (2) interpersonal relations, (3) material well-being, (4) personal development, (5) physical well-being, (6) self-determination, (7) inclusion, and (8) rights. Since then, each of these domains has been more precisely defined by identification of the most common indicators (Schalock, 2004). In this literature review Schalock found that the most frequent mentioned indicators for self-determination are (1) autonomy/personal control/independence, (2) goals/personal values, and (3) choices.

Much work is still to be done before it is possible to reach a consensus regarding quality of life for persons on the autism spectrum. In this paper I will often use data and conclusions from research on quality of life for persons with intellectual disabilities. That is, it is not sure that these conclusions are valid for persons with both intellectual disabilities and autism. However, my most important goal in this paper is not scientific validity, but to start a discussion on self-determination as a guiding concept in intervention programs for persons on the autism spectrum with intellectual disabilities.

To assess what is meant to be assessed

It seems obvious that quality of life assessments have to include both subjective and objective components. It is not enough merely to look at how often a person with autism has the possibility to make choices, or how independent he is in everyday life. Just as important is to assess how satisfied he is with his own life or how he perceives his own well-being. However, a subjective definition of quality of life for persons with intellectual disabilities is far from unproblematic (see Hatton, 1998, for a review). A discrepancy between subjective and objective measures of quality of life is not uncommon. For example, persons with intellectual disabilities generally tend to report higher levels of subjective quality of life than

can be shown by objective measurements. One possible explanation is that persons with intellectual disabilities often have low expectations on the services they attend (Hatton, 1998).

One of the problems with only using subjective measurements of quality of life for persons with intellectual disabilities is how to know what is actually assessed (Hatton, 1998). In an interview, for instance expectations, experiences, and linguistic skills might influence the answer in the wrong direction. I will go back to my example with the worried father to show how this can happen. It emphasizes how important it is to incorporate knowledge of autism in the interpretation of the answers.

It is easy to understand the worries the father had. From an outside point of view it in fact sounds like a monotonous and boring life. The father was relieved, but there are arguments for calling the answer into question. I am sure that the son is not lying, but arguments built on knowledge about autism suggest that there can be reasons for believing that he is not able to grasp the whole question.

According to Kanner (1943, 1971) a major feature of the "autistic disturbance" is what he called *insistence on sameness*. He reported that many of the children in his original study got upset when their routines were disrupted. Kanner claimed that insistence on sameness seemed to be closely related to other behaviors, such as repetitive behaviors, rigidity, narrow-mindedness, and perfectionism. Today the insistence on sameness in well known to (almost) every practitioner, and adherence to rituals and routines is part of the diagnostic criteria in DSM IV (American Psychiatric Association, 1994). It is listed under the heading of restricted patterns of behaviors, interests and activities, including restrictions in both actions and thoughts.

Restrictions in behaviors and thoughts are a strong argument for questioning the reliability of the answer the father got. Insistence on sameness is almost always seen as something negative, that the person with autism is literally *restricted* by his or her routines. But many persons with high-functioning autism or Asperger syndrome refer to rules, routines and sameness as something positive, something that makes everyday life easier. Susanne Schäfer (1996), a German woman with high-functioning autism, writes that she always appreciates what she calls a well-planned day, that is, a day that follows the usual routine, but that she can stand a break in her routines – if the break is predictable. Obviously, for many persons on the autism spectrum routines make sense in a chaotic world.

Closely associated with insistence on sameness is the fact that children with autism (and I suppose it is not too presumptuous to extend it to also include adults with autism) explore the world to a lesser extent than typically developing children (Pierce & Courchesne, 2001). Consequently, children with autism have fewer experiences than other children in general, and therefore lose many opportunities to learn and develop skills and interests. In this case it means that the son perhaps has no or only one positive experience of alternative ways of living.

To increase the personal control

In his review of indicators for self-determination Schalock (2004) puts autonomy, personal control and independence under the same heading. That is, control over one's own life is not only defined as being able make decisions, but also being able to do things as independently as possible. That is, practitioners have both to pass over power to the individuals with autism, and offer guidance to improve the independence.

The son of the worried father is highly verbal and has no problem formulating his thoughts. So in this particular case it was quite simple to get a reliable answer. But most persons with both autism and intellectual disabilities have great difficulties expressing themselves, and even worse, they are seldom given an opportunity to take part in the big or small decisions involving their own future (Sheppard-Jones et al., 2005). Generally, practitioners tend to not let persons with disabilities participate either in the discussions or the decisions.

> Many professionals find it difficult to pass control to their clients or patients. Sometimes this is because they assume that people with disabilities whom they support are unable to exercise control. (Brown & Brown, 2003, s. 227)

In many cases this is an illusion. Persons with autism and intellectual disabilities can take a much larger part in these decisions. It is, rather than a question of ability, a pedagogical question. So there have to be other reasons as well. Brown and Brown continue:

> Unfortunately, it is sometimes thought easier for the care worker to take over entirely. (…) They feel comfortable when they are directing, organizing and practicing what they believe in and what they are trained to do. Thus, a move toward client empowerment requires a change in their philosophical and practical approach, and this poses an ethical dilemma for many professionals when it conflicts with the historical approach of their own profession. (s. 228)

Talking to practitioners, they often express a wish to give the persons with autism in their care a life as good and meaningful as possible. That is, most practitioners have good intentions and they absolutely do try to give each individual a full support to reach his or her highest degree of quality of life. In practice, however, this is not always the case. The problem is not only the ethical dilemma Brown and Brown describe. There are other problems as well. As David Gray (1997) has pointed out, the practitioners have to be aware not only of their own personal values and the values of their profession, but also of the values built into their organization. These values can, for example, be found in the goals, as well as the means and the methods in their pedagogical intervention program.

It is quite common that practitioners try to make us believe, or perhaps even believe it themselves, that their intervention program is the only *right* or *true* way to support a person with autism. The concept of evidence-based intervention has indeed become very fashionable, and by that, is often misused. There are at least two common mistakes in the use this concept. In the first place, the concept of evidence-based intervention sometimes is mistaken to mean a successful intervention for every person with autism. Therefore, we can hear advocates of different programs asserting that their program is evidence-based and by that the only intervention that allows every person with autism to make sure progress. In the second place, evidence-based is seen to be replaceable with entirely based on scientific findings. However, I would contend that it is beyond doubt that all pedagogical interventions for persons with autism include values. That is, there is nothing like a purely evidence-based intervention. Facing these facts, some practitioners seem to give up any scientific framework. Instead, they find a solution in the rule "anything goes". From their perspective, treatment is a matter of finding what works at a particular moment with an individual with autism. Advocates of different intervention programs, they say, tend to lose sight of the individual. It all end as a competition between ideas or methods.

Making values in interventions explicit

It is no solution to let go – anything does not go. Woodbridge and Fulford (2004), writing on values-based practice in mental health care, make a strong point of the need for bringing together research evidence and values. With a starting point in a definition of evidence-based medicine (Sackett et al., 2000, cited in Woodbridge and Fulford), they elaborate a practice built on (1) the best research evidence, (2) clinical expertise, and (3) client values. Translated into the field of autism, clinical expertise could be defined as the ability in the everyday practice to use clinical skills and experiences to identify each individual's strengths and weaknesses, the risks and benefits of potential interventions for that particular individual, and his or her personal values and expectations. This means, that a practitioner has to take the implicit values of the intervention program as well as the values of the individual with autism into consideration before implementing a pedagogical goal.

The values in an intervention program can be found both on a global level and on an individual level. Both of these have to be explicit if the intervention is going to succeed.

The global level: the definition of autism

The global level deals with the values incorporated in for example the diagnostic criteria and the key concepts of autism. David Smukler (2005) objects to the way autism is described. In everyday language, he writes, autism often is a very negative word ("an individual *suffers from* autism; autism *strikes*; autism is *cruel*"), but even scientific descriptions of autism contain a number of negative values. Autism is often explained or defined in contrast with so called normal functioning. That is, autism is seen as a lapse from the normal or as a lack of specific qualities. Consequently, autism is described in negative formulations, for example *abnormalities, strange and puzzling behaviors,* and *impairment*. According to Smukler, it is time for alternative narratives about autism.

> Incorporating autistic voices into representations of autism offers an important counterbalance to professional limitations by challenging us to interpret autism as a form of human variation instead of human insufficiency. (Smukler, 2005, s. 22)

This alternative narrative is already present. Many "inside autism reports" give a quite different perspective on autism compared with the traditional scientific image of autism. These accounts often put focus on the different perception, how hypo- and hypersensibility to stimuli have lead to big difficulties in the everyday life and in social interactions. These first person accounts have lead to new scientific perspectives. Infant studies have pointed out not only hypo- and hypersensibility to stimuli among infants that later are diagnosed as having autism, but also difficulties in orienting attention to social and nonsocial stimuli, and motor impairments (e.g. Teitelbaum et al., 1998, Kern et al., 2006, Björne, forthcoming). That is, persons with autism do not necessarily lack in sensorimotor experiences. Rather, their experiences are different (Bogdashina, 2003).

In focusing on different – not deficient – sensory experiences, the first person accounts implicitly give firm guidance for intervention programs. Sensory experiences, attention, and motor skills are central in all

learning and influence all experiences of the world. If an infant has different experiences in these areas, this will affect the whole development. With different sensory experiences, a different way of attending and a different way of moving and using the body, the cognitive abilities will develop in a qualitatively different manner. Jim Sinclair, who has autism, describes this in a very illuminating way.

> Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. (Sinclair, 1993)

An intervention program has to take these first person accounts into consideration when the goals are defined. If persons with autism have a totally different cognition, a lot more than learning style has to be adapted.

The individual level: normalization

Many intervention programs for persons on the autism spectrum have normalization as an unexpressed or unconscious goal, in the sense that they define a successful intervention as an intervention leading to a decreasing amount of so called autistic behaviors. Autistic behaviors seem to be something negative per se, which has to be minimized or, at least, controlled. That is, success is not defined from the individual's point of view. It doesn't matter what the individual himself thinks about the behavior, if it is subjectively experienced as restricting or not.

There is an agreement among researchers that each individual values the core domains differently, and that the values vary in each individual during a lifetime (Wehmeyer & Schalock, 2001). That is, the unique interests, values and experiences of an individual will inevitably influence his or her opinion of what is needed for reaching satisfaction with life. Although an adaptive behavior is a strong predictor of individual quality of life for persons with intellectual disabilities, it is not the sole predictor and, even more important, not related to satisfaction with life (Kraemer et al., 2003). The intention to give persons with autism possibilities to participate in the society is often good, but it is usually adapted to neither the qualitatively different cognition in autism, nor the preferences of the individual. Many intervention programs try to adapt the persons with autism and teach them to act normally, rather than trying to adapt the society and make the society accessible to everyone. Therefore, in many cases we have to call the goals of these intervention programs in question.

In Woodbridge and Fulford's (2004) values-based practice it is essential to know *whose* values the intervention reflects. In every decision the values of the person with autism have to be taken into account. This is in accordance with the second indicator for self-determination: personal values and goals (Schalock, 2004). However, to take the values of the individual into consideration is not enough.

> Decisions should be made in partnership between those directly concerned, not by outside 'experts'. (Woodbridge & Fulford, 2004, s. 29)

The key is to work in collaboration as equal partners. According to Woodbridge and Fulford it is important to involve not only the individual in the decisions, but also for example his or her family and the staff who take part in the person's everyday life. Often the practitioners have to step into a new role, from the role of the expert prescribing solutions, to the role of a partner taking the values and priorities of the individual with autism as a starting point of the discussion. It is important to stress that the family or the practitioners cannot replace the person on the autism spectrum in the decisions. Even if the family would make the same decisions as the person himself, it would not be the same from the perspective of quality of life. Self-determination is an important tool to increase the quality of life for persons with intellectual disabilities in the sense that there is a correlation between high self-determination and a high subjective satisfaction with life. (Wehmeyer & Schwartz, 1998, Schalock et al., 2005, Lachapelle et al., 2005).

Obviously there are limits to how large part a person with autism and severe intellectual disability or a child with autism can take in life decisions. In these cases the family often has the best knowledge of the person's preferences and how the person perceives his well-being, even when the person has moved to a group home (Schwartz & Rabinovitz, 2003). Therefore the family often is the best advocate for their relative with autism. The ability, however, to make choices is not to be underestimated. Lohrmann-O'Rourke and Browder (1998) have in a literature review shown that persons with severe intellectual disabilities have individually unique and distinct preferences and, worth noting, that there are strong arguments for scientifically valid ways to assess the preferences and that these methods are more reliably than proxy measures. Lohrmann-O'Rourke and Browder stress that third party opinions may not always yield valid results. Today there is an emerging consensus "that individuals with intellectual disabilities should be involved directly in the measurement of their quality of life, and that proxies be used only if absolutely necessary because of significant communication limitations" (Verdugo et al., 2005, s. 710).

Complementary guiding concepts

Taking self-determination for persons on the autism spectrum seriously implies more than building the intervention on the individual's values and increasing his or her personal control and possibility to make choices. I will, in the remainder of this paper, discuss some complementary guiding concepts in intervention programs for persons on the autism spectrum with intellectual disabilities. These guiding concepts are not to be mistaken for pedagogical guidelines, such as modifying the environmental setting, giving predictability, or teaching functional skills. The concepts I focus on in this paper are concerned with more basic guidelines. Each of these complementary concepts, as well as self-determination, can be seen as a necessary means for the individual to reach the highest possible degree of quality of life. But none of them alone is sufficient. First taken together they have the power to make a difference.

The first complementary concept is holism. Any action or intervention will inevitably influence more than one area of functioning and therefore it is not possible to intervene with only a single part of the individual. Therefore, an intervention program has to take a holistic perspective. Holism is not only including areas of functioning, but also implies a lifelong perspective. The importance of taking a lifelong perspective when working with persons on the autism spectrum cannot be overestimated. By starting to plan for an independent adulthood already in the preschool years and try to hold on to that plan (if it still appropriate and with suitable adjustments) the child will have better possibilities as an adult. A lifelong perspective helps the collaborating team around the child to stick to the main goals and teach the child functional skills, that is, skills that are as necessary and useful in the daily life for the child as for the adult. Without a lifelong perspective it is far too easy to teach the child behaviors that are adequate or cute given the child's age, while it will be perceived as inappropriate later. This often means that the child has to learn a new behavior a few years later. For example, many signs for going to the toilet, which are proper for the young child, can be offensive or even indecent when it used by an adult. This process also includes the unlearning of the old behavior, and this is far more complicated than simply learning a new one. A lifelong perspective is as important in adulthood as in childhood. The adult on the autism spectrum has the same need for a lifelong perspective as the child.

Having self-determination as a guiding concept presupposes an individual perspective. This is the second complementary concept. Individuals with autism differ from each other. Although they all have the core characteristics of autism in common, these characteristics are manifested in a wide range of ways and the manifestations usually change within a person several times during life. However, it is not only the manifestations of autism that make persons on the autism spectrum differ from each other. Their unique values, interests, family situations and experiences differ as well. What is seen as meaningful for one person is not necessarily meaningful for another. That is, quality of life has to be defined individually and therefore the intervention programs will differ from one person to another. Or, in Szatmari's words

> The key was not to expect Frankie and Heather to follow the standard curriculum or the usual parenting guidelines, but for adults to first adapt to the child's way of thinking and *then* move the child along his or her own developmental pathway. (Szatmari, 2004, s. 173)

To be able to adapt to the individual's way of thinking, the practitioners have to have a solid knowledge of autism and how this condition affects the individual. Building the intervention on solid knowledge of autism is the third of the complementary concepts. It is time to move away from the view that autism is a deficit and towards a view of autism as a qualitatively different cognition. Sinclair (1998) argues that practitioners have to support autistic people (Sinclair prefers the term *autistic* to *person with autism*) in living as autistic people. That is, autism is an indistinguishable and inseparable part of the person and therefore persons with autism have to learn to live *with* their autism. The argument can be put this way: If we accept that autism has a biological cause, a cause that leads to a different way of perceiving the world, we have to take that argument seriously and draw the right conclusions: a different perception leads to a different cognition, and that leads to different values. If we accept this conclusion, we have to meet persons with autism as we meet persons from other cultures – with respect for their values, their way of thinking, and their way of living. To meet somebody with respect does not mean that one part has the privilege to set the rules. Respect is a matter of bridging a gap between cultures, to compromise, and to view persons on the autism spectrum as autonomous individuals. We, who belong to the non-autistic culture, have a responsibility to facilitate for persons with autism to live in and take part of the community, to make the community accessible to every citizen. Respect implies that practitioners have to pass over power and start to collaborate as equal partners. Respect also implies that the intervention has to emanate from the individual and his or her personal values.

Conclusion

In this paper I have argued for the need to include self-determination as a guiding concept in pedagogical interventions for persons on the autism spectrum with intellectual disabilities. It is time to put focus on the individual and the question how he or she can be supported to reach his or her highest degree of quality of life. To reach this goal, practitioners have to pass over power to the individual with autism and see him or

her as a partner and to start working in collaboration. Persons with autism have to be given pedagogical tools, advice, and input from others, so that they can make informed choices and take control over big and small decisions concerning their own lives. To be successful, the intervention has to include important indicators of self-determination such as personal control, personal values, and choices, complemented by a holistic view, and solid knowledge of autism.

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PREPARING STUDENTS WITH AUTISM SPECTRUM DISORDER FOR WORK: A SCHOOL TO WORK TRAINING PROGRAM AND THE IMPORTANCE OF RELATIONSHIPS

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Transition practices

Transitions are significant times in our journey through life. Supporting young people to make a successful transition from school to post school life can be a time of high anxiety for both the young person and their parents/carers especially when the young person has a disability/ies. "To cope with frustrations, varying perspectives, and to obtain desired outcomes, individuals with disabilities and their families should be encouraged to play central roles in the transition process" (Nisbet et. al., 1992; Stineman et. al., 1993, cited in Rusch & Chadsey, 1998, p. 242).

Over recent years there has been an increasing emphasis on designing and delivering varied and flexible academic, cultural and vocational education and training programs in schools. The latest report from the Dusseldorp Skills Forum on "How Young People are Faring Key Indicators 2004" gives a broad overview of the current experiences of young Australians and the ways in which these experiences have changed in recent years. All states in Australia are seeking to improve overall educational outcomes that are vital to better transitions. They have introduced key curriculum innovations designed to improve retention, learning and the link between school and work. The report also recognises the personal and social benefits associated with higher levels of education and the costs of a poor transition from school to work. "Failure to make a satisfactory transition from initial education to employment or further education can be costly for the individual and society and subtract from any improved outcomes achieved in initial education" (Dusseldorp Skills Forum, 2004, p. 37).

The South Australian Government's Strategic Plan has six objectives, three of which focus on improving wellbeing, building communities and expanding opportunities. The South Australian Youth Engagement Strategy, a collaborative cross-agency program, has been set up to further these objectives and to assist young people access quality learning opportunities that are most appropriate to their aspirations and needs. One of the aims of the Strategy is to strengthen effective transitions to further education, training or employment.

The Department of Education and Children's Services Statement of Directions 2005-2010 highlights learner wellbeing and engagement as goals for educators: "Staff in all sites … play an important role in fostering engagement and wellbeing so that each child and student is able to achieve their best and enjoy their educational experience" (p. 8). In line with South Australian State Government and Department of Education and Children's Service's (DECS) initiatives to address student engagement and wellbeing, the profile of transition education has been raised considerably. There is an expectation that all students, including those with disabilities, will develop enterprise skills and attributes and have an awareness of how their communities work.

More recently the DECS *Futures Connect* initiative, which aims to increase the partnerships between schools, training providers, industry and youth service agencies, is maximising the educational and vocational choices available to students by ensuring they have access to a broad range of education pathways particularly in the senior years. Schools have a responsibility for the development of individualised transition plans for all students, to the integration of careers development activities into their curriculum as part of the development of transition or 'exit' plans, and to the provision of access to relevant curriculum in the senior years which reflects the life aspirations of the students.

In our society many young people with disabilities are vulnerable to long term unemployment and associated health and security deterioration. Whilst students with disabilities have access to vocational training programs and work related experiences within their schools or community, the students' success in obtaining meaningful post school options has been limited.

The People with a Disability Training and Employment South Australia (Department of Further Education, Employment, Science and Technology, 2006) report notes that in comparison to people without reported disabilities, people with a disability tend to have lower levels of income, schooling, qualifications and employment status. The disadvantage in the labour force is reflected in lower levels of participation, higher incidence of part-time work and higher unemployment.

There is a lack of research literature in Australia and overseas relevant to the topic of transition from school to adult life for students with disabilities. Kohler & Chapman (1999) conducted an extensive

literature review of documents published between 1990 and 1997 relating to the topic of transition from school to adult life with emphasis on practices directed toward positive outcomes for students with disabilities. They initially identified 106 candidate documents but after rigorous screening in relation to research-oriented criteria, chose to review only 20 of these.

Kohler & Chapman (1999) concluded that the authors of these documents "have demonstrated a wealth of creativity in the form of conceptualizing factors that may be related to positive transition outcomes and the development of ideas for interventions" (p 30). However, they also reported that many of the projects described in these documents lacked details about specific interventions and practices and the evaluation processes of the programs were often poorly designed and controlled. Thus the ability to generalise findings is limited and may "serve as a barrier to the development of new knowledge about effective transition-related practices" (p 33).

Longitudinal studies in Australia and overseas have confirmed this limited post school success for students with disabilities. Australian researchers Burrows, Ford & Bottroff (2001) have cited many studies (Goode, Rutter & Howlin, 1994; Howlin, Mawhood & Rutter, 2000; Kobayashi, Murata & Yoshinaga, 1992; Ruble & Dalrymple, 1996; Szatmari, Bartolucci, Bremmer, Bond & Rich, 1989; Venter, Lord & Schopler, 1992). These studies have suggested that, despite potential to work, students with autism spectrum disorder are infrequently employed in integrated community settings, often attend sheltered workshops and/or specialised day activity, or residential services. They are socially inactive and reside at home with their family. Those who do find regular employment are frequently in low status occupations, which often have limited tenure.

Literature on exemplary transition practices consistently touts the critical importance of career guidance and counselling services in assisting young people with disabilities (and their families) in making short term and long term plans which lead to meaningful employment outcomes (e.g. Rusch & Chadsey, 1998; Wehman, 1996, cited in Burrows et. al. 2001). Furthermore, a number of follow-up studies have indicated that successful employment in integrated community settings is positively correlated with an effective transition planning process that incorporates opportunities for students to work in non-sheltered adult environments during the school years (e.g. Brown et. al., 1984; Hasazi, Johnson, Hasazi, Gordon & Hull, 1989, cited in Burrows et. al., 2001).

The School to Work Training Program

In 2001 a forum existed in a region of outer metropolitan Adelaide known as the Adelaide Hills. The forum linked secondary school based personnel who worked with students with disabilities, with personnel from relevant services and agencies within the Adelaide Hills region, that provided support to students with disabilities in their transition from school to work. Although a separate entity, the forum was part of the broader regional community partnership, which was funded to broker a range of transition activities and programs for all students and to harness the resources of agencies, volunteers and the education and training sector in delivering those activities and programs.

Members of the Post Compulsory Forum for Students with Disabilities in the Adelaide Hills (FSDAH), the forum's official title, discussed the need for some students with disabilities, in particular a group with autism spectrum disorder, to be able to access school to work training which was specifically tailored to meet their needs.

A key group of members of FSDAH brokered the establishment of a school to work training program for the identified group of students and in 2002 a School to Work Training Program for eight secondary students with autism spectrum disorder in the Adelaide Hills district was implemented. Although it was initiated by FSDAH, it was a collaborative program between DECS, Autism SA, the students' schools and their parents/carers. The Forum members and the DECS' *Futures Connect* Coordinator had input into the development of the program and supported the access to some funding from the broader regional community partnership.

In the report on the outcomes of the initial year of the program it was recommended that funding be sought from DECS to operate the program for the next two years. This was forthcoming and the program enabled six of the eight students from 2002 and two other students to complete further modules of the tertiary qualification, the TAFE[1] Certificate 1 in Employment Skills Training and a

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1 TAFE - Technical and Further Education. Government owned and operated tertiary technical training institutions providing a range of vocational education courses from Certificate to Degree level.

South Australian Certificate of Education (SACE) unit[2]. 2004 was envisaged to be the final year of the program for this group of students and would provide the opportunity for the students to complete the prerequisites for Certificate 1 in Employment Skills Training.

A major component of the Certificate, namely the work placement component of 60 – 80 hours needed to be completed in the final year. The viability of outsourcing delivery of the remaining modules including work placements and support was investigated. Discussions occurred between DECS, FSDAH, Autism SA, FWS Employment Services (a disability employment agency), the students' schools and their parents/carers. It was expected that six students would participate in the course and that four would complete their Certificate 1 in Employment Skills Training. An agreement was reached between FSDAH (on behalf of DECS) and FWS Employment Services for this to happen.

The students' school records were accessed to ascertain the modules still needing to be completed and any additional modules completed within the school curriculum, that is, not as part of this program. Completion of modules and skills practice occurred at FWS Employment Services training room, on a fortnightly basis over ten weeks. The other two students, who only participated in the course for the first time in 2003, completed any remaining modules within their school curriculum.

Program goals

Goals for the program, the students, and the students' schools were identified.

For the program:

- to bring the group of students together on a regular basis at a neutral venue to address specific needs in relation to accessing relevant post school options.

For the students:

- to participate in a structured small group learning environment with explicit teaching of social, self-management, coping, daily living and personal care skills

- to have opportunities to develop and practise work readiness skills

- to increase their knowledge and ability to access realistic and relevant post school options.

For the schools:

- to increase the ability of staff to provide appropriate curriculum and methodology for students with autism spectrum disorder with a focus on meeting the post school transition needs of these students

- *to foster positive relationships between the students, their parents/carers and their schools.*

Key considerations in implementing the program

Students

Many adolescent students with autism spectrum disorder experience high levels of anxiety about various aspects of their lives including self-esteem, motivation, relationships with adults and peers, school and post school options. (Davies, 2005). These students are more prone to develop depression and/or patterns of school refusal which is concerning for the student, school staff and parents/carers. (Eaves, Ho & Eaves, 1994, cited in le Roux, Graham & Carrington, 1998). It was important for the program to engage student interest and motivation and guarantee student success.

Students with disabilities and students with autism spectrum disorder often face barriers to participation in training and employment because that are not aware of the opportunities available or perceive too many barriers to pursuing post school options. This program endeavoured to link the students with a range of post school options and to give them the confidence and skills to access future opportunities.

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2 SACE - South Australian Certificate of Education. Post compulsory schooling is for the most part, prescribed by the requirements of the South Australian Certificate of Education (SACE). All students, including those with disabilities, have the right to participate in a program of studies that is described within the SACE framework.

Schools

Meeting the academic, social and training needs of the diverse student population is an ongoing challenge in all schools. It is also in the secondary school years that behaviour issues arise or increase for some students with autism spectrum disorder. Another important aspect of this program was to provide professional learning opportunities for personnel working with the students in their schools so that their knowledge and skills increased and that opportunities for the students to generalize skills learned in the program to other settings was increased.

In order to meet accountability requirements the curriculum offered each year in the program (modules from TAFE Certificate 1 in Employment Skills Training) was accredited within the existing South Australian curriculum framework

Parents/Carers

Transition from school to adulthood can be a complex, stressful time for individuals with disabilities and their families. Families must negotiate the effects of changing role relationships with their children; changing security for daily care from known, mandated school services to unknown, diverse and perhaps difficult-to-access adult services; and changing patterns of family living and interactions. (Hanley-Maxwell, Mayfield Pogoloff & Whitney-Thomas, 1998, cited in Rusch & Chadsey, 1998).

Research has consistently suggested that there is a need to develop collaborative family-school relationships in transition planning and that family participation in the transition process is crucial to the success of the individual with a disability. (Brotherson et. al. 1986; Everson & McNulty, 1992; Nisbet et. al. 1992; Jamison, 1993, cited in Rusch & Chadsey, 1998). With this in mind, members of the Forum who initiated this program ensured that the families of the students were involved in the planning, ongoing delivery and evaluation of the program. Information sessions were held each year before the program commenced, families were encouraged to visit the program while it was operating, program staff provided written and verbal feedback throughout the course of the program and families participated in the graduation ceremonies held at the end of each year.

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Criteria for inclusion in the program

There were four criteria for student inclusion: (1) enrolled years 7 – 12, (2) in a mainstream class, (3) had an identified autism spectrum disorder and (4) met additional risk criteria (attendance at risk, school placement at risk, student/family well being at risk, transition to work likely to be an issue, additional support allocated).

With these criteria, Table 1 shows the distribution of students by year level, gender and impairment for 2002-2004.

Table 1. Student Profile 2002 – 2004 by year level, gender and impairment

Year Level	Male	Impairment	Female	Impairment
7			1	C
8	1	C		
9	1	C		
10	2	C – 2	1	I, C
11	2	I, C –1; P - 1		
Total 2002	6		2	
8	1	C	1	C
9	1	C	1	C
10	2	C-2		
11	2	C-1; I, C -1	1	I, C

12	1	I		
Total 2003	7		3	
9	1	C	1	C
10			1	C
11				
12	3	I-1; C-1; I, C-1		
Total 2004	4		2	

Key: C – communication language impairment, I – intellectual impairment; as used in the DECS Students with Disabilities Eligibility Criteria

Venue

In order to facilitate connections between training, school curricula and the workplace, it was decided to operate the program at a non-school venue. "Educational services are only truly effective if they produce benefits in other settings and with other people. To increase the student's ability to generalize skills outside the classroom, it is important the teaching occur in a variety of settings" (Jefferson & Putman, 2002, p. 76). In 2002 and 2003, the Adelaide Hills district tertiary education TAFE facility was used in an effort to empower the students to believe in their ability to be successful in managing personal, work and community opportunities. In 2004, the FWS Employment Services training room was the venue and the students were also placed at suitable worksites with appropriate support. "Students with disabilities are often all too aware of what they cannot do, and often are not as aware of their unique strengths and abilities" Wehmeyer, 2002, p. 3).

Personnel

In 2002, 0.3 teacher time was provided by DECS and 6 hours support time was provided by Autism SA. In 2003, this was increased to 0.4 teacher time and 12 hours support time. The program staff, therefore, had sufficient time to liaise with and provide training and development for the relevant staff from the students' schools. This liaison was important to facilitate the integration of the program content and methodologies with school curriculum content and to consider issues within the school. The extra time was also used to facilitate increased involvement, ownership and responsibility by relevant staff from the students' schools. In 2004, the FWS Employment Services trainer and work placement support staff facilitated the program; Autism SA provided support time for the five days that the program operated at the FWS Employment Services training room.

Structure of the day

The students' day was structured to provide opportunities for success within a supportive environment and to take into account what is known about the learning characteristics of students with autism spectrum disorder. Marcus, Garfinkle & Wolery (2001, cited in Roberts, 2004) suggest that effective programs utilize the following intervention strategies: clarifying meaningful information, organisation and scheduling, teaching across settings and people, active directed instruction, individualization of teaching materials and curriculum, provision of visual supports and using strengths and interests to help with areas requiring development.

When they arrived at ~ 9.30am the students were able to mingle and chat with one another and the adults, and make themselves a drink and have something to eat. The atmosphere was relaxed and welcoming. When the adults sensed that the students were calm the students come together for more formal learning. They were initially given details of the day's program and expectations, and had input into how best these expectations could be achieved. The timing of a 15-minute morning tea break was also negotiated. The students were continually encouraged to take an active role in planning and to take responsibility for their learning and behaviour.

Throughout the day the adults interacted with the students in a respectful manner, accommodated their specific needs and negotiated the achievement of formal work to meet the accreditation requirements of the program. The students were also encouraged to recognize when their anxiety levels were rising and to take 'time out' in ways that had been mutually negotiated and were appropriate to workplace protocols.

At lunchtime (~1 hour) the students and adults walked to the local shops and purchased their lunch. This was a valuable part of the day as it enabled the students to practise life (money) skills, and it also

facilitated the development of friendships. The day ended at 2.30pm. This was necessary to allow the required time for the students to return to their schools so that they could access their usual transport home: some of the students had to use the school bus.

Program content

McDonnell, Mathot-Buckner & Ferguson (1996, cited in Stuart & Smith, 2002) emphasized the need for an "effective and rigorous employment-training program that would identify the skills students [with disabilities] would need to participate successfully in the post school employment setting. Students need

- work experience and work-related behaviours,

- work interests and preferences, and

- supports necessary to ensure success in employment settings" (p. 235).

Table 2 shows the details of the program content. Emphasis was placed on developing the students' knowledge, skills and understanding of workplace requirements within an accredited curriculum framework.

Table 2.

Content of the program and changes in program, 2002-2204

Focused on developing social and interpersonal skills

- Workbook modules from TAFE Certificate 1 in Employment Skills Training

- Social skills support material from Autism SA

Module Topics 2002

    Social Skills

    Workplace Interaction

    Practical Money Skills / Personal Income

    OHSW – Safety Signs and Information

    Personal Presentation

    Keyboarding First Stage

    Resumes and Portfolios

    WAT (Workability Assessment Tool) and WARE (Workability Assessment Individual Report) forms (Centrelink – Disability Employment Indicator)

Module Topics 2003

    Job Interviews

    Managing Time in the Workplace

    Personal Income

    Planning Future Directions

    Rights and Responsibilities in the Workplace

    Working and Training in a Group

Module Topics 2004

Work Ethics: Rights and Responsibilities in the Workplace

In 2004 the six students also undertook a five day supported work placement. The students, with the support of their parents, negotiated the type of workplace with the FWS employment Services trainer and placement officer. Individual student needs determined the amount and frequency of support provided in the workplace. As part of their participation in the 2004 program the students were registered with the job placement agency and had access to ongoing support to obtain employment.Each year guest speakers from various organisations eg Flinders University of South Australia and Centrelink[3] spoke to the students about topics such as post school options, community support organisations and relationship skills.

Program results and evaluation

Each year all students completed the modules in the workbook and therefore obtained one SACE unit. The four students who participated in the program for the three years also completed the requirements to obtain the TAFE Certificate 1 in Employment Skills Training. The results of the program were further analysed in relation to the expected outcomes for students and schools.

Quantitative and qualitative data was collected pre and post program from the students, their parents/carers and school representatives. The tools used included questionnaires, Likert scale surveys, interviews and observations. The assessment criteria for each module also provided valuable information to inform the evaluation process. The rigor of the evaluation process impacts on the ability to make conclusions about the outcomes being met. Due to a major organizational restructure and a series of personnel changes, and the subsequent loss of data, it is not possible to provide an in depth evaluation of the program over the three years in which it operated. However, information from 2002 was available and is used to give some insight into the effectiveness of the program.

Students

Outcome 1: Improved abilities in the areas of social, self-management, coping, daily living and personal care skills

During the first session the students discussed why they were participating in the program and what they hoped to learn. There were four common themes in their responses: to develop social skills and work related skills, to improve communication skills and to be away from their home school environment. Towards the end of the program the students completed two feedback/evaluation proformas (refer to Appendices 1 and 2). The pre and post program information provided by the students gave some qualitative indication of improved abilities in the skills outlined. However, the evaluation tools and processes used were insufficient to empirically support the achievement of this outcome.

Outcome 2: Improved ability to cope and participate in school routines, the school learning environment and attendance at school on a regular basis

The Teacher Evaluation proforma (refer to Appendix 3) was expected to provide qualitative data that could be used to evaluate this outcome. Despite repeated requests, three schools did not provide either pre or post program information. Of the five students for whom information was available, teachers identified the following areas of concern pre program – social interactions, tolerance of change and independent work skills. At the conclusion of the program teachers were asked to comment on any changes observed in the areas of concern. This information was sought during the last two weeks of the year and possibly impacted on the number of responses received. Two teachers provided post program information and noted that the students showed an increased ability to self-regulate their behaviour and reported some instances of the students showing an awareness of another person's perspective. Student attendance data was obtained from the schools' files and indicated a decrease in the students' absences for both illness and unexplained absences in the semester that the program operated compared to the other semester in the year. This decrease ranged from 8% to 25%.

Outcome3: Development of work readiness skills

All of the students completed the workbook modules that were adapted from the TAFE Certificate 1 in Employment Skills Training. This gives some indication of the development of work readiness skills but only the four students who participated in the 5 day work placement in 2004 were able to show generalization of these skills to a real workplace situation.

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3 Centrelink – Australian Government social welfare agency.

Outcome 4: Increased awareness of realistic post school options

The students' responses to questioning by the program staff about what they learned from guest speakers provided some information that can be used to evaluate this outcome. All of the students commented on what they think they might like to do when they leave school. Two of the students specifically mentioned that they now see tertiary education as an option.

Outcome 5: Development of local community networks

During the second half of the program three students began emailing one another on a social basis and met one another on the weekend on two occasions at one another's places. Their parents reported that their child had previously sought to develop friendships but this was not successful. The parents were pleased that their child had initiated this kind of social interaction. The students' knowledge of community support agencies was increased by the participation of the guest speakers in the program; two students independently accessed a support agency within four weeks of listening to an agency representative.

Outcome 6: Experience in a tertiary learning environment

All students attended all of the sessions with the exception of one student on one day who was ill. It is interesting to note that those students, whose schools had a 'student free' day during The Adelaide Show Week, chose to attend the program even though they were given the option of not doing so.

Outcome 7: Increased sense of self-esteem

Anecdotal observations and qualitative information from the program staff and support personnel, the students' teachers and their parents noted the following as examples of the students' increased self-esteem – more erect body posture, talking positively about the future and willingly participating in group discussions and activities. Two of the students commented on their feeling better about themselves on their feedback proforma.

Outcome 8: Increased capacity to manage change

Because of the less than rigorous evaluation process, information about the achievement of this outcome was not readily available. Anecdotal evidence for two students does indicate their increased capacity to manage change. One student became very reluctant to participate in the program two days before it was due to start. He expressed concerns about not knowing anyone at the program and the transport arrangements. A familiar support worker was made available to accompany this student to the first two sessions and she talked through the transport arrangements the day before with the student. After five weeks the student was going to the program without support and did not show any anxiety about the changing transport arrangements. Another student coped well with his mother's one-month absence – his family and school staff had been concerned that this would negatively impact on the student's stress levels and could result in increased outbursts of anger. This did not occur and his teachers reported increased on task behaviours and improved assessment grades.

Outcome 9: To achieve SACE unit(s)

All students completed the modules in the workbook and achieved one SACE unit.

Outcome 10: To achieve modules towards the TAFE Certificate 1 in Employment Skills Training

All students completed the modules in the workbook, which form part of the TAFE Certificate 1 in Employment Skills Training.

Schools

Outcome 1: Relevant staff from the students' schools will participate in training and development opportunities on the site of the proposed program

At least one teacher and/or support worker from each of the students' schools visited the program on at least one occasion. They were able to observe the strategies used by the program staff when working with the students and participated in discussions with the program staff about how these strategies could be used in the students' schools. Another benefit of these visits was for the school staff to see the students successfully participating in a learning program and interacting appropriately with adults and peers. Senior Staff members from three of the schools also visited the program. All of them reported positively on the program. There was an 'open door' policy for the parents, support services personnel and school personnel. Two of the students' parents spent some time with the students and staff. This 'open door' policy worked well despite the fact that individuals with autism spectrum disorder often have difficulty coping with changes in routine.

Outcome 2: Staff confidence in managing the student within the local school is improved

As previously noted, teacher evaluation post program was received only from two teachers. This may have been due to the infrequent interaction between the program staff and relevant staff from the students' schools. Because the students were off site their home school teachers may not have felt a sense of involvement and ownership in relation to the program. A more formal program of interaction between the program staff and relevant school personnel would need to be established in a future program. Because of the lack of reliable and valid data, it is not possible to conclusively state that this outcome was achieved. One of the teachers did comment on her increased confidence in managing the student's outbursts and of feeling more relaxed when working with the student in a counselling role.

Outcome 3: Staff skills in implementing strategies, approaches and/or curriculum modifications especially in post school transition planning for the students is improved

Because of the reasons mentioned above, it is not possible to state that this outcome was achieved. Two of the staff who visited the program took note of the modules in the students' workbooks and undertook to incorporate further modules from Certificate 1 in Employment Skills Training in the students' curriculum.

Outcome 4: Staff knowledge of options and agency support available for the students is increased

The program staff gave explicit information about the guest speakers and other agencies to staff who visited the program. It is not possible to report on the use of this information by school staff.

Outcome 5 Improved relationships between the school and carers

Specific information about the relationship between the school and carers post program was not sought. One of the students in the program had been having great difficulty at school and the parent/school relationship was poor. On two occasions staff from Autism SA reported that this parent and two other parents had spoken favourably about their child's participation in the program. However, it is not possible to conclude that this translated into improved relationships with their child's school.

Issues

The effectiveness and sustainability of transition programs similar to that described in this paper has been questioned in research (Rusch, Kohler & Hughes, 1992; Rusch, Kohler & Rubin, 1994, cited in Kohler & Chapman, 1999). Short-term positive effects were identified but the evaluation data and methods were unable to provide "details about specific effective ways of implementing educational experiences that are associated with long-term outcomes" as suggested by Kohler & Chapman (1999, p. 32). Objective measurement instruments need to be used to reliably inform sound evaluation practices so that replication of successful programs can be supported. These evaluation practices also need to be extended over longer periods of time to ascertain the efficacy of instructional components and practices in transition programs. Robust data is needed to measure post school outcomes achieved by young people with disabilities in relation to employment, independent living, social and recreation, and community participation.

Since this program operated mechanisms have been put in place to facilitate the tracking of post school outcomes for students with disabilities in the South Australian public education system. Preliminary discussions are also occurring with other education sectors, relevant agencies, business, labour and community groups about the need for strategic planning for collaborative service delivery and funding of transition programs for young people with disabilities. The impact of special, time-limited funding on transition-related education and services needs to be addressed so that the sustainability of effective programs and practices is supported.

Conclusion

This program enabled a group of students with autism spectrum disorder to experience some success in their education. This is evidenced by the achievement of SACE units, and partial or full completion of TAFE Certificate 1 in Employment Skills Training. It was based on an expectation of success and high achievement and the philosophy that all students have a right to a relevant post school pathway.

The collaborative partnerships between students' schools, their parents/carers, DECS and non-DECS support services, Autism SA and agency personnel were a crucial factor in the ongoing operation of the program and the achievement of positive student learning outcomes. Those involved in the program developed action plans with agreed outcomes and used their problem solving, negotiation and management skills to ensure that the program's goals were achieved. When required, they encouraged, enthused and supported one another to improve the achievement and wellbeing of the students and all involved in the program.

The sustainability of programs such as this relies on the ongoing commitment of personnel from a diversity of groups and on funding arrangements. Given that *Making Connections: Improved Collaboration and Coordination Between Government Agencies and With Industry Partners* and *Building Community Capacity* are currently two of DECS' Strategic Directions, there is impetus to establish and/or extend programs such as this one. Improved educational and employment pathways for all young people supports the social and economic sustainability of local communities and reinforces the importance of schools to their communities.

The challenge is for education systems to plan and deliver effective transition to post school options services for all young people, including those with autism spectrum disorder, that address individual needs. The young person must be the focus of, and participate in, transition planning. By working collaboratively teachers, parents/carers and others involved in transition planning can facilitate access to the services the young person needs rather than be constrained by the services available.

Acknowledgements

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APPENDIX 1

Concentration Level	0	5	10

Self	
Peer	
Peer	
Adult	

Application Level	0	5	10
Self			
Peer			
Peer			
Adult			

Task Completion	0	5	10
Self			
Peer			
Peer			
Adult			

Social Engagement	0	5	10
Self			
Peer			
Peer			
Adult			

Empathy for Others	0	5	10
Self			
Peer			
Peer			
Adult			

APPENDIX 2

STUDENT EVALUATION

	0	5	10
Social Skill Integration			

Comment

	0	5	10
Relevance of Program			

Comment

	0	5	10
Value of Program			

Comment

APPENDIX 3

TEACHER EVALUATION

As part of the evaluation of the School to Work Training Program for Students with Autism Spectrum Disorder would you please identify areas of concern that impact on _____ ability to effectively access the curriculum and participate at school. At the conclusion of the Program you will be asked to comment on any changes observed in these areas.

Pre Program
➢

Post Program
➢

0029

THE DEVELOPMENT OF SOCIAL FIRMS TO SUPPORT THE EMPLOYMENT OF PEOPLE WITH AUTISM SPECTRUM DISORDERS IN SCOTLAND

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1. Background

A recent partnership between a group of autism specific service providers, led by Autism Initiatives UK, has resulted in the development of a Social Firms initiative for the benefit of people with ASD throughout Scotland. This multi-agency unconstituted partnership was set up via the Steering Group of Number 6 (The One Stop Shop for adults with Asperger Syndrome and High Functioning Autism in Lothians) as a result of the growing need to respond to the employment ambitions of adults with Autism Spectrum Disorders (ASD) in unique and diverse ways.

A series of meetings took place between the partner agencies and advice was sought from Social Firms Scotland and current Social Firm providers. It quickly became apparent that there was no shortage of ideas for the development of Social Firm businesses but what the ASD service provider group lacked was the business and commercial experience and background to progress these business ideas. Consequently the partnership agreed the desirability of a coordinated approach to the development of Social Firms for people with ASD in Scotland via the appointment of a Social Firms Coordinator and agreed that Autism Initiatives UK should take the role of lead agency in this project.

All the partner agencies in the project have an interest in the development of Social Firms for people with autism:

IntoWork:

IntoWork provides support to people with ASD to access and maintain employment in Lothians. IntoWork manages an emerging Social Firm, (Bits and Bobs, a craft material recycling project) and sees the development of Social Firms opportunities as a natural extension to the range of employment support opportunities they provide.

The Scottish Society for Autism

The SSA are a major service provider in Scotland and currently provide a number of day opportunities throughout central Scotland including a Craft Workshop, Café and Horticultural units which have the potential to develop into Social Firms and offer their current service users opportunities for real employment.

National Autistic Society:

The NAS provide a range of supports and services through the UK. In the West of Scotland they currently run the Prospects employment support scheme which enables people with ASD to access and maintain open employment. The NAS sees the development of Social Firms as an excellent opportunity to extend employment options for people with ASD and have had preliminary discussions regarding the development of a Social Firm in partnership with another provider in the Tayside area.

Autism Initiatives UK

AIUK provides a range of services throughout the UK. In Scotland it has developed a range of services and provides the One Stop Shop for Adults with Asperger Syndrome or High Functioning Autism in Lothians. Many users of this service struggle to access the open employment market and require a more supportive working environment, often where the job can be created around their specific skills and unique abilities. AIUK has agreed to host the ASD Social Firm Coordinator post on behalf of the multi agency group and can offer a central support and administrative base.

Edinburgh and Lothians Asperger Society

Members of ELAS have been at the forefront of supporting a Social Firms initiative and have identified at least 2 specific business proposals that can be explored as options for Social Firm development. Their members include those in work and those who struggle to find and maintain appropriate employment.

Parents of Adults with Autism

The local parents group in Edinburgh recognise that people with ASD are often prevented from accessing the workforce despite their talents and skills because of the impact of their ASD.

This project is unique and innovative in that it brings together a number of independent ASD voluntary sector agencies, ensuring people with ASD are the primary beneficiaries of the project.

2. What is a Social Firm

A Social Firm is a form of social enterprise where a business is developed to provide employment opportunities for people with disabilities or other disadvantages, to access mainstream employment.

Social Firms aim to offer a solution to social and economic exclusion for those farthest from the labour market. It is a business which is created for the employment of people with a disability, using the production of goods and services to achieve its social objective. A significant number of employees are people with a disability and every worker is paid a market rate wage appropriate to the work whatever the productive capacity.

A business approach to a Social Firm is essential (at least 50% of the firm's turnover should be earned through sales of goods and/or services). Although many Social Firms may have emerged from a parent charity, it will have full legal status as an independent business.

It will have a business plan, and management structure that reflects the firm's primary trading purpose and employment objectives for people with a disability.

Often a Social Firm will offer employment to those furthest from the labour market who need a higher level of support than is available in open or sheltered work settings.

Some Social Firms are developed to offer experience of employment with the intention that the employee will eventually move onto other more mainstream employment where possible. Others are established to offer a more permanent employment solution with no expectation that the employee will move on.

There are 3 distinct examples of Social Firm developments, all of which may be appropriate for projects in relation to people with ASD.

- Emerging Social Firms can be developed from existing projects or services

- Developing a business idea as a Social Firm from scratch

- Buying into an existing business as a going concern and developing it as a Social Firm

3. Employment for People with ASD in Scotland

There is generally a low level of unemployment in Scotland and many vacancies go unfilled.

○ Unemployment rate: 5.6% of population

○ Claimant count rate (seeking employment): 3.3% of population

For people with health or learning disabilities it is recognised that it is those with severe learning disabilities who find the greatest difficulty in accessing employment. (Boardman, *et al* 2003)

There are a number of generic employment support schemes for people with disabilities but very few are specifically set up to accommodate the unique support needs that a person with ASD might have. Those that do exist, tend to focus on those for whom a minimal level of support is required to access or maintain open employment.

The desirability of work for people with autism is widely recognised. In the survey "Inclusion and autism: is it working?", (NAS 2000), when asked what would most improve your life and make the most difference to your being included, the most common answer was finding an appropriate job.

During the day, many adults with ASD are accommodated within traditional "day services" which focus on supporting social and leisure opportunities. Whilst this is an important aspect of a person's life, it neglects

the employment potential that many people with ASD have and the benefits of fulfilling occupational activity.

4. People with ASD in the workplace

The motivations that lead us all to seek employment are equally applicable to the person with ASD (financial, social identity and status, social contact, structuring of time and activity and a sense of achievement). However it is important to recognise that the prioritisation of these motives are unique to individual and particularly the social motivations may be particularly some of the more social motivations may not be high priorities for the person with ASD.

The difficulties that can face people with ASD entering the workplace are well documented and the underestimation of the skills and capacities of a person with ASD make the transition to employment a difficult one.

Fortunately there are recognised ways of supporting people with ASD to gain and maintain employment and are the principles behind the work of IntoWork and The National Autistic Society in their employment support schemes. The development of these strategies would be core to the development of any new Social Firm for people with ASD as well as being central to supporting generic Social Firms to be more accessible for people with ASD:

- Gradual introduction to the work situation, with support

- Specific job tasks which are made clear in written form to the employee

- Written, diagrammatic or pictorial instructions

- A structured work pattern which enables the employee, as far as possible, to complete one task before moving onto the next

- Clear line management and an informed supervisor, or mentor, who can be available to give rapid advice

- Checklists and timetables for work to be done

- Initial supervision

- Explicit rules of behaviour and advice about unwritten rules of the workplace

- Consistency from colleagues

- Immediate, clear and open feedback about the standard of work done

- Guidelines for colleagues about how they can meet the individual needs in the workplace

- Contingency plans for dealing with unbearable stress e.g. a place to go for refuge, and contact with someone who will give support.

Bicknell,A (1999)

People with ASD also have many recognized strengths that they can offer a potential employer. These strengths should be matched and utilised in identifying appropriate business opportunities for Social Firm development:

- Conscientiousness and reliability

- Punctuality

- Reluctance to bend rules

- Attention to detail and accuracy

- Ability to work and not to be distracted

- Competence in subjects such as mathematics, accounting, computing, science, engineering, technical drawing or design

- Ability in tasks requiring a high degree of organisation and memory for facts.

5. What a Social Firm approach can offer a person with ASD

A Social Firm is likely to have an inclusive and supportive approach to those who are seeking work. Also they are likely to be small enterprises which can more easily create a sense of belonging, security and consistency.

A Social Firm can be developed around the specific skills and interests of individuals or groups. This is particularly attractive for people with ASD who may have difficulty generalising skills, flexibility to new environments and adapting to new workplaces and may have specific but limited skills and interests.

It can also be a route into employment for those who are only able to consider one specific job or part of a job.

Many people with ASD have a varied developmental profile with advanced skills in specific areas and significant deficits in others. Focusing on the persons skills and abilities and not their difficulties is a recognised model of good practice in supporting people with ASD.

It is recognised that employment in Social Firms provide a bridge between health and employment, clearly demonstrating significant health benefits such as improved mental health and social functioning. (Boardman *et al* 2003)

There are significant social and self esteem benefits to the individual as an employee who can start to identify themselves by a job title rather than being a "service user"

Consequently there are some clear motivations for the ASD agencies to set up Social Firms:

- o As a natural extension of existing employment / occupation schemes

- o Job creation is an essential remit of the agencies work

- o To generate an income stream to support other work or reduce costs of maintaining a service

6. The Scotland Social Firms Project

In the sprit of partnership working and to ensure the best use of resources in the ASD service sector it was agreed by the partner agencies that the appointment of an ASD Social Firms Coordinator for 2 years would be the preferred route for the development of ASD Social Firms. It was agreed that Autism Initiatives UK should host the post but the work of the post holder would be shared between the partner agencies.

The Project has two distinct objectives of helping ASD agencies to develop Social Firms and to help existing generic Social Firms become better equipped to offer employment opportunities for people with ASD.

Specific Project Outcomes were identified:

- The development of more than 6 active Social Firms projects during the 2 year period giving real employment opportunities for over 30 adults with ASD.

- Guidelines for the development of Social Firms for people with ASD that can be used by individuals and groups.

- "Good practice" guidelines to support existing generic Social Firms to become more accessible for people with ASD.

- An annual conference / seminar on Social Firms for people with ASD to share good practice and support developments.

- Building knowledge and capacity within each agency regarding Social Firm employment possibilities for people with ASD.

A number of potential Social Firm projects have been identified which included:

Bits and Bobs

Run by IntoWork, "Bits and Bobs" is an existing arts and crafts recycling project which is an emerging Social Firm and requires support to develop the business to offer real employment opportunities.

Asperger Employment Agency

A web based agency matching and marketing the specific skills of people with Apserger syndrome (e.g. proof reading, editing, IT skills). This would enable home and part time working situations which may be ideal for some people with ASD.

Craft mail order service

Throughout Scotland there are a number of day services and projects for people with disabilities who are producing high quality craft work but without sufficient retail outlets. A mail order service to sell these products could indirectly support a number of other charities as well as offer employment on the IT and administrative side.

Horticultural businesses

Several charities in Scotland run horticultural based day services which produce and sell a wide range of stock. These projects need business support to move towards offering real employment to their workers.

City Cycles

A cycle repair, maintenance and hire service base in the business district of Edinburgh, which would capitalise on the central location of Autism Initiatives UK base in Scotland.

Other examples of existing generic Social Firms in Scotland such as recycling projects, bed and Breakfast hotels, Café's and Sandwich shops also offer models of businesses that have proved to be successful and could be explored for specific groups of people with ASD.

The Social Firms Coordinator would support the respective agency involved to explore the business potential of each project and develop business plans where appropriate.

An ASD Social Firms Coordinator will be employed by Autism Initiatives for two years. They will report to the Director of Services, Scotland. The ASD Social Firms Coordinator will be fully managed, supervised and supported by Autism Initiatives and take advantage of the autism specific training and development that the organisation can offer. It is anticipated that the Social Firms Coordinator will have some business development experience and insight which is the element of expertise that is absent from the partner agencies.

The multi agency group of ASD service providers that have met and established the project will form a Steering / Advisory group. The Coordinator will formally report to the group every 6 months and meet with them quarterly. This is in addition to the ongoing work of the Coordinator with each partner agency to support the development of their own Social Firm initiatives.

Each of the ASD service provider agencies have knowledge of their own members and service users with ASD who struggle to find and sustain suitable employment. Many may be receiving a traditional day service or have no occupational support at all. It is the unmet and uniquely challenging occupational needs of this group that have stimulated the development of the ASD Social Firms project. People with ASD will be involved in each business and they will form the majority of the workforce in each ASD Social Firm. Where possible, people with ASD will be employed at all levels of the business and included in the management, development and strategic planning of the enterprise.

7. Update and Future Plans

It was anticipated that by Spring 2006, funds would have been identified to enable the employment of the Social Firm Coordinator and the project would be beginning to show how real employment opportunities will increase for people with ASD. Unfortunately this has not happened.

Funding has been sought from various charitable foundations but this has not yet been successful. This is a surprising outcome, as the remit of the project clearly matches with the funding focus of a number of potential donors (employment, inclusion, economic development).

Also the economic climate in Scotland's care sector has meant that none of the agencies involved have significant unallocated resources which could be put towards the project.

However there are still some funding applications pending and the project has been accepted as appropriate and is through to stage 2 of the Big Lottery Fund, (A decision is expected later this year).

Despite the difficulties in funding the project, there is still a commitment shared by all partner agencies and the anticipated outcomes are still seen as valid and worthwhile.

It is hoped that by the time of the presentation of this paper at the World Autism Congress (November 2006) funding will have been secured and the project's future clarified.

Sustainability

Funding of such projects is often, rightly, linked to the sustainability of the project. It is essential that in the climate of limited funding, there is a continuation strategy beyond the end of the funding period to ensure that the expectations and successes of a project are not lost.

The aim of this project is to support the development of Social Firm expertise within the partner agencies. At the end of the 2 year period the network of ASD Social Firms will be sufficiently informed, knowledgeable and skilled to maintain the momentum behind the development of Social Firms for people with ASD.

Autism Initiatives UK will then continue to facilitate the network of ASD agencies in relation to Social Firm development. Support from the Scottish Services Autism Network (SASN) would be sought to ensure the knowledge and expertise is disseminated as widely as possible.

(The Scottish Autism Service Network has been funded by the Scottish Executive and set up to develop a service that will provide a central resource offering direction to provision and to share good practice, information and resources with local groups and services across Scotland.)

Evaluation

Plans to ensure comprehensive evaluation of the project are already in place.

The Social Firms Coordinator will report to the multi agency Steering / Advisory group. The work plan and the aims and objectives of the project will be used to measure its impact and success.

Questionnaires will be distributed through the ASD agencies at 9 and 21 months to gain feedback and provide additional focus for the project.

Autism Initiatives UK have developed an internal quality assurance system which will be adapted and applied to the ASD Social Firms project to ensure that it maintains a focus on its primary outcomes.

There will also be use of recognised tools for evaluation in the Social Firm context.

2 examples are:

- Providing and Improving: A Quality Impact Toolkit for Social Enterprises – New Economics Foundation www.meweconomics.org

- From the Balanced Scorecard to the Social Firm Performance Dashboard – Social Firms UK (A tool to measure the impact and performance of Social Firms)

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HOW DIAGNOSIS ALTERED MY EMPLOYMENT AND LIFE

L Deimel

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I consider it a gift, honour and a privilege to be here speaking here about my story.

I want to communicate how my diagnosis has helped me in my work and life. I will talk about my life plus work before and after diagnosis in addition to the diagnosis experience. I want to illustrate by my life experience that diagnosis can be very useful - and that is an understatement.

I can explain how some of my Asperger syndrome affects me (not anyone else's Asperger syndrome, which may be similar, but won't necessarily be the same as **my** Asperger syndrome, it's like "**my** baby").

I can be literal in what I say so you may want to bear that in mind as I speak. I also often say 'may' and 'might', etc, to guard against the possibility of being inaccurate. I hope you can understand that.

I should say now that I have a mild form of Asperger syndrome with obsessional anxiety, so when I mention my Asperger syndrome in the talk, I really mean my mild Asperger syndrome.

WORK AND LIFE BEFORE SUPPORT AND DIAGNOSIS

Prior to obtaining a diagnosis I didn't know how to explain myself to other people. This caused difficulty for example in maintaining employment. I checked things over and over; I was too frequently asking people questions. On occasion, I was asking the wrong people questions which must have made things worse. For example I may have received different and conflicting advice. Any conflicting advice would no doubt have increased my at the time undiagnosed obsessional anxiety.

As I did not have support and diagnosis, along with little understanding of self, I was effectively, in part, drifting. Drifting from one job to the next, from one course to the next. As I lived in a Vicarage my parents' church was the main focus of my social life. I did want to leave home but recall thinking I would be often ringing home regarding anxiety to do with cleaning. The idea of me leaving home was talked about minimally, but there was no idea of how it could happen.

I had a happy childhood. At school there were some difficulties. At 16, I really wanted to leave and get a job – people wanted me to go to college and get some computer qualifications, but I was determined to work.

FIRST JOBS

I did IT (Initial Training) and YT (Youth Training). I was told I would be given three different placements so I would get some idea of what work I wanted to do. My training co-ordinator, however, seemed to want me to settle into a job – was that because that would have been a success for her? My Mum remembers that I was not happy when this became clear and so I insisted on getting the three placements. I resented the change of plan. I now know that this is classic Asperger syndrome literalism.

The final placement fell apart quite badly and a manager said I wouldn't get a job; he was very rude. It may be worth saying that my Mum told me this later, I must have forgotten at least some of it, blanked it out.

I then tried various temporary jobs which didn't last. The reasons included a lack of understanding/support and me not trusting myself that I was doing a good enough job, I suppose. This lack of trust in myself would have led to my keeping asking questions. I also drifted from one course to the next. This may sound arrogant, but if it were not for my Asperger syndrome I think I could have got a job without doing all the courses I was doing at that time (because of my school education).

COLLEGE TIME AND ASPERGER SYNDROME SUGGESTED

I eventually decided to go to our local college full-time after not being able to keep a job or at least be happy in a job. I would get some qualifications as well.

All was not straightforward though, even though I wasn't working for other people. I had a problem with having to be available for work and go to college at the same time. I didn't actually claim the benefit I was entitled to as a result. My parents supported me. At college I saw a counsellor who said something along the lines of that if I signed on (claimed benefit) I would be living in her office. So she obviously knew I

would be that worried about claiming benefit. Really the anxiety would have been about being "available for work". I could have claimed benefit as the college would have written a letter explaining the situation, but I "jumped the gun", due to anxiety.

I did GCSE Maths at college and I was the star pupil, my tutor wanted me to do A Level Maths. I got at least ten computer qualifications at distinction level.

During this time I was seeing a psychologist because my Mum had told our doctor I had had difficulties settling into work – our doctor knew me and how tense I was! After a while the psychologist said he thought I may have Asperger syndrome. I didn't know what that meant, and my parents knew little more. (*Nothing was done about it more than just saying I may have Asperger syndrome, it's a bit like what someone said, something like "your car's broke, but that's all I am going to say"*). Our doctor said we should leave it for a few years rather than getting a label at *19 years of age for me. I might grow out of it!*

This psychologist told my Mum he thought I wasn't ready for work but I was determined! (I didn't find out what the psychologist thought until much later, after the next job I am going to talk about had ended, fallen apart). In fairness the psychologist didn't know what to suggest. This is why I want to share what later helped me. I hope that the organization which helped me, autism.westmidlands, can be replicated around the world, so that later psychologists do know what to suggest!

LAST JOB BEFORE DIAGNOSIS

I stayed on the books of the college for more than two years as a student before applying for and obtaining a job at the same college, but on a different campus. My tutors thought I could do the job. However, I knew I was different in some way, even after the interview, even before the job was offered to me. I didn't know how to explain myself to other people so I didn't. But I knew the employer would find out eventually if I got the job. You could describe it like having been in a maze and not knowing the way out.

The job was fine at first, but the same old difficulties started to rear their ugly head. I kept asking questions over and over again.

Instructions in that job were not literal enough for me. E.g. my manager was going away, so she said something like "Laurie will do this." I don't remember what it was, but that is unimportant, the fact is she was laughing and so I thought she was joking. She wasn't. That was one thing I should have checked!

After a bit in the job, my manager said something about trusting in myself. You know what I mean, when you get a job you get a kind of honeymoon period, people accept maybe you being slower or whatever, asking questions more. But they expect this to stop with time – with me it didn't. They said I would get quicker but I actually got slower.

My manager usually went to lunch before me, but one day in the week, she let me go before her, as I went to a church lunchtime service. (My faith helps me, my problems have seemed less after praying and that even includes checking). I recall a day, when my anxiety was affecting not just me but my manager as well *to such a degree that my manager had to leave the room and therefore go to lunch before me,* even though it was a day when I would have otherwise gone to lunch before my manger. That is quite a memory and quite a statement. The difference in that job was that my anxiety was so much more obvious than it had been prior to working for another person. For example, I was doing well at college, but that I think was as I was working for **myself, not another person**, so I didn't need to communicate so much and I feel I would have been less worried about errors.

In that job my manager suggested and/or actually tried limiting my time to ask questions, e.g. just in the morning, but I don't think that worked. It was a good idea, but maybe its better to ensure the person knows why they are different, instead of saying don't do that as it's not productive.

Targets were set for me in the job e.g. do five out of fifteen tasks in a given time. If you know you are going to struggle to meet the target you are going to choose the easier bits aren't you? I must have known I was up against it, so chose the easier five out of the fifteen bits of work. Later the person who asked me to do five said something like "I didn't say which five!"

I was in such distress that my parents decided to start the process of diagnosis. They saw our doctor who was very supportive. I visited what is now known as autism.westmidlands. The visit was to discuss support for me in my job, which may have been possible but I would have been embarrassed, I feel, as I'd already been in the job a year. Having support from day one (or before) is different.

In any case, support depended on being diagnosed as having Asperger syndrome. At the autism office, Andrea whom, my Mum and I visited said later "your Mum suspected you may have Asperger syndrome, but felt that if you did, you were at the most able end of the spectrum. She was worried that a formal diagnosis may put you at a disadvantage in finding work and wasn't sure whether you'd get any concrete

benefit from it. I discussed the pros and cons with her, and at the time we were planning the development of ASpire, so it seemed like it would be worthwhile for you to have an assessment. And the rest, as they say, is history!!" (ASpire = Asperger Syndrome People Into Real Employment).

Around this time, my parents wrote to my employer detailing the fact that I may have Asperger syndrome in addition to explaining a bit about Asperger syndrome. About two weeks' later the employer said "You haven't changed have you?" Well I wasn't likely to, I still haven't completely and that was more than six years ago!

My manager's manager said something like "You can go to London on your own, yet you have issues with the work here". (I have enjoyed travelling on long trips – I've been to Bulgaria and back in a day!) I think he was trying to say "I can't understand your condition". Maybe he couldn't work out my complicated condition. I think he also said/asked me about the sheet on Asperger syndrome which was sent by my parents, "Is that just the way you are?"

My parents told my manager that they were seeking a diagnosis for me, but she didn't understand. All this took time and eventually, _before_ we managed to obtain an official diagnosis, I was offered a leaving package from my job.

In fairness to the employer, they did let me leave on good terms. For example they set up a meeting for me with a Disability Employment Adviser and said I could do a course at the college I had been working at, with no time limit and the employer would pay for the course. I may still do that, but that maybe Asperger syndrome literalism. It has been six years+ already, so "no time limit" may not mean six years or more!

I want to add though that I was thinking thoughts like "will they cope when I have left?" <u>They wanted me to leave and I was thinking - will they cope</u>! That was anxiety. However someone I worked with I met, socially, and he told me effectively that my former manager had to work longer to make up for the work I was doing, prior to leaving.

During this job was a dark time in my life in many ways. I recall not liking switching the light off at night at least once _at home_ which was unusual for me and a sign that something was wrong. Not to be arrogant, but I guess I must be stronger now though for that experience, to have gone through fifteen months of work without knowing what I now know. (It's hard enough at times knowing about the Asperger syndrome, let alone not knowing.) It was a valuable time really, e.g. I can talk about it now. It's kind of ironic that if I hadn't got that job I may not have been diagnosed even now. So I was unemployed and I was feeling naked just after leaving that job. Earlier I was drifting and then I could, so to speak, drift no more. You could say I had become driftwood – and the driftwood had found its shore.

However I was still waiting for diagnosis. I was given an appointment with a Disability Employment Adviser. I saw her one morning – she was rather puzzled as to what to do, and didn't know much about Asperger syndrome (echo!).

Then that same day, someone from a specialist college for people with disabilities visited her to say that they were starting to take in people with Asperger Syndrome, as residents, (answer to prayer!) (The specialist college is called Queen Alexandra College). This meant I might be able to leave home! When I had an offer of a "try-out" place I decided to go but I suppose there wasn't much option. I did a short "taster" placement there while waiting for diagnosis. I do remember crying about this before going – presumably this was transitional anxiety. However it did turn out better than I was feared, even though I had suicidal thoughts.

ACTUALLY GETTING DIAGNOSED

The doctor who had said I would grow out of my disorder earlier on eventually worked hard to help me to get to see someone to diagnose me. My parents had read some of the books written by a particular professional (Professor Digby Tantam) and were most impressed, so they insisted on having him to do the diagnosis. They wanted to get the best possible advice as they didn't want me to be "labelled" wrongly. (However I was now 23 yrs and hadn't grown out of the Asperger syndrome).

The actual diagnosis meeting I attended included me talking and then with my Mum in the room as well. My Mum also completed a questionnaire relating to my early years of life to assist the diagnostic procedure.

It's worth mentioning that the plan regarding the transport my Mum and I would take to the diagnostic meeting changed. I want to stress that I didn't like the plan changing, which I think is a trait of at least some Asperger syndrome people. Basically my Dad wasn't going to the diagnostic meeting, which is not what I had expected. At the time I was sharing most of my anxiety with him rather than with my Mum. That was part of the change which I found distressing. Another change was that we would travel in a train, not in a car. I was very upset. However it was OK on the day.

At the diagnostic meeting, I didn't want to hear the fact that I had Asperger syndrome. However, the diagnosis when it did come through (mild Asperger Syndrome with obsessional anxiety) was one of the best things to ever happen to me, what with all the consequences that have come from it. Among other things I have realised that anxiety is one of the main side effects from <u>my</u> Asperger syndrome.

To part quote my diagnosis report, "reassuring a person with this problem (i.e. anxiety) makes the problem considerably worse; firstly, because it does not address the underlying anxiety, which is a significant one". Also "reassurance does not encourage a person to find their own ways of resolving their anxieties". (I am now attempting to address my anxiety with a package which includes a relaxation CD and phone counselling; the package claims to overcome anxiety).

AFTER DIAGNOSIS

The month after the diagnostic meeting, I started back at the specialist college I had done the "taster" placement at. Without the diagnosis this would not have been possible as funding would not have been available. Then who knows how my life might have turned out?

I was still very anxious. My Mum recalls me washing door handles and my clock. I recall washing my mobile phone under a running tap; even later when employed. (Maybe my Mum remembers more because I may have blocked out some of these memories unconsciously.) (I do recall other things I have done which were not useful but I think were as a result of my literalness, for example putting terps in the washing machine!)

I was anxious about germs. At college I washed my hands to such an extent that my hands were bleeding and I think I needed plasters on them. This was world level anxiety, not Premiership level, world level! Settling in to the college wasn't completely stress free. I didn't like it when we as students weren't supposed to do something yet the staff then did that very thing. In whatever area of life to my mind either you have a rule about doing things in a particular way or you don't have a rule at all, it's not rocket science. (Although I may not always keep to all rules!)

However in the early part of the time I was back at the college, I thought that I didn't need to go home as automatically, but I did to begin with. Over time I went home less and less. I have visited the village where my parental home is without even visiting my Mum! I began to meet new people, for example at the local church.

The course I was doing included work placements. I recall how happy I was at getting my first placement, maybe that feeling included knowing someone was willing to work with me again. This was about a year after my last job had ended, the job within which I related to me as driftwood. In the work placement, I still wrote far too much detail down; for example when recording information from a packet onto the computer, I would record too much information from the packet I was looking at. Checking would have, I presume, still slowed my work down.

But it was good as well. I got a round of applause when I left; I arranged for us to go to the pub when I was leaving. At least some people knew more about my disorder and my anxiety from the start which must have helped.

After one and a bit years my funding at the college was running out so what would I do then? That was not an easy time – where would I live, where would I be working – would I be working at all? A meeting was set up at my college house with my Mum, my psychologist, Dominic, my tutor Hazel and last but no means least two staff from what is now autism west.midlands. (Claire and Andrea). Everyone was agreeing on what was best for me which was good as conflicting advice can be a problem for me. I should not go back to live with my Mum and Dad; a job would be good for me. These people thought I was now ready for work! An ASpire worker suggested that I "disclose" my condition at interview which would mean that ASpire could then help me to obtain and sustain employment.

The support of ASpire has been a key element in my work. However without diagnosis this would not have been available.

By God's grace I fairly soon obtained a room in a shared house with minimal support very near to where I had been living whilst at college thus affording me some continuity and stability in my environment. I was still going to the college to help them out and I was looking for work again. Just before my birthday I obtained the knowledge that I would have a job. The employer were very good as they were willing to wait for my new support worker, Caroline, to be ready to support me in work. I had disclosed my condition (although they needed reminding so it obviously hadn't showed much at the interview!) There was two months + from when I found out about the job to actually starting the job. I have been working for the same employer now for more than four years with seven different managers plus changes in office and support workers, not to mention changes in job.

SUPPORT AT WORK

Work with support has felt like being in a different world, to being without support. ASpire helped me get going in the job and did a lot of groundwork even before I started, including enabling Access to Work to be in place. I was able to give a sheet detailing support worker and DEA (Disability Employment Adviser) to interviewers. Claire, from ASpire attended an interview with me. ASpire set up meetings and some training with my new colleagues. My support workers have met me at my work and I have visited support worker(s) at their office and other venues. It is good that they can be flexible as it may be easier to talk about certain issues outside my workplace – I am glad a support worker (Caroline) suggested that. Caroline was my first support worker and she encouraged me to postpone anxiety, which I was grateful for. (I could have postponed more anxiety though).

A support worker has written instructions for me, therefore making them easier to follow. A support worker has up till now usually attended my appraisal meetings (but I am being challenged to think about whether I need a support worker in a future appraisal meeting). The honesty which goes with my condition could be potentially awkward as if anything major happened the manager may ask me what happened. I now feel that I would access support to help me to word my response. (Also although I can be trusted I have been able to withhold some of the truth – I think I got this phrase from Marc Segars "The Battles of the Autistic thinker – a survival guide for people with Asperger syndrome.)

Generally, ASpire are on the other end of the phone for me. For example, even when my own support worker, currently Simon, has not been available, the other staff at ASpire have been helpful and supportive; including Jo who answers the phone for the support workers. (I also have received support from Lisa). I did have a big problem once with a particular job in the same organisation (as I have been working in for more than the last four years) but this time the situation was much better because my disorder was known about. With support from four of the ASpire team - Matt, Claire, Claire and Morag, my situation was better than a previous experience of employment without support. However, it was a relief to get out of that job and return to a more suitable one.

WORKING RELATIONSHIPS

As I said above, part of my Asperger syndrome was explained to my colleagues before I started the job. People certainly make more allowances for me than prior to diagnosis. However, someone jokingly said something like "he (Laurie) hasn't got a condition" – I can take that as a joke but may never know how much they meant it as a joke even if I push them to find out.

Different managers, naturally, have approached my disorder in different ways. Some of their approaches did actually make me feel worse, including giving too much reassurance as this led to me thinking "this has gone beyond reassurance; this has become not taking responsibility." Although I have asked for the reassurance so I can't really blame them! However the fact that I have worked for seven different managers, is significant to me because I have survived that degree of change – and as I touched upon earlier, transitions aren't always the best thing for me!

I have also experienced receiving conflicting advice, sometimes even between my support worker and my manager. This doesn't help me! However I think in that instance I may go by what my manager says, although I would more than likely check again with my manager!

So, a lot of my life is better. My third manager wrote "I don't see Laurie as the guy who has AS. AS is not what Laurie is about. Laurie's the guy who works for me, at times is funny especially when talking about Newcastle. He's the guy who rides to work, does the secure prints and so on." He seems a little confused as he wrote "AS is not what Laurie is about"; then he wrote "AS is only part of what Laurie is about" - but this I realize is my literal streak! (I support Newcastle).

CONFIDENCE

All of this helped my self-confidence. I think my confidence must have started to increase at the specialist college. We went on an Outward Bound week in Wales while I was there and I think at least one person said that I came out of my shell then, that I was the "star" of the week. However I think being employed has helped a lot. As Claire of ASpire said once "the positive value of employment is that it can give a lot of **confidence**, predictability and routine". It is good to know that I have an office to go to and work to do.

My point is that having employment can affect one's confidence in other areas of life. For example, I went on my own to a camping week in London in 2004. We stayed in a Tent City – there were other Christians there and we were helping with different projects across London. For example clubs for youngsters. I think that if I had still been looking for work without success it would have been harder for me to go to the Tent City and everything else it meant. However, I had a sense of "all will be well" before that week and most of the week exceeded that "all will be well."

Another more domestic example is that of one of my kitchen cupboards! I arrived home from work one day and a cupboard of mine had been taken down as a result of something being done in the kitchen. Before then, I would have been very upset and angry at the change. However the thing was I didn't mind too much because my fourth manager (at work) had spoken a good word to me. That felt good and I think enabled me to cope with the change better than otherwise. It was a cupboard, that was all – a cupboard on the wall! I had and have a faith, a roof over my head, good people around me, not to mention my job so a cupboard was not necessarily like a big thing.

Of course, other things helped me as well. However there was concern for me prior to getting a job, around the time of my specialist college course nearing its end. People were saying then things like "will he cope without a job?" It may have been seen as essential for my well being; but I may not have liked hearing the phrase similar to "will he cope without a job?" It is still true that having a job is a good thing to have. However, I have felt at least in part, that even if my job was taken away something like "you can take away my job but not my esteem, my more confident nature, my experience, my increased self awareness". In other words you can't take my soul by taking my job.

I think it is worth mentioning that before diagnosis I had a time when I got so used to not working that I preferred that state, to such a degree that I think I was glad that I didn't get work from a local employment agency on at least one occasion. I think it is easy to become used to not working, especially if you do not like transitions.

That said, as you know, I did have a job later on, prior to diagnosis. I think that, even though I did become as I said driftwood in that job, having that job helped me to want to work again. If this needs confirming in any way, I can quote Claire Fennell of ASpire who after my diagnosis, said about me, he was "determined to get a job".

SELF AWARENESS AND WIDER HORIZONS

I am now more aware of myself which I hope has become evident by listening to me today. I have read books about Asperger syndrome, for example **Martian in the Playground**, by Clare Sainsbury and **Making Sense of the Unfeasible** by Marc Fleisher. I would recommend them both and found the latter book inspiring.

As I may have touched on, I still visit my parental home, which is about an hour or more away by public transport, but although I still have stuff there it is more of a place to visit now. Going there has felt like a retreat, more homely than my present untidiness! The example I am thinking of is when I stayed at my parental home longer when I was going through a difficult time in a job I mentioned, **post diagnosis. I even had suicidal thought then**.

My parents still support me, for example with claiming benefits and they understand me more than most, if not all other people. However on at least one occasion I haven't gone to my parental home for weeks. I visit the football club in the village they live in and I can see myself still doing so even after my parents no longer live there. To put it in a nutshell, and this is in no way against anyone, "pre diagnosis my parents' church was my main social focus, now I see my parents' church as a part, a very good part, but simply a **part** of the village".

I now have friends in the church near to where I live and keep in touch with someone I met at the specialist college. I also have contact detail of at least another person from the specialist college. I go to an Asperger syndrome discussion group that meets in a pub once a month. I have attended other activities related to my local church and on occasion revisit my parents' church. I went to France in the summer and maybe going to Norway to see a new contact there. There are also my housemates! I have a busy, sometimes hectic, social life. Then there is my full time job!

CONCLUSION

I don't want to be arrogant but I am not wrong when I state that the driftwood I had become turned into a tree of hope, so to speak, to inspire and give light to the Asperger syndrome people not yet diagnosed or employed. My life is not a perfect light but it has been going along a road lit with a far better light than before diagnosis. Things are not perfect but "Rome was not built in a day". If I can get and keep a job for more than four years, albeit with some support, plus keep that job every working day with no sick leave then there is hope for people not yet diagnosed. (To be honest I have had medical appointments in addition to being sick when on leave!) However, I realise that I have a mild form of Asperger syndrome so I do not wish the whole of severe Asperger syndrome on anyone. Briefly I will say that Asperger syndrome people can, in part, enrich the world with their ability, their difference, no matter how severe or mild their Asperger syndrome is. There is always to hope a better life with Asperger syndrome. For me, one example was one of my post diagnosis managers actually saying words to the effect of she was glad when I came back from my holiday!

In a nutshell, I knew I was different even when I had interviews for jobs **before diagnosis** but didn't explain myself as I can now, **after diagnosis**. I want to see the day when there is no more misunderstanding and no more unemployed Asperger syndrome people who want to work. Everyone has ability, it's just finding the ability in amongst all the challenges. In addition, finding the ability in the, dare I say it, negative impression some give of Asperger syndrome.

I would like to end the talk with the following thought – one of my post diagnosis managers said that he would like to clone me. He wanted to clone me **even with my mild Asperger syndrome**.

There follows pictures of me.

The below shows me as a little boy; to show I was a happy little boy.

The below shows me during the time I was employed in the job, within which I became **driftwood, prior to diagnosis**.

The below shows me during the time I was employed, after **diagnosis**; with **support** available to me.

0032

AUTISM SPECTRUM DISORDERS, CULTURE AND SEXUALITY

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INTRODUCTION

I have noted an increasing number of consultations about young people with an ASD who are experiencing difficulties because of inappropriate sexual behaviour. Much of this behaviour appears to happen because the individual has failed to grasp (or has not been taught) the sexual rules of society or who has not taken context into account. This paper will reflect on how we can support people with Autism Spectrum Disorders (ASD) to attach importance to culture, society, rules and mores associated with the relationships and sexual behaviour going on around them.

How and when do young people acquire their understanding of what it means to be a boy or a girl or to have a relationship, especially when *language* powerfully constructs the way people see the world and the way they make sense of their experiences of themselves and others? Friendship skills and interpersonal understanding need to be taught but the young person's personal motivation and emotional involvement in the process are vital; one must be involved in the process of being a good friend.

Most of the (limited) research into sexuality and ASD has used a narrow definition of sexuality and has focused on observable sexual behaviour. We need to broaden the definition to include intimacy, emotional aspects of sexuality and relationships, self-esteem, attitudes and cultural values (Gray et al., 2000; Koller, 2000, Harpur et al 2003). The experience of being male, female, gay, straight, sexually active or celibate is mediated by the society and cultures in which we live. How then do people with Autism Spectrum Disorders absorb and learn the rules and rituals of their culture, and link their behaviour to the relationships and sexual behaviour going on around them? Behaviour which does not conform, is often subject to sanctions and I have had to work with increasing numbers of young people who are in trouble due to inappropriate sexual expression. In Britain and many other societies young people with ASD are bombarded with sexual images and attitudes via the media which they find difficult to integrate with the rules they are taught (Jackson 2002).

In the past, many parents and professionals denied the importance of sexuality and reproductive health education and services for persons with autism, believing these individuals had no sexual feelings or desires and were not suited to have families of their own. Fortunately, many changes in societal thinking have taken place, (Schwier, and Hingsburger 2000) and the focus now is on promoting the reproductive and sexual dignity and autonomy of persons with developmental disabilities including autism spectrum conditions.

This presentation aims to allow participants to consider the essential approaches and ideas about relationships, sexuality and vulnerability when working with children and young people with ASDs. Biology, social and cultural, interactional paradigms have been suggested in order to understand

the development of gender and these point to the areas of socio-sex education needed in autism (Stainton Rogers and Stainton Rogers 2001). It will also look at the need to teach to cultural norms so that problem sexual behaviour does not develop.

Key themes in the literature

- One impetus for children with disabilities engaging in problem sexual behaviour can be sourced in experiences of abuse, disempowerment, distress and violation

Problem sexual behaviour as a function of the context:

- The sexual development of children is often neglected or denied by individuals in the child's context (Schwier and Hingsburger 2000)

- A lack of privacy and opportunities to develop appropriate boundaries (Couwenhoven 2001)

- Children with disabilities who engage in problem sexual behaviour display a wide range of behaviour from self-directed behaviour to penetrative acts targeted towards others.

The different backgrounds of people may cause them to have different expectations and attitudes towards disability, sex and relationships. The different expectations affect how and what they learn and even if they are taught about sex. Without enculturalisation, people are unable to think, behave, and develop

emotionally in order to function in society. However, culture is always changing and individual behaviour within a culture varies greatly.

Sex has been a taboo in many countries, but are attitudes gradually changing?

Because of the spread of HIV/AIDS the recent 2006 International AIDS conference has suggested that all cultures need to be more open to discussing sex and sexual practices. Around the world recent radio programmes have been discussing many areas.

In Brazil, many young men strongly believe that in their relationship with women they need to be macho; 18 year old Ghanain, Berenice Akuamoah, talks on UNICEF Radio about boyfriends; 'The Vagina Monologues' inspired Lebanese playwright Lina Khoury to write a play about women's issues that played to packed houses in Beirut this spring. Finding a palatable alternative word to 'vagina' was a task in itself as the censors banned the Arab word for Vagina. They used the word 'Cocoa' instead. Indonesians have been hotly debating a proposed Anti-Pornography Bill that would outlaw revealing clothing and kissing in public. But even in the USA Johanna Greenberg had never had the 'birds and bees' talk from her parents (WMPG's Blunt Youth Radio Project)

Cultural universals in sex education

There is a basic biological need to have sex

- Can be overcome by culture and ego

- Religious celibacy

Avoidance: shunning of sexual relations among family members

Codes of behavior: rape is always wrong, politeness, dress ……

Infections: can be transmitted through sexual activities. Safe sex.

Homosexual behavior

- Found in numerous other cultures

- Trans-gendered or third-gender people

- U.S. is one of the few Western societies that tries to regulate sexual behaviour, both heterosexual and homosexual

Culture can be defined as the network of customs, rituals and rules that provide social coherence in a group – to 'belong' to the group requires following the groups rules and engaging in its rituals and customs.

Cultural source of information e.g. body image, gender roles

Within the rules, rituals and customs of cultures and subcultures (e.g. religious groups, bikers, Goths) are particular expectations of how men and women should behave, what it means to be male and female and so on.

A focus on language and functional skills development without a linked focus on emotional and social interaction has been a limitation in many educational interventions with people with an ASD.

How and when do young people acquire their understanding of what it means to be a boy or a girl or to have a relationship, especially when *language* powerfully constructs the way people see the world and the way they make sense of their experiences of themselves and others? Friendship skills and interpersonal understanding need to be taught but the young person's personal motivation and emotional involvement in the process are vital; one must be involved in the process of being a good friend.

A gender stereotype is a rigid set of beliefs about what men and women are like and labels those who deviate from these expectations as odd or unusual. Groups vary considerably in their expectations of appropriate behaviour in terms of gender. Some young adults with autism are unaware of the differences between men and women. Many boys with Asperger syndrome find a safe haven in mixing with girls at school and some girls with AS prefer the games that boys play and both may mimic the actions and behaviour of the opposite sex. All experience a 'culture lag' with their peers (Jansen 2005) missing out on learning the skills of adolescent relationships. Young people should have the chance to explore gender differences and how ethnicity and sexuality can influence people's feelings and options. Stereotyped

gender roles. More extreme in younger children and teens and towards to opposite gender. Increased flexibility is learnt from teenage peer groups. Depends on the culture.

Modelling and imitation, two way misinterpretation of signals, choice of partner

Young people can be exposed to a wide range of attitudes and beliefs in relation to sex and sexuality. These sometimes appear contradictory and confusing. For example, some health messages emphasis the risks and dangers associated with sexual activity and some media coverage promotes the idea that being sexually active makes a person more attractive and mature. In AS socio-sexual skills can be well known in theory, but sometimes give rise to problems in practice, (Henault and Attwood 2002).

Teaching communication skills is vital including non-verbal communication. To be able to fit in young people with ASD need to learn the language of the teenage subculture, so that they can fit in more easily but also to prevent them from being teased. Filipinos know the soft handshake as welcome or goodbye greeting. But take into consideration that the initiative for handshaking has to come from the woman. A firm handshake is more the norm in the west.

Which arm and finger movements are going to upset someone? If someone puts his hands on his hips, he is looked as arrogant or that he is angry. In some cultures it is regarded as impolite – even offending -, if a person is beckoned with curled index finger or a pointing index finger is used. To show the outstretched middle finger is in many other parts of the world, an obscene gesture.

In Japan, silence is just as important as speaking. In the West, silence is considered as an awkward moment and we try to mask this uncomfortable feeling with words.

The uncommitted face of the Japanese is very common. It is considered rude to overtly express your emotions in public. The "Poker Face" is used to cover up negative emotions as well as used as a shield to protect your privacy. People with ASD have to be taught to recognise emotion in facial expression.

Eye contact is often a Western signal for confidence or sincerity and it is frequently taught as a skill to those with ASD. For example, in the United States it is customary for two people who are having a conversation to maintain eye contact during most or all of the conversation. People who are unable to maintain eye contact during a conversation are often looked upon as untrustworthy or rude

In many cases, the Japanese consider direct and constant eye contact a rude gesture that means defiance or challenge. The Japanese may shift their eyes or look down to show respect to another.

The Japanese do not show signs of affection or emotions in public. Young couples may be seen holding hands, but it is embarrassing to see spouses kiss in public In many countries a kiss on both cheeks is a normal greeting.

In Asian and Middle-eastern cultures it is appropriate for the same sex to walk hand in hand but not the opposite sex. This can look quite strange to western eyes.

Vulnerability, infatuation

Individuals with AS and high functioning autism have levels of sexual desire and imagery comparable to those of the general population. The Asperger Syndrome sexual profile differs in several respects from that of the general population. The body image, sense of belonging to one's sex, and the erotic imagery of individuals with AS seem to be less influenced by social norms. Adults with Asperger syndrome would appear to act according to their internal desires regardless of whether they are directed to a person of the same or the opposite sex.

Can be very vulnerable to inappropriate approaches, suggestions from others. Consent issues are difficult to understand for many adolescents. 'I said no but he did not stop.'

Misunderstanding of friendship, 'I thought he wanted to be a friend but all he wanted was sex.'

Make sure that behaviours which were fine as a child are no longer carried out as an adult e.g. stroking women's hair or feet as severe penalties will be imposed.

Education in sexuality

Current research (Stokes and Kaur 2005) suggests that there is a difference between typical adolescents and able adolescents with autism in sexual behaviour that is consistent with the nature of and autism spectrum disorder. Adolescents with autism tend to display poorer social behaviours and more inappropriate sexual behaviours. They engage in fewer behaviours related to privacy, have poorer knowledge regarding privacy issues and have had less sex education.

In the most recent studies (Henault 2006) it is suggested that children and adolescents with an autism spectrum disorder need sexual education in a structured, systematic and concrete way but that it must also include socio-sexual skills, and rules on behaviour and relationships (Couwenhoven 2001).

Although it is problematic to teach a certain set of rules, to judge certain values and behaviours to be 'better' than others, all people who work with young adults with ASD are aware of the problems if rules are not taught. Unfortunately teaching young people the facts about friendship or sex is not in itself an effective means of promoting healthy friendships or sexual relationships. They need to have the experience of having friends. This can also be confusing. Each year at college I have young men who think they might be gay as they like going to the cinema or a football match with another male student from college. I have to say that this is the enjoyment you have with a friend which they have no experience of.

BODIES

- Women's and men's bodies,

- Naming of private parts, the differences and similarities.

- Puberty changes -menstruation and wet dreams

Depending upon their level of understanding:

SEX - PHYSICAL AND PRACTICAL ASPECTS

- Touch, public touch – identifying boundaries and appropriate behaviour

- Masturbation

- Heterosexual activity - including consequences. Information on pregnancy

- Same sex activity - including consequences. Sexual health information

- Contraception

- Sexual health information

SEX - SOCIAL ASPECTS

- What does sex mean?

- Why do people do it?

- How do we learn about sex?

- Who can/can't we have sex with and why? Discussing laws and societal rules

- Right times and places – public and private.

- Keeping safe - discriminating between appropriate and abusive relationships

- Learning about others attitudes, opinions and beliefs

It is vital to teach friendship skills and as your child gets older so should his or her friends.

If people with an ASD are sexually active, what do they need to know?

- Consent

- Contraception

- Saying no and coping with people saying no to them

- Consequences (physical, emotional, social)

Can only be done with certain people in certain places (has rules)

People providing sex education have attitudes and beliefs of their own about sex and sexuality and it is important not to let these influence the sex education that they provide. For example, even if a person believes that young people should not have sex until they are married, this does not imply withholding important information about safer sex and contraception. Attempts to impose narrow moralistic views about sex and sexuality on young people through sex education have failed (Collins, Alagiri and Summers 2002). Rather than trying to deter or frighten young people away from having sex, effective sex education includes work on cultural attitudes and beliefs, coupled with skills development that enables young people to choose whether or not to have a sexual relationship taking into account the potential risks of any sexual activity.

Knowledge and positive attitude Providing clear and practical information is vital. It is important to emphasis that sex is normal and healthy in the right place and at the right time. In most cultures masturbation is normal behaviour when carried out in private. It is however, essential to recognise that some cultural beliefs about sex conflict with other equal opportunities perspectives.

Conclusions

- o Become familiar with your own values

- o Explore and recognise the values of others

- o Understand the implications of these values for education

- o Determine where the differences lie

- o Determine how to best overcome the differences

  - o Expose students to diverse resources

  - o Choose diverse examples

  - o Examine "cultures" within your school/college/society

Individuals with ASD should have the right to fulfil their sexual needs, to

- o receive training in socio-sexual behaviour

- o have access to the sexual knowledge they can manage

- o have the right to express sexual impulses in a socially/culturally acceptable way

- o have the right to love and be loved

- o have the right to a consenting sexual and intimate relationship

The ways in which these rights are met, have to be defined by the needs, expectations and capabilities of the individual with ASD. Values and morals are an essential part of this discussion.

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Radio links   http://www.bbc.co.uk/radio/noscript.shtml?
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0033

SEX EDUCATION AND AUTISM SPECTRUM DISORDERS

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Introduction: an overview of the literature on sex education for persons with autism spectrum disorders

Although parents (Torisky & Torisky, 1985), professionals (Ford, 1987; Haracopos & Pedersen, 1992; Hellemans, 1996; Hénault, 2006; Koller, 2000; Melone & Lettick, 1985; Mesibov, 1982) and persons with autism spectrum disorder (Newport & Newport, 2002; Pukki, 2003; Lawson, 2005) have highlighted the importance of sex education for individuals with autism spectrum disorder (ASD), little has been published on this topic.

Mesibov (1982) put forward some basic assumptions on sex education for people with autism, that twenty years later are still very valuable. First, he states that individuals with autism experience sexual drives, behaviors and feelings with which they need assistance. The amount and the timing of the assistance have to be adapted to the level of need. Second, sexual education has to be based on a dialogue between parents and professionals, which has to be started before problems arise. The dialogue has to deal with values (which behaviors should be taught) and techniques (which behaviors can be taught). Third, sex education has to take place in a structured, individualized, concrete manner, using the same techniques as in the teaching of other skills. Fourth, the teaching of appropriate sexual behavior is a priority, since society is frightened of the sexuality of individuals with handicaps and might be little tolerant of deviant behavior. Fifth, a developmental approach for teaching sexual skills is the most effective. Teaching programs have to be matched to the level of functioning of the person with autism. Sex education has to be considered in the context of all aspects of the persons functioning, e.g. communication level, social skills, cognitive and conceptual abilities. Sexual skills can be broken down in a hierarchy of four levels: discrimination skills (which behavior is appropriate in which situation, place, and time?); personal hygiene; body parts and functions; a comprehensive heterosexual sex education program. For each of the levels the author gives valuable advices on teaching techniques. Hellemans (1996) has expanded this concept to seven levels: discrimination skills; personal hygiene; body parts and functions; masturbation; sex education in the narrowest sense (intercourse, conception, pregnancy, birth, birth control, sexually transmitted diseases); emotional guidance and support (explaining autism, acceptance of the sexual and relational limitations related to ASD, searching for alternative ways of satisfying sexual expression); counseling in dating skills and development of an intimate relationship (emotional reciprocity, perspective-taking, setting and accepting limits, responsibility, norms and values). Ford (1987) asked the question whether individuals with autism are capable of engaging in mutually satisfying relationships. She suggested that, without ignoring the social difficulties of individuals with autism, the potential exists for the development of an intimate social and sexual relationship that could give mutual pleasure. She stressed the importance of giving information on four topics: biological and social/emotional growth; social skills development and families; (sexual) exploitation; the development of intimate relationships. According to the needs of the individual with autism informational goals have to be chosen and opportunities to use the taught information have to be created. Sex education finally has to be embedded in social skills training and opportunities to interact with peers must be organized. Koller (2000) gave a short overview of teaching methods and sexuality curriculums for people with autism. She concluded that the question is not if sexuality education can or should be provided for individuals with autism, but how it will be offered. Pukki (2003) stressed the fact that much of the literature on ASD and sexuality focuses on problems. Lawson (2005) hoped that "sexuality and its rightful, respectful and fullest expression" would be available to individuals with ASD as it is to neurotypicals.

Only a handful of sex education courses for individuals with ASD have been published. Lieberman and Melone (1980; Melone & Lettick, 1983) developed a curriculum on sexuality and social awareness training for "moderately autistic and/or neurologically impaired individuals". They suggested that the existing programs on sexuality training for people with mental retardation couldn't be used for people with autism due to their problems with social relations and communication. Melone and Lettick (1983) reported that the program was extremely successful, according to the pre- and posttest scores and behavioral observations. The data on which this conclusion was based, have not been published. Detmer, Dalrymple and Sinex (1987) published a booklet with concrete advices on sexuality training for people with autism. The last revision of this brochure (Gray, Ruble & Dalrymple, 2000) includes the assessment of sexual knowledge, the development of an individualized curriculum and an overview of teaching techniques. The curriculum contains learning about growth and development; learning about appropriate touching; prevention of sexual abuse; masturbation (how, when and where); establishing a menstrual routine; the development of dating skills. The booklet finishes with an account of the model of Hingsburger, Griffiths and Quinsey (1991) applied to persons with autism, to understand and intervene with

inappropriate sexual behavior. Meister et al. (1994) have developed a group format for parents of individuals with autism to empower them on the sexuality education of their children. The format contains sessions on sexual development, masturbation, sexual abuse and talking on sexuality. Pre- and post-group measures were used to assess changes in levels of parental stress and a goal attainment scale was completed. The authors concluded that the parents did become more comfortable being sexual educators. The results of the objective measures have not been published. Newport and Newport (2002) were the first persons with a diagnosis of AS to write a book on sexuality in which they give advice on sexual issues to adolescents and adults with ASD, their parents and caregivers. Hénault (2006) recently published a sociosexual education program intended for adolescents and adults with Asperger's Disorder. Besides the usual sex education topics the course also covers gender identity, sexual orientation, emotions, love and friendship, intimacy and communication.

Sex@autism.come, a new sociosexual education course

In 2002, a group of Belgian professionals working in the field of autism started developing a sociosexual education course intended for borderline/normally intelligent adolescents and adults with ASD. In 2003 VMG, an organisation for people with mental retardation published a sociosexual education course for adolescents and adults with mental retardation. The slides used in this program turned out to be very suitable for people with ASD and could be used without changes. The didactic methods and other materials of the program however had to be adapted to the specific needs of persons with ASD. The Dutch version of the first part (sex education) of the program "Seks@autisme.kom" (Hellemans, Vermeulen & Conix, 2006) will be published shortly. The program is based on a broad view on sexuality. Sex education in the narrowest sense has to be related to social and communication skills training, learning about emotions and desires, relational education, development of identity, coming to terms with autism, acquiring a set of norms and values and preparing for adulthood. The second part of the program which is in preparation, will cover these topics. The program is focused on the positive aspects of sexuality. Individuals with ASD have the same sexual feelings and desires as everyone else and have a right to a satisfying sexual life. The program has to be embedded in a schedule of sexual and social-relational education which ideally should contain four steps:

1. Parents give basic sexual education from an early age on.

2. Formal sexual and social-relational education in individual or group sessions is started at about 11 years. Some of the didactic material of "Sex@autism.come" may be used. Once a year booster and elaboration sessions are being organized. The complete program is suitable for groups of adolescents of about 15 years. The program is accompanied by sessions for parents.

3. Participants in the training have individual sessions with a coach or mentor in which important topics of the program are individualized and elaborated.

4. Parents and caregivers take care of the transfer of skills to the daily practice.

Sometimes a fifth step is necessary: therapists with experience in autism and in sexual problems have to treat specific sexual problems (e.g. paraphilia) which have come to the surface in the course of the program.

The first sex education-part of the program contains 10 sessions of 2 hours with a break. All of the slides, drawings and worksheets are available on a CD-ROM delivered with the book. The material may be adapted to the needs of each particular individual or group. The participants have a file in which they keep the abstracts of the sessions, copies of slides and drawings and a list of new words and concepts. After each session the teacher makes an abstract on "green pages". Topics to be discussed with the individual mentor are written on "yellow pages" and included in the file to be shown to the mentor.

Content of the workshops:

Session 1. The male and female body.

Session 2. Physical changes during the course of life

Session 3. Sexual feelings

Session 4. Masturbation

Session 5. Sexual relations

Session 6. Pregnancy

Session 7. Parenthood and heritability

Session 8. Homo- and bisexuality

Session 9. Sexually transmitted diseases

Session 10. Contraception

The didactic method takes into account the typical problems in information processing of people with autism such as thinking and perceiving in details; literally misunderstanding information; rigidity in applying rules; information overload when too many details are presented versus filling in the gaps with faulty beliefs when too little information is provided. The didactic material is simple, clear and explicit. Photographs are preferred to drawings since they are easier understood by individuals with ASD. Each session usually is started with a slide. Questions are asked about the images ("do you know what this photograph shows?"). Step-by-step knowledge and skills are expanded. Not only factual knowledge is being taught but also social knowledge (e.g. perspective-taking, sociosexual rules, norms and values, illegal sexual behaviour). The try-outs of the new program "Sex@autism.come" were very successful. A Nonequivalent Pretest-Posttest Control Group Design-study has been done. The results are not yet complete.

Conclusion

1. Individuals with ASD are sexual beings with sexual feelings, needs and behaviour. As for neurotypicals education on sexuality and relationships is important for them. A shortage of sex education programs specifically intended for persons with ASD exists. The new courses of Hénault (2006) and of our group are filling the gap for borderline/normally intelligent individuals with ASD. Sex education programs for less able individuals are very much needed.

2. It is important to do research on the results but also on possible negative side-effects of these programs.

3. Finally it is necessary to take care of the implementation of these programs. Van Bourgondien et al. (1997) reported that the majority of staff members working in group homes for adults with autism hadn't received any training in the handling of sexual issues. Parents often feel incompetent to give sex education to their child with ASD. Training sessions for parents and caregivers have to be organized.

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0034

INFANTS AT RISK: EARLY SIGNS OF PRE-AUTISM DIAGNOSIS AND TREATMENT

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In the eighties, when the age for diagnosing autism was lowered to three years old (PDD was unknown in those days), we thought this was an early diagnosis.

In the nineties, the diagnostic age was lowered to two years and we realized that even that is not early enough.

Over the past eighteen years of interviewing parents of children who have been diagnosed with the autism spectrum, I have been hearing the same words over and over again:

"My child had a completely normal development until the age of one year, and then I began to notice regression..."

We often ask ourselves the crucial question: What happens during those months of transition between the first year of life and the second that causes regressive processes in such cases?

If we base our knowledge on a theory like that of Mahler who talks about the process of emotional development of a baby in three stages, the autistic stage, the symbiotic and the separation-individuation stage, we can construct a number of hypotheses to explain this thin line and maybe refute them again.

On the other hand, I occasionally hear a mother saying, "From the beginning I felt something was wrong with my baby, but everyone told me I was being a hysterical mother"...

Deep inside them, mothers know what scientists discover – that relationships between babies and mothers are interdependent…

Over the past decade, I have studied the first year of life of children who have been treated at the Mifne Center, which treats young children with autism.

More and more families came to their initial interview at the clinic, equipped with extensive documentation about their baby from the moment it was born. This material is fascinating if it is taken apart carefully.

The symptoms observed in some of the babies were minor, meaning that the majority of parents would probably not notice anything irregular.

When watching the videotapes of these babies from an analytical aspect, however, it is possible to gather data indicating warning signs, or what the Americans would call "red flags".

Diagnosis

While speaking about diagnosis during the first year of life, we have to be careful and use the term "an **attachment disorder which may develop into a syndrome diagnosed later on as the autism spectrum".**

There is no comparison between the effect of intensive treatment on an eight month-old baby and one aged eighteen months.

The developmental process of the brain during the first year is the most dynamic of our entire lives. The baby is exposed to stimuli that have a decisive effect on cell growth and this opportunity never returns.

This is related to the early signs in pre-verbal infants during their first year of life, as they were identified at the Mifne Center. Most of the signs are familiar but perhaps not in this format and at this young age.

The signs relate to an ongoing disorder in attachment development during the first year of life.

Red flags:

1. **Excessive passivity**

Lack of crying, immobility, lack of interest in surroundings. These babies show an overt tendency to passivity and do not achieve those crucial stepping stones of initial interest in their surroundings, as can already be seen from two and a half to three months.

We often hear it said, my child is an angel, he never cried, we didn't know there was a child in the house, from the start I slept through the night….

2. Excessive activity

As with constant crying that hasn't had a medical diagnosis, this is a lack of physical calmness, which is a symptom at the opposite pole of the previous point. It is interesting to note some children who were obviously passive, changed to being hyperactive during the second year of life.

A study by Professor Volke in Zurich shows that babies who cry incessantly are more likely to become hyperactive.

3. Refusal or resistance to feeding or nursing

The whole subject of breastfeeding is a topic unto itself.

A high percentage of children treated at the Mifne Center who were diagnosed with the autism spectrum, showed an inability to adapt or regulate their eating habits already during their first days of life, or at least during the first months.

It is interesting to monitor these children whose sense of smell is so delicate and who tend to smell every object, especially foods, and to hear from the mother what went on right from the beginning.

Some mothers report that their baby screwed up his face in a way that looked like disgust by the smell of the breast.

4. Lack of reaction to a voice or the presence of a parent.

Doesn't turn his head, doesn't smile or babble. The first thing that must be tested thoroughly is the child's hearing. In most western countries, gone are the days when children with autism were diagnosed as hearing- impaired and treated with hearing aids.

Does audio sensitivity cause gradual disassociation?

According to Francis Tustin, a psychoanalyst and important researcher in the field of autism, the answer is a resounding – yes.

A baby who responds to the presence of a parent, but not to the sound of his or her voice, will be assumed to have a hearing impairment, whereas a baby who responds to a voice but doesn't react to a presence, will be assumed to be indifferent or having developed a fear of the adult in question.

Babies who suffer from fear or indifference to their surroundings don't usually begin to babble in the early stage.

Babbling is a function of bonding in the same way as language is a function of contact.

5. Aversion to parental touch (or any other person)

Brainwave tests show that the brain responds to touch already during the seventh month of pregnancy, which supports the assumption that the baby is capable of responding to attempts like these even when he is still in the womb.

In reference to the previous category it is interesting to mention Alfred Tomatis who developed an auditory method that relates to the skin as a continuation of the ear, the tactile part as one large ear!

What was considered for years as a lack of sensitivity is now clearly oversensitivity.

6. Lack of direct eye contact (Eye contact exists with objects)

Making eye contact is not easy. We all know people who find it hard to look you in the eye. More than any other part of the face, the eye is the most sensitive, the most revealing, the most self-conscious.

Even the word "pupil" comes from the Latin word "pupa" for doll.

In the book called "Mother-Infant Attachment and Psychoanalysis – the Eyes of Shame", Mary Ayer offers a fascinating theory about the eye of shame. She tries to understand what the baby sees when he looks into his mother's eyes.

She suggests that shame is a characteristic that originates from environmental failure and is already rooted in the early developmental stage that began with the meeting of the infant's eyes with those of his mother, and that this has a decisive emotional effect on the rest of his life.

7. Delayed motor development

This is often characterized by hypotonia and all developmental stages are delayed. There are also children with high stiff muscle tone. And yet this parameter should not represent a significant criterion because some of the children who are diagnosed later on with autism do indeed show an especially quick motor development.

8. Rapid growth of the circumference of the head in relation to the initial point

In 2002, Professor Courchesne published his research in San Diego, in which he compared forty-eight young children diagnosed with autism with a control group of normal children.

The group of autistic children showed the circumference of the head as being smaller at birth, but during a year of growth, the circumference grew rapidly compared to the other group.

A reasonable definition is offered by

Dr. Margaret Bauman, Harvard Medical School:

Normal brain development is not a monologue but a dialogue, in which the brain generates neural circuits and the child's experiences determine which ones survive.

The first year of life is a critical period for this experience-guided growth.

The brain's circuitry would expand haphazardly as cell growth outpaced experience, creating a chronic sensory overload, which could possibly explain sensory oversensitivity in such children.

The first unit for Detection of Infants at Risk with an Attachment Disorders was established by the Mifne Center at the Sourasky Medical Center in Tel-Aviv.

The unit is directed under the direction of Dr. Kaysar, using the ESPASI diagnostic scale developed at the Mifne Center (presented at the conference).

At least two characteristics of the eight signs have to exist, over a period of at least three weeks.

All the relevant medical tests have to be carried- out before testing for a suspected attachment disorder.

Infants who are found at high risk following to their assessment, are referred to the Mifne Center.

The Mifne (Turning Point) Center was established in 1987.

 It was the first model of early intervention for autistic children in Israel to recognize the importance of individual therapy, intensive treatment and parental participation.

The basic concept underlying the therapeutic model, views the family as an organic unit. This slide, reminds us of the family constellation into which the child is born, as well as the reciprocal influences between the two systems, mother – child, that are influenced by broader ones.

To understand the baby's characteristics we first have to understand the inner world of his parents. The nuclear family takes an active part in the intensive therapy, that starts with a two weeks of a residential segment, all day, 7 days a week.

This is followed by an aftercare program when the family returns home.

This short term therapy aims to give the family the opportunity reflect upon themselves and their baby, to get a better understanding of their needs.

During the process, parents learn how they can create a supportive, encouraging environment, to help their child thrive.

Special attention is given to the siblings in the family, who are included in the program according to their age.

A video case study

The baby, Ada, 5 months old, the youngest infant ever treated at the Center, underwent ten days of intensive sensor and emotional process. She was treated during all her waking hours, with the family taking an active part in the therapy and receiving an enormous amount of guidance.

Ada was treated at home for a period of a year by her parents and one therapist.

At two years old she began to attend kindergarten with her peer group. Ada is now six years old, she is functioning well above her peer group in all spheres of development. She is very attached to her parents and sister

0035

THE EARLY DETECTION OF PRE-VERBAL AUTISTIC CHARACTERISTICS USING AUTISM DETECTION IN EARLY CHILDHOOD (ADEC).

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Abstract

While children under two years of age can often be identified by trained clinicians the behaviours critical for early diagnosis have not previously been recognised, operationalised and documented, thereby making diagnoses difficult for non-specialists. Tools typically used to facilitate diagnoses often show poor psychometric properties with children under three years of age, with many tending to over-identify this cohort. Using available literature, existing tests, and our own research we have identified 16 behaviours we consider best predict the development of Autistic Disorder in young children. This paper presents the psychometric qualities of this new screening tool: Autism Detection in Early Childhood (ADEC). The ADEC provides clearly operationalised behavioural measures thought to be indicative of Autism in the early years and, as it focuses on pre-verbal behaviour, it is suitable for children as young as 12 months. Data shows the ADEC to have excellent test-retest reliability as well as inter-rater reliability. Convergent validity was assessed by correlating total scores on the ADEC with scores obtained using three commonly used autism diagnostic instruments: CARS, CHAT and ADI-R. Overall the data show the ADEC to be an extremely effective screening tool, with excellent specificity and sensitivity, that can be used with little training to identify children suspected of having or of developing Autism.

Introduction

The behavioral manifestations indicative of a diagnosis of Autistic Disorder (AD) include social and communication difficulties and ritualistic behaviours. Although some of these behaviours may be directly related to the neurological origins of the disorder, others may develop as a result of these earlier deficiencies. Young & Brewer (2002) described these early symptoms that are considered to be direct manifestations of the underlying neurological abnormalities as core-deficit linked behaviors. These behaviors are present in very young children with AD, but may be modified or disappear as the child grows older. As the child develops and becomes more affected by environmental factors such as intervention procedures, secondary behaviors may develop, perhaps as a way to compensate for these underlying neurological deficits (Young et al., 2003). The ideal time to make a diagnosis of AD should therefore be at a young age, preferably before the age of 2 years, when core-deficit linked behaviors are most conspicuous and in their purest form (Siegal, 1994; Sigman et.al., 1995). Despite this, our understanding of autism typically relates to behavioural differences more common in older children. Further, most commonly used diagnostic tools require the absence of behaviours, the non-appearance of which might not be significant at 18 months. Examples of such behaviours include verbal skills and the development of peer relationships. As a result many practitioners who are naïve to other more significant signs of the disorder miss the diagnosis entirely. Those practitioners who may have some suspicions but are not aware of other indicators of the disorder are inclined to maintain a "wait and see" approach until it is clear that the failure to develop these recognised abilities has become significantly atypical. This ultimately causes a delay in diagnosis which can cause distress for families who are seeking answers, and frustration when the diagnosis finally arrives and they reflect on the valuable intervention time lost.

The aim of this research is to present a screening tool called Autism Detection in Early Childhood (ADEC) [1]. The ADEC clearly operationalises these core-deficit linked behaviours in order to create a greater awareness of these early signs. The ADEC is marketed as a screening tool that can be used by non-clinicians. It allows people involved in working with the child, including the parents, to understand the specific deficit(s) the child is presenting with, thus allowing these behaviours to be targeted through intervention. By using this tool a clinician can articulate the specific "autistic traits" that cause them concern rather than suggesting this as a potential diagnosis, which is in itself alarming

As yet there is no tool that is sensitive to autism in the early years that does not over-identify children with other diagnoses. Two of the most common tools used to identify the disorder have problems. The Childhood Autism Rating Scale (CARS, Lord, Rutter & LeCouter, 1994) is one of the most widely used tools developed for the detection of Autistic Disorder in children over 2 years of age. Nevertheless, the authors recognise it is not reliable for use with children between the ages 2 and 3 years (Lord, et. al, 1997) or with older children with mental ages below 18 months. Moreover, as it predates DSM-IV and DSM-IV-TR criteria it does not reflect current diagnostic criteria. As a result, many of the behaviours addressed in this scale are not specific to AD as it is currently diagnosed. These behaviours include, among others; poor language, lack of affect, self-injurious behaviours, cognitive impairment, shyness, hyperactivity or hypo activity, taste sensitivities and fearfulness. As this tool only provides a global score, increased

scores on any of these behaviours not specific to autism could cause an elevated score, resulting in a clinician considering a diagnosis of autism. In addition, a trained clinician is required to administer this tool as familiarity with autism and typical development is required in order to make comparative judgments.

Unlike the CARS, the Checklist for Autism in Toddlers (CHAT) was specifically designed to detect autistic disorder in children as young as18-months. Recent research, however, using 16,235 children showed that the CHAT was able to detect only 19 of 50 cases of childhood autism (Baird et al., 2000). The CHAT has been shown to have a very high specificity, that is correctly classifying typical children as typical (around 98-100%). However, the sensitivity (identifying those with autism as having autism) of the CHAT is fairly low: only 20-38% of children with autism were identified using the CHAT, depending on the classification of risk of autism. Screening a month later showed that sensitivity dropped to 19-20% and the specificity rose to around 100% (Baird et al., 2000). Although the CHAT was designed as a screening tool, not a diagnostic tool, its poor sensitivity makes its usefulness questionable.

The ADEC was designed to overcome some of these limitations. Behaviors were identified and operationalized using retrospective parental reports (see Young, et al., 2003), literature reviews, pilot research (Royal, 1998,) and video analyses (Clifford, Young, & Williamson, 2006). The ADEC includes 16 distinct items with each item directed at behaviours considered to reflect core-deficit linked behaviours (see Appendix A). All behaviors are operationalised in terms of observable characteristics, making its implementation suitable for individuals with limited training. The ADEC includes a manual with examples and non-examples of each behavior to enhance inter-observer reliability (Young, et.al., 2002). In addition, each behaviour is considered unique to the disorder of autism or not commonly found in children with other disorders. Previously published work using the ADEC has shown it is able to correctly differentiate children with autism from children with other disorders and typically developing children (see Young, 2006).

This paper presents data relevant to the psychometric qualities of the ADEC. The aim was to develop a screening tool that was easy to administer, required little training or familiarity with AD, but was a reliable and valid tool able to correctly identify children at risk of developing the disorder, while excluding children who did not have AD or presented with a disorder other than AD.

Method

Participants

The data reported are from 269 participants involved in a number of studies being conducted within the Early Intervention Research Program at Flinders University in South Australia. One hundred and forty-nine participants in this study were diagnosed as having AD (131 male, 18 female) either by two independent practitioners or through a multi-disciplinary assessment at Autism SA. Of the remaining participants, 60 were considered to be typically developing (39 male, 21 female) (TYP), and 60 were diagnosed as having a language disorder or other disorder (42 male, 18 female). This group is referred to as the "other developmental disability" group (ODD). In order for a diagnosis to be accepted by Autism SA, and thus allowing a child to be eligible for state funded services, they must obtain a CARS score of more than 30 and meet DSM-IV-TR criteria for Autistic Disorder.

The data were not all collected at the one time as CARS scores were collected from trained professionals at the time of diagnosis and the ADEC score were collected following referral to the EIRP. If the referral was not accompanied by a CARS score, and therefore a diagnosis was required, a CARS, ADEC and Autism Diagnostic Interview- Revised were completed at that time. The ages of the first assessment we have on each child are presented in Table 1.

Table 1. Mean age in months of first CARS and ADEC scores for each group.

	CARS	ADEC

Group	M	SD	M	SD
Autistic Disorder	35.78	12.37	41.46	14.78
Other Disability	38.04	15.57	38.8	15.41
Typically Developing	N/A	N/A	41.3	14.00

Materials

The Autism Detection in Early Childhood (ADEC) focuses on preverbal behaviors which can be identified in early infancy and are not dependent on receptive language. It has a behavioural orientation that leads to objective measurement: each characteristic of interest is operationalized in terms of overt behaviours that can be easily observed and objectively measured. Such behaviours include failure to follow a point, lack of response to name, poor joint attention and limited play (see Appendix A for full list of items). .

The Childhood Autism Rating Scale (CARS; Schopler et al., 1980) was administered by a trained clinician as a measure of the severity of autism and a comparison measure for the ADEC. The CARS is a diagnostic tool designed for use for children aged over 2 years, with good inter-rater reliability, and high internal consistency and concurrent validity (Schopler & Mesibov, 1988). In addition, Schopler et al. report the CARS to have high criterion-related validity when correlated with clinical ratings. Researchers administer the CARS to the primary caregiver by asking questions to elicit responses concerning areas of the child's life. Subscales include measures of imitation, verbal and nonverbal communication, body use and activity level. Scoring is based on a continuum, with 1 indicating age appropriate behaviour, 2 indicating mildly abnormal behaviour, 3 indicating moderately abnormal behaviour and 4 indicating severely abnormal behaviour.

The Checklist for Autism in Toddlers (CHAT; Baron-Cohen, Allen & Gillberg, 1992) was designed as a screening tool for infants aged 18 months. It consists of a 9-item parental report and a 5-item observation based report. Only 5 items are used in the algorithm to determine likelihood of AD (pretend play, protodeclarative pointing, following a point, pretending, producing a point). If a child fails all five key items, they have a high risk of developing autism.

The Autism Diagnostic Interview- Revised (ADI-R; Lord, Rutter, & LeCouteur, 1994) involves an extensive parent/caregiver interview which seeks information about more than 100 specific behaviors exhibited currently and in the past. Substantial training in the administration is required. The ADI-R is a thorough and seemingly exhaustive, semi-structured, investigator-based interview. Results of psychometric examination indicate that the ADI-R is a reliable and valid instrument for diagnosing autism in preschool children.). Inter-rater reliability, internal consistency and interclass correlations are very high for children over the age three years (e.g., Lord, et al., 1994). Research has as yet failed to demonstrate the efficacy of this test with children less than 20 months.

Procedure

Participants for whom data are presented were each involved in various studies being conducted at Flinders University. Although all children completed the ADEC, CARS were not conducted on 18 of the typically developing children. There was no reason to suspect the development of these children was anything other than typical as all were attending mainstream day-care centres. Parents and care-givers were asked if they had any concerns about each child's development and all responded in the negative. .ADI-R scores are only available for those children who were diagnosed by the first author (N=82).

Results

Inter-rater reliability

For the ADEC, inter-rater reliability was available from 179 assessments over a 2.5 year period. Twelve raters participated in these assessments. The correlation between the first and second ADEC administered, irrespective of rater was very high (r=.97, p <.001). Similarly a high inter-rater reliability was found for the CARS using 216 participants over a 2.5 year period involving the same 12 raters (r=.90, p <.001). CHAT scores were collected from 167 participants on two occasions. Once again the interval ranged from two weeks to 2.5 year using 12 raters and a high inter-rater reliability was obtained (r =.95, p <.001).

Internal Consistency

The ADEC was shown to have very good internal consistency; Cronbach's α = .85. Cronbach's α did not differ significantly with the removal of any specific item. Total scores on the ADEC also exhibited excellent test-retest reliability. The correlation between ADEC score at diagnosis and the child becoming involved in the EIRP was high (r =.82, p <.01). The interval between these two data points ranged from 3 weeks to 18 months.

Further analyses were carried out on test-retest reliability and inter-rater reliability assessing each of the ADEC items separately, administered with a two week interval by different raters. All items exhibited very good reliability (r > .30, p <.001). The following items: use of words, gaze switching, use of gestures, following a point and functional play were all greater than .5. Response to name, upset when blocks were disturbed and response to sounds were not as reliable as the other measures.

Diagnostic discrimination

Three developmental categories (autism diagnosis, typically developing and other disability diagnosis) were compared for each diagnostic tool. Means, standard deviations and ANOVA statistics are shown in Table 2 for comparisons of ADEC, CHAT and CARS scores across the three developmental categories.

Table 2: Descriptive statistics and ANOVA results of ADEC, CHAT and CARS scores comparisons across developmental category for all children.

Instrument	Developmental Category	M	SD	ANOVA statistics
ADEC	Autistic	15.32 [a]	6.76	
	Typically developing	4.54 [c]	4.27	F (2,265) = 69.15 p < .001
	Other disability	9.00 [b]	6.68	η^2 = .34
CHAT	Autistic	2.22 [a]	1.79	
	Typically developing	0.49 [b]	0.89	F (2,151) = 16.43 p < .001
	Other disability	1.54 [b]	1.60	η^2 = .18
CARS	Autistic	34.12 [a]	5.20	
	Typically developing	16.54 [c]	2.08	F (2,2389) = 168.8 p < .001
	Other disability	27.50 [b]	6.24	η^2 = .59

Note: Means with different (letters as) superscripts reflect significant post-hoc differences using Tukey's homogeneous subsets post-hoc tests.

It is evident that all three diagnostic tools are good at discriminating between those children who have been diagnosed with autism and those who are typically developing. Overall, the CARS provided the best discrimination between groups. For these data, the CHAT was the only instrument to discriminate only between the autism and non-autism groups. However this is likely to be a function of the smaller sample sizes of the two non-autism groups for this instrument and probably reflects a lack of statistical power. Both the CARS and the ADEC were shown to not only discriminate autistic children from non-autistic children but also to discriminate between the "other disability" group and the typically developing children, implying that both instruments not only assess autism but may also tap into the broader construct of disability, more generally. The CARS provides greater information about discrimination between all three developmental groups as evidenced by the greater effect size (η^2 = .75 .59). Nevertheless the greater effect size associated with the CARS appears to come at a cost where those with other disabilities may be over-diagnosed as having Autistic Disorder.

This set of analyses was repeated removing all children over 42 months of age. The descriptive statistics are shown in Table 3. For younger children, a similar pattern of results was obtained. However, with this younger group, the ADEC appears to offer advantages over both the CARS and the CHAT. Although the CARS has superior discrimination (η^2 = .38) compared to the ADEC (η^2 = .28), this is only in terms of discriminating between autistic and typically developing children. The second aspect of a good autism instrument is the discrimination between autistic children and children with other disabilities. These data show that the ADEC is a better instrument in achieving this goal. A comparison of the difference in means, between the other disability group and the (a) autistic and (b) typically developing children groups, highlights this interpretation. For the CARS, the difference between the other disability group and the autistic group is *smaller* (indicating that these groups are more similar according to the CARS ratings) than is the difference between the other disability group and the typically developing group (indicating that these groups are more different according to the CARS ratings). Conversely, the difference between the other disability group and the autistic group is *larger* than is the difference between the other disability group and the typically developing group.

Table 3. Descriptive statistics and ANOVA results of ADEC, CHAT and CARS scores comparisons across developmental category for children younger than 42 months of age.

Instrument	Developmental Category	M	SD	ANOVA statistics
ADEC	Autistic	15.11 [a]	6.44	
	Typically developing	5.65 [b]	3.90	$F(2,102) = 19.89$
				$p < .001$
	Other disability	9.52 [b]	6.33	$\eta^2 = .28$
CHAT	Autistic	1.75 [a]	1.56	
	Typically developing	0.50 [a]	1.00	$F(2,34) = 1.87$
				$p = .17$
	Other disability	2.40 [a]	1.34	$\eta^2 = .10$
CARS	Autistic	34.18 [a]	5.18	
	Typically developing	15.88 [b]	1.18	$F(2,87) = 26.26$
				$p < .001$
	Other disability	29.87 [a]	5.66	$\eta^2 = .38$

Note: Means with different (letters as) superscripts reflect significant post-hoc differences using Tukey's homogeneous subsets post-hoc tests.

Given the ADEC was designed for young children, only data for children aged under 4 years were included in the next analyses. Using an ADEC cut-off score of 13, the sensitivity (correctly identifying people who have autism) was 72 %. The specificity (correctly identifying children who are not affected) is also high at 80%. These percentages improve to 90% and 88% respectively when only younger children (less than 30 months) are considered (see Figure 2). These data are even more impressive when the ODD group is removed, given their diagnostic status was uncertain, and the comparison only involves those with a confirmed diagnosis of autism and typically developing children. Using a cut-off of 13 once again the sensitivity rises to 100%, while the specificity drops to 70% for all the children and 95% and 100% respectively for the younger children (less than 30 months). (see Figure 3).
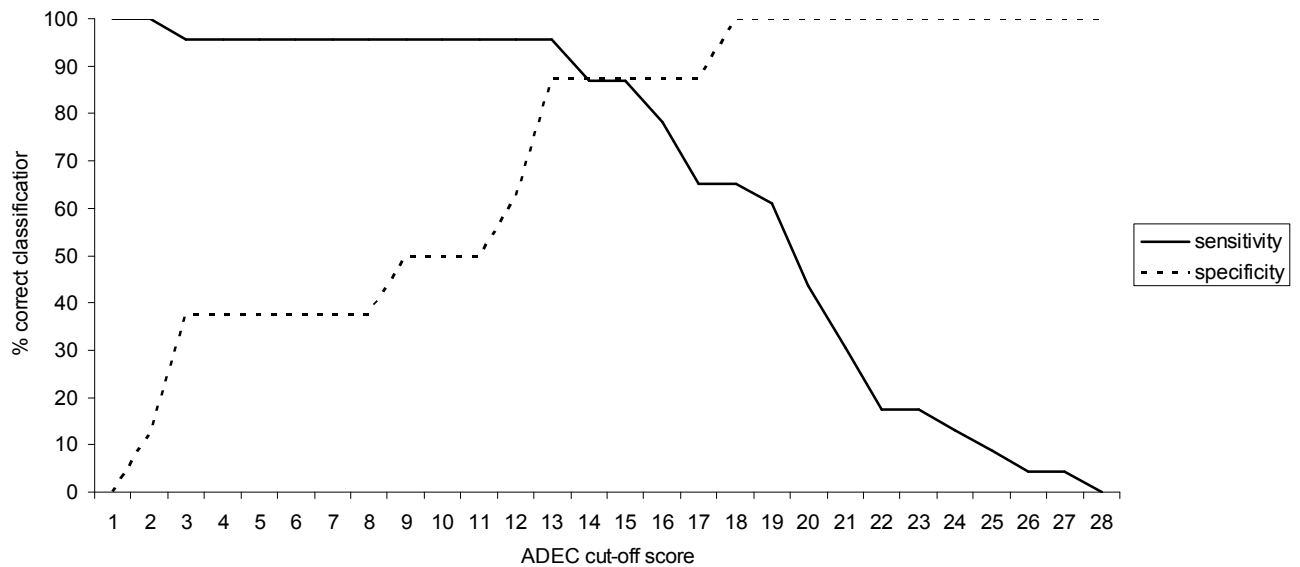
Figure 2 Discrimination using the ADEC as a function of potential cut-off score between (a) those with a confirmed diagnosis of autism [*n* = 23] and (b) those with [or likely to have] another disability but no confirmed diagnosis of autism [*n* = 8] for children up to 30 months of age.
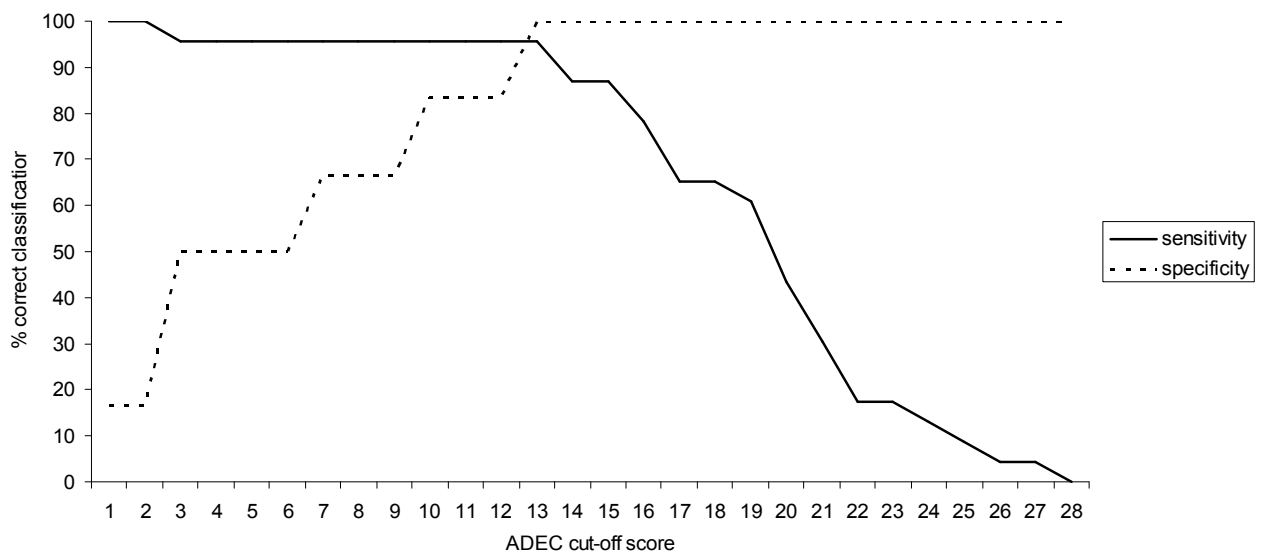

Figure 3. Discrimination using the ADEC as a function of potential cut-off score between (a) those with a confirmed diagnosis of autism [*n* = 23] and (b) typically developing children [*n* = 6] for children up to 30 months of age.

Construct Validity

Table 4 shows that the ADEC has excellent construct validity. It correlates well with the three other tests commonly used to detect Autism. Overall all three measures are well correlated.   These correlations are consistent for measure taken at diagnoses and also during the initial assessment for entry into the Early Intervention Program. .

Table 4

Correlations between ADEC and ADI-R total and subscales and CARS at time of diagnosis

	ADEC	ADI-R Total (N=85)	ADI-R Social	ADI-R Communi-cation	ADI-R Repetitive behaviours	CARS
ADEC		.		.		
ADI-R Total	.48**	.				
ADI-R Social	.51**	.87**				
ADI-R Communication	.56**	.81**	.69**			
ADI-R Repetitive behaviours	.08	.50**	.34**	.23*		
CARS	.34** (.57**)	.33**	.43**	.36*	.27*	
CHAT. (N=14)	-.62* (-.74**)[a]	-.46	-.53	-.69*	.33	-.33 (-.40)

* denotes p<.05

** denotes p<.01

[a]Numbers in parentheses show the correlations between these measures at initial assessment for EIRP where N=87.

Discussion

The data presented above show that the ADEC is an excellent screening tool that can be used to identify Autistic Disorder among young children. It has high sensitivity and specificity, is reliable and valid. The advantages of this tool over existing tools are that it is easy to administer, requiring less than 10 minutes, is based on clearly operationalised behaviours known to be indicative of autism in the early years and requires little training or familiarity with typical or atypical development.

Although many of the participants involved in this study were older than the age for which the ADEC was developed, this was unavoidable given diagnoses are typically still delayed. Nevertheless, the data reported here are consistent across all age cohorts and we found no evidence to suggest that the data differed for different cohorts. The possible exception here is that the test was more specific and sensitive among the younger children. This can only be viewed as positive, given other tests designed for this age group such as the CHAT have failed to meet these aims.

The ADEC was found to have excellent reliability (internal consistency, test-retest, & inter-rater) and was also found to reliably discriminate autistic children from typically developing children. Given all items showed acceptable levels of reliability and all contributed to the high internal consistency of the total scale suggests all items should be retained pending further analyses with other samples and other research groups.

Although the CARS showed the strongest discriminating power in distinguishing between three groups of children (autistic, typically developing, other disability) this superior discriminating power came at a diagnostic cost. ANOVA shows that the CARS appears to detect a general disability factor. In fact, mean CARS scores were *higher* for the other disability group than the autism group. Overall, the CARS taps into general disability but also over diagnosed (for autism) those with other disabilities. It should be noted here that as a score of greater than 30 is required for a diagnosis to be recorded in the State of South Australia, one might expect the CARS to provide superior diagnostic capabilities, given diagnoses in all cases were dependent upon this tool.

Overall, it is clear that the ADEC is presenting with sound psychometric properties and should be considered for use when screening for children with autism. Further research should involve longitudinal work with at risk children and studies that attempt to replicate thee findings.

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Appendix A

Behaviours assessed by the ADEC:

1. Response to name - child turns to look at tester's face when his/her name is called.

2. Imitation of motor behaviours - child copies physical gestures demonstrated by tester.

3. Line up blocks - child becomes upset when the tester disturbs a line of blocks.

4. Gaze switching– child shows an attempt to engage the caregiver's and/or tester's attention to object/event.

5. Eye-contact - child looks into tester's eyes during a game of peek-a-boo.

6. Use of gestures – child spontaneously (without prompting) waves goodbye

7. Appropriate "functional" play - child plays using toy in the way it is intended.

8. Pretend play – child uses an object as if it is another object, or attributes properties to an object which it does not have.

9. Reciprocity of smile - child responds to the smile of the tester/caregiver by smiling in return.

10. Response to sounds - child demonstrates unusually adverse reaction to familiar household sounds.

11. Gaze monitoring – the either child follows tester's point or gaze by turning their head to look in the same direction in which the tester is looking,

12. Response to verbal command – child responds to caregiver's verbal command.

13. Demonstrates use of at least one word – child uses a word, may be as a response to prompting from the caregiver.

14. Appropriate posture for being picked up - child assumes appropriate posture (raising arms and/or elbows making armpit/s available) when caregiver approaches them to lift them up.

15. Appropriate posture: nestling - child nestles into caregiver's body when held/picked up.

16. Ability to Switch Tasks - child is happy to follow testing procedure and change tasks as the testing demands.

0036

ADULT CHILD INTERACTION THERAPY USING VIDEO: A PRELIMINARY INTERVENTION PROGRAM FOR PRE-SCHOOL CHILDREN WITH AUTISM

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1. Introduction

The purpose of this paper is to describe a preliminary treatment model, Adult Child Interaction Therapy (ACIT), which has been adapted to be used with young Autistic Spectrum Disordered (ASD) children and their carers prior to them beginning enrolled in a structured course of Early Intervention.

This paper is structured as follows- Firstly, a brief introduction into Parent Child Interaction Therapy (Cummins and Hulme, 1997; Kelman and Schneider, 1994) and adult-child patterns of interaction will be discussed. This will then be followed with how ACIT has successfully been adapted and used as a preliminary treatment program for young Arabic speaking children with Autistic Spectrum Disorders. Cultural and linguistic considerations will be discussed. This will be followed with how the sessions are structured, how data is collected and how the parents' progress is evaluated. Based on clinical observations and parental report the effectiveness of this type of therapy tool as well as the limitations that it presents will be briefly discussed. 'Adult' in this paper will be used to refer to the parent or primary carer.

The patterns of interaction between a parent and their child will vary considerably and will be affected by a number of factors, including the child's cognitive and language level, parent's educational level, and cultural and socio-economic background (Wall, 2004). Extensive research has been conducted into comparing differing patterns of interaction between parents of normal children and those of children with language and communication disorders (Fey, 1986; Peterson and Sherrod, 1982). Parental directiveness has been found to be negatively correlated with the rate of language learning (Cross, 1978). Excessive use of questions and use of imperatives has also been found to be negatively correlated with language acquisition (Gleitman and Gleitman, 1977). Children need to receive an input that is neither too simple nor too complex (Barnes et al, 1983). In addition, many therapy models are based on analysing various components of interaction and how the interaction can facilitate the development of language (i.e. Hanen and Floor Time).

2. The Philosophy of Adult Child Interaction Therapy

ACIT focuses on the interaction between the parent and the child and is based on the Parent Child Interaction (PCI) therapy model (Kelman and Schneider, 1994). The PCI therapy model is also a pre-school program of intervention and is used for the management of children with varying degrees of language difficulties. The PCI program (Kelman and Schneider, 1994) operates over a six-week period and the child attends twice per week. The package of care consists of a three-step assessment process, and includes a detailed parent interview, a child assessment and a parent-child interaction assessment. Once the child is enrolled onto the six-week course the parent and child receives weekly 20 minute individual sessions as well as the child attending weekly group therapy sessions. The parent also attends a weekly parent group meeting. Each child's progress and parental goals are reviewed at the end of the course, and future management is discussed. The families are then offered a follow-up appointment three months after completion of the course when the child is reassessed and progress is measured. In a preliminary study conducted by Kelman and Schneider (1994), 28 language impaired children aged between 3;03 to 5;01 were followed through a course of PCI and then reviewed three months later. At the end of the therapy 88% of the parents had achieved their goals. Regarding the children's development, 50% of the children were discharged at the review and 46% of the children who attended required ongoing structured therapy input for treatment of their language impairment.

This is also the premise and motivation of ACIT. Studies have shown that an adult's changing the patterns of their own verbal and non-verbal behaviour can improve the child's communicative competence without the need to focus directly on the child's language (Kelman and Schneider, 1994; Lamb and Easterbrooks, 1981; and Cheseldine and McConkey, 1979). Although this may be true for language-delayed children, children with ASD also require long term, structured intervention. The primary aim of the PCI therapy is to " *help the parent identify and modify these patterns so that the underlying difficulties could then be treated more effectively*" (Kelman and Schneider, 1994, page 92).

What distinguishes the ACIT model from other similar therapy models, although the underlying philosophy is the same, is the detailed analysis of the parent's verbal and non-verbal behaviour in relation to the interaction with their child, using video playback. The parent's understanding of their non-verbal and verbal behaviour therefore facilities the 'pairing process' and helps them gain a more accurate understanding the

child's strengths and needs. The pairing process is part of the verbal behavioural model of teaching language. It is the initial teaching stage preceding the teaching of discrete trials, where the adult establishes a relationship with the child and identifies reinforcers.

During the pairing process the adult is expected not to place any demands on the child and to provide tangible reinforcement with verbal praise, whilst observing their child's willingness to interact with them. It has the been the clinical experience of the author that many parents find this initial pairing stage difficult as they do not know or understand what is required from them.

Children will attempt to produce language which corresponds linguistically with the language used by the adult they are interacting with (Hausendorf & Quatshoff, 1992); thus, it is important that a parent is aware of the language they are using, i.e. syntactic and lexical use, and adapt their language according to the child's needs. For preschool ASD children who are often pre-verbal, this can be extremely challenging for the adults.

Many adults frequently report that they would like to know what they specifically can and cannot do during the pairing process. In addition, as adults we are often unaware of our interactive non-verbal behaviours until we observe ourselves on video (Cummins and Hulme, 1997). An adult may have been verbally told that they should not ask questions and should follow their child's lead, however, until they have watched themselves on video it can be difficult for them to assess their behaviour and how it is affecting their interaction with their child. In addition, with video play back the parent can actively observe their interaction with the support of the clinician by seeing their own accomplishments and the effect of the positive changes made. Subsequently, observations can be made by those involved in the interaction rather than by those who have looked on. From the analysis, aims can be identified and they can be objectively measured and observed.

2.1 The Adult Child Interaction Therapy Model

ACIT has been successfully used in Cairo for several years and has been adapted for young children on the Autistic Spectrum of Disorders (ASD) as part of an early intervention program. It is an initial treatment protocol adapted for Arabic speaking families from a variety of socio-economic backgrounds. It is used prior to parent and child being enrolled in an intensive early intervention program. It is therefore used either pre- or post diagnostically, with children aged between 2 to 5 years, although it can be used with older children. It is not a substitute for structured intervention but rather complements the child's therapy by ensuring that appropriate interaction and potential learning takes place across environments. It also works in a complimentary way with verbal behaviour and is used to facilitate the pairing process.

The importance of early intervention and structured supported parental involvement with ASD children is a well-established clinical protocol in the U.K. and the U.S (Wall, 2004). It is vital to involve parents in their children's therapy whilst ensuring that the parents are supported and informed. Most of the parents who are enrolled into ACIT either have not received a diagnosis for their child or a diagnosis has recently been made and they are emotionally vulnerable and affected by the early symptoms of their child. Due to their child's young age parents typically have difficulties playing and interacting with their child and the early symptoms exhibited by their child will cause a variety of psychological and physical stresses on the parent (DeMyer, 1979). The role of the clinician is to emotionally support the parent by providing them with the necessary knowledge so the parent is able to analyse their interactions and consequently facilitate the development of their child's communication and language skills. Due to varying socio-economic and parent educational levels it was important to develop a model, which is not dependent on high levels of literacy. By using video feed back and a structured rating scale it is therefore possible for the clinician to achieve this goal and for the parent to achieve their interaction goals.

Therefore, the main principle of ACIT is to develop a solid partnership with adults, establishing trust and an understanding of their child's needs. By enhancing the adult's knowledge and understanding of their child, through the clinician's theoretical and clinical expertise, the parents' objectives can be worked on with positive outcomes (Cummins and Hulme, 1997). The unique feature of ACIT includes the use of video, which is used for detailed analysis of the interaction between the adult and the child. This is used to highlight positive interactions that would otherwise be difficult to recall. Interactions are transient and often unnoticed. Children with Autism do communicate, but non-verbal or verbal positive interactions are often masked by sensory and attention difficulties.

Thus, to summarize, the most unique feature and what differentiates ACIT from other similar parent-therapist programs is the use of video that is used to analyse in minute detail the momentary nature of communication. In using video a visual record of most aspects of interaction between the adult and the child can be achieved from which detailed analysis can be made. Observations can be made by those involved in the interaction, i.e. the adult (parent/carer), rather than by those who have looked on. From the analysis, aims can be identified and they can be objectively measured and observed.

2.2 Linguistic and Cultural Considerations

The awareness of Autism in the Middle East has in recent years increased and has been supported by local and international non-governmental organizations, as well as by vast quantities of information available on the internet. However, the number of trained professionals in Cairo, both in the private and public sector, who work with and specialize in working with children and their families with ASD is very limited. In addition, the literature and resources available to parents in Arabic are sparse and mostly consist of translated literature that are often non-culturally specific (Fahim, 2004, UNESCO Beirut), although efforts in recent years are being made to rectify this situation.

In addition, many of the families of children requiring support are either from lower socioeconomic spheres, where levels of literacy may be limited and play materials are not readily available, or, from higher socio-economic spheres where the expectation is for the clinician and 'Nanny' to provide services, which are financially subsidized by the parent. Culturally, parents view doctors or clinicians as needing to take the lead role and do not understand why *they* are required to play with their child and not the clinician. The extended family plays a vital role in the dynamics of families in Egypt; it is therefore also important to involve other primary carers whilst still focusing on the parent.

Therefore, the following considerations were necessary when designing an appropriate intervention model- (1) to ensure that the adults would be actively involved from the very beginning, as they would have an ongoing fundamental role in the service provisions of their child, (2) to develop a relationship built on trust, so that the importance and differences of roles of the clinician and the adult are understood, (3) to create a system which would not be restricted to or dependent on high levels of literacy, (4) to have a system which includes mothers, fathers and members of the extended family, i.e. grandparents and (5) to use an intervention program that was not dependent on specific play materials or a specific environment. Really nice, just needs to be stated in parallel sentences..

3. The Intake Procedure and Assessment

The first step in ACIT is an adult interview that usually lasts between 60-90 minutes and is conducted with both parents and/or primary carers. This is a similar format to the one used in PCI therapy (Cummins and Hulme, 1997). Most parents will already have had an initial intake interview when first referred to the clinic and they will have answered questions regarding birth, developmental and medical history. The aim of the interview is to understand the structure of the home, the parenting styles, the involvement of the extended family, the parents' perception of the difficulties and what they are most concerned about. The parents primary concern may be difficulty during bath time and not the child's poor language skills. The adults are also invited to discuss their children's previous therapy experiences and their involvement with their child. It is important for the clinician to have an understanding of the child's natural environment so that recommendations and aims can be realistic and achievable. This also helps the clinician understand the level of emotional support that may be needed. At the end of the interview, the parents' concerns are summarised and the philosophy of ACIT is explained to them. The parents are given an appointment for an Adult-Child Interaction Assessment and they are informed that they will be videoed playing with their child. Written permission to make the recording is obtained and rarely do parents refuse.

During the assessment one parent and the child are observed playing together using a variety of play materials. Once the parent and child begin playing they are videoed by the clinician who remains in the room. Using the camera typically does not affect the behaviour of the parent or the child (Lytton and Zwirner, 1975; Hembree-Kigin and Bodiford McNeil, 1995). Depending on the child's age, the room is set out with a variety of toys to cover a range of play levels from exploratory play to pretend and symbolic play. These may include a water table, cause effect toys, play-dough and pretend toys. The recording is made for approximately 20 (below says 10)minutes. This helps the adult to feel comfortable with the idea of being videoed and allows the clinician time to analyse in detail both the adult and child's verbal and non-verbal behaviours prior to the start of therapy. The analysis is not shared with the adult but is used as a baseline for comparison at the end of therapy.

4. Therapy Sessions

The block of ACIT consists of five therapy sessions. Each therapy session lasts for 60 minutes and the adult and child are both present. Parents often bring a carer or extended family member who plays with the child during the parent clinician discussion. Sessions one to four are once a week. Session five, which is the review session, is conducted 6 weeks after completing session 4. Between sessions four and five the child and adult are enrolled into an intensive 6-week early intervention program, where parental involvement is still required.

4.1 Therapy Session 1 (week 1)

The adult and the child are invited into the therapy room where the play materials have already been set

up, covering the different developmental stages of play. A seating arrangement for the adult and clinician is set up at one end of the room for the adult discussion. The clinician begins by reiterating the philosophy of ACIT and makes the links between how this is related to the pairing process (Sundberg and Partington, 1998). The structure of the session is also explained so the adult knows what is expected of them. The adult is then asked to play with their child for 10 minutes as they would at home and that they will be videoed. They are reassured that they do not need to make their child perform. The clinician remains in the room and records the adult and child using a hand held video camera.

At the end of the recording period the therapist makes a positive statement about the interaction and invites the adult to join her/him to discuss the video at the table where the rating scale and a pen have been placed. The clinician then addresses the child and informs the child that they will play on their own while the adult who was videoed sits with the clinician. If a carer has also accompanied the family, they are asked to enter the room and play with the child while the clinician and the adult analyze the video. The adult and the clinician watch the video together and the adult is invited to make a positive statement about their communicative behaviour and how this has had a positive affect on their child's performance. The adult is then given the pen and the aims of the self-rating scale are explained to them. For each aim, the adult is asked to rate him/herself based on his/her observations from the video and not from their previous interactive history. The rating scale ranges from zero to three, where three signifies appropriateness and consistency of doing something and zero signifies inappropriateness or, that they never do something. The rating scale is a qualitative assessment tool, which is subjective, however its purpose is to help the adults analyze the appropriateness of their interactions and how this is affecting their child. It is important that the adults fill in the self-rating scale themselves. It also helps the adults take responsibility for their interactions in a positive non-threatening manner. If an adult and the clinician do not agree on one of the aims, the video is rewound and the adult is asked to comment in relation to what they have seen.

Once the rating scale has been completed the adult is asked to select an initial aim that they would like to work on and this is asterixed and dated. If the adult says they do not know how to choose an aim, they are guided to the aims that were scored lower. There is no hierarchy as to which aim should be worked on first; one aim successfully worked on will have a positive affect on other aims (Cummins and Hulme, 1997). For example, if the adult is not asking questions, this will affect their ability to talk about what the child is doing. If the adults position themselves where it is easy for them to see the child, the child will be more likely to initiate communication with them. It is important that adults choose the behaviour they want to change, as these will aid their understanding of their needs and their child's.

The adult is then asked to play again with their child, using their aim and a second video is made for 5-10 minutes. After the recording is made the adult is asked whether or not they felt that they had achieved their aim, using an open-ended question. The video is watched and the adult is asked to highlight from the video when they achieved their aim and to consider the positive impact that this has had on their child. The clinician positively reinforces this, by saying for example, "Did you talk about what he was doing here? And how did your child respond?" The clinician then reiterates the positive affect the adult's behaviour has had on the child. For example, "Yes, because you were talking about what he is doing he is looking at you, learning new words and allowing you to be more involved in his play".

The session is summarised and the adult is asked to play with their child using the selected aim for 10 minutes, for at least four times during the week. The 10 minutes is referred to as their "special time" (Cummins and Hulme, 1997). They are advised that it is more beneficial for them and their child to play consistently and frequently for 10 minutes at a time than it is for them to play for 30 minutes twice per week. Some adults require support in deciding when during the day they can conduct their special time, e.g. during bath time or in the morning before nursery and a brief discussion takes place as to where and when they will practice their aim. The aim is written at the top of a homework sheet, which is used by the adult as a record of their play sessions. The homework sheet has the aim written at the top and allows the adult to note what they played with, what they observed and how they felt the session went. This is later used to identify both reinforcers and activities that can be used with the child when they join the intensive early intervention program. For those adults who are illiterate, they are told the aim and asked to either keep a mental note of what they did or to ask a family member to act as a scribe.

4.2 Therapy sessions 2-4 (weeks 2-4)

The structure of sessions 2-4 follow the same format and sessions continue to be once per week. Parents have a new aim each week; therefore, they build on their success and have sufficient time to achieve one aim before trying a new one.

At the beginning of each session the adult is asked to recap their aim and asked how their special time sessions have been. The homework sheet is used to facilitate this dialogue and the adult is positively reinforced for carrying out their special time. The adult is then asked to play with their child using their previous aim. The adult and the clinician once again watch the video to assess whether or not the aim has been generalised and maintained. The adult is asked to highlight positive changes that they have

observed in their behaviour and in their child's. They are then asked to select a new aim from the rating scale.

For children who are ASD, changes in the child may be subtler, so the emphasis is placed on the changes in the adult's behaviour and how in the long run this will affect the child. The importance of pairing (Sundberg and Partington, 1998) and what this entails is again reiterated.

4.3 Week 10- the review session

After session 4 (i.e. the fourth week) the child begins a six-week early intervention program. During this time the child receives group therapy, individual therapy and the adult continues to attend a weekly individual adult training session. These sessions are not videoed. The aim of these session are for the adult to gain more insight into their child's behavioural needs, advice on how these behaviours can be modified and ideas for activities that are appropriate to be done during their special time. In addition, the clinician assists the adult in monitoring their schedule of special time and selecting appropriate activities. Three group adult- workshops are also conducted during the intervention block where principles of behaviour modification and an introduction to verbal behaviours are discussed.

 At the end of the six-week intervention program, i.e. week 10, the child's progress over the 10 weeks is evaluated. During the review session the adult and the child are video recorded for the last time. The adult and clinician watch the first video and the adult is then shown the second video to be able to observe the positive changes and progress in their child. The adult is asked to re-evaluate himself or herself using the same rating scale; however, their scores from their first evaluation are concealed. The adult's previous scores are then revealed to them to identify their progress. A diagnostic report summarising the therapy and the adult's aims is given to the adult with the necessary therapeutic recommendations as well as the video of all 5 video sessions.

5. Conclusion

The philosophy of Adult Child Interaction Therapy acknowledges that as clinicians we are not the experts on the child, this is the role of the parent. However, we can use the information given to us about the child as well as our clinical knowledge to build a complete picture about the child and their needs. Whilst the child is the focus of our work we must not ignore family issues, which will vary across time, differ from one family to another and vary from one culture to the next.

By being open to communication and encouraging the sharing of information we can help the parents to objectively understand the needs to their child and how they can support their child's communicative development. The use of video acts as a supportive tool where the parent is able to see how their behaviour affects their child's and vice versa. Having experienced positive interactions and established a trusting relationship with the clinician, the parent is better prepared and equipped to begin the journey of intervention.

The effectiveness of this treatment model has been supported through clinical observations. It has been used as a preliminary treatment over the past seven years and has been used with more than 60 children with ASD and their families. The clinical observations of the author and progress that has been observed in both the adults and the children have supported the use of this therapy tool. The observations come from qualitative analysis based from parental report and analysis of the videos. At this point no quantitative formal research has been conducted into the efficacy of Adult Child Interaction Therapy. The qualitative clinical observations of the author have shown that, although the rating scale used is a subjective method of analysing the adult's behaviour, there is a direct correlation between the parent's change in behaviour and the progress of the child.

When adults who have taken part in ACIT have been asked if they had found the therapy useful, most adults report that using this method of treatment facilitated the pairing process and that it had helped them to develop a positive relationship with their child. Most of the parents also reported that the use of video had helped them to better understand their child's needs and how their behaviour was directly related to their child's. Most of the parents are able to practice their 10-minute special time sessions at least three times per week and can generalise and maintain their aims across environments, whereas fewer parents are able to consistently conduct regular verbal behaviour sessions that require structured intervention.

There is ample evidence to support the notion of early identification and intervention for children with ASD (Wall, 2004; Davis, 2001;Powell and Jordan, 1997). Parents need access to relevant information to advise and guide them in using appropriate interventions with their child. Play is a powerful medium for learning, it is therefore crucial at an early stage to help the parent to plan and implement strategies that will encourage the development of their child's interaction, communication and imagination through play. Activities that use the child's preferred interests and toys are most likely to be successful. The parent is reassured that results will not be immediate, but, with patience and flexibility, once the child begins to

tolerate the adult's closer presence real progress begins. The author's clinical observations support the use of video when working with adults and children with ASD; however further research is required to determine the efficacy and value of ACIT as a treatment tool.

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0037

CHILDREN WITH AUTISM SPECTRUM DISORDER IN A RESIDENTIAL SETTING

Bente Laustsen, Rikke Linck

Sofieskolen, Bagsværd, Denmark

In our presentation we will focus on children with autism in a residential home, how we work with them, and how we collaborate with their parents.

Our presentation is focusing on the practical work, with examples from daily life in a residential setting. Through this presentation we hope to give inspiration and knowledge to similar work in other places.

Our work is based on experience from many years in all-day-programs from Sofieskolen in Denmark, a special institution with both kindergarten, school/leisure, and residential homes for more than 50 children and youngsters. Sofieskolen has worked with these challenges since 1964, and is one of the first special institutions for childeren with autism in the world.

In this presentation we will direct your attention to the following aspects:

1. Parents/family´s points of view

Why do parents make this decision? Do family traditions and network play a role? And how? Does economi play a role? How do families/parents react emotionally with the decision? And how does the child react?

3 examples from 3 different families and kids will give you information on how we deal with these issues in an economically rich welfare society like the Danish.

2. How to begin

Collaboration between parents and professionals: the importance of life-stories from parents, their hopes, anxieties and expectations. Concrete guide lines and schedules, visual files, assessments, important visual materials to support the starting process for the child and parents.

We will give you concrete exsamples of how the childs moving in takes place at Sofieskolen, and reflect the importance of: Parents are experts on behalf of their child, we are experts on autism and special education

3. Structure, content and activities

Structuring both the physical and the mental environment is of the outmost importance for the child. At Sofieskolen parents are confident to share the role of care-taking, and they believe that this will increase the possibilities of development for their child. In order to reach this goal, a close cooperation between professionals and parents are of outmost importance.

At the residential setting we focus on: how to create an enviroment that will give maximum opportunities for the child to act independantly in the environment and learn to manage life-skills and become self-functioning.

Through a lot of examples on physical structure, visual materials and guide systems, and by giving you exsamples from our work with social training, group-talks, understanding of own disabilities, we will share with you our attemt to create a home enviroment for the children, that will give them optimal possibilities to develop their skills.

4. Treatment enviroment

Sofieskolen is (see below) a special-institution with different units and treatment-entities for the children and youngsters with autism.

In this part of our presentation we will focus on a few organizational issues: creating a mutual paedagogical platform, how we understand autism and the basic deficits, the paedagogical philosophy behind structured teaching, visualization, the inside out understanding of the childs cognition and behavior.

(Sofie skole is a treatment-center, containing daycare and residential places for children and youngsters with autism spectrum disorder. The institution was esablished in 1964, situated in a suburb of the capital Copenhagen, and has her Royal Highness Queen Margrethe as proctector.

In 1964, with financial support from the nationwide organization „psykotiske Børns vel" (The Well-being of Psychotic Children) as well as private funds, Else Hansen established Sofieskolen in a smaller residential manor villa. Else Hansen was the mother to a child with autism. At that time there were no special (effortts) for children with autism in Denmark. The institution grew bigger and moved into new premises in 1968.

Today Sofieskolen contains; A kindergarten of 6-10 children, a school unit with 38 pupils, integrated with a leisure-time-unit, and 3 residential homes (with 12, 8 and 6 children). These are all-day programs at Sofieskolen.

It is rather unique to have a institution constructed in this way. It enables us to work with coherence and wholeness in the childs life.)

0038

DEVELOPING 'AUTISM-FRIENDLY' RESPITE SERVICES WITHIN THE TEACCH MODEL

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This paper identifies how Northamptonshire County Council has developed 'autism-friendly' respite care services over the past fifteen years. It outlines some of the major characteristics of these services, as well as describing some of the challenges that have been faced and that remain.

Why does respite care matter?

Respite care (or 'short breaks', as it is increasingly known in the UK) is an important support service to families with children with autistic spectrum disorders (ASD), providing benefits to families, children with ASD and the state alike.

Benefits to families

Respite care has long been identified as a key support for families with children with ASD (Bristol and Schopler, 1983; Factor, Perry and Freeman, 1990), and effective respite care can reduce family stress (Chan and Sigafoos, 2001; Gray, 1994). Families with children with ASD often have limited informal support, and using respite care services can help them engage in activities that cannot be undertaken with the child (Boyd, 2002; Preece and Jordan, 2006a; Randall and Parker, 1999). Many families that receive satisfactory respite care consider it to be vital in helping them continue caring for their child (Beresford, 1994).

Benefits to children

Effective respite care can also provide benefits to children with ASD (Carlin, Morrison, Bullock and Nawaz, 2004; Tarleton and Macaulay, 2002). Typically developing children often have opportunities to spend short periods of time away from home: for example, 'sleeping over' at the homes of friends, or extended family members. These opportunities are often unavailable to children with ASD, due to factors such as the limited informal support available to the family, or the child's behaviour. Respite care can provide these with social opportunities and can provide an environment in which they can make steps towards independence, learning and consolidating new skills and preparing for adulthood.

Benefits to the state

Finally, effective respite can help prevent family breakdown (Aldgate, 1998) and reduce the need for out-of-home placements: this is financially, ethically and practically beneficial for the state and service providers. Moreover, when children with ASD remain in their local communities, it is easier to develop appropriate adult services to meet their needs, and to transition them into their adult placements.

Limitations of respite care services regarding families with children with ASD

Unfortunately, although it seems clear that respite care can be beneficial to families with children with ASD, many families have unsatisfactory experiences of such services. Many individuals with ASD are excluded from services, either due to their behaviours (Trenenan, Corkery, Dowdney and Hammond, 1997; Van Bourgondien and Elgar, 1990), or because they fail to meet eligibility criteria (Oberheim, 1996). Children with ASD often spend years on waiting lists without ever receiving a service (Barson, 1996; Sargent, 1995). When services are accessible, these tend to be provided for a generic clientele of 'disabled children'. Parents of children with ASD often find such services inadequate or inappropriate. Staff are often found lacking in skill and understanding (Forrest, 1994; Hand, 1994). Further problems often arise from issues such as the wide range of disabilities catered for and the mix of children, the types of activities on offer, and ecological factors (such as noise, light, colour, space, safety, security and staffing levels) (Barson, 1998; Oberheim, 1996; Sargent, 1995).

The Northamptonshire approach to providing services for people with ASD

Since 1990, social care, education and health service providers in Northamptonshire – a largely rural county in the centre of England – have developed a multidisciplinary approach to the development of its services for people with ASD (Preece, Lovett, Lovett and Burke, 2000). This approach has been underpinned by the consistent use, across settings and age groups, of the TEACCH structured teaching approach (Schopler, Mesibov and Hearsey, 1995). Specialist services include autism-specific classrooms (in primary and secondary schools, across special and mainstream educational settings), long-term residential care for children and adults, day services and job coaching, family support and respite care.

The support of Autism Independent UK, a local voluntary organisation, has been crucial in establishing and maintaining the links between Northamptonshire and Division TEACCH at the University of North Carolina, Chapel Hill.

Respite care in Northamptonshire

Lindsay (1996) argues that a spectrum of respite care services should be provided to meet the spectrum of different purposes that 'respite' care performs. In Northamptonshire, *domiciliary* respite care needs (where care is provided in the family's own home) are provided by external agencies, or supported through direct payments to the family. *Holiday* respite needs are addressed through a range of supports, from signposting to organisations that provide grants to providing direct payments to provide workers to support the child on a family holiday, or to support the child in their own home while the rest of the family go on holiday. *Emergency* respite care is provided by residential placement (with a maximum stay of 28 days) or through short-term fostering: this service would be used in situations such as when there were child protection issues concerning the child with ASD's immediate family, or if the main carer were hospitalized. By far the greatest demand, however, is for regular, *planned* respite care. This is addressed through two methods of service delivery: family-based and residential placements.

Family-based respite care

Prewett (1999) identified a nationwide shortage of family-based respite care placements for children with ASD. To address this issue locally, the county has recruited and trained autism-specific family-based carers. Each carer is contracted to provide 182 days of care per year, in their own home, for which they receive remuneration of approximately £14,000 per year. One to two children at a time will stay at their home, and each carer supports up to eight families. This service has focused particularly on supporting families with younger children, or children who find it hard to cope with group living. No formal evaluation of the service has yes been undertaken, but informal evaluations have been positive, and placement stability has been high (Preece, 2003).

Residential respite care

Residential respite care is provided at 82 Northampton Road, Wellingborough. This 6-bed home, established in 1993, provides a service to over 40 families, with children aged between 7 and 18 years. Breaks are pre-booked, with a maximum of 4 consecutive nights at a time. The level of support each family receives is dependent on a number of issues – the family's assessed level of need; the child's age, needs and wishes; bed availability – and currently ranges from about 20-100 nights per year, with an average of 30-40. The home has an annual budget of c£422k per year. A night's respite care therefore costs the county £195 – the service is provided free to families. The service was formally assessed in 1999 (Preece, 2000), 2001 and 2004, and has been cited as an exemplar of good practice by the UK Department for Education and Skills (Carlin *et al*., 2004).

Making residential respite care work for children with ASD and their families

Making residential respite care work for these children is potentially very difficult. Nonetheless, this model of service delivery remains one of the most effective and viable tools for providing families with regular, dependable and effective breaks and for giving children with ASD positive social opportunities. So what are the key elements in making this work, and how are they addressed at 82 Northampton Road?

Physical environment

82 Northampton Road is a large, seven-bedroom house located in a small town near the centre of the county. It is decorated in pastel colours (as bright or dark colours may be over-stimulating) and is largely 'clutter-free', to reduce confusion and over-stimulation). The six bedrooms available for children are individualised to address different needs (e.g. some have access to running water, some do not; some have waterproof floor coverings, some have carpets).

Clarity of physical structure is important to children with ASD (Schopler *et al*., 1995) and so the areas of the home – bedrooms, dining room, TV room, playroom, toilets, bathroom, transition area – have clear purposes and are clearly identified and labelled. The home has two separate gardens – a larger outside play area, and a smaller sensory garden – and the building is externally secure, with external doors operated by electronic keypad and window locks. Other safety features include built-in wardrobes and cupboards, alarms on all bedroom doors, strengthened glass in all windows and flush ceiling lighting.

Staff team, skills and expertise

Staff skills and expertise are crucial in making respite care work. 82 Northampton Road's staff team comprises a professional staff team of the registered manager, two Senior Residential Care Workers, four Residential Care Workers, and three Night Residential Care Workers, supported by care assistants, a

cleaner and a clerical assistant. The staff-child ratio during waking hours is always 1-2, (or better, if required). At night, a member of night staff is awake at all times, with one member of the professional team sleeping-in at the home, and another on call at all times.

At 82 Northampton Road, staff are consistently trained within the same model of working. The fact that all staff undertake this training maintains consistency of approach and prevents 'therapist drift'(Jordan and Powell, 1996) away from good practice. All staff undertake in-house induction training regarding ASD, before attending a 3-day TEACCH seminar presented by Gary Mesibov and colleagues from Division TEACCH: these seminars are held locally each year. All of the home's professional staff attend a five-day, hands-on TEACCH workshop (these are also held locally every year), as well as undertaking training in other approaches used by the service, such as the Picture Exchange Communication System (PECS) (Bondy and Frost, 1994) and Social Stories (Gray and Garard, 1993). Staff have also been supported to undertake certificated training, including the Certificate of Higher Education in ASD (University of Northampton) and the University Certificate in Autism (University of Birmingham).

Assessment and review

Regular and effective assessment and review is essential to ensure that services provided are appropriate. All families referred to the service have an initial assessment of their needs carried out by their social worker, and the decision to authorise referrals is made by the county's Disabled Children's Resource Panel.

A keyworker from the 82 Northampton Road team is allocated to the family, and this worker will, prior to the child's first stay, carry out an autism-focused assessment, addressing the child's physical needs, self help skills, communication, social interaction, education, recreation/leisure interests, behavioural issues, spiritual/racial/cultural needs and family needs. This is followed up by an initial intensive three-month assessment, during which the team will seek to identify the most appropriate group of children in which to place the child, preferred activities, and so on. A full review is held at three months – including the parent(s), child, keyworker, social worker and other relevant professionals (such as teachers, speech and language therapists) – and then annually.

Quality monitoring of the service is addressed in three ways. Monthly responsible individual visits are carried out in accordance with the Care Standards Act 2000, to ensure that the home's systems are regularly checked. These are supported by unannounced inspections carried out by the Commission for Social Care Inspection, the independent body that inspects, regulates and registers the service. Finally, the use of TEACCH in the home is regularly assessed using a structured teaching checklist adapted from that developed by Division TEACCH.

Grouping of children

For children to have a positive experience of respite care it is vital that they are brought in with children whose behaviours they can tolerate, in groups that are not too large, and who share similar interests (so that appropriate group activities can be undertaken). At 82 Northampton Road, children's respite care is timetabled so that they are in compatible groups, taking account of issues such as age, interests and skills.

The home also operates a weighting system with regard to occupancy levels. Some children's behaviours and/or needs are such that they may be assessed as having a weighting of 'x 2' (that is, they are equivalent to 2 children) or even more. This is used to identify the total number of children the home can accommodate at any time (the maximum number (taking weighting into consideration) cannot exceed 6.

Introducing children to the service

Children with ASD find it difficult to deal with changes to their routine, and so children must be carefully introduced to the service. Their keyworker will initially visit them at the family home, and will be there at the residential home for their initial visits. Where positive routines have been developed at home, these are replicated as much as possible. TEACCH schedules at the same level of abstraction and complexity as those used at school are developed – or in some cases the children are initially 'dropped back' to simpler levels of structuring as they are in an unfamiliar environment – and extra visual information (such as visual calendars and sleep charts) are provided to help children cope with the residential experience.

Individualisation and coordination

Each child who attends 82 Northampton Road has individualised schedules (telling them the sequence of events), work systems (showing them how to carry out tasks – such as dressing, washing or using the toilet) and communication systems. These can range in complexity and abstraction from objects (Ockelford, 2002) to written systems, and are individualised to ensure that they are appropriate for the child using them (Faherty, 1998). Furthermore children's daily schedules are developed so that, as much as possible, the activities they undertake are built around their interests and strengths. Thus, at any time,

up to six different children may be in the home – all on potentially different levels of scheduling – engaged in different activities.

In order to manage this individualisation it is essential that staff are flexible, as each group of children is different, with different interests, dislikes and group dynamics. The role of the keyworker is vital in ensuring that appropriate structure is in place and that colleagues are fully informed of the children's needs. Multiple copies of schedules, picture symbol cards, photographs and objects are made by the keyworker (as inevitably these necessary tools for daily living get lost, destroyed or wear out). The keyworker also liaises regularly with the child's school, parents and other professionals, to ensure that the systems in place for the child remain current and appropriate, taking account of and advances the child has made, or difficulties they are having. Regular and frequent staff briefings are held, updating information on the children.

Activities are coordinated through the use of the children's daily schedules and through careful timetabling and planning throughout the day. Before the start of each shift, children are allocated to staff, whose responsibility it is to identify and plan the activities that child will undertake during the shift. The shift is planned as a group, synchronising activities to avoid clashes, and each shift has a shift leader who is responsible for the coordination of activities. This is not necessarily always the most senior member of staff: the role can vary, both to give more junior staff experience and to ensure consistency and continuity (such as if, for example, a senior member of staff has to leave the home, or will be otherwise occupied during the shift). Again, visual structure (such as choice systems) and visual information are vital, to help the children access their preferences, cope with waiting, and understand when preferred activities will occur; and it is vital that the timetable includes providing the children with time and space to be autistic.

Dealing with bedtime difficulties

Many children with ASD have sleep problems and poor or maladaptive bedtime routines (Williams, Sears and Allard, 2004): indeed, seeking to get a good night's sleep occasionally can be one of the reasons that families initially seek to access respite care. Often these maladaptive routines – such as getting in bed with their parents, or 'bed-hopping' during the night – are based around people at home, and are not generalised to the respite care setting. To try to help children get used to the residential setting, positive routines (where they exist), such as listening to relaxing music, or a supper-bath-bed routine, are replicated; and children wherever possible consistently use the same bedroom to increase their feelings of routine and security. Furthermore, night staff are seen as vital members of the professional staff team (who work on their own more than their day colleagues) and they are trained and briefed in the same way as their colleagues who work in the day.

Accessing the community

Accessing the community, and learning to undertake and enjoy community outings and activities, is an important part of the respite care experience. Children attending 82 Northampton Road engage in a wide range of trips out, going to places such as play areas, parks, swimming, ten pin bowling, museums, cinemas, to restaurants and to the seaside. Again, TEACCH structure and work systems are consistently used to ensure that the children understand what is happening, to minimise their anxieties and confusion, and to clarify when activities are finishing (and what is going to happen next).

Parental involvement

Parental involvement and support is essential, as parents are viewed as co-therapists and as a vital part of the 'treatment team' within the TEACCH model (Mesibov, Shea and Schopler, 2005). The service has a parents' group, which meets with the Team Manager and the registered manager on a quarterly basis, and regular newsletters are sent out to all families using the service after these meetings. Keyworkers maintain regular contact (at least monthly) with all families either by home visit or telephone. Moreover, parents are regularly consulted about their experience of using the service (Preece, 2000), and regarding service development.

When asked what they felt was important in a respite care service for families with children with ASD, the parents using the service stated that clarity of purpose and function (that the home provided only respite care, and that it was ASD-specific) was essential. They felt that it was vital to have confidence in staff, their abilities and understanding; to feel that were working in partnerships with professionals working within a positive staff culture; and to know that the service provided high quality physical and emotional care within a structured yet homely environment.

Limitations and shortcomings

The multidisciplinary strategy developed within Northamptonshire, and the consistent use of the TEACCH approach across agencies and age groups, has enabled professionals and parents to work together for the benefit of children with ASD and their families over the past two decades. However, there are still significant limitations and difficulties facing parents, professionals and the children themselves.

Service gridlock and funding issues

The respite services are running at full capacity, and are operating waiting lists. Some families have had to wait over a year between being assessed as in need of a service and actually starting to receive it. Due to pressures on the county council's budget, there is little chance currently of further service development taking place.

Statutory services are also dependent upon the philosophical and budgetary imperatives and ambitions of politicians, at both a national and local level. Changes in political direction, different standpoints regarding what and how services should be provided, and the impact of pressures in other areas of the public sector, can all impact upon services.

Unmet need

When the respite care service for children was planned – in the early 1990s – there were approximately 100 children with a diagnosis of autism in Northamptonshire. There are now about 600 children with a diagnosis of ASD. The level of service available has not risen in line with the population, and a study of families in the county (Preece and Jordan, 2006a) has identified significant levels of unmet need. Over half of families who participated in the study want respite care now, and over two thirds feel that they will need it in future: however, only about a quarter are currently in receipt of services.

Unmet need is particularly significant among families who have higher functioning children, younger children or who do not have a social worker; and is exacerbated by social workers' limited understanding about ASD and its impact on the family (Preece and Jordan, 2006b).

Consultation with the children themselves

Though the attitudes and opinions of parents regarding respite care are well documented, there has been little research undertaken with children with ASD regarding their experience of receiving respite care. Where research has been undertaken (Preece, 2002), it has highlighted the importance of consistency of approach across settings. It is further suggested that staff members' skills and knowledge of individual children, staffing levels and the demands of other children are critical factors impacting upon children's experience of respite care. More research – using individualised and appropriate methods of consultation – is required in this area of study.

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0039

COUNTRY AUTISM SERVICES: A SATELLITE SERVICE FOR RURAL AND REMOTE WESTERN AUSTRALIA: BEST-PRACTICE INFORMING SERVICE PROVISION

A Maley

Disability Services Commission, Perth, Western Australia, Australia

Western Australia (WA) is the biggest state in Australia. It is 975,096 square kilometres (376, 486 square miles) and has a population of 1.9 million. Of that, 518450 people live in rural and remote areas (Australian Bureau of Statistics website, 2003 data). In 2003, there were 100 children with an autism spectrum disorder in country Western Australia eligible for early intervention services from Country Autism Services (CAS) at the Disability Services Commission (DSC), a state government department. Disability Services Commission funds a range of services for people with a disability, including autism. CAS is based in Perth, the capital of WA. For children with autism, funding is provided until they attend Year 1.

Prior to 2001, CAS operated with a small team of psychologists trained in Autism Early Intervention., who worked autonomously. Each psychologist was allocated a region within WA to provide services to and how they did that was decided upon by that psychologist, on an individual-child basis. State government funding at that stage was provided directly to the family and the psychologist liaised with the family and devised a plan on how to best spend the money allocated. One of the major problems with this system was that, whilst the family had the money to spend on services, there were no specialised autism services in the rural and remote regions for the child to receive. Money was usually allocated for paying the psychologist to visit the town, including airfares if required, and spend time training up any Therapy Assistants the family could find in the town. Programs set up were overseen by the psychologist from the Perth base. There was disparity within this system, as families who lived in very remote locations had to spend all their funding on one or two visits from the psychologist, due to the distance from Perth they lived and the cost of airfares and car hire. By contrast, families who lived closer to the metropolitan area were able to use funding for Therapy Assistant time as well as funding several more visits by the psychologist, as there were no airfare or hire car costs involved (generally government fleet cars were used for trips requiring only driving).

In 2001, the way funding was provided by the WA government changed, with service providers now receiving the funding rather than the family. With this change, it was clear that CAS could not continue to run as it had been. It was decided that any changes that occurred must be in line with best-practise principles for autism. So, what changes were made?

There were three major areas that were addressed for change. These were parent training and participation; goal selection for the children with autism; and system evaluation.

Parent Training and Participation

Research supporting parent involvement in early intervention programs for children with autism has been around since the 1970s (Moroz, 1989). The way parent training is presented has evolved over the decades, with the most recent incarnation looking at parents as partners in intervention in a collaborative manner. Training programs for parents also moved away from just training the primary care-giver, usually the mother, to training members of the extended family, such as grandparents (Moroz, 1989).

Prior to 2001, CAS offered workshops as requested by parents. This consisted of a one- to two-hour workshop presented in the family home by the psychologist working with the child. From 2001 to present, CAS strived to increase both the amount of workshops on offer and the topics presented. Currently, CAS has a comprehensive workshop timetable that is ever-expanding and evolving. Workshops are offered in two different media currently: live presentation or presentation via video conferencing to the local area. Due to the introduction of video-conferenced workshops, CAS was able to increase the number of hours of training one family could access by 28 hours. CAS now runs over 444 hours of workshops throughout the years. Figure 1 shows the increase in hours of workshops offered to families under the 'old' CAS and the 'new' CAS. Figure 2 shows the increase in the number of parents attending workshops since the introduction of video-conferenced workshops and the 'new' CAS.
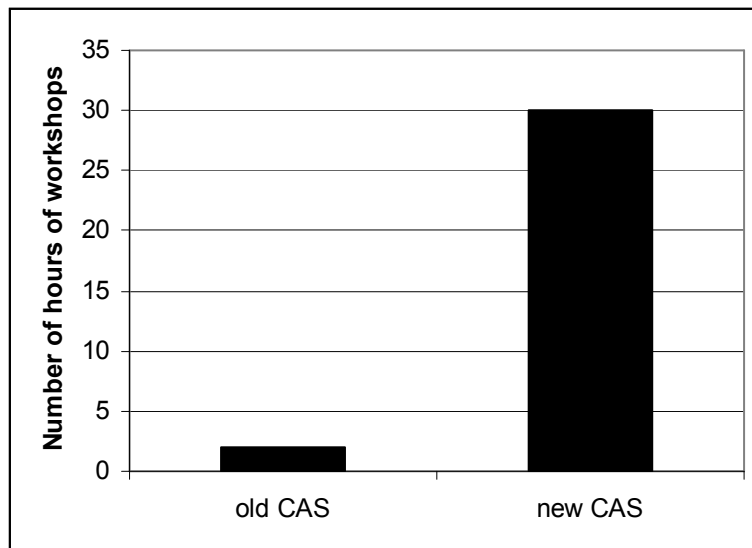
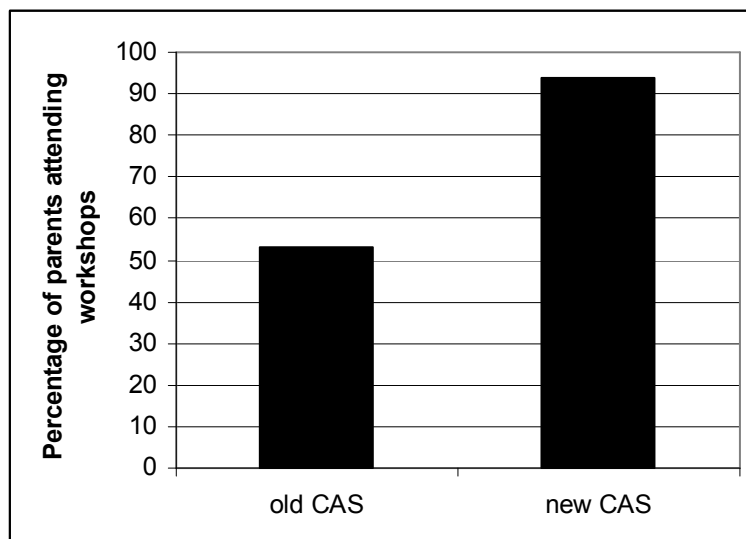Figure 1. Number of hours of workshops offered per year per family.

Figure 2. Percentage of parents attending workshops.

These newly-devised workshops initially consisted of a six-week (two hours per week) basic training course that covered functional analysis, behaviour management and promoting development. Based on parent feedback, which indicated that parents were finding it difficult to attend for six weeks, this workshop series was streamlined to a four-week course, still two hours per week. The focus of this is to provide beginner information on how parents might start to work out why their child is behaving the way they do and teaching them about behaviour change. The workshop focussed on both reducing unwanted behaviour and promoting desired behaviour. DSC funds services that utilise the methodology of Applied Behaviour Analysis (ABA). CAS uses several methods of teaching based ABA including Discrete Trial Training, Structured Activities, Environmental Engineering and Incidental Teaching. These methods of teaching as explained throughout the workshops as methods of increasing or teaching desired behaviours. DSC does not allow the use of punishment. Punishment is explained during the training; however the main focus of the training is the alternatives to punishment and how to change behaviour using positive behaviour management strategies.

As part of the workshop changes, CAS also devised workshops about 'special topics' such as solving sleeping difficulties, how to run play dates, and toilet training. Again, since the introduction of video-conferenced workshops, CAS has been able to target a larger audience. Families of children with older children with autism (outside the early intervention age range) and children with other disabilities have also been informed of the workshops and have shown good attendance. Workshops have been created specifically for this additional audience, such as one that looks at issues in puberty and sexuality. Workshops run throughout the year and are also presented upon request.

In addition to the workshops run for parents, workshops are presented for Therapy Assistants. The Therapy Assistant training consists of eight hours of theoretical training followed by direct instruction in the presence of the child and in the family home. Supervision of therapy assistants occurs at least fortnightly after initial training has been completed. Finding Therapy Assistants still remains an issue in rural and remote locations. By utilising video conference facilities, retention of Therapy Assistants has improved. This is due to the additional support and training CAS is able to offer to the Therapy Assistants, with supervision sessions being held via this medium. In the past, Therapy Assistants were given intermittent training and support and there was much disenchantment with the employment arrangement. The new funding system also meant improvements could be made to the hourly rate of pay they received and administration support could be offered more systematically.

The workshop series is ever-evolving. Future directions include a life-long learning package targeting goals throughout the life time. This future workshop series will take advantage of web-based learning and a DVD series which will allow an even wider audience to access vital training.

Goal setting

Best-practise literature for autism early intervention focuses on the family-centred approach. This involves having the families involved in every aspect of early intervention (Wehman, 1998), including goal selection. Goal setting needs to be coordinated, integrated, and collaborative across individuals working with the child and communication must occur between team members (New York State Dept of Health Early Intervention Program, 1999). This includes the use of Individual Family Service Plans (IFSP) for each family and child to outline goal selection.

In light of this, CAS introduced IFSP case conferences every three months for the duration of the child's time with CAS. A Family Support Network concept was introduced to the family, where they identified people in their lives that are supportive to the family. This could include extended family members, professionals working with the child, school staff, or day care staff. Members of the Family Support Network receive invitations to each of the IFSP meetings. Figure 3 shows the type of attendees at IFSP meetings under the old CAS system. Figure 4 shows this information for the new CAS. As a consequence of expanding the attendees at the IFSP meetings using the family-identified Family Support Network, goals were being selected and supported by a multi-disciplinary team.

Evaluation system

Any early intervention service needs to have an evaluation system in place (Freeman, 1997). Prior to 2001 there were no evaluation systems in place at CAS. To address this problem, CAS introduced a two-part evaluation system. The first part, targeting individuals, related to the IFSPs. Goal targets were able to be assessed every three months at the IFSP meetings and strategies put in place to address why the goal was not met and work on strategies to make goal attainment possible. In addition, positive results were also assessed. The second part of the evaluation system, which targeted the group, was a biennial review of families which consists of survey of all families on aspects such as family functioning, the impact of autism on the family, parenting styles, and autism symptomatology. The results of these surveys allow CAS to evolve on a number of fronts. CAS is able to assess changes in the way families discipline their children – an important aspect when planning workshops focusing on parents changing their children's behaviour. CAS is able to assess whether the families of the children enrolled in the service are able to adapt to the changes that are needed to have healthy family functioning. CAS is able to assess whether as a group, autistic symptomatology and challenging behaviors are being reduced. And finally, CAS is able to assess whether, as a group, skills improvements are taking place.
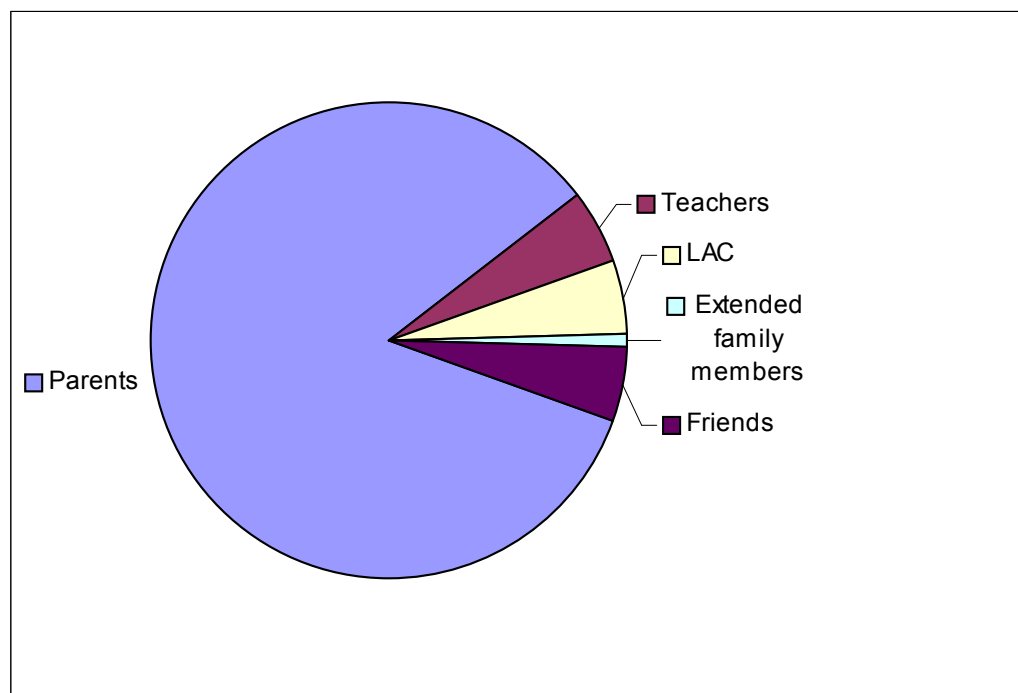
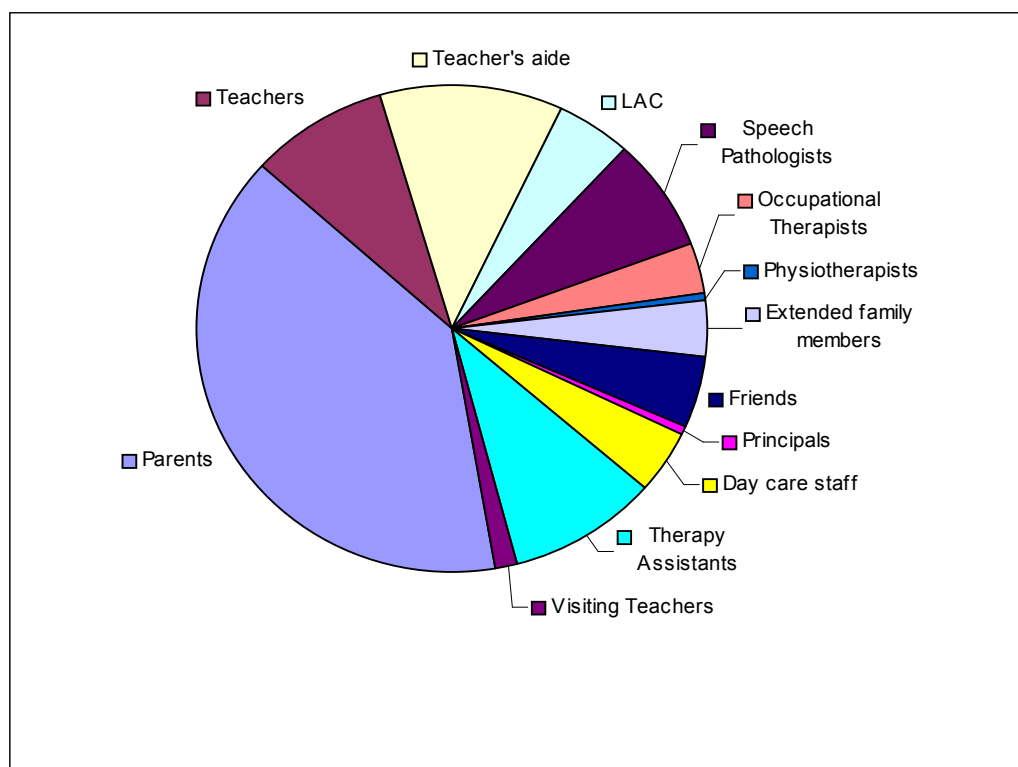Figure 3. Attendees at IFSP meetings under the old CAS system.

Figure 4. Attendees at IFSP meetings under the new CAS system.

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DEVELOPING AUTISM SERVICES – A KENYAN EXPERIENCE

M M Mburu

Autism Society of Kenya, Nairobi, Kenya

The Autism Society of Kenya was founded in 2003 by three determined ladies – Felicity Nyambura Ngungu, Grace Wanja Manyara and Monica Magna Mburu - who were all struggling with the same issues – lack of services for autistic children.

The Autism society was born from many years of frustration on the part of parents of autistic children in Kenya. I found out that my son, Robin, had autism when he was five years old. He had been attending a regular kindergarten and I had ambitions of placing him in one of the "good" schools when he reached primary school age. Alas, that was not to be. He was unable to cope with anything touching academics and he was assessed at a private school where I was told he had autistic tendencies.

The diagnosis sent me on a long quest for information. There was nothing at all in the book shops or libraries. I also spend hours digging through old "Reader's Digests" at my parents farm and I came across some articles which were not very illuminating because Robin was not like the children described in the stories I managed to dig up.

In 2003, I came into contact with two other ladies – Felicity and Grace – who were struggling with the same issues. We sat together and the idea to form a parent' driven organisation to place the autism issues into the spotlight, and to set up services for autistic persons, was born.

Felicity Ngungu, who has a grandson with autism, had developed a programme for her grandson in her home. She took over the care of her grandson and this began a long journey of exploration and discovery. She discovered that dietary intervention played a very important role in the management of autism. Her daughter sent her the book "Biological Treatment for Children with Autism and PDD" from the United States and she studied this book carefully. These books are not available in Kenyan book shops or libraries. She then went ahead to implement the ideas and put the theory into practice. The implementation of the gluten and casein free diet had immediate and dramatic results. Andra's hyperactivity ceased. For the first time in his life, he was able to sleep through the night, he was no longer crying for no reason and life in the Ngungu household became more calm and quiet – until she met Monica and Grace and a host of other parents who brought their children to her house to consult on the dietary approach.

In conjunction with the dietary approach, Felicity linked up with an occupational therapist who began a schedule of sensory integration with Andra. They had programmed daily activities that helped to develop his social and communication functioning and enhanced the benefits obtained from the dietary intervention.

We sat together and drafted a constitution as well as a project document which outlined our vision for the society that we wanted. At about this time, we had a brief meeting with the Director of Medical Services who was very supportive. He shaped our plans and encouraged us to set up a Non-governmental Organisation, which would have a long term vision to address the gaps in service provision to autistic persons in Kenya. As a consultant paediatrician he had come across many autistic children in his practice. He was very excited to meet with us because he was more aware than most that there was no programme in place to address these children's needs. Consequently, in August, 2003, we mobilised other parents to form the organisation and sent the papers for registration.

Having done that, we could not just sit back and wait, so we decided that we needed to urgently open an Autism Unit in a public primary school as our children, just like any other, have a right to access the appropriate education for their needs.

The first thing that we did was to mobilise these same parents to form a self-help group to run the autism programme. The parents came together and planned on how to run the programme. We identified the school – City Primary School – which had empty rooms in which we could run the programme. We approached the school administration and were received warmly by the then Headmaster. We employed one teacher, one occupational therapist and two teacher's aides. On September 9th, 2003, we officially opened the unit – the first of its kind in Kenya.

It is a sad fact that many autistic children are locked out of educational establishments because they are unable to cope with the difficult behaviours that accompany autism. We opened the autism unit with only 7

children, and one more joined after the first month. We faced tremendous financial difficulties that first term. Parents contribute to a central fund that finances the programme.

Our occupational therapist developed an assessment form in collaboration with Kenyatta National Hospital Occupational therapy department which is used to assess the children before admission into the programme. This is a paediatric assessment form which not only serves to confirm the diagnosis of autism, but also to identify any potential co-morbid syndromes.

The treatment options that we are focusing heavily on are dietary intervention, sensory integration, social skills training and behaviour intervention. We are also running a lunch and break feeding programme at the Unit, and this is based on the gluten and casein free diet. We insist that all children enrolled in the Unit must be put on this diet full time, or the benefits of the programme will be minimised. We have seen incredible gains in many of the children. Some, who were completely non-verbal, have started talking. All have calmed down, and hyperactivity no longer seems to be an issue in our children.

The Autism Society of Kenya has become the recognised authority on Autism in Kenya. We are recognised by the government. We hold consultations and assessments on a regular basis. We have had more than 400 consultations since the inception of the programme. We are getting referrals from various sources. We provide advice on the diet and other management tips that could help them.

In 2004, ASK was awarded the top prize by the Commonwealth Education Fund for having the most innovative project of 2003. This prize came with an initiation to join the CEF partnership family. Consequently, in 2005, CEF funded the Autism Society of Kenya to launch a mass public awareness and advocacy campaign on autism in Kenya. The strategy that we are using is to identify districts in Kenya, and we targeted 4, that were likely to be open to the establishment of autism units and then organise parent seminars in collaboration with the district hospital occupational therapy departments and the District Education offices.

At the beginning of 2005, we linked up with Voluntary Service Overseas (VSO), Kenya Institute of Education (KIE), the Ministry of Education and the Ministry of Health and Kenyatta University to develop a position paper on the status of Autism in Kenya. The document also helped to remove autism from the category of mental health disorders to its rightful category of developmental disorders. This document formed the backbone of an autism stakeholders workshop that we held in June, 2005. A comprehensive action plan was developed which we are currently implementing in collaboration with our stakeholders. This is what is guiding our activities through the year 2006. *(A copy of the workshop report will be available as an exhibit at the presentation).*

The year 2005 saw ASK visiting communities outside Nairobi to hold autism sensitisation forums with parents as well as teachers and staff dealing with children with special needs.

Following this approach, parents in Kisii came together and formed a self-help group and they established an autism unit at a public primary school - Kisii Primary School. This unit is also struggling although the ASK has given it some support. We have donated some therapy equipment to help to enhance their sensory integration therapy unit, and we sent them an occupational therapist from Nairobi to run the therapy programme.

In July, 2005, we visited Nyeri and held a seminar at the Nyeri Provincial hospital. We had a very good attendance with about 15 parents attending. We used this opportunity to disseminate the information about the diet as well as provide information about autism and its management. Following this, we visited the Karatina District Hospital where we held a meeting with the hospital staff and two parents. They were excited to hear about our programme and asked us to return and run a full day seminar for parents. This was duly organised and we returned on August 17th to run the seminar on the 18th. This was very successful. We had a participation of more than forty parents and staff from several hospitals in the area including the district one and some private hospitals. The parents formed a support group at the end of the day and determined to open an Autism Unit at a primary school. This was accomplished in September. We have also supported this unit with some therapy equipment.

ASK holds an annual autism awareness walk. This year the theme was "Walk with us to Free the Autistic person from the Agony of the Chains". We are hoping to raise enough funds to open five more autism units in Nairobi in 2007. This will be critical as we know that there are more than 400 autistic children in the Nairobi environs who are not being catered for. The vision of the Autism Society of Kenya is that all autistic children in Kenya will be placed in schools. It is also critical that the youth with autistic spectrum disorders are placed in appropriate vocational training programmes.

One major achievement of the Autism Society of Kenya in 2006 has been the publication of two books. One, the recipe book, entitled "Health Cooking for Persons with Autism", which contains lots of information about autism and has made possible the availability of such information in Kenyan bookshops for the first

time in history and is retailing at Ksh. 300/= only. The other publication, entitled "Developing a Good Autism Programme" is the result of a programme development workshop held in our office in January, 2006. We put together a team comprising staff from the office, a special education teacher and an occupational therapist to design programmes for autistic persons of all ages, and to refine the assessment tools used by these professionals. This is a very useful book which is based on the programme that we are offering at the autism unit, and is actually founded on the principles that autistic children have the right to access a holistic curriculum which should be aimed at developing their individual skills and talents. *(Copies of these publications will be available as exhibits at the presentation).*

The Autism Society is further enhancing its programme by developing a youth programme for people with developmental disabilities. This will be implemented in September. The programme will follow the curriculum guidelines laid out in the book. This will offer a holistic curriculum and individual plans will be developed for each of the young people attending the programme.

Another major achievement that ASK accomplished in August was the organisation of a sibling support group meeting which was very successful. The participants were aged from 7 years to 25 years, with some facilitators. It was a very illuminative session and the children and youths spoke very freely about their concerns. We are envisaging that this will be the first of many such group meetings. The children unanimously asked for more support group meetings as well as training sessions to teach them how to work effectively and manage their autistic sibling. This will be taken into account when planning our next year's work.

The Autism Society of Kenya has come a long way in a relatively short time and will be forging ahead to reach even greater heights while reaching out to the autistic people of all ages in Kenya who are really suffering.

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0041

FUNCTIONAL CURRICULUM

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JESSY

In the seventies, there was no "functional" curriculum; no consistent curriculum to prepare Jessy for a job after school was over, certainly none that gave her the skills to be a "mail clerk".

Jessy was placed with normal 11th and 12th graders in an "Office Procedures" course. She also learned about cooking and using a sewing machine in home economics along with normal classmates…. Jessy was enrolled in a resource room for all other classes.

In the office procedures course, Jessy learned to type but has never used it in her job as she is intolerant of errors. Teaching her bookkeeping was totally unrealistic, because she could never have been a secretary. Jessy could do the bookkeeping exercises as I had taught her math skills at home but without full understanding. The photocopy skills taught have proven useful, not in her job, but in her drawing and painting.

Neither did the school teach her the leisure skills or domestic skills so essential in her adult life. All these skills were taught over the years by me or by various Jessy-companions, mostly untrained teenagers or college students.

When she "aged out" of school at 22, they tried out various jobs before she started in the mail room. There, the minimal reading and writing the resource room teachers had worked on for 9 years were essential, although the reading and writing she was taught at school was not specifically directed towards job readiness. The kind and patient people in the mailroom taught Jessy the skills she needed on the job. She learned what to do and they learned what was not possible for her to do. She has been employed there for more than 25 years.

All this was in the seventies, and Jessy was the first autistic student the school had encountered. I imagine there's more of a functional curriculum today.

Clara Claiborne Park

Personal correspondence (2006)

Overview

In schools across British Columbia (BC), Canada, curriculum guidelines with defined Provincial Learning Outcomes (PLO's) for each grade prescribed by the Ministry of Education, remain the foundation of instruction in BC schools.

Cultural expectations, traditions and values also influence what is actually taught in BC schools. For example such cultural "norms" as fair play, turn-taking, courtesy, and appropriate "audience" manners, are largely assumed to be behaviours that need to be taught and reinforced by the school as well as the home and community at large.

Curriculum expectations exact different "weightings" at various grade levels and serve as a point of emphasis and focus in a student's school career. For example, 5-6 year olds are expected to demonstrate

basic literacy skills but would not be expected to be able to do algebraic equations. As a result, learning to print and read letters and words is emphasized in early education and instruction is directed to supporting and reinforcing literacy goals.

Foundational literacy skills are considered important in society. It is not uncommon for students in British Columbia who have significant developmental and intellectual delays to continue to receive support in mastering some elements of a primary education even in late adolescence. A curriculum that includes functional academic skills should be pursued whenever an individual is ready to learn basic literacy and numeracy skills. In addition, some students will require direct teaching of domestic, community, and leisure skills in order to be as independent as possible in their lives outside of school. Acquiring these skills increases the student's independence, community access and opportunities to engage in meaningful adult employment.

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Curriculum Considerations

Adapting and Modifying Curriculum

Some students with Autism Spectrum Disorders are able to successfully follow the basic grade level curriculum with or without additional support provided by a teacher or teaching assistant in one or more subject areas. These students are able to manage and often excel in the regular subjects at their grade level but have major challenges in social situations, developing meaningful relationships with their peers, and participating successfully in the social environment of the school

Other students with ASD may require adaptations to the basic curriculum in one or more subject areas. The use of curricular adaptations implies that the student will attain the standard learning outcomes expected for secondary school graduation. For a large number of students with ASD, especially those students who are of average or above average cognitive ability, the provision of thoughtful adaptations are an essential requirement if the student is to achieve curricular learning outcomes and perform consistent with their intellectual potential.

Deschenes, Ebeling & Sprague (1994) developed *Adapting Curriculum & Instruction in Inclusive Classrooms*. Their model included a teacher's desk reference and a staff development kit. The staff development kit was created as a tool for classroom teachers to assist in adapting and modifying curriculum and instruction for learners with developmental disabilities. The teacher's desk reference provides teachers with examples of adaptations in three key areas: curriculum materials, instructional formats, and classroom organization/behaviour management. In keeping with the learning outcomes and provincial standards prescribed by the Ministry of Education in British Columbia, the original nine (9) curricular adaptations were revised as seven adaptations and two modifications. They are as follows:

Seven Types of Adaptations

1. Size: Adapt the number of items the student is to learn or complete

2. Time: Adapt the time allotted for learning, task completion or testing

3. Input: Adapt the way the information is delivered to the student

4. Output: Adapt how the student can respond (e.g. Instead of answering questions in writing, allow a verbal response; use a communication picture book; allow students to demonstrate knowledge with hands-on materials)

5. Difficulty: Adapt the skill level, problem type or the rules of how the student may approach the work

6. Degree of Participation: Adapt the extent to which a student is actively involved

7. Level of Support: Increase the amount of adult or peer interaction/support the student has to initiate and complete a particular task.

Two Types of Modifications

1. Modify the goals or outcome expectations while using the same materials

2. Provide different instruction and materials to meet a learner's individual goals.

The authors also discuss the assumptions and beliefs behind adapting curriculum and instructions:

- It is appropriate and desirable to adapt curriculum and instruction for any student who is not succeeding in the classroom whether or not that student has an identified disability.

- Adaptation is not new; teachers adapt for individual students every day. This is often an intuitive process for most teachers.

- Adaptation increases the likelihood of success for more learners. As inclusive classrooms become the norm, the ability to adapt curriculum and instruction will be essential for dealing with increased student diversity.

- Adaptation is best approached through a collaborative problem solving process, with shared responsibilities by all who have a stake in the education of the student (e.g. general education teachers, teachers of students with disabilities, principals, peers, teaching assistants, families and related services staff).

- Adaptation starts with individual student goals. The IEP planning group and other ongoing student support teams work together to identify educational goals and objectives and to plan and implement needed adaptations.

- Adaptations maximize participation in typical curriculum and instruction. The starting point for planning adaptations for individual student s is the goals and activities for the general education classroom... When adaptations are needed, least intrusive adaptations are attempted first and adaptations are faded when they are no longer needed.

- All students can learn what is important for them to learn. It is the role of all educators to assist learners in meeting academic, social and affective goals.

- Adaptation can be supported by innovative instructional strategies (e.g. cooperative learning, thematic instruction, hands-on activities, and projects).

Modified Curriculum

A significant number of students with a diagnosis of ASD may need more extensive modifications in some areas of the academic curriculum as well as alternative curriculum that are typically not addressed within the regular school program. The IEP for these students should reflect goals, objectives and instructional techniques for teaching basic living skills, personal hygiene, social and communication skills, and behavioural management/self control. The IEP should also define those replacement behaviours that will need to be taught in place of challenging behaviours which interfere with life in the school and community.

Other students with ASD may require some modifications to the academic curriculum while they continue to partially participate in elective classes. For example, these students might participate in electives such as culinary arts, graphic arts, keyboarding, metal arts, music and drama. Core subjects such as math and English might be taught in the resource room and would likely require significant modifications.

The use of program modifications implies that the student will be attaining quite different learning outcomes from those of the regular student. The decision to opt for curricular modifications is significant. Implicit in that decision is the fact that a student will ultimately leave school with a School Leaving Certificate rather than the Grade 12 Dogwood Diploma. This fact impacts considerably on the individual's choices for future employment or education, and the decision to modify a program is to be undertaken only after considerable discussion with the student's family.

Students who are on a modified program and will not receive a Dogwood Diploma will likely require significant changes to instructional programming. For example, a non-verbal student with an intellectual disability could have a modified program goal of learning to recognize store names and, lacking verbal skills, may indicate his or her "reading" of the names by pointing to them as they are read by someone else.

Matching the Curriculum to the Student's Needs and Abilities

Students with ASD, as with other students, need to be cognitively and developmentally prepared for meaningful learning to occur. Attempts to teach concepts beyond the student's level of understanding will fail. A state of "readiness" to acquire concepts involves cognitive ability and consideration of the

developmental stage and age of the student, as well as exposure and involvement in meaningful learning opportunities.

Functional Curriculum

Students who are not able to follow either an adapted or a modified version of the traditional curriculum may require a functional curriculum. A functional curriculum offers specific instruction in basic life skills not typically taught within the regular classroom. Students with ASD often have difficulty in learning life skills such as personal care, domestic, and employment skills. Successfully performing life skills requires the student to take into consideration another's perspective, to be self reflective, to incorporate past experiences into current situations, and to make judgments based not only on past experiences but also on the particular events occurring in the moment. Deficits in these skill areas will significantly affect a student's quality of life within the school, home, and community environments.

Teaching Functional Skills

All students have the right to an education that teaches skills and abilities that will promote increased autonomy and independence both in and out of school. It is important to acknowledge that students with ASD who also have an intellectual disability require a functional skills curriculum that is taught in environments where application of the learned functional skills will be supported. Educational teams must collaborate to insure that these students are provided ample teaching opportunities to help them acquire those skills necessary to facilitate their independence within the community.

What is a functional skill and what determines the functionality of a skill? Functional skills are those skills that must be performed by someone else if the student has not learned to perform them himself. Typically, these skills fall into five domains or categories:

Domestic and Self-Care

Students with ASD may require direct teaching in some or all of these areas: personal grooming, hygiene, toileting, dressing, planning meals, shopping, preparing meals, and performing household chores. Although the tendency is to think that these skills are only taught to those who have significant cognitive impairments, there are some ASD students with higher cognitive abilities who also require direct teaching in some of these areas, particularly personal hygiene. The instructional approaches may differ but the critical need is reflected when a lack of knowledge can affect health, social mobility, and opportunities to find a job.

Functional Academics

Students with ASD who also have an intellectual disability are often able to acquire some academic skills through specialized teaching techniques. Most students can learn to recognize their names, relay a birth date and address, tell time, make change, write their signatures, read lists, use calculators, measure and set a timer, read recipes, or follow simple procedures. For others, functional academics can mean learning to use a visual schedule, follow a theme board, walk safely from home to a store, and recognize pic/syms to do their grocery shopping. Participation in all of these academic experiences enhances self awareness, self esteem, and confidence. The ability to recognize danger zones, differentiate between private and public, as well as determine what is edible and what is poisonous, are critical life skills. These skills help promote greater independence and mobility.

Vocational or Job Skills

In order to succeed in future employment situations, job skills alone are not sufficient. Older students with ASD frequently require additional support systems and greater consideration by both the employer and the non-handicapped co-workers in the work experience setting. Although most students with ASD, across levels of cognitive ability, may require support and assistance in vocational and job skills, students with ASD who also have an intellectual disability will require both supports and modified job requirements that take into account their level of intellectual capacity. Some students will be able to learn the actual job skills in the work site itself. Other students will benefit from practicing prerequisite skills in the classroom prior to accessing the work site. Collating, sorting, and assembly tasks are useful for teaching left to right sequencing, top to bottom, and clear beginnings and endings.

Volunteer work opportunities for students with ASD range from sweeping parking lots, picking up litter at local parks, delivering flyers and newspapers, stocking shelves at the neighbourhood grocery store, shelving library books at the local library to farm work such a cleaning horse stalls and picking produce.

The teacher or classroom support staff will need to discuss the requirements of the work setting in advance. If a student is going to successfully learn a task that he or she would be performing in a work placement, it is important to task analyze the steps before the student attends the work site. The teaching

staff will need to include the steps involved in completing the task as well as the teaching instructions for each staff member who will be accompanying the student to the work site. Videotaping a regular employee doing the actual tasks will also enable the student with ASD to become familiar with the work setting and the work required. Creating a theme board or a visual schedule using photographs, pic/syms, or words will also help the student to follow the specific sequence of steps involved in selected tasks

Social Mobility and Leisure skills

Social mobility refers to a person's capacity to be able to access environments as well as communicate effectively within those environments. Some students with ASD will need to have leisure programs built into their daily schedules.

Students with ASD often require direct teaching and repeated practice to learn hobbies, sports and games; how to access video games; or how to use technology to entertain themselves or others. Teaching these skills and activities helps to promote the concept that these are important aspects of a successful and fulfilling lifestyle. Scheduling these as a part of a weekly program helps to create routines that facilitate social connections, alleviate loneliness and boredom, and promote physical health and wellbeing.

Leisure skills may be practiced in all environments: home, school, and community. At school, leisure skills may be taught as part of the physical education program as well as within extracurricular activities. At home, students can enjoy leisure skills with an after school care worker, siblings, or peers in their neighbourhood.

Some leisure skills such as a watching a video or listening to music may be enjoyed alone. Community events at church or community centers offer opportunities to share leisure time with family and friends. Visits to the gym, physical fitness center, pool, skating rink or riding arena offer additional leisure opportunities for individual or group participation.

Community Mobility

Teachers who support students with ASD recognize that personal safety is a very real issue. In order to ensure that students remain safe within the community environment, a functional community based program addresses issues such as using public transportation, safely crossing streets and intersections, accessing public and private places, community services and leisure centers, and demonstrating appropriate behaviour in public places such as restaurants, pools, and banks.

PLANNING FOR MAXIMUM SUCCESS

Factors to Consider When Implementing a Functional Curriculum

- Age of Student: Curriculum content is likely to be more functional for the student if it is age appropriate.

- Present Levels of Ability: It is important to focus and build on a student's strengths.

- Language and/or Communication Ability: The way a student communicates his/her needs, wants, and desires to others must be established to provide meaningful programming.

- Preferred Learning Modality: Recognizing the preferred learning modalities or approaches for each student will help determine the methodology that will be used to teach functional skills.

- Functionality: Consider the degree of functionality for program content and materials across the environments when determining curricular content.

- Principle of Partial Participation: Determine the adaptations necessary to allow the student to engage in as many activities as possible. Refer to *Seven Types of Adaptations* discussed previously in this chapter.

Non-Functional Skills

Brown (1984) discusses the importance of non-functional skills in the life of individuals with disabilities. These are skills that would not be performed by others but which add meaning and enjoyment to the life of the individual. Reading a magazine, painting, listening to a CD, and inserting a DVD into the machine are examples of non-functional skills that may need to be incorporated into program planning in the school.

The school team should not assume that the student knows these skills if he or she has not been assessed in these skill areas or received direct instruction in using participating in these activities in a variety of environments. Remember, students with ASD, particularly those with cognitive challenges, do not automatically generalize skills across environments and people. They must be taught in the environment in which the activity takes place.

Least Restrictive Environment

Functional skills do not need to be taught in complete isolation from the student's peers. Philosophical and pedagogical considerations, ministerial and school board policies, and individual student needs must be taken into consideration when determining how and where to teach students important skills within a school program. BC Ministry of Education guidelines on inclusion and integration are as follows:

The principle of inclusion adopted in British Columbia schools supports equitable access to learning by all students and the opportunity for all students to pursue their goals in all aspects of their education. The practice of inclusion transcends the idea of physical location, and incorporates basic values that promote participation, friendship and interaction.

Integration is one way to achieve inclusion. Integration encourages students with special needs to participate and interact fully with other students in neighbourhood schools and to develop friendships. Integration involves placing students with special needs in classrooms with their age and grade peers, then providing them with the necessary support, accommodations and adaptations-determined on an individual basis-to enable them to be successful.

However, this does not mean that students with special needs must spend 100 per cent of every day in neighbourhood school class placements with their age and grade peers. The goal is to meet their educational needs and the educational needs of all students. The emphasis on educating students with special needs in neighbourhood school classrooms with their age and grade peers does not preclude the appropriate use of resource rooms, self-contained classes, community-based training or other specialized settings.

Special Education Policy Framework for British Columbia, June 1995

Partial Participation

A student's program can occur in a wide variety of least restrictive environments. For some students this may involve the concept of partial participation. Partial participation enables the student with ASD to participate to the maximum extent possible in both school and non school environments. Partial participation might include turning the pages while a classmate reads the story, or passing out the instruments in music class rather than playing an instrument. Over time, the degree of participation should be increased through direct and systematic instruction. Partial participation in chronological age-appropriate environments and activities is educationally more advantageous that exclusion from these environments and activities and often results in the student being perceived by his classmates as a more valuable, contributing, member of the class.

Skill Cluster Instruction and the Individualized Curriculum Sequencing Model

Skill cluster instruction and the Individualized Curriculum Sequencing model (ICS) form an ecological approach to teaching functional, age appropriate tasks and activities (Guess & Helmstetter, 1986). Ecological instructional goals focus on teaching skills that the student needs to function as independently as possible in the home, community, school, and recreational domains, in other words, life skills.

The domains are divided into sub-environments within the larger environment. For example, the home is an environment subdivided into separate rooms where particular activities or functions occur. The student learns that cooking and eating most frequently occur in the kitchen; brushing teeth and washing hands and face occur in the bathroom; and sleeping, resting or quiet play occur in the bedroom.

Since the goal is to teach people with autism to be independent within various environments, specific skills must be performed frequently to become mastered and generalized in all domains. The specific skills being taught can and should be learned simultaneously in the home, the community, and the school.

Curriculum sequencing recognizes the need for continuous training across domains in order to achieve generalization. This is a horizontal format which concentrates on teaching a particular skill in a number of environments. For example, a student must undress and dress upon rising in the morning, before and after physical education class in school, before and after swimming at the community pool, and again at bedtime in the home.

An ICS model identifies the skill to be taught and emphasizes distributed trial presentations and concurrent task sequencing. In other words, it teaches a particular skill at different times throughout the course of the day, in the context of related activities, across a number of environments.

To teach the concept of "on and off" using the ICS model, the teacher would look at all the sub-environments where the student may be throughout his or her day. Each adult in the student's environment would practice teaching "on and off" in a particular class or activity. Mom and Dad could design a similar matrix for the home, and the respite worker or recreational therapist could design another matrix teaching the same skills in the community or recreational setting.

Community Integration

Community integration implies that every student has the right to participate fully in his or her community. It involves being able to navigate throughout the various communities that the student with ASD participates in, ranging from school to home to the community activity centre. It involves being able to participate in age-appropriate activities in the community in which one lives, plays, study's and works. The definition of "community" varies according to the age of the student. For example:

To a preschooler, the community typically consists of:

- the classroom and the school play areas

- transportation occurring on the school bus, riding in the family car, or walking around the immediate neighbourhood

- familiar places in the area around the home that might include local parks, pools, theatres and movies

To an elementary school student the community expands to include:

- the classrooms, hallways, restrooms, gymnasium, office, and playground. Instruction usually incorporates a mix of auditory, visual, and kinesthetic teaching styles.

- community activities such as church; bowling; swimming; attending school events in which siblings participate; eating in restaurants; grocery shopping; going to the cinema, theatre, or music festival; attending craft fairs, garage sales, markets and shops; and participation in organized sports

- a variety of transportation modes including the school bus, traveling with parents, traveling with peers and families; walking and bicycling with/to friends within the immediate neighborhood.

To a middle school student the community expands further to include:

- one or more classrooms with the teachers more frequently using the lecture style of instruction. With the addition of elective classes, additional teachers and new classmates may be introduced. There may be more commitments to before and after school responsibilities including the opportunity to participate in clubs and school dances

- a variety of transportation modes including independent travel to and from school and around the community. Students may begin to use public transportation, if available and appropriate and bicycle use with/to friends within the neighborhood may continue.

- Extracurricular activities such as dances, parties, athletic events or outings; team trips and competitions; making one's own purchases at fast food restaurants; ordering for self at restaurants; making purchases at convenience, grocery, and discount stores; trying on clothing and making choices; attending movies with peers; hanging out at the mall (depending on parental and community norms).

To a secondary school student the community might include:

- Daily instruction provided by a variety of teachers in several different classrooms. Students may be required to follow a complicated schedule (some schools work on a 4

day rotational basis) and now are asked to keep their materials in a locker, taking out only the books necessary for the classes of the day. Teachers rely primarily on a lecture style and there may be a different set of classmates in each class.

- employment on a part time basis.

- Travel opportunities with friends by bus, car, walking, skateboarding or biking.

- Extracurricular activities that may involve greater distances from home such as going snowboarding at a local mountain, attending rock concerts, competitions, class trips to distant places, and playing games in the community.

- Generalization of life skills from the home to the school to the community at large.

Summary

All students are entitled to an appropriate curriculum in the least restrictive environment in the BC school system. That curriculum should reflect the strengths and abilities of the student as defined by current formal and informal assessments. Goals and objectives must be meaningful to the student, achievable, clearly stated and recorded, and aim at maximum independence for post school life. Regular reviews must be done to insure that the appropriate educational program is being provided in an appropriate setting. Collaboration between school personnel, parents, and other community support staff is critical to ensure successful learning of adaptive behaviours and the functional skills necessary for full integration into adult community living. This functional skill development should be reflected in the student's IEP. It is important that the school team work collaboratively with families and caregivers as programs taught in more than one setting should be compatible for maximum effectiveness. Through collaboration, systematic instruction and extensive opportunities to practice skills in all environments, students with autism spectrum disorders are provided with an education that best meets their individual needs.

0042

ASPERGER'S SYNDROME VERSUS REACTIVE ATTACHMENT DISORDER

AN IDEOGRAPHIC CASE STUDY

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Asperger's syndrome has often been misdiagnosed as various other disabilities. Although in the South African context, there is a recent move away from the medical model to a more needs driven model, it is argued that misdiagnosis of Asperger's syndrome may lead to an inappropriate course of action and placement which may be detrimental to the development of the learner. A recent clinical assessment of a learner referred to a unit for autism spectrum disorders (ASD) in South Africa, revealed a wrong diagnosis of Asperger's syndrome by a variety of professionals. After admission to this unit, more in-depth observations in both structured and unstructured settings as well as further clinical assessment of the family dynamics suggested a reactive attachment disorder rather than Asperger's syndrome. An ideographic case study illuminates the pitfalls of Asperger's disorder versus reactive attachment disorder.

Criteria for Asperger's syndrome:

For the purpose of this study Gillberg's (1989) diagnostic criteria were used as this set of criteria was used at the initial assessment.

1. Social Impairment (at least two of the following):

    a. Inability to interact with peers

    b. Lack of desire to interact with peers

    c. Lack of appreciation of social cues

    d. Socially and emotionally inappropriate behavior

2. Narrow Interest (at least one of the following):

a. Exclusion of other activities

b. Repetitive adherence

c. More rote than meaning

3. Repetitive routines (at least one of the following):

a. On self, in aspects of life

b. On others

4. Speech and language peculiarities (at least three of the following):

a. Delayed development

b. Superficially perfect expressive language

c. Formal pedantic language

d. Odd prosody, peculiar voice characteristics

e. Impairment of comprehension including misinterpretations of literal/implied meanings

5. Non-verbal communication problems (at least one of the following)

a. Limited use of gestures

b. Clumsy/gauche body language

c. Limited facial expression

d. Inappropriate expression

e. Peculiar, stiff gaze

6. Motor clumsiness

Poor performance on neuro-developmental examination

Ideographic Case History

L is a 4-year-old male who was referred to the unit for learners with autism spectrum disorders (ASD) by a psychologist who suspected possible Asperger's syndrome using the abovementioned criteria. This diagnosis was based on informal observation and interview with the parents as no specific medical or psychometrical tests exist through which a diagnosis can be made. L attended a mainstream nursery school at the time. His class teacher mentioned lack of emotion and class participation, specifically gross motor activities. At school he reportedly displayed frequent temper outbursts and insisted on playing with a specific toy clock.

The parents were asked to complete a comprehensive biographical questionnaire from which the following information was gathered: L was born vaginally at full term. The pregnancy was uncomplicated, although the mother reported that L was unplanned and that the parents were not married at the time. He smiled at 3 months although the parents mention that it was very rare. Reportedly, L's language development seemed to be on par with his chronological age and vocabulary seemed advanced. The parents also reported that L is motor clumsy and that he walked only at 18 months. At 6 months the mother, who was looking after L at home, placed him in a crèche for "socialization". She mentioned that "he was not responding much". According to reports from the crèche, L kept to himself and would only occasionally show an interest in the other children. This profile of development seemed to be typical of that of an individual with Asperger's syndrome. The parents ascribed this to the fact that L was frequently hospitalized during his first year for German measles, Tonsillitis and Gastroenteritis. The parents became concerned about L's development when their second baby was born and they realized that L was "not into people" and would only play with a toy clock or with spinning toys. This further contributed to the possibility of Asperger's syndrome. In addition the parents reported severe aggressive acts towards the little brother. They mentioned that they couldn't even relax on good days because another incident awaits them. At one point L broke his nose and cut his lip from dashing his head against a door. Additional complaints from the school that had difficulty in managing his behavior led to referral to a psychologist.

The Initial Evaluation

L was seen by a team consisting of a psychologist, speech therapist and occupational therapist attached to the unit for ASD. Informal observation reflected a little boy who did not distinguish between familiar and unfamiliar individuals. It was specifically noted that L made no contact with the mother. When left to play, L ignored the other children and physically pulled away when the other children approached him. Eye contact was fleeting and only used when he wanted a specific toy (a clock) to play with.

Language usage was good although not directed at peers. L would also only address adults on his terms. Although no overt stereotypical behaviors were observed, it was felt that the reported insistence on playing with specific objects only as well as the need to have a predictable routine as described by the parents might be because of the presence of a Pervasive Developmental Disorder. (Lombard, J.C. 2004)

The Griffiths scales of Mental Development were administered with the following results. Although the Griffith's mental development scales are not normed on the South African population they are based on developmental norms that are universally applicable to all children.

Chronological age: 46 months

Mental age: 43 months

General quotient: 93

Scale	Mental Age	Sub quotient
Locomotor	34 months	74
Personal/social	40 months	87
Hearing/speech	50 months	108
Eye-hand coordination	40 months	87
Performance	44 months	96
Practical reasoning	48 months	104

The abovementioned scores reflect a typical Asperger's syndrome profile with a general functioning in the average to the above average range as well as relatively better developed verbal than non-verbal skills. (Peeters & Gillberg, 2003. p. 34).

The parents were desperate for appropriate school placement as L's present school apparently felt that they could no longer manage his increasingly difficult behavior. Staff at the unit for autism spectrum disorders felt that placement at this unit may be beneficial to both L and his parents. L's progress would be monitored constantly with a view to placement in a less restrictive environment as soon as L was ready. Staff was however concerned about L being a weekly boarder at this young age but the parents seemed eager to have him attend. The parents were advised to attend a monthly support group for Asperger's syndrome in an effort to empower them to appropriately address L's needs.

Observation Report

L adapted extremely well to the unit as well as the boarding facility. His precocious independence was disturbing given that he was only 4 years old. He immediately seemed to thrive on the attention in a small group as well as the highly structured programmes. He did not ask about his parents but still preferred adult company to that of his peers. Of particular concern was that   L refused to go home over weekends when the parents came to pick him up. Aggressive acts towards his peers were still observed and further analysis of this behavior clearly indicated that it occurred specifically when other children receive attention from the classroom teacher. L seemed to be very sensitive to any action from others that may appear to be rejection. Obsessive play was still observed but not in a way that it lead to distraction. Crying and sulking behavior often occurred especially when he did not get his own way. Perceptually L progressed rapidly although he tended to ignore instructions and would only react on his terms.

Within the first months of L's admission an informational meeting was held for grandparents of learners attending the unit. L's paternal grandparents were specifically invited as they expressed concern about his welfare and frequently contacted the staff at the unit to enquire about his well being. After the formalities of the grandparents' morning, L's grandparents were to take him to their home for the weekend. Staff at the autistic unit was perplexed to observe the interaction between L and his grandparents. None of the previously observed aloofness and lack of appropriate interaction were observed. When prompted to tell

more about their experience of their grandson, the grandparents reluctantly told of suspected verbal and physical abuse at home. They mentioned that the mother would leave L to stay with them for extended periods without so much as a phone call. When it is time to go home L would pretend to be sick and refuse to leave with his parents. The grandparents reported that they are witness to the mother screaming at L and telling him that she hates him and wishes he had never been born. They felt that L was in a potentially dangerous situation at home due to the mother's inability to control her temper. They further reported that the mother at one point sat on top of L and wanted to strangle him. It emerged that neighbors have called the police on several occasions because they felt that L was being abused.

A follow up meeting was subsequently held with the parents where it seemed that the parents are excessively harsh and punitive and that they have unrealistically high expectations of their son. An interview with the mother reflected a difficult childhood characterized by neglect and abuse. The parents admitted to having serious marital difficulties that are aggravated by L's frequent temper tantrums and manipulatory behavior. The mother describes herself as having a quick temper, short fuse and explosive. The father added that she is very controlling to which she agreed.

At this time a psychiatrist who consults at the unit for autism suggested possible reactive attachment disorder and suggested that the case be followed up at a family clinic closer to their home. The parents were informed that their son may be inappropriately placed and that other options are investigated.

Reactive Attachment Disorder

L was observed in both structured and unstructured situations for the presence of possible reactive attachment disorder. Diagnosis is only possible through observation and in-depth family history. Attachment disorder is described as a "serious, relatively fixed emotional and behavioral disturbance in a child whose early attachment relationships were abnormal" (Attachment Disorder. What the experts say http://www.jbaassoc.demon.co.uk/kate/attachmentexpert.htm). Diagnostic guidelines according to the ICD -10 Classification of Mental and Behavioral Disorders suggest the following:

A. Onset before 5 years

B. The child exhibits strongly contradictory social responses that extend across social situations

C. Emotional disturbance is shown by lack of emotional responsiveness, withdrawal reactions, aggressive responses to the child's own or other's distress

D. Some capacity for social reciprocity and responsiveness is evident in interactions with normal adults

E. The criteria for Pervasive Developmental Disorders are not met

- **Asperger's syndrome**

- **Autism**

- **Childhood Disintegrative Disorder**

- **Mental Retardation**

- **Rett's Disorder**

(http://www.mental-health-matters.com/disorders/dis_details.php?disID=80)

During this time the parents reluctantly came for additional sessions with L at a family clinic. The parents insisted that L suffered from Asperger's syndrome and this was the only reason why they agreed to attend sessions. It seemed that the parents read up on Asperger's and found an "acceptable" label for their child's difficulties. This diagnosis did not imply any responsibility on the parent's part and allowed L to be a weekly boarder away from home. It was almost a situation of Munchausen by proxy!

The follow up evaluations

The case was followed up over several weeks. The parents continued to feel like victims of Asperger's syndrome. At the request of the father he was seen without his wife. During this consultation he expressed fear of his wife and explained that he had plans to leave her and take the children with him. L was taken from the autistic unit by the father and placed at the previous nursery school. This school was contacted by the social worker and alarming information was obtained. It was reported that when L was first admitted at 6 months of age, he was very passive and would just lay and watch movement. He made no effort to sit and the back of the head was very flat as if he had lain for long periods. L reportedly never approached his

mother to greet her nor did she ever display love or affection towards him. Staff at the school observed scratches on L's face. When asked about it he mentioned that his Mommy did it because he was naughty. As L became increasingly familiar with the social worker of the case, more and more evidence of abuse was obtained from L. (Holford L.& Ridley,W. 2004)

Initially L was oppositional and insisted performing tasks on his terms. He was frequently distracted by his obsessions and his attention had to be refocused on the task at hand. He appeared to be very fearful of gross motor tasks where he might get hurt or injured. He expressed anxiety that the therapist may lock him in a room when he failed at a task and upon questioning indicated that he does get locked in his room at home when he does something wrong. L. indicated that he gets smacked in the face and on the bum and that he sometimes bleeds on his forehead. (Bales,G. 2004)

Concluding Remarks and Discussion

From the abovementioned it was felt that L. does indeed fulfill the criteria for a diagnosis of reactive attachment disorder as opposed to that of Asperger's syndrome. As he has workable intellectual potential he requires placement in an environment where his social skills can be developed which would not be the case at a facility for learners with autism or Asperger's syndrome. Further in-depth family intervention was also indicated to enhance parenting skills. (Bales, 2004)

Unfortunately all contact was lost with the family shortly after the father removed L from the autistic unit. He returned to his earlier nursery school but has since left. It is believed that the parents got divorced.

While experience with both Asperger's syndrome and reactive attachment disorder is still relatively limited in South Africa, involvement in this case has highlighted the importance of appropriate clinical diagnosis. The long-term implications of these cases should be considered in terms of early intervention and follow up. Resources should extent to identify similar cases timorously with sufficient empowerment of all stakeholders to seek (and find) appropriate help. Further research in this area is awaited with interest.

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0044

MCDD: A SUB-GROUP OF PDD-NOS OR A PSYCHOTIC DISORDER?

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Introduction

The combination of early onset impairment in affect regulation, high levels of anxiety, disturbed social relationships, and periods of thought problems has been recognized by child psychiatrists throughout the past five decades and is not a rare phenomenon (Towbin, Dykens, Pearson, & Cohen, 1993). In the past 'childhood schizophrenia' and 'borderline syndrome of childhood' were the most common labels to describe this group of children, and more recently, 'childhood schizotypal disorder' or 'schizoid personality' were used (Petti & Vela, 1990). Cohen, Paul, and Volkmar (1986) suggested the term Multiplex Developmental Disorder (MDD) for which they proposed a specific set of diagnostic criteria. They emphasized that the social impairment seen in these children was suggestive of autism, and they therefore considered MDD as belonging to the group of Pervasive Developmental Disorders (PDDs) (Cohen et al., 1986; Towbin et al., 1993).

MDD was defined by disturbances in three domains. First, impaired regulation of affective states, which was manifested by anxiety and fears. Second, impairment in social behavior, which was manifested by detachment, social disinterest, withdrawal, and aggression. This second domain was most reminiscent of PDD. And third, impaired thought processes, which were manifested by magical thinking, unusual thoughts, and difficulties in separating fantasy from reality (Cohen et al., 1986). Though Cohen et al. (1986) positioned the MDD concept under the umbrella of the PDDs, they also recognized the overlap with several DSM-III (APA, 1980) personality disorders (i.e., Avoidant Disorder, Overanxious Disorder, Schizotypal Disorder).

Towbin et al. (1993) modified the criteria slightly, and changed the term MDD to Multiple Complex Developmental Disorder (MCDD). To validate the MCDD construct and its distinct position from other psychiatric disorders, Towbin et al. (1993) compared a group of 5-13 year old children who fulfilled criteria of MCDD (n = 30) with a group of children with DSM-III-R dysthymic disorder (n = 30), and conduct disorder (CD, n = 30). Children with MCDD were significantly younger at their first mental health contact, had significantly higher scores on internalizing and externalizing problems on the Child Behavior Checklist (CBCL; Achenbach, 1991), and showed significantly more difficulties in relating to peers.

These data showed that MCDD differed from externalizing (e.g. CD), and from internalizing (e.g. dysthymic disorder) disorders on symptom variables, but did not elucidate whether MCDD children can be differentiated from PDDs. Van der Gaag, Buitelaar, Van den Ban, Bezemer, and Van Engeland (1995) found that children with MCDD (n = 105) showed more anxiety and thought disorders, but were less disturbed on social responsiveness, interest in non-functional aspects of objects, and resistance to change, compared to children with autistic disorder (n = 32). This study was limited by the selection procedure of children with MCDD. They were selected only from a larger group of children with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). This seemed to implicate that MCDD can not occur outside PDD-NOS, whereas Towbin et al. (1993) already showed that only a third of their children with MCDD had a clinical diagnosis of PDD-NOS.

Currently, MCDD is not a separate construct in DSM-IV (APA, 1994). The early onset of the symptoms, impairments in multiple areas of development, the related social deficits, and its pervasive character make that the diagnostic classification mostly used for these children, is PDD-NOS (Ad-Dab'bagh & Greenfield, 2001; Towbin et al., 1993). Previous research indicated that MCDD can be delineated from autistic disorder (Van der Gaag et al., 1995). However, the question whether MCDD can be separated from other PDDs has not been answered yet. In this study, children with PDD-NOS were compared to children who fulfilled research criteria of MCDD on several standardized, valid, and reliable measures of psychiatric disorders, thought problems, and social contact and communication problems. Based on the previous findings by Towbin et al. (1993) and Van der Gaag et al. (1995), we hypothesized that children with MCDD would have more psychiatric disorders, and more thought problems than children with PDD-NOS. Further, we expected children with PDD-NOS to show more social contact and communication problems than children with MCDD.

Methods

Participants

The study sample was selected from 503 children, aged 6 – 12 years who were consecutively referred to the outpatient department of child and adolescent psychiatry, Erasmus Medical Center Rotterdam, the Netherlands, between July 2002 and September 2004 and who were all rated on MCDD and PDD-NOS criteria. Referrals were comprised of a large variety of child psychiatric disorders (e.g. externalizing disorders, internalizing disorders, PDDs). For 12 (2.4%) children the MCDD and/or PDD-NOS research criteria were rated incompletely and these children were excluded from further analyses. This eventually yielded 491 children for whom all MCDD and PDD-NOS criteria were rated.

Twenty-nine (5.9%) children met research criteria for a diagnosis of MCDD. The parents of four of these children refused to participate in the study, thus in the MCDD group, 25 children were included (mean age = 9.12, SD = 1.56, 88% boys, and 12% girls). Eleven of them (44%) met research criteria for PDD-NOS as well, but they remained included in the MCDD group. Of the remaining children, 86 (17.5%) met research criteria for a diagnosis of PDD-NOS (mean age = 8.48, SD = 1.83, 86% boys, and 14% girls). Intelligence quotients (IQs) of all children were assessed by using the Dutch version of the Wechsler Intelligence Scale for Children-Revised (WISC-R; Van Haasen, De Bruyn, Pijl, Poortinga, Spelberg, Van der Steene, et al. (1986); Wechsler, 1974). Children in the MCDD group had a Full Scale Intelligence Quotient (FSIQ) of 92.42 (SD = 15.40), a Verbal Intelligence Quotient (VIQ) of 94.67 (SD = 18.27), and a Performance Intelligence Quotient (PIQ) of 92.13 (SD = 13.40). Children in the PDD-NOS group had a FSIQ of 90.06 (SD = 18.34), a VIQ of 91.05 (SD = 18.45), and a PIQ of 92.39 (SD = 20.43). The MCDD group did not differ significantly in age, gender, FSIQ, VIQ, or PIQ (p > .05) from the PDD-NOS group. Further, children within the MCDD or the PDD-NOS group did not show significant VIQ – PIQ differences (p > .05). With respect to PDD-NOS, a recent study confirmed these findings. No VIQ –PIQ differences were found in Dutch children with PDD-NOS (De Bruin, Verheij, & Ferdinand, 2006).

Ethics

Parents or caretakers of the children had all signed informed consent forms prior to participation in the study. Children of 12 years old signed the consent forms themselves as well. The Medical Ethics Committee of the Erasmus Medical Center approved the study.

Assessment

PDD-NOS research criteria

DSM-IV (APA, 1994) provides 12 explicit criteria, equally divided over the three domains of social interaction, communication, and stereotyped interests and repetitive behaviors. At least six criteria must be met for a diagnosis of autistic disorder. However, for a DSM-IV diagnosis of PDD-NOS, criteria are not specified as such. The PDD-NOS category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction, plus either deficits in verbal or non-verbal communication skills, or stereotyped interests and repetitive behavior, but the criteria for a specific PDD are not met. No specific items or scoring algorithms are provided.

Buitelaar, Van der Gaag, Klin, and Volkmar (1999) created research criteria for PDD-NOS. Children with clinical diagnoses of autistic disorder (n = 205), PDD-NOS (n = 80), and non-PDD diagnoses such as mental retardation and language disorders (n = 174) were compared on the 12 criteria for autistic disorder. Both ICD-10 (WHO, 1993) and DSM-IV (APA, 1994) classification systems were used. They found that a short set of seven criteria, derived from the 12 original criteria for autistic disorder, discriminated best between the PDD-NOS group and the group of non-PDD children. These seven items were divided over the domains of social interaction (four items), communication (two items), and stereotyped interests and repetitive behavior (one item). The items are listed in Table 1. To diagnose PDD-NOS, at least three items had to be present including at least one social interaction item, and the child should not meet criteria for autistic disorder or other types of PDDs. This classification rule resulted in a sensitivity of 94%, specificity of 83% and yielded a total predictive value of 89%. The onset item, impairment prior to the age of 3, differentiated significantly between children with PDD-NOS and non-PDD, but did not improve the overall classification rule and was therefore not included. With this scoring rule, children could meet criteria for PDD-NOS by only showing impairments in social interaction and no impairments in communication or stereotyped interests. However, if criteria from these other two domains were set as mandatory, sensitivity would be reduced to 84% and total predictive value would diminish to 83%. Therefore, impairments in communication and stereotyped interests were not set as mandatory in the classification rule (Buitelaar & Van der Gaag, 1998).

In the current study, a diagnosis of PDD-NOS was based on these explicit research criteria (Buitelaar et al., 1999). Nine different child and adolescent psychiatrists were responsible for rating the research criteria. Rating was based on assessment of early development through current level of social, communicative, and adaptive functioning, obtained via semi-structured interviews, carried out with the parents or caretakers, as well as psychiatric observation of the child in a one-to-one situation (e.g. Semistructured Clinical Interview for Children and Adolescents [SCICA], McConaughy & Achenbach,

2001). School and other relevant medical information was obtained, as well as psychological assessment information. Immediately after all diagnostic procedures were finished, a multidisciplinary team obtained consensus with regard to the final DSM-IV (APA, 1994) classification, and PDD-NOS research criteria were ticked as present or absent. Subsequently, the algorithm, of which the rater was unaware, was used to decide whether the threshold for a research diagnosis of PDD-NOS was met.

MCDD research criteria

In an attempt to better differentiate PDDs, Cohen et al. (1986) introduced heuristic diagnostic criteria for an early onset developmental disorder characterized by anxiety and deficits in affective regulation, and impaired social relationships. These symptoms were identified from a review of 400 children characterized by 'deviant human relationships and disorganized, bizarre thinking' (Dahl, Cohen, & Provence, 1986). The term MCDD was proposed by Cohen et al. (1986) to describe these young children. The original criteria were divided over three domains; impaired regulation of affective state (six criteria of which two had to be present), impaired social behavior (four criteria of which one had to be present), and thought disorder (four criteria of which one had to be present). The symptoms had to be present longer than 6 months and the child should not meet criteria for autistic disorder.

Buitelaar and Van der Gaag (1998) subsequently examined the sensitivity and discriminative power of these 14 MCDD criteria in children with MCDD (i.e., who scored above the threshold for MCDD criteria) (n = 103), autistic disorder (n = 32), and non-PDD diagnoses such as mental retardation and language disorders (n = 96). They found that the contribution of several criteria in establishing the classification of MCDD was redundant, and constructed a simplified scoring rule. A short set of eight MCDD criteria had the strongest discriminative power (three criteria for affective dysregulation and anxiety, two for impaired social interaction, and three for thought disorder). The MCDD criteria are listed in Table 1. When at least five out of eight criteria were present, the total percentage of correctly classified children was 95% for the differentiation between MCDD and non-PDD, and 87% for the differentiation between MCDD and autism.

In the present study, the procedure of rating the MCDD research criteria was identical to the aforementioned rating of PDD-NOS research criteria. We carried out an inter rater reliability study on 30 randomly selected children (27%). Two clinicians independently rated all MCDD and PDD-NOS research criteria. Agreement between the raters on the presence or absence of a PDD-NOS diagnosis was good (κ = .62). Agreement for MCDD diagnosis could not be calculated as MCDD did not occur once in this sub sample. Further, we computed a score for the total number of PDD-NOS and MCDD criteria rated positive by each rater for each child. The intra class correlation coefficient (ICC) between these scores by the two raters was high (ICC = .89 and .79 respectively), indicating excellent agreement for PDD-NOS and MCDD criteria (Cichetti & Sparrow, 1981).

Psychiatric symptoms and disorders

CBCL/4-18

The Child Behavior Checklist/4-18 (CBCL; Achenbach, 1991) was used to obtain standardized parent-reports on children's problem behaviors. The CBCL covers 118 problem items, and for the present study, groups were compared on the scores on eight syndrome scales (Withdrawn, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent Behavior, and Aggressive Behavior). Average scores from mothers and fathers were used. CBCL data were available for 84.9% of the children (of which 48.7% was rated by mother only, 41.4% by father only, 6.3% by both parents, and for 3.6% it was unknown who filled in the CBCL). For the other 15.1%, parents did not fill out the CBCL.

DISC-IV

The Dutch version of the Diagnostic Interview Schedule for Children – version IV (DISC-IV; Ferdinand & Van der Ende, 1998; Shaffer, Fisher & Lucas, 1998) is a highly structured interview to assess DSM-IV Axis I psychiatric disorders in the past year, in children and adolescents. The parent version of the DISC-IV (DISC-IV-P) for parents of children aged 6 to 17, was used to assess how many percent of the children in each group had anxiety disorders, mood disorders, schizophrenia, and disruptive behavior disorders. Also the presence of hallucinations and delusions was assessed, as well as the total number of DISC/DSM-IV disorders in each group. Studies of earlier versions of the DISC-P have shown good test-retest and inter rater reliability (Schwab-Stone et al., 1993; Shaffer et al., 1993; Shaffer et al., 1996). The DISC-IV compared well with its earlier versions (Shaffer, Fisher, Lucas, Dulcan, & Schwab-Stone, 2000).

In this study, psychologists, research assistants, and psychology undergraduate students (supervised by psychologists) had all been trained by the authors of the Dutch DISC-IV (Ferdinand & Van der Ende, 1998) who, in turn, had been trained as trainers at Columbia University New York by the authors of the original

DISC. The interviewers were blind to any other diagnostic information about the child. DISC-IV data were available for 99.1% of the children. The other 0.9% was not available due to parent's refusal to be interviewed.

Thought problems

CAFAS

The Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, 1997) is a valid and reliable rating scale (Hodges & Wong, 1996) which assesses the child's degree of impairment in functioning due to emotional, behavioral, or psychiatric problems. Only the Thoughts subscale of the CAFAS (i.e., obsessions, eccentric speech, paranoia, incoherent thoughts, loose associations, delusions, hallucinations) was included in this study. It was scored in the same manner and by the same clinicians as the MCDD and PDD-NOS research criteria. The CAFAS was available for 100% of the children.

FTD criteria

Van der Gaag et al. (1995) showed that in MCDD children formal thought disorder (FTD) was present. Thought disorder can be interpreted differently by different clinicians. In order to obtain an unambiguous judgment of FTD, DSM-III criteria in the section form of thought, under Schizophrenic Disorders (APA, 1980): illogical thinking, loose associations, incoherence, and poverty of content of speech (criterion A6) were used. Illogical thinking was rated when inappropriate causal utterances were used and explanations were illogical. Loose association was rated when the child suddenly changed the topic of conversation, to an unrelated topic, without preparing the listener for this topic change. Incoherence was rated when the rater was unable to understand the contents of the child's speech, and poverty of content of speech was rated when the child did provide the listener with adequate length of speech, but did not elaborate on the topic. The clinician rated the four signs of FTD as present or absent. A total FTD score (range 0 – 4) was also calculated. This was carried out by the same clinicians as the rating of the MCDD and PDD-NOS criteria. The clinician's ratings were made immediately after administration of the SCICA (McConaughy & Achenbach, 2001) which is a semi-structured respondent based interview with the child. Assessment took 45-60 minutes and focused on issues such as difficulties in school, the home situation, or with friends. Rating of the FTD criteria took at most five minutes per child.

For 30 (27%) randomly selected children, FTD signs were rated by two independent clinicians. Agreement between the raters was fair to good (κ= .52 for illogical thinking, κ = .63 for loose associations, κ = .71 for incoherence, and κ = .54 for total FTD). Due to a low base rate, reliability of poverty of content of speech was not studied. FTD criteria were rated for 99% of the children.

Social contact and communication problems

ADOS-G

The Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord, Rutter, DiLavore, & Risi, 1999) provides a standardized context to observe PDD related behaviors in the domains of social interaction, communication, imagination, and stereotyped behavior. In this study, the different groups were compared on the subscales Communication (i.e., stereotyped language), Reciprocal Social Interaction (i.e., eye contact), the combination of Communication and Reciprocal Social Interaction (which constitutes the algorithm), Imagination/Creativity, and Stereotyped Behaviors and Restricted Interests (i.e., unusual sensory interest in play material or person).

Lord et al. (1999) showed that the psychometric properties of the ADOS-G were good. The diagnostic algorithm of the ADOS-G allows for classification of participants as having a non-spectrum disorder (N.S.), autism spectrum disorder (ASD), or autism. The distinction between the three categories depends on symptom severity. Non-spectrum disorder indicates that the child may have another psychiatric disorder, but a PDD is not present according to observations in the ADOS-G. The ADOS-G is particularly effective in differentiating between autism or ASD and N.S. (sensitivity 90%-97% and specificity 87%-94%), and is a little less effective in the differentiation between autism and ASD (sensitivity 87%-100% and specificity 68%-79%). A false positive classification of autism on the ADOS-G was considered more acceptable than a false negative classification of N.S. on the ADOS-G.

Psychologists who conducted the ADOS-G in this study were all trained by certified ADOS-G trainers. ADOS-G classifications were available for 97.3% of the children. In 2.7% of the children the ADOS-G could not be completely administered due to the child's refusal to cooperate.

Data analyses

Independent-samples t-tests (two-tailed) were used to compare the two groups on CBCL syndrome scale scores, total number of DISC/DSM-IV disorders, CAFAS Thought Problems scores, FTD total scores, and ADOS-G domain scores. Further, chi-square tests were performed to assess differences between the two groups in separate DISC/DSM-IV disorders, the four FTD criteria, and ADOS-G classifications.

In addition to these tests for statistical significance, effect sizes were calculated in order to evaluate the magnitude of the differences. An effect size of .20 was considered as small, of .50 as medium, and an effect size of .80 and above was considered as large (Cohen, 1988). For the independent samples t-tests, Cohen's d was calculated as a measure of effect size. To estimate the magnitude of the association in the contingency tables of the chi-square tests, the phi-coefficient was calculated. Phi is a Pearson product-moment coefficient calculated on two nominal, dichotomous variables. Phi of .10 - .20 is considered a weak association, of .20 - .40 is a moderate, of .40 - .60 is relatively strong, of .60 - .80 is strong, and phi above .80 is considered a very strong association (Rea & Parker, 1992).

Results

Psychiatric symptoms and disorders

In Table 2 means and standard deviations of the two groups on the different CBCL syndrome scales are shown. Apart from the syndrome scale Thought Problems which was higher for the MCDD group (t[98] = 2.453, $p < .05$, $d = .57$), groups did not differ on the syndrome scales ($p > .05$). Small, albeit non-significant effect sizes were found for Anxious/depressed, Delinquent Behavior and Social Problems, i.e. higher scores for the MCDD group on the first two syndrome scales and higher scores for the PDD-NOS group on the latter scale. These scores were in the expected direction.

In Table 3 the percentages of children with DISC/DSM-IV disorders in each group are shown. Children in the MCDD group had an average of 3.80 DISC/DSM-IV disorders ($SD = 3.11$) whereas children in the PDD-NOS group had an average of 2.21 DISC/DSM-IV disorders ($SD = 2.04$). The difference was significant (t[30.335] = 2.406, $p < .05$) with a medium effect size ($d = .68$).

Further, chi-square tests indicated there was an association between group membership and some of the DISC/DSM-IV disorders. In Table 3 it can be seen that in the PDD-NOS group only 5.9% had a Separation anxiety disorder, whereas in the MCDD group this was 20.0%   (χ^2[1, $N = 110$] = 4.659, $p < .05$). The phi-coefficient indicated a moderate association. Similarly, Obsessive compulsive disorder was present in 36.0% of the MCDD group and in 7.1% of the PDD-NOS group (χ^2[1, $N = 110$] = 13.739, $p < .01$), which showed that children in the MCDD group had much higher rates of obsessive thoughts and compulsive behaviors than children in the PDD-NOS group. Children in the MCDD group also had higher frequencies of disruptive behavior disorders. Oppositional defiant disorder was present in 60.0% of the MCDD group, and in 37.6% of the PDD-NOS group (χ^2[1, $N = 110$] = 3.944, $p < .05$), Conduct disorder in 24.0% of the MCDD group and in 5.9% of the PDD-NOS group (χ^2[1, $N = 110$] = 7.046, $p < .05$). Thus, compared the PDD-NOS group, children in the MCDD group showed significantly higher rates of aggressive, violent, and oppositional behaviors according to their parents. The associations (Φ) were all weak to moderate.

Although none of the children received a DISC/DSM-IV disorder of Schizophrenia, 8.0% of the MCDD group (and 1.2% of the PDD-NOS group) had at least one delusional experience (i.e., people spying on you, people talking about you, holding a conspiracy against you) during the past year, which lasted for at least a month ($p > .05$). Further, in 12.0% of the MCDD group (and 2.3% of the PDD-NOS group) at least one hallucination (i.e., hearing voices) occurred during the past year, which also lasted for at least a month (χ^2[1, $N = 110$] = 6.458, $p < .05$). Thus, children with MCDD had a higher rate of delusions and a significantly higher rate of hallucinations than those with PDD-NOS.

Thought problems

The mean score on the CAFAS Thoughts subscale was significantly higher in the MCDD group ($M = 16.00$, $SD = 7.07$) as compared to the PDD-NOS group ($M = 10.00$, $SD = 8.81$) (t[109] = 3.122, $p < .01$, $d = .71$). Thus, children in the MCDD group showed significantly more paranoia, incoherent thoughts, and delusions according to ratings of the clinician.

In Table 4 it can be seen that in 76.0% of the MCDD group the FTD criterion loose associations was present, whereas in the PDD-NOS group loose associations were present in 48.2% of the children (χ^2[1, $N = 111$] = 6.006, $p < .05$). The strength of the association was considered moderate. Thus, according to the clinician, the speech of children in the MCDD group contained higher rates of unexpected topic changes than the speech of children in the PDD-NOS group. Other FTD criteria or FTD total score did not differ significantly between the groups.

Social contact and communication problems

In Table 5 means and standard deviations of the different ADOS-G domains in the MCDD and PDD-NOS groups are presented. Whereas, children did not differ on any of the domains ($p > .05$), there was a significant association between group membership and ADOS-G classification. Only 36.0% of the MCDD group had ADOS-G classifications of autism or ASD, whereas this was true for 62.2% of the PDD-NOS group ($\chi^2[1, N = 107] = 5.337$, $p < .05$, $\Phi = .22$). This can be considered a moderate association (Rea & Parker, 1992). Five (55.6%) of the MCDD children with ADOS-G classifications (autism or ASD) also fulfilled PDD-NOS research criteria, but the other 4 (44.4%) did not.

Results on two of the ADOS-G domains showed a trend of differences in the expected direction ($p < .10$) with small to medium effect sizes. Higher scores for the PDD-NOS group were found for Reciprocal Social Interaction and for Communication plus Reciprocal Social Interaction. The latter constitutes the two domains in the algorithm.

Discussion

This was the first study, to our knowledge, that tried to delineate MCDD from PDD-NOS. Children who fulfilled standardized criteria of MCDD were selected from a large sample of children referred to an outpatient mental health center. Most previous studies, a priori, considered MCDD as a pervasive developmental disorder (PDD). However, empirical evidence for this assumption was not available. Therefore, in the present study, children with MCDD were selected, independently of the presence or absence of a PDD classification. In total, 25 children with MCDD were selected. Indeed, whereas 11 of those also fulfilled criteria of PDD-NOS, 14 did not. This, in itself, already showed that MCDD should not necessarily be regarded as one of the pervasive developmental disorders. Instead, it could be a disorder that often coincides with PDD, but may also be present by itself.

However, the present study provided additional evidence for the point of view that MCDD can be delineated from PDD-NOS. Children who fulfilled criteria of MCDD clearly differed from the PDD-NOS group on a number of other symptom dimensions, which supported their divergent validity. The significance of the present study's findings becomes clear all the more because a large battery of standardized assessment procedures was used, which made the results independent of informant (clinician, parent, or child), method of data collection (interview versus questionnaire), or diagnostic construct (e.g., DSM-IV versus CBCL based taxonomy) that was used.

An important distinction between the MCDD group and the PDD-NOS group was found with respect to the number ADOS-G autism or autism spectrum disorder classifications that were yielded, which was 36.0% in the MCDD group, and 62.2% in the PDD-NOS group. This was all the more remarkable because the groups did not differ on any of the ADOS-G domains. This may be related to the fact that the algorithm for an ADOS-G classification includes items from different domains, but does not include all items from all domains. Apparently, those children in the MCDD group fulfilled criteria for ADOS-G classifications to a far lesser extent than those in the PDD-NOS group. This can be considered as a reason to consider MCDD as a distinct construct. Of course, it can be argued that a number of MCDD children did not fulfill criteria of PDD-NOS, which automatically reduced the propensity that they would receive an ADOS-G classification. This would constitute an extra argument to consider MCDD as a separate entity. Unfortunately, our study lacked the statistical power to test if differences between MCDD children with versus without PDD-NOS were present.

On three other important domains, MCDD children showed higher problem levels than those with PDD-NOS. First, they had higher frequencies of DISC/DSM-IV anxiety disorders. For instance, they showed higher levels of separation anxiety. This may be related to the disturbed or ambivalent attachments that characterize MCDD (Cohen et al., 1986; Towbin et al., 1993). They also had a higher rate of obsessive compulsive disorder. Severe obsessions and compulsions may resemble symptoms of psychosis or thought disorder. The coexistence of obsessive compulsive symptoms and psychosis has been described extensively (e.g., Byerly, Goodman, Acholonu, Bygno, & Rush, 2005; Eisen & Rasmussen, 1993; Ganesan, Kumar, & Khanna, 2001) and seems to apply to MCDD as well. The largest effect sizes, and thus the largest differences between the groups were found on measures of psychotic thought problems (e.g., CAFAS Thoughts subscale, CBCL Thought Problems syndrome scale). Clinicians more often rated the presence of paranoia, incoherent thoughts, loose associations, delusions, and hallucinations in MCDD children, as compared to those with PDD-NOS. Also parents of MCDD children reported the occurrence of hallucinations more often than parents of children in the PDD-NOS group.

A third domain on which children with MCDD showed higher problems levels than

those with PDD-NOS, was the frequency of DISC/DSM-IV disruptive behavior disorders. More specifically, they showed higher rates of oppositional defiant disorder and of conduct disorder. ODD and CD are disorders characterized by behaviors such as aggression, lying, stealing, violence, disobedience, and anger (APA, 1994) which may be reflected in the impaired regulation of affective states as seen in MCDD children (Cohen et al., 1986; Towbin et al., 1993).

Because of the social contact problems in the criteria of MCDD, its pervasive character, the early onset, and the deficits in multiple areas of development, the diagnostic classification mostly used for MCDD children is PDD-NOS (Ad-Dab'bagh & Greenfield, 2001; Towbin et al., 1993), in particular because MCDD is not an official DSM-IV or ICD-10 classification. The current study showed that MCDD children have impairments in social contact, but to a lesser extent than children with PDD-NOS, and furthermore, as discussed above, they also showed more anxiety, disruptive behavior, and psychotic disorders than children with PDD-NOS. Therefore, in our opinion, MCDD should not necessarily be placed under the PDDs. For example, one could also argue that MCDD should be regarded as a psychotic disorder, as a variety of psychotic thought problems and hallucinations seemed to be characteristic of MCDD, and showed the largest effect sizes between the groups.

Summarized, MCDD can be regarded as a disorder characterized by the presence of anxiety, disruptive behavior disorders and psychotic thought problems, that seems to constitute a diagnostic category not only different from autistic disorder, but also different from PDD-NOS. A different etiology and treatment approach may therefore apply to MCDD versus PDD-NOS.

Clinical implications

If MCDD would be a separate disorder, it would be useful to diagnose MCDD symptoms in clinical practice, independently of the presence or absence of a PDD. If clinicians considered a diagnosis of PDD-NOS as a prerequisite for the presence of MCDD, in the present study MCDD MCDD would have been missed in 56% of the cases (i.e., 56% of the children who fulfilled criteria for MCDD did not meet criteria for PDD-NOS).

Another issue related to this is whether clinicians will be able at all to reliably distinguish between MCDD and PDD-NOS. In practice PDD-NOS is often regarded as the most complex diagnosis to make in the autistic spectrum and is difficult to differentiate from autism (e.g., Buitelaar et al., 1999; Volkmar et al., 1994; Volkmar & Wiesner, 2004). Interrater reliability of diagnosing PDD-NOS within the autistic spectrum is low (e.g., Towbin, 1997; Volkmar, Klin, & Cohen, 1997). To solve this problem, use of standardized procedures in clinical practice would be very useful.

Considering MCDD as a disorder that can be delineated from PDD-NOS also has research implications. The symptoms covered by MCDD may occur in combination with a variety of psychiatric disorders, not only PDDs, and therefore, children who fulfill criteria of MCDD should not only be selected from a group of children with PDD-NOS, but also from children with other PDDs or other psychiatric diagnoses.

Limitations

The inclusion of children from only one outpatient department limited the generalizability of the findings, and also referral biases could have played a role. A university department of outpatient child and adolescent psychiatry is generally not the first institution that children with psychiatric problems are referred to. Therefore, the sample of the present study may not represent the target population of all children with PDD-NOS and MCDD. Also, samples of children with PDD-NOS and MCDD may vary across different sites and countries. The research criteria used in this study to classify PDD-NOS were considered reliable and standardized, but were nevertheless developed mainly by Dutch authors and are not necessarily used at other national or international sites. Future multi-center and epidemiological studies in possibly more representative samples are needed to test the present study's findings.

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Table 1

PDD-NOS and MCDD research criteria (Buitelaar & Van der Gaag, 1998)

PDD-NOS

1. Qualitative impairments in social interaction:

a. Marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye

gaze, facial expression, body postures, and gestures to regulate social interaction

b. Failure to develop peer relationships appropriate to developmental level

c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with

other people

d. A lack of social or emotional reciprocity

2. Qualitative impairments in communication:

a. In individuals with adequate speech, marked impairment in the ability to initiate

or sustain a conversation with others

b. Stereotyped and repetitive use of language or idiosyncratic language

3. Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities:

a. Stereotyped and repetitive motor mannerisms

MCDD

1. Impaired regulation of affective state and anxieties:

a. Unusual or peculiar fears and phobias, or frequent idiosyncratic or bizarre

anxiety reactions

b. Recurrent panic episodes or flooding with anxiety

c. Episodes of behavioural disorganization punctuated by markedly immature,

primitive, or violent behaviours

2. Impaired social behaviour:

a. Social disinterest, detachment, avoidance, or withdrawal

b. Markedly disturbed and/or ambivalent attachments

3. The presence of thought disorder:

a. Irrationality, magical thinking, sudden intrusions on normal thought process,

bizarre ideas, neologism, or repetition of nonsense words

b. Perplexity and easy confusability

c. Overvalued ideas, including fantasies of omnipotence, paranoid preoccupations, over engagement fantasy figures, referential ideation

Note. MCDD = Multiple Complex Developmental Disorder; PDD-NOS = Pervasive Developmental

Disorder Not Otherwise Specified.

Table 2

CBCL syndrome scale scores of the PDD-NOS and MCDD groups

CBCL syndrome scales	PDD-NOS (n = 72)	MCDD (n = 22)	p-value	Effect size (d)

	M	SD	M	SD		
Withdrawn	6.20	3.70	5.91	2.64	.563	.08
Somatic Complaints	2.03	2.45	2.41	2.70	.379	.15
Anxious/ depressed	8.28	6.16	10.09	6.22	.091	.29
Social Problems	6.66	3.13	5.66	3.13	.065	.32
Thought Problems	3.59	2.59	5.10	2.76	.016	.57
Attention Problems	10.12	4.55	9.43	4.42	.374	.15
Delinquent Behavior	2.98	2.70	3.48	2.36	.272	.19
Aggressive Behavior	15.74	8.91	16.41	8.86	.661	.08

Note. CBCL = Child Behavior Check List; M = mean, MCDD = Multiple Complex Developmental Disorder; PDD-NOS = Pervasive Developmental Disorder Not Otherwise Specified; SD = Standard Deviation.

Table 3

DISC/DSM-IV disorders in the PDD-NOS and MCDD groups

DISC/DSM-IV disorders	PDD-NOS (*n* = 85)	MCDD (*n* = 25)	*p*-value	Effect size (*Φ*)
Social phobia	10.6%	16.0%	.475	.07
Separation anxiety disorder	5.9%	20.0%	.046	.21
Specific phobia	37.6%	56.0%	.102[a]	.16
Agoraphobia	7.1%	8.0%	1.00	.02
Panic disorder	1.2%	8.0%	.129	.18
Generalized anxiety disorder	7.1%	4.0%	1.00	.05
Selective mutism	0.0%	0.0%	n/a	n/a
Obsessive compulsive disorder	7.1%	36.0%	.001	.35
Posttraumatic stress disorder	0.0%	0.0%	n/a	n/a
Major depressive episode	9.4%	20.0%	1.00	.14
Dysthymic disorder	1.2%	4.0%	1.00	.09

Manic episode	1.2%	12.0%	.036	.24
Hypomanic episode	2.4%	8.0%	1.00	.13
Schizophrenia	0.0%	0.0%	n/a	n/a
ADHD, inattentive type	40.0%	40.0%	.100[a]	.00
ADHD, hyperactive/impulsive type	27.1%	40.0%	.215[a]	.12
ADHD, combined type	20.0%	24.0%	.666[a]	.04
Oppositional defiant disorder	37.6%	60.0%	.047[a]	.19
Conduct disorder	5.9%	24.0%	.016	.25

Note. [a] : the p-value of Chi-Square Test is stated. In all other cases the p-value of Fisher's Exact Test is stated due to expected cell counts less than 5. ADHD = Attention Deficit Hyperactivity Disorder; DISC-IV = Diagnostic Interview Schedule for Children – version IV; DSM-IV = Diagnostic and Statistical Manual of mental disorders – 4th edition; MCDD = Multiple Complex Developmental Disorder; n/a = not applicable; PDD-NOS = Pervasive Developmental Disorder Not Otherwise Specified.

Table 4

FTD ratings in the PDD-NOS and MCDD groups

FTD ratings	PDD-NOS (n = 86)	MCDD (n = 25)	p-value	Effect size (Φ)
Illogical thinking	28.2%	44.0%	.137	.14
Loose associations	48.2%	76.0%	.014	.23
Incoherence	25.9%	36.0%	.323	.09
Poverty of content of speech	35.3%	24.0%	.290	.10

Note. FTD = Formal Thought Disorder; MCDD = Multiple Complex

Developmental Disorder; PDD-NOS = Pervasive Developmental Disorder

Not Otherwise Specified.

Table 5

ADOS-G domain scores in the PDD-NOS and MCDD groups

ADOS-G domains	PDD-NOS (n = 82)		MCDD (n = 25)		p-value	Effect size (d)
	M	SD	M	SD		
Communication	1.99	1.04	1.68	1.63	.263	.26
Reciprocal Social Interaction	5.09	2.80	3.92	2.71	.069	.42

Communication and Reciprocal Interaction	7.07	3.46	5.64	3.96	.083	.40
Imagination/ Creativity	.78	1.28	.44	.71	.203	.29
Stereotyped Behaviors/ Restricted Interests	.98	1.13	1.32	1.44	.215	.28

Note. ADOS-G = Autism Diagnostic Observation Schedule – Generic; M = mean; MCDD = Multiple Complex Developmental Disorder; PDD-NOS = Pervasive Developmental Disorder Not Otherwise Specified; SD = Standard Deviation.

0045

VISUAL ACCESS AND COMMUNICATION SYSTEM (VACS) FOR CHILDREN WITH A PSYCHIATRIC DIAGNOSIS:

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ABSTRACT:

Weskoppies Hospital is a in-patient psychiatric facility, which provides short-term intervention for children with a psychiatric diagnosis, whose minds as well as their bodies have been damaged by the intrusions of sexual abuse, violence or neglect. The need for a workable system that would allow for appropriate intervention in terms of medical and therapeutic input was identified. Unica School for Learners with autism spectrum disorders and Weskoppies Hospital Children's Ward's multi-disciplinary teams have a long standing working relationship during which similarities between autistic children and children with a psychiatric diagnosis were identified. Unica School uses visual support to create structure, understanding and predictability for their learners. It was found that this structure in turn creates harmony in the interpersonal relations between learners and staff and enhances therapeutic and learning effectiveness.

Most children that are admitted to the Children's Ward were in some or other way exposed to trauma. These children are so overwhelmed that they have lost the ability to adapt. Psychological trauma causes the child to feel helpless and powerless. The way Herman (1994:34) defines trauma helps us to make sense of what happens internally with these children that were exposed to different forms of trauma. She distinguishes between ordinary responses to danger and traumatic reactions:

"The ordinary human response to danger is a complex, integrated system of reactions, encompassing both body and mind. Threat initially arouses the sympathetic nervous system, causing the person in danger to feel an adrenalin rush and to go into a state of alert. Threat also concentrates a person's attention on the immediate situation. In addition, threat may alter ordinary perceptions: people in danger are often able to disregard hunger, fatigue, or pain. Finally, threat evokes intense feelings of fear and anger. These changes in arousal, attention, perception and emotion are normal, adaptive reactions. They mobilize the threatened person for strenuous action, either in battle or in flight."

"Traumatic reactions occur when action is of no avail. When neither resistance nor escape is possible, the human system of self-defense becomes overwhelmed and is organized. Each component of the ordinary response to danger, having lost its utility, tends to persist in an altered and exaggerated state long after the actual danger is over. Traumatic events produce profound and lasting changes in physiological arousal, cognition and memory. Moreover, traumatic events may sever these normally integrated functions without clear memory of the event, or a person may remember everything in detail but without emotion. She may find herself in a constant state of vigilance and irritability without knowing why. Traumatic symptoms have a tendency to become disconnected from their source and take on a life of their own."

In the unit great attention is paid to the interpersonal relationships between the children and psychiatric sisters. A need to facilitate this process was also identified. Awareness of the child's emotional state as well as the effect it has on others is created. Rules implemented are focused on not harming the self as well as others. Choices are offered to calm the child e.g. thinking chair or silent table.

Due to trauma children cannot process and think about thoughts in a normal way. They experience incoming information as destructive external forces as invading the self. This is a primitive kind of thinking which depends on manipulation of what is felt to be things in themselves, substitute words and ideas. (Bion: 1959). Rather than using symbol formation, traumatized children use manipulation through projective identification. Traumatized children project internal fears of rejection and abuse onto staff and friends and relate to significant role-players the same way they internally feel about the traumatic event. The language we use to communicate to them triggers these children's lack of a protective or filtering mechanism for emotional stimuli. Insensitive and negatively perceived communications towards them become something unthinkably frightening, and are projected in the form of aggressive outbursts, sexualized behavior or withdrawal. Failed containment results in persecutory anxiety of the violent re-entry of projective identifications. (Bion: 1962b).

Whatever the cause, the inner worlds of traumatized children with special needs are extraordinarily impoverished. In traumatized children the function of the mind that makes thoughts thinkable is impaired. Thoughts therefore become mentally indigestible and unthinkable as much as its actual positive or negative content. (Waddell: 1998). It seems at times they have virtually nothing to hold onto internally. Words and meaning get lost due to the difficulty in thinking their thoughts.

Containment of hope is just as important for the development of thinking. This project is aimed in helping children to soothe their minds and transforming the auditory and mental digestion problem in a way in which their experiences can become more normal. This process can eventually evolve through an experience of an introjective process whereby the child can internalize a good enough experience to create a less traumatic experience of the world. By creating a "holding" environment for the children admitted at the ward we saw the opportunity for assisting them with a visual support system. The reliability and regularity provided by the visual system and the firm structure, provides an opportunity for consistency to create a safe internal experience. Containment can be seen as an essential ingredient for traumatized children in their path to healing.

Bion's model of "container-contained" (1962b) focuses on the relationship between mother and infant and between therapist and patient as well as nursing staff and children admitted. At the same time, it is a theory of the mind, of how the mind functions. Bion argued that in order to be able to think, and reflect on experience, sense impressions and raw emotions have to be transformed or processed by the psyche into thoughts. Children learn from experience. A child need adults to help them process overwhelming raw emotions and if adults fail in the "container-contained" function the child's only way of dealing with these frustrations is by evacuating the thoughts. (Bion: 1962). This mindlessness in traumatized children can be observed in their attacks on the self by e.g. Cutting themselves.

It is argued that a sense of order, predictability and familiarity creates internal harmony, which in turn enhances therapeutic and learning effectiveness. In addition, individuals learn through a variety of ways. (Savner, Myles:2000). Many research studies have shown that not only learners with autism, but also individuals with similar disabilities perform best when provided with clear and consistent visual cues. (Vaughn& Horner:1995; Pierce& Screibman: 1994;Attwood, Frith & Hermelin:1988).

Learning through seeing enables children to learn more quickly, reduces aggressive or self-injurious behavior, decreases frustration and anxiety, and provides independence and assist individuals to work independently. In short, visual supports help traumatized or special needs learners to understand their world better. (Savner, Myles: 2000). The use of ordered sequences increases an individual's familiarity with interactions and facilitates communication by promoting more active participation in social exchanges. (Siegel-Causey & Ernst: 1989). Through the regularly recurring activities of the day, caregivers develop predictable patterns in their interactions with children. Predictable patterns in turn help children to become more involved in their exchanges. In the caregiver-child relationship, by organizing daily activities into a regulated, sequential format, children are allowed to become more familiar with the structure of the immediate environment. The opportunity to predict familiar events is vital to the child's understanding of rules, structures and components of communication and language. (Gregory & Hartley:1995).

It is important to note that visual supports are useful regardless of the learner's IQ, specific diagnosis or level of communication skills. (Attwood, Frith & Hermelin :1988) Despite seemingly well-developed expressive language some children may not process information that is given to them verbally in an effective manner. Hodgon, 1995 postulates that: "The use of visual communication tools is not determined by a student's ability to talk. These tools are valuable with both verbal and non-verbal students. Their use is determined in part by the student's ability to take in information and make meaning from it." This capacity can only exist if the containing function has been internalized.

The Visual Access and Communication System (VACS) was then custom made for the Children's Ward. This specialized visual board and card system consists of:

- Ward program for multi-disciplinary team

- Daily schedules into am/pm

- Individual schedules for each child

- Calendar and weather board

- Visual ward rules card system

- Photo's displayed of nursing staff on duty

- Side effects visual chart for nursing staff

- Activity tags to structure children's whereabouts

Frustrating factors due to the intense emotional strain on nursing staff as well as insufficient funding in providing efficient facilities in catering for the children in hospital was experienced. Various facilitating meetings were held with nursing staff. The project was funded from donations as the hospital had no funds available.

Nursing staff were initially not trained to implement the VACS. Nursing staff were given in service training by the psychologist of the Children's Unit as well as Unica's speech therapist.

In addition to the structured approach we also focus on a less punitive communication style. Efforts are made to be aware of verbal as well as non-verbal communication. The Visual Access and Communication System focuses on a less punitive interaction method in assisting children in understanding their emotions and to facilitate responsibility in a non-punitive way. Staff members are made aware of the underlying meaning of what the child is communicating. Having this understanding enables staff members to contain their own emotional reactions to the children, and thus, to responding a containing, rather than controlling or punitive way. Traumatized children are left with a "mindlessness" that can lead to misunderstanding. Children seek to connect and re-connect in different ways in feeling safe internally. They need containment, belonging and reassurance and often feel unsafe in the need to seek connection. In order to connect and communicate children use projection. Projection is the automatic process whereby contents of the child's own unconscious internal world are identified to be in others. What is unconscious will be either repressed or projected. Every connection in a way is a re-discovery of aspects of us as mirrored by the other. Children tend to project their own wounding/unresolved issues/longings and dependency needs onto caregivers. Their need to control stems from a sense of insecurity and uncertainty about themselves and life circumstances. Whatever the cause, traumatized children with special needs have an inner world that is extremely impoverished.

In working with emotionally deprived children we came to realize that in language different meanings get lost. A potentially unlimited number of descriptions and explanations are possible, not one of which can be ruled as being superior or inferior in representing any phenomenon or situation. (Gergen: 1994; Gergen: 1999). In our communication with children the implication of this statement is that everything we hold about ourselves on the world could be otherwise. There is nothing about "reality" that demands particular account and we can therefore use our language to construct alternative worlds, as we are not locked into any convention of understanding. (Gergen: 1999). From this perspective Gergen contends that a social constructionist epistemology is a generative epistemology in that it provides a conceptual framework in which a potential multiversity of possibilities is available for the emergence of generative discourses, new forms of language, different ways of interpreting the world and different patterns of representation that simultaneously challenge existing traditions of understanding and offer alternative ways of relating (Gergen: 1999). An 11year old boy's only way of communicating after cutting himself with a piece of glass was "there is nothing wrong with me". "Nothing" in his frame of reference had a different meaning. He had lost all his previous attachment figures and after exploring what he meant we could assist the staff members in understanding through his eyes the nothingness of being in a world of abusive and rejecting parent figures. Internally he had nothing to hold on to he felt objectless and the loss of his self was verbally communicated with a different meaning through language.

The presence of one meaning does not deny the presence of the other. The one position does not replace the other. They are both present. By providing space to allow for the emergence of both positions, we can create an opportunity to gain a glimpse into how children create meaning with regard to their world and others. By allowing space for an emerging dialogue we can also allow for the consideration for the different ways of relating, thereby allowing for the emergence of new perceptions and meaning which, in turn, could create a possibility for change. Change is not seen as the replacement of one perception with another. It recognizes that all the voices will always be present, especially if they are culturally or socially embedded discourses. (Ward:2002). Change can cause significant anxiety but by organizing the daily routine of the children in a predictable and non-threatening visual schedule, anxiety is reduced. The purpose of this project was to stimulate dialogue with and within the multi-disciplinary team members and the children admitted, in a way that allows for an exploration and an openness that can offer opportunities to explore a multiversity of possibilities of the meaning of verbal communication through language.

Where our conventions of representation and language are embedded in relationships, these relationships are sediment in broader relationships of discourse and culture. Without a shared language of representations these "forms of life" would not exist in the form that they do. Our language constructs our worlds and is the essence of our realities. (Gergen: 1999). The VACS overcomes the obstacles of language barriers by assisting the child by a visual card system understandable for different language groups.

Most individuals with severe handicaps or trauma find it very difficult to be spontaneously productive without consistent, external structure. (Nuru:1985) It is argued that the reliability and regularity as well as the firm structure provided by the VACS will also pave the way to a consistent and safe internal experience for children whose bodies and minds have been damaged by sexual abuse, violence or neglect and not only learners with ASD or another diagnosable conditions. As a result of organizing the external structure of these children, their impoverished inner worlds may find healing through an introjective process whereby the child can internalize a predictable path to a less traumatic experience of the world.

Rorschach studies have shown that children exposed to various forms of traumatic life events display problems in disordered thinking and inaccurate perception (Margot Holaday:2000). Trauma interrupts the child's naïve belief that the world is dependable and predictable and the people in it follow logical rules based on trust and fairness, and it also disrupts the belief that there is appropriate punishment for people who do bad things. When children cannot comprehend or make sense of what happened to them, life becomes irrational, illogical and confusing. Reality is no longer understood in the same way as it was before the trauma, and traumatized children and adolescents appear to have learned that people are likely to be unsupportive or undependable and that the environment is likely to be dangerous and capricious. Predictable patterns in turn help children to become more involved in their exchanges (Margot Holaday:2000). Pynoos et al., in Margot Holaday, (2000), highlighted the effects of traumatic stress on the mind, body and society. Their conclusions showed severe cognitive problems including an interruption in the normal developmental task of "narrative coherence" i.e., children's ability to organize narrative material into a beginning, middle, and end". The VACS program facilitates this process in helping children understand that the day and week has a beginning, middle and end.

Since the implementation of VACS the nursing staff have found changes in the behavior of the in-patient children which are directly connected to, and attributed to the VACS program. These benefits may be summarized as follows:

- The children are better able to communicate their needs and frustrations through the discipline and structure provided through the card system.

- The children follow the structure set out per day and find it easier to comply with the set structure, potentially through the sense of predictability, and having the structure visually accessible on the board.

- The nurses found that the children accept responsibility for their own behavior and daily tasks. The children have taken the initiative to fetch the items for the daily structure and request the staff to set up the day for them, before the staff have done this activity.

- The children have become more disciplined and less oppositional towards the staff. They display eagerness to follow the daily rules and are less disruptive in conforming to the ward structure and rules. The children seem to use the VACS as a form of security and have found a way of using it as a form of enjoyment.

- The nursing staff have found that the in-patient children are more likely to display self-control than before the program was implemented.

The nursing staff reports direct benefits to themselves through the implementation of the VACS Program:

- Through the training provided during the implementation of the Program they have a greater appreciation and understanding of the underlying feelings and dynamics of the child. Through this they aim to deal with the underlying causes of behavior, rather than the behavior itself. This has led to changes in their interaction and disciplining of the children.

- The staff report feeling less anxiety as a consequence of dealing with disruptive children.

- The VACS allows time to complete other functions for which they are responsible. There is less global disruption in the ward, and less of an ad hoc management style of the nurses in dealing with the children in the ward.

- The nursing staff report feeling they are making more of a dynamic contribution to the treatment of the children, while also influencing their work milieu in a positive manner.

The VACS program has illustrated how visually based interventions and a less punitive communication style play a role not only in the development of child-staff relations, but also how this bond enhances emotional connectedness and attachment.

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0046

CREATIVITY IN AUTISM (PSYCHIATRIC DISORDER)

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Genius, Creativity and Talent:

From time immemorial human kind has searched for the roots of creativity. The Oxford English Dictionary defines genius as "native intellectual power and of an exalted type, such as is attributed to those who were esteemed greatest in ay department of art, speculation or practice; instinctive and extraordinary capacity for imaginative creation, original thought, inventions, or discovery. Often contrasted with talent". Undoubtedly, the capacity for higher order thinking is that distinguishes the person with genius. In his understanding of genius, Ezra Pound noted that it "is the capacity to see 10 things where the ordinary man sees 1, and were the man of talent sees 2 or 3, plus the ability to register multiple perceptions in the material of his art".

Creativity and Autism:

Many features of High Functioning Autism / Asperger's syndrome enhance creativity. Certainly, the ability to focus intensely on a topic and to take endless pains to produce a creative work is a characteristic feature of this syndrome. Persons with HFA / ASP have an extraordinary capacity to focus on a topic for very long periods (days on end – without interruption even for meals). For this reason they can be termed workaholics and show a remarkable capacity for persistence. They are tremendously energetic, tremendously imaginative, particularly in the visual area. They are independent thinkers and don't pay a great deal of attention to what other researchers are doing. The Savantism or special ability in mental arithmetic etc. does occur in persons with autism. Of course this is only a minority. At the other end of the spectrum persons with High Functioning Autism often show tremendous creativity ability above what would be expected by IQ. Somehow there appears to be an overlap between High Functioning Autism and creativity that is not linked to IQ. OF course basic IQ is necessary. Beate Hermelin estimates that one or two in 200 of those with Autism Spectrum Disorder have genuine talent.

Autistic Intelligence:

Hans Asperger saw autistic intelligence as being unconventional "unorthodox, strangely pure and original, akin to the intelligence of true creativity".

Genes and Genius:

To achieve true genius in terms of creativity it appears that there is a combination of genes that need to be inherited. Clearly there are multiple genes of small effect involved. No amount of musical teaching for example will create a Mozart. It is necessary to have the genetic background first before the musical teaching can have a beneficial effect.

Genius and Madness:

This is a topic with a very long history and indeed the poet Dryden stated "Great Wits are sure to Madness near ally'd – And thin Partitions doe their Bounds Divide".

The Male Brain and Creativity:

Clearly in relation to autism and Asperger's syndrome which is more common in males it would appear that the male brain is more successful in certain kinds of creativity particularly in maths, engineering, and computer sciences. The male brain is less integrated, more literalised, better at doing research of a systematising kind, and poorer at relationships particularly those involving empathy.

Lewis Carroll an example of High Functioning Autism or Asperger's syndrome. He wrote Alice in Wonderland. Lewis Carroll's childhood interest included snails and toads among his intimate friends. He tried to encourage civilised warfare among earthworms. His biographer Cohen noted that his language was peculiar and paradoxical. He was a shy lonely academic who was also interested in mathematics. He had poor peer relationships. He was poor at small talk. He got on better with children. He was a very obsessional rigid person. He was endlessly compiling lists. He was a workaholic and a perfectionist. Alice in Wonderland shows an autistic type narrative. He had a harsh conscience something that is common in persons with Asperger's syndrome but also showed perverse behaviour in his photography. He is probably the greatest children's writer of all time and his High Functioning Autism, Asperger's

syndrome, and his immature personality helped him to see life from a child's perspective and made him an extraordinary successful children's writer.

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0047

HUMOUR IN AUTISM AND ASPERGER SYNDROME

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Humour plays an important role in the life of every human being. Although we all take humour more or less for granted, humour is a very complex phenomenon and humour research is taking place in a variety of disciplines including psychology, linguistics, philosophy, medical science, sociology and many other areas.

HUMOUR AND AUTISM

What is the relevance of humour and autism? There has been a general understanding that people with autism and Asperger Syndrome – I will use the term here interchangeably – do not understand humour. According to Hans Asperger

'They are not able to laugh at themselves, they are ... 'rarely relaxed and carefree and never achieve that particular wisdom and deep intuitive human understanding that underlie genuine humour' (Asperger, 1944, p. 82)

There has been very little empirical research into humour in autism, apart from some work done by Van Bourgondien & Mesibov, 1987; Mesibov & Stephens, 1990; St. James & Tager-Flusberg, 1994; Reddy, Williams & Vaughan, 2002; Emerich et al., 2003. The general conclusions of these studies are that in young children with autism simple forms of humour are intact such as tickling, funny sounds, teasing, etc.

Some people with autism do understand basic types of humour, both verbal and non-verbal, e.g. slapstick humour, simple jokes, riddles etc. This understanding of humour, however, is not in line with their overall developmental level.

On the other hand, there are many anecdotal and parental reports that individuals particularly with higher functioning autism/Asperger syndrome do understand and appreciate humour (Everard, 1976; Ricks & Wing, 1975).

For example the paper by Werth, Perkins and Boucher (2001) describes a female – Grace - with HFA who produces puns, jokes and word plays which are mainly based on her obsessional interests. Her humour is described as very original which is in line with the well documented idiosyncratic language and neologisms as already alerted to by both Kanner and Asperger.

Another example of a person with very good humour is a young woman called Jenny, who I know personally. She has a moderate level of functioning, her verbal abilities are well developed and she produces and responds to verbal and non-verbal humour. Examples of her verbal humour are her own word creations, based on favourite movies and computer games. Non-verbal humour includes acting out funny scenes such as grimaces, funny walks in the style of Mr. Bean and Basil Fawlty). She also is a great mimic and is able to perfectly imitate – verbally and non-verbally - other students in her school and residential setting.

DEFINITIONS OF HUMOUR

Here are a few definitions of humour:

'Humour is such a complex and human phenomenon, any understanding of it will necessarily enrich our understanding of thought in general' (J.A. Paulos, 1980)

Humour plays a major role in human life; humour helps in communicating ideas, feelings and opinions (Brownell and Gardner, 1988)

Humour is a core part of human behaviour and considered to be a defining human attribute (Nahemow, 1986)

All of these definitions emphasize the importance and centrality of humour in human life.

TYPES OF HUMOUR

But what exactly is humour? There is no definite agreed upon terminology among   humour researchers. The different types of humour are mainly distinguished into verbal and non-verbal humour:

- Verbal Humour: e.g. figure of speech, word play, comic sounds or funny words, riddles, irony – (where a statement or situation implies both a superficial and a concealed meaning which are at odds with each other), wit, sarcasm, satire, parody, self-irony, ridicule and nonsense.

- Non-Verbal Humour: e.g. slapstick (exaggerated or unexpected gestures and movements), practical jokes, absurdity or surreal humour, visual humour such as cartoons, etc.

The general understanding is that the majority of people with autism are impaired in the understanding and production of these types of humour. We might find some explanations for the underlying causes of these deficits in some of the theories of humour which have been proposed.

THEORIES OF HUMOUR

Many different theories of humour have been put forward over the years from multi-disciplinary fields emphasizing different approaches to humour appreciation. For our purposes we concentrate on some physiological/psychological and cognitive dimensions of humour. We begin with Freud on whose theory other subsequent humour theories (e.g. Koestler, 1964) are based on.

Sigmund Freud originally dealt with aggressive humour; he interpreted humour and laughter as disguised expressions of unconscious wishes, often of a sexual or aggressive nature. In his later writings Freud emphasized the more positive effects of humour. In his exploration of humour, *'Jokes and Their Relation to the Unconscious' (1905)* Freud suggested that *'laughter can release tension and 'psychic energy'*. Freud described humour and laughter as instinctive means of reducing emotional arousal. According to Freud (1928, 1950), humour was one of the best defence mechanisms for reducing the impact of emotional experiences that would otherwise have serious negative effects on a person. He described humour as a *'a rare and precious gift'*.

The same thinking is echoed by Allport (1950) *'the neurotic who learns to laugh at himself may be on the way to self-management, perhaps to a cure'*.

Darwin (1872) had put forward the idea that laughter was an expression of joy and a form of social communication and necessary for survival.

BENEFITS OF SENSE OF HUMOUR

Freud's Relief theory of humour is still of great relevance today. Many studies have shown that having a sense of humour can protect from everyday stresses; it enhances one's sense of physical wellbeing and is beneficial for emotional wellbeing. Humour helps in coping with stress, enhances self esteem, and helps with relationships and other interpersonal problems. Studies have shown stress-moderating effects of sense of humour, i.e. people with a good sense of humour are better able to handle stress and also mood disturbances. There is some evidence that depression may be improved by humour. There also appears to be a relationship between measures of sense of humour and coping styles and self esteem. Taken together, it seems that a good sense of humour may help to protect from the negative effects of stresses in daily life.

Unfortunately, the majority of people with autism do not appear to have a sense of humour and miss out on the benefits of humour. Their inability to cope with stress and the co-morbiditiy with affective disorder in this population is well documented in the literature.

The main other theories of humour are cognitive theories.

INCONGRUITY THEORY OF HUMOUR

Cognitive theories in general analyze the structural properties of humorous stimuli or the way they are processed. The best known cognitive theory of humour is the 'incongruity theory'. Aristotle (382-322 B.C.) originally stated that incongruity was a necessary prerequisite for humour. The German philosopher Immanuel Kant in the eighteenth century also advanced a theory on incongruity. Today writers and researchers in general agree that one of the main components of both verbal and also physical humour is 'incongruity'. What is incongruity?

'Incongruity is intended in a wide sense, comprising the following oppositions: expectation versus surprise, the mechanical versus the spiritual, superiority versus incompetence, balance versus exaggeration and propriety versus vulgarity' (Paulos, p. 102).

On of the major theories of humour, is the 'incongruity resolution model' (Suls, 1972). According to this model *humour appreciation is a problem-solving task in which the punch-line, which is incongruous with the body of the text, must be detected and then reconciled with the lead.*

Basically, the incongruity theory is a linguistic theory, it explains the linguistic structure of jokes, but does not take into account the environment in which the joke was told. Humour also involves a variety of other cognitive functions, including problem solving, memory, and mental flexibility. All these processes as research has shown are impaired in autism.

SOCIAL AND AFFECTIVE ASPECTS OF HUMOUR

However, apart from the cognitive processing of humour there are also social affective and cultural aspects involved in humour appreciation: the sharing of fun and laughter with others, emotional engagement with others, and the feelings of closeness with others. Real humour appreciation also requires an affective response and needs to be placed in a social context.

'Humour depends on so many emotional, social and intellectual facets of human beings, and is particularly immune to computer simulation and therefore difficult for persons with autism' (Paulos, 1980, p. 51).

We are all aware of the problems individuals with autism experience in the emotional and social domain. Another important component in humour appreciation is that humour is not a solitary activity; humour and laughter are shared with others.

'Sharing humour and laughter requires emotional attunement, an interest in the topic of the laughter and an interest in the laughter of the others as an affective state in its own right'. (Reddy et al, 2002, p. 220).

The humour researcher Ted Cohen writes that 'in the end, it is the intimacy of sharing jokes that matters. We need reassurance that something inside us is echoed in another. That we are not alone with the feelings. According to Cohen

' we tell jokes because they invite a certain intimacy, and when that intimacy is achieved, we know we have reached someone else. Someone else feels or responds as we do, and in knowing this we know we are not alone'.

Most importantly, Cohen insists that the main point of a joke is *'that they give us pleasure, and that they are not solitary pleasures'.*

Research has shown that children with autism have difficulties in sharing with others. They do not share objects, experiences, attention and affect with other people. Particularly mutual emotional sharing, reciprocity, empathy are areas of impairment in autism which as a consequence leads to problems in experiencing the interpersonal and affective aspects of humour. In addition, the difficulties in facial perception individuals with autism have may play a role in recognizing humorous affect in others in addition to their affective difficulties.

HUMOUR IN NORMAL DEVELOPMENT

Research (Ekman 1973, 1984) shows that humour and laughter is universal among humans. Darwin (1872) already stated that humour is a 'hardwired' characteristic of the human species. Laughter in babies can be observed as young as 4 months of age (McGhee, 1979), therefore supporting the theory that laughter is innate.

According to child developmentalists humorous interactions are vital to the social development of children, they encourage playfulness (Bruner & Sherwood, 1976) and understanding of other's emotional attitudes, expectations and intentions (Stern, 1985) and are considered to be precursors of joint attentional abilities (Mundy, Sigman & Kasari, 1993). These are all areas of impairment in young children with autism.

NEURAL SUBSTRATES OF HUMOUR

Where in the brain is Humour? Specific neural structures that mediate humour have been reported in both the right and the left hemisphere.

RIGHT HEMISPHERE (RH)

According to research (Shammi & Stuss, 1999) the major brain region involved in humour appreciation is the Right Hemisphere (RH). Damage to the right but not the Left Hemisphere affects verbal humour appreciation. RH impaired patients have the ability to recognize a joke but have great problems in understanding the meaning of the joke. Also, RH patients can understand slapstick humour that does not involve Theory of Mind abilities or sophisticated linguistic abilities.

A recent ERP (event-related brain potential) study by Coulson and Williams (2005) with healthy adults supported these findings. [ERPs are specialized techniques used to measure electrical activity of the

brain.] This study found that semantic activations in the two hemispheres are different, with only the RH being activated in joke comprehension.

Memory also plays a major role in comprehension and appreciation of humour. Understanding of humour involves the interpretation of current information based on past experience (Shammi & Stuss, 1999). -PET **(**positron emission tomography) studies have confirmed that the right frontal lobe is implicated in the retrieval of autobiographic memories**.**   Research findings particularly indicate the role of the right frontal lobe in autobiographic memories.

Taken together, the main neural basis of humour appreciation seems to be the right frontal lobe, given its ability to integrate cognitive and affective information. In addition to the very strong Right Hemisphere involvement, research also indicates contributions of the Left Hemisphere and diverse neural networks.

LEFT HEMISPHERE (LH)

A recent fMRI study on humour (Goel and Dolan, 2001) showed that separate and different networks are activated depending on the type of humour under investigation. For example, semantic juxtaposition (incongruity) uses a bilateral temporal lobe network, whereas phonological juxtaposition (puns) activates a Left Hemisphere network involving areas of speech production.

Another study found involvement of the left temporal cortex (Wernecke's area) and the left inferior frontal gyrus (Broca's area**)** in incongruity tasks. Some activation in the equivalent Right Hemisphere areas were found, which were, however, less intense.

The study by Goel and Dolan (2001) is particularly important as it also identified a separate and distinctive network for the affective components of humour by showing a significant activation in the medial ventral prefrontal cortex and the bilateral cerebellum. These results indicated that a differential system underlies the cognitive and the affective processing of humour.

'We were able to separate the cognitive aspects of jokes from the affective aspect. The cognitive aspect involves the mental set shift. I could tell you a joke and you may get the joke but not find it funny. There you have the mental set shift but you don't have the component associated with the funny joke' (Goel & Dolan, 2001).

This finding might explain some of problems individuals with AS have in humour appreciation. Taken together, it appears that both hemispheres are involved in humour appreciation. Traditionally the Left Hemisphere has been associated with analytical, logical, local and rational processing while the Right Hemisphere is synthetic, Gestalt holistic, global and intuitive with respect to processing in several domains. The Left Hemisphere seems to be involved in the cognitive interpretation of humour whereas the Right Hemisphere is needed for the more affective appreciation, i.e. seeing the funny side of the joke, bursting out in laughter etc.

LIMBIC SYSTEM / AMYGDALA

The limbic system is a brain structure which is located in the medial temporal lobes and is concerned with visceral processes particularly those associated with emotions. The amygdala is a small almond-shaped structure which is part of the limbic system and has a specific role with regard to social behaviour. The limbic system, particularly the amygdala plays an important part in processing emotions and also mindreading. Patients with bilateral amygdala lesions are impaired in recognizing facial and vocal expressions of emotions. Failure in processing these affective signals will certainly impair humour interactions. We are all aware that individuals with autism have problems with emotion recognition and theory of mind.

I am now going to examine whether there is a link between the neurological findings of humour and the underlying neurological brain bases of autism and the various psychological theories of autism.

HUMOUR AND PSYCHOLOGICAL THEORIES OF AUTISM

The Frontal Lobe Theory of autism was originally proposed by Damasio and Maurer (1978) and is based on similarities between the main behavioural characteristics found in autism and frontal lobe patients including impaired social development, stereotyped and compulsive behaviour, communication and attention deficits, resistance to change, lack of initiative and spontaneity, very concrete thinking, etc. The two main psychological theories of autism, the Theory and Mind and Executive Functions Theory are based on a possible frontal lobe dysfunction. The Weak Central Coherence Theory of autism (Frith, 1989, Frith and Happé (1994) also has some potential to explain the lack of humour in autism. This theory does not indicate any specific brain region for subserving a central coherence. Happé proposed diffuse abnormalities of brain structure, citing evidence of brain overgrowth.

HUMOUR – COMMUNICATION AND THEORY OF MIND

Communication

The deficits in verbal and non-verbal communication which the majority of people with autism experience are of course one of the main reasons for their lack of humour. Being able to communicate effectively is necessary in any social context and vital for the appreciation of verbal humour. Pragmatic language deficits are widespread in autism, which include literal interpretation, inability to understand the speaker-listener relationship, non-conforming to conversational rules, problems with storytelling etc. There is no doubt that verbal humour is related to intact language abilities.

Impairments in non-verbal communication such as gesture and mime may explain the lack of understanding of non-verbal humour in autism.

Theory of Mind (TOM)

The pragmatic deficits in autism are closely linked to the impaired mindreading abilities in autism. Evidence of Theory of Mind impairment has been found in individuals with autism of all developmental levels, including HFA and Asperger syndrome. There is also a strong link between the ability to explain non-literal messages, e.g. lies, jokes, pretence, irony, sarcasm and theory of mind abilities (Happé 1993, 1994).

RIGHT HEMISPHERE AND THEORY OF MIND

When we looked at the specific neural structures for humour we showed that the Right Hemisphere plays a very dominant role. Likewise, there is substantial evidence that Theory of Mind capacities may be lateralized to the Right Hemisphere (RH).

 Here is some research evidence:

- Patients with Right Hemisphere damage have problems with Theory of Mind (TOM).

- The Right Hemisphere is necessary for activation of representational sets and integration of meaning and memory.

- The Right Hemisphere is considered to be necessary for 'hot' or more affectively charged TOM problems (Brothers and Ring, 1992)

- TOM impairments play a major role in the problems Right Hemisphere damaged patients have in humour appreciation (Brownell et al., 2000).

It appears that intact Right Hemisphere functioning as well as mindreading abilities are crucial for understanding and appreciation of humour.

RIGHT HEMISPHERE AND PERSONAL MEMORY

The right frontal lobe also plays a role in personal or episodic memories and self-awareness. As already previously mentioned, these are cognitive processes which as are necessary for humour appreciation. There is substantial empirical evidence that self-awareness and episodic memory are impaired in individuals with autism, which presents a further problem for humour understanding.

EXECUTIVE FUNCTIONS

The RH is also associated with Executive Functions, an umbrella term for mental operations, including shifting of mental set, cognitive flexibility in general, working memory, planning, attention, etc. For example, Executive Functions involve the ability to plan and organize one's thoughts and develop the necessary steps to achieve a desired outcome. All these mental processes are involved in the production and appreciation of humour. The ability to hold information in mind (working memory) is necessary for both verbal jokes and non-verbal cartoon tests of humour appreciation (Shammi & Stuss, 1999). Their research also showed that verbal humour was correlated with verbal abstraction ability and shifting of mental set. Flexibility in thinking is of great importance for the cognitive 'Incongruity theory of Humour' (Suls, 1972) which I mentioned previously. In order to understand a joke many cognitive functions are required including mental shifts, balancing between expectation and surprise, the mechanical versus the spiritual, and many more mental processes. Impairment in executive functions has been found across the autistic spectrum including Asperger syndrome.

WEAK CENTRAL COHERENCE

Individuals with autism have difficulties in integrating diverse information at different levels, including the integration of contents across narratives and discourse. They are said to have a weak central coherence which would explain their inability to understand the global meaning or gist of a story or a joke, which would affect their general understanding of humour.

SUMMARY: NEURAL AND PSYCHOLOGICAL THEORIES

To summarize, based on neuropsychological evidence, almost all mental operations involved in the comprehension of humour are impaired in autism and to a lesser extent in Asperger syndrome including linguistic abilities, pragmatics, theory of mind skills, episodic memory, self awareness, executive functions and central coherence. The main brain regions involved in these processes are in particular the Right Hemisphere and in more general terms the Frontal Lobes, which have extensive reciprocal connections with

-          the hippocampus (memory)

-          temporal lobe/limbic system and amygdala (memory and affect)

-          cerebellum (affect, cognition, attention).

All these brain regions have been implicated in the neuropathology of autism (e.g. Bachevalier, 1994; Courchesne et al., 1994; Damasio and Maurer, 1978).

LINGUISTIC, PHILOSOPHICAL AND MATHEMATICAL HUMOUR

It appears that specific types of humour, including, linguistic, philosophical and mathematical humour are preserved in very gifted individuals with autism/AS.

Paulos (1980) in his book on mathematics and humour writes that *'reversal or permutation of the grammar of a sentence often results in humour' …'a grammatical or combinatorial humour such as found in spoonerism, puns, transformation etc'.*

Some individuals with Asperger syndrome with excellent linguistic abilities enjoy this type of grammatical humour which to others may not appear funny at all, in fact to quote Paulos (1980) it could be described as quite 'tiresome'. This type of humour is largely based on the ability to use language in a very flexible way and therefore being able to create a kind of artificial, grammatical type of humour.

For example, words in a sentence can be put together or put in brackets in different ways which then have different semantic interpretations. For example **'**I saw a man eating shark in the aquarium' can be interpreted as 'I saw a (man eating) shark' or 'I saw a man (eating shark)'. This is an example of a riddle based on surface-structure ambiguity which is much appreciated in individuals with HFA/AS.

A similar, but 'deeper sort of humour' is **'**philosophical humour' which is based on misunderstandings derived from the 'confusion of the logic of a given statement or situation' which is also a favourite with people with AS.

For example, the Austrian philosopher Ludwig Wittgenstein (1953, 1958) who also had Asperger syndrome stated that *'a serious work in philosophy could be written that consisted entirely of jokes. One "gets" the joke if and only if one understands the relevant philosophical point'.* An example of this type of Wittgensteinian spoonerism is: 'Hangover: the wrath of grapes'. For the majority of people with autism, however, this would be very difficult to understand.

There are also great similarities between mathematical abilities and humour. It is well known that mathematicians more than any other professional group have a robust sense of humour and are very fond of word plays and jokes. Here are a few quotes on the subject of Mathematics and Humour (Paulos, 1980):

'Understanding the "correct" logic, pattern, rule, or structure is essential to understanding what is incongruous in a given story – to "getting the joke".

 'Both mathematics and humour are economical and explicit' … 'they are short and make sense without much context'.

Individuals with Asperger syndrome have problems with context but many have intact or superior mathematical abilities. It is no surprise, that mathematical type of humour is very much appreciated by individuals with AS. An example of an individual with highly developed linguistic and mathematical abilities

is the already mentioned Ludwig Wittgenstein, one of the most influential philosophers of the 20th century, keenly interested in mathematics, logic and science who also had Asperger syndrome.

WITTGENSTEIN'S HUMOUR

Wittgenstein discovered the meaning of jokes towards the end of his life when he discovered context and mindreading. Only when he was about 40 years old Wittgenstein moved from an exclusive focus on himself and language to begin to understand social context and the complexity of social relations. What comes natural in normal developing children in early childhood, Wittgenstein achieved through enormous effort over many years. Only then he began to understand humour, when he was able to see things from another person's point of view. Many of his contemporaries commented on his sense of humour. Bertrand Russell described Wittengstein's humour as 'witty'. Others thought it was 'childlike' which is a common feature in Asperger syndrome. Wittgenstein liked American comic-style humour as found in detective stories, which had simple emotional lines and uncomplicated plots. A favourite joke of his went as follows:

'A fledgling leaves the nest to try out its wings. On returning, it discovers that an orange has taken its place. 'What are you doing there' asked the fledgling. 'Ma-me-aid,' replies the orange.

There was also certain crudeness to some of his humour. One of his most humorous aphorisms was *'don't try and shit higher than your arse'.* Equally in his letters he used similar 'toilet humour'. Closing an address that ended with WC1, he drew an arrow to WC and wrote that it didn't mean 'lavatory'. He particularly liked nonsense humour. For example, he was very fond of the adjective 'bloody' which he found extremely funny and would begin letters to his friends with 'Dear Old Blood, and end them 'yours bloodily, or 'yours in bloodiness'. Wittgenstein was also an excellent mimic, a talented stand-up comedian. He was able to do all sorts of mimicry of accents, styles, and ways of talking. The skill of mimicry is quite different from that of acting, where role playing is essential. Mimicry involves a one-dimensional interpretation of a character, and it is not surprising that Wittgenstein excelled at it. In contrast, taking on a persona of a character would have created huge difficulties for him, since he lacked empathy, consistent with Asperger syndrome. Quite obviously, people with autism are often good at mimicry - as already mentioned in the case of Jenny, the young woman with autism who is also a brilliant mimic - but have problems identifying with a character.

 Wittgenstein studied humour in his philosophy and believed that humour was not a mood but a way of looking at the world. Humour was not something superficial that could easily be erased in a person but something altogether deeper. Monk, Wittgenstein's biographer claims that understanding humour, like understanding music, provided an analogy for Wittgenstein's conception of philosophical understanding. It was not in the discovery of facts or construction of theories but in having the 'right point of view', i.e. from which to 'see' the joke, to appreciate music, clarify philosophy, etc. But the real problem was how to find a way to explain or teach the 'right point of view'.

Another person with Asperger syndrome, Lewis Carroll, famous for his classic book 'Alice's Adventures in Wonderland' also was very found of nonsense humour.

CARROLL'S HUMOUR

There are some interesting similarities between the philosophical writings of Wittgenstein and the work of Lewis Carroll (Pitcher, 1966). Both were concerned with nonsense, logical confusion, and language. However compared to Wittgenstein who was tortured by these things, Carroll at least in his writings was delighted by them and brilliantly incorporated them into 'Alice in Wonderland' and 'Looking Glass'.

Here is an example of Carroll's humour which also relates to the topics Wittgenstein wrote about demonstrating a purposeful confusion of the logic of a situation.

She (Alice) ate a little bit, and said anxiously to herself, "Which way? Which Way?" holding her hand on the top of her head to feel which way it was growing, and she was surprised to find that she remained the same size (Alice in Wonderland, page 10).

This example shows the confusion about the logic of certain notions. One does not put the hand on one's head to check if one is growing taller or shorter – unless ones neck is growing. Like Wittgenstein, Carroll also had a brilliant mathematical mind, made great contributions to mathematics and according to Bertrand Russell, Carroll had 'the *stuff of a great mathematical logician'.*

ANALYSIS OF HUMOUR IN AUTISM

As mentioned at the beginning of this talk, Hans Asperger (1944) believed that the children he described had problems understanding humour. On the other hand, he also mentioned that they were highly creative, imaginative and original and their humour *'can range from word-play and sound associations to precisely formulated, truly witty comments'.* Likewise, Kanner (1946) mentioned the highly creative and metaphorical language in children with autism. Creativity and imagination are characteristics which are not usually

expected to be found in autism; impoverished imagination is part of the triad of impairments (Wing, 1996). Research has shown that autistic creativity is mainly limited to topics of special interests and restricted to imagination within the non-social world and is more reality-based than imaginative. As we have shown, some individuals with HFA/AS seem to master the cognitive processing of humour, as portrayed by the production of sophisticated puns and word games. Those individuals possess highly developed linguistic and computational abilities and approach humour form a more cognitive / intellectual perspective and are able to grasp the cognitive basis of humour. This interpretation is in line with the previously mentioned imaging evidence of differential systems underlying the cognitive and the affective processing of humour (Goel and Dolan, 2001). In many instances this type of humour appears to be learned and does not seem to have the purpose of sharing interaction with others. The most important ingredients, emotional response and reciprocity are missing. Humour and laughter are very social experiences, which can help to unite people and play an important role in social cohesion. We are all aware that even the highest functioning individuals with AS have severe problems in the social domain, which can lead to isolation and depression.

However, there is still this minority of people with autism/Asperger syndrome who as described in some of the anecdotal reports are able to produce, apprehend, share and enjoy humour despite of difficulties with mindreading. Interestingly, the majority of these accounts are based on females with autism (Mesibov, 1992; van Bourgondien and Mesibov, 1987; Werth 2001; Lyons and Fitzgerald, 2004). Is it possible that females with autism/Asperger syndrome are less socially impaired than males?

Whether the humour shown in individuals with autism is reciprocal or not, there is evidence that some of them greatly enjoy their own typical sense of humour which can be quite wide ranging and there is no doubt that their humour seems to greatly enrich their lives.

THERAPEUTIC USE OF HUMOUR

As I have already mentioned at the beginning, a sense of humour is beneficial in coping with stress, it helps to decrease tension and aggression, it has an impact on mood it increases positive moods and decreases negative moods, such as anxiety and hostility, it enhances self esteem, increases social cohesion, and is in general good for a person's psychological and emotional well being. Some evidence of the therapeutic use of humour in psychopathology, e.g. in antisocial personalities (Martens, 2004) suggests that humour contributes to a better social and emotional awareness and self insight in these patients.

We believe that the use of humour as behavioural intervention to reduce anxiety and aggression in autism may be of great practical importance. Similarly, the use of humour as a tool in educational settings, as part of social skills training as well as the use of humour in psychotherapy e.g. teaching people to adopt a more playful frame of mind, should be encouraged. Humour greatly enriches the life of human beings and people with autism should not be excluded from the benefits humour has to offer.

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0048

OCCUPATIONAL THERAPY INTERVENTION FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS

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The Brown's School & The University of Kwazulu-Natal, South Africa

Overview:

"Occupational Therapy Intervention for children with Autism spectrum Disorders."

Is a review of local and international literature in the fields of autism and Occupational Therapy in order to gain insight into the current practise of occupational therapists working with children between the ages of 3 to 12 years who have been diagnosed with Autism Spectrum Disorders. Areas covered include both assessment and treatment approaches used in the various treatment settings. Specific assessment areas include sensori-motor and fine motor development, visual perception, visual memory and visual motor integration. Treatment approaches covered include sensory integration, sensory motor and the behavioural approaches. Visual aids have been included to demonstrate some the difficulties these children present with at the time of assessment, treatment using the various approaches on an individual and group basis and pre and post occupational therapy intervention. The review also looks at the challenges faced by the occupational therapist dealing with this population, and more specifically in the South African context.

Introduction:

There has been a definite increase in the public awareness of Autism Spectrum Disorders (ASD's) as indicated by Gabriels & Hill, 2002. The increase in prevalence of ASD's has possibly lead to the need to educate the public. Given the high rates of population occurance (Gabriels & Hill, 2002 and Peeters & Gillberg, 1999), it is likely that health and educational facilities serving children with special needs can expect to see a greater number of children with ASD's. Case-Smith & Miller (1999) argue that with the increasing prevalence, practitioners need to understand the performance and occupational problems incurred by children with PDD and to develop competency in the intervention approaches advocated for these children.

The role of the OT in Autism has only recently been brought to the forefront as indicated by the lack of relevant literature. A possible reason for this could be that the diagnostic criteria do not primarily warrant the need for a referral to an OT, as opposed to for example, the speech therapist who would help the child deal with problems in communication (which falls within the diagnostic criteria).

It is important to note that a large percentage of these children present with symptoms that are not regarded as essential for making a diagnosis, however they are clinically significant as they can severely affect and underlie many aspects of the child's functioning.

These have been summarised under the following headings:

- Sensory Processing
- Motor Performance
- Fine Motor
- Cognition
- Visual Perception
- Visual Motor Integration
- Daily Functioning

❑ Sensory Processing Problems
Sensory processing difficulties are common in children with Autism (Willard & Spackman, 1993). In a study done by Case-Smith & Miller (1999), of 200 children with autism, 95 % presented with sensory modulation difficulties.

According to Anzalone and Williams (1999) some authors have suggested that the sensory disturbance is a primary deficit underlying autism and not simply an associated problem.

Ayres (1979) described three aspects of disordered sensory processing that may be found in this population. These could be summarised as follows:

- The inadequate registration of stimuli, which leads to the child ignoring relevant aspects in the environment.
- Faulty modulation, resulting in perceptual distortions including under and over–reactivity.
- Failure of sensory input to trigger positive affective responses, which causes the child to avoid new sensori-motor activities as mastery of those tasks is not intrinsically pleasurable.

Anzalone and Williamson provide three clinical profiles of SI dysfunction which are commonly seen in children with Autism:

1. Hyperreactivity

2. Hyporeactivity

3. Dyspraxia

1. Hyperreactivity
These children have a low sensory threshold and a bias toward a sympathetic nervous system (Sympathetic responses are those that indicate activation of the central nervous system such as increased blood pressure, heart rate and respiration).

In some children, the sensory overload becomes so threatening that they respond with an involuntary behavioural and physiological shutdown.

2. Hyporeactivity
These children have a high sensory threshold, i.e. they require a lot of sensory input for registration and activation. Often these children have not registered new sensory input and therefore have minimal information on which to base any interpretation. They do not learn from the environment because they have not noticed it.

3. Dyspraxia
Praxis can be understood in 3 steps:

a. Ideation (formulating goal)
b. Motor planning (figuring out how to accomplish the goal, this step involves problem solving based on sensori-motor awareness of the body).

c. Execution (carrying out the planned action)

Note that a child may not fit into a specific category, but may have a combination of symptoms.

Assessment of Sensory Processing

Assessment tools:

Parent interview or questionnaires (daily activities, sensory tolerances and preferences)
Observation in natural context (play, relationships, lunch times, transition between activities)
Infant and Toddler Checklist (De Gangi, 1995)
The Sensory Profile (Dunn, 1997)
The Miller Assessment for Pre-schoolers (Miller, 1998)
Test of sensory Functions in Infants (DeGangi and Greenspan, 1989)
SIPT or SCSIT (Ayres, 1979)

Aim: to ascertain how the child processes sensory information and deals with environmental challenges and not on specific skills or milestones the child demonstrates.

❑ **Motor performance**

Many children with ASD have generalised hypotonia with hyper-extensibility at some joints. Often their postures are poor (APA, 2000 & Bauman, 1999), gait is not a smooth movement, and activities that require bilateral co-ordination are executed poorly (Bauman, 1999). The DSM IV reports the presence of motor clumsiness and awkwardness in individuals with Asperger's syndrome, though to a mild degree, however it may affect participation in sporting activities (APA, 2000) and in social settings (Peeters & Gillberg, 1999). Difficulty in motor performance could possibly stem from one or a combination of the three steps in dyspraxia as mentioned earlier.

In practice, fine motor difficulties include:

- Shoulder and wrist dissociation.
- Crayon/pencil grip/ scissor grip.
- Eye hand co-ordination
- Bilateral integration for threading, tearing and other supportive functions of non-dominant hand.

Due to these fine motor difficulties, co-ordination tasks such as writing, colouring, cutting and self care, e.g. lacing, tying laces, doing buttons, are usually either not performed or performed at a poor quality. This is supported by Gabriel & Hill (2002), who maintained that motor imitation and execution of skilled motor tasks are also areas of difficulty for these children.

Assessment of Motor Performance

Gross Motor

Assessment tools used:

Clinical Observations (Ayres, 1979)

Observation on play ground

Fine Motor
Assessment tools used:

Colouring in and cutting samples
DTVP2 (Eye hand co-ordination, visual motor speed, spatial relations)
Beery (VMI, Motor co-ordination)
Writing samples
Detroit
   ❑   **Cognitive Difficulties**

According to Santangelo & Folstein (1999), children with ASD usually have accompanying learning difficulties. Regardless of the level of functioning, the profile of cognitive development tends to be uneven, ranging from mild to profound (DSM-IV, 2002: pg71-72).

Children with ASD typically demonstrate very concrete thinking, experience difficulty with concept formation, reasoning, abstract thought, processing information related to integration and generalisation of concepts (Bauman, 1999) and intellectual and emotional insight. Bauman (1999) further suggests that these children tend to be better visual learners than auditory learners. This is also supported by Case-Smith & Miller (1999).

Attention
Most children with ASD experience difficulty in attending, are easily distracted and hyperactive and cannot interact constructively with materials and objects. At a school age, they tend to work best with routine and highly structured work environments (Bauman, 1999; Case-Smith & Miller, 1999).

According to the DSM IV, symptoms of overactivity and inattention are often observed in Asperger's Syndrome (APA, 2000: pg81). Hyperactivity, short attention span and impulsivity have also been reported in Autistic Disorder (APA, 2000: pg72).

   ❑   **Visual Perceptual Difficulties**

Hill & Kodituwakku (2002) describe visual-spatial, visual organisation and visual matching skills as areas of strength for this population.

On formal testing, these children tend to, more often than not, score better on visual perceptual subtests of the DTVP2 than of those subtests that also have a motor component. However, they usually present with difficulty in integrating visual perceptual areas as observed by classroom performance. A possible reason for this could be that visual perceptual tests tend to test visual perceptual areas in isolation, e.g. position in space, visual figure ground, etc. (view slide on handwriting- reversals present however child scored in average to above average ranges on the DTVP2 subtests). Furthermore, Gabriel and Hill (2002) maintained that individuals with Autism perform well on detail-oriented strategies.

The DSM IV reports visual spatial skills as a weakness in individuals with Asperger's Syndrome.

Assessment of Visual Perception

Informal assessment tools:

Matching objects to object, object to picture, picture to picture
Sorting, Catergorising
Puzzles
Construction/building toys

Formal assessment tools:

Developmental Test of Visual Perception 2 (DTVP2)
Test of Visual Perception Revised (TVPS-R) (non-motor)
Gesell Test for Pre-schoolers
Beery (Visual Perception)

❑ **Visual Motor Integration Difficulties**

Hill & Kodituwakku (2002) reported visual motor integration skills, such as drawing and copying, as often impaired due to fine motor deficits.

The DSM IV concurs that visual motor skills are an area of weakness for these children.

Assessment of Visual Motor Integration

Informal assessment tools:

Copying a pattern (concrete – tower, pegboard pattern or abstract level -paper)

Copying form the board or page

Writing

Formal assessment tools:

Beery (Visual Motor Integration)
DTVP2 (Copying subtest)
Writing sample (Durell or WRIT)

❑ **Difficulties in Daily Functioning**

Adaptive functioning is described by Gabriel & Hill (2002), as the 'individuals effectiveness in meeting the standards expected for his or her age by his or her cultural group'. Gabriel & Hill (2002) further mention that children with autism demonstrate adaptive functioning deficits that exceed their cognitive deficits.

Children with ASD find it most difficult to communicate with other people, understand their behaviour, deal with materials, situations and people in a creative way. (Peeters, 1997)

Peeters and Gillberg (1999:76) suggest that these children experience pronounced difficulties with transferring skills form one situation to another and from person to person.

Assessment Challenges

Given the extreme variability in the presenting symptomatology, learning styles, and potential response to intervention, the assesment and treatment of children with ASD's poses many challenges to the OT (Kurtz, 1993)

According to Kurtz (1993), only a small percentage of high functioning persons with autism have the ability to comprehend and co-operate in formal standardised testing. In support of this, Watling, R, et. al. (1999), maintain that standardised tests usually require skills that are compromised in children with Autism, i.e. focussed attention and understanding of verbal instructions.

Shulman (2002), maintain that although modifications in standardised assessments negates the meaning of the standardised scores, modifications are likely to produce the most valid and useful information.

Watling study:

- ✓ Non-standarised tests and clinical observations were used often in assessments.
- ✓ Practice patterns with this population included frequent collaboration with other professionals during assessment and intervention.

Treatment

Various assessment and treatment approaches have been employed in the management of children with ASD's, however no one method has been proven to be more effective than the other. Due to the extensive difficulties these children experience, a comprehensive intervention programme would be required.

The study carried out by Case-Smith & Miller (1999), which investigated the practice of occupational therapists with children with PDD in the United States, revealed that therapists primarily provided direct services and appeared to use holistic approaches in addressing multiple performance and functional areas. The choice of approach used by the therapist is influenced by several factors including the therapists' level of specialist knowledge and the amount of time and resources available (Kurtz, 1993).

Sensory integration and environmental modification were found to be most frequently applied approaches, whilst child-centered play was reported as being used by some therapists (Case-Smith and Miller, 1999).

Watling, et. al. (1999) reported that treatment with this population, was usually provided with predominant use of sensory-based intervention techniques and positive re-enforcement. Theoretical approaches employed in ascending order included Sensory integration (SI), developmental and behavioural approaches.

One to one sessions were used most frequently (Case-Smith & Miller, 1999 and Watling, et. al, 1999).

Factors affecting discharge include practice setting and phase of intervention (Watling, et. al, 1999.)

Sensory Integration Approach

The Sensory Integration approach has been found to be useful in understanding and addressing these deficits.

Sensory integration is a process that involves organising sensation from the body and environment for adaptive responses (Ayres, 1979).

Intervention targets 3 different levels:

- Helping parents to understand their child's behaviour and fostering relationships.
- Modifying the environment to meet the child's sensory needs.
- Direct intervention to remediate identified problems.

The primary goal is to facilitate adaptive behaviour by providing appropriate, graded sensory experiences for the child with the disorder.

Treatment of hyperreactivity:

- ✓ Decrease or prevent sensory overload and assist modulation of sensory reactivity.
- ✓ Achieve an optimal level of arousal and attention
- ✓ Create a safe and supportive environment.

- calming techniques, deep pressure, proprioception

Treatment of hyporreactivity:

- ✓ Provide adequate sensory experiences to achieve and maintain a desired sensory threshold.
- ✓ Achieve an optimal level of arousal and attention.
- ✓ Support social and environmental interaction.

- Sensory rich environment, low intensity proprioception and pressure touch

Treatment of Dyspraxia:

- ✓ Difficulty in ideation- improve sensory modulation and ability to interact within environment.
- ✓ Motor Planning- Improve body scheme by increased tactile and proprioceptive feedback and improve ability to initiate and sequence motor strategies. Provide opportunities for problem solving.
- ✓ Execution- improve motor skills

Behavioural Approach

Behaviour therapy is concerned with improving specific behaviours or skills through the structured manipulation of re-enforcement.

The belief is that all behaviour is learned. The desired behaviours can be gradually moulded through the introduction of a reward system, and undesired behaviours punished.

Kurtz (1993) cite crucial elements to the success of behavioural approaches, namely:

1. Identification of meaningful reinforcers to the child.

2. The need for reinforcements to directly follow behaviour and be consistent.
   Considerable evidence exists supporting the effectiveness of behavioural therapy in improving communication and social competence in children with autism (Kurtz ,1993).

However, this approach has been criticised for failing to address the underlying causes of maladaptive behaviour, as well as for not generalising changes to other areas of the child's behaviour (Kurtz in Hopkins & Smith, 1993).

Sensory Motor Approach

Sensory motor approach (emphasis is placed on normal sensori-motor development)

Low Tone:

Provide proprioceptive input through joints by weight-bearing, using elevated surfaces.
Wrist dissociation:
Use activity that encourages combined flexion and extension of wrist
Fine manipulation activities:
Improve grasp/ grip
Eye hand co-ordination (tracing, pricking, mazes, dot to dot)

Relevant Studies

The study carried out by Case-Smith & Miller (1999), which investigated the practice of occupational therapists with children with PDD in the United States, revealed that therapists primarily provided direct services and appeared to use holistic approaches in addressing multiple performance and functional areas.

Sensory integration and environmental modification were found to be most frequently applied approaches, whilst child-centered play was reported as being used by some therapists.

Watling, et. al. (1999) reported that treatment with this population, was usually provided with predominant use of sensory-based intervention techniques and positive re-inforcement.

Smith and Bryan (1999) from Ohio State University investigated the effect of sensory integration in pre-school age children with Autism.

It was found after SI therapy that all the children had better goal directed play. There was a sequence of different actions and possibly improved motor planning as well as reduced sensory defensiveness, especially tactile defensiveness. There were fewer non-engaged behaviours such as aimlessness, stereotypical and unfocussed behaviour. Despite sensory integration the children were still non responsive as far as their interactions with adults and peers were concerned.

Summary

Occupational therapists are seeing more children with ASD's in both clinical and school based settings. Assessment and treatment challenges arise due to the varying symptom presentation. Non-standardised testing and observation within natural contexts appear to be more effective methods of assessing these children. The approaches used predominantly include sensory Integration, Developmental and Behavioural Approaches, however a comprehensive programme is deemed more appropriate for this population.

Most authors agree that further research needs to conducted to evaluate the effectiveness of these approaches.

There is no accurate statistics on the prevalence of ASD's in South Africa and a review of local literature also reveals a paucity of information regarding the assessment and treatment modes used in the management of children with these disorders.

According to Prithiviraj (2005), it is essential to take into account the ethnic, cultural and language factors when considering the development, diagnosis and treatment of childhood disorders.

Research in South Africa has been hampered due to the lack of necessary resources, problems with access and communication and political strife. Furthermore, African countries are faced with questions concerning differing diagnoses and co-morbidity when compared to western countries (Madu, 2003).

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0049

HOME PROGRAMS FOR DEVELOPMENT DISABILITIES: INTERVENTIONS TO SUPPORT PARENTS AND OTHER FAMILY MEMBERS

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Introduction

Impact of family and other significant people on successful implementation of ABA programs in the home. Could be extended to school settings, training therapists. Appetitive vs. aversive control.

RFT / ACT

Experience

My son, ABA/VB, families, family therapy, Gestalt, medical/biological sciences, now ACT.

ABA and the child's environment

ABA program only part of child's overall environment.

Family and others may have no involvement in program yet have significant impact on it and on the child.

Family likely to have no explicit understanding of, let alone training in, ABA.

Wider environment should support ABA program as far as possible and certainly should not inadvertently undermine it.

Family members will be the most salient SDs and SPs, the most strongly conditioned reinforcers and punishers.

Implication: family has the most power to make the program or to break it (other things being equal, and assuming viable program content and effective trainers).

Contingencies operating that do not promote the child's acquisition of appropriate and socially important skills, that block their acquisition, and that promote the acquisition of inappropriate ones.

The focus of ABA (in this case that the child is affected by and acts upon his/her environment in comprehensible and demonstrable ways) demands that not only the family's behavior but also their attitudes etc be addressed.

Implies that the family's understanding of ABA and understanding of their own effects on the program also be addressed. This is genuinely asking a lot of the family.

Family contingencies

Inappropriate modelling

Thicker schedules of reinforcement than therapists

Reinforcement of undesirable behaviors; likely to be intermittent as well

Extinction or even punishment of desirable ones

Undermining of the use of MOs

Thus we are asking family members to allow their behavior to be shaped so as to make the a major set of the child's contingencies more favourable to success of the program.

I am asking how we can increase the willingness of parents to allow this.

This paper attempts to suggest how the family might be made more likely to respond favourably to the challenge.

Education about ABA

In UK at least, understanding of ABA in a parlous state.

Even people on ABA list serves running ABA home programs for their children seem to have a negative view of it.

For many, behaviour/behaving = good/bad desirable/undesirable and not simply what we spend our time doing.

Anticipating what comes later, could say that behaviour/ABA for them is over-influenced by evaluative relational frames.

Is this because of an over-emphasis on compliance training, or even more importantly an under-emphasis on teaching? (Not in ABA generally but on many programs).

Do most parents really understand why we ask them to implement what we do? Evaluation of parents' and carers' understanding of ABA and providing of extra information and education if necessary at that start of a program.

Hostile education departments, school districts, health services. KSAs state that services should be provided only where physical and social environment will support their use; this intended to apply to the individual, but I would suggest is also relevant to a team – often home program operating in an environment that does not support the use of ABA. Often true of children in school "integration" as well.

Child may be receiving ABA services but parents having analysis, or something else. Also maybe child receiving cranial osteopathy, herbs, homeopathy, sensory integration therapy, or other approaches that, sometimes unwittingly, have their "ABA moments" (Floortime, Options). How to have these conversations? Sometimes parent to parent will work better.

ABA way of seeing a child's autism and/or behavior is not socially reinforced and most parents will have to be educated out of a medical/psychological or at any rate non-behavioral model.

Parents often confused about which treatments are most effective, and unclear about what types of problems the child will face when older (Konstantareas, 1990).

Aversive control

The arrival of a child with autism into the family is a stressor/likely to be perceived as an emergency. The situation will have powerfully aversive elements which could be expressed as wanting the autism to go away/the child to be cured or to find a cure.

Behavior analytic treatments of autism are time and labour-intensive. Requires consistency on the part of the parent, readiness and willingness to tolerate aversive interactions with the child.

Financial drain on parents

Stress can arise from the realization that treatment for their children might always be necessary (Mesibov, 1983).

Parents of children diagnosed with autism tend to experience a great deal of stress (DeMyer, 1979; Holroyd, Brown, Wikler, & Simmon, 1975),

Difficulties in finding and maintaining access to appropriate supportive services, as well as the limited understanding by many health professionals of the disorder, school and treatment facility are significant contributors to stress (Cutler & Kozloff, 1987; Unger & Powell, 1980, McCubbin, Cauble, & Patterson, 1982).

Negative self-evaluation

Autism – mothers uncertain if they had the ability to be a competent mother to these children (DeMyer, 1979; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981).

- feel less competent as parents (Rodrigue et al., 1990).

It will usually be true that more time and effort is required to raise a disabled child than a non-disabled one, and that the presence of such a child in the household constitutes a more disruptive influence than the presence of a non-disabled child and may also be likely that these parents have less control over their well-being than parents of non-disabled children. Parents of autistic (and other developmentally disabled) children must somehow learn to live with these adversities nearly every day.

Feel responsible and blamed for their children's conditions, frustration and anger deriving from all-too-common delayed diagnoses, wait list status, or experiences with ineffective treatments can also occur (Konstantareas, 1990).

Mothers of children diagnosed with autism tend to feel less satisfied in their marriages than mothers of non-disabled and other developmentally delayed children (Rodrigue et al., 1990).

Parents using specific coping strategies such as active problem solving, help-seeking, and utilization of available resources tend to cope better with the demands of raising a child diagnosed with autism, while parents using strategies described as avoidance and wishful thinking tend strongly to cope less effectively (Darling, 1979; Denhoff & Holden, 1971; Frey et al., 1989)

Thus setting up and implementing a program, learning new ways of understanding autism and behavior, and the task of changing one's own behavior, are all likely to be under significant aversive control for the family, all in the service of making the horrible situation go away, or at least get somewhat better.

We know that aversive control tends towards a narrow focus, rigid responding, impaired creativity and low flexibility. ABA professionals' control will be appetitive.

Appetitive control

What if the family's involvement could be brought under appetitive control? What would that look like? How could it be achieved?

ACT and possible alternatives to ACT

ACT – appropriate: parents must weather chronically high levels of aversive feelings and still run a program

Cognitive Fusion. Humans reinforced by their socio-verbal community for deriving relations among events. Under some circumstances this can lead humans to treat words as if they were the objects, events, or experiences they designate. "context of literality".

A parent may expect a poor quality of life for the child with autism and feel hopeless or sad about that imagined outcome (hasn't happened yet) or may expect the child to act out at playgroup and feel anxious about the prospect (hasn't happened yet).

The premise of ACT is that feeling bad is not a problem. The problem appears to be that unlike non-humans, we take steps to avoid the aversive feelings themselves (Experiential Avoidance). May do ineffective things to reduce sense of hopelessness about child's future or avoid taking child to playgroup to escape the anxiety.

ACT seeks to replace EA with acceptance.

Acceptance does not involve either wanting or tolerating.

The goal is to identify and connect with personal values and goals and surmount impediments to their pursuit.

Might seek to help parents distinguish between the thought: "I can't do this anymore" (run the program) and having to follow the behavioral rule specified in that thought. Could then consider the merits of the rule.

Parents applying this combination of willingness and cognitive defusion to a variety of stressful or distressing situations could be expected to respond more effectively.

Emotions and thoughts are beyond one's control. While this might generally be viewed as a self-defeating proposition, the effect can be quite the opposite. The need to control them disappears. Given the arguable guarantee that relatively intense unpleasant thoughts and feelings will continue to arise while raising a child diagnosed with autism, such an approach could be considered very adaptive.

Has been noted that that "shame and guilt could immobilize constructive action" in such parents. Presumably, those feelings would do so by compelling the parent feeling them to avoid situations that intensify them.

Thoughts about a lack of parenting competency and doubts about one's ability to adapt to the strains of a child diagnosed with autism could be directly addressed as well.

ACT might also be used to attack problems arising from parents' lack of understanding of autism. They might believe that they have to know "more" about autism before they can do anything (verbal rule). Given such a rule, a lack of understanding and clear expectations might engender anxiety and relative immobility. While it certainly may help to know these things, it may not always be necessary. Knowing or not knowing the causes for autism, for example, does not change the fact that consistently providing a child diagnosed with autism with the right learning experiences will improve the condition. Similarly, not knowing what the future holds for the child and his/her family also does not eliminate the benefits of effective teaching in the present. From an ACT perspective, a parent could be confused about autism's causes and unclear about what will happen down the road, and still move effectively toward his or her valued goals. The verbal rule that states one must know these things to move forward must simply be recognized as "talk", not "truth", and the discomfort that comes with this talk must simply be experienced for what it is.

One final example of the applicability of ACT to parents of children diagnosed with autism is related to Western cultural beliefs about what constitutes a life worth living.

Typically – money, comfort, success, usually "feeling good", independence

Parents of children diagnosed with autism adhering to such a verbal rule, and the children themselves, would have a "bad" life.

Summary

- potential to more readily accept aversive and stressful

- may focus their attention more on those public aspects of the environment that can be changed for the better and less on private events, such as thinking and feeling, that may not be amenable to direct attempts at change

- may give these parents the tools to actively defuse problematic cognitive appraisals of themselves and their children

- minimize the destructive effects that unpleasant emotions such as guilt and shame exert on behavior

- defuse blame and accept destructive urges without acting on them

- enhance the quality of interpersonal relationships between parents,

foster a helpful perception that limited views about what constitutes a good and worthwhile life may not apply to them or their children.

0050

USING AAC (VISUAL) STRATEGIES FOR DEVELOPING EMOTIONAL AND PROBLEM SOLVING SKILLS

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Mayer and Salovey (1997) have defined emotional intelligence as a complex and multifaceted skill which includes the abilities to accurately perceive, evaluate and express emotion in oneself and others, access and/or generate emotions so as to facilitate appropriate thoughts in problematic situations, to understand and analyse emotions so as to use them in social interactions and to reflectively regulate emotions so as to promote emotional and intellectual growth. All of these skills are essential for the successful management of life tasks such as learning, forming relationships, solving everyday problems, and adapting to the complex demands of growth and development. Often one of the important 'missing' links is social and emotional learning that impacts negatively on the individual's achievement; quality of life, often can be the underlying cause for incidence of challenging behaviours and affects the quality of relationships surrounding the individual (Elias, Zins, Weissberg, Frey, Grenberg, Haynes, Kesler, Scwab-Stone & Shriver, 1997).

Facilitating the development of these skills is indeed a challenge, but by understanding the reasons why the individual has difficulty with developing these skills instructional adaptations and accommodations necessary to meet their needs can be identified. Some of the skill difficulties associated with developing emotional intelligence can be categorised into four areas: cognitive, receptive, expressive and social interaction skills as outlined in the table. As each individual differs in terms of their abilities, interests and experiences not all of these will be relevant to the individual you interact with.

Cognitive	Receptive	Expressive	Social Interaction
a. Attention	k. Receptive Language delay	q. Expressive language delay	z. Conversational skills
b. Discrimination	l. Limited access to information due to sensory impairment	r. Word finding difficulties	aa. Non verbal communication
c. Self regulation		s. Echolalic speech	bb. Access to a limited range of activities
d. Schemata	m. Auditory memory difficulties	t. Unintelligible communication (e.g. tired)	cc. Narrow or limited range of interests
e. Understanding consequences	n. Difficulties with transitions	u. Articulation disorders	dd. Coping with emotions
f. Memory	o. Weak Central Coherence	v. Phonological disorders	ee. Opportunities for social learning
g. Executive functioning	p. Saliency	w. Dysarthtria	ff. Making friendships
h. Metacognition		x. Dyspraxia	
i. Theory of mind		y. Stuttering	
j. Sensory impairment affecting information processing			

Therapists, teachers and parents can act as coaches for emotional development, teaching and modelling skills to help the individual set and reach personal goals.

This presentation will provide a framework which parents, teachers, aides, counsellors, therapists can use to act as a coach to help the individual develop the skills, attitudes, and values necessary to acquire social and emotional competence to their full potential.

The framework for developing emotions and problem solving skills is an adaptation of strategies described by various authors Attwood (1998); Bens (1999); Bloom and Bhargava, (2003; 2004); Freeman and Dake

(1997); Howlin, Baron-Cohen & Hadwin (1999); Goldstein (1998); Greenberg and Kursche (1994); Gray (1994); McAffee (2002) and Lovecky, (2004).

The framework will address such areas as helping the individual understand the language of feelings and emotions along with knowing how to effectively manage and resolve problematic situations. Information on how to make the necessary accommodations or adaptations to enable the individual to be successful and learn at their level will be provided.

We will use Jessica's story (a young girl with Autism) to demonstrate a variety of communication strategies to help her manage positive and negative emotions related to anger, stress, frustration and anxiety. Some of the strategies that will be discussed include:

- **The use of social stories**

- **Visual timetables**

- **Leisure and transition tools**

- **Auditory Integration Training**

- **Understanding emotions**

- managing problems

Social stories

The implementation of social stories has been very beneficial for Jessica. These have proved to be very successful in changing some inappropriate behaviour, giving her expectations of how she should act in certain situations.

The stories are written in a very positive style and language and we have been guided by the procedures set out in Carol Gray's book when writing them.

We read one or two of these stories everyday to her for a fortnight to target specific problems, and for us, this has been one of the keys to alter her behaviours.

Visual timetable

Another successful strategy was the implementation of her timetable board.

The board is used to show the daily and weekly events using visual laminated cards attached to the board by Velcro.

Jessica refers to the calendar to see what she is doing for the day or what is coming up during the week.

She finds this knowledge of events quite comforting. It takes some of the fear of the unknown away.

It even gives her the opportunity to plan her own activities by placing things she wants to do up on the calendar.

Leisure and transition tools

Jessica finds some activities and transitions difficult, for example recess and lunch times at school and going for long drives. She finds the use of a leisure bag very helpful and provides her with the security that she needs to reduce her stress. Jessica's leisure bag usually has an Ipod, dot-to-dot book and some Lego blocks.

Auditory Integration Training (AIT)

Treatments involve listening to specially frequency-modified music through a set of headphones

for 20 half-hour sessions over a 10 day period.

Jessica is very hypersensitive to sound.

- The vacuum cleaner would see her run screaming from a room,

- thunderstorms would terrify her,

- general household appliances like a mix-master would torment her,

- supermarket car parks were also a source of fear and anxiety.

The AIT assisted in reducing her sensitivity to sound and found benefits reflected in other areas.

- Jessica has less difficulty with being touched and groomed

- Jessica's fears and anxieties in general have reduced

- Jessica is generally more aware and responsive.

Identifying and Understanding Feelings

We have also done a lot of work assisting Jessica to identify and understand her feelings and to some extent the feelings of others.

Jessica keeps a " happiness" journal which includes photographs, remnants and drawings of things she associates with being happy.

We worked with her to rank her feelings using colours. Jessica chose to associate the colours:

- red for happy

- blue for a little upset,

- brown for mad

- black for angry

We developed colour coded cards with each colour relating to the feelings she has identified.

The cards give her strategies to calm down.
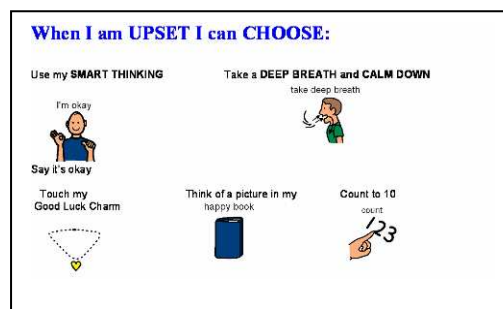
Jessica carries her "Calm Cards" with her to school each day.

If she gets stressed she knows that she is carrying with her, a ready reminder of how to cope with particular feelings and this has helped her to manage situations which can make her very anxious.

Now able to identify her feelings through the use of colours –

In fact the many people in her support network now refer to Jessica's colours to identify how we are feeling or how she is making us feel.

Jessica has learned to identify a range of emotions and deal with them using her tools.

She has also learned to recognise a range of emotions in other people.

Comic stripping
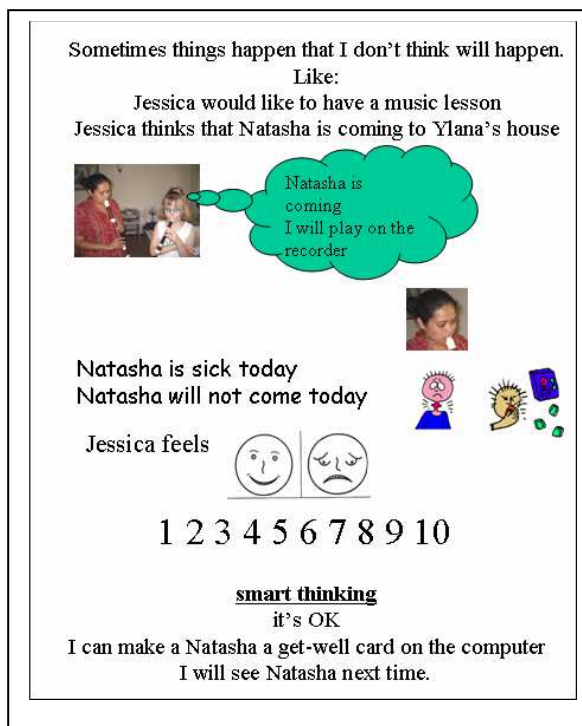
Social stories are really effective for problems that you see coming or behaviours you want to change.

But how do you cope with the unexpected? Imagine – you are in a public place and she is starting to have a melt down – what can you do?- comic stripping. The following example is a copy of a real one we have used on the day. The animation is not great as it is very hard to draw in a stressful situation.
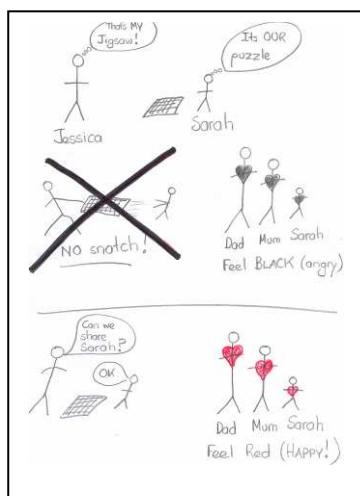
Problem solving

We have given Jessica some strategies for enhancing her problem solving skills. She is learning to:

- know what a problem is

- how she feels when she has a problem

- identify the intensity of a problem

- figure out some solutions

- use systematic problem solving plans
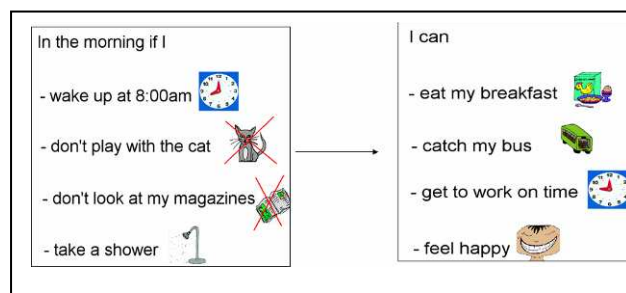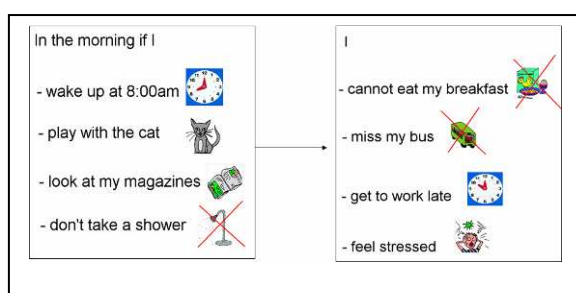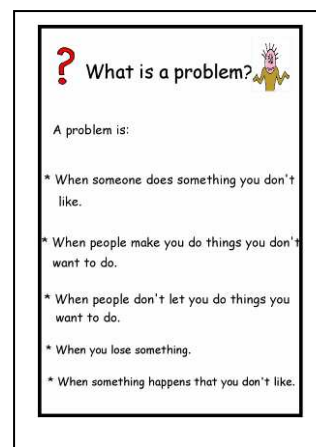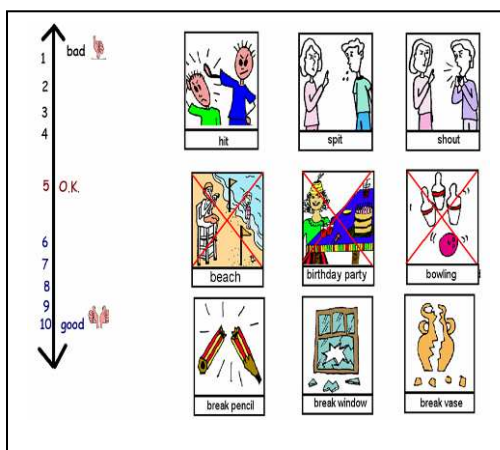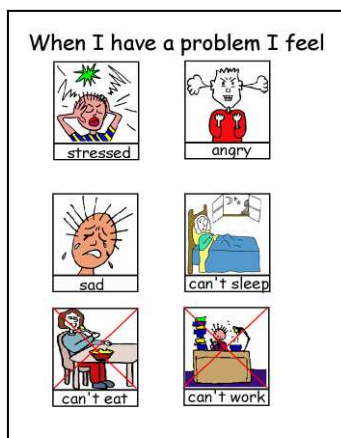
Conclusion

Individuals with Autism may engage in behaviours that stem from difficulties with expressing their emotions and difficulties with solving problems. As the more competent communication partner our role is to assist the child, adolescent or adult we interact with learn how to communicate their emotions and deal with problems in constructive ways. Depending on the type of communicator we can play a crucial role in helping the individual to learn these critical life long skills.

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0051

UNDERSTANDING SENSORY AND EMOTIONAL RESPONSES IN DEVELOPING COMMUNICATION IN CHILDREN WITH AUTISM SPECTRUM DISORDER

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Severe difficulty with sensory processing and emotional regulation is a hallmark of Autism Spectrum Disorder. Study after study has found that people with autism do not process information as others do and it has been suggested that essential connections between key areas of the brain either were never made or do not function at an optimal level.

Behavioural issues are often the biggest barrier to learning when working with people on the Autism Spectrum. Our success in achieving our therapy goals is often closely linked to our skill in understanding and managing difficult behaviour. In understanding underlying sensory and emotional issues, we are usually able to provide more effective input as we adjust our intervention to the particular individual we are working with.

Sensory responses

"Autism is a way of being. It is pervasive. It colours every experience, every sensation, perception and thought." (Burne J. '05)

People with autism have a wide range of sensory and perceptual deficits or excesses. They have trouble reading faces, emotions, behaviour and body language and getting consistent meaning from spoken words. They often seek out unusual quantities of certain types of sensations and are extremely hypersensitive to other types.

Heightened sensitivity manifests in social interaction and behaviour. Oversensitivity may lead to withdrawal from interaction with people but a connection to a world of objects to which they may become obsessively fixated. Removal of a chosen object may lead to an extreme response such as a screaming tantrum.

A dysfunctional tactile system may lead to self-imposed isolation, general irritability, distractibility and hyperactivity.

Hypersensitivity to vestibular stimulation may result in fearful reactions to ordinary movement activities such as walking down stairs.

Proprioceptive dysfunction may result in clumsiness, a lack of awareness of body position in space, odd body posturing and motor planning difficulties.

Signs of sensory integration difficulties

Hypersensitive: over reactive, sensitive to stimuli, sensation avoiding

Hyposensitive: under reactive, poor registration of stimuli, sensation seeking

The Senses:

Sight – visual scrutiny, sensitivity to light (e.g. flash of a camera), visual perceptual difficulties - see details not whole picture, insecurity with height and movement

Matching, pairing or ordering of objects and symbols

Fascination with coloured and shiny objects

Blinking compulsively

Switching lights on and off

Staring past things, into space or through things

Smell – smelling of objects, smell aversions

Taste - taste aversions resulting in eating difficulties

Hearing – ignoring, hypersensitivity

Touch – overly sensitive or under reactive to touch, hyper or hypo-oral, high pain threshold

Movement/proprioceptive dysfunction:

Dropping things repetitively

Jumping, rocking, hand shaking, flicking objects, chin-tapping, head banging, self-injurious behaviour

The spinning of things or oneself

Physical clumsiness or apparent carelessness

Clapping

Social/emotional/attention:

Easily distracted

Activity level that is unusually high or unusually low, impulsiveness, lacking in self-control

Inappropriate laughing

Inability to unwind or calm self

Difficulty making transitions from one situation to another

Emotional responses

People with autism show disturbed anxiety modulation. An increase in anxiety often results in an increase in stereotypical motor mannerisms or obsessive-compulsive behaviour. A highly sensitive child with autism will display a wide range of psycho-emotional disturbances. His cognitive development may be limited by rigid thought patterns, lack of imaginative capacities and poor understanding of everyday concepts. People with autism tend to over focus on one detail. This may result in the person missing the peripheral cues about what is happening around and events are unexpected sometimes resulting in overwhelming panic or meltdown. Emotional or sensory overload may be triggered too easily in people with autism and this often results in shut down.

"…we have come a long way from the tortured little boy who battled to process the overwhelming sensory input that invaded his world on a daily basis – its sights, sounds, smells. Prior to intervention the world for Daniel was often an extremely overwhelming, bewildering place. We could not take him anywhere new without him going into complete sensory overload. His response was to panic and run to escape or shut down." (Sharon '03, mother of Daniel, 9 years old)

When sensory or emotional overload occurs, meaning systems can shut down and the senses can become extremely acute. Sounds and touch may become intolerable. Over-stimulation can make it difficult for an individual to organise behaviour and concentrate and may lead to a negative emotional response to touch sensations.

The meaning carried by intonation and gesture can be shut down, resulting in the listener not receiving emotional cues. The meaning of social rules and words can be lost resulting in comprehension difficulties.

"I can hear the sounds, he said, I just don't understand what people say to me a lot of the time." (Williams,'99)

"The perceptual problems of deafness, muteness and blindness are experienced as very real. They are nevertheless, caused by extreme stress, brought on by an inabilty to cope with emotion." (Williams,'92)

Communication is an area of significant difficulty for people with autism. It involves social interaction and relating. When the directness of relating is too great shut down often occurs.

"For me, my expressive difficulties were secondary and sprang from these primary inconsistencies in my perception of the world around me and in the complex psychological defense systems I created to compensate, which trapped me even more." (Williams,'92)

"The more predictable and calm the voice, the less emotional fear it inspires."

"Laughing can be inextricably tied up with the overload the speaker triggers, at which point the speaker's words are little more than a meaningless hum of noise." (Williams,'92)

"Sometimes I heard and understood and other times sounds or speech reached my brain like the unbearable noise of an onrushing freight train. Noise and confusion at large gatherings overwhelmed my senses." (Grandin,'93)

Communication difficulties

Deviant language development

Echolalia – poor receptive language, need for extra processing time, enjoyment of the sensation of repeating

Pronominal reversal

Idiosyncratic, stereotypical and repetitive speech

Cognitive-semantic deficits – difficulty with object relations and making sense of the world

Pragmatics – refers to how we use language and other non-verbal means to exchange information, people with autism have difficulty integrating sources of information from different sensory systems to understand verbal input (e.g. noticing the smile on another's face, observing the way one person touches another, assessing tone of voice).

There are difficulties initiating and terminating conversation, maintaining a conversational topic, taking turns, making judgements as to the appropriateness of their utterances.

There is often a lack of appropriate non-verbal communication such as eye contact, facial expression and gesture.

Prosody – refers to the intonation and rhythm of speech

Prosody of speech is often deviant. There may be distortions in intonation and rhythm of speech resulting in a quality that is monotonous or high-pitched. Volume may be too loud or too soft and there may be over-precision of articulation or accents.

Developing communication in children with ASD

People with autism often have severe auditory processing difficulties combined with sensory integration and emotional difficulties.

Difficulty with meaning and making sense of the world makes communication very hard and it often takes repeated practice of the use of utterances in different contexts with different conversational partners to develop basic verbal communication.

"Speech is hard for me. I can make people think I am "normal", but it takes so much effort and energy. Some times more than others. These times seem to fluctuate at random unless stress is involved. There are, on occasion, still times when I want to talk, but I can't." (McKean '94)

Speech therapy needs to focus on the various components of language – the form, content and use.

We need to work on various areas – oral sensory, articulation, language and vocabulary, pragmatics and prosody.

Intervention can consist of both intensive drills and communication enhancement and should focus on functional communication as gains in communication skills can reduce challenging behaviour.

Reduce linguistic complexity. Children with autism often say more than they understand.

Avoid verbal overload, irrespective of the person's apparent level of language ability – speak gently but in a firm, clear manner. Monitor what you say to the child with autism and keep your sentences short and clear, allowing time for processing of information. Also allow extra time for formulation of verbal utterances.

Minimise visual and auditory distractions.

Use visual cues and prompts – pictures, signs, gestures, social stories.

Provide simple concrete guides to the world such as picture timetables or place activities in a sequence.

Expand the child's understanding of relations that exist between objects and events.

Provide structure.

Prepare the child for changes in routine to decrease anxiety.

Try to maintain sameness in the child's environment and a predictable routine where possible.

Initially, try to present activities in a similar sequence or routine and gradually desensitise the child by gently going through the motions of the activity.

A child with ASD may take longer to learn new skills.

Introduce new activities gradually, practise skills in different contexts and keep repeating at the child's level and persevere.

"… I have never known an autistic child to be unable to learn anything at all. It may take days or months, a year or two even, but with enough support and consistent input, I believe these children can learn a whole lot, more than we can conceive for them, sometimes." (Miller,'06)

"Last night I was bathing Ian. As always, I tapped him on the thighs with my cheery, "Come on, wash your legs" and then Ian, in the littlest of little voices – I could so easily have missed it – said quietly but very clearly: "Ouch. That's sore."

I apologized profusely to him, wondering, of course, if I've been hurting him unintentionally for month after month, enthusiastically rapping his legs to encourage him to wash them. Poor chap! It was such an exciting moment, though, and so completely unexpected." (Fiona '06, mother of Ian, 10 years old)

Treatment of children with ASD

Ongoing evaluation should be part of treatment and should involve observations of responses to sensory and general environmental stimuli.

We need to get to know the child and find what motivates and what bothers him so that therapy can be adapted to be more effective. We need to observe and find the specific pattern of responses each child shows as we see different clusters of symptoms in different children. Treat each child individually. What works successfully for one child may not always work for another.

People with autism seek out what they need.

Allow some behaviour, especially initially when anxiety may be increased.

A sense of control and predictability decreases anxiety.

Be tolerant of fixations/obsessional interests. These should be directed into constructive channels. Allow some time, use as a motivation. One will find an amazing variety of motivational objects or activities. Give controlled access to interests.

When interests are unacceptable try to stop them through explaining why the interest is not acceptable, if the person's level of comprehension is adequate. Alternatively try to replace them with more appropriate behaviours.

Circumscribed interests that are shared with another person with similar interests can be used to encourage conversation and social interaction. It is during these shared interactions that we often see an improvement in social skills - empathy, humour, listening and complimenting.

Stereotyped behaviour is monotonous, repetitive and rhythmic and is not goal directed. To stop a stereotyped behaviour it must be replaced with some type of external stimulation or distraction. Once a child is able to self-monitor, there can be specific times where the child is free to engage in stereotypical behaviour.

An increase in inappropriate behaviour may be an indicator of stress, frustration or sensory or emotional overload. Very often, behaviour is communicative.

The two most frequent causes of stress and behavioural difficulties are a lack of a simple, clear, understandable, predictable structure to each day and pressure to perform above the child's level of ability. We often see precocious development of certain areas but this is not always functional ability.

Motivation and imitation are important starting points in working with people with ASD.

Weaknesses are usually the ability to process language and the ability to provide their own structure and organization.

Strengths are usually visual skills and rote learning.

Conclusion

Until we know how to prevent Autism Spectrum Disorders, the challenge is to help people compensate for them.

Structure and empathy – cornerstone of treatment. Through understanding sensory and emotional experiences and responses in people with Autism we are able to have more empathy and provide more effective treatment.

"Understanding the nature of the highly sensitive engenders respect, compassion and tolerance for their differences and promotes endurance in the caregiver." (Goldberg,'05)

"We need to relate to such children in terms of how they perceive the world, then the children may find the trust and courage to reach out step by step at their own pace." (Williams,'99)

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0052

20 YEARS OF PECS, THE PICTURE EXCHANGE COMMUNICATION SYSTEM:

A WIDELY USED INTERVENTION TO PROMOTE FUNCTIONAL COMMUNICATION SKILLS

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The Picture Exchange Communication System (PECS) offers a systematic approach for developing communication skills using a picture-exchange system. Originally developed by Andy Bondy, clinical psychologist, and Lori Frost, speech and language therapist, in the USA for pre-school children with autism, PECS is now being successfully extended to a wider range of children with communication difficulties and also to older students and adults. Starting in the US 20 years ago, PECS is now seen as a significant initiative in the field of autism and communication difficulties, with interest spreading from the UK into Europe and internationally. The first PECS training workshop was held in UK in 1998 and in South Africa, at the Vera School in Cape Town, in 2004.

PECS combines behaviour analytic and developmental perspectives and the resulting approach is child-centred and functional, emphasizing communication that is relevant and meaningful to the child. Critical in PECS is the student spontaneously *initiating* communication with other people, rather than responding to prompts. As pictures are 'exchanged' for items the student wants, not only is the programme highly motivating, but *approaching and interacting* with another person (essential elements of communication) are built in from the outset (Bondy & Frost 1994).

PECS offers students, sometimes for the first time in their lives, a calm, clear means of communicating with others. The associated reduction in behaviour difficulties is a commonly reported finding (Carpenter et al. 1998; Frea 2001). The programme is divided into six phases ranging from teaching the student to request items using single pictures in Phase I, to constructing increasingly complex sentences and commenting on the environment in Phase VI.

This paper provides an overview of PECS followed by an update of research findings and discussion of some current issues and common misconceptions.

Development of PECS in the USA

PECS was developed by Dr. Andy Bondy, clinical psychologist and Lori Frost, speech & language therapist 20 years ago through their work with students in the Delaware Autistic Program (DAP), USA. They reported that 80% of pre-schoolers arriving at their school had no functional communication skills, and for many this remained the case in spite of high levels of specialist teaching (Bondy & Frost 1994). Reviewing the research literature related to this population and their own practice at DAP, they were increasingly aware of the shortcomings of traditional approaches:

- Direct methods of teaching children with autism to talk are slow & disappointing. For children to progress with vocal imitation they need to be able to attend, to give eye contact and to imitate another person. All very difficult for children on the autistic spectrum.

- Signing, although more visual, requires similar skills: looking, attending and copying actions. In spite of some initial success, signs are rarely used spontaneously by children with autism in any meaningful communication (Carr 1982). The child's learning is often described as "prompt dependant" in that it only happens in response to a prompt by another person. For example, the teacher says: "what do you want?" or "sign biscuit" and the child then produces the sign, or an approximation of the sign. Fine motor difficulties can lead to the development of very idiosyncratic signing, which further limits the 'audience'. It is increasingly recognized that a major problem with signing is that it is not understood in the wider community.

- Picture-pointing schemes depend on a different set of skills: before you can begin communication training you need to work on picture discrimination, matching pictures to objects and shaping up a pointing response. The absence of pointing skills is one of the earliest indicators of an autistic spectrum disorder and teaching this can be a lengthy process. Also, some students enjoy self-stimulatory tapping and it is often difficult to distinguish this from genuine attempts to communicate. But most significantly, picture pointing does not involve social approach. If a child points or taps on a picture and no one is nearby to see this, is this really communication? Prompt-dependency often becomes a feature of this approach as children are encouraged to respond to prompts such as "point to the ball", "what is this?", etc., so again spontaneous acts of communication are rare.

- Many traditional approaches start by teaching the child to label or 'comment' on objects in their world. If shown a picture of a ball (or the actual item) and asked "what is this?" the child needs to say "ball". If the child is successful, the outcome for the child is purely social: "Yes, well done, it's a ball". For many children on the autistic spectrum, such social rewards are very weak motivators. These children do not choose to engage in interactions for the sake of sharing information or receiving social consequences.   In contrast, lessons based on 'requesting' (e.g. "I want the ball") are much easier as here direct consequences (receiving the ball) can be highly motivating and help establish learning.

It was in response to these issues that PECS was developed. It arose out of the direct work with students who were failing to develop functional communication skills and key features included:

1) Use of *pictures*, not speech or signing.

2) *Social approach* built in from the start, as child must interact with another person to exchange the picture for the item wanted.

3) Emphasis on spontaneous communication, with the child *initiating* the communication rather than responding to prompts from adults.

The Pyramid Approach to Education

Implementation of PECS is based on the Pyramid Approach to Education, developed by Dr. Andy Bondy. This broad-spectrum applied behaviour analysis approach establishes effective learning environments for children and adults at home, at school, or in the community. The system uses the three-dimensional characteristics of a pyramid as a way to organize the complex issues associated with effective teaching strategies. These strategies are based upon the science of why actions occur and change- the field of behaviour analysis. The Pyramid Approach next suggests a focus on issues related to 'what' to teach. There are four key areas here: a) functional objectives, including long-term plans, b) systematic and powerful reinforcement systems designed to motivate all learners, c) functional communication and social skills which addresses what people need to learn with regard to interacting with other people, and d) minimizing and responding to contextually inappropriate behaviours. The Pyramid Approach stresses that we must determine the factors of which problematic behaviours are a function and find functionally equivalent alternative behaviours to systematically promote. Long-term successful reductions in problematic behaviours will only occur if the first three elements are fully in place.

Once these issues related to 'why' and 'what' are addressed, then the model focuses upon 'how' to teach. The core issues involve a) generalization, both in terms of stimulus and response factors, b) types of lessons, including discrete trial and sequential lessons, as well as teacher- vs. learner-lead lessons, c) lesson strategies, including those involving prompts as well as shaping, and d) minimizing and responding to errors. Finally, the model revolves around the issue of how to take and analyze data to assure that effective teaching strategies are in place. The Pyramid Approach to Education allows professionals from different backgrounds and perspectives, as well as family members, to collaborate while taking a problem-solving orientation to issues related to effective teaching.

An Outline of The Six Phases of PECS

As the focus of PECS is meaningful communication from the student's perspective, the starting point will always be 'requesting', i.e. encouraging the student to 'request' items of interest in his/her environment. This will only commence after a "reinforcer assessment" has been completed. In other words a list is constructed following observation, discussion and systematic assessment, of items and activities the student is interested in, forming a hierarchy from most to least preferred. Some students have a limited number, others a very wide range of items they would be interested in communicating for, hopefully including both edible and non-edible examples. Once this is achieved Phase I can begin.

Phase I

In Phase I students are taught how to spontaneously request items they want. As *spontaneous* communication is the goal, great care is taken to avoid introducing verbal prompts, such as "what do you want?" or "do you want a biscuit?", etc. Critical at this point is for the student to *initiate* communication, so two adults will be needed to start the programme. The first adult, the "communicative partner", will entice the student with a desired item (e.g. favourite ball). As the student reaches for the ball the second adult, the "physical prompter", will physically guide the student to pick up the picture of 'ball' and release it into the open hand of the communicative partner. As soon as the student releases the picture into the adult's hand, the adult says "ball!" and immediately gives the student the ball. Physical prompting is gradually faded, so the student independently hands a picture to the adult in exchange for the item. During Phase I students learn a great deal about the 'nature' of communication, paralleling typical child development. As

early as 6 months, and before words develop, typically developing children have learnt to approach their audience (mum or dad), to deliver a message (vocalization or babbling) and to enjoy the pleasurable consequences (parent smiles, repeats the vocalizations). Similarly in Phase I students using PECS are learning to approach a person, deliver a message (picture) and enjoy the consequences (receiving the item they wanted). Just as typically developing children do not use actual words during this early learning period, so the children using PECS do not necessarily discriminate the picture being exchanged. The important lesson at this stage is 'how' to communicate and that it has a positive outcome for the 'speaker'. Use of words (discrimination of pictures) comes later. Communication does not equal speech and students on the autistic spectrum have much to learn about the former if any emergent speech is to be useful.

Phase II

As soon as the student is able to independently exchange a picture for a desired item, Phase II begins. Here the objective is to increase the spontaneity and persistence of the communication. If pictures are always placed directly in front of the student along with an obliging open-handed adult, spontaneous communication is unlikely to result! Step by step students are taught to travel greater distances to find the adult and also to fetch the picture. The communicative partner will deliberately turn away so the student needs to develop greater persistence to get the picture exchanged for the desired item or activity. A range of different pictures is used, but always presented one at a time at this stage, and further generalization is encouraged by involving different people and doing PECS in a variety of settings. If PECS is only used at snack time, it is not PECS! A communication book is introduced in Phase II. This comprises a ring binder with Velcro strips, allowing 2 inch laminated pictures to be stored and easily removed. Older students or adults may use smaller, 1-inch pictures and a Filofax-size binder. The low-tech simplicity of using pictures/symbols/photographs/product labels is appealing and manageable, but should not be equated with the view that no skills are needed to implement the programme! The recently revised PECS Training Manual (Bondy & Frost 2002) details the implementation at each phase, and attendance at a 2-day accredited PECS workshop is recommended as basic initial training for parents and professionals.

Phase III

Phase III starts once the child has become a persistent and spontaneous communicator, using a range of single pictures, in different settings across the day, with a variety of different people. Now discrimination training begins as the child is taught to select from 2 or more pictures placed on the front of the communication book. Having learnt 'how' to communicate, the child now needs to be more specific about the message being delivered. Typically developing children move from babbling to single words, and children using PECS need similarly to move from the more general 'ticket exchange' to a specific choice of the correct picture. Picture recognition is taught within the context of PECS communication, which is more meaningful and motivating for most students. New cards are added gradually and systematically, depending on the ability of the child to discriminate, as this will vary greatly. The PECS Training Manual (Bondy & Frost 2002) offers some useful strategies if the child has difficulty with discrimination and the 2-day workshops provide details of how to apply them in practice. By the end of phase III students should be able to find and open their PECS communication book, locate the correct picture, travel to the communicative partner (CP) and communicate their needs by handing the picture to the CP.

Phase IV

Once discrimination of pictures is established, the programme focuses on developing sentence structure. This is essential if the second major language function, 'commenting', is to be achieved (e.g. "I see the plane"; "I hear thunder", etc.). When typically developing children are at this single word stage, they use both commenting and requesting, with roughly equal frequency. The listener knows from the intonation or accompanying gestures whether the single word is a request or a comment. Students using PECS wont have these resources and therefore we need to provide a sentence structure to allow these distinctions to be made. In Phase IV students learn to construct simple sentences on a detachable sentence strip using an "I want" icon followed by a picture of the item being requested. The whole sentence is now handed to the adult in order to maintain the social approach developed in phases I to III. Adults help the student to point to the pictures as they read back: "I want bubbles".

Phase V, VI and Attributes

Until this point the child always initiates the communication. Now in Phase V the child is taught to respond to the direct question "What do you want?", again by completing the now familiar sentence strip. Responding to this question form is an important stepping-stone to Phase VI, where the goal is 'commenting' in response to a question. The student is now taught to label or comment on objects when asked questions like "What do you see?", "What do you have?", "What is it?", etc. For some students commenting can be a difficult step in view of their relative insensitivity to social reinforcement, as already discussed, and it may be more helpful to develop further complexity within the 'request' sentence structure

they have already mastered. Teaching attributes such as "I want the big, red balloon" or "I want the orange drink and 2 biscuits" may be easier for some to master than teaching "I see the balloons", etc. However, for social interaction to develop, the importance of commenting is clear. It is also vital that students learn to comment about external events if they are to learn how to comment on their inner feelings (my ear/tummy/leg hurts; I feel sick/happy/sad, etc.) A child is isolated and vulnerable without the ability to express these feelings.

PECS, Speech Development and Research Findings

The evidence from many years of research suggests that an augmentative communication system, such as PECS, helps rather than hinders the onset of speech, and this is certainly supported in more recent PECS studies. From the outset Bondy and Frost (1994) emphasized that the aim of PECS was to give the student a functional communication system. However, they were delighted to find that many students developed speech after more than 1 year on the programme. From their study they reported that 76% of students placed on PECS acquired speech as either their sole communication system or augmented by a picture-based system. There are now many studies showing similar gains in speech development following PECS training, for example:

- Schwartz, I.S., Garfinkle, A.N., Bauer, J (1998) report on a study that followed 18 preschool PECS users for a year. The results of language samples taken at snack time and during free-choice activities indicated that PECS use generalizes to untrained settings and may have concomitant effects on untrained language functions.
- Charlop-Christy, M. H., Carpenter, M., Le, L., LeBlanc, L.A., & Keller, K. (2002) used a multiple baseline design with 3 pre-schoolers with autism and reported increased speech in all students, along with gains in social communicative behaviour and decreases in problem behaviour.
- Ganz, J. & Simpson, R. (2004) examined the role of PECS in improving the number of words spoken, increasing the complexity and length of phrases, and decreasing the non-word vocalizations of three young children with ASD and developmental delays. Participants were taught Phases 1–4 of PECS. The results indicated that PECS was mastered rapidly by the participants and word utterances increased in number of words and complexity of grammar.
- After 4-5 weeks of PECS teaching up to Phase III, Carr and Felce (in press) showed increases in speech production, either in initiating communication with staff or in responding, or both in 5 out of 24 children. No children in the PECS group demonstrated a decrease in spoken words after receiving PECS teaching. In the control group, only 1 of 17 children demonstrated a minimal increase and 4 of 17 children demonstrated a decrease in use of spoken words after a similar period without PECS teaching.
- In a recent randomized group experiment by Yoder and Stone (2006) they found that PECS was more successful than RPMT (Responsive Education and Prelinguistic Milieu Teaching) in increasing the number of non imitative spoken communication acts and the number of different nonimitative words used at the post treatment period.

Bondy and Frost (1994) also found a significant reduction in behaviour difficulties as PECS skills and speech developed, as similarly reported in a later study by Carpenter, M., Charlop-Christy, M.H., LeBlanc, L., & Kellet, K. (1998). Frea (2001) reported that aggression was eliminated with the use of PECS in a multiple baseline study of a pre-schooler with ASD.

In 2001 the first independent pilot evaluation of PECS in the UK was funded by the Sainsbury Family Charitable Trust and co-ordinated by Professor Patricia Howlin and Iliana Magiati. The project (known as the Alice Project) took place over a 6 month period, involving 8 schools in the south of England with 2-day PECS training for staff and parents and 6 half-day visits by consultants from Pyramid Educational Consultants to support PECS implementation. The independent evaluation reported statistically significant increases in the level of PECS attained by the children and in their PECS vocabulary and frequency of PECS use over time. Gains were noted to have occurred very quickly following the PECS training. There were also improvements in children's general level of communication, although these were slower to occur, and in problem behaviours (Howlin and Magiati 2002).

During this pilot study data was also collated by the Pyramid consultants at their monthly support visits and their reported findings parallel the independent evaluation (Baker 2001). After six visits over a six month period, the vast majority of children (85%) achieved well beyond the early stages of PECS, reaching sentence structure level or above (Phases IV-VI). 40% of the total, excluding students who had already started PECS prior to the project, reached Phase VI ('commenting') by the end of the project. Interestingly, all class teachers said PECS training had affected their teaching style; that they allowed more initiation from students and had reduced their own verbal output.

Following the success of the Alice Project, a larger-scale and more tightly controlled study of the effects of PECS training was recommended and has been completed in the UK. The independent researchers, Greg Pasco, Kate Gordon, Tony Charman and Pat Howlin, describe it as the first group-randomised control trial (RCT) of PECS and one of the largest studies ever conducted of an intervention for children with autism. Seventeen special school classes in England were recruited, involving 84 children (4 to 10 years) all with formal diagnoses of autism and with little or no speech. Classes were randomly allocated into one of three groups: Immediate Treatment, Delayed Treatment and No Treatment. All children were assessed and filmed 3 times over 2 years. The results of this large RCT study will hopefully soon be published in a peer-reviewed journal.

PECS Myths and Misconceptions

Over the past ten years or so, PECS has become an acronym that is well recognized in the field of autism intervention. While many people have heard of PECS, though, there are a lot of myths and misconceptions about what the Picture Exchange Communication System really is. Outlined below are some of the most common myths (Reed 2005)

If we're using pictures of any kind, we're using PECS.

PECS is a specific protocol for teaching expressive use of pictures for an individual to communicate wants and needs, and to comment about the world. If the basic protocol has not been implemented according to Frost and Bondy (2002) then it's not PECS!

We're using a visual schedule, so we're using PECS.

PECS is an expressive communication system for the individual with severe communication impairment. Visual schedules are about receptive understanding. The Pyramid Approach to Education makes use of visual schedules, but users do not exchange the pictures in a communicative fashion.

PECS is only for people who don't speak at all.

PECS can provide a very effective functional communication system to individuals with no verbal communication, but it can also teach important skills to those who talk. The PECS protocol emphasizes teaching a person to approach others to initiate a communication interaction. Some people may talk, but don't understand that need for a social approach – they may talk to an empty room or to the fridge. These individuals may be able to learn about the social approach through PECS. Other people may talk, but will only do so if asked a question or told to use their words. These individuals may be able to learn about spontaneous, self-initiated communication through PECS. PECS can be an alternative communication system for those who don't speak or an augmentative communication system for those who do.

PECS is only for young children.

PECS has been used around the world with people aged from 14 months to 85 years. While the learning process may be different for people at different ages or with different types of communication impairment, PECS can be an effective functional communication system right across the age range.

PECS just teaches people to request.

Requesting is the first skill taught in PECS, but the protocol's final phase focuses on teaching commenting (e.g. I see, I hear, I smell). PECS is not about a person just getting his/her needs and desires met, but about communicating with other people in his/her world.

If a person asks for something using PECS, we have to honor the request, and that will just produce a "spoilt brat".

The PECS protocol involves honoring every request during Phases I and II. This is the time when the person learning PECS is developing his/her trust in the communication system. If we start saying "No" too early, the person learning PECS may give up trying to communicate, because his/her experience is that it doesn't always work. Once the individual has mastered Phase II of PECS, we can be confident that s/he is a persistent communicator, and it then becomes appropriate to teach the concept that a person can ask for what s/he wants, but the answer will sometimes be "No".

If we use PECS, the person using the system won't learn to speak.

As with any other alternative communication system, the use of PECS will increase the likelihood that a person will become a verbal communicator. Research has been carried out looking at the emergence of speech in PECS users, and the results indicate that speech may well be an outcome of PECS. What we also know is that even if a person doesn't start to speak with PECS, that person will have an effective way of communicating with lots of different people in his/her world.

PECS is only for people with autism.

PECS was developed at the Delaware Autism Program in the United States and did therefore have its origins in the field of autism intervention. What has been discovered over the 20 years since the inception of PECS is that it can serve as an effective communication system for a range of individuals with communication impairment. PECS is being used with individuals with autism, Down syndrome, cerebral palsy, Cri-du-Chat, Angelman's syndrome, developmental delay, language disorder, developmental verbal dyspraxia, head injury … and the list goes on.

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0053

INITIATING THE PICTURE EXCHANGE COMMUNICATION SYSTEM (PECS) IN AFRICA – PHASE ONE AND TWO

VERA SCHOOL FOR LEARNERS WITH AUTISM

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Background: Vera School

Vera School for Learners with Autism situated in Cape Town, South Africa was founded in 1970 and currently has 85 learners with Autism Spectrum Disorders (ASD). The learners, aged 3 to 18 years, present with a wide range of intellectual functioning. Vera School is the oldest of only 5 government schools in South Africa catering for learners with ASD. The school has a full staff compliment of 50 (including the principal, deputy principal, 11 educators, 13 teaching assistants, hostel staff, 1 psychologist, 2 speech therapists and 1 occupational therapist). Many of the learners have limited or no functional speech and therefore require alternative and augmentative communication (AAC) systems.

How PECS got to South Africa

There is a lack of training at tertiary level in ASD-specific intervention in South Africa and limited resources and access to training. In May 2000, the school principal (Fanie Minnaar) attended a National Autism Society (NAS) Conference in Glasgow, Scotland. At this conference he attended presentations on **TEACCH** (Treatment and Education of Autistic and related Communication-handicapped CHildren) and **PECS** (Picture Exchange Communication System). He returned to the school with a long-term goal of properly implementing TEACCH and PECS training at Vera School. In 2001, the school's Governing Body appointed a full-time fundraiser and fundraising proposals were compiled for staff training. Large donations were needed to fund the training by qualified, international trainers. In 2002, the funding was acquired and the TEACCH training was conducted in 2003. At this time, we began corresponding with the Pyramid Educational Consultants (UK office) regarding the PECS training and arrangements were made to have the first 2-day workshop in South Africa in 2004.

Vera School: Training model

This training model is advocated by the school and was first applied by Margaret Golding when she did the TEACCH training at Vera School in 2003. This model, combining theoretical and practical input and implementation under the guidance of the trained expert, was found to be very effective for the TEACCH training. During negotiations with Pyramid Educational Consultants, the school requested that a similar model be applied for the PECS Training. The In-service ("*On the job*") Training Model consists of the following steps:

Step1	Trainer(s) conduct an 'internal audit' of the school – to determine needs, structure of school and ways to implement the training.
Step 2	Staff receives the theoretical input (with a strong experiential, practical focus).
Step 3	Staff implements the approach with support – trainer(s) help implement by demonstrating and then the staff implement under their supervision.
Step 4	Period of implementation without supervision (implement '*low and slow*').
Step 5	Trainer(s) return to assess and evaluate progress, refresh skills, help with 'stuck points', and give suggestions for the way forward.
Step 6	The staff continues implementing independently.
Step 7	Educators present re. implementation of approach in the classroom and the combination of the current approach with other classroom practice.

PHASE ONE: "The Exchange"

In April 2004, after many months of preparation, PECS finally arrived in Africa. The first PECS training was held at Vera School, and was presented by *Sue Baker* (Director of PECS, UK) & *Julia Biere* (UK consultant). Sue and Julia presented the **PECS two-day workshop**, on 15 & 16 April 2004. This workshop is the basic accredited training in PECS and is recommended for anyone who wants to teach PECS to individuals with communication difficulties. A total of 75 people attended this workshop including the entire Vera School staff, a few parents, and other educators and therapists from special schools around South Africa. Sue and Julia held a Saturday morning parent workshop at the school, introducing PECS to a group of 30 interested parents and family members. The following week the PECS consultants spent three days in our classrooms (19, 20 & 23 April) and implemented PECS training with 14 learners selected from 5 classes.

All the educators and teaching assistants were included in order to give them experience in implementing the beginning stages of PECS training and as many parents as possible were involved. What followed was an exciting wave of PECS training that had the whole school buzzing. Learners that had never communicated with us before started to use this picture-based system to initiate communication and a few learners quickly progressed through the initial phases and were using sentence level requests by the end of the week. An exciting development was that a few learners started to verbalise in sentences for the first time and use their vocabulary (previously used inconsistently and often inappropriately) to appropriately and spontaneously make requests. The consultants returned to the UK, and the staff carried on with the original 14 learners and started implementing PECS with other learners. By December 2004 we had 28 learners using PECS (from Phases I to IV).

PHASE TWO: "Distance and Persistence"

In 2005, we continued to grow the use of PECS at the school. With only one speech therapist and limited access to PECS consultants (only via email and telephone); we started to struggle with certain learners and certain aspects of the PECS training. Phase III (picture discrimination) became an issue as the staff struggled with learners 'stuck' in this phase. The learners who had reached Phase IV (sentence level) needed further training in using attributes and developing commenting (Phase V-VI), but we had only implemented the initial phases of the training with the consultants and had limited knowledge of training these later phases. We began to experience the frustration of trying to develop PECS as a complete communication system, used throughout the day in a variety of activities and in all contexts (school, home and hostel).

Fortunately, Pyramid Educational Consultants were keen to follow-up and keep the momentum going from the initial workshop and so they offered to return in 2005 for a further workshop and further consultation. In July 2005, Sue Baker & Julia Biere return to Vera School and held a **PECS Review, Practice and Problem Solving** workshop (1-day) followed by 2 days of consultation. 50 people attended the follow-up workshop on 18 July 2005 (including most of the Vera staff, a few parents, and therapists from other special schools). On the 20 & 21 July 2005, Sue and Julia worked in 7 of the classes with 30 learners and their educators, teaching assistants & hostel staff. The consultants focused on Phase III error correction, Phase IV with attributes and introducing commenting (Phase V-VI). They also demonstrated some of the additional communication skills from the PECS training protocol (e.g. asking for 'help' and using Let's make a deal). While their first visit established learners' motivation to communicate (using high levels of reinforcement) and the basic skills of PECS, the second visit focused on extending and generalizing these skills, so PECS would be used not only to request reinforcers in structured sessions, but as a means of communicating across the day. The workshops and consultations have been vitally important for the correct implementation of the PECS.

Feedback from PECS Consultants (July 2005)

During their July visit the PECS consultants provided oral feedback to the staff and then after the visit they sent written feedback to the school. These were some of the positive remarks they made about the PECS implementation at the school:

➢ LOTS of learners with PECS books; books hanging up in 'base' in classrooms

➢ Extensive vocabulary in books; systematic picture scheme (pictures all same shape and size)

➢ Lots of learners up to Phase IV and some on attributes

➢ Lots more speech

➢ Confident PECS use by many learners – good foundation skills acquired

➢ Clear commitment to teaching communication by staff

➢ Schedules in some classes

➤ Calm environment with positive staff attitudes, nice teamwork; backup support from Senior Management apparent

Goals for future PECS Implementation:

The consultants identified the following goals for future PECS Implementation at the school:

➤ Teach learners to carry communication files to different activities and locations; shift to seeing PECS as their 'voice', so needs to be with them *at ALL times*

➤ Extend PECS beyond structured sessions and snack to all activities across the day; initially aim for 1 or 2 exchanges in each different activity

➤ Ensure learners hand over the sentence strip after constructing a sentence, even if they verbalise the sentence (communication only takes place when directed to another person)

➤ Use natural voice when 'reading back' the sentence strip

➤ Most learners at Phase IV have 12+ pictures in their books and are ready to move on to using attributes and to commenting.

➤ Work on the 9 critical communication skills (individual timetables; help, break, wait, etc.). Use the checklist in PECS Manual to prioritise for each learner. Put Let's Make a Deal and other Reinforcement first systems in place

➤ Staff to use PECS Checklist to monitor own and colleagues' skills on regular basis, to check quality of PECS implementation

➤ Key staff to support PECS implementation in hostel

➤ Plan for further parent support and training

➤ Selected staff to do PECS Implementer's Certification

➤ Ongoing link with Pyramid Educational Consultants: distance supervision through package of phone calls, emails and video submissions

➤ Further training & consultancy in 2006

We started implementing some of these suggestions immediately and the school management realised that in order to maintain and extend PECS use and ensure that educators, assistants, hostel staff and parents were implementing the system correctly a full-time speech therapist was needed to focus on the AAC needs of the learners.

PECS Congress – November 2005:

Our school was invited to present at the PECS International Congress held in London in November 2005. Over 20 countries from all over the world were represented at the Congress, which marked 20 years of PECS. We were the only representatives from South Africa and the only country in Africa where PECS is being implemented. The information contained in this paper was presented at the Congress (including PECS use to date) by the author. The international presenters spoke of similar difficulties with implementing PECS with limited resources.

The educators and parents at the school were asked to provide written feedback on the benefits and limitations/difficulties with using PECS. The following is a summary of their feedback:

Educators' Comments

Benefits
COMMUNICATION
➤ Learners started communicating more spontaneously ➤ Increased communicative intent with ALL- clear communicative intent

- ➢ Communication between learners and staff increased

- ➢ Improvement in eye contact

- ➢ Able to approach any communicative partner

- ➢ Ability to communicate *with* a person

- ➢ *"empowered to communicate"*

SPEECH

- ➢ The development of speech and language skills

- ➢ More spontaneous speech

- ➢ Improved speech with verbal learners – slows down process, facilitates better sentence construction

- ➢ Some started speaking in sentences

- ➢ Constructing longer sentences

- ➢ Increase in vocabulary

- ➢ Use normal volume of speech

- ➢ Use longer sentences with the PECS sentence strip

- ➢ Decrease in echolalia

- ➢ Use complete and appropriate sentences

- ➢ Promoted speech development in all the learners.

SOCIAL

- ➢ More social since PECS "forces" social exchange

- ➢ Better social interaction – make eye contact before asking

- ➢ Increased confidence and enjoyment of social interaction with peers

BEHAVIOUR

- ➢ More control over environment & life, therefore better behaviour

- ➢ Fewer tantrums and problematic behaviour – learners can make their needs known and be specific.

- ➢ More mature, self-confident and autonomous

Difficulties / Limitations

- ➢ Making the ideal number of exchanges per day

- ➢ Time constraints (not enough time for individual input for all learners)

- ➢ When all learners use PECS in class – everything takes longer if you are using PECS effectively

- ➢ When a child is the only learner in the class using the system - difficult to cater for his unique needs.

- Initial phases need 'two-to-one' situation without distractions - need more hands for physical prompting at early stages

- All facilitators need to be trained and understand the various phases for maximum benefit

- New personnel and volunteers without training

- Incorrect implementation of PECS

- Communication books can be cumbersome

- Bulky file not user-friendly on the playground

- File carried over the shoulder restricts free play

- Learners playing, swinging, spinning files

- Missing pictures

- Difficulty maintaining the communication files

- Damage to the learners' clothing due to the hook Velcro on the cover of the file.

- Not always having the vocabulary in the PECS file that the chills requires

- Learners not always motivated/focused

- Depend on an adult to ensure the child has the file with him

- Commenting not spontaneous

- Need to back-step to previous phases (some learners regress)

- Parents reluctant to use PECS at home

- Lack of family support

- Reciprocity remains on the level of single exchanges.

- PECS not used at all levels throughout the day

Parents' Comments

Benefits
- Improvement in communication
- "PECS is an easy way to communicate and understand your child's needs"
- "Before we had to guess and try to figure out what he wanted, but now we have an indication of what he wants."
- "Sometimes at home he is able to tell us what he wants without using PECS"
- "When M.M. started with PECS he was very enthusiastic. He enjoyed it. Getting him to do things with PECS was easy"
- PECS covers most of the communication areas
- Child uses sentence structure spontaneously (with the augmentation of the PECS)

- ➢ Improved grammar - uses complete and correct sentence structure.

- ➢ Started to make requests without the PECS (same sentences without prompting).

- ➢ Carried over to other contexts.

- ➢ Spontaneous verbal requests in complete sentences

- ➢ Made sure that he was understood - persistent in communicating his message

- ➢ Gets your attention before requesting

- ➢ Colour concepts now established

- ➢ Behaviour changes: more relaxed, less repetitive and less anxious in public places

Difficulties / Limitations

- ➢ Very time-consuming

- ➢ "I have to initiate the PECS most of the time"

- ➢ Need to remind child to fetch his file.

- ➢ Child only wants to make a single exchange for his food at mealtimes – resists multiple exchanges

- ➢ Communication still very limited

- ➢ Inability to share information

- ➢ Lack of motivation – needs adult to facilitate use

- ➢ PECS file bulky and cumbersome.

- ➢ Not having the specific vocabulary in the PECS file that the child needs for specific requests

- ➢ Tapping too hard to get the adult's attention

- ➢ Not using the commenting sentence starters or certain attributes

- ➢ Unnatural format of requesting (i.e. "I want ____).

Progress and developments in 2006:

This year has been another busy year at Vera School with growing numbers of learners starting in the preschool section of the school with little or no functional speech. Ten new learners have started on PECS this year, with more expected. The School Governing Body agreed to fund a second speech therapist so that there would be a full time speech therapist to focus on PECS during 2006. With a speech therapist available full-time, we have had training for parents and other significant caregivers, new staff, hostel staff and ongoing input and monitoring of the PECS training in the classes. The speech therapist works closely with the educator in the classroom context, implementing and expanding each learner's communication system. Of the 11 classes, 9 include PECS users at present. The school currently has 42 learners using PECS (ages range from 3 to 18 years) with only 4 learners in Phase I – II, while 13 learners are in Phase III and 25 learners are in Phase IV-VI. Of the 42 learners, 23 learners are able to verbalise their requests using intelligible words and 5 learners are attempting to vocalise while using PECS. One learner no longer uses PECS as he has moved onto effectively using speech as a primary mode of communication without the augmentation of PECS.

PECS use at Vera – September 2006

PECS Phase	Number of Learners	Learners using speech	Learners vocalising

	in Phases of PECS	with PECS	with PECS
Phase I-II	4	0	0
Phase III	13	4	0
Phase IV	12	7	4
Phase V-VI	13	12	1

The graph below represents the growth in the PECS use of learners at Vera School from April 2004 to September 2006. The total number of learners using PECS is represented, as well as the number of learners in each phase of the PECS training at various stages during this 2-year period.
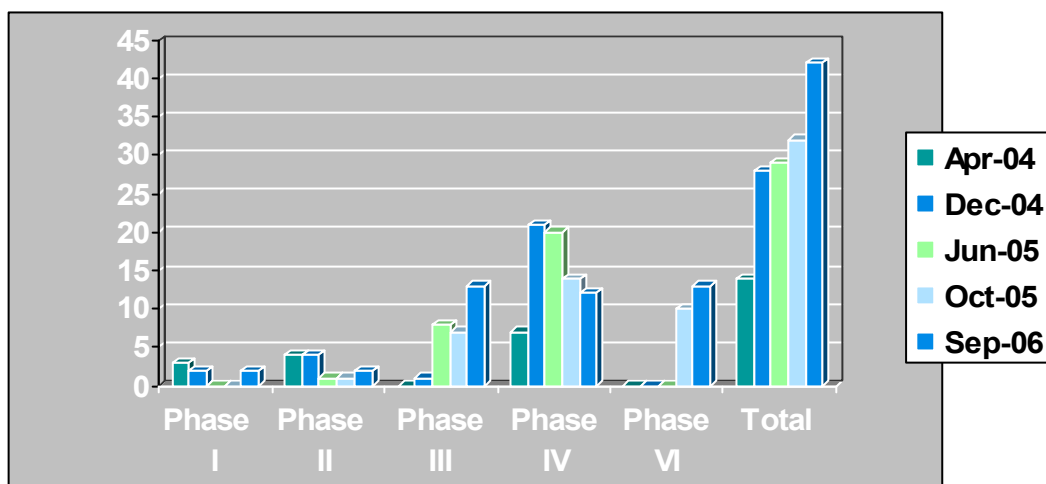
The Future of PECS at Vera School

The school continues to see the benefits of implementing this communication system for many of our learners with severe communication difficulties. *Lori Frost* (one of the co-developers of PECS) will be providing a one-day workshop **Incorporating PECS Across the Day** in October 2006 at Vera School (prior to her presentation at the Autism Congress). The staff look forward to this workshop and further developments in the PECS users in the school. The Governing Body has extended the second speech therapist post for 2007 allowing ongoing focus on the vital communication skills of learners with limited or no functional speech. We are currently videoing staff members for the implementer's certification and providing input to new staff, parents and hostel staff.

The Future of PECS in South Africa

South Africa is a developing country with limited resources and little access to ASD-specific interventions. To remain informed of new approaches and properly implement various well-known interventions, the special needs schools for learners with ASD have been forced to raise funds (often large amounts that can take a number of years to obtain) in order to have qualified trainers brought into the country from overseas. Most of the schools do not have access to the necessary funds and the training is therefore simply not available. Even when initial training has been done, we are faced with limited support systems and no local consultants or trainers to follow-up on issues and stuck points. Vera School has been privileged to receive the TEACCH, Makaton and PECS input over the past few years, but realise that the ideal of having the entire staff trained with follow-up consultation is not a reality for most schools in the country. We hope that in future, Pyramid Educational Consultants will consider setting up an agency in the country and will hopefully start training around the continent. At the moment this system is only an option for a select group of children with only a handful of professionals in the country having attended the initial workshop. Although interest is being expressed by a number of different groups, the funds and trainers are not available for further workshops. It will also depend on the organisations and agencies that represent the ASD-specific interventions to provide outreach services to Africa. In order for these interventions to be implemented correctly and be successful it takes vision, determination and major investments of time and finances. Vera School has made a small, but important start in upgrading service provision for the ASD population, but there is clearly a lot of work to be done in South Africa and the rest of Africa before all of the needs of children and adults with severe communication difficulties can truly be met.

0054

EXPLORING THE ADVANTAGES OF AUGMENTED REALITY

FOR INTERVENTION IN ASD

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Abstract

Research and practice have demonstrated that both visual and computer mediation of learning is very facilitatory in autism spectrum disorders (ASD). Virtual Reality (VR) has extended and enhanced those benefits but still leaves some more severely affected individuals unable to generalise their learning to new situations. Augmented Reality (AR) Technologies offer new opportunities for providing visual information to people with autism in real (although augmented) situations and have the potential to further facilitate learning. In this paper we explore some ways in which AR can augment the reality seen by the individual with autism that, as we suggest, can be of high educational benefit. We suggest its use in pretend play training; regarding help on the distinction of the self from others; for augmenting communication and social understanding; for one's own emotional awareness; for improving attention patterns; for teaching object permanence and for concept development through what we call 'superimposed pictograms'.

Introduction

There is evidence that the visual sense is the best preserved in autism spectrum disorders (ASD) and that even concepts that do not typically evoke visual images, activate the visual areas of the parietal and occipital cortex in those with ASD (Kana et al., in press), the presumed site of visual imagery. In concordance with that, it has been found that the majority of those with ASD are visual rather than verbal learners (Grandin, 1995; Jordan & Riding, 1995) and, although adaptable to other modalities, the most commonly used teaching programme for those with ASD (Mesibov, TEACCH Programme) was developed using, and still most commonly uses, visually mediated learning.

Computer assisted learning (CAL) is also possible in a range of modalities, but it too is most commonly available as visually mediated learning. It has been argued that CAL is an effective, comfortable and facilitative context for learning in individuals with ASD in that it offers structure, visual mediation of learning, opportunities for repetition, affective engagement and, additionally, control of the learning environment (Jordan, in press; Murray, 1997; Murray & Aspinall, 2006; Murray & Lesser, 1999; Trehin, 1994). Virtual Reality (VR), as a computer based program, may also be assumed to provide a facilitatory environment for people with ASD, but may have enhanced effects (especially in terms of generalisation) because of its greater capacity to engage and direct attention, offer control of the environment, and engage the participants emotionally (e.g Herrera et al., in press; Parsons et al., 2005; Strickland, 1992).

However, as was shown by Herrera et al. (in press), even with VR, some individuals with ASD (especially those with additional learning and language difficulties) may still find it difficult to generalise their learning from the computer environment to real-life situations, especially when dealing with novel domains. Augmented Reality (AR) offers a further facilitation for this generalisation. As we discuss below, by using real life experiences, but augmenting them in a way that facilitates learning for those with ASD, it is hoped that it will be possible to provide the most facilitative form of learning yet available. Such situations are at present experimental but technological advances are likely to make them more accessible to all. Research is still needed, however, to determine the best methodology for AR facilitation.

Augmented Reality

What is Augmented Reality?

Augmented reality is a field of computer research that aims to develop technology for combining information we perceive from the real world with computer generated information. An ideal technology for augmenting reality will allow the user of that technology to perceive augmented elements with such a degree of realism that augmentations of the reality couldn't be distinguished from the reality itself.
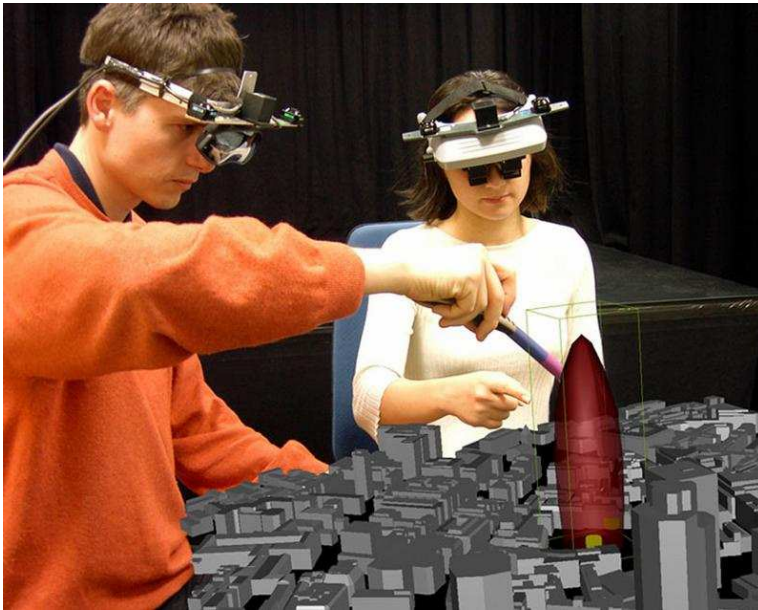
Figure 1: Example of an AR application that simulates new buildings within a 3D city map (http://idw-online.de/pages/de/image16073)

This type of technology-mediated reality is possible by ideally wearing invisible and unperceivable technology. However, we need to consider the current limitations of the state-of-the-art technology when considering possible AR applications for people with autism.

State-of-the-art of Augmented Reality Technologies

Nowadays there are dozens of technological solutions for including graphical augmentations to the reality we perceive. According to Bimber and Raskar (2003) they can be classified as those based on stereoscopic displays and those based on non-trivial projection screens.

Stereoscopic displays

Within the stereoscopic range, the most widely used solutions are 'Augmented Reality Displays'. Those displays are "image-forming systems that apply a set of optical, electronic and mechanical components to generate images somewhere on the optical path in-between the observer's eyes and the physical object to be augmented" (Bimber & Raskar, 2003). The following figure (Fig. 2) illustrates the different possibilities of where the image can be formed.
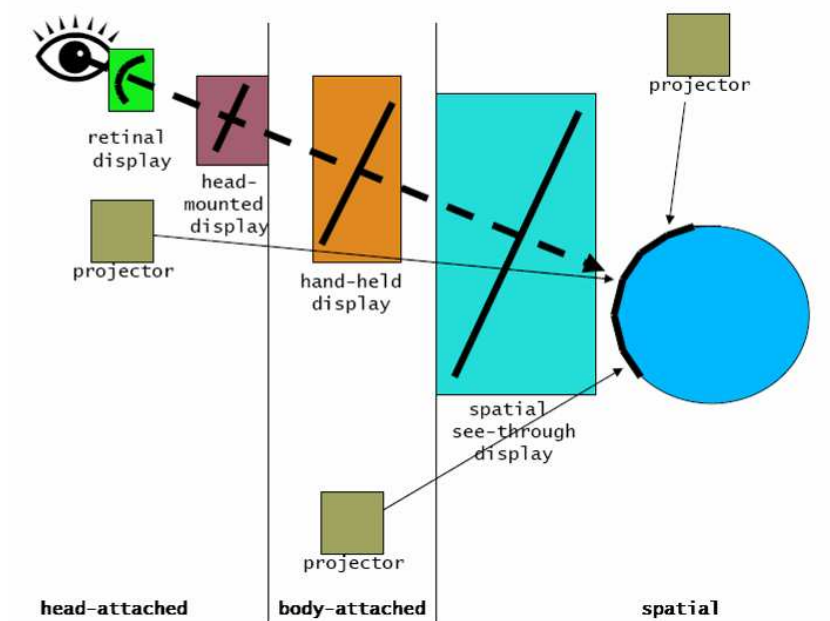
Figure 2: Image-generation for augmented reality displays

Perhaps, the most common solution of AR displays are head-mounted displays (that augment reality from the user's subjective perspective), video see-through (that makes use of video-mixing and then displays the merged images) or optical see-through (that makes use of optical combiners).
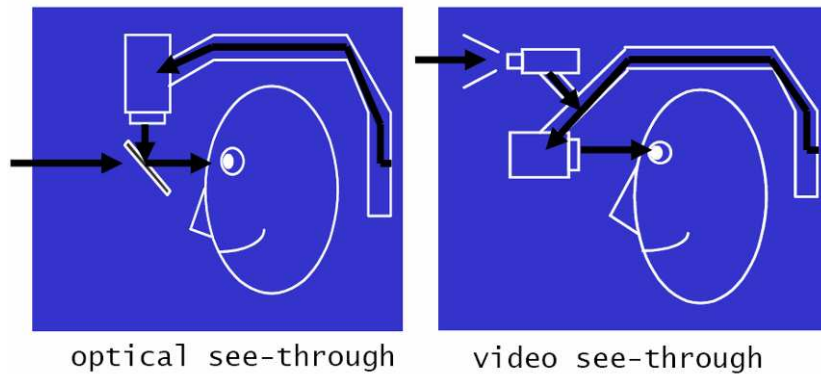

Figure 3: Video see-though and optical see-through (Azuma, 1997)

In the 'video see-through' (Fig. 3, right) the user receives a unique visual input that consists of a video that already mixes both camera-captured reality and augmentations. In the 'optical see-through' alternative (Fig. 3, left), the user still has the possibility of directly perceiving the real environment and, thanks to a half-silvered mirror, augmentations are included within his/her visual field.

Other pedagogically interesting 'optical see-through' solutions are Mirror Displays. Using full or half-silvered mirrors, these displays are typically used for achieving optical effects such as optical combination of graphics with the real environment. Among other things, this can allow the user to see himself / herself (objectively) in a half-silvered mirror together with graphical augmentations.

Non-trivial projection screens

In Spatially Augmented Reality (SAR), the user's physical environment is augmented with images that are integrated directly in the user's environment, not simply in their visual field (Raskar et al, 1998, 1999). Up to now, the application of these projection techniques involves the use of white objects and irregular surfaces (that include the geometry of the objects to be projected) as projection screens (Fig. 4). This fact very much increases the complexity of the application of this technology.

Fig. 4: Left: white object to be augmented. Right: the same object augmented through non-trivial projection techniques (Raskar et al, 2002)

Reliance on computer vision and perception

The hardware for making graphic augmentations possible is not the only problem to be solved in order to produce augmented reality. To correctly locate a graphic augmentation within the user's field of view, computer vision and computer perception techniques need to be applied. These techniques allow computers to "understand" image content, a necessary step before including augmented reality. The computer must know in real-time the coordinates (two-dimensional or three-dimensional) of every element of the real world in order to augment them. For example, in order to augment a person's head (by, for

example, adding a virtual helmet), the computer has to recognise the head in the video-captured image, and this must be done on a real time basis for the experience to be interactive.

For the type of applications explored within this paper, a critical type of technology is the one that allows the computer to know about the user position, posture and movements at each moment in time. For this to be possible, there are special solutions known as 'motion capture' (mocap) that can be acoustic, electromagnetic or optical (Fig. 5), with this latter one being the most used and less obtrusive as there is no need for any cable. They are based on several cameras and spatial position is obtained from all perspectives. A set of markers (Fig. 5) are worn by the participant and detected by infra-red cameras for obtaining the exact position of several key points (such as hands, head or limbs) of the participant body in real time.

Figure 5: ART Tracking system markers

As this technology may still be too intrusive for someone with ASD, solutions based only on computer vision (without additional technology or devices) are required to solve this problem. Up to now, there is no commercial version for such a solution, although this technological solution is under study in some research groups and projects (as in HUMODAN, IST-2001-32202 funded by the EU), where some relevant results have already been obtained but not in real time (our requirement). The progression of computer vision techniques are expected to solve this problem in the near future.

Single-user and multi-user applications

The majority of the solutions outlined above can occur both within single-user or multi-user frameworks. For educational purposes, the possibility of having two or more users (i.e. the individual with autism and the teacher or a peer) that share the augmentations of a given reality will be of great value.

A desired future of AR

There are some technologies that have the potential of advancing towards the ideal AR we mentioned earlier. This may be the case with another subtype of Stereoscopic display approaches: Volumetric displays (Blundell & Schwarz, 2000). With this technology, projectors directly illuminate spatial points within a display volume. Possible solutions are Solid-state volumetric displays (Langhans et al, 2003) that generate visible photons (light) within a transparent host material (gases, crystals or electro-active polymers) by stimulating optically active ions with special energy sources. Ions at known three-dimensional positions within the host materials can be stimulated by crossing energy beams, such as infra-red lasers, ultraviolet sources of radiation, or electron beams (Bimber & Raskar, 2003). As can be expected, the final (not currently feasible) objective of these technologies will be to use air as the host material for projecting augmentations.

Advantages of Augmented Reality

When we compare AR with other kinds of technology-mediated realities such as VR, we can see some advantages and disadvantages that bring us closer to how AR could be better used and integrated with other (complementary) approaches.

It is tangible

AR can be considered as tangible presence (Herrera, Jordan & Vera, 2006) in that the moment-to-moment awareness of ourselves in the process of perceiving and acting in the world (presence) is much more natural than other state of the art technologies such as Virtual Reality.

Virtual Reality is a simulation of Reality. Augmented reality, on the other hand, is directly connected to Reality itself. The need to transfer acquired knowledge from AR to Reality seems to be less than from VR to Reality. This is a great benefit in autism, where appropriate use of relevant stored knowledge is an area of significant difficulty (Jordan, 1999).

Includes body representation

An important component in order to be able to experience agency within VR is being able to perceive our body within the virtual environment in which we are interacting. Moreover, as 'presence' in virtual environments can be seen as the typical moment-to-moment awareness of ourselves in the process of perception of the world (Herrera, Jordan & Vera, 2006), the perception of our own body is really fundamental in order to truly perceive ourselves. In fact, the accurate and updated representation of the user body is one of the challenges of current VR research (Tang, Biocca & Lim, 2004). Hence, the advantage of AR when compared to VR is clear and simple: in AR we can directly see our real body. If we take into account the necessity reported by people with autism about their need to visually track their own movements to maintain awareness (Lawson, 2003; Williams, 1998), this fact become even more important.

Issues about Predictability

Typical human processing is based on an understanding of the world and those within it that is largely socially mediated (Hobson, 2002; Trevarthen et al., 1996). Social referencing abilities give the child emotional security in exploring the world and allow supported assessments of what is safe (and can be explored further) and what is dangerous (and should be avoided). Without that support, the child with ASD (and later the adult with ASD, unless they have been able to learn about the world cognitively) responds purely (and uniformly) according to temperament, being fearful of all new things or having no fear of anything, including no sense of danger. Because much learning is associative in ASD, and persons with ASD may not attend to relevant features of the environment that affect outcome, they may expect outcomes to follow a course of actions or events, not realising that key aspects may be different. Alternatively, they may fear even minor changes in routine, not appreciating that the overall outcome can remain unaltered (because the changes are not relevant) or that the same outcome may follow from different courses of actions (one can end up having an ice-cream whether one goes to the greengrocer or the library first, for example).

Not understanding how the world works, therefore, can lead to failures or mistakes in predicting outcomes of events but this is even more the case when people and intentions are involved. People with ASD commonly act like radical behaviourists, trying to predict what someone will do next on the basis of what they have done before (either in terms of the preceding action, or in terms of behaviour that was rewarded or punished in the past). This is at best an inefficient, inexact and slow process. In typical human interactions we base our predictions on our intuitive understanding of what other people *intend* (or what we imagine they intend). That provides us with a frame through which we are able to predict at speed and with an acceptable (although not perfect) degree of accuracy. Without that intuitive understanding of others, prediction become a laborious and often incorrect process of 'working out' what will happen.

One reason why VR is helpful in ASD, is that it enables the environment to be more controllable and thus more predictable. Augmented Reality, where the base scenario is Reality, cannot be considered to be as predictable as VR. The level of control over the events occurring in the environment is lower, unless we use AR in an environment with a high level of structure (a TEACCH environment, for example), as can be done in Reality. This makes it more difficult to design than VR, but also makes it easier to generalise and thus more useful in the education of individuals with ASD.

In addition to this, there are limitations to the current development of AR technology. Many of the current state-of-the-art AR technologies have many unwanted effects such as difficulties in screen refreshing, involuntary occlusion of AR markers and then the lack of Augmented elements where they were expected. This has the potential to increase the problems of those with ASD. Furthermore, within augmented reality settings we cannot give the individual the control over the speed at which the environment is processed, and this too is a significant disadvantage in ASD, where a high speed of processing is a crucial barrier towards learning.

Despite all these apparent disadvantages, however, we can consider AR as a useful intermediate step when transferring teaching from Virtual Reality to Reality. Thus, we can facilitate most of the learning under VR conditions and use AR as a generalisation tool.

Imagination and magic

For teaching pretend play and for understanding imagination, VR offers the advantage of it being possible to show imaginary transformations explicitly (Herrera et al, in press). For example, a pair of trousers can be transformed into a road (Figure 6). Within that tool ("I am going to act as if…" by Herrera et al, 2005),

when imaginary transformations are being taught then presented images are framed into a think bubble. If what is being taught is the concept of Magic, then the same set of transformations are shown but this time without the think bubble, trying to illustrate that this kind of situation can occur "magically" in 'reality'.

Figure 6: Snapshot of the tool '*I am going to act as if* …'

In the recent past, these magic transformations were only possible in fantasy stories or films. With AR, however, this can be done in a much more interactive way: augmentations can be included within the visual flow that goes from reality to the user with autism.

Thus, for training in imagination (and distinguishing it from magic transformations) AR can be considered as a better option since the combination of reality and virtuality that it provides makes it ideal for this purpose. This is one of the fields that is currently under development in the Autism & Learning Difficulties Group of the University of Valencia

How can AR be used for intervention in Autism?

Distinction of the self from others

One of the key problems in ASD is a failure or delay in developing a sense of agency and distinguishing self from other (Hobson, 2002; Jordan, 1999; Russell, 1996). This in turn leads to differences, and commonly difficulties, in all kinds of cognitive processing, including perception, memory, problem solving, emotion regulation, pragmatic language and social cognition. Augmented self perception should enable the external cueing of internal mechanisms, enabling the sense of agency and self (and, therefore, other) to develop from the 'outside in' in a way that is often necessary in autism (Grandin, 1995; Williams, 1996)…

Environment reactions (cause-effects) can be augmented and made more salient to the person with autism. This also will help in the development of a sense of agency, as well as helping control of behaviour and the capacity to learn from one's experiences.

With multi-user AR, we can augment the environment by highlighting different perceptual and conceptual points of view which will speed up the process of social cognition, making it clear that the viewpoint depends on the viewer: another aspect of agency and self: awareness of others.

Highlighting, structuring and marking the limits between self and others will aid understanding. If the distinction of the self from others (and the notion of others) is fostered further through reciprocal imitation (Nadel & Aouka, 2006), then we can have virtual characters that automatically imitate everything we do (obtaining information about what we do through motion capture techniques). This would help to engage individuals with ASD in reciprocal imitation. These techniques are the core element in many interactive interventions (Jordan, 2004) but AR might be able to produce the same benefits in a more cost effective manner (once development costs have been eliminated) and in a way that is very adapted to the learning strengths of those with autism (Jordan, in press; Murray, 1997)

Adding visual cues to the thought process underlying the person's own agency (distinguishing functional acts, playful acts and imagination) seems to enable the person to pay attention to their own role and thus become involved in a more subjective way (Herrera, Jordan & Vera, 2006).

These technologies will enable us to develop ways of using secondary mediation (AR) to help the individual to focus his/her attention on his/her primary mediation and so foster agency and intentionality by gradually reducing the augmented elements about. The ideal intervention programmes might be those that firstly use VR, then AR and, finally, just reality.

Augmented Communication

In the field of disability there are many strategies for 'Augmentative Communication', aimed at widening the channels for social communication. In our project we intend to augment a channel of communication (the mental one), which is not always available to individuals with ASD. This will add to the interaction of people with ASD, augmenting (and thus making 'visible') certain aspects of the communicative process that mediate between emitter and receiver.

Augmented videoconferencing will enable 'face to face' interaction in order to widen the communication channel between the emitter and the receiver. This will be done by including augmented visual information about the thoughts and beliefs which underlie and mediate this communication. This is building on work that has already been shown to be beneficial to teach social understanding in autism, such as that which used thought bubbles (McGregor et al, 1998, Herrera et al, 2005) and comic book conversations (Howlin et al, 1999, Monfort, 2001), and making it accessible to those with more severe difficulties.

Emotion awareness and identification

A significant problem in autism is the failure, or extreme delay, in recognising emotions, primarily in the self and later in others. Damasio (2000) has elucidated the mechanisms that might underlie such problems and Hobson (2002) has explored some of the consequences of such a failure. Most interventions have by-passed the core problems and concentrated on teaching pattern-recognition or cognitive 'working-out' as a way of recognising facial expressions of emotions in others (Baron-Cohen et al's Mind Read Software). As might be expected, such attempts have had only limited success, generally with the more able and confined to the particular domains taught. There is little evidence that they help in the core problem, for example, of becoming aware of one's own emotions in time to enact a strategy appropriate to the situation (e.g. responding to anger with a taught anger-management technique rather than simply being engulfed by anger and reacting with behaviour that is not under conscious control).

AR offers a clear advantage in relation to this. As AR is built up over the reality, then the emotionally charged situations that may naturally occur can be used for this training. A further possibility is to incorporate biofeedback technology (such as Galvanic Skin Response/Conductance Sensors) to visually represent important changes.

Attention patterns

Social Attention Patterns: One of the key defining features of autism is the failure to find social stimuli salient and to direct attention to stimuli judged relevant to the task in hand (Klin, 1991; Klin et al., 2002; Murray et al, 2005). By combining AR with eye-tracking technologies we can define ways of directing the attention of the individual with autism towards relevant social stimuli in real time. An example of this is the work of Mobahi and Karahalios (2004), where they have used AR to increase saliency of social stimuli by highlighting human faces from the rest of the environment.

Attention Patterns towards objects: In AR settings, augmented elements can be seen as 'zones of interest' or 'zones that have a greater potential for exploration' and thus have greater potential to get the attention of the user with ASD. This will enable the manipulation of the interests of individuals with ASD that others without ASD carry out through social interaction, but is otherwise difficult, if not impossible, in ASD.

Concept of Object Permanence

The possibility of playing with the appearance/disappearance of augmented elements can facilitate work on learning that objects have the property of permanence. This is a necessary precursor to developing referential language and social interaction as well as symbolic play, but it may be delayed in autism, especially where there are additional general learning difficulties. Peekaboo games or the 3-cup trick (Spanish 'trileros') where swindlers use three opaque face-down glasses and a small ball that is initially hidden under one of them and after some movements they supposedly change its position and the innocent "victim" has to guess where it is –usually in the swindler's pocket. The latter "game" involves an understanding of 'means-ends' relationships and also the tracking of movements (i.e. the final place is determined by the number and type of transformations that have occurred). At more advanced levels, individuals with ASD may do very well in mathematics until it comes to algebra. This too is probably related

to the need in algebra to keep track of transformations and understand their reversibility. One of us is currently engaged on testing this with software designed to make these steps visually transparent (Jordan & Hewett, in progress).

Pictogram understanding and concept development: superimposed pictograms

The development of concepts related to objects follows different paths in people with autism, with an over-categorisation being frequent when seeing objects that are normally seen as belonging to a given (already known) category:

> "I would learn how to tackle a given situation in one context but be lost when confronted by the same situation in another context. Things just didn't translate. If I learned something while I was standing with a woman in a kitchen and it was summer and it was daytime, the lesson wouldn't be triggered in a similar situation if I was standing with a man in another room and it was winter and it was night-time. Things were stored but the compulsive over-categorisation of them was so refined that events had to be close to identical to be considered comparable" (Williams, 1996)

Together with this, especially in those with additional general learning difficulties, people with ASD have trouble with abstracting what is common in stimuli and this affects their development of everyday 'fuzzy'; concepts such as 'tables' or 'red' or 'old' (Grandin, 1995). They find scientific concepts much easier to acquire because they are taught their criterial features and do not have to acquire them through abstraction from experience.

The possibility of having 'superimposed pictograms' (Fig. 7) over real objects and people so that the individual with ASD can see the connection between the image and the pictogram in real time is one of the greatest potentials of AR. Although it might appear that photographs, for example, would be easier to understand and use for communication than symbols, this has often proved not to be the case in autism. The reason seems to be that photographs are as complex as reality (or almost so) and thus allow as much opportunity to fix onto some non-representative feature (such as the shoes someone is wearing as their identity marker). Using symbols, therefore, may allow much better generalisation of the symbol to other exemplars (all girls, or all drinks, rather than a particular one) and then to other symbolic representations, such as words. AR can help the individual make the connection and for this kind of 'pictographically augmented reality' a possible solution is the use of infra-red markers (Fig. 5) as trackers of the body posture and object position and orientation, and then generate a mixed image that includes the reality perceived at every moment together with superimposed pictograms. Images such as the one in Figure 7 will be obtained on a real time basis.

This area of teaching is one of the current research and development lines of the Autism & Learning Difficulties Group at the University of Valencia.

Figure 7. Superimposed pictograms, by the University of Valencia

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INTERACTIVE PLAY FOR CHILDREN WITH AUTISM

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Introduction

Play is a significant feature of early childhood that emerges through a vast array of relationships and experiences that are defined by the quality of the interactions that children have with significant people in their lives. It is also essential to view play from a developmental paradigm since it is not a stage that we have to go through to reach adulthood but is a continuing feature of how we have fun, make discoveries, take risks and accept challenges throughout our lives. Early play with caregivers provides the foundation for understanding the nature of social relationships and it is these interactions that will influence all future relationships with others. Whether they are playing alone or with others, children become involved in activities from which they learn to experience a wide range of emotions that help in regulating both social and cognitive behaviour. Throughout these exchanges there is constant encouragement for them to develop independent actions and thoughts. The caregiver provides assistance as and when it seems appropriate so that a child is gradually being prepared psychologically and socially for their future independence. It is often overlooked that children are engaging in social play during those early interactions and that it is the process of social engagement with one other person that will lead to the emergence of co-operative play with others. It is clear then that the child's main carers have a considerable responsibility in establishing opportunities for mutually significant interactions. Such experiences lead children to develop a greater understanding of intentionality and reciprocity as well as serving as a regulator for emotion and behaviour (Feuerstein et al, 1991).

Vygotsky (1978) believed that play is not only significant in reflecting development but also in leading it and it is predominantly his theories that have been influential in promoting the importance of play as a vehicle for social interaction. Vygotsky's view was that play was vital in mediating cognitive growth but the potential for this only occurs when there is an adult facilitating for the child's learning experience. It is the interplay of the contextual nature of the play, the child's disposition and the role of the play partner that will significantly affect the development of social understanding and social behaviour. Thus a child who remains isolated from such experiences will not gain the knowledge required for establishing social relationships, leading to impaired cognition and affect development.

> Play is an integral part of childhood, a unique medium that
>
> facilitates development, social skills, decision making skills
>
> and cognitive development in children. Play is also a medium
>
> for exploration and discovery of interpersonal relationships,
>
> experimentation with adult roles, and understanding of one's
>
> own feelings. Play is the most complete form of self expression
>
> developed by the human organism.

Landreth, 2001:4

In recognising how play supports children's developmental needs this implies that all children need time to discover their world in ways that are enjoyable and motivating. As Greenspan and Wieder (1998) state, so often children with disabilities are not given appropriate opportunities to play because more functional activities are deemed more relevant for them to learn. Consequently they can miss out on play experiences, particularly those which form the basis for developing communication and establishing relationships. Play skills are frequently used as a measure of cognitive development in children with autism but this has a tendency to highlight deficits in play that can lead to a number of assumptions about a child's capacity for play. From birth all children show a strong desire to be active and master the environment and will make use of whatever means is available to them; this includes the unique ways in which they interact with their environment.

Establishing Connection

Hobson (2002) describes how the connections made between people are one of the most powerful influences on development. Lazarus (1991), Schore (1994) and Siegel (1999) also acknowledge that it is

not just the experience of relating to another person to have ones needs met but the quality of the relationship that will have a significant impact on emotional and intellectual growth. Unlike other disabilities or deprivations in childhood, autism is unique in that there is a significant neurological dysfunction that results in the poor development of relatedness to another, compounded by impairments in the emotional and communication aspects of interpersonal relationships. For children with autism, establishing connectedness through interactive play creates a new therapeutic alliance that can become the catalyst for the development of meaningful relationships.

The basis upon which all encounters are made involves the sharing in sensory-affective experiences. Through engagement in shared play, more secure bonds between the child and the play partner can be established so that as the child gains trust and confidence, together they seek out more elaborate ways of interacting and connecting. It is through this process of interdependence that there is greater potential for the enrichment of the relationship. In order to experience connectedness there has to be an encounter that is based on unconditionally valuing the child as he or she is. By responding in the present to the play experience it also acknowledges the relationship without preconditions or expectations. According to Moustakas (1982) being attentive to the child enables the play partner to gain insight into the child's emotional world, providing him or her with a sense of adequacy and worthiness. Such immediacy offers a containing and congruent presence that has the potential to provide empathetic contact (Hazler and Barwick, 2001).

Neurobiological studies have shown that the chemicals that run the body and the brain are the same chemicals that are involved in emotion (Pert, 1999). Where interactions are based on positive arousal factors the brain produces more of an energy flow which has been found to significantly impact on the development of the right hemisphere of the brain that is responsible for socio-emotional functioning (Sunderland, 2006). During interactive play the potential for increases in smiles and eye contact is heightened because there is a greater emphasis on the amplification of positive states which stimulate the child's responsiveness (Schore 2001). In young children who are pre-verbal, smiling and laughing occurs predominantly during face to face interactions with a parent rather than when they are left alone to occupy themselves. This signifies the importance of the face in facilitating the socio-emotional connection between them. Identifying the deficits that individuals with autism have in understanding and using facial expressions to denote specific emotions (Adolphs et al, 2001; Grelotti et al, 2002), might contribute to a better understanding of a developmental pathology but it would appear to be more relevant to consider the impact that positive relationships have on brain development and how an increase in playful interactions can bring about potential changes in brain function.

Playful interactions help to determine the development of trust in the relationship and act as a key indicator of attachment security. Studies by Shapiro et al (1987), Rogers et al (1993), Capps et al (1994) Dissanayake and Crossley (1996) and Yirmiya and Sigman (2001) have identified that children with autism were able to develop secure attachments but the motivation to interact was more dependent on core needs such as for food or comfort, or self needs such as requesting preferred objects, people or situations, rather than an intentional desire to share an experience with another. Numerous studies are now focusing on the neurobiological influences of attachment and bonding on the child and parent (Carter, 1998; Uvas-Moberg, 1998; Modahl et al 1998; Insel et al, 1998). Their findings suggest a strong correlation between positive states of social arousal and emotional regulation and the release of neuro-endorphins such as oxytocin and vasopressin. A study by Hollander et al (2003) suggested that raising oxytocin levels in individuals with autism led to a reduction in repetitive behaviours and an increase in social processing and feelings of trust and security that are a feature of social bonding. What was little understood in the mid 1900's was that it was not just the adult who developed the bonds of attachment through nurturing the physical and emotional needs of the child, but what the parents and child create together. If the child with autism has difficulties with emotional reciprocity and social engagement this will undoubtedly influence how parents and carers interact with the child.

PARENT

needs   needs

Attachment

Fig 1. Att_____s mutua__
CHILD

The Flow of Communication
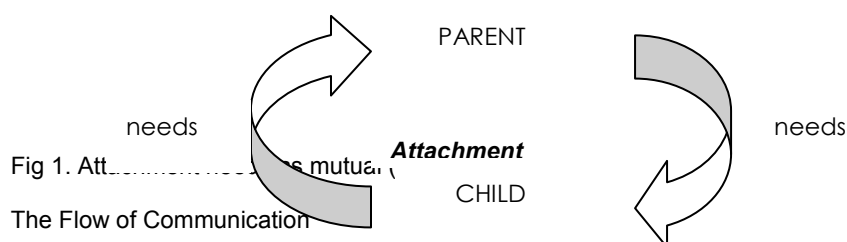
Participation in playful encounters that establish feelings of connectedness have the potential for developing more elaborate ways of communicating. It is also essential that any situation that involves positive engagement is seen as supporting the foundations for communication and the development of language. Brazelton et al (1974) noted that it is the pre-speech and proto-conversational activities that occur during playful interactions in infancy that provide the opportunities for increased participation in the

social world and thus the extent to which children effectively communicate with others. As Griffiths (2002) points out, playful exchanges have within them their own narrative qualities, whilst interactions that are not emotionally engaging will limit the child's understanding of the linguistic structures required for meaningful communication. For children with delayed speech any reparative work is achieved through the increasing responsiveness of the adult to,

- engage with the child at his or her developmental level

- react positively by mirroring the child's actions and vocalisations

- provide opportunities for the child's self-expression and self-evaluation

- link the child's utterances to meaningful experiences, and

- assist the child in developing intentional communication.

Playful interactions provide a meaningful context for observing the qualities inherent in how children are communicating. Using an interactive play approach that offers an empathetic and positive presence, the child's capacity to extend and participate in communicating, increasingly rests within the child. As Rhode, cited in Alvarez and Reid (1999) suggests, the therapeutic role of play and interaction for children with autism is to help them to 'find a voice of their own'.

The use of toys and activities for self-expression, creative expression and emotional release enable children to establish different narratives that can be represented through their play. These include drawings and paintings, sandplay, using puppets and drama sequences as well as representational toys. As each of these activities involve different levels of social contact so this in turn will increase their communicative competence (Landreth, cited in Schaefer, 1993). It is within the established framework of the interactive play that children come to recognise that having choice and some control over the way in which objects are played with, increases the desire for more intentional and spontaneous communication. As they come to acknowledge that the person is attending to him or her it also heightens the involvement in communicating and this is because they are not dependent upon prompts to gain what they want. In order to make sense of their play experiences and communicate them to others, children employ a range of non-vocal, facial, physical and hand gestures to act as messages for others to interpret. Augmented communication systems that have been devised for children with social communication difficulties often inappropriately emphasise the development of speech and language that has not been underpinned with the pragmatics of communication.

Potter and Whittaker (2002) carried out research that identified some of the ways in which children's spontaneous communication can be encouraged. It seemed that the most effective strategy was to encourage children to respond to environmental cues, such as objects and toys. The non-directive use of play allows objects to be presented in a way that the child can initiate a request or choice, rather than wait for a cue by the adult. This spontaneity leads to increased self-discovery and exploration and when shared with another person, it creates the potential for the child to make more use of spontaneous communication. Another significant factor in their findings was that the adult's over use of verbal prompting and questioning limited the extent to which children were able to communicate spontaneously. Similarly, when communication is engineered to meet the needs of the adult there is less potential for spontaneity and generalisation of the acquired skill. With less adult-directed communication, the child has an opportunity to respond to toys and objects and even the play partner with more intention and independence than might previously have been observed.

The presence of a supportive play partner who becomes involved in sharing the communicative experience of the play, aids the child's ability to generalise these skills and highlights the potential that play has for altering previously established patterns of thinking about the use of verbal and non-verbal

language. Unlike language, which is a highly structured mode of communication, the pragmatics of communication are much more diverse and complex (Bruner, 1983). For those children who have difficulties in comprehending the vast array of linguistic and communicative functions that are the basis upon which all relationships are developed, the need to sustain opportunities for more spontaneous

ways to communicate will be essential to their understanding.

Dawson and Adams (1984) and Nadel and Pezé (1993) found in a study that children with autism were more socially responsive, showed more eye contact and played with toys in a less perseverative manner when an adult imitated their behaviour. Most interactional approaches for children with autism emphasize the key role of the adult in imitating the vocalisations and actions of the child to increase and promote the development of language. Imitation is an essential aspect of body and linguistic mapping that are a fundamental requirement for intersubjectivity and non-symbolic communication (Trevarthen et al, 1998).

Meltzoff and Gopnik (1993) also recognised that developing an understanding of others, including their mental states is developed in the context of mutual imitation. Hobson (2002) describes the ability that is now being identified in very young infants to copy the actions of another, as communication before thought. Synchronicity and reciprocity that are significant features of parent-infant interactions, are clearly early forms of imitative behaviour. Jones (1996) considers that children's ability to imitate a parent's oral gestures occurs not because of an innate response mechanism but as a result of the child's 'coincidental matching of interesting stimuli with the infant's behavioural expressions of interest and exploratory motivation' (p.1968). Both play and language are symbolic representations of thought that are related to an action. Lewis' study (2003) suggest that there are a number of key factors that account for this relationship which are not so clearly defined in relation to play and language development in children with autism. However, she cites the research of Carpenter et al (1998) who found that when parents synchronised their behaviour and verbalisations with those of their child during play, there were significant gains in linguistic development.

Children's play provides an essential context for learning about communication and language. Experiences that enable the child to initiate and maintain joint engagement facilitate the acquisition of the conventions of conversation and the ability to respond to the actions and language of another (Powell and Jordan, 2001). Providing a narrative also shows an interest in what the child is doing, creating an empathetic response that builds on learning language in the context in which it is used. The narrative is kept simple and maintains a natural flow. Children with delayed language need to hear the rhythm of spoken language that matches their pattern of movement and interactions with objects. Making the speech disjointed, breaks down the language into isolated chunks and reduces opportunities for the child to learn about the flow of two-way conversation. Commenting on the child's activity rather than directing it enables the child to develop an awareness of language forms. This internalises the experience and teaches the child how language relates to actions, objects and emotions.

It is through play rather than verbal discussion

that they are able to give us an account of the

most significant aspects of their lives.

Schmidt Leven (1996:21)

Children with autism can be supported in the transition towards an increasing understanding of communication through the establishment of cooperative and enjoyable patterns of interaction that provide both companionship and challenge. Children who have not had sufficient experience of early forms of play and interaction may become limited in their capacity to engage in meaningful communications with others. They are more likely to have language difficulties and may show a preference for being alone rather than sharing the company of others. Having established the communicative partnership there is greater potential for the child to respond to others and develop new ideas for both play and interaction. The important factor for the play partner is to have much higher expectations for the child's communicative capabilities that will lead to an enhancement of the interaction. Communication is not just an exchange of ideas, an opportunity to solve problems and gain mastery over experiences but is essential in defining a relationship with another person. The capacity for children to participate in a diverse range of communicative experiences will be determined by their motivations, temperament and response to stimulation as well as the system or environment which makes up their social world.

Creating Meaning

A crucial component in the construction of meaning is an innate drive to make sense of the world and when this corresponds to individual motivations it increases the internalisation of the experience and the likelihood of more permanent changes in behaviour. Interactive play not only contains the experience in a way that it is meaningful to the child with autism, it also provides an integrated mode of learning that supports cognitive development and social understanding. This occurs as the adult provides playful activities that focus on extending the child's conceptual awareness, encouraged through self-discovery and the exploration of objects and ideas. Socio-cultural theories recognise that the adult's involvement in the learning process is one of establishing a co-construction of meanings through which individuals communicate their shared thoughts and emotions (Bruner, 1990; Trevarthen, 1995).

Vygotsky (1978) stressed that the internalisation of the experience is predominantly understood within the context of an individual's relationship with their environment and in particular, their social interactions. It is therefore essential that the value placed on play reaffirms the significance of a child-centred approach to the development of knowledge about the world and in particular, social relationships. The personal relevance which individuals attach to explorations of the world around them is based on their own

perceptual understanding and this influences how it comes to be interpreted and acted upon. Interactive play therefore has an adaptive function in that it is based on the creation of a shared system of experience and any learning that takes place occurs when the activity is extended beyond that which the child would not otherwise reach alone. It is in the construction of a dynamic spiral of support that children will then be able to develop more active skills in concept formation, language and symbolizing (Rowland, 1987).

The process of intellectual growth is dependent upon the need to establish feelings of competence not just in terms of making sense of experiences via thought and action but through the emotional significance that the individual gives to them (LeDoux, 1996). LeDoux believes that children who are deprived of play opportunities or who are not sufficiently supported in overcoming difficulties in social interaction will have a weakened ability to develop conceptual understanding and abstract thought. Rather than view children with autism as having a weakened ability to play, it is crucial that the shared play experience is seen as aiding conceptual development, representation and abstract thought. Bailey (2002) also recognises that play functions as a cause as well as a consequence of the child's ability to develop self-awareness, to understand fantasy and reality and even the intentions of others and as such adults have a significant role in creating the conditions in which to develop these skills.

It is in the creation of the social and emotional dependency of the adult-child relationship that the child began to develop the capacity to respond and make sense of his experiences. The cognitive processes which underpin the internalisation of experience cannot be separated into structures of thinking, perceiving, or affect since they all impact on how information is stored in the memory. Isaacs' (1966) early theories of intellectual development recognised that 'children's cognitive behaviour is not a set of separate relation-finding units but a complex and dynamic series of adaptive reactions and reflections' (p52). Furthermore, whilst these structures exist, they cannot be developed without the appropriate stimuli.

The construction of meaning is not based on intellectual competence but is a model of cognitive processing that has at its core the experience-dependent relationship. Embedded within this experience-dependent model is a growing awareness of the separateness of the self to others that is crucial to the child's ability to interpret and gain further knowledge and understanding. Likewise, children who remain at the exploratory phase of object recognition will have a less developed sense of self than those who are using objects to represent their thoughts. Without a level of social stimulation children will be less able to develop new concepts about objects or use them in a representational way.

By extending the use of the preferred object or activity, meanings will not destroyed in the process of reorganisation but can be re-experienced. In this way both play partners would be seeking ways to make interactions more enjoyable and meaningful. There is a sense of equilibrium that is maintained while new and different concepts are introduced. Increasing access to play using toys and other materials that can be used in variety of ways implies a greater potential for concept development, emerging as a consequence of a reaction to stimuli and the ability to discriminate and recognise relationships. Typically, children develop the capacity to utilise these skills quite rapidly in early development not only because they are essential for physical survival but because they help to establish meaningful interactions with the world. The construction of concepts is based on shared experiences that provide high levels of stimulation and where the child's understanding is fostered by acknowledging his or her interests in the world. This is a further reason to observe how the child's play fits into an existing conceptual framework or schema.

Commenting or attending to what the child is doing increases the child's awareness not only of the activity but also his or her mental state. This provides a linguistic and conceptual scaffold from which the child can begin to understand how mental states influence behaviour (Meins et al, 2002). The ability to make this connection indicates a new pattern of cognitive processing that is essential to the development of concept formation and symbolic understanding. The presence of a play partner helps to promote the child's awareness of the significance of their actions and achievements. Whilst the ability to attach emotional significance to an experience is fundamental to a child's concept development, he or she is also reliant upon others to value it for its originality.

By having insight into the child's inner world, the support offered creates the potential for extending how particular objects can be presented. In the development of awareness of the separateness of self to objects, children will shift between moments of integration and disintegration with their environment. The facilitation of the play experience provides a secure base from which children can increase their conceptual understanding and develop an ability to discriminate, make associations and solve problems. An increase in the associations a child is making through play will result in being able to discover more uses of the object and enable him or her to develop more flexible ways of thinking. The use of different resources and toys for interactive play activities should provide opportunities for experimentation, construction and representation that enable images and ideas to be given an objective form. It is within the shared experience that the potential for shared realities and shared meanings emerge. The use of objects also enables children to formulate rules, categorise and plan and as a consequence they are able to develop more abstract ways of thinking. With opportunities to practice what they already know children can revisit the same concepts and build new ones.

Children with autism do not differ in their ability to use organizational strategies to help them make sense of their experiences and the complex processing mechanisms that they employ to organize their actions should not be underestimated. Rather, it is the way in which information is processed that affects how they relate it to others; this includes how emotional reactions are used to aid their interpretation of what is meaningful. The need to organise experiences is an essential feature of concept development that is dependent upon repetition and practice. Play that enables children to categorize, recognise patterns and sequence objects or events raises the potential for increasing levels of abstraction (Franklin, 1994). Hence the organisation of play into specific repertoires can also be seen as an attempt to create meaning. Establishing preferences for certain types of play or particular play activities also ensures that the salient features are securely explored and mastered. All play regardless of its mode consists of internal and external organisational principles that will support and encourage concept development. When children use play to organise their thoughts and actions it shows an inbuilt capacity to solve problems and establish some coherence with increased complexity. Once these organisational structures are in place, with the help of a play partner, the child can gain new insights into different ways of thinking and behaving.

Developing Imagination

As children's play becomes more intentional and there is an increase in curiosity and exploration, crucial connections are made between ideas and actual events that result in more symbolic acts being created. The integration of the social experience and the ability to respond to experiences in unique and innovative ways is an essential feature of the creative process and playful interactions that include elements of spontaneity and enjoyment will have a profound influence on children's ability to develop flexibility, symbolic awareness and representational thought. Spontaneous exploration and sensory play experiences result in highly personalised interpretations or perceptual images that are the earliest form of representation and fundamental to the development of imagination. Regardless of their level of intellectual functioning all children will need opportunities to develop imaginative and creative ways of thinking, to enable them to develop confidence and experience a sense of wonder and enjoyment. Rather than see imagination and creativity purely from a developmental perspective, it is perhaps more pertinent to recognise that the ability to imagine is rooted in the realities and perceptions that are highly personalised and meaningful and occur within a context that gives the individual a feeling of 'psychological safety'. Frith (1989) makes the point that rather than look at deficits in brain function in individuals with autism, it is more relevant to refer to the perceptual sensitivities to incoming stimuli. These perceptions are clearly linked to how children playfully interact with their environment and the ability to internalize and develop an emotional response to an experience, becomes an expression of creativity and a powerful means of communication. Children who are deprived of creative or playful experiences or who are directed too much in their play will continue to relate to the world either in chaotic or rigid and inflexible ways.

What is required is a more holistic approach that views the process of play from birth through to adulthood that understands how the development of imagination emerges through key changes in patterns of thinking. This includes the symbolic interpretation of events and the creative use of objects as well as the ability to engage in pretend and socio-dramatic play. Creative experiences that allow children to consciously and unconsciously represent themselves through their use of sensory materials, narrative and the arts, will influence how they relate to others and in response, how others relate to them. The key components in the development of imagination that are explicitly represented in play and the creative arts are clearly linked to the affective processes that are nurtured in playfulness, spontaneity, creativity and humour. The motivation to explore, experiment and represent that is embodied within the creative process will impact on children's cognitive development and are implicit within an interactive play approach.

The key to the development of playfulness and children's creative and imaginative potential emerges from sharing in their focus of interest and providing opportunities for more authentic communication. Hadley (2002) describes this as 'getting inside the flow of children's play' so that through their actions and awareness they are able to become more reflective and consciously alter ways of thinking about things that are familiar to them. Play, regardless of its mode can be described as a creative act because children are constantly acting upon different experiences and consciously or unconsciously exploring the relationship between themselves, the object and the activity. Evans and Dubowski (2001) describe this as a creative dialogue that results from the child developing the ability to symbolically represent or create something new from what is familiar. Inherent in every individual is the need to create and when this is achieved through interaction, encouragement and spontaneous exploration, they are increasingly able to represent and attach different meanings to their experiences. As an intentional behaviour and non-verbal method of communication, play makes use of symbols that help children to redefine their personal view of the world and understand the actions of others. Symbols emerge through this creative expression and provide shared meanings in which concepts are formed and relationships can develop (Winnicott, 1971).

When children are able to hold on to images from something that is familiar and transform objects and props and even themselves in drama or imaginative play it increases their ability to develop more complex mental connections and to process information 'as if' and act upon it (Thomas, 1997). It is important that children are given support to find different ways to play otherwise they do not develop the flexibility to

extend their learning in increasingly complex and creative ways. Wentworth (2001) believes that any experience that enables a person to become deeply involved and has an intentional goal that involves the merging of action and awareness, provides the foundations for creativity. The ritualised and repetitive play of children with autism can equally be regarded as a highly creative act because it is a representation of their unique perspective, thoughts and feelings about their world. By giving time for the child to reflect on the exploration and manipulation of the play objects that are being mirrored by the play partner, it heightens the child's symbolic understanding and aids the development of the imaginative use of the object. In therapeutic terms this is at the core of the creative process.

Providing the stimulation for more creative acts is dependent upon the individual's curiosity and the intrinsic and extrinsic rewards that are likely to influence how objects and ideas are explored. Creativity also involves elements of risk-taking and challenge that are key to cognitive development and underpinned by the individual's affect and attitude towards the experience. Whilst for many people being creative occurs in isolation from others there are also those whose creativity can be encouraged by the nature of the positive interactional process that is made available to them.

The affective processes involved in play enable children to extend how they creatively represent their knowledge and understanding of the world. Play therefore becomes a social act in which shared meanings can be expressed through language and action. Stories and narrative that are stimulated from children's own experience become an essential component of the developmental process through which they come to learn more about themselves, their culture and their physical world. (Cattanach, 1997). The use of objects and characters in story making also enables children who are less competent in verbal communication to create narratives via visual and tactile play experiences and can include music, movement, drama and the use of puppets. Using a kinaesthetic approach enables children to transform, alter or even repeat situations that can result in an increase in their ability to respond more imaginatively to the shared experience. It is within the safety of the relationship that has been created that they are able to draw on their own interests and experiences to create and invent something new.

Within the context of the mutual experience children with autism are able to increase their confidence in using a range of different media to make representations and develop insight into more complex ways of communicating that are not dependent on language. Jontes (2005) recognises that the ability to communicate creatively through play is clearly linked to the developmental process and their core emotional needs. It involves a visuo-spatial and kinaesthetic intelligence and an expressive and aesthetic awareness that all children have the capacity to develop when given the appropriate experiences.

Conclusion

The use of relationship-focused interventions has highlighted a fundamental shift away from the focus on individual difficulties in social responsiveness, to recognizing how individual family members will have a major influence on the child's social development (Webster et al, 2004). As Gil (1994) points out, parents and carers participating in play enhances their understanding of the play experience for the child and creates the possibility for deeper emotional contact. Dunn (1993) argues that the quality of relationships is not dependent on differences in social or cognitive competence but the extent to which social understanding is used within a relationship. It has been a key theme in this paper that socialisation is not something that is done *to* a child but *with* the child in a complex system of emotional regulation and communication. Interactive play provides a safe therapeutic space where children are able to explore aspects of the self and extend learning and cognition through the dynamic process of discovery and the enjoyment of relating to others.

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0056

MAPPING THE AUTISM SAFARI: AN INNOVATIVE MODEL OF INTERVENTION USING PARENT EDUCATION, COACHING AND SUPPORT

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Autism Spectrum Disorder (ASD) refers to a group of developmental impairments that include autism and Asperger's Syndrome. All of the disorders involve varying degrees of impairment in communication, social interaction and behaviour.   For the families of children with an ASD, the pressing issues often centre on behaviour, communication, socialization and independence. The children are trying their best to adapt to an environment which threatens to overwhelm them, but it is inevitable that some of their experiments will be inappropriate or counter-productive. The family must intervene firmly and thoughtfully to offer the child acceptable ways of meeting his or her needs and learn important skills to enhance their ability to become more fully engaged in all aspects of their communities.

Geneva Centre for Autism (GCA) has developed a comprehensive, outcome based curriculum of education and training for parents. The training is offered in small groups followed by individualized coaching sessions. The curriculum reflects the 10 key features that are common to all Geneva Centre for Autism programs premised on evidence-based practices. These features are individualized, based on assessment and, to the greatest degree possible, involve the person with an ASD throughout the service planning and implementation process. Outlined in the Geneva Centre for Autism Skill Building Model of Service they include:

1. Teach age-appropriate functional skills in context.

Linking skills to their regular and functional use and providing individualized, specific instruction in all environments will enhance capacity for successful community inclusion. Individual motivation is an essential consideration when teaching these skills.

2. Utilize the principles of applied behaviour analysis to increase positive behaviour and teach adaptive skills.

These principles are used to target specific behaviours for change and to teach new adaptive behaviours. Behaviour assessments and positive interventions compatible with the needs of each individual ensure the best outcomes. Positive reinforcement, motivation, prompting, fading, generalization and maintenance of behaviour change are essential components of interventions.

3. Provide structured, routine activities and multiple opportunities for practice.

Incorporate predictable, structured activities to enhance the individual's ability to cope and learn. Many individuals with ASD benefit from direct teaching sessions with multiple opportunities for practice to capitalize on their rote learning strength.

4. Pair instruction with individually designed visual aids and supports.

Because most individuals with an ASD are strong visual learners, visual aids can help to regulate behaviour by providing information, reducing anxiety and assisting with change and transitions. Visual supports are implemented individually, as required, based on initial and on-going assessments.

5. Address sensory processing and motor planning differences.

It is important to recognize and assess sensory processing and motor-planning differences in order to teach self-regulation skills and design environmental accommodations.

6. Teach self-management skills.

Self-management skills (such as relaxation techniques, Social Stories and utilizing daily planners) enable individuals to cope with their disorder by increasing independence, reducing anxiety and building self-confidence.

7. Teach choice-making skills.

It is essential to teach choice-making skills and provide frequent opportunities and motivation for individuals with ASD to make choices. This can build self-esteem, increase attention, enhance communication skills, and encourage learning and serves as an effective behaviour management tool.

8. Teach functional communication skills.

It is essential to teach individuals with ASD to communicate with a variety of communication systems, for a variety of reasons, with a variety of communicative partners, in a variety of situations. Research indicates that an increase in functional communication skills is linked to a decrease in challenging behaviour.

9. Teach social understanding and social skills.

Social skills are a strong predictor of long term outcome and are identified as a priority by individuals and families. The development of social skills and the ability to recognize when and how to use them addresses a primary area of need for individuals with ASDs. These skills can be taught individually and in groups. In order to promote generalization of social skills, individuals need to practice them across multiple environments.

10. Individualize each intervention plan to meet the unique needs of the person with an ASD, family members and other mediators.

Clinical interventions are based on an on-going assessment of the specific needs of each person. The implementation plan must be developed in partnership with the person with an ASD and other mediators. This ensures that the plan accommodates the schedules, resources, skills and commitment of all parties involved.

PARENT EDUCATION, COACHING AND SUPPORT MODEL

Our parent education and training begins with a series of 6 Foundation Workshops. The Foundation Workshops provide parents with essential information to enhance their understanding of the disorder and the ways it affects their child's day to day functioning. The content helps them to begin to see their child from a different perspective. Empowered with this knowledge, they are in a better position to make the right choices for their child and family and to be effective advocates for what is in the best interest of their child/family. All 6 workshops are repeated monthly throughout the year. They are:

- **Introduction to Autism**

Provides parents with an overview of the diagnostic criteria for all Autism Spectrum Disorders-focusing primarily on autism and Asperger's Syndrome.

- **Intervention Options**

Provides parents with the lay of the land in terms of possible interventions that they could investigate as an intervention plan for their child. Evidence based interventions as well as other interventions parents will her/read about are covered. The goal is to provide parents with enough information so that they can make informed choices about interventions they might want to try with their child.

- **Understanding Behaviour**

Provides an overview of the behaviour issues in Autism. The range of possible causes or functions of behaviour.

- **Communication**

Provides parents with an introduction to the communication disorder aspect of the autism disgnosis. It provides parents with an understanding of both expressive and receptive difficulties and an introduction to methods that can assist each.

- **Sensory Motor Development**

Provides an introduction to the sensory differences that many individuals with autism may experience and particularly their impact on behaviour. It provides parents with an overview of motor planning issues in autism and how these may impact on learning.

- **Learning and Teaching**

Includes an understanding of the learning styles of individuals with autism from both a strength and weakness perspective. The session begins to provide parents with the types of specialized teaching strategies that are most effective for individuals with ASD.

Following The Foundations parents participate in our comprehensive service that combines training with individualized coaching for each family.   Based on the most pressing needs for their child and in consultation with the multidisciplinary team, parents are scheduled into one of the four series of training workshops. These are offered in small groups. Families eventually rotate through all four, based on their needs. Each series includes four in-class sessions and two coaching sessions that are covered over an eight week period. The series are:

1. Communication

2. Behaviour

3. Social Skills and

4. Daily Living Skills

We have also developed a parallel series that is specifically designed to address the needs parents of children with Asperger's Syndrome. They include:

1. Communication

2. Anxiety and Behaviour

3. Social Understanding and

4. Daily Living Skills

An outline of the content of each session is provided below:

Each group takes two evening or day in-class sessions at our Centre over two weeks. The parents then take a two week break during which time they receive individualized coaching sessions in their homes. These are followed by another set of 2 in-class sessions and a coaching session conducted in the home or office depending on the preference of the parents.   Ongoing follow up support is provided for maintenance either in an office setting or in the family home as appropriate and needed.

COMMUNICATION SERIES

The training focuses on building skills in parents so that they have confidence in their ability to teach their children to communicate using a variety of communication systems, for a variety of reasons, with a variety of communicative partners, in a variety of situations. Research indicates that an increase in functional communication skills is linked to a decrease in challenging behaviours.

As an outcome of participating in the Communication Series, parents can expect to be able to:

- Give instructions using various prompts (visual, gestured and physical)

- Identify the ways and means their child communicates

- Understand the importance of a "total communication" system for their child

- Understand various augmentative communication systems

- Understand how to "tempt" their child to communicate

The sessions are interactive in nature and use practical strategies that parents can apply right away with their children. The series covers both expressive and receptive communication needs, familiarizing parents with the use and function of the communication assessment tool, augmentative communication systems and goal setting.

BEHAVIOUR SERIES

Parents are taught to utilize the principles of applied behaviour analysis to increase positive behaviour and teach adaptive skills. These principles are used to target specific behaviours for change and to teach new adaptive behaviours. Behaviour assessments and positive interventions compatible with the needs of each individual ensure the best outcomes. Positive reinforcement, motivation, prompting, fading, generalization and maintenance of behaviour change are essential components of interventions.

As an outcome of participating in the Behaviour Series, parents can expect to be able to:

- Identify and define a target behaviour

- Complete an ABC analysis on the target behaviour

- Define the function of their child's behaviour

- Identify ways to structure the environment to optimize their child's learning and prevent undesired behaviours

- Identify effective ways to respond to their child's behaviour

- Determine replacement skills to teach

- Describe how they would use reinforcement to increase desired behaviours in their child.

Activity based training focuses on building skills in parents to enable them to identify and operationally target behaviours, complete an ABC analysis (not to become behaviour analysis but develop skills to understand their child's behaviour). They explore ways to prevent/change a behaviour, how to give instruction, introduce choice, and adapt the environment. Together they problem solve on effective/ineffective responses, what replacement skills to teach, use of reinforcement and appropriate reinforcements for their child. Parents are encouraged to introduce visuals in the child's environment to increase comprehension and decrease confusion and anxiety and accommodate their child's sensory/diet needs.

SOCIAL SKILLS SERIES

Parents are familiarized with the importance of teaching social understanding and social skills. Social skills are a strong predictor of long term outcome and are identified as a priority by individuals and families. The development of social skills and the ability to recognize when and how to use them addresses a primary area of need for individuals with ASDs. These skills can be taught individually and in groups, and are practiced across multiple environments in order to promote generalization.

As an outcome of participating in the Social Skills Series, parents can expect to be able to:

- Identify and prioritize a "social skill" to teach their child

- Complete a task analysis for a particular skill

- Describe the pre-requisite skills needed to teach a particular social skill

- Identify the learning style of their child

- Describe strategies and tools that can be used to teach social skills

- Select effective reinforcement for their child and describe how to use it to teach social skills

- Describe how to maintain and generalize newly acquired social skills

Parents are engaged in problem solving activities to reinforce the various teaching concepts. Parents are trained and empowered to be able to identify and prioritize a social skill to teach, break it down by task analysis into teachable steps, understand the prerequisite skills for that social skill and take a step back if necessary to teach these. Parents are taught how to identify their child's learning styles or strengths, choose tools that will accommodate these including reinforcements and know how to teach generalization of the skill.

DAILY LIVING SKILLS SERIES

The goal is to build skills in parents so that they have confidence in their ability to teach their children age-appropriate functional skills in context. Linking skills to their regular and functional use and providing individualized, specific instruction in all environments will enhance capacity for successful community inclusion. Individual motivation is an essential consideration when teaching these skills.

As an outcome of participating in the Daily Living Series, parents can expect to be able to:

- Identify and prioritize a "daily living" skill to teach their child

- Complete a task analysis for a variety of skills

- Identify their child's learning style

- Describe relevant sensory motor accommodations

- Identify the motor or sensory difficulties that may impede skill acquisition

- Demonstrate effective prompting to teach a skill

- Demonstrate how to fade prompts

- Explain how reinforcement is used in teaching a skill

- Describe some techniques used to teach a skill

- Describe how to maintain and generalize learning

- Identify ways to introduce visual aids into the environment to optimize their child's potential

Once again practical strategies delivered in a facilitative fashion, parents are provided with support in order to build their skills and confidence to be able to prioritize the daily living skill that is most important to work on, learn how to break it down into teachable steps, determine the necessary prompts and tools and identify the types of visual aids that may help. Parents are taught to use visual schedules, choice boards, social stories, first then boards, token boards for reinforcement and the value of generalization.

ASPERGER'S SPECIFIC PARENT TRAINING

As mentioned, Asperger's specific series workshops have been developed to address the unique needs of the children with Asperger's Syndrome and their parents.

ASPERGER'S COMMUNICATION SERIES

The following outcomes have been identified for skill building for parents involved in the Communication Series:

- Describe how communication and learning abilities of verbal ASD individuals are inter-related.

- Describe how social difficulties affect building friendships, coping with bullying and teasing, and understanding the social world.

- Describe various communication intervention options available for their children

The focus is on teaching parents about the communication needs of verbal individuals, building friendships, bullying, teasing, and being able to 'read' others' behaviour.

ASPERGER'S ANXIETY AND BEHAVIOUR SERIES

The following outcomes have been identified for skill building for parents involved in the Anxiety and Behaviour Series:

- Understand the importance of affective education

- How sensory and motor differences impact their child's day to day functioning

- Strategies for reducing stress and teach coping skills

- Understand the link between anxiety, behaviour and anger issues for individuals with Asperger's

In this series parents are taught about affect and recognizing emotions in self and others, sensory differences and sensitivities that effect focus, attention, learning etc. The focus is on self management and learning to control one's own behaviour through adapted anger management techniques and relaxation exercises. Parents develop an understanding the impact of anxiety on behaviour and coping strategies for individuals with Aspergers.

ASPERGER'S SOCIAL UNDERSTANDING SERIES

The following outcomes have been identified for skill building for parents involved in the Social Understanding Series:

- Understand and appreciate the styles of individuals with Asperger's Syndrome

- How individuals with Asperger's Syndrome learn reading, writing, spelling and modifications that could enhance these skills

- Difficulty with social understanding and theory of mind and how this impacts on social communications and interactions.

- Ability to identify intervention strategies to assist with social communication, conversational skills, hidden curriculum and social understanding.

During this series the central focus of parent training is on the next level of social skill teaching. For individuals with Asperger's it is not only important to learn the behaviours associated with socialization and the reasons behind them. Parents learn about Theory Of Mind, the hidden curriculum of human interactions, and other aspects of social understanding.

ASPERGER'S DAILY LIVING SERIES

The following outcomes have been identified for skill building for parents involved in the Daily Living Series for parents of individuals with Asperger's:

- Identify and prioritize a "daily living" skill to teach

- Complete a task analysis for a variety of skills

- Identify their child's learning style

- Describe relevant sensory motor accommodations

- Identify the motor or sensory difficulties that may impede skill acquisition

- Demonstrate effective prompting to teach a skill and how to fade prompts

- Explain how reinforcement is used in teaching a skill

- Describe some techniques used to teach a skill

- Describe how to maintain and generalize learning

- Identify ways to introduce visual aids into the environment to optimize their child's potential

This training is similar to the Autism specific Daily Living Series with altered teaching methods to accommodate the different learning styles of individuals with Asperger's Syndrome.

Central to our Series Workshop training is the emphasis we have placed on ensuring that the sessions are less didactic and more facilitative with a wide range of practical strategies. Group activities and role play sessions are utilized in the sessions to problem solve and aid learning. The focus is on simplifying the concepts and providing practical strategies parents can take home and apply immediately. The small groups allow the consultants to use a facilitative approach to train parents on effective techniques they can choose to implement a behaviour plan or teach a new skill (making sure that they have time, the child is rested, relaxed, receptive to learning, the parents have energy, there are no distractions, the skill is functional, the expectations are consistent, parents are ready to make small changes if the child is not acquiring the skill and above all to make it fun for both). Consultants build in enough time and use a variety of activities and homework assignments to enhance parents' understanding of concepts like extinction burst, why it occurs, strategies for addressing it, the importance of following through, planned ignoring, when one should interrupt, block or redirect. The importance of generalization, maintenance and strategies for ensuring that children can perform without prompts is addressed.

INDIVIDUALIZED COACHING

Parents have told us in the past that the hardest part is taking the concepts from a workshop and figuring out how to put them into practice back at home. The individualized coaching sessions interspersed throughout the training sessions address this difficulty.

After seeing the child in an office setting as part of the multidisciplinary assessment, the first coaching session is always conducted in the home to provide an opportunity for the consultant to see the child in his/her natural environment.

The coaching sessions are utilized to demonstrate the techniques taught in class, and individualize them for each child and family.

Parent training is ongoing as the role play technique is used to support parents in demonstrating mastery of the content covered during in-class sessions. Video taping is also utilized as part of the live coaching sessions. The videos are watched and analyzed with the parents with the goal of integrating the learning and practicing practical implementation of techniques.

FOLLOW-UP SUPPORT

Once parents have completed the Series Workshops, support is provided to ensure that existing skills continue to develop and new skills are acquired. Parents receive this support individually (Clinic service) with a Behaviour Communication Consultant, a Speech Pathologist, Occupational Therapist or any member of the multidisciplinary, team as appropriate. Group service is provided as part of follow up support as well for families who may be dealing with the same issues.

OUTCOMES

The benefits of this model that combines small group parent training, individualized coaching and support have included the following**:**

- Increased understanding of the disorder

- Parents knowing empirically the child's abilities and difficulties

- Ability to teach different skills

- Direct parental involvement in selecting target behaviours/skill areas for intervention

- Training is more relevant to home environment and community

- Enhanced maintenance and generalization of gains made

- Increased sense of control and self-efficacy

- Improved interactions with their child

- Improved family functioning (happiness, stress, interest and communication style).

- Prevents the development of more severe problem behaviours

- Opportunity to network and share experiences.

Studies have shown that parent training is effective whether done individually or in small groups. Our model combines the power of both. It is tailored to Autism Spectrum Disorders and the multidisciplinary team ensures that it is considered in the context of family issues and the larger context of services the child/family is receiving. Parent feedback has confirmed the value of learning with and from other parents who have children with similar needs and or abilities. As a service delivery model it meets the Centre's goal of providing more comprehensive training and support and more interaction to more families in an efficient and cost effective way.

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0058

HURDY GURDY, A SONG OF LOVE

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Introduction and Background

My son was born in April 1990. Like all first time mothers, I fell deeply in love, and what follows is the consequence of that event. In his puny, peri-natal state, Donovan had a way of fixing you with his eyes, locking you into his deep, violet pool of space. At times I felt almost intimidated in his presence, as though he knew things that I couldn't even begin to phrase. But mostly I was caught up by a deep emotional bond that replaced the umbilical cord, but which continues to work in much the same way. Without support in this life, Donovan will not survive. This is the story of a 'life support machine' for Donovan and others like him.

As Donovan grew from babyhood into a toddler, whilst not apparent to me, I became aware that 'significant' others in his life experienced a lack of cuddliness or connectedness, when they attempted to pick him up or interact with him. He had a lump-like quality in the arms if scooped up unexpectedly, and a tendency to appear deaf, while being extremely active, fearless and independent, sometimes alarmingly so! When I observed other mothers, I noticed their toddlers stayed close by, checking periodically that their moms were within sight. Not so Donovan, once decided, he would head off in a certain direction with a Forest Gump like determination, without a backward glance. By the time I was pregnant with my second child, Donovan's behaviour had become unusual enough to warrant investigation at the local childrens' hospital. By the time he was two and a half, he had been diagnosed with pervasive developmental disorder. There followed a period of trying a variety of schools, ostensibly set up to cater for disabilities like his, but none seemed to be able to assist, particularly when taking into account the needs of the family as a whole. I was a single, working mom, with two children. We were all struggling to cope with Autistic Spectrum Disorder. Eventually we found Camphill School in Hermanus, Western Cape, where Donovan settled well, between the ages of six and eleven. It was a happy, serene place with caring and dedicated staff, committed to creating an inclusive lifestyle for people with intellectual disabilities. However, there were two drawbacks. Donovan was away from home for long school terms and then home for long holiday periods in between. Both stretches seemed too long. Holidays became extremely difficult to manage. Secondly, it would not be a place where Donovan could remain beyond his school years. I needed to make a plan for his future.

Investigations (in 2000) showed that facilities for youth and adults with intellectual disabilities in South Africa were limited. Facilities specifically for youth with intellectual disability, and potential for anti-social and challenging behaviour, were virtually non-existent. Most facilities had a strict code of conduct, which, if breached, would lead to the resident being required to leave, thereby creating constant stress for families, with regard to future security of their loved one. Very few facilities for youth or adults would accept someone who was both active and not toilet trained, and with a penchant for spreading his own faeces.

People with autism are, in many instances, excluded form the few residential facilities for learning disabled adults on account of their specific needs for an environment that is sympathetic to the nature of their disabilities. The nature of autism as a disability imposes major demands on the way a home is set up in terms of routines, communication processes, physical structures and access to expertise, to cope with this demanding and puzzling disorder. While the facilities for children with autism in South Africa are extremely limited, they are far superior to those available to children once they leave the

confines of school. Aging parents find themselves increasingly unable to cope with the physical and emotional demands of their adult autistic children. The only options have, until now, been state psychiatric hospitals, which are not geared to meet the needs of adults with autism, and hold the fear of abuse and neglect often associated with large institutions. Behavioural problems usually worsen in such environments, making it less likely that long term patients will ever be accepted into another placement, should one arise. Years of painstakingly won gains, in terms of improved quality of life for people with autism are lost, when they find themselves placed into an environment that must seem overwhelmingly arbitrary, after the familiar and sympathetic structures of their school days.

The current policy of the state health departments is to de-institutionalise all except those who require hospitalization due to ill health. This is generally a laudable and positive approach but one that does not recognize autism as a life long disability that may require substantial infrastructural support to create an environment within which people with autism may experience some quality of life. There is currently no state support for providing such infrastructure in the form of community based homes.

With the support of my partner, I decided to set up a home which could cater to the changing needs of a person with Donovan's condition. A place which could become home for him, where he would be safe, both physically and emotionally (i.e. a place that would continually endeavour to understand his world, rather than vice versa) and where he would enjoy 'safe and secure tenure'. We turned to Donovan (1960's folk/rock singer) for inspiration, and were captured by the images conjured in the gentle, haunting tune of his "*Hurdy Gurdy Man*", who "comes singing his songs of love". Our home was to be called Hurdy Gurdy House, a name appropriate in its association with constant change and movement, as well as, hopefully, a song of love.

Aims and Objectives

Our aim was to provide a permanent, community based, non-institutional home for people situated on the autistic spectrum disorder. Our vision was that the home would provide a space for people with autism, and severe social difficulties, to develop as fully as possible within an environment adapted to suit their needs.

There are three main objectives for Hurdy Gurdy House:

a) To enable residents to live lives which are as fulfilled and developed as possible within an environment that is loving, safe, secure, constant and nurturing.

b) To enable families of the residents to share as much as they are able in the lives of those disabled persons and to provide peace of mind for families that their members are safe in a secure and permanent facility.

c) To develop and train staff to care for persons with autism in a residential facility, and to encourage these staff to reach their full potential.

Methods: How we started

We spent the best part of a year (2001) exploring different options, visiting other homes and facilities, and looking for suitable premises. A small group was constituted as a reference group (i.e. sounding and steering board) for the development of the home, as we had no previous knowledge or experience of this territory. This group consisted of staff from the Vera School for learners with autism, and others from the (then) Society for Autistic Children of the Western Cape, as well as family of another youth with autism. We had begun to make contact with other families who were interested in the concept. These families confirmed our view that there were no residential facilities set up to cater for persons with autistic spectrum disorder, once they were beyond school going age.

We found premises, borrowed money, bought a house, advertised for staff, renovated the house to make it safe (including safety glass and burglar bars), informed the neighbours, fenced the pool, contacted the authorities about rezoning (to be allowed to house more than five residents), found a lawyer who assisted with the rezoning, attempted to register with social services, invited the local health inspectorate to visit, sent emails and letters to people informing them of what we were doing, pondered over specifics such as staff shifts, staff training, budgets, contracts, enrolment forms, policies for the home, setting up a Trust to oversee the home, applying to become registered as a charity, etc. Later we were to discover the need for pay slips, procedures to pay taxes, unemployment insurance, staff records, grievance procedures, keeping records of meetings, developing an ever-growing host of policies and procedures, obtaining tax-exempt status, and developing funding proposals.

We chose to locate HGH in Penhill, a semi-rural suburb on the outskirts of Cape Town, where the pace of life is a little slower than in the suburbs closer to the city. Penhill still has dirt roads, minimal traffic, no street lights, no water-borne sewerage and access to vineyards for recreation (walking, horse riding, cycling and swimming). Having lived for some years ourselves in Penhill meant that our neighbours were already partially exposed to ASD through their interactions with Donovan. Also, although removed from the centre of Cape Town, the area has good shopping facilities nearby as well as reasonable access to public transport.

The premises comprise seven bedrooms, one double staff bedroom with en suite facilities, 2.5 further bathrooms, an outside laundry, outside staff quarters, an outbuilding for therapies/activities, a large swimming pool and garden. The house could originally accommodate a maximum of six residents, plus two to three sleep-in staff. We subsequently converted an extra room into a bedroom, allowing us to accept another resident. We estimated a need for eight care giving staff, allowing for back-to back shift work.

It became clear that this could not be done without some outside financial assistance. We approached the provincial departments of Health, Education and Social Services, to discover that this was a road that would take many years. We received support and encouragement from Autism South Africa, as well as

financial assistance to renovate the house prior to the arrival of the first residents. The Society for Autistic Children of the Western Cape (now Autism Western Cape) contributed generously to keeping us running for most of our first year.

Hurdy Gurdy House opened its doors in November 2001 to two residents with autism. The staff consisted of live-in house parents, and two additional caregivers. By early 2002 we had five residents, boys ranging from eleven to twenty-three, and a young woman in her twenties. Now (2006) we have seven residents (all male) and a staff complement of nine, including a house manager who lives on the premises. Two residents are partially sponsored, the rest are fee paying.

Our experiences

We endeavour to have a daily routine embedded in the cycle of life at HGH. This programme is based on the TEACCH principles, including providing visual cues to daily activities and sequences of events. The programme includes walking, swimming, riding and other physical activities, as well as gardening and participation in household chores. Crafts and self help skills also feature, and popular weekly events such as regular *braais* (barbecues) on specific days of the week. Birthday celebrations, picnics and occasional outings to the beach are special treats. Some residents have had the opportunity to be included in sheltered workshop activities (nearby) where appropriate. There is a small farmyard and feeding and cleaning of cages forms part of the daily routine for some residents. It has been extremely challenging to get a daily routine consistently implemented at HGH. Part of the reason for this is the lack of time and resources to spend on staff training, as well as co-ordination across shifts. Ideally, training should be implemented at the home, so as to make practical sense of the theory of the chosen program.

The program implementation is heavily dependent on the training and dedication of the staff. Hampered by limited funds, human resource management has become our most difficult task. Attracting, training and retaining dedicated and capable staff in an environment where few are available and the demand is growing, is a constant struggle.

We are fortunate to currently have a trained psychiatric nurse, with many years of experience in caring for people with low functioning autism, who manages and resides at the home. Most of our caregivers

have generally not been exposed to autism, or care giving, when joining us and require a five week period of orientation and training (in which time they shadow other staff members and receive induction from the manager).

We endeavour to constantly build on the skills of our staff; some examples of training which has been offered include:

- Calm and Safe Training from Sussex Autistic Trust (intensive workshop)
- Calming and Restraint training from Christine Goldstone from Owl Housing, UK (one week's in-house training)
- Assistance in program development (using TEACCH) by staff of Alpha School for learners with autism
- TEACCH training provided by AWC and ASA (ongoing)
- TEACCH training and general autism awareness by Margaret Golding
- Time spent observing and discussing with teachers and carers at Camphill School in Hermanus
- In house training in Applied Behavioural Analysis from a Masters student in Applied Behavioural Psychology from the University of California who stayed for a period of three months at Hurdy Gurdy House
- St Johns Ambulance First Aid courses at Hurdy Gurdy House (evenings)
- Child and Youth Care Workers Certificate courses (part-time)
- In-house training and advice from staff of Vera School
- Attending Occupational Therapy sessions at Alexandra Hospital in Maitland
- Visits and discussions from occupational therapists and psychologists from Alexandra Hospital
- Fire fighting training
- Managing the aggressive person with intellectual disability (Two day workshop offered by Western Cape Forum for Intellectual Disability)
- First aid level one (practical and written) presented in Xhosa by the SA Red Cross society.
- Gardening course at Brooklyn Chest hospital through Stone Dragon (voluntary association centre for practical survival through entrepreneurial skills)

While volunteerism is still a relatively new concept in South Africa, we have been fortunate to have benefited from excellent volunteers, from England and Germany, and have also had excellent service from local youngsters in our community. We are very fortunate to have a very good working relationship with the nursing and medical staff at Alexandra Hospital, who have been very supportive in assisting where possible with medical advice and assistance.

Residents:

Initially Hurdy Gurdy House opened with two residents (J and DW), joined shortly afterwards by Donovan, and A, all of whom are still resident at HGH. L was the next resident to join HGH and the only female to date. She unfortunately left us at the end of 2003 to immigrate with her family to the UK. We have had two other transient residents: D, who spent about six months at HGH, was considerably higher functioning than the other residents and eventually left to stay in the care of his mother. W, a youngster from our local community, was also placed at HGH for about six months. His family were only able to cover about a quarter of his fees, and he relied on subsidization from the general fundraising for the balance. This proved to be unsustainable and we were forced to ask his family to find alternative arrangements, which was very disappointing, as well as traumatic for the family. At the end of 2004 we were joined by M (partially sponsored) and G, and more recently by WW who is partially sponsored by National Lottery funding. All residents are males, mainly due to the preponderance of males within the spectrum. They range in age from 16 to 28; three are verbal, and one is deaf and mute in addition to his autism. Four are on chronic medications to control behaviours associated with ASD.

We have an Admissions Policy that stipulates that all prospective residents will be subject to a three month trial period which may be extended. The decision as to whether or not a prospective resident will be admitted is made by an admissions committee consisting of Hurdy Gurdy House trustees or persons nominated by them.

Whilst Hurdy Gurdy House caters mainly for those on the Autistic Spectrum, residents with other diagnoses may be admitted (up to 25% of residents) provided that they fit in with the other residents in the home and that their admission is compatible with the broad objectives of the home.

There is currently a waiting list for places at Hurdy Gurdy House. The plight of families struggling without assistance to manage is heart rending. The vast majority are single female headed households, most of whom would be unable to afford the fees even if a place should become available. There are currently no other residential homes specifically set up to manage people with autism and challenging behaviour in the Western Cape, and HGH receives weekly calls for help from families and social workers who are desperate to find placements.

Governance and Legal Structures

Hurdy Gurdy House is constituted as a charitable Trust, in which annually elected trustees have an oversight role to ensure that the Trust fulfils its objectives (as spelt out earlier). The trustees also exercise overall financial accountability for HGH and ensure that a set of annual financial statements are audited and an AGM is held. They also and appoint the management committee to act on their behalf.

The day to day running of the home is the responsibility of a House Manager (Mon to Fri). The house manager manages two teams of four caregivers each, working back to back shifts. The Management Committee (currently consisting of parents) oversees and supports the management of the house. Fig 1 shows the current reporting structure of management in HGH, which is, however, under review, and suggested changes will be presented at the next AGM. All parents and trustees work in a voluntary capacity.

Figure 1: Management Structure of Hurdy Gurdy House Trust
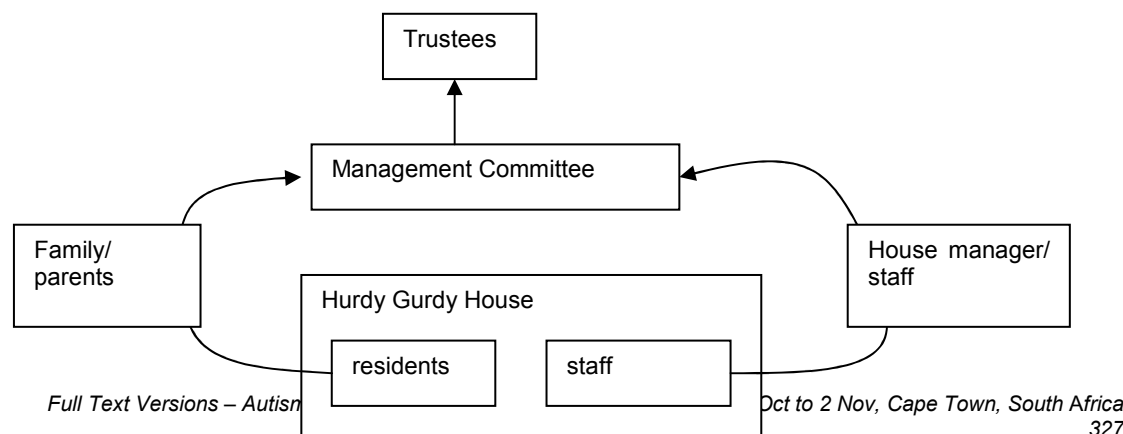
It took about two years for the Trust documents (deed and constitution); the non-profit organisation (NPO) and public benefit organisation (PBO) status of HGH Trust to be finalised. Before obtaining these documents it is difficult to undertake fund raising activities.

Budgets and Fundraising

At present Hurdy Gurdy House is without any financial support from government. Our annual expenditure is close to half a million rand, 55% of which is on direct staff costs. Roughly 30% of this

needs to be funded through our own fund raising initiatives; the rest is covered by fees paid by the residents/ their families. Meetings have been held with the Departments of Social Services and of Health, to attempt to secure state funding. It is apparent that HGH falls within the ambit of the Department of Health, and despite the fact that a number of our residents are potential (and previous) occupants of beds at psychiatric hospitals, and that simple maths would indicate the savings involved in supporting group based community homes (cross-subsidised as they are by fee-paying residents), we have not yet had the benefit of government support. We have been grateful to receive support from the National Lottery which has enabled us to offer a sponsored place at Hurdy Gurdy House to a person with autism, from a disadvantaged family. This funding has also assisted in upgrading the skills of our staff with further training. However, administrative delays in payments and lack of information and communication with grantees, have made National Lottery funding a tenuous route for ourselves and many other charities, without access to large (or even moderate) financial reserves.

We have been extremely fortunate to benefit from many generous and kind people adopting HGH in many different ways. A huge support from Prof George Ellis, 2004 winner of the Templeton Prize for Science and Religion, has meant that HGH has been able to survive.

We received a sizeable donation from Mrs Mary Ellis. Autism South Africa have regularly supported HGH with grants and donations, as have organisations like Syringa Trust. National Lottery awarded us a grant for training staff, and towards funding a bursary for a disadvantaged family, in 2004. To date they have only paid over half of the promised money, which has put us under severe stress, having accepted a bursary student whom we now need to carry, until the grant money is paid to us.

We have also been the recipients of ongoing, regular monthly contributions from a couple of kind families and individuals. This continued support is extremely heartening and we hope to grow this as a future support base. Support from local newspapers who have put us in touch with various volunteer groups, including a church youth group who have supported us with work parties at HGH and taking our residents on outings. We have also been supported by both Round Table and Rotary organisations.

Apart from a part time bookkeeper who receives an honorarium, Hurdy Gurdy House does not employ any persons that are not directly involved with caring for the residents. All other administrative and oversight work is done by volunteers.

Ongoing challenges

Our largest challenge remains human resource management, particularly staff recruitment, support and training. This area has become a minefield, both in terms of compliance and burdensome paper work, as well as the challenges of bringing out the best in our staff which are also our biggest asset. Security of tenure remains another challenge as the Trust has no assets and rents the property on the basis of a long lease agreement. The lack of a vehicle also hampers the smooth running of the home. It is a constant source of concern that there is no immediately available vehicle in case of an emergency, and that all shopping (in all weathers) is done on foot or with the help of kind neighbours.

The establishment of this residential facility has been extremely challenging and it cannot be sustained in its present form. For individual parents to take sole responsibility for managing an operation as complex as this, in a voluntary capacity, is neither desirable, nor feasible. Besides funding, I would claim that the primary issue is one of capacity. A facility such as HGH should ideally be managed, or at least capacitated, by the state. Such support or capacitation would include: assistance with staff training; benchmarking; subsidised municipal services; health and hygiene support from community clinics; educational program support from local special needs schools; assistance with fast tracking registration of facility with the necessary authorities for the purposes of oversight; assistance with compliance for labour laws; waiving of red tape in bringing in volunteers from overseas; assistance with legal and insurance issues; and many others, apart from direct financial subsidisation.

Most, if not all, of our residents have been excluded from one or more facilities for the disabled. Our dealings with provincial government departments have led us to the point where the state

acknowledges its responsibility, but still does not make funds or assistance of any kind available. We have held discussions with the departments of Social Development and Health since 2003, and have been attempting to register with the Department of Health since December 2004. After a lengthy (and largely one-sided) process we were informed in July 2005 that there is unfortunately no money for any new homes to be subsidized.

The service levels we have received from the South African Police Services (in dealing with theft and other more serious charges) and the department of Labour (in attempting to comply with the labour laws without incurring the costly assistance of a labour lawyer) have been utterly dismal. It took the South African Revenue Services more than twelve months to process our application for Public Benefit Organisation status. Many donors require a PBO certificate in order to qualify for tax exemption. Poor service of this kind places additional burdens on micro enterprises, already struggling to survive in the increasingly sharp, slick and competitive world of non profits. The legislative and bureaucratic burdens placed on small non-profit organisations can be crippling.

Future of HGH

Future developments at Hurdy Gurdy House will depend very much on our ability to secure funding.

It is vital that the home start to function in a way that is more independent of parents. With regard to this, the Trust is currently in discussion with Autism Western Cape with regard to the possibility of their playing a leading role in the management of the house in future. We are hopeful that introducing professional management, as opposed to parents operating in their "spare time", will greatly improve the service that this small facility has to offer.

It is hoped that our learning experiences Hurdy Gurdy House will be a platform upon which can be built many other such community based, small group homes for persons suffering from a condition which cripples not only the individuals if they are left to suffer in inappropriate facilities, but also their families, who struggle with an enormous burden of care. More homes are needed so that mothers of special children can rest in peace, and know there is another umbilical cord to take over when they are no longer here to come singing their songs of love.

0060

POSITIVE BEHAVIOUR SUPPORT IN APPLIED SETTING – STAFF TRAINING AND IMPLEMENTATION FACTORS

G Martin

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A History Of The Callan Institute

Springing from the Christian values and holistic approach advocated and practised by its founder, the Hospitaller Order of St. John of God is dedicated to the provision of social, educational, welfare and health services. It has a mission to ensure that persons availing of its services receive the highest quality care, education, training, treatment or assistance in accordance with their needs. It does this taking care to embrace the values of Compassion, Care, Respect and Hospitality (Hospitaller order Of St. John of God, 1988).

In 1994, St. John Of God Hospitaller Order commissioned a study to look at how episodes of Challenging Behaviour were dealt with in within it's services. As a result of this study, The Callan Institute for Positive Behaviour Support (2006) was established using a model adopted from The Institute of Applied Behaviour Analysis in Los Angeles (2006). The Role of the Callan Institute is to promote the use of these effective, non-aversive methods for working with people who have an intellectual disability behaviours that challenge so that they can enjoy community participation with satisfaction, dignity and respect.

Services provided include Behaviour Support Plans, Positive Futures Planning, Systematic Instruction, Crisis Intervention and Periodic Service Review. These services are provided through individual consultation, staff training, and regular support to staff who implement Behaviour Support Plans within the Order's Services. A 1995 report showed that St. John of Gods were providing services to approximately 1,493 service users, primarily located along the East Coast of Ireland. Between 224-420 of these service users were estimated to have behaviours that challenge at that time (see Figure 1 & 2 below) (McClean & Walsh, 1995). St. John of God Services primarily serve people with intellectual disability and now support in excess of 2,940 service users. It is unclear how many of these men and women may carry a diagnosis of an ASD if fully assessed. Recent studies suggest that current prevalence rates in Ireland are approximately 60 in every 10,000 births (Fitzgerald et al, 2002), which translates to 363 births per year (Central Statistics Office, 2002).

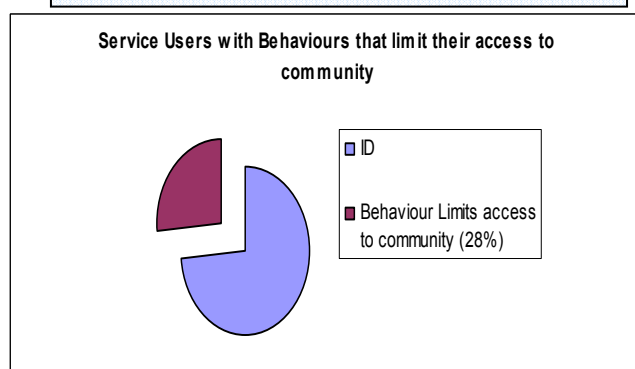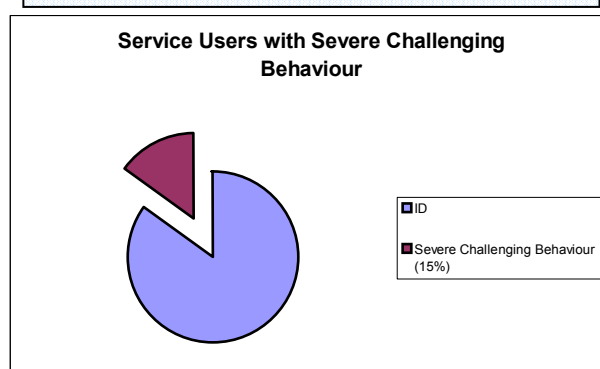| *Figure 1: Service users with Behaviours that Limit their access to ordinary community facilities (Approx 420)*	*Figure 2: Service Users with Very Severe Behaviours that Challenge i.e. tissue damage to themselves or others within the last 3 months. (Approximately 224)*

Service Users with Behaviours that limit their access to community

- ID
- Behaviour Limits access to community (28%)

Service Users with Severe Challenging Behaviour

- ID
- Severe Challenging Behaviour (15%)

1. Positive Behaviour Support Model:

The model of Positive Behaviour Support (PBS) that has been used by The Callan Institute is 'Multi Element Behaviour Support' (MEBS) which originated from work by Donnellan et al (1988). Figure 3 below outlines the main features of the model. It is based in a functional assessment. This information is then used to develop a behaviour support plan that deals with proactive and reactive strategies. It then examines the context or support systems in which these strategies are to be implemented, and finally looks at a range of outcomes for the individual service user. MEBS is ideally suited to the needs of individuals with Autistic Spectrum Disorders, as it provides the flexibility to accommodate existing ASD specific programmes, such as Picture Exchange Communication Systems (Skills teaching); TEACCH Strategies (Direct Interventions) or specialised dietary programmes (Environmental Accommodations).

Figure 3: A Model of PBS – Multi Element Behaviour Support

↓　　　Assessment & Functional Analysis

Proactive			Reactive
Environmental	Skills Teaching	Direct Interventions	
•Setting •Interactions •Activities •Choice •Variety	•General skills •Functionally equivalent skills •Functionally related skills •Coping & tolerance skills	•Reward no behaviour •Reward low rates of behaviour •Reward alternatives •Co-operation training •Satiation	•Ignore •Redirect •Feedback •Instruction •Facilitate •Stimulus Change •Active Listening •Crisis Intervention

↓

Support Systems

↓

OUTCOMES					
Speed & Degree of Effects	Generalisation	Maintenance	Side Effects	Quality of Life	Social Validity

Functional Assessment:

In the functional assessment, a thorough case history and observation of naturally occurring opportunities are used to establish what purpose the communication is serving for the person. Once the function of the behaviour is established, we are better placed to try to meet those needs in a more efficient, dignified and appropriate way (Carr et al, 1999).

Proactive Supports:

Proactive Supports are designed for use *prior to behaviours occurring.* They include Environmental Accommodations, Skills Teaching Strategies and Direct Interventions. Environmental Accommodations are steps that we can take to alter and improve the physical, interpersonal or programmatic environmental so it suits the individuals' needs more closely.

Skills teaching strategies seek to give the person functional, useful skills that will improve their quality of life and enable them to communicate their needs more effectively. This element incorporates the Functionally Equivalent Skill, or skill which is designed to directly communicate the same function as the target behaviour (Donnellan et al, 1988). Direct interventions are strategies whereby behaviour is brought under control quickly and effectively using contrived behavioural strategies such as reinforcement schedules, stimulus control and satiation (Cooper, Heron & Heward, 1987).

Reactive Strategies:

Reactive Strategies are the actions taken *while a behaviour is occurring.* These are designed to be non-aversive strategies such as active listening, redirection, facilitation, instruction, feedback or stimulus change. In extreme cases of high risk of injury to self or to other people, a person might require certain restrictive reactive strategies, for example the administration of a PRN medication, restraint or the loss of a privilege. These must be carefully and ethically designed and used only by fully qualified professionals if, and only when, *all* other proactive strategies have been tried and been proven to be ineffective. In addition, the particular restrictive strategy proposed must be proved to be effective and justified (Chance, 1998). For

most behaviour support plans, if these latter stages of reactive strategies do have to be employed, they quickly become redundant as proactive strategies are implemented and staff become faster and more effective at intervening when behaviour does occur.

Outcomes:

Traditionally, success in behaviour support methods has been assessed by measuring the reduction in behaviours displayed by the person. This model expands the outcomes examined to include Quality of Life Indicators; indications that the results of behaviour support have generalised to other settings, people or behaviours; measures to see if benefits of behaviour support can be maintained over time; monitoring and looking for reduced use of restrictive procedures (for example time spent in restraint or PRN medication administered) and Social Validity, or how acceptable the treatment strategies are to those receiving them, their families and circles of support. Examining this broad range of outcomes ensures a holistic, dignified approach of support for the service user.

2. Particular Case Training

The Specialist Model:

Given the size of the Orders' services across Ireland, the traditional 'specialist' model of delivering behaviour supports was felt to be insufficient. With the specialist model, resources are typically focused on a specialist team, who after designing and perhaps initially implementing a plan, withdraw from that case and move on to the next referral. Alternatively, these specialists resources may be focused on a treatment unit, where after assessment and initial treatment, the person is discharged from that unit back to their home, where supports may not be as structured.

The number of specialist required to design, deliver and maintain supports to the estimated 450-840 people requiring supports (pro-rated from McClean & Walsh, 1995) would be impractical given current resources in Intellectual Disability Services in Ireland. In addition, indicators of length of stay show that the specialised assessment or treatment units tend to become long stay units very quickly and throughput of service users is minimal (Newman & Emerson, 1991). Finally, for those service users who are discharged back to their home environment where the appropriate supports are not in place, behaviour can quickly return to baseline.

Research (McClean et al, 2005) indicates that supports designed by people working directly with a service user are just as effective as those designed by specialists, if they are designed with appropriate training and under clinical supervision. The interventions are *more* likely to be adhered to if the plan is designed by the service user's existing circle of support, rather than by a 'drop in' specialist. In addition, the service user is much more likely to benefit with the supports being put into place in their natural environment and becoming part of their every day lives rather than having to adapt to reduced supports later on, as may happen with the specialist model (Hoefkens & Allen, 1990)

Particular Case Training:

For this reason, The Callan Institute has employed the model of 'Particular Case Training' for PBS (Dench, 2005). Using this model, a participant undertakes 9 months of training with The Callan Institute with 9 lecture / contact days. Here, they learn about the functions of behaviour, how to conduct a functional assessment, how to design supports and how to implement these supports in context.

In between contact days, participants apply their new skills with a service user in their workplace under the clinical supervision of The Callan Institute, mentorship of a local contact trained in PBS and management supervision from their line manager. It is assessed through a mixture of academic tasks and practical casework which in multi media format such as video, verbal presentation, role pay, written submissions and by supervisor feedback of performance in the workplace.

This course is run in collaboration with the Dublin Institute of Technology (2006), who in 2001 agreed to award graduates with 5 ECTS (European Credit Transfer System) at Masters Level. In addition, the Psychological Society of Ireland now awards Continuing Professional Credits for attendance, so the course is recognised as adhering to best practice for Behaviour Support. Outcomes of training are evaluated in three main ways:

1. outcomes for the individual

2. outcomes for the participant (taking part in the training course)

3. outcomes for the Organisation.

Individual Outcomes:

Individual outcomes are currently measured primarily through looking at changes in rates of behaviour, although plans are underway to more formally capture the other outcomes described in the model above. Results are shown below in Figure 4 (McClean et al, 2005):

Figure 4: Category of Behaviour Change Relative to Baseline:
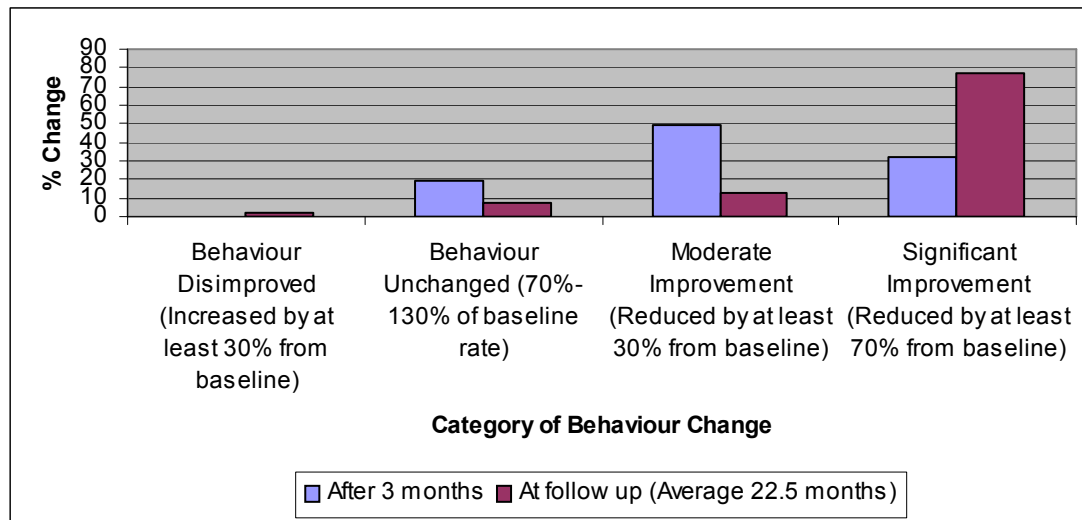
Participant Outcomes:

Participant Outcomes are first measured by looking at their satisfaction ratings (96% of participants rate the course as 'very interesting' on a scale of 1-7; 94% of participants rate the course as 'very relevant to my work' on a scale of 1-7). The knowledge acquired is then assessed. Successful graduates must attain a score in excess of 85%. This can be broken down into component areas as shown in Figure 5 below.

Figure 5: Participant Competencies (Pass Rate = 85%)
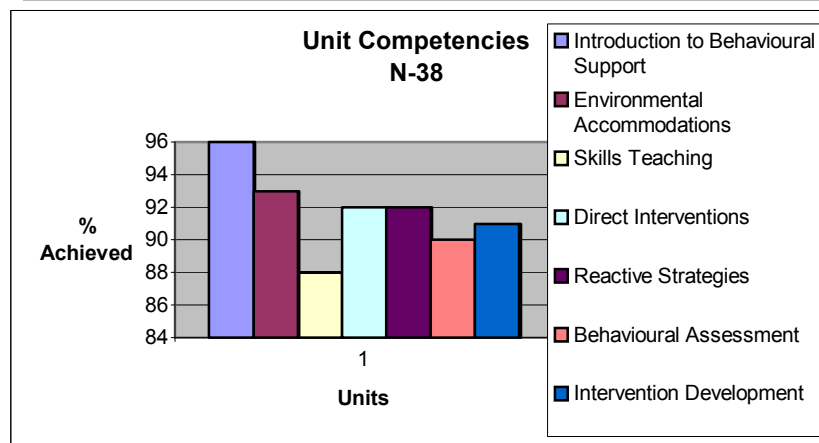
There is also evidence that staff attributions change as a result of this particular training, which in turn can affect their on-the-job performance. Trained staff are more likely to invest more energy and time in attempting to understand the function of a behaviour and to affect behaviour change rather than merely attending to behaviour management (Gordon, 2005).

Measuring the impact of training on staff knowledge and practice is key to developing self sufficient behaviour supports within a service. In order to evaluate this, a research project is currently under way. Using The McKenzie Assessment of Student Knowledge (2001), A Reaction Questionnaire and evaluating the Portfolio of Students Competencies, the aims of this research are as follows:

1. Measure Pre-Post Questionnaire to assess knowledge change

2. Measure Reaction Questionnaire to assess participant satisfaction with input style

3. Examine student portfolio to assess quality of work across content and input areas

4. Qualitative analysis of data to look for novice/expert differences in use of language pre/post training.

Organisational Outcomes:

The Organisation also obtains benefits from this format of training. The primary benefit is the availability of knowledge *on-site* and that it is readily available. This significantly increases access to behavioural services for service users and the speed of response with which interventions can be put into place. Indeed, with the skills that staff have acquired, a formal behaviour support plan may not be required in some cases where staff have developed skills to automatically respond more appropriately to people's needs and to intervene early with behavioural issues. This also reduces costs for an organisation with relation to the formal clinical input required. McClean (2005) estimates training costs of providing PBS through particular case training to be €1,160 per capita, compared to the costs of providing these supports through specialist services, which he costs at approximately €4,740.

3. Maintenance of Behaviour Support In Services

Several keystones are vital in maintaining PBS in services. These include the use of an effective quality assurance tool like the Periodic Service Review (LaVigna et al, 1994), staff appointments with protected time to conduct and manage behaviour supports within a service, ongoing training, a top down commitment to PBS and a bottom-up culture of PBS.

The Periodic Service Review:

The Periodic Service Review is both an instrument for assessing the quality of a service and a system for maintaining quality improvement over time As a system of self-management, it is proactive and non-aversive, leading to realistic goal setting and improved morale among staff teams. It operates by listing the vital ingredients in maintaining behavioural supports as performance standards. These include all the interventions designed specifically for the person who is being supported, and the team and organisational supports required for effective PBS. Implementation of each of the requirements is checked (0 / -) and the percentage of performance standards in place is represented on a graph. In this way, implementation of behaviour support can be represented and directly compared to its effects on a service users' behaviour. A hypothetical example is shown in Figure 6 below.

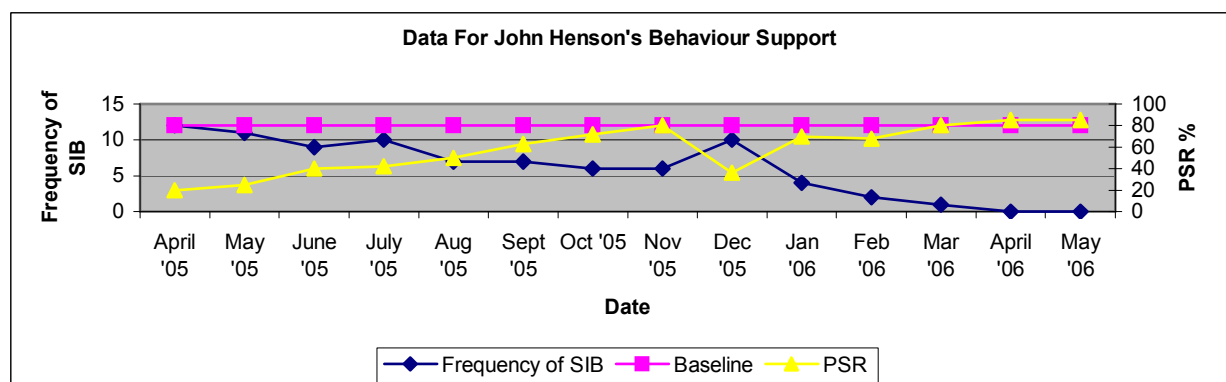**Data For John Henson's Behaviour Support**

Figure 6: A Sample of A Periodic Service Review Score with Behavioural Frequency:

Ongoing Training

Although the Particular Case Training Model has been proved to be very effective in designing and implementing effective behaviour support plans (McClean et al, 2005), additional training resources are vital for their generalisation and maintenance. To this end, the Callan provides additional training.

Of particular use are Introductory Workshops in PBS. Primarily, these are intended for the wider circle of support of the service user who is receiving behaviour support. It allows staff and family members to explore the values and principles of PBS. In turn, they can better understand what is going on and why,

when an assessment is being conducted, and so can become more involved in the process and support the person conducting it. Introductory workshops are often conducted over a 1, 2 or 3 day duration (The Callan Institute, 2006).

For staff who have already completed the 9 month PBS Course, refresher training is provided to update skills and to provide support for graduates to take on further assessments in their workplace. With staff turnover, it is often the case that a staff member who originally wrote a behaviour support plan no longer works directly with that particular service user. In this case, Keyworker Workshops can be very effective. This is a brief courses run over 3 half days, which imparts the skills required to re-evaluate the function of the behaviour and to get the behaviour support plan up and running again if maintenance has lapsed.

Supervisor and Mentor Workshops are provided to impart the skills to effectively support staff as they work with people who require behaviour supports. In addition, specific training needs are addressed on an as needed basis. Examples of workshops conducted over the last year include Augmentative Communication, Autistic Spectrum Disorders, Supporting Children in Foster Care, PBS in the Classroom, Working with the Elderly, and Systematic Instruction.

Top Down Commitment

For effective PBS to take root, there has to be commitment to the principles and values throughout the service. This ensures that the culture of PBS can be established, so that these ways of interacting with people permeate to all service users, staff and families. Some ways in which this can be established from a top down approach is to ensure that Directors and Service Managers are trained in PBS. Clinical teams also require intensive training in PSB in order to be able to support front line staff in the design of behaviour supports. This reduces the workload of the individual clinician, and ensures that appropriate clinical supervision is available to staff. PBS encourages and requires an interdisciplinary approach.

Management of data is also a crucial aspect. Without developing structures of accountability and regular reviews, maintenance is unlikely to occur, particularly once a particular behavioural crisis is over. A particularly effective way of encouraging regular review is to incorporate behavioural reviews into existing structures of review, such as Individualised Education Plans or Personal Outcome Measures (Council on Quality & Leadership, 2005).

Effective, proactive use of incident reports is also vital for good behaviour management in a service such as identifying patterns of behaviour, service user needs, staff training requirements or organisational changes that may need to be effected. It is also essential that staff who complete these incident reports receive feedback from supervisors in a timely manner to check on their well being after an incident, to feedback on any restorative action that is being taken and to emphasise the value of this information and so encourage continued submission of incident reports.

Bottom Up Commitment

Again, the Culture of PBS needs to permeate throughout the whole system to ensure that its values and principles are employed in everyday interaction. Way to achieve this are to ensure full participation from service users who are the centre of the PBS process. Where practical, they should be involved in all aspects of the assessment process and should collaborate in the design of the interventions they require. Again, this will ensure that the service user and their team can take ownership of their behaviour support, and so increase the likelihood of maintenance.

Data collection is vital for ongoing PBS – it will inform the progress of behaviour support, assist in clinical decision making and support proposals for funding. All staff need to be aware of, and trained in, the importance of providing accurate information on the status of a service users' progress or on the difficulties they are experiencing, through data collection (Cooper et al, 1997).

Finally, training a critical mass of staff in PBS is very important. An individual embarking on providing PBS in an environment where the values and principles are not yet established, may find it quite difficult and potentially quite isolating as they try to implement what may be novel interventions in a unit. Therefore, it is recommended that a number of staff within a unit are trained together in how to conduct an assessment, so they can support each other through the process. In additional, the introductory training for the rest of the staff / family as described above can be hugely beneficial in encouraging a team approach in this situation.

The Role of Behaviour Practitioners:

Although the design and implementation of behaviour support is strongly encouraged to come from staff working directly with service users and from their circle of support, a key component of maintaining behavioural supports in a service is the establishment of dedicated positions for behaviour practitioners. In this role, behaviour practitioners act as facilitators, advocates and enablers to promote the most effective

implementation of PBS within their service. Staff appointed to these positions come from a variety of backgrounds including Nursing, Behaviour Analysis, Psychology & Social care. Traditionally, under the specialist model and in educational settings, this role would have primarily focused on assessment and the design of implementation plans for individual service users. However, the role is now a lot more varied and centres around three main tasks:

a) Training

Training is a large part of the Behaviour Practitioners job. Primarily, the job involves training staff and families in PBS values and strategies. However, depending on local needs, micro-training is often provided by way of teaching specific topics, such as ASD awareness, TEACCH, PECS, Augmentative Communication or Skills teaching. Support workshops are run, such as those for sibling support or family support, and training is conducted for the Service Users such as friendships and sexuality programmes, self advocacy, self management, friendship clubs, etc.

b) Casework

In addition to carrying an individual caseload, a behaviour practitioner is often responsible for managing and supervising the broader caseload carried by front line staff. They act as mentors for staff undertaking casework, and may provide casework forums and review sessions for teams engaged in PBS work.

c) Management of Behaviour Support Services

The role often involves acting as a link between the front line staff and clinical / management teams. The Behaviour Practitioner is responsible for representing the needs of service users and their circles of support, and for implementing management structures to monitor and maintain behaviour support services. This allows the behaviour practitioner to evaluate the impact of PBS services and to identify areas that require support and training in a very realistic, practical way.

In Ireland, the concept of a dedicated Behaviour Practitioner position within a service is relatively new and the role is still undeveloped and undefined in many cases. The Callan Institute provides support to the staff appointed to these positions by way of the Behaviour Specialists' Forum established in 2004. Through this, the Behaviour Practitioners meet once a quarter from both within the Order and from external agencies to share their knowledge, experience and ideas and work on projects related to challenges they are experiencing. Current projects in progress are around the development best practice guidelines for the post, and around integrating the training and philosophies of PBS with the need for grounded personal safety techniques.

4. Measuring Effectiveness of Positive Behaviour Supports

Service User Outcomes:

Service User Outcomes are based on a broad range including quality of life, generalisation, maintenance, social validity of interventions, reduction in side effects and clinical effects. A study is currently being developed to examine the clinical effects and to evaluate the accuracy of functional hypothesis development amongst staff. Using The Checklist of Challenging Behaviour (Harris et al, 1994), The Motivation Assessment Scale (Durand et al, 1992), The Quarterly Update Sheet and The Behaviour Support Plan Status Report (The Callan Institute, 2006), this study aims:

1. To establish a baseline of behavioural issues across services

2. To look at the functionality of behaviours across the Order

3. To measure the implementation of existing behaviours support plans

4. To measure the quality of the PBS Plans in existence in relation to ethics, human rights, and best scientific practice.

5. To establish the prevalence of ASD within the service and other areas requiring specific supports (e.g. dual diagnosis).

Organisational Outcomes:

In order to develop best practice, the Callan Institute has over the last year, been looking at issues of organisational readiness, or how well prepared an organisation is to engage in the process of PBS. This work has taken the indicators of effective behaviour support and asked services if, in their perception, the indicators are in place and how significant they feel they are to PBS in their service. It is hoped that from this study information will be yielded as to the importance of various aspects of PBS in the perception of

staff. It will also identify some of the areas that organisations need to consider prior to (or concurrent with) introducing PBS to their organisation (Dench et al, in preparation).

Additional research is required into organisational benefits such as cost effectiveness, transfer of learning back into the environment, on-the-job performance of employees and achievement of strategic development plans. (Garavan et al, 2003)

5. Conclusion:

PBS is an emerging field which has proved to be effective in reducing behaviours (Carr, 1999), increasing quality of life, reducing the use of aversive techniques, initiating behavioural change which can be maintained over time and generalised to different settings, and which service users, staff and families feel comfortable using. It is a holistic approach which embraces the values of person centeredness, normalisation, protection of human rights and promoting personal dignity.

After 10 years of providing these supports, a process to evaluate PBS on the level of participant, service user and organisation is vital in creating a clear path for the future. Of primary importance of these are service user outcomes, as the success or failure at this level will guide the development of the field.

The design of ASD specific services is a challenge being faced by many of Ireland's larger services which have historically not provided dedicated services for people with ASD. The holistic approach of Positive Behaviour Support can provide life long, dignified support that can be incorporated into the persons' natural environment as so is an ideal approach to adopt going forward with a community model of services. An efficient methodology of training allows PBS to be provided on a wider scale than previous clinical assessments. However, in order to validate this, a thorough evaluation of all of the outcomes beyond clinical effectiveness is urgently required to take this work out of the clinical field and out into the community to make meaningful life changes for people.

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0063

EMOTION MANAGEMENT TOOLKITS FOR CHILDREN ON THE AUTISTIC SPECTRUM

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Children and Emotional Resilience

Children need a certain amount of resilience to be able to cope with the ups and downs that occur as part of living. They need to learn how to cope with life's disappointments and troubles, to bounce back from stressful experiences, recover from misfortune, ready to try again another time.

As children face the rough and tumble of life they are emotionally challenged. When they regulate their emotions and respond to life's uncertainties and challenges in constructive ways, they are demonstrating the intelligent use of their emotions - intentionally making their emotions work for them rather than holding them captive.

To achieve this end, children need to develop five emotional capabilities: knowing one's emotions; managing emotions; motivating oneself; recognizing emotions in others; handling emotions (Salovey and Mayer 1990). These domains are hierarchical, with each domain building on the previous domains.

Emotional resilience is a valuable skill for all children. It is about being in control and believing in one's ability to work through setbacks and risk situations in a capable, effective manner. This capacity for resilience empowers the child to develop coping behaviours, to persist in the face of failure, to bounce back with confidence and a healthy self-esteem.

'A resilient mindset provides a basic foundation and reservoir of emotional strength and can be called on to manage daily challenges' (Brooks and Goldstein 2003).

Children and Emotions

Emotions are regulators of behaviour within oneself and in interaction with others.

Children need to know their emotions, recognize an emotion as it happens. They need to express, understand and regulate their emotions, recognize emotions in others, and handle relationships with others if they are to be well-adjusted, contented, positive and resilient individuals. They need to learn that all emotions are okay, and that they are entitled to their emotions.

Children need to realize that others' emotional experience can differ from their own. They have got to develop an understanding that others have emotions also. They need to develop the ability to interpret the emotional behaviours of others. This means reading other people's emotions by tone of voice, facial expression or body language, not necessarily words.

Children who can understand their own and other people's emotions, are in a stronger position to solve social conflicts than children who have not developed an understanding of their own / other's emotions. They are also in a more fortunate position when it comes to maintaining social relationships with others.

Children need to develop an emotional vocabulary, identify emotion- eliciting situations, recognize their emotions and what their emotions mean, understand that they can feel one way and act in a different way, and that they can change their emotions by changing their thinking, doing and physiology.

Children need to learn to project their emotions forward, predicting the outcome of their behaviours as well as distinguishing between emotions, thinking, doing and physiology. They need to respond to their emotions and express them safely and assertively, proportionate to the circumstances.

Children need to let their emotions drive them but not take control of them. Unexpressed emotions get stored up, causing hurt, anger, depression, anxiety, and poor self-image. Children often lash out at others when they feel sad, upset, frustrated, embarrassed, humiliated, or excluded. Angry outbursts and overreacting are often the result of not expressing underlying emotions.

An increase in escalating emotions and challenging behaviours probably indicates an increase in stress. It is important to get to the root of the child's emotions, what may be driving the emotions in the first place. For example, the emotional roots of anger are guilt, fear, hurt and helplessness (Leaman 2006 p. 30).

Children need to recognize personal body signals as their emotions are escalating so that they can take charge of their emotions rather then let their emotions have power over them. This way they are developing emotional strength, flexibility and resilience, staying engaged and connected under pressure.

Children benefit from learning how to deal with people, events and things that escalate their emotions. These emotions may be pleasurable or distressing. Children also need to understand the situations that produce their emotional states (e.g., the link between loss and sadness) and what they can do or /and think to change emotional states.

The Relationship Between Autistic Spectrum Disorder, Emotion Management and Behaviour Development and Management

Children on the autistic spectrum, to a greater or lesser degree, present with subtle or significant difficulties in communication, socialization and imagination. Communication difficulties may be the result of misunderstanding the meaning of words and the speaker's intentions, intonation patterns, facial expressions and body language. Socialization complications may result from difficulties relating to people in meaningful ways, developing friendships, and empathy. Imagination difficulties may include rigidity in thinking, ritualistic behaviours and obsessional behaviours.

Consequently children on the autistic spectrum may be oblivious to, overwhelmed with, or bemused by social nuances. As a result they may not accurately decode and interpret the social cues of their environment. Behaviours including unruliness, aggression, detachment, isolation, disorientation, frustration and stress may be some of the coping mechanisms children with ASD adopt as they attempt to survive this complex terrain of the social world.

Our challenge is to teach children with ASD more appropriate means of behaving and adapting to their environment.

Teaching not Telling

Children on the autistic spectrum benefit from being taught constructive ways of behaving in the social world. This teaching needs to be based on the paradigm of behaviour teaching and learning.

The basic principles of this paradigm include the following: responsibility for behaviour sits with the owner of the behaviours and support is given to the learner; what you teach is what you get – where you teach it is where you get it; if you always do what you have always done, you will always get what you have always got; plan behaviour teaching; when teaching emotion management, teach generalization not one site mastery.

Our challenge with emotion management is to teach children appropriate ways of behaving and adapting to their environment. Instruction in the use of the emotion management tools should be direct and specific. Explain and discuss the purpose of / for the tool as well as how to execute the tool, where and where. Be explicit when teaching the tool. Give instruction in a manner that appeals to children's learning styles. Never be vague or ambiguous in language content. Model the tool prior to inviting the children to role-play using the tool across different social scenarios. Get the children to practice using the tool in real life contexts. Provide children with feedback and correction. Continually assess children's mastery using the emotion management tools. Provide additional instruction as required.

In this teaching process, concentrate on the children's ability to generalize their emotion management strategies across social contexts.

The Role of the Adult

To support children with ASD learn to regulate their emotions the adult needs to take on the role of social coach. This is an intentional and deliberate role.

Effective social coaches have the ability to actually understand each child and know each child's preferred way of learning and connecting with the social world. They teach in a way that enables children to learn. They focus on children developing mastery as a social player in the real world.

The coach assists the children predict the game ahead, advises what emotion management tools to use and names potential pitfalls ahead. The coach cannot use the tools for the child, the child needs to use the tools for themselves. The coach will intentionally position themselves on the sidelines as the supporter of the child, debriefing later on with the child – after the child has executed the tools in the real world.

Children learn in ways that are identifiably distinctive. According to the American psychologist Howard Gardner (1983)[4] there are at least eight different 'frames of mind', eight distinctive intelligences. Some children are word smart (verbal / linguistic), number smart (logical / mathematical), picture smart (visual / spatial), body smart (body / kinaesthetic), music smart (musical / rhythmic), people smart (interpersonal / social), and self smart (intrapersonal / introspective), nature smart (naturalist).

Make sure you choose instructional strategies that cater for these eight intelligences: read it, tell it, write it, talk it, listen (word smart), think critically about it, evaluations, sequencing, itemizing, problem solving, logic games (number smart), visualize it, puzzles, 3-D modelling, draw it, murals (picture smart), hands on, dancing, manipulate, role playing, relaxation (body smart), sing it, listen to it, chant it, jingles, pantomimes, lyrics (music smart), interact with it, collaborate, converse, social gatherings, conferencing (people smart), personal reflections, make choices with regard to it, solo projects, diaries, journaling (self smart), connect it to living things, nature encounters, nature field trips, stories about natural objects, plants and animals (nature smart).

Provide wide-ranging opportunities whereby children can explore the emotion world, learn to understand their own and others emotions, and express their own emotions appropriately. Support children learn how to articulate their emotions and respond to their own and others emotions, safely and legally.

Remember, children do not start out knowing the names of emotions any more than they do the names of animals or toys. They must be taught.

Let's Get Down to SOME Practicalities

Here are some 'hands on' emotional literacy ideas to use with children to get then talking and thinking about their emotions:

- Create a 'Feelings' work bank – happy, glad, friendly, kind, thoughtful, caring, sad, worried, mad.

- Suggest words that children can use to express their feelings and describe actions.

- Create emotion face masks.

- Play mood music and invite children to move to the music. Compare and contrast the emotion mood music.

- Draw or paint emotion stick figures and make up social stories with the stick figures as the central characters.

- Emotion cartoon strip sequence stories.

- Play emotion charades – act out emotions. The audience predicts the self talk that may accompany the emotion being portrayed.

- Create a feelings book – camera shots of child expressing that feeling; a magazine cut out of someone expressing that feeling.

- Make up an emotions-thinking-doing-physiology dictionary.

- Puppet shows presenting hypothetical social situations to encourage range of possible solutions to social conflict.

- Have group discussion about friends and friendships.

- Talk self talk (helpful and unhelpful) aloud and invite the children to guess the emotions.

- Create various scrapbooks illustrating different emotion. Compare and contrast scrapbooks.

- Use felt board faces to depict different emotions. Discuss self-talk accompanying these emotions.

- Invite children to journal their head and heart version of events.

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[4] Gardner proposed the eighth intelligence Naturalist in 1998.

- Pass the sentence – 'This is how I felt when … and this is what I was thinking …. '; 'When I was thinking … I was feeling …'

- Take photographs of children demonstrating staying calm behaviours. Display these photographs on a bulletin board and invite the children to add thinking and talking bubbles.

- Create emotion faces mobiles - angry: frowning, squinting, pouting, open mouth; worried: eyes open widely or clenched tightly, lips pressed together, hands on face or forehead.

- Write a poem/jingle/rap/chant about different emotions / characters. Include the head and the heart part to the character adventures.

Emotion Management Toolkits

Emotion management toolkits combine practical strategies that children can use – proactively and reactively – in response to stress inducing and emotion escalating situations. The purpose of using these tools is to regulate one's emotions, not to ruminate and obsess about the situations.

Tools are used to support children balance their emotions, not suppress them. When emotional upsets are left unchecked that can interfere with one's emotional health and well-being.

As Goleman (1995) explained …'Students who are anxious, angry, or depressed don't learn; people who are caught in these states do not take in information efficiently or deal with it well … When emotions overwhelm concentration, what is being swamped is the mental capacity cognitive scientists call 'working memory', the ability to hold in mind all information relevant to the task at hand.' (Goleman pp. 78-79).

'Tools' represent the term strategies and 'toolkit' the storage place for these strategies.

What Tools go in the Toolkit?

Events that may cause emotion escalation for one child may not cause escalation for another child. Consequently each child's emotion management toolkit will be distinctive to that child. It will contain the emotion regulation tools that each child needs to support them understand, express and manage their emotions. The coach works with the child to decide what tools are most appropriate for their specific social emotional needs and then teaches and coaches the child in the proficient use of the tools in the real world.

Tools may change over time – some will remain constant, some may be discarded, others will be added.

The range of tools is many and varied, a sample of which follows: About Me Tool; Affirmation Tool; Choice Making Tool; Connections Tool; Dial-A-Smile Tool; Doing Something for Others Tool; Exercise Tool; First Response Tool; Loving Tool; Survival Bag Tool; What to When … Guidebook Tool.

Children can use the tools in isolation or in combination. They can be used on the spot, before or after a stressful event. They are portable, do not depend on others and do not cost money.

Tools will need to be taught to the children. Children may require tutoring in the use of the tools as they develop their competencies and capabilities as emotion management tool user's.

The benefit of the toolkit is only as good as the children's efforts in using the tools. Learning to use the tools in and across social contexts will take time. It will require persistence and determination, a willingness to 'have a go', a readiness to be reflective. It will entail the companionship of a social coach, willing to walk alongside the child, teaching and tutoring the child so the social emotional world becomes less a minefield and more a mindfield of golden opportunities.

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0064

COMMUNICATION, UNDERSTANDING AND AUTISM: IN SEARCH OF COMMON GROUND

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I

I attended a boys-only high school with a strong commitment to tradition, which was reflected, among other things, in the school uniform. Long grey trousers, ties, and above all the blazer, the symbol of the school, green with badge, which we had to wear even in the heat of summer. I found this extremely uncomfortable, and had a sense that it was unnecessary, illogical, cruel and unjust. But when I occasionally raised my voice against it, my peers were uninterested, and the teachers – some of them very good teachers, intelligent, original and sympathetic – just took it for granted that this was the way it was and everyone was happy with it. I could only conclude that the school was full of a bunch of mindless conformists who had been so deeply brainwashed that they didn't know what had been done to them.

I had been told that there was "something wrong" with me. I had known for years that I didn't fit in with other kids, and I had the scars in my thoughts to show how nasty they could be about this. At thirteen I had gone into the mental hospital and been diagnosed with something or other. I don't recall the terms "autism" or "Asperger's syndrome" ever being mentioned to me: just "developmental disorder", and I didn't have much of an idea what that was supposed to mean. All I knew was that it had something to do with not fitting in socially with other kids, and I knew that about myself anyway. Nor did I think of it as a problem. I had the good fortune to be raised in a family that valued logical thinking (which I was good at), intellectual inquiry, independent thought and rebellion against injustice. (This was during the last days of apartheid; I had the sense that our government was a tyranny that, like many tyrannies before, was destined to meet its well-deserved downfall.) If other kids didn't like the way I did things, if they didn't share my intellectual interests, if they didn't seem to think seriously about anything at all, if they were ready to torment anyone who did things differently from how they did – that was their problem, not mine. If, as I was told, people wouldn't accept you unless you ate certain foods in certain ways, looked a certain way and wore certain clothes in a certain way, and went through all manner of meaningless verbal and non-verbal rituals – that was just stupid and unfair. If people couldn't recognise cruelty and injustice when they saw it, when it was perpetrated on them – that just meant they had been brainwashed. And if the shrinks thought my different approach meant there was something wrong with me – so much the worse for the shrinks. By nature or by nurture, I knew better. The problem was with everyone else: it was a problem of stupidity and obsessive conformity.

It did not occur to me that, at a very basic level, some things might bother me that didn't bother other people. If I had thought much about my dislike of being hugged – let alone kissed – I would have concluded that I experienced such things as intrusions and exercises of power, perhaps as one of the games people played of pushing each other around. It would not have occurred to me that these things just felt different to me than to other people at a fundamental physical level, or that this might also be the case with clothing. Nor would it have occurred to me that my simple and limited tastes in food were not just a personal thing or a matter of nonconformity, but a response of my tasting machinery, which got – gets – overwhelmed by unfamiliar and complex combinations of flavours and textures. Nor would it have occurred to me that I couldn't handle shopping malls and suchlike because the sights and especially the sounds were just plain physically overwhelming to me in a way that they weren't to other people. How could it have occurred to me? I couldn't get inside other people's heads and see what their sensory experiences were like, any more than they could get inside mine. I was perhaps already sufficiently dismissive of other people that I wouldn't have wanted to know what it was like for them anyway – and, quite probably, if the question had arisen, quite a few other people would have had the same reaction to me. Nor did anyone think in my early adolescence of mentioning sensory difficulties to me as an important aspect of autism, "Asperger's syndrome" or "developmental disorder". Perhaps the psychiatrists who diagnosed me didn't think it was important; it is at least as likely that they didn't know about it at all.

In any case, none of this seemed relevant when I got to university and was doing things I wanted to do and associating with people I liked. I could become part of a group and go wild and do the student thing. If my strange eating habits persisted, if it was occasionally mentioned to me that there was something odd about my mannerisms and interactions, it seemed to me that it didn't matter all that much, or if it did, maybe it was something I could learn to do something about: I'd learnt so much already. Other people might have learnt more: maybe that was why so many of my friends found it easy to make a long series of phone calls to organise an event, while I would quickly get exhausted and frustrated if I tried. It was perhaps less easy to account for my tendency – considerably more pronounced for me than for many of my friends – to fall behind with my studies when I was getting into the extracurricular stuff. Rather odd in a bright student, one might have thought – but even if I had thought much about my rather obvious and unusual tendency to

focus very intensely on only one thing at a time to the neglect of everything else, it wouldn't have occurred to me to connect it with some meaningless shrink-talk about "Asperger's Syndrome", or with the scattered and fragmented difficulties in social interaction that I continued to experience, no matter that I was a social being and a member of groups in a way I had never been before. Nor did the repeated occasions on which it all got too much for me and I got stuck and dropped out and couldn't do anything at all seem to fit any particular pattern of how I worked – until, after yet another crisis while studying for my master's, I was finally introduced to the writings of my fellow autistics.

The things that hadn't fitted together weren't all to do with sensory processing: they included matters of how I focused, my interests, the overall structure of my life, and of course the many dimensions of social interaction. But it was that much more fulfilling to get a picture that made sense, not only of how I related (or didn't relate) to people or of the larger patterns of how I liked to live my life, but of my tastes in food and all the little things that would inexplicably stress me out and so much more that people had found baffling about me. "Asperger's syndrome" had been just a word, a label, a way of dismissing me and pushing me out of the way; autism, as understood by Jane Meyerding and Frank Klein and Jim Sinclair and Michelle Dawson and Amanda Baggs, became a central pattern of my life, a way of making sense of much that had gone wrong and of much that had gone right, at the smallest scales as well as at the largest. Comparing notes, knowing other people's experiences, knowing their stories, seeing common patterns and variations among them, enabled me to fit it all together, gave me an understanding that (among other things) equipped me better than ever before to cope when things went wrong. And since small things could go wrong, understanding the small things was important as well.

II

I have said that the pattern I found didn't all have to do with sensory processing. But it is striking how many autistics allude to difficulties in this area as a major factor in their lives. (Temple Grandin is a well-known example.[cxliii]) It is equally striking how little attention it gets from professionals. Not that they ignore it altogether. Tony Attwood, for instance, gives a useful summary overview of some sensory difficulties.[cxliv] But he opens his chapter saying: "About 40 percent of children with autism have some abnormality of sensory sensitivity. There is now evidence to suggest that the incidence may be the same for Asperger's Syndrome." If the writings I have read by autistics are anything to go by, this is a huge underestimate; I would conjecture that the figure is far closer to 100 percent. Why might such an error arise, and what difference could it make?

I am oversensitive to touch, but not to anything like the extent that Grandin is.[cxlv] I am sensitive to sound, but I have nothing like the extreme and particular sensitivity of a boy mentioned by Attwood, who was thrown into distress by the sound of a distant hand dryer that nobody with him could hear.[cxlvi] Such cases are common on the autistic spectrum, but do not exhaust the possibilities of sensory processing difficulties. My sensitivities are more subtle and may show up only when I'm under stress for some other reason, but they're still there and still important. All the accounts I've mentioned describe far more serious sensitivities than mine, but that doesn't mean my sensitivities don't make a big difference to me. If you're a researcher or clinician on the lookout for extreme sensitivity, you may miss milder and subtler sensitivities like mine. This could lead to statistical underestimates, and more importantly, perhaps, to failure to notice things about people like me that can nonetheless be important factors in our lives.

If differences of degree pose a challenge in understanding the importance of sensory factors in autism, differences in kind complicate the issue further. As I have said, I am oversensitive in touch, hearing, taste and possibly a little in sight; but my sense of smell is toned down. Grandin has noted the possibility of hyposensitivity or undersensitivity in autism,[cxlvii] but it does not seem to be as much discussed as oversensitivity. This leaves open the possibility of a vast range of impairments. I am sure every other autistic person's sensory difficulties differ significantly from my own, and each one from every other. If there is this much variation, with some far more affected than others, and many affected in ways that are not obviously noticeable, it is hardly surprising that experts who seek a single generalisable theoretical approach tend to turn away from sensory aspects. This is in contrast to the oddities of our social interactions or lack thereof. Whether because we just don't interact, or don't want to, our try to but can't, or manage to do so in what strikes neurotypicals as very strange ways, it is clear that nobody on the spectrum interacts "normally", that all of us are in some way "disconnected" from important aspects of NT social life. This becomes obvious to anyone who is able to reflect on the matter, whether NT or autistic. It is of enormous importance, but its importance in comparison with sensory factors tends to be exaggerated because the social factors seem so much more unified and are often so much more observable. As in my case, this can be an important obstacle to the self-understanding of individual autistics.

III

The underestimation of sensory factors in comparison with social factors can also be an obstacle to the theoretical understanding of autism. The modular approach favoured by Simon Baron-Cohen and others might seem a useful way to seek understanding of sensory difficulties. Should we not be looking for one or

more specific, unconscious, automatically operating, inherited structures in the brain that are responsible for sensory processing and integration and have somehow gone wrong in autistics?

But in the book that made his name,[cxlviii] Baron-Cohen makes no mention of the specific sensory issues in autism, focusing entirely on the social and communicative aspects. He looks for impairments, not in any basic sensory processing modules, but in modules with social and cognitive significance: a shared attention module and a theory of mind module. He explains that the function of the shared attention module is to build

> triadic representations, [which] specify the relations among an Agent, the Self, and a (third) Object … Included in a triadic representation is an embedded element which specifies that Agent and Self are both attending to the same object … For example '[Mummy-sees-(I-see-the-bus)]'.[cxlix]

The theory of mind module is described as "a system for inferring the full range of mental states from behaviour … representing the set of *epistemic mental states* (which include pretending, thinking, knowing, believing, imagining, dreaming, guessing, and deceiving) …".

It may well be that something like these modules does exist. It is certainly a fascinating hypothesis. And there is plenty of evidence to suggest that both joint attention and theory of mind are impaired in many autistics, at least for some part of their lives. But I suggest that these impairments are far less universal than sensory difficulties of one sort or another, when one looks at the spectrum as a whole. Indeed, without taking due note of the sensory aspects, Baron-Cohen notes differences on the spectrum regarding the modules he discusses. He takes the view[cl] that in some autistics the shared attention mechanism does operate while the theory of mind mechanism does not. This is curious, given that he has earlier[cli] suggested that theory of mind depends on the input of the shared attention module, which would suggest that if both are turned off, the explanation should be sought in a primary impairment of joint attention rather than of theory of mind. If joint attention is then, as it were, switched on again, what would stop theory of mind from working? But perhaps a more nuanced extension of Baron-Cohen's approach could get around this.

What concerns me more is Baron-Cohen's approach to those autistics who plainly have capacities for both joint attention and theory of mind. He is clearly aware of that motley collection of auties who are commonly referred to as having Asperger's Syndrome, although he makes no explicit reference to us in the text. But when he goes into detailed discussion of our abilities, he rather curiously takes Grandin as a proxy for the entire group.[clii] Moreover, rather than draw on Grandin's own extensive writings, he insists on basing his discussion exclusively on the account of a fellow professional, Oliver Sacks. Rightly noting that Grandin's achievements "would be almost impossible without the basic concepts of beliefs and desires", he goes on to present evidence of some failure in her theory of mind mechanism. He quotes Sacks's attempt to account for her inability to appreciate certain plays of Shakespeare: "They seemed to arise from her failure to empathise with the characters, to follow the intricate play of motive and intention." He quotes Sacks's account of how she thinks about social interaction:

She had built up a vast library of experiences over the years, she went on. They were like a library of videotapes … She would play these over and over again, and learn, by degrees, to correlate what she saw, so that she might then predict how people in similar circumstances might act.

He goes on to present a summary:

Adopting what in chapter 1 I called the Contingency Stance, in place of her inability to use the Intentional Stance[cliii] in the normal way, gives Temple Grandin some predictive power over the apparently unpredictable nature of human action … Sacks notes that Temple [sic] is still gullible, a target for all sorts of tricks and exploitation, as a result of "her failure to understand dissembling and pretence" … She must "'compute' others' feelings and intentions and states of mind, to try to make algorithmic, explicit, what for the rest of us is second nature.

Baron-Cohen runs into trouble here, both by taking Grandin alone as a representative case and by relying on a third person instead of her own account. Could he, or Sacks, talk so simply of "her failure to understand dissembling and pretence" if they had taken account of her statement, illustrated with examples from her childhood, that "I have always understood deception"?[cliv] Does this not suggest that she has used the Intentional Stance for longer and with greater sophistication than Baron-Cohen seems to think? And even if she is relying on the Contingency Stance, does this mean that all other "high-functioning autistics" or "people with Asperger's syndrome" are doing the same? If some mindreading impairment prevents Grandin from appreciating Shakespeare, what about the many autistics who do enjoy Shakespeare and other sophisticated literature? Neither lack of theory of mind nor lack of joint attention are anywhere near universal on the autistic spectrum: that is, there are plenty of us on the spectrum whose theory of mind and joint attention work fine, but who have lots of autistic characteristics in

communication, social interaction, sensory processing, and indeed all aspects of our lives. If we want to understand autism, I suggest that we look at some of the most universal features, see how they might arise in the brain, and see how they might in turn, under some circumstances, give rise to common and important but not universal impairments, such as joint attention and theory of mind.

IV

It might be interesting to look at sensory processing for some such primary impairments. Grandin and other autistics have many suggestions on this score; Baron-Cohen briefly raises a related possibility, that "a capacity for joint attention may itself rest on a capacity for shifting attention flexibly, both socially and non-socially … The joint attention problems are secondary to attention shifting deficits."[clv] But I want to take a look briefly at a different possibility, more directly related to communication and social matters and also suggested by Baron-Cohen's work. He devotes a long chapter[clvi] to "the language of the eyes", including the capacity of the eyes to convey emotion. But he curiously associates the deep and complex significance of the eyes with a single module, the eye direction detector. In introducing this module,[clvii] he identifies three main functions: detecting the eyes, detecting the direction of eyes and interpreting gaze as seeing. He goes on to argue[clviii] that the EDD is intact in autistics. But this contention, while highly plausible in itself, is surely in tension with the view that, say, the emotional significance of the eyes is a straightforward achievement of the EDD. After all, the failure to make sense of the eyes is surely far more universal in autistics than the lack of theory of mind. This includes not only the emotional significance of the eyes, but such basic elements as their use in punctuating conversation.[clix] It is very common for autistics who do learn to "make eye contact" to report that it is strenuous for them; that they do not gain information from it; that if they do – if they have learnt some of what the language of the eyes conveys and are able to see things being communicated – this takes considerable intellectual effort; and that NTs they interact with tend to be left with the sense that the autistics are just staring or not making eye contact properly – as if we are not sending the right signals.[clx] All this fits with my own experience.[clxi]

I suggest that in addition to the eye direction detector and the other modules proposed by Baron-Cohen, there is a distinct eye language module, or perhaps a body language module that includes such things as gesture and tone of voice as well as that complex system of communication that is so misleadingly bunched together under the heading of eye contact. This is surely no less plausible than Noam Chomsky's hypothesis of a module for processing the grammatical structure of verbal language in the more usual sense; but I would suggest that they must be separate modules, because the structures of the two systems of communication are very different; moreover, verbal language appears to be unique to human beings, while it seems likely that many other species use body language systems similar to ours. Nonetheless, both modules would have communicative functions, albeit involving very different kinds of communication.

What I am suggesting, then, is that the body language module, whatever may be the details of how it works, is switched off in autistics, and that this is as universal a feature of the spectrum as we are likely to find. I am sure it is not the only important neurological factor in autism: I do not think it can stand in a simple causal relationship with the various sensory processing impairments, although it would surely be worth investigating what more subtle kind of relationship there might be. But what I want to do now is look at how a switched-off body language module might contribute to a failure of joint attention. In a break with tradition, I will begin with an example, not from an autistic child, but from an autistic adult.

Not long ago, buying daily newspapers in a 24-hour garage shop, I found myself in the unusual situation of having a large number of small coins making up the exact total price of the papers (ten rand and twenty cents). Naturally, it took the cashier some seconds to determine that the handful of little coins added up to the correct value, but there came a point when she could see this, and I could see that she could see it. I do not know how I saw this: maybe it was just the fact that she started putting the coins in the till, but there was no conscious inference; I was immediately aware. At least on my side, then, this episode fulfilled one basic requirement of joint attention: I could see that she saw the value of the change.[clxii] But there is certainly a lot more to joint attention than that, and in this case it could be that other requirements were unfulfilled. It is not even certain that she could see that I saw the value of the change; to take it a step further, it is quite possible that there was no way, without conscious inference, or indeed at all, for her to be aware that I saw that she saw.[clxiii] If an NT had been buying the papers, he might well have sent signals with his eyes that could have made her aware of his perception; I might not be able to send the right signals. It may be, then, that impairment of body language often leads autistics to fail to achieve joint attention.

If NTs frequently use body language to set up joint attention, as I suspect they do, this device is not available to autistics; if there is a need to indicate to someone what we are looking at, we may well have to do so by some other means. And if the use of body language, particularly eye language, is especially widespread in infants' acquisition of joint attention, it would not be surprising if autistic infants failed to acquire joint attention in the "normal" way; unless they found some other way of doing so, it might be expected that they would not acquire it at all. What I am suggesting is that there is nothing wrong with

autistics' capacity to engage in joint attention, but our body language impairment can prevent any of us from doing so in a great variety of situations, and when we are infants, if we don't find another way, this impairment can prevent joint attention from getting started. We can fail to achieve joint attention because the other party doesn't see that we see something – because we don't send the right signals. We can also fail to achieve it because we don't see that the other party sees something – because we don't pick up the signals the other party is sending. A failure of joint attention is a *failure to see*[clxiv] at some level; in the kind of autistic-NT interactions I am discussing, the failure to see can happen on either side, or on both sides! But either way it is a result of the autistic body language impairment.

I should emphasise that this claim that the body language impairment is fundamentally important is more important than the suggestion that body language is modular. The modular idea has a lot of appeal to it, but could quite easily be wrong, or at least too simple. But my own experience and the accounts of my fellow autistics leave me a lot more confident of the universality of the body language impairment. I am as confident about this as I am about anything in the neuropsychology of autism, and I am just as sure that this impairment has a major part in accounting not only for failures of joint attention but for many other things that NTs find odd about autistics. Not that it is the only basic element; sensory confusion can also play a major role. For instance, a lot of autistics may fail to acquire spoken language because their hearing is too scrambled to recognise it. But this is not the only factor in language acquisition.

V

The question of the basic impairments in autism and the great range of differences they give rise to is complex, challenging and interesting; but rather than go into detail, I want to return to the point that, when joint attention fails, there can be a failure to see on either side, that of the autistic or that of the NT. It seems to me that this point extends to higher levels. For instance, when autistics *do* achieve joint attention with NTs, this can be a result of special efforts on both sides. Lacking NT methods, the autistic must find some other way of seeing what the NT sees and establishing the sharing of attention; the NT too must set aside the expectation that NT signals will be used to establish joint attention and must learn to do so in some other way, learn to develop a sense of how the autistic does it. This, of course, happens all the time: even many "low-functioning" autistics probably manage to share attention with those close to them. But there is always something unusual about interactions between autistics and NTs: any NT who first encounters an autistic is likely to be baffled. Probably those who are best able to establish joint attention and communicate with us are those who know us best, our family and friends; that is to say, those who have had a lot of practice. But even they mess up all the time. When communication is established, it is often a matter of muddling through by trial and error, by a combination of NT methods and whatever specific methods each individual autistic manages to develop for herself.

How might this be improved? First, by not taking things for granted: an NT who tries to communicate with an autistic in an NT way, assuming that the autistic can use NT methods, is sure to fall short at some point.[clxv] But this should be narrowed down a little: assuming the autistic is completely ignorant and stupid won't get you anywhere either. Some idea of what is involved in autism would surely help. If you are trying to maintain communication with me, it would help if you knew about my sensory sensitivities and anything else that might throw my brain out of line. A general idea of what kind of sensitivities can arise would certainly help, but you need to recognise our individuality too: to take a crude example, you might run into trouble if you assumed my sensitivities were the same as Grandin's. Autism is complicated, many-layered and difficult to understand. It is hard enough for a deaf person and a hearing person to communicate, but here the key is simple: the hearing person must understand that the deaf person communicates not by speech but by signs. There are perhaps a lot more things the autistic person can't do, and they're more subtle and harder to recognise, but some attempt to understand them can help NTs communicate with autistics, as well as helping autistics to understand ourselves.

In the meantime we are baffled. NTs are baffled by autistics and autistics are baffled by NTs. It's not just that there doesn't seem to be a natural and obvious way for us to communicate with each other: our lives, our ways of being, are so extremely different. Many things that are simple and easy for NTs and fundamental to how they live their lives are damned near impossible for autistics, and it's the same in the other direction. For a lot of the time we just aren't interested in the same things. It's hardly surprising that we don't get each other, that people on either side of the gap are completely at a loss in trying to figure out what those on the other side are thinking. Something similar, after all, happens in encounters between people of different cultures, when the differences in ways of thinking and ways of life are learnt rather than biological. How often, in such encounters, is each side left with the impression that the other is just plain stupid or crazy? They just don't know things that are obvious to us. And when one culture is in a position of power in relation to the other, that just makes it worse. It is too easy for the powerful to conclude that there is something right with them and something wrong with the powerless, and to feel justified in trying to make the powerless more like the powerful, or exploit them, or just push them out of the way. The consequences of this behaviour echo down the centuries in the cries of the oppressed. And so it is between NTs and autistics. If we often don't get what you're thinking or what you want, it may frequently

not be a result of an impaired theory of mind mechanism, but of a lack of common ground. After all, autistics often get the impression that NTs lack theory of mind, or just don't get it.[clxvi]

Not that we shouldn't theorise. As I have said, understanding autism is an important step in establishing communication and building common ground. And understanding neurotypicality is important too; indeed, the two go together. This is implicit in Baron-Cohen's work. His interest in the theory of mind module is not just a matter of its supposed impairment in autistics, but of its significance in the lives of NTs.[clxvii] His theory may be wrong in detail, as most theories are, but he has hit on an important point. If there is something autistics lack, understanding this ties in with understanding what NTs have; of course, this works the other way as well. However, theories on their own aren't enough for mutual understanding or even for self-understanding. I am sure no amount of theorising could have done as much for me as knowing some of the stories of my fellow autistics. If our stories are ignored, if we are treated as mere objects of clinical study, understanding is limited to what clinical study can find – which may not even include all the things it might look for! Our sensory impairments are surely of interest to clinicians, but if I am right, the clinicians systematically underestimate them. It is story-telling that brings them to the fore.

An exclusively clinical approach can undermine understanding in any number of ways. If you think of us as deficient in theory of mind, or "empathy",[clxviii] or whatever other basic human capacity, you are likely to think us incapable of even *having* stories, and will surely be less inclined to take our stories seriously. Looking at us from outside, you may see things that we wouldn't see from outside; but we can see things from outside that you won't see from inside as well. And we may also see things about you from outside that you don't see from inside. One might suggest that autistics should tell stories about autism and theorise about neurotypicality, while NTs should tell stories about neurotypicality and theorise about autism. But apart from the fact that any halfway decent theory of autism is going to be a theory of neurotypicality, and vice versa, the division of labour never really works as neatly as that. In practice, the story-telling and the theorising are going to be shared among all of us and are going to feed into each other. Thus do we find common ground.

Steve Biko, a great hero and martyr of the South African liberation struggle, held that to achieve freedom, the oppressed have to stop thinking negatively of themselves, in the terms used by the oppressors. So it is for autistics. The autistic writers who mean most to me are those who affirm that there is nothing wrong with us, that we don't need a cure, that we are simply different. I have tried to illustrate how medical thinking can actually hinder the theoretical neurological understanding of autism; it surely hinders autistic self-understanding and autistic self-confidence.[clxix] The alternative is not to claim that autistics are superior. At a personal level, this is what I did as an adolescent. Perhaps it was the best way I could survive, in my ignorance, better at any rate than internalising the idea that something was wrong with me. But true understanding, mutual understanding, involves a break with the idea that difference requires a valuing of one and a devaluing of the Other.

That is why so many of us prefer to be described as "autistics" rather than "people with autism". This is both an affirmation that autism is part of who we are and a rejection of devaluation by medicalisation. We talk of "people with Aids" because Aids is a problem, something people would rather not have. Autism is not a problem, a disease or a disorder; it is part of our identity.[clxx] And to me, at least, it looks as if the classification of autistics as Asperger's, high-functioning or low-functioning is a classification in terms of how close we are to NTs, involving a sense of neurotypicality as some sort of norm. Would we be able to capture the rich diversity of the NT way, or ways, of being by classifying NTs in terms of how close they were to autistics – when the reasons for their proximity or distance may vary tremendously among individuals? Such a classification might not be altogether useless, but would not carry us very far. And the same goes for autistics. One person may be "low-functioning" for some basic sensory reason; in another it might be a lot more complicated; and a lot may depend on the environment in which we find ourselves. I would probably not be speaking to you today if my circumstances had not been such as to allow me to receive an advanced education. And if I had not had a sympathetic and supportive family, I might not be speaking at all, anywhere: even as it is, speaking is tough, and there are times when I'm not up to it.

By setting aside crude classifications and medicalisation, we put ourselves in a better position to understand autism and neurotypicality, in their unity and diversity, in theories and in stories. By affirming difference without devaluing anyone, we put autistics in a better position to help themselves individually and collectively, to live their lives with confidence and pride – and we can do the same for NTs. By recognising strengths and weaknesses on both sides, we begin to see that NTs can help autistics without trying to change them, and that autistics can help NTs without trying to change them either. This is the message from my fellow autistics that has inspired me and enriched my life. It is a message that many choose not to hear, preferring to think that difference needs disorder and requires cure; but it is a message that is getting out. Attwood and Baron-Cohen have both sent supportive notes to the Aspies for Freedom website.[clxxi] Contacts are being established. Understanding autism – and understanding neurotypicality – can be an open and collaborative project, a celebration of difference. It need not be the closed, elitist effort of a few NT specialists seeking power, control and the elimination of diversity.

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0065

THE INNOVATIVE USE OF PHOTOGRAPHIC LEARNING AND COMMUNICATION STRATEGIES TO WEAVE THE TRIAD OF IMPAIRMENTS

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As ever-increasing numbers of children are receiving a diagnosis of autism, we need a **practical guide for teaching and reaching** children in a way that will maximise their potential and support them to become contributing members of society.

We must however have some grasp of what autism is and the barriers it creates before we can devise strategies to circumvent the difficulties and allow communication, social interaction and learning to take place.

There is wide spread acceptance that autism is distinguished by the co- occurrence of impairment in social interaction, social imagination and social communication. It is critical to address these three core aspects (Known as Wing's triad) concurrently, as every impairment in autism has links with the other, overflowing and pervading each other. The complex and pervasive nature of these impairments implies the necessity of establishing good intervention practice in a collaborative, practical working model.

Communication difficulties are prominent in children with autism and is the most significant obstacle for both them and us. Every communication skill that a child with autism acquires liberates them from the frustration of using their behaviour to communicate. There is no greater gift to give them, than the gift of **effective reciprocal** communication **based on their understanding of the world.** It is critical however to remember that communication is more than speech, although we tend to expect only speech and accept only speech. The use of photographic communication provides these children with the means to communicate in natural settings, using concrete logical representations with consistent meaning.

Communication is the foundation upon which all other learning is built and is essential for a child's successful and appropriate participation in their daily activities. Behaviour and learning patterns are significantly influenced by the ability to perceive, organize and process information.

For many children with autism it is obvious that behaviour difficulties or difficulties with social interaction are a result of not understanding what is happening in their lives or what expectations people have of them. One cannot truly understand the behaviour of children who have autism without understanding the nature of autism as these behaviour challenges can be significantly more complex than those of other children. Too often behaviour difficulties are addressed without understanding the causes and addressing the underlying impairments.

It is also important to recognise autism as a condition with important educational consequences. Without the capacity to motivate and involve, the knowledge of how to structure situations and to promote learning, knowledge of autism will not translate into good practice. Children with autism learn best when intervention is planned, systematic and individualised. Goals and objectives need to address each area of the triad as well as each curricular area in early childhood and school. It is critical to work within the interest and ability of each child to assist generalisation of learning.

Inclusion of children in local education programs is a national objective in New Zealand. For this to gain wide acceptance procedures must be available to assist these children in dealing effectively with communication, behaviour and learning issues. Rather than isolating children with autism from typical pre school and school activities and from their peers to provide only individual instruction, we teach within a context of developmentally appropriate activities and routines in the mainstream educational facility.

The importance of teamwork (all professionals, parents and caregivers working together) can't be emphasized enough. Parents are involved as active participants in the planning and intervention.

This teaching presentation is a collaborative approach between a professional and a parent. We endeavour to give parents and professionals hope, encouraging them to form interactive intervention partnerships by successfully addressing the triad of impairments with the use of **P**hotographic **L**earning **A**nd **C**ommunication **S**trategies **– within mainstream educational settings.**

Conclusion

The results of our work have been astounding - a fantastic achievement for the many children who have previously remained locked up in their own world.

Based on our experiences with autism it seems the following issues are rated highly in intervention:

1. The use of **P**hotographic **L**earning **A**nd **C**ommunication **S**trategies

2. **Early intervention**

3. A **structured predictable programme**

4. An acknowledgement of the impact of and appropriate **treatment of sensory problems**.

5. **Broadening and directing special interests**.

6. Using sensible **well planned behaviour management** techniques.

7. Having a **good knowledge of autism** and the individual child.

8. **Including children with autism** in mainstream settings in a way that supports not just physical inclusion but also curricular and emotional inclusion.

9. **Weaving the triad**

Bronwyn Julian is the parent of a seven year old son who has autism. In this presentation she poignantly describes some of her journey with her son and specifically the use of **P**hotographic **L**earning **A**nd **C**ommunication **S**trategies in their lives.

Whatever a child's ability of *difabilty (Different ability)* – all children deserve the opportunity to maximise their potential alongside their peers. We have learnt that no matter what start a child with autism has in life, there is always hope in changing the outcome. Behind a façade of indifference is a beautiful depth of potential and it is up to us to expose and develop that potential.

We believe we can always do something more – something better, because a child with autism is counting on us.

0066

ADDRESSING PROBLEM BEHAVIOUR DEMONSTRATED BY STUDENTS WITH AUTISM

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Abstract:

Some students with autism present with some unusual and challenging behaviours, and may not respond to the usual methods of behaviour management. Challenging behaviours often result in self-injury, injury to others, cause damage to the physical environment and/or interfere with the acquisition of new skills, and/or socially isolate the learner. These problem behaviours impede their learning and social interactions, often excluding them from learning situations.

This paper describes a step-by-step process which facilitates positive behaviour support systems and strategies within the context of four special schools, in New Zealand, where the author is contracted as psychologist within an integral school-based team which includes teacher, teacher aide, speech and language therapist, occupational therapist physio-therapist, and behaviour therapist in two of the four schools. The process helps to guide school teams through the processes of defining the problem behaviours; gathering information to provide a greater understanding of the behaviour determinants; developing a hypothesis concerning the purpose of the behaviour; designing a plan for positive behaviour support (including crisis management); and, finally, implementing and evaluating, this plan. The goal is to encourage team members to work collaboratively to develop an understanding of factors affecting a student's challenging behaviour, to prevent problem behaviour, and to design interventions that lead to positive life-style changes.

This discussion accepts differences in how each school implements positive behaviour support processes, and offers an overview of some of the strategies involved. The results of these processes provide a continuum of whole-school procedures which respond to individual needs and are responsive to the preferences, strengths, and needs of individuals with challenging behaviour.

Addressing Problem Behaviour Demonstrated by Students with Autism

Autism, or autistic spectrum disorder, is a neurodevelopmental syndrome characterised by difficulties in social interaction with other people, communication deficits, as well as restricted and stereotyped patterns of interest and behaviours. Autism essentially affects the way a person communicates and relates to people. The term "autistic spectrum" is often used because the condition varies from person to person. It has a major impact on the lives of children and their families. Although current research links autism to biological or neurological differences in the brain, much remains unknown about the causes of these differences. Both genetic and environmental factors are being studied as possible causative factors. At present, no definitive cause has been identified for autism.

Children with autism may present with some unusual and challenging behaviours, and do not always respond to the usual methods of discipline. It is frequently necessary for schools and families to develop a systematic and individualised plan for changing behaviours. It is important that any behaviour intervention plan is based on an understanding of the characteristics of autism, as well as knowledge of the strengths and needs of the individual student.

General characteristics of children with Autism Spectrum Disorders include:

- *Cognitive:* Uneven development of cognitive skills; relative strength in processing visual versus verbal information.

- *Social skills:* Difficulty understanding social rules such as taking turns and sharing; problems understanding and reading the emotions of others; difficulty taking the perspective of other people; problems initiating and maintaining interactions and conversations with other people.

- *Communication:* Trouble responding to verbal information presented at a fast pace; trouble understanding multiple-step commands; inconsistent understanding of verbal information; a need for verbal information to be repeated, especially information that is new.

- *Organisation/self-direction:* Difficulty screening out distractions; difficulty completing activities independently and initiating work activities; problems organising free time and stopping one activity and moving on to the next; difficulty being flexible, shifting

- Although anxiety is not identified in the DSM-IV criteria, many individuals with autism, as well as their parents and teachers, identify anxiety as a characteristic associated with autism. This may be related to a variety of frustrations:

  - not being able to express oneself

  - difficulties with processing sensory information

  - the need for predictability, and having difficulty with change may result in an anxious response to new situations and last minute changes

  - difficulty understanding social expectations.

Typically, the person with autism will have fewer skills to cope with stressful situations and may have learned a number of unusual behaviours to deal with them which will interfere with their learning and interactions. It is important to remember that the person is not the problem; it is the conditions that give rise to them. The challenge to the teacher is to understand what might give rise to problem behaviours and respond appropriately. Some of these behaviours may be extreme and challenging.

Challenging problem behaviour can impact on safety, result in loss of instructional time, and lead to physical or educational exclusion. There has been growing dissatisfaction with many common traditional behaviour management methods because they are often focused exclusively on consequences, unacceptably intrusive, and/or ineffective in producing meaningful changes in student behaviour[5]. In response to these concerns, current approaches are individualised and better suited to various educational environments.

Because the student with autism does not always respond to the usual (traditional) forms of discipline and behaviour management[6], an individualised behaviour plan is based on an understanding of the student's autism and recognises that the behaviour, in most instances, has a function. Behaviours may indicate that something is difficult for the child. Traditional approaches to behaviour modification may not work with the child with autism, for example:

- Communication difficulties make it hard to understand logic or reasoning.

- The child with autism may not be motivated to please others or may be motivated by unusual things.

- The child may not understand the cause and effect relationship between behaviour and rewards. Similarly, the child is unlikely to understand that the punishment is a consequence of their inappropriate behaviour.

- The child may not generalise positive behaviour changes from one situation to another.

- The child may have established routines that may include negative behaviours.

Positive Behaviour Support strategies do not merely focus exclusively on the student, but also include changing environmental variables such as the physical setting, task demands, curriculum, instructional pace and individualised reinforcement.

It is an approach to intervention that offers a process for designing individualised approaches to support students experiencing behavioural difficulties in school, home, and community environments (Bambara, Mitchell-Kvacky, & Iacobelli, 1994[7]; Koegel, Koegel, & Dunlap, 1996[8]). Punishment and other negative consequences have not been effective at either improving long term behavioural problems, or preventing students from presenting antisocial behaviours which may be disruptive to their own or others' learning, or

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dangerous and/or destructive and potentially harmful to themselves or others. Use of PBS, on the other hand, decreases the need for more intrusive or aversive interventions (i.e., punishment) and can lead to both systemic as well as individualised change. Positive behavioural support incorporates functional behavioural assessment and leads to behavioural intervention plans that are positive (i.e., proactive, educative, and functional) in nature.

Unlike traditional behavioural management systems, which view the individual as the problem and seeks to "fix" him or her by focusing on merely eliminating the challenging behaviour per se, positive behavioural support (PBS) strategies and functional behaviour analysis (FBA) view systems, settings, and skill deficits as parts of the "problem" and provide strategies to change those. PBS and FBA can help practitioners and parents understand *why* the challenging behaviour occurs - its function or purpose for the individual. Moreover, PBS and FBA provide a framework for helping the child to change challenging behaviours. These approaches are characterised as long-term strategies to respond to individual needs, alter environments, and explicitly teach functionally equivalent skills to both enhance the student's quality of life, and at the same time to minimise / prevent problem behaviours which impact on learning and participation.

PBS aims to increase positive and socially valid behaviours across the home, school and community settings. By focusing on the *contexts (antecedents)* and *outcomes (consequences)* of the behaviour, it is possible to determine the *function(s) i.e. purpose* of the behaviour, and to make the problem behaviour less effective and efficient, and make the *desired behaviour* more functional. This often involves *changing systems, altering environments and teaching new skills*, as well as *focusing* on the problem behaviour, including (Diagram 1):

- Changing the classroom environment

- Increasing predictability and scheduling

- Increasing choice-making

- Reinforcing positive behaviours

- Making curriculum modifications and adaptations to materials and teaching methods

- Providing more "scaffolded" support by more knowledgeable peers or adults
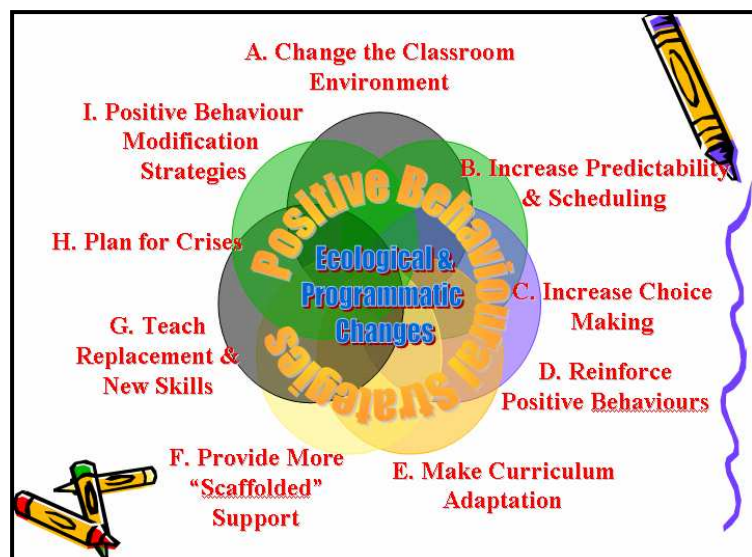
- Teaching replacement and/or new functionally equivalent skills

- Planning for crisis, proactively

- Using positive behaviour modification strategies

The most crucial part of devising PBS plans is the *Functional Behavioural Assessment* (FBA), which reveals information about the antecedents, consequences, and frequency of challenging behaviour. Conducting FBAs doubles the success rate of an intervention. This includes an A-B-C analysis (Antecedent; Behaviour; Consequence), and investigates the function(s) (purpose) of the problem behaviour.

PBS plans are *individualised* and *data-based* and include procedures for monitoring, evaluating and reassessing the process. Since they have the greatest influence on their children's development, families are seen as a very critical part of this process. PBS, therefore, should be a *collaborative* effort among parents, school psychologist, teachers, therapists and administrators.

The object of special schools in New Zealand is to improve learning outcomes for their students, by minimising the effect of challenging problem behaviours which may impede learning and become barriers to life experiences in their communities. Inclusive practice in special schools is about providing these students with the support they need to access learning - whether it is therapy, adaptations to the learning programme or environment, specialised teaching approaches and strategies, and/or specialised equipment or materials. In the author's opinion, efficacy of such inclusive programming rather than

placement (that is, whether they attend a special school or a regular school) is the issue, although each type of schooling presents different opportunities and challenges.

The school-based psychologist supports parents and teaching staff, within the framework of the school system – working as a member of the trans-disciplinary or, in some cases, multidisciplinary team – in a collaborative style. He operates within the shifting paradigm toward services guided by problem solving and *evaluated by the achievement of positive life outcomes for the person and his/her family*. A problem-solving orientation is distinguished by its purpose: to improve student participation and learning and enhance the individual's life outcome success. Problem solving is a systematic process that includes the functional behaviour assessment of challenging behaviour of students and their environments, identification of needs, development and implementation of positive behaviour supports to meet needs, and the monitoring and evaluation of outcomes. This orientation permits any theoretical approach in the design of interventions, but uses improved student performance and educational participation as a criterion for measuring success. This perspective is focused on enhancing functional behaviours and learning competencies by:

- clearly identifying challenging problems

- analysing the factors contributing to a problem, setting goals and analysing the resources available to attain the goal

- utilising data to develop and implement interventions

- monitoring progress towards goals and modifying interventions as needed

- evaluating outcomes and interventions

The problem-solving perspective benefits students through a range of services facilitated and/or supported by the school psychologist. Direct services may include individual and group counselling, skills training, brief family therapy, and crisis intervention. Indirect services may include consultation with parents, teachers, teacher aides and other therapists, functional behaviour assessment, and professional staff development. The expected outcome of these services is the enhanced behavioural functioning and learning participation of the students and the increased application of effective psychological special education practices by parents, teachers, and other professionals.

The four New Zealand special schools, where the author provides services, have taken the following steps, albeit in different ways, to introduce and facilitate positive behaviour support systems:

- Developed a Behaviour Support Team comprising members from teaching, therapist and management

- Weekly Behaviour Support Team meetings – for discussing referrals and planning

- Introduction of PBS to staff at whole-school staff meetings

- One school provided support to three staff members to attend four Friday lectures and written assignments to complete a PBS course at the University of Auckland

- On-going teacher professional development training has highlighted

    o Creating a Positive Classroom Climate

    o Understanding Student Characteristics & Implications for Instruction

    o Instructional Approaches & Classroom Strategies

    o Structuring the Learning Environment

    o Managing Challenging Behaviour - Using Positive Support Strategies

    o Non Violent Crisis Intervention strategies, to prevent behaviour escalation

- A format for Crisis Intervention has been designed

- Teacher Guidelines for Action when Challenging Behaviour is presented (Fig 1, next page)

- A Transdisciplinary team, initially informally introduced, has continued to support teachers in learning and behaviour issues. Transdisciplinary means the teacher(s) and therapists from two or more disciplines meet regularly to work together across traditional disciplinary or professional boundaries to share their skills and knowledge. This problem-solving process aims to coordinate positive learning and behaviour programmes in the classroom. This process has been successfully implemented across satellite settings, and may now be implemented in the base schools.

- An Intern Psychologist, specialising in Applied Behaviour Analysis (ABA), is employed to promote, and model, best practice in applied behavioural sciences in two of the schools.

- Parent Support Groups have been established to support parents in dealing with problem behaviour in positive ways, while strengthening their own families

- Teacher Aide training in PBS, including induction of new teaching staff that focuses on effective teaching practices, and seeks to provide a systematic structure of support for beginning teachers and support staff.

The next steps are:

- To offer ongoing staff training to collect data through formal naturalistic observation, using Scattergraphs and A-B-C analysis

- To further develop the Behaviour Support Team's role in activating teacher or therapist referrals for behaviour support towards a Behaviour Intervention Plan. This will include (1) describing the behaviour; (2) gathering Information; (3) developing an hypothesis as to the function or purpose of the behaviour; (4) designing a positive behaviour intervention plan, in consultation with teaching staff and parents; (5) monitoring the implementation of the behaviour plan; and, (6) evaluating the plan (Figure 1).
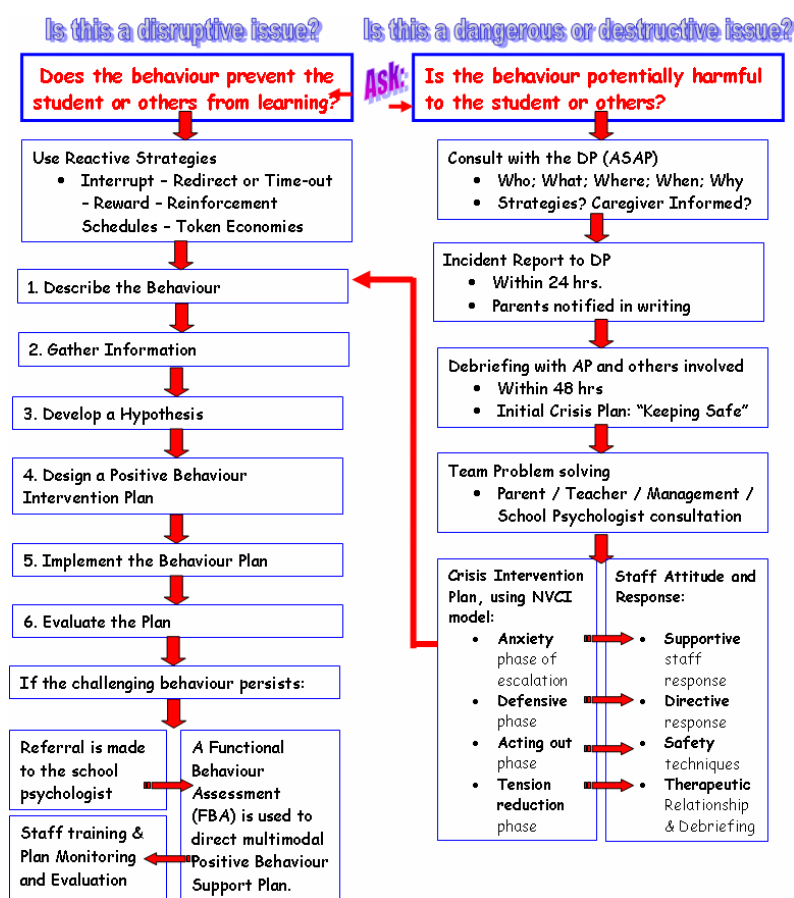
A team-based approach is essential to the effectiveness of PBS and consists of the most relevant people to the individual's life. The team members are typically responsible for implementing the positive behaviour support plan. A positive team response or attitude in solving a behaviour problem is searching for greater understanding of the context of the problem behaviour. The following questions may help:

Figure 1 Teacher guide to actions when a challenging behaviour is presented, which may either be dangerous, or disruptive

1. What are the underlying difficulties that might cause this problem?

2. In what situations, or at what times, does this behaviour occur?

3. How often does this behaviour occur?

4. What does this behaviour mean from the child's perspective?

5. How does the pupil's behaviour differ from that of other children of the same age?

6. What new skill could the child learn to better handle this situation?

In order to develop a positive behaviour support plan, the team must gather information about the problem behaviour(s) and the settings in which these behaviours occur. To accomplish this, a functional assessment is conducted and with the results of this assessment, combined with personal goals and characteristics, a behaviour support plan is developed. The behaviour plan includes a number of components:

- Strategies for teaching and increasing social competency and communication skills that will serve as replacement skills for the problem behaviour;

- Strategies for preventing the problem behaviour before it occurs;

- Strategies for dealing with the problem behaviours when they occur, through a crisis management plan;

- Strategies for monitoring progress and developing any necessary adjustments to the plan.

Proactive strategies, which focus on prevention of challenging behaviour, is more effective than reacting to problem behaviours. It is, therefore, prudent to identify environmental factors that may be associated with increased anxiety[9], and the resulting challenging behaviour. It is suggested that such behaviour may be prevented if the student is given opportunities for calming throughout the day, consisting of brief periods of relaxation activity such as:

- going to a special calm area in the classroom or school

- listening to music with headphones

- having a favourite object or activity

- engaging in a preferred repetitive behaviour

    o Remember, what is calming for one child may increase anxiety for another!

Problem behaviours may be prevented by making changes in the environment, such as:

- defining the physical layout of the classroom so that the individual understands the location and purpose of each functional area – these boundaries help answer the question "where is it and what happens there?"

- minimizing visual and auditory distractions and/or sources of sensory overload

- providing a visual structure (e.g., daily schedules or visual cues), to let the person know what activities will happen and in which order – these visual cues answers the questions "what do I do?" and "what comes next?" - providing a clear and predictable routine

- incorporating a sensory diet into the student's daily routine (i.e., sensory experiences that are calming for him or her)

Providing a programme that emphasises the development of functional communication, in a predictable and rewarding environment, can help to reduce the frequency and severity of problem behaviours.

Further positive programming strategies may include:

- teaching communication skills using an appropriate form of communication, depending on the abilities of the student

- teaching social competency skills, using video modeling and direct teaching approaches

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[9] Teaching Students with Autism Spectrum Disorders, Chapter 5, Challenging Behaviours, 2003, Department of Education, Government of Newfoundland and Labrador

- identifying the functions of challenging behaviours and teaching functionally equivalent appropriate replacement skills or behaviours

- providing visual supports to clarify instructions and teach new concepts and skills

- using social scripts to teach behaviour for situations that pose a problem

- providing a clear schedule and using it to prepare the student for transitions between activities and to prepare for any changes in the routine that may occur

- teaching the student to make choices and providing opportunities for choice within the schedule

- teaching relaxation (self-calming) techniques

- reinforcing appropriate behaviour with reinforcements that are meaningful to the individual student, for example, using a *token economy* - A system of reinforcement for desired behaviour can be set up, in which receiving a token is contingent upon the student performing the completion of tasks or other appropriate behaviour. Earned tokens are then "cashed in" for designated reinforcers known to increase behaviours for that student, such as tangibles (desired objects) or preferred activities (time on the computer, use of music, or access to a favourite person). Tokens can provide an immediate pay-off for the student, which is a stronger reinforcer than waiting until the end of day. A token system is more effective than social reinforcers for some students with autism who do not respond to social reinforcers such as praise. When using a token system, teachers should still pair the awarding of token with praise so that the tokens can eventually be phased out and replaced by more natural reinforcers in the student's life. Use of a token system as punishment, by removing tokens (response cost) is not advisable.

Structuring the environment, and the above positive strategies may prevent challenging problem behaviour in several ways. Firstly, it focuses on helping individuals understand what they are expected to do, and helps with transitions from one task to another, thereby reducing problem behaviours often caused by frustration and confusion. Secondly, it uses the individuals' need for a precise, predictable, detailed work system, which simplifies and clarifies activities. Thirdly, such predictability calms and reduces anxiety and may reduce those types of obsessive and repetitive (self-stimulating) behaviours that people with autism engage in to organise (self-regulate) and comfort themselves.

This discussion accepts differences in how each school has implemented positive behaviour support, and offers an overview of some of the strategies involved. The results of these processes provide a continuum of whole-school procedures which respond to individual needs and are responsive to the preferences, strengths, and needs of individuals with autism who demonstrate challenging behaviour. These multi-modal strategies aim to prevent problem behaviour by developing a systematic plan for intervention which is based on an understanding of the characteristics of autism. A comprehensive behaviour plan should include a thorough assessment of the function or purpose of the behaviour and the context in which it occurs, to determine the underlying contributing factors. Assessment should also include gathering significant information about the student, such as likes and dislikes, frustrations, communication skills, strengths and needs, how the student interacts socially, and the typical responses to sensory stimuli.

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[cxxxiv] Clinical longitudinal observation since 2000 at the Eldon Health Clinic UK by Michael Ash.

[cxxxv] Appendices are available on request from the author via email Thomson.mary.i@edumail.vic.gov.au. The appendices detail the WAS programs and services and the 2005 Outreach/Resource Data, the autism specific training programs in Australia and the United Kingdom, a Job Profile for Teachers of Students with Autism Spectrum Disorder and the Course Development Steering Committee.

[cxxxvi] There are a number of distinct diagnoses within the broad category of ASD disorders. Autistic Disorder is diagnosed where the core impairments are severe, including an intellectual impairment. Diagnosis of this condition usually occurs before 36 months of

age. Other ASD diagnoses include Asperger Syndrome (AS) and Pervasive Developmental Disorder- Not Otherwise Specified (PDDNOS), both autism spectrum disorders but with IQs in the average range. These disorders are likely to be identified at a relatively later age. Most often these students start mainstream schooling at prep age and the full clinical picture of AS may only become evident subsequently up to age 10 (Gillberg 2004). In Australia approximate prevalence rates of autism across the spectrum is almost *6 per 1000* individuals, ie. people with autism who will require ongoing support throughout their lives, and as high as *9 in 1000* individuals where those with Asperger Syndrome (AS) and milder social impairments of the autistic type are included (Autism Victoria 2000). Autism affects males at a ratio of 4:1 and AS at a ratio of 3-6:1.Given prevalence figures in Australia it is likely that every school of 100 students will contain one or more students with ASD.

cxxxvii ASD is a complex developmental disorder that acutely affects social functioning, learning, communication and behaviour. Beginning at an early age and typically continuing throughout their lives, individuals with ASD have difficulty relating appropriately to others, present with a wide range of language and communication disorders and peculiarities, frequently have difficulty following and mastering unmodified school curriculum, an obsessive interest in environmental sameness, and are well known for their difficult –to –understand behaviour. Moreover children and adolescents often have irregular patterns of cognitive and educational strengths and deficits, including splinter skills and discontinuous abilities (Simpson et al 2003).

cxxxviii Temple Grandin (56 years of age) has a successful international career designing livestock equipment. She completed a PhD in Animal Science and now is Assistant Professor of Animal Science at Colorado State University.

cxxxix Therese Jolliffe is an autistic person with a PhD for research into autism.

cxl The ATI was created as a specific use organisation for the delivery of specialist teacher training in the area of students with ASD. The ATI is a Registered Training Organisation (approved to delivery recognised training) that exists as an unincorporated entity under the wider umbrella of WAS. It is a cutting edge initiative of WAS and has broken new ground in the fields of Special Education, Teacher training provision and Vocational Training in Australia. It is aimed at both teachers in specialised autism settings and those in mainstream schools. The Autism Teaching Institute is equipped with a lecture space, training rooms and a specialist library. The existing infrastructure at WAS is used for the specialist practicum ie. classrooms and teaching resources.

cxli The ATI employs the skills and expertise of autism specialists in such areas as diagnostic clinicians-psychology, speech pathology and social work, on an as needs basis.

cxlii The ATI has seconded a number of staff from WAS who are undergoing formal professional development in vocational education and training. A spin off effect of employing experienced teachers from WAS is that expert knowledge is being recorded in the form of detailed role competencies.

cxliii Grandin 1995, pp. 62-81. Klein, Sinclair and Meyerding are other examples.

cxliv Attwood 1998, pp. 129-140.

cxlv Grandin 1995, pp. 62-67.

cxlvi Attwood 1998, p. 131.

cxlvii Grandin 1995, p. 53.

cxlviii Baron-Cohen 1995.

cxlix Ibid., pp. 44-45. For further discussions of the intricacies of shared attention, or joint attention, to use the more usual term, see the references in note 22.

cl Baron-Cohen 1995, p. 127.

cli Ibid., p. 55.

clii Ibid., pp. 139-143.

cliii The concept of the Intentional Stance – the "ability to attribute the full set of intentional states (beliefs, desires, thoughts, intentions …)" (ibid., p. 21) is due to the philosopher Daniel Dennett. Baron-Cohen describes the Contingency Stance as involving "learning or innately recognising the behavioural contingencies between another organism's behaviour and their effects … to adopt this stance is to characterise the organism as a behaviorist – the most obvious alternative to a mindreader" (pp. 25-26).

cliv Grandin 1995, p. 136.

clv Baron-Cohen 1995, p. 138.

clvi Ibid., pp. 97-120.

clvii Ibid., pp. 38-44.

clviii Ibid., p. 64.

clix Attwood 1998, p.24.

clx Klein has an excellent account at home.att.net/~ascaris1/more-aba.html.

clxi I should point out that I have been placed under far less pressure to make eye contact than many autistics. Nor, on the other hand, have I made any systematic effort to understand this baffling thing called the language of the eyes. Perhaps some day I will, though I'm not sure that it's worth any more effort than learning isiZulu, Spanish or one or more sign languages, and there are so many languages to learn. And if the accounts of my fellow autistics are anything to go by, I cannot expect ever to be able to use eye language in the consistent and effortless way NTs do, or without very great strain.

clxii Compare Baron-Cohen's account of joint attention, quoted on p. 4 above.

clxiii Peacocke 2005, p. 302. Something like this requirement is probably part of what Naomi Eilan means when she says: "In joint attention everything about the fact that both are attending to the same object is out in the open, manifest to both subjects." (Eilan 2005, p. 25). John Campbell's different approach makes allowances for a similar requirement (Campbell 2005, p. 293). Eilan et al eds (2005) includes a number of papers exploring the complexities of joint attention, including the three already quoted; several others in the collection engage with the significance of joint attention in autism.

clxiv I assume the visual modality, partly for convenience and partly because it is probably the modality that is most commonly involved in such cases; but the issue arises with other modalities as well.

clxv Sinclair (1989) gives the following account of not taking things for granted:

> I had a friend who, with no formal background in psychology or special education, figured out for herself some guidelines for relating to me. She told me what they were: never to assume without asking that I thought, felt, or understood *anything* merely because *she* would have such thoughts, feelings, or understanding in connection with my circumstances or behavior; and never to assume without asking that I *didn't* think, feel, or understand anything merely because I was *not* acting the way she would act in connection with such thoughts, feelings, or understanding. In other words, she learned to *ask* instead of trying to *guess*.

clxvi Jared writes in a discussion at http://www.autistics.org/library/AE2000-ToM.html:

> Because Autistic people see most normal people as seeming to assume everyone is like themselves, and would react as they would in the same situation, normal people may often seem to lack "Theory of Mind" to many high functioning Autistic people. On the other hand, normal researchers are tempted to assume lack of or deficiency in "Theory of Mind" when Autistic people don't automatically jump to these conclusions.

This discussion, while often lacking in rigour, is a good example of autistics engaging critically, seriously and openly with theories of autism.

clxvii Baron-Cohen 1995, pp. 1-7

clxviii This term is used in so many ways and carries so much emotional content that I am doubtful if it has much use at all in serious understanding.

clxix In the words of Klein (http://home.att.net/~ascaris1/lfa.html):

> I know for a fact that higher-functioning autistic children, including those that are significantly lower functioning than I, definitely do notice that their parents are not accepting them as they are. They may not speak, but they can detect the attitude that they are not okay as they are. When they are repeatedly scolded for behaviors that are natural to them, and when their parents have the mentality of combating a condition that is a part of who they are, they definitely figure it out … Trying to teach the child to act more normally (because, to a parent, high-functioning autism looks like a set of behaviours, not a different way of perceiving the world) gives the message that the child is not acceptable unless he hides his true self beneath a mask of normality. When he responds to the scolding or aversives that well-intentioned normal people give him to teach him to be normal, and is praised for it, he can see that he is punished for being himself and rewarded for being someone else.

clxx The classic statement of this position is Sinclair 1999.

clxxi The messages are at http://www.aspiesforfreedom.com/index.php?page=libraryview&document=tonyatwood and http://www.aspiesforfreedom.com/index.php?page=libraryview&document=simonbaroncohen, respectively.