

ERRATUM

page 215, paragraph 1, first sentence: "its" for "it's"

**IDENTIFYING AUTISM IN INFANTS AND
YOUNG CHILDREN**

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ABSTRACT

Parents of children with autism report noticing abnormalities and problems with their child's development at an early age, often during infancy. However, diagnoses are usually made at an age beyond that recommended for the commencement of early intervention. Research on the reliability of early diagnosis and the identification of early features of autism has paved the way for the development of autism screening tools.

This study aimed to develop and evaluate a screening tool for autism for use with infants and young children with developmental delay. Stage 1 involved the identification of emotional and behavioural problems unique to young children with autism. Previous research had demonstrated the use of the Developmental Behaviour Checklist (DBC) (Einfeld & Tonge, 1995) as a screening tool for autism in children and adolescents (aged 4 – 18 years) with intellectual disability (Brereton, 1999). The first stage of this study aimed to evaluate the efficacy of the DBC (Einfeld & Tonge, 1995) as a screening tool for autism in children with developmental delay aged 18 - 48 months. Subjects consisted of 60 children with autism and developmental delay and 60 children with developmental delay without autism. Parents of the children completed the 96 item DBC (Einfeld & Tonge, 1995) rating the behaviour of their child within the past 6 months.

Analyses aimed to identify those items of the DBC which best predicted the diagnosis of autism. Univariate logistic regressions were performed to establish which items of the DBC differentiated the autism and control groups. A confirmatory factor analysis

was performed with the 30 items identified by the univariate logistic regressions. Factor loadings were then used to develop the DBC screening algorithm. Receiver Operating Characteristics (ROC) analysis was used to evaluate the overall performance of the DBC algorithm as a screening tool for autism. Using a cut point of 0.60 or greater, 17 DBC items were selected to create a DBC autism screening algorithm. Analyses revealed that with a cut-off score of 11 this 17-item version of the DBC-P performed well as a potential screening tool, with an Area Under the Curve of 0.874, sensitivity of 0.8750, and specificity of 0.6909.

Stage 2 of this study involved testing the efficacy of this autism screening tool, the Developmental Behaviour Checklist Early Screen (DBC Early Screen), developed in Stage 1 of this project. The DBC Early Screen was tested in two independent studies. The first of these studies involved applying the DBC Early Screen to children referred for a specialist autism assessment. The second study involved applying the DBC Early Screen to a community sample of children referred with developmental delay.

The first of the evaluation studies compared the results of screening using the DBC Early Screen with a sample of children referred to an autism assessment clinic. In a sample of 38 children with developmental delay (aged 23 - 48 months), 35 (92.10%) of the children referred received a clinical DSM-IV diagnosis of Autistic Disorder. Thirty (78.95%) subjects screened positive (DBC Early Screen total score at or above 11) and 8 (21.05%) screened negative. A sensitivity of 0.80 was obtained, specificity of 0.33, and efficiency (correct classification rate) of 0.76. A predictive value of a positive test of 0.93 was obtained along with a predictive value of a negative test of 0.13.

The second evaluation study involved the screening of a community sample of children referred to a service for children suspected of developmental delay using the DBC Early Screen. In a sample of 22 children (aged 23 - 49 months), 15 screened positive using the DBC Early Screen. Of those who screened positive, 12 (80%) received a clinical diagnosis of DSM-IV Autistic Disorder and 3 (20%) did not. Of those who screened negative, 3 (42.86%) were diagnosed with Autistic Disorder while 4 (57.14%) did not have Autistic Disorder. Using these results to establish the efficacy of the DBC Early Screen resulted in a sensitivity of 0.80, specificity 0.57, and efficiency of 0.73. A predictive value of a positive test of 0.80 was obtained along with a predictive value of a negative test of 0.57.

The sample was also examined in terms of those who received the broader diagnosis of a Pervasive Developmental Disorder (Autistic Disorder, PDD NOS, and Asperger's Disorder). This resulted in a sensitivity of 0.82, specificity of 0.80, overall classification efficiency of 0.82, predictive value of a positive test of 0.93, and predictive value of a negative test of 0.57. Notably, specificity was improved when the results of the DBC Early Screen were compared to clinical diagnoses of Pervasive Developmental Disorder and non Pervasive Developmental Disorder.

This study has successfully developed a potentially effective screening tool for Pervasive Developmental Disorders in infants and young children with developmental delay. Further community screening trials are warranted to establish its clinical utility in larger populations.

DECLARATION

The research for this thesis was conducted by the author in the Monash University Centre for Developmental Psychiatry and Psychology between February 1998 and December 2001. The work is original, and to the best of the candidate's knowledge, contains no material which has been accepted for the award of any other degree or diploma in any university or institution, nor does it contain any material previously published or written by another person except where due reference is made in the text.



Kyle M Gray
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This thesis is dedicated to the memory of my Poppa, and to my Nan whose strength and determination never ceases to inspire me.

CHAPTER 1

AUTISM

1.1 Definition

Autism was first described by Kanner (1943) in a series of case studies. Kanner described in detail 11 children (8 boys and 3 girls) he classified as having an "inborn autistic disturbance of affective contact" (1943, p. 250). In this seminal paper the fundamental characteristic of this syndrome was described as being an inability to relate in an ordinary way to other people and situations which is present from birth. Other characteristics included a failure to use language for the purpose of communication, echolalia, pronoun reversal, good rote memory, an anxiously obsessive desire for the maintenance of sameness, normal physical appearance, and good cognitive potential (Kanner, 1943).

Various authors went on to expand upon and further delineate these criteria for autism including Creak and colleagues (1964; 1961), Rutter (1978), Wing and Gould (1979), and Denckla (1986). Rutter's (1978) definition, which was based upon Kanner's original description and the research which subsequently followed, was particularly influential in the development of subsequent published diagnostic criteria. Criteria included impaired social development that is out of keeping with the child's intellectual level, delayed and deviant language development out of keeping with child's intellectual level, insistence on sameness (stereotyped play patterns, resistance to change, or abnormal preoccupations), and onset before 30 months of age (Rutter, 1978). The observation that children with autism also frequently have an intellectual disability resulted in the emphasis on taking mental age into account when assessing a child's

behaviour (especially in relation to social and language development) (Rutter, 1978). In order to facilitate comparability across research studies, it was emphasised that all researchers needed to define their samples using these criteria.

Diagnostic criteria for autism were added to standard classification systems by the American Psychiatric Association (American Psychiatric Association, 1980) and the World Health Organisation (1978). Revisions to these criteria took place over subsequent editions, resulting in the current diagnostic criteria published in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994) and the International Classification of Diseases (ICD-10) (World Health Organisation, 1993), hereafter referred to as DSM-IV and ICD-10 respectively. The revisions have resulted in criteria which are now conceptually equivalent (Volkmar, 1998).

For a diagnosis of autism, both the DSM-IV and the ICD-10 require impairments in three key areas of development; (i) qualitative impairment in social interaction, (ii) qualitative impairments in communication, and (iii) restricted, repetitive and stereotyped patterns of behaviour, interests and activities. Each classification system lists symptoms within each of these three areas, requiring a total of at least six symptoms, with a minimum of two from the area of social interaction, and at least one each from the areas of communication and restricted, repetitive and stereotyped patterns of behaviour, interests and activities. Onset of the abnormalities or delays must be before the age of 3 years in the area of either social interaction or development of social attachments, language as used in social communication, or symbolic or imaginative play (American Psychiatric Association, 1994; World Health Organisation, 1993).

1.2 Prevalence

The American Psychiatric Association (1994) reports the prevalence of autism to be 2-5 cases per 10,000. The reported prevalence of autism has varied considerably across both time and place from as low as 3.1 per 10,000 (Treffert, 1970) to as high as 21.1 per 10,000 (Honda, Shimizu, Misumi, Niimi, & Ohashi, 1996) and even 31.0 per 10,000 (Arvidsson et al., 1997). This wide variability is likely to be due in part to the different diagnostic criteria used across epidemiological studies and differing methods of ascertainment of cases. A review of the prevalence literature by Fombonne (1997), taking into account the different definitions of autism and differing study methodologies, concluded that 5 - 5.5 per 10,000 was the best available and most robust prevalence estimate for autism. Other reviews have suggested a rate of approximately 1 per 1,000 (Fombonne, 1999; Gillberg & Wing, 1999), while a recent study of the prevalence of autistic disorder in preschool children in a defined region of England reported a rate of 16.8 per 10,000 (Chakrabarti & Fombonne, 2001).

The reported male to female ratio in autism has remained reasonably consistent across studies at 3 - 4:1 (Bryson, 1996). The rate of intellectual disability in autism is reported to be in the range of 75 - 80% (Bryson, 1996; Bryson & Smith, 1998), with the majority in the moderate to severe range of intellectual disability (American Psychiatric Association, 1994; Wing & Gould, 1979). It has been estimated that approximately 25% of people with intellectual disability also meet criteria for a diagnosis of autism (Bryson & Smith, 1998). Developmental regression (e.g. regression in language, social skills, play skills, cognition) after a period of normal development has been estimated to occur in approximately 20 - 49% of cases of autism (Hoshino et al., 1987; Kurita, 1985;

Rutter & Lord, 1987; Tuchman & Rapin, 1997). Such regression is usually first observed between 1 and 3 years of age (Tuchman & Rapin, 1997).

1.3 Aetiology and associated medical conditions

The cause of autism is currently unknown. Early theories of the cause of the disorder attributed the condition to parenting style, particularly to a cold, unresponsive, and detached style of mothering (Bettelheim, 1967; Kanner, 1973b). Research and clinical experience have proven this theory to be incorrect (Schopler, 1971), thus leading researchers to search elsewhere for causal factors.

Autism is currently recognised as being a neurobiological condition involving central nervous system dysfunction (Anderson & Hoshino, 1997; Minshew, Sweeney, & Bauman, 1997), the origin of which is unknown. The role of genetics in this condition is now also established, and autism has been identified as the most strongly genetically influenced of all multifactorial childhood psychiatric disorders (Rutter, Silberg, O'Connor, & Simonoff, 1999). Twin studies of autism have suggested a strong genetic liability (Bailey, Le Couteur, Gottesman, & Bolton, 1995; Folstein & Rutter, 1977; Steffenburg et al., 1989) and emphasised the broad range of social and communicative deficits across the normal range of intellectual ability (Folstein & Rutter, 1977). Family history studies, showing increased risk of autism in siblings (Baird & August, 1985; Bolton et al., 1994; Gillberg, Gillberg, & Steffenburg, 1992; Ritvo et al., 1989), also lend support to the notion of genetic influence. It is probable that there is a genetic aetiology or influence, but the precise nature of its role is yet to be determined. It is likely however, that autism is not a single gene disorder, and that multiple, interacting genes are involved (Bailey, Phillips, & Rutter, 1996; Rutter, Bailey, Simonoff, &

Pickles, 1997; Spiker, 1999). Statistical modelling techniques have estimated that the involvement of more than 10 genes is unlikely, with a model of 3 producing the best fit (Pickles et al., 1995).

It has been estimated that at least 25 - 30% of individuals with autism have associated medical conditions, for example sensory impairments, tuberous sclerosis, neurofibromatosis, and epilepsy (Bryson & Smith, 1998). However, a recent review of epidemiological studies concluded that there is no evidence of an association between autism and disorders such as neurofibromatosis, Down's syndrome, cerebral palsy, congenital rubella, or phenylketonuria (Fombonne, 1999). Fombonne's (1999) review concludes that the rate of medical conditions in autism is approximately 6%. Epilepsy occurs in approximately 20 - 35% of individuals (Bryson & Smith, 1998; Minshew et al., 1997; Tonge, Dissanayake, & Brereton, 1994), with a peak of onset in adolescence (Bryson & Smith, 1998). Higher rates of epilepsy have been reported in those with severe levels of mental retardation (Fombonne, 1999). Tuberous sclerosis has been calculated as occurring in 0 - 3.1% of those with autism (Fombonne, 1999).

1.4 Outcome

Long term follow-up studies of those diagnosed with autism have routinely found overall outcome to be poor. Around 50% of children with autism remain without useful communicative speech (Lord & Rutter, 1994). Less than 10% have been estimated as being able to lead independent lives in adulthood (Gillberg, 1991; Wing, 1989). Studies have found that in the majority of cases social, behavioural, and communication deficits and impairments persist through to adolescence and adulthood (Ballaban-Gil, Rapin, Tuchman, & Shinnar, 1996; Gillberg, 1998; Gillberg & Steffenburg, 1987; Larsen &

Mouridsen, 1997; Rutter, 1970; Rutter, Greenfeld, & Lockyer, 1967; von Knorring & Hagglof, 1993; Werry, 1996), with a poor to very poor outcome in at least 60% of samples. Such outcomes have also been reported in studies of children with high functioning autism (Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989). High levels of psychopathology, which persist over time have also been reported in children and adolescents with autism (Brereton, 1999).

However, outcome in autism is variable, as demonstrated in case studies of children with positive outcomes (Schwartz, Sandall, Garfinkle, & Bauer, 1998). Normal to good social adjustment was found in 14% of cases (9 out of 63) by Rutter, Greenfeld, and Lockyer (1967) in a longitudinal follow-up study of children diagnosed with infantile psychosis. In Japan, a follow-up study found that 43.2% of their sample of 201 children with autism showed improvement between 10 - 15 years of age (Kobayashi, Murata, & Yoshinaga, 1992), while Gillberg and Steffenburg (1987) reported fair to good outcomes in 17% of cases. A small study comparing outcome in those diagnosed with autism and those diagnosed with Asperger's Syndrome reported a fair to good outcome in 3 of the 9 cases with autism compared to a similar outcome in 7 of the 9 cases with Asperger's Disorder (Larsen & Mouridsen, 1997). A recent review of the outcome literature has concluded that a good outcome is seen in approximately 5 - 15% of cases, while a poor to very poor outcome in terms of social adjustment is seen in 60 - 75% of cases followed through to adolescence or early adulthood (Nordin & Gillberg, 1998).

A number of longitudinal studies in autism have also examined predictors of outcome in autism. As early as 1955 in a follow-up of 42 subjects, Kanner observed that the presence or absence of language in early childhood might have prognostic implications

(Kanner, 1973a). Since then, it has consistently been shown that IQ and language development are the most reliable predictors of outcome. Rutter and colleagues (Rutter et al., 1967) found 4 main variables which proved to show significant associations with outcome; namely IQ, speech (presence of useful speech by 5 years of age), severity of disorder, and amount of schooling (at least 2 years). Sex, evidence of brain injury, family situation, and the presence or absence of a period of normal development prior to the onset of the disorder were all found to be unrelated to outcome (Rutter et al., 1967). The prognostic value of psychiatric and psychological assessment was thus emphasised in this and subsequent studies of this longitudinal data (Lockyer & Rutter, 1969).

When Lotter conducted an 8 year follow-up study of his original epidemiological sample (Lotter, 1966), the best single predictor of outcome was a measure of speech (Lotter, 1974). In addition, speech and IQ together correlated more highly with outcome than any other combination of variables (Lotter, 1974). Similarly, Gillberg and Steffenburg (1987), found that the children with an IQ greater than 50 in their preschool years had a better outcome than those with an IQ of less than 50.

Communicative speech before the age of 6 years also contributed positively to outcome (Gillberg & Steffenburg, 1987). A longitudinal study in Japan which examined outcome in 201 young adults with autism also found IQ to be a good predictor of outcome (Kobayashi et al., 1992). In a review of the literature examining predictors of outcome in autism, Nordin and Gillberg (1998) concluded that the results of a cognitive assessment at the time of diagnosis is the single best predictor of outcome. It was also concluded that the absence of communicative speech by the age of 5 - 6 years is indicative of a poorer overall long-term outcome. It is also important to note that

longitudinal research has shown that IQ remains stable throughout childhood in children with autism (Lockyer & Rutter, 1969; Lord & Schopler, 1989; Rutter, 1983).

CHAPTER 2

EARLY DIAGNOSIS AND FEATURES

2.1 Early diagnosis

2.1.1 Age of recognition

It is generally accepted that the onset of autism is in infancy (Volkmar, Stier, & Cohen, 1985), within the first 30 months of life (Gillberg, 1989; Rutter, 1978). The age at which problems with development are first noticed or suspected has been asked of parents across a number of studies. One of the first studies in this area retrospectively surveyed the parents of 74 young children (mean age 3.77 years) with autism and found that approximately 50% of the families were concerned about their child's development by 12 months of age (Ornitz, Guthrie, & Farley, 1977). A similar study from Japan found that of the 129 parents surveyed, 71% reported that they had first noticed problems by the age of 2.5 years (Ohta, Nagai, Hara, & Sasaki, 1987). Over half of the parents (57%) reported first noticing problems between the ages of 18 to 30 months. Overall, the ages at which the parents of children with autism first noticed abnormalities in their children varied from 6 months to 3 years 10 months of age (Ohta et al., 1987).

A survey of the parents of 50 children with autism by Volkmar, Cohen, and Paul (1986) found the reported average age of onset to be 1.5 years, while in 44 of the 50 cases (88%) onset was reported as being between 2.5 and 4 years of age. A mean age of 13 months was reported in a study of the parents of 49 adolescents with severe mental retardation (Fombonne, 1995). The DSM-IV field trial for Autistic Disorder estimated the age of onset as being 12.7 months (Volkmar et al., 1994).

A survey of 1,800 subjects at the Division of the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) found that 52.2% of parents reported noticing something was wrong with their child at or before the age of 18 months (Short & Schopler, 1988). The average age of recognition of problems for this sample was 20 months. In a survey of the parents of 80 children with autism, De Giacomo and Fombonne (1998) reported an average age of recognition of 19.1 months. In a survey of 51 parents, Siegel, Pliner, Eschler, and Elliott (1988) found that parents expressed initial concerns to paediatricians by the time the child was 18 months of age. Rescorla (1986) reported that parents noticed clearly deviant behaviour before 30 months of age. A further survey of 173 parents of children with autism found that 65% of parents suspected problems with development before the age of 24 months (Frith & Soares, 1993). A similar survey undertaken by Smith, Chung, and Vostanis (1994) found that on average parents felt something was not right before the age of 18 months.

A large scale survey of 1,294 parents by Howlin and Moore (1997) found the average age at which parents first became aware of developmental problems to be 1.69 years. This survey found that almost half of the parents (48%) first became aware of developmental problems between the time of birth to 2 years of age, and that by the child's third birthday, the vast majority of parents (93.1%) had anxieties about their child's development (Howlin & Moore, 1997).

A small survey of the parents of 11 children with autism found that on average parents first noticed problems when the children were aged 13.86 months (Baranek, 1999). A comparison group of children with developmental disabilities without autism, reported first noticing problems on average at the age of 0.75 months. This large difference is

most likely to be due to the fact that 6 of the sample of 10 children with developmental disabilities had a diagnosis of Down's syndrome, which is usually identified at a very early age.

In summarising the results of these studies (see Table 2.1), the vast majority of parents suspect problems with their child's development well before the child is 24 months of age. Despite this, the average age at which parents first seek help for these problems has been reported as 27.6 months (range 1 month - 38 years) (Howlin & Moore, 1997) and similarly 24.1 months (De Giacomo & Fombonne, 1998). Howlin and Moore (1997) found that on average parents tend to wait 6 - 7 months from when they first become concerned about their child to when they first seek help, whilst 23% of parents waited up to 12 months and 9.4% waited up to 2 years (Howlin & Moore, 1997). Similarly De Giacomo and Fombonne (1998) reported that on average parents waited 5.2 months before first seeking help.

A number of these retrospective surveys asked parents whom they first consulted regarding their concerns. The majority first consulted either their general practitioner (GP) or health visitor (De Giacomo & Fombonne, 1998; Howlin & Moore, 1997; Smith et al., 1994), with a small proportion initially consulting a paediatrician (9.3%) (Howlin & Moore, 1997).

Table 2.1

Age of Recognition / Onset

| Study | N | Age of recognition of problems |
|-------------------------------|-------|--------------------------------|
| (Baranek, 1999) | 11 | mean of 13.86 months |
| (De Giacomo & Fombonne, 1998) | 80 | mean of 19.1 months |
| (Fombonne, 1995) | 49 | mean age of 13 months |
| (Frith & Soares, 1993) | 173 | 65% before 24 months |
| (Howlin & Moore, 1997) | 1,294 | mean age of 20.3 months |
| (Ohta et al., 1987) | 129 | 57% between 18 - 30 months |
| (Ornitz et al., 1977) | 74 | 50% by 12 months of age |
| (Rescorla, 1986) | 274 | before 30 months of age |
| (Short & Schopler, 1988) | 1,800 | mean of 20 months |
| (Siegel et al., 1988) | 51 | by 18 months of age |
| (Smith et al., 1994) | 127 | before the age of 18 months |
| (Volkmar et al., 1986) | 50 | mean of 18 months |
| (Volkmar et al., 1994) | 454 | mean of 12.7 months |

2.1.2 Age of diagnosis

Five studies have retrospectively surveyed parents in an attempt to establish the age at which their child was first diagnosed with autism (summarised in Table 2.2). A survey of 51 parents found the average age of diagnosis to be approximately 4.5 years of age (Siegel et al., 1988). A retrospective survey of 173 parents of children with autism aged 2 - 37 years, found that 30% of the sample were first professionally diagnosed at or before the age of 3 years (Frith & Soares, 1993). Forty-six per cent of the sample were diagnosed between the age of 3 - 5 years, 17% between the ages of 6 - 11 years, and 7%

at the age of 12 or above (Frith & Soares, 1993). A survey of 127 families in the United Kingdom divided the sample into an older (age range 10 - 20 years) and younger (age range 1 - 9 years) group (Smith et al., 1994). It was found that on average the younger group were diagnosed at a significantly earlier age than the older group (3.63 years compared to 6.89 years of age) (Smith et al., 1994). Another survey of 1,294 parents of children with autism in the United Kingdom found the average of diagnosis to be 6.11 years (Howlin & Moore, 1997). In the small study by Baranek (1999) parents reported an average age of diagnosis of 32.55 months, considerably higher than the average of 3.40 months reported by the parents of children with developmental disabilities without autism.

A review of the early intervention studies in autism has suggested that the optimal age for the commencement of early intervention is less than 4 years of age (Rogers, 1996). In light of this suggestion, diagnoses need to be made earlier than research indicates is current practice.

2.1.3 Difficulties of early diagnosis

There is a clear discrepancy between when parents first notice problems with their child's development and the age at which a diagnosis of autism is made. Table 2.2 provides a summary of the results of research examining the age at diagnosis, indicating that the vast majority of children are diagnosed with autism well after the age of 3 years. Comparison of this table with Table 2.1 reveals a marked contrast between the age at which parents recognise that their child has problems with development, and the age at which a diagnosis of autism is given. A delay of 4.42 years has been reported, from the time at which families first began to be concerned about their child's

development to the time they received a diagnosis (Howlin & Moore, 1997). A delay of 3.81 years from the time of first seeking professional help to receipt of a diagnosis has also been identified through this extensive survey of parents (Howlin & Moore, 1997).

Table 2.2

Age at Diagnosis

| Study | N | Age at diagnosis |
|------------------------|-------|---|
| (Baranek, 1999) | 11 | mean = 32.55 months |
| (Frith & Soares, 1993) | 173 | 0-3 years - 30% 3-5 years - 46% 6 + years - 24% |
| (Howlin & Moore, 1997) | 1,294 | mean = 6.11 years (73.32 months) |
| (Siegel et al., 1988) | 51 | mean = 4.5 years (54 months) |
| (Smith et al., 1994) | 127 | young group mean = 3.63 years (43.5 months) older group mean = 6.89 years (82.7 months) |

One of the reasons for this delay is attributed to the various difficulties and challenges of diagnosing autism in young children. An accurate diagnosis of autism in infants and young children involves differentiating autism from a variety of developmental disorders including mental retardation, hearing impairments, speech and language disorders, and severe attachment and neglect problems (Rogers, 2001). Baron-Cohen, Allen, and Gillberg (1992) and Stone and Hogan (1993) have highlighted the problem of using diagnostic criteria which emphasise areas of social and communicative development which are in general, difficult to assess in preschool children. Behaviours

can change rapidly during the early childhood period in all children (Lord, Storoschuk, Rutter, & Pickles, 1993). In young children with autism, symptoms can vary over time, and possibly present only intermittently (Ornitz, 1973), thus making careful and extended observation essential. This is often the case with repetitive and stereotyped behaviours, which are frequently not observed in short observation sessions in a clinical setting.

A follow-up study of children diagnosed with autism at 2 years of age found that a number of changes had occurred in the rates of behaviours by follow-up at 3 years of age (Lord, 1995). A number of items which were found to differentiate the children with autism from those with speech and language delays without autism at 2 years of age, were found to be more prevalent in the children with autism at age 3. These included abnormalities in understanding gesture, sharing enjoyment, greeting, social reciprocity, and directing attention, all of which showed higher rates in the children with autism. A number of behaviours decreased in prevalence in the children with autism from age 2 to age 3, including abnormalities in the use of another's body as a tool, interest in children, and unusual sensory behaviours. This study clearly demonstrates the behavioural changes that can occur in young children with autism within a brief period of time.

Difficulties in distinguishing between autism and mental retardation (Vig & Jedrysek, 1999) and language disorders without autism in young children (Marcus & Stone, 1993) also complicate the diagnostic process. The differentiation of children with autism with a mental age of less than 18 months from those nonverbal children with developmental delay without autism, or with language impairment has been identified as particularly

difficult, with a resulting over diagnosis of autism in these groups (Lord et al., 1993; Rutter, 1999). Difficulties potentially arise in this group of nonverbal, severely delayed children due to problems in differentiating deviance in their behaviour from severe global delay (Lord et al., 1993).

A lack of specialised training of primary health care professionals has also been proposed as a reason for the reported delays in diagnosis (Baron-Cohen et al., 1992; Ornitz, 1973; Vostanis, Smith, Chung, & Corbett, 1994). The relative rarity of the condition also contributes to this problem (Baron-Cohen et al., 1992) by reducing the amount of exposure to and knowledge of autism compared to other, more prevalent conditions, as does the shortage of specialist services (Chung, Smith, & Vostanis, 1995; Vostanis et al., 1994). Early attempts to overcome this difficulty were made by authors such as Prior and Gajzago (1974) who published a list of signs to aid medical practitioners in early detection.

The relative scarcity of assessment measures designed to be used specifically with young children and standardised assessment procedures have also contributed to the difficulty in diagnosing autism in young children (Chung et al., 1995; Vostanis et al., 1994). Difficulties have also been attributed to a reluctance to apply the diagnosis in preschool children, due to concerns over unduly alarming parents, or labeling children prematurely (Marcus & Stone, 1993). The fear of litigation if a diagnosis is proven to be incorrect is also likely to be a contributing factor.

2.1.4 Stability of early diagnosis

Despite the difficulties of diagnosing autism in preschool children and the concerns inherent in diagnosing in early childhood, autism has been recognised as one of the most reliably diagnosed disorders in child psychopathology (Lord, 1991). Further, a number of studies have shown that the diagnosis of autism in preschool children remain stable over time.

Gillberg et al. (1990) followed up 21 children who were given a preliminary diagnosis of autism at 8 - 35 months of age. At follow-up 6 - 13 months later, 20 were found to meet criteria for a diagnosis of autism both by the author and by an independent psychiatrist. In a study of 30 children aged 25 - 35 months with delayed speech and language only 3 changed diagnostic classification when re-evaluated at age 3 by a clinician blind to the results of the initial assessment (Lord, 1995). One child met criteria for autism at age 2, but not at age 3, and 2 children who did not receive a diagnosis of autism at age 2, met diagnostic criteria at age 3. A study examining the accuracy of autism diagnoses in children under 3 years of age demonstrated that of the 25 children who received a diagnosis at age 2, 24 remained on the autism spectrum (Autistic Disorder or Pervasive Developmental Disorder Not Otherwise Specified – PDD NOS) at approximately age 3, whilst 18 retained a specific diagnosis of autism (Stone et al., 1999) at reassessment by clinicians blind to the results of the first assessment.

A sub-sample of 11 children from a study assessing the psychometric properties of the Infant Behavioral Summarized Evaluation (IBSE) (Adrien, Barthelemy et al., 1992), were diagnosed with autism prior to the age of 2 years. Re-examination of these 11

children after the age of 3 years confirmed the diagnosis in all cases (Adrien, Barthelemy et al., 1992). Results of a prospective screening study of autism in children have shown that of the 10 children who received a diagnosis of autism at 18 months, all 10 had the diagnosis confirmed at 42 months of age (Baron-Cohen et al., 1996; Swettenham, 1996). No information was given in the studies by Adrien et al. (1992) and Baron-Cohen et al. (1996) as to whether those who conducted the diagnostic assessments at the second evaluation did so blind to the results of the initial evaluation and diagnosis.

2.1.5 Importance of early diagnosis

The parents of children with autism face a considerable number of stressors (Marcus, Kuncze, & Schopler, 1997). These may include failure on the part of professionals to provide an accurate and informative description of their child's problems, confusion regarding treatment options, the unresponsive and aloof nature of their child, and difficult behaviour in public (Marcus et al., 1997). Other stressful factors can include feelings of frustration, guilt, anger, depression, disappointment, resentment over having a disabled child, and marital and financial difficulties (Harris, 1994; Howlin et al., 1987; Rutter, 1985). The general effects of having a child with autism were demonstrated in the reports of the interviews conducted by DeMyer (1979), with parents describing feelings of guilt, anger, sadness, failure, and a general lessening of joy in life.

Comparisons of children with autism, Down's Syndrome, and developmental delay have found that the parents of a child with autism report higher levels of stress and more difficulties with adjustment (Sanders & Morgan, 1997). Children and adolescents with

autism have also been shown to have higher levels of behavioural and emotional disturbance when compared to children and adolescents with an intellectual disability without autism, children with Fragile X Syndrome, and children with Down's Syndrome (Brereton, 1999). These high levels of disturbance have been demonstrated to be reasonably stable over a 9 year period of time (Brereton, 1999), thus providing a source of ongoing difficulty for parents.

Many parents of children with autism have great difficulties actually obtaining a diagnosis of their child's disorder. Parents have reported that obtaining a referral to a specialist is often a difficult and frustrating process (Howlin & Moore, 1997). At their first consultation parents are all too frequently told that there is no cause for concern (Howlin & Moore, 1997). This unsatisfactory outcome is also reported by 20.5% of parents at second referral and even at 10% of subsequent referrals (Howlin & Moore, 1997). Such difficulties and frustrations in actually obtaining an answer to or acknowledgement of the concerns of a parent in relation to their child's development are an undeniable source of worry and stress.

Although there is some emerging evidence that some treatments, such as applied behavioural analysis (Lovaas, 1987) and programs offered by Division TEACCH (Mesibov, 1997; Ozonoff & Cathcart, 1998) might be of benefit, no clearly efficacious comprehensive treatment has yet been empirically established for autism (Rogers, 1998). There is also a lack of randomised controlled studies in early intervention for children with autism (Smith, 1999). However, there is consensus that children seem to benefit most when intervention is started early (prior to 4 years of age) (Harris & Handleman, 2000; Rogers, 1996). It has been speculated that although the full effects

of early intervention are as yet largely unknown, it has the potential to contribute to the prevention of the development of maladaptive behaviours and improvement in the parents' understanding, acceptance and mental health, thus influencing a family's ability to cope and deal with their child's disorder (Baron-Cohen et al., 1996). Difficult behaviour can escalate if left untreated and may become entrenched and beyond the control of parents, making later intervention extremely difficult or unsuccessful (Howlin & Yates, 1989). Assisting parents to develop skills and strategies to deal with problems when they first arise has the potential to improve parental mental health and reduce later child behaviour problems and family stress (Howlin & Moore, 1997).

There are a number of benefits to the early identification of children with autism. Early diagnosis of autism facilitates the provision of early and appropriate intervention (Baron-Cohen et al., 1996; Chung et al., 1995; Filipek et al., 1999; Marcus & Stone, 1993; Vostanis et al., 1994), and the provision of early support and alleviation of parental distress (Baron-Cohen et al., 1996; Howlin, 1999; Vostanis et al., 1994). Delays in obtaining a diagnosis can lead to frustration and distress for parents (Chung et al., 1995; Howlin, 1999) and delay clinical treatment and appropriate education (Chung et al., 1995). The recognition of the genetic basis of autism also has implications for genetic counselling and family planning (Howlin, 1999).

It is clear that if children with autism and their families are to receive the timely treatment and support they require, early diagnosis of autism is essential. Early and specialist diagnosis also requires the provision of preventive interventions (Howlin, 1999). Surveys of parents have supported this view, emphasising the importance of

early diagnosis and the need for support, practical help, and counselling after diagnosis (Howlin & Moore, 1997; Smith et al., 1994).

2.2 Features of autism in infants and young children

2.2.1 Initial concerns of parents

A number of studies have focused on the developmental problems that first cause the parents of children with autism to feel that something is wrong with their child. The most frequently reported initial concerns of parents are in the area of language and communication. All of the surveys of parents initial concerns reveal that delays in speaking and other language and speech problems are the symptoms which they are most concerned about, followed by abnormalities in social development such as being indifferent to or upset by social approaches, and having poor relationships with peers (De Giacomo & Fombonne, 1998; Frith & Soares, 1993; Howlin & Moore, 1997; Ohta et al., 1987; Siegel et al., 1988; Smith et al., 1994). Other areas of initial parental concern include rituals / stereotypies, sleeping or feeding problems, motor delay, emotional problems, medical problems (Frith & Soares, 1993), a lack of responsivity to others, and a lack of imaginative play (Smith et al., 1994).

A survey from Japan found that 84% of parents reported their initial concern to be delayed speech and or other speech problems (Ohta et al., 1987). Other reported initial concerns included poor response to others (55%), restlessness and hyperactivity (45%), ignoring verbal commands as if deaf (32%), and not being good at forming personal relationships (26%) (Ohta et al., 1987). Siegel et al. (1988) found that 98% of parents

reported concerns in the areas of language development, social development (84%) and motor milestones (34%). The parents of 80 children with autism surveyed by De Giacomo and Fombonne (1998) noted concerns in the areas of language and speech development (74.4%), medical problems or a delay in milestones (25.6%), abnormal socio-emotional response (39%), nonspecific behavioural difficulties (25.6%), and autistic-type behaviours (14.6%). When asked about their first concern over half of the parents (53.7%) nominated language and speech development (De Giacomo & Fombonne, 1998).

An extensive survey conducted by Howlin and Moore (1997) found that while a substantial proportion of parents reported a delay in talking or other language problems as the behaviour which first gave them cause for concern (40.9%), 19.3% reported abnormalities in social development, 12.7% general behavioural problems (e.g., tantrums), 7.1% delays in motor milestones, and 5.6% concerns about hearing. A further 3.7% of parents nominated ritualistic and obsessional behaviour as their primary cause for concern, 2.2% cited medical problems (e.g., epilepsy), 1.5% failure to develop normal play, and 3.8% 'other' (including toileting and eating problems, concerns about schooling). The remaining 3.1% reported no worries until a professional expressed concern (Howlin & Moore, 1997).

It is clear that the most prevalent early cause for concern in the parents of children diagnosed with autism is a lack of speech and language development. However, it is not clear whether these observed early delays are autism specific or an early symptom of nonspecific developmental delay (De Giacomo & Fombonne, 1998; Johnson, Siddons, Frith, & Morton, 1992). A study of infant developmental screening in the UK

found that autism specific symptomatology, such as deficits in the area of social development and lack of responsiveness to people, was not evident until 18 months of age (Johnson et al., 1992), supporting the general finding that parents' earliest concerns are not in the area of autism specific behaviours. It has been reported that once developmental level is controlled for, concerns about speech and language do not influence the age of recognition of problems (De Giacomo & Fombonne, 1998), suggesting that developmental delay is the primary factor being identified by parents. Children with more severe autistic symptomatology (as measured by the Childhood Autism Rating Scale) have not been shown to be identified any earlier than those with less severe symptomatology (Rogers & Di Lalla, 1990). However, it has been suggested that the more severe the cognitive impairment, the earlier difficulties and problems are observed by parents (Short & Schopler, 1988).

2.2.2 Early features

A variety of methodologies have been used by researchers in an attempt to establish the early identifying features of autism in preschool aged children (children under 6 years of age). These have included individual case studies, analyses of the home movies taken by parents of children who go on to receive a diagnosis of autism, retrospective reports from parents, and a small number of prospective studies. The most limiting factor to the findings of a number of these studies is the lack of a developmentally delayed or intellectually disabled comparison group. Due to the high rate of intellectual disability in children with autism, the lack of such a comparison group makes it impossible to know whether the features identified as early indicators of autism are unique to children with autism, or are a characteristic of children with intellectual disability. The findings of the research on the early features of autism will therefore be

examined within three groups – uncontrolled studies, controlled studies, and prospective studies.

2.2.2.1 Uncontrolled studies

Case studies, clinical descriptions, home movies, and retrospective surveys provide some preliminary indications of potential early features of autism in children. However, the lack of control or comparison groups does not enable any firm conclusions regarding early identifying features of autism to be drawn from this research.

Case studies and clinical descriptions have included the original work in the field of autism by Kanner (1943), accounts of case histories (Clancy & McBride, 1969; Eriksson & de Chateau, 1992; Polan & Spencer, 1959), and prospective case studies (Dawson, Osterling, Meltzoff, & Kuhl, 2000; Sparling, 1991). Features of autism identified by these studies are summarised in Table 2.3.

A number of researchers have used home movies and videotapes made by parents as a means of investigating the early features of children with autism (Adrien, Faure et al., 1991; Bernabei, Camaioni, & Levi, 1998; Maestro, Casella, Milone, Muratori, & Palacio-Espasa, 1999). This methodology has the advantage of not being subject to the accuracy of retrospective recall of parents, but is disadvantaged by the fact that the films are often limited in their content and in some cases lack sound. Parents usually make such films as a record of a significant event in the life of their child and family. As a result, they are typically of a child's birthday, Christmas, or other similar event. As they are intended as positive celebrations, they are unlikely to include the full range

of a child or infant's disturbed behaviour. Features of autism identified by these studies are summarised in Table 2.4.

Table 2.3

Uncontrolled Case Studies and Clinical Descriptions: Early Features of Autism

Identified*

| Features of autism | | |
|---|---|---|
| • delayed / deviant speech | • considered deaf | • echolalia |
| • lack of ability to form social relationships | • failure to adjust body / posture to that of person holding them | • does not organise perceptions meaningfully |
| • slow to learn 'yes' | • conformity an effort | • activities lack purpose |
| • does not smile | • does not respond to name | • has ability to classify objects |
| • unresponsive to affection | • easily frustrated | • mechanical repetition of activity |
| • failure to assume anticipatory posture prior to being picked up | • unresponsive to human voice | • obsessive-compulsive characteristics |
| • hyperactivity | • hand flapping | • withdrawn |
| • distractible / short attention span | • reduced / deviant preverbal vocalisations | • hypersensitivity to approach, touch, loud noise |
| • rocking and head banging | • sensorimotor difficulties | • autonomic over arousal |
| • toe walking | • sleeping difficulties | • does not engage in imitative games |
| • quiet and undemanding | • irritable when disturbed | • lazy suckers, requiring long feeding periods |
| • limited eye contact | • inattentive | • perseveration with one activity |

*(Clancy & McBride, 1969; (Dawson, Osterling, Meltzoff, & Kuhl, 2000; Eriksson & de Chateau, 1992; Kanner, 1943; Polan & Spencer, 1959; Sparling, 1991)

Table 2.4

Uncontrolled Home Movie Studies: Early Features of Autism Identified*

| Features of autism | | |
|---|---|---|
| • abnormal eye contact | • lack of attention | • motor abnormalities |
| • lack of variability of emotional expression | • failure to initiate communication | • lack of anticipatory movements / postural |
| • absence of smiles | • lack of facial expressions | • tendency towards isolation |
| • hand flapping | • too quiet | • emotional lability |
| • obsessive / stereotypic behaviour | • lack of protective movements | • anxiety when faced with new situations |
| • self-stimulation | • lack of social interest | • lack of social turn-taking |
| • lack of pretend play | • lack of social games | • mood disturbance |
| • difficulty dealing with objects | • vocalisations stereotyped / echolalic | • bizarre posture / movement / mimicry |
| • difficulties communicating by gestures | • declarative pointing / showing rare | • stereotyped sensorimotor activity |
| • intolerance of frustration | | |

*(Adrien, Faure et al., 1991; Bernabei et al., 1998; Maestro et al., 1999)

A number of researchers have retrospectively surveyed parents on the early behaviours of their children diagnosed with autism or reviewed the case files of children with autism for details on early development (Greenspan & Wieder, 1997; Stone, Hoffman, Lewis, & Ousley, 1994; Volkmar et al., 1986). Features of autism identified by these studies are summarised in Table 2.5.

Table 2.5

Uncontrolled Retrospective Surveys: Early Features of Autism Identified*

| Features of autism | | |
|--|--|--|
| • ignores people | • emotionally distant | • avoids eye contact |
| • looks through people | • fails to show affection / interest when held | • poor speech tone / rhythm |
| • pronoun confusion | • echolalia | • ignores toys |
| • absence of imaginative play | • abnormal social play | • regression in 2 nd / 3 rd year |
| • lack of complex gestures | • lack of awareness of others | • impaired imitation |
| • preoccupied with spinning / whirling objects | • abnormal nonverbal communication | • fails to respond to noises that others notice |

*(Greenspan & Wieder, 1997; Stone et al., 1994; Volkmar et al., 1986)

None of the studies of early features of autism described thus far were controlled. That is, they did not compare the early behaviour of the infants with autism with that of typically developing infants or with that of infants with developmental delay. In light of this design feature, it is possible that the behaviours described as early indicators of autism are neither unique nor specific to autism, thus substantially limiting the conclusions that can be drawn from this research.

2.2.2.2 Controlled studies

A number of studies have been conducted which compared the features of young children with autism to typically developing children, children with developmental delay, or to clinical samples. These have included a case study, home movie studies, and parental reports.

2.2.2.2.1 Controlled case studies

One case study has been reported which used a typically developing child as a comparison (Kubicek, 1980). This case study involved observations from a filmed interaction between a mother and her 16 week old son who was later diagnosed with autism. A similar filmed interaction between the mother and the child's fraternal twin was available for comparison. The twins were originally filmed as part of a longitudinal study of genetic influences on social development. The first twin was diagnosed with autism at the age of 2½ years, while his brother developed normally. Features observed in the twin later diagnosed with autism included: a lack of eye contact with the mother, a lack of facial expression, gaze directed towards the ceiling, head turned away from the mother, and rigid posturing. None of these features were noted in the interaction between the mother and the typically developing twin.

2.2.2.2.2 Controlled home movie studies

The first author to make use of home movie material was Massie (1978a; 1978b). In the first of these studies, Massie (1978a) compared movies of 15 typically developing children with those of 13 children later diagnosed with early childhood psychoses. The focus of the study was mother-infant reciprocal interaction, focusing specifically on feeding, holding, eye gaze, and touching. Ratings by judges blind to diagnosis showed

that in each category the typically developing infants and their mothers achieved higher scores in the area of attachment than the mothers and infants later diagnosed with early childhood psychoses. For all modalities of child and maternal behaviour, there was a trend towards poorer ratings in the early childhood psychoses group compared to the typically developing group. However, there were no significant differences between the two groups for eye gaze and touching. Massie (1978a) speculated that the group of children who later received diagnoses of early childhood psychoses, received a different and less positive form of mothering than the typically developing children, but stressed that this did not imply that style of mothering caused the psychosis.

In the second of these studies conducted by Massie (1978b), home movies of 10 children later diagnosed with early childhood psychoses were analysed and compared to movies of 10 children with no psychiatric diagnoses. The movies were analysed frame-by-frame for information on the nature of the social interaction between the mother and infant, initial signs of pathology, signs of abnormalities of motor development, and indications of neurological abnormality. Signs of abnormal development which were observed in 4 or more of the cases before 24 months of age, included flaccid body tone, a lack of attentiveness or response to people, lack of excitement in the presence of their parents, vacant / unfocused gaze, less than normal activity, little smiling, self-absorption, lack of visual pursuit of people, avoidance of their mother's gaze, hand flapping, plasticity of expression, uncoordinated body movements, flattened affect, and little or no purposeful activity. It was noted that in 9 of the 10 cases that were later diagnosed with early childhood psychoses, the parent's behaviour was described as being inappropriate from the earliest weeks of life. Examples given of this inappropriate behaviour included not allowing the child to attach to the parent, for

example through the use of eye-to-eye gaze or chest-to-chest contact, and not allowing reciprocation of their child's attachment through frequent inattention to their child's intention, activity, mood, or affect. It has been noted however, that due to the fact that such parenting was present from the earliest weeks of life, it is unclear whether the differences observed in the children studied were due to innate child differences or disturbed patterns of parenting (Stone, 1997).

Rosenthal, Massie, and Wulff (1980) used home movies made by parents of children later diagnosed with childhood psychoses and a typically developing group of children to examine cognitive development in the first 2 years of life, with a focus on the sensorimotor period. Each group consisted of 14 children (9 males and 5 females). Differences in cognitive development were found between the groups of children. A number of the children who were subsequently diagnosed with childhood psychosis were seen to progress through the sensorimotor period of cognitive development, but at a slower rate than the typically developing children. Other prepsychotic children appeared to be fixated at earlier stages of sensorimotor development.

Lösche (1990) compared a group of 8 children later diagnosed with autism to 8 typically developing children in the areas of sensorimotor and action development. Ratings made by independent raters blind to diagnostic status revealed that the children differed significantly in their development along the stages of sensorimotor development, and that these differences were especially apparent in the 22 - 42 month age period. It was found that while actions by the children with autism became less frequent during the age of 22 - 30 months, actions in the group of typically developing children increased. Joint social play was demonstrated in one-third of all episodes for

both groups during the 13 - 21 month age period, however in the 22 - 30 month age period this decreased to one-quarter of all episodes for the children with autism and increased to half of all episodes for the typically developing group of children. Differences between the two groups in the amount of symbolic play were noticeable after 30 months of age, with the children with autism showing no symbolic play.

Adrien and colleagues (1993; 1991; 1992) have conducted a number of studies using footage from home movies in an attempt to identify early features of autism. In one such study a group of 10 children diagnosed with autism and atypical autism, DSM-III-R (American Psychiatric Association, 1987) criteria, 8 of whom were male, were compared to a group of 10 typically developing children. The films of important events in the first 2 years of the children's lives were analysed using the 33-item Infant Behavioral Summarized Evaluation scale (IBSE) (Adrien, Barthelemy et al., 1992) by raters blind to diagnosis. Each film was rated twice, at the end of the child's first year and at the end of their second year. Auditory items were unable to be rated, as the films had no sound. Comparisons between the two groups before 12 months of age found 9 behaviours which significantly differentiated the children with autism from the typically developing children: (i) poor social interaction; (ii) no social smile; (iii) lack of appropriate facial expressions; (iv) lack of appropriate gestures and/or expressive postures; (v) too calm; (vi) hypoactivity; (vii) hypotonia; (viii) no expression of emotions; and (ix) unstable attention, easily distracted. Comparisons made after the age of 12 months found that the symptomatology was more marked, with the raters giving higher scores for the items and the addition of 5 more symptoms which differed significantly between the children with autism and the typically developing children. These items were ignores people, prefers aloneness, no eye contact, stereotyped

behaviour, and unusual postures. The increase in the intensity and frequency of symptomatology in the children with autism after 12 months of age was not observed in the typically developing children.

A similar study examined films of 11 male children when they were 0 - 2 years of age (Adrien, Perrot et al., 1992). Ten of the films were made before any pathology was suspected. A control group of 5 typically developing children for whom films were made during the same age period and in similar situations was used as a basis for comparison. Analysis of symptomatology revealed 5 types of abnormal behaviour which were observed before any pathology was suggested: (i) no or abnormal eye contact, (ii) problems with expression / understanding of emotions, (iii) poor social interaction, (iv) disorders of motor tone and behaviour, and (v) atypical behaviours (odd, stereotyped behaviour). Nineteen items in the areas of socialisation, communication, adaptation to environmental situations, tactility-tone-motility, emotional and instinctual reactions, and attention-perception were regularly scored in the children with autism. Specific items in the area of socialisation included ignores people, prefers to be alone, poor social interaction, and no eye contact. Items in the area of communication consisted of a lack of appropriate facial expressions, no social smile, and a lack of appropriate gesture and/or expressive postures. Hypoactivity and hyperactivity constituted the items in the adaptation to environmental situations category. In the area of tactility-tone-motility, specific items included stereotyped behaviour, hypotonia, unusual postures, too calm, and overly excited. Heteroaggressiveness, autoaggressiveness, and no expression of emotions made up the category of emotional and instinctual reactions. The final area, attention-perception, was characterised by unstable attention, distractibility, and abnormal eye contact.

A further study by Adrien, and colleagues (1993) comparing the home movies of 12 children with autism to those of 12 typically developing children further supported the results of the previous publications of this research group. Analyses revealed 13 items of the IBSE (Adrien, Barthelemy et al., 1992) which differed between the children with autism and those with typical development in their second year of life. These items were: ignores people, prefers aloneness, poor social interaction, no social smile, no eye contact, lack of appropriate facial expressions, lack of appropriate gestures and/or expressive postures, too calm, hypoactivity, hypotonia, unusual postures, no expression of emotions, and unstable attention / easily distracted.

Other studies using home movies taken by parents have also used typically developing children as a basis for comparison. Osterling and Dawson (1994) examined the home movies of children's first birthdays. A comparison of 11 children with autism and 11 typically developing children revealed fewer joint attention behaviours and significantly more autistic symptoms in the children with autism. Four behaviours were found to correctly classify 10 of the 11 children with autism and 10 of the 11 typically developing children: (i) pointing, (ii) showing objects, (iii) looking at the face of another, and (v) orienting to name.

Another study which used the same behavioural coding system as Osterling and Dawson (1994), compared 25 children with Autistic Disorder (10 children) or PDD NOS (15 children) with an age matched group of 25 typically developing children (Mars, Mauk, & Dowrick, 1998). Analysis of the home videos of a social event taken when the children were aged between 12 and 30 months revealed significant differences

between the groups. Follows verbal directions, looks at faces, shows objects, alternates gaze, looks at people, points with gaze, expresses words, and imitates verbalisations all occurred with greater frequency in the typically developing children, and were found to significantly differentiate the children with Pervasive Developmental Disorder from the those in the control group. A discriminant analysis using the items follows verbal directions, speaks words, looks at faces, imitates vocalisations, fails to orient to name, points vaguely, exhibits alternating gaze, and shows objects was found to accurately identify all cases of Autistic Disorder. All the cases of PDD NOS were correctly identified as being on the Pervasive Developmental Disorder spectrum, although 6 were identified as cases of Autistic Disorder. Interestingly, a discriminant analysis using only the item 'looks at faces', was found to correctly identify 7 of the 10 children later given a diagnosis of Autistic Disorder, but only 5 of the 15 children diagnosed with PDD NOS. The authors concluded that factors of joint attention were the strongest early indications of being within the autism spectrum (Mars et al., 1998).

A study by Baranek (1999) focusing on sensory-motor measures and social behaviours utilised home video material of children when they were 9 –12 months of age. This study compared the behaviours of 11 children with autism, 10 children with developmental disabilities, and 11 typically developing children. The author used behavioural categories devised from a literature review to compare the behaviours of the children. Nine variables were found to differ significantly between the groups: (i) object play, (ii) looking at camera, (iii) unusual posturing, (iv) number of name prompts, (v) orientation to visual stimuli, (vi) mouthing objects, (vii) social touch aversions, (viii) visual staring / fixation on objects, and (ix) affect rating.

More stereotyped inappropriate play was observed in the developmentally disabled group along with less looking at the camera compared to the autism and typically groups. Unusual posturing was observed with greater frequency in the developmentally disabled and autism groups compared to the typically developing group of children. The autism group required more prompting to respond to their name, responded less visually, and tended to mouth objects more often compared to the other two groups. Social touch aversions were found to be more common in the autism group, while visual staring / fixation on objects was more common in the developmentally disabled group. Lower affect ratings were obtained for the developmentally disabled group in comparison to the other two groups.

The nine behaviours for which differences were found were entered into a discriminant function analysis. Overall 93.75% of the subjects were correctly classified, 90.9% of the autism group, 90% of the developmentally disabled group, and 100% of the typically developing group. A second discriminant function analysis was run with just the autism and developmentally disabled groups, with an overall correct classification rate of 95%, with 100% of the autism group being correctly classified and 90% of the developmentally disabled group.

A study by Werner, Dawson, Osterling, and Dinno (2000) examined home video footage of 15 children later diagnosed with autism spectrum disorders, 8 of whom were later diagnosed with Autistic Disorder and 7 with PDD NOS, according to DSM-III-R criteria (American Psychiatric Association, 1987). Three of these children were described as having late-onset autism; that is their parents reported the absence of symptoms prior to the end of the child's second year of life. These tapes were

compared to those of a group of 15 typically developing children. The videos consisted of footage filmed when the children were 8 - 10 months of age. The videos were coded within three categories: (i) social behaviour, (ii) communication behaviour, and (iii) repetitive behaviours. No significant differences were found between the groups. However, when the three children with late onset autism were removed from the sample, the children with autism were found to be less likely to orient to their name being called than were the typically developing children. A tendency for the children with autism to be less likely to look at another person while smiling was also reported, although this did not reach the level of significance.

Although these studies of behaviours of children with autism observed in home movies used comparison groups, all of the studies, with the exception of Baranek (1999), used typically developing children as controls. This results in a set of differentiating behavioural features, which may simply be a feature of developmental delay in the children with autism, rather than inherent early features of autism. All of these studies consisted of small sample sizes, thus further limiting any conclusions to be made from their findings. A further issue relates to the use of the term 'childhood schizophrenia' or 'childhood psychosis' employed by some of the earlier studies (e.g. Massie, 1978a; Massie, 1978b). Prior to research which established that autism was not the childhood manifestation of adult schizophrenia (Kolvin, 1971; Kolvin, Garside, & Kidd, 1971; Kolvin, Humphrey, & McNay, 1971; Kolvin, Ounsted, Humphrey, & McNay, 1971; Kolvin, Ounsted, Richardson, & Garside, 1971; Kolvin, Ounsted, & Roth, 1971) and the introduction of the diagnostic category of Pervasive Developmental Disorders in DSM-III (American Psychiatric Association, 1980), this was the only official diagnosis available for use with children with autism. This results in a body of research which is

difficult to interpret due to confusion regarding the exact diagnostic status of the subjects.

2.2.2.2.3 Controlled group comparisons - comparisons with typically developing infants, developmentally delayed infants, and clinical samples

As conclusions from the findings of research studies which did not use control or comparison groups are limited, a number of researchers have employed controlled group comparison designs. Comparison groups have included typically developing children, children with developmental delay, and clinically derived samples.

In the late 1970's Ornitz, Guthrie, and Farley (1977; 1978) compared the behaviour of 74 children with autism aged 16 - 75 months to that of 38 age matched typically developing children. The parents of the children completed a symptom inventory prior to being given any diagnostic information about their child. Using retrospective reports of the first and second years of the children's lives, the first study found significant delays in the development of the children with autism (Ornitz et al., 1977). These delays were noted in the areas of motor abilities, speech, early communication, verbal comprehension, and to a lesser extent, perception of surroundings. The children with autism were found to differ significantly from the typically developing children on a large number of items specific to the area of social relating. On all of these items, the behaviours were more common in the children with autism. The items were: very hard to reach, ignores people as if they did not exist, avoids looking people directly in the eye, acquires things by directing another's hand, looks or walks through people as if they did not exist, responds to being held by clinging without interest, responds to affection by ignoring, responds to being held by becoming rigid, seems unaware of

mother's absence, responds to being held by going limp, seems not to need the mothering person, and becomes agitated or frightened by unfamiliar persons (Ornitz et al., 1978).

A significantly larger percentage of typically developing children were found to respond to affection with pleasure, give a responsive smile to the mothering person, respond to being held by cuddling, and to show a normal interest in toys (Ornitz et al., 1978). The children with autism were also found to differ significantly from the typically developing children on a number of items relating to speech: repeats questions instead of answering them, repeats words or phrases from the past with little relation to the present, uses speech with poor tone or rhythm, misuses or mixes up pronouns, asks for something by repeating the sentence used by others, and uses hollow-sounding speech. All of these behaviours were more common in the children with autism.

The children with autism were found to differ significantly from the typically developing children on a number of items relating to sensory perception: ignores or fails to respond to sounds, excessively watches the motions of his hands or fingers, stares into space as if seeing something that was not there, preoccupied with things that spin, lets objects (toys) fall out of his hands as if the object did not exist, preoccupied with minor details, preoccupied with the feel of things, agitated at being taken to new places, dislikes or refuses to hold / chew food in his mouth when first offered table foods, agitated by loud noises, agitated when being tossed playfully in the air, flicks objects away as if to make them disappear, agitated when riding in an elevator, unaware of painful falls and bumps, preoccupied with unimportant noises, agitated by things that

feel rough, and is preoccupied with odours ignored by others. Again, all of these behaviours were found to be more common in the children with autism.

A number of items in the area of repetitive and stereotyped patterns of behaviour and interests were also found to be significantly different between the two groups: flaps his arms or hands in a repetitive way, whirls around without apparent reason, rocks his head or body, maintains a fixed uncomfortable position, runs or walks on his toes, bangs his head, ignores toys as if they did not exist, physically able to do things but rather does not want to do them, does something over and over again, uses toys in a bizarre way, becomes attached to an unusual object, repeatedly rearranges toys, and agitated when given new toys or clothes. Similar to the behaviours listed previously, these behaviours were also more common in the children with autism. Although no one symptom was reported to be present in all of the children with autism, 85 - 90% of children were reported to ignore people as if they did not exist and to be emotionally very hard to reach (Ornitz et al., 1978).

As was discussed in relation to the studies which used home movies to compare the behaviour of children with autism and typically developing children, reports of comparisons between children with autism and typically developing children using the reports of parents are also unable to conclude whether the listed behaviours are autism specific or a function of common cognitive deficits. In an effort to address this issue, research has been conducted comparing the early features of children with autism with those of developmentally delayed children without autism, as well as typically developing children. Such comparisons enable more definitive conclusions to be made regarding autism specific features in young children.

The early symptoms of autism were examined in a group of 85 children with autism by Hoshino and colleagues (1982). Two comparison groups were used; one consisting of 150 typically developing children and the other of 64 children with developmental delay. In interviews, parents were asked to recall their child's behaviour before the age of 2 years. Analyses revealed 27 early symptoms of autism. These were divided into four groups: (i) personal relations disorder, (ii) perception disorder, (iii) sleeping disorder, and (iv) setback course.

In the category of personal relating, features such as not looking at others, not imitating others, being indifferent to others, no reaction when called by name, not being bashful with strangers, fond of being alone, having an expressionless face, not following the mother, not getting into the habit of being held, behaving as if deaf, not smiling at mothers, not smiling at others, not following the mother visually, and having no interest in playing peek-a-boo were identified. Abnormalities in the area of perception consisted of being hypersensitive to the taste of foods and being insensitive to pain. The third group of behaviours, disorder of sleeping, involved irregular arousal rhythm and short hours of sleep.

The term 'setback course' was used to describe a group of behaviours involving the loss of previously acquired words, loss of the capacity to imitate, and becoming incapable of pointing at objects. Other symptoms characteristic of the children with autism which were significantly different across the groups included being overly quiet, running away when not watched, having an intelligent-looking face, being indifferent to animals, hating to be held, and smiling with an empty expression.

A diagnostic questionnaire was used by Ohta, Nagai, Hara, and Sasaki (1987) to examine the kinds of behaviour that parents observed in their children with autism when they were young. The types of behaviour that were observed in the children with autism were compared to the reports of early symptoms by parents of children with developmental delay. The samples consisted of 141 children with autism and 33 children with developmental delay. It was found that items concerning delayed speech and/or other speech problems, along with items regarding social behaviour were reported more frequently by parents as early symptoms in the group of children with autism than in the group of children with developmental delay. Specifically, a lack of ability in forming interpersonal relationships, poor response to others, poor relationships in peer group situations, and ignoring verbal comments as if deaf were reported significantly more often as features of the children with autism.

Dahlgren and Gillberg (1989) retrospectively compared the behaviour of 26 children with autism to 17 age and sex matched mentally retarded children and 22 population representative children, also age and sex matched. Parents completed a 130 item questionnaire regarding their child's behaviour in the first 2 years of life. Items which differentiated the children with autism from those with mental retardation and from the population representative sample were in the areas of social behaviour, communication, perception, play-behaviour, and rhythmicity. In the area of social behaviour, the significantly different items were found to be: (i) does not like to be disturbed, in his/her own world and (ii) content if left alone. Two items in the area of communication revealed significant differences between the groups, (i) does not try to attract adult's attention to own activity, and (ii) difficulties imitating movements. In the area of

perception, significantly different items were: (i) strange reactions to sound, (ii) empty gaze, (iii) overexcited when tickled, (iv) does not seem to react to cold, (v) bizarre looking at objects, patterns and movement, and (vi) there is (or has been) a suspicion of deafness. Four behaviours were found to characterise the children with autism in the play-behaviour category: (i) attachments to odd objects, (ii) only playing with hard objects, (iii) does not play like other children, and (iv) occupies self only when left alone. The significantly different items in the area of rhythmicity were: (i) severe sleep problems, and (ii) days and periods when he/she would seem much worse than usual. Three items were highlighted as having the strongest discriminatory power: (i) strange reactions to sound, (ii) does not try to attract adult's attention to own activity, and (iii) empty gaze.

One study which examined whether autism could be predicted on the basis of infant screening tests found a number of features at 12 months of age which distinguished children with autism from those with developmental delay (Johnson et al., 1992). The files of infant screening records were searched in order to gather a sample of 13 children who were later diagnosed with autism and two comparison groups of children. The two comparison groups consisted of 19 children with mild or moderate learning difficulties without autism and a random sample of records of 19 children with no known developmental disabilities or problems. Areas of development included in the screening assessments were motor development, visual development, hearing development, and social development. According to an examination of the children's files, there were no significant differences between the groups at 6 months of age. There were slightly more frequent reports of motor and vision problems in the group of children with mild learning disabilities. There were no reports of concern about social

development in the group of children with autism at 6 months of age. However, at 12 months of age it was found that problems were reported more frequently in all categories for the children with mild learning disabilities. For the group with autism, the incidence of reported problems was still low at this age. At 18 months of age the normal comparison group had low frequencies of problems, whilst in the mild learning disabilities group abnormalities remained high across all areas. In the group of children with autism there was a high rate (57%) of reported problems in the social area at 18 months of age.

The evaluation of the psychometric properties of a structured parent interview, the Parent Interview for Autism (PIA), for the gathering of information relevant to the diagnosis of autism in young children also provides information regarding the early features of autism (Stone & Hogan, 1993). The PIA consists of 118 items, which assess behaviour in the following dimensions: (i) social relating, (ii) affective responses, (iii) motor imitation, (iv) peer interactions, (v) object play, (vi) imaginative play, (vii) language understanding, (viii) nonverbal communication, (ix) motoric behaviours, (x) sensory responses, and (xi) need for sameness. The early behaviours of a group of 58 children with autism (mean age of 38.6 months) and 36 children with developmental delay without autism (mean age of 42.1 months) were compared. Group differences were found for 6 of the 11 dimensions: (i) relating, (ii) imitation, (iii) peer interactions, (iv) imaginative play, (v) language understanding, and (vi) nonverbal communication. All of these differences indicated more behaviours characteristic of autism in the group of children with autism. Using four of these dimensions as predictor variables in a discriminant function analysis, (social relating, peer interactions, motor imitation, and nonverbal communication), 78% of the sample was correctly classified. Eighty-six per

cent of the autism sample and 63% of the sample of children with developmental delay were correctly classified.

A retrospective survey of the concerns of parents regarding their child's development between 12 - 18 months of age was conducted by Vostanis and colleagues (1998). The sample consisted of 121 consecutive clinic referrals, 39 children with autism, 15 with atypical autism, 13 with Asperger syndrome, 20 with learning disability, and 14 with semantic-pragmatic disorder. The questionnaire completed by the parents consisted of 22 items which made up the subscales of communication and language, social relationships, and play behaviour. It was found that the autism and learning disability groups differed significantly on most of the items of the questionnaire. A diagnosis of autism was found to be best predicted by the play behaviour items and a lack of referential gestures. Factor analysis revealed three factors with the heaviest loading for the group of children with autism: (i) lack of desire for physical contact, (ii) lack of social communication, and (iii) lack of imitative skills. Playing with the same or an unusual object or toy was also predictive of a diagnosis of autism.

There are a number of problems with studies which employ retrospective recall of parents or carers to collect information regarding the early behaviours of children diagnosed with autism. It is possible that the parent's recollection of the child's behaviour a number of years ago is inaccurate. Asking parents of very young children with autism to recall the early behaviours of their children is one way of minimising this problem, as demonstrated in the study by Stone and Hogan (1993) discussed previously. It is also possible that the fact that the child has been diagnosed with autism and the parent has become knowledgeable about this condition since receiving the diagnosis,

may influence their responses to questions or bias how they recall the actual early behaviour of their child. The mere labelling of the child's behaviour may thus influence the way in which parents recall their child's early years as they interpret their child's behaviours within the framework of the diagnosis and their current knowledge of this condition. Gillberg (1989) has also raised the issue of what he refers to as "environmental perceptiveness" (Gillberg, 1989, p. 25). This relates to the fact that parental retrospective observations are dependent upon factors including the degree of parent alertness in observing abnormalities in their child's development, parental age, social circumstances, educational level, personality, intelligence, the presence or absence of age peers, and parental mental health. There is therefore potentially substantial error inherent in any methodology that is reliant upon retrospective parental recall.

One way of overcoming these difficulties is to ask parents the questions about their child's early behaviour before they are given the diagnosis (e.g. Ornitz et al., 1977; Ornitz et al., 1978). Case file examinations, such as that carried out by Johnson et al. (1992), eliminate this particular problem, but create new difficulties in that case notes may not be sufficiently comprehensive. The fact that a file does not mention a particular behaviour is no guarantee that the behaviour was not present.

Another way of avoiding the potential error inherent in studies dependent upon retrospective parental recall is to study the behaviour of children with autism while they are still young. Methods of collecting information in such contemporaneous studies have included structured observation of the child (e.g. Adrien, Barthelemy et al., 1992; Snow, Hertzog, & Shapiro, 1987), interviewing of the parents (e.g. Lord, Rutter, & Le

Couteur, 1994; Lord et al., 1993), and assessing the child's abilities in specific areas (e.g. Wetherby, Yonclas, & Bryan, 1989). A discussion of the findings of these studies follows.

Snow, Hertzig, and Shapiro (1987) examined deficits in affective expression in a group of children with autism and a group of children with developmental delay without autism. Each group contained 10 children whose ages ranged from 2 years 6 months to 4 years. The mean age in both groups was 3 years 4 months. Children were observed interacting with 3 different partners, their mother, an unfamiliar child psychiatrist (male), and a nursery school teacher (female) the children had known for a approximately 1 month. The interactions were videotaped and a behavioural observation rating scale was used to code behaviours observed in the interactions. The children with autism were found to display significantly less affect than the children with developmental delay. This finding was due to the marked difference in positive affect displayed by the groups, with the children with autism displaying significantly less positive affect than the children with developmental delay. The children with autism displayed significantly more negative affect with the unfamiliar child psychiatrist than with either their mother or nursery school teacher. This difference was not apparent in the group of children with developmental delay.

Wetherby, Yonclas, and Bryan (1989) focused on the communicative profiles of a group of children with developmental difficulties. Three of the children had autism, 4 had Down's syndrome, and 4 had specific learning impairments. All of the children were aged less than 5 years of age, with the mean age of the autism group 38.7 months, Down's syndrome group 33.5 months, and the group of children with specific learning

impairment 26 months. All of the children had delayed language development and were functioning at the prelinguistic or one-word stage. The results of the children with developmental difficulties were compared to the normative data of Wetherby, Cain, Yonclas, and Walker (1988). All of the 15 children in the normative sample displayed joint attention behaviours. The proportion of this behaviour fell into the normal range for all of the children with Down's syndrome, however all 3 children with autism showed a deficiency or absence of joint attention acts. This was also true for the youngest child with specific learning impairment. The generalisability of these findings is however, clearly limited by the small sample sizes.

Adrien and colleagues (1992) examined the behaviour of 89 children aged 6 - 48 months. Thirty-nine of the children met DSM-III-R criteria (American Psychiatric Association, 1987) for a diagnosis of autism, 33 had developmental delay without autism, and 17 had no problems with development. The children with autism and those with developmental delay were matched on both their global and nonverbal developmental quotients. Two raters made observational ratings of the behaviour of the children from videotapes using the Infant Behavior Summarized Evaluation (IBSE) (Adrien, Barthelemy et al., 1992). Ratings were made on a scale of 0 - 4 based upon the observed frequency of the abnormal behaviour. Analyses revealed 19 items that differed significantly between the children with autism, developmental delay, and the typically developing children. The differentiating items consisted of: ignores people, prefers aloneness, poor social interaction, no social smile, no eye contact, abnormal eye contact, lack of verbal communication, lack of appropriate facial expressions, lack of appropriate gestures and/or expressive postures, no or poor imitation of gestures or voice of others, inappropriate use of objects, stereotyped behaviour, unusual postures,

does not differentiate people, no expression of emotions, unstable attention, easily distracted, no reaction to auditory stimuli, bizarre responses to auditory stimuli, and behavioural variability.

Discriminant function analysis was used to establish the accuracy of the items of the IBSE in discriminating the children with autism from the children with developmental delay and the children with autism from the typically developing children. Using the 19 items that were found to differ significantly between the groups of children, 83.3% of the children with autism and the children with developmental delay were correctly classified. Sensitivity (or true positive rate), the probability of having a positive test result among those who have a positive diagnosis (Kraemer, 1992), was 84.6%.

Specificity (or true negative rate), the probability of having a negative test result among those who have a negative diagnosis (Kraemer, 1992), was 81.8%. The second analysis showed that the items of the IBSE correctly classified 94.6% of the children with autism and the typically developing children. The sensitivity was 92.3% and the specificity was 100%. The results indicate that using the items of IBSE, it is more difficult to distinguish children with autism from those with developmental delay than it is to distinguish children with autism from typically developing children.

The reliability and validity studies of the Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994; Lord et al., 1993) with preschool children provide information on the features distinguishing 25 young children (mean age 46.76 months) with autism from 25 children (mean age 44.72 months) with developmental delay. Items of the interview assessing the social area which showed significant diagnostic differences across the children with autism and the children with developmental delay included: failure to use

eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction, failure to develop peer relationships, a lack of seeking to share own enjoyment, and a lack of social emotional reciprocity and modulation to context. The children with autism had significantly higher scores in this area, indicating greater abnormality. Other significant items in this area included holding arms up to be lifted, separation anxiety, social smiling at 2 years of age, attention to voice, affection, seeking comfort, demonstrating a sense of humour, joining in the activities of others, sharing the pleasure of another, and greeting.

In the area of gesture for communication, significant differences were found for pointing to express interest, conventional gestures, nodding of head, and head shaking (Lord et al., 1994; Lord et al., 1993). For all of these items the children with autism scored higher than the children with developmental delay, indicating greater abnormality. The children with autism also received higher scores in the area of play and imitation, including spontaneous imitation, spontaneous play, and imitative social play. Items assessing verbal communication were compared across the 2 groups for those children who had phrase speech. The only significant finding was for social chat. Although differences were found in other aspects of language, small sample sizes and low to zero scores on some of the items in the young sample resulted in the nonsignificant nature of these differences. Significant group differences were found on items assessing babble as an infant, age at which first words were spoken, emotional gestures, enactive gestures, elicited gestures, understanding gesture, and the comprehension of language. In the children who were verbal, significant differences were found in the areas of immediate echolalia and understanding the plots of simple stories.

In the area of restricted and repetitive behaviours a number of items showed significant differences between the children with autism and those with developmental delay. These included verbal rituals, hand and finger mannerisms, other complex mannerisms, and unusual sensory interests (Lord et al., 1994; Lord et al., 1993). Again, the children with autism scored significantly higher in this area than the children without autism, indicating greater abnormality. Items regarding self-injury, food fads, unusual fears, lack of curiosity, lack of initiation of appropriate activities, and sensitivity to noise, were also found to discriminate between the children with autism and those with developmental delay.

Charman and colleagues (1998) examined social-cognitive abilities in children with autism, Pervasive Developmental Disorder (atypical autism, Asperger's Disorder, and PDD NOS), and developmental delay without autism at 20 months of age. The autism group consisted of 8 children and the Pervasive Developmental Disorder group of 11 children. The developmental delay group consisted of 8 children who met criteria for either Expressive or Mixed Receptive-Expressive Language Disorder. The children were assessed in the areas of empathic response, spontaneous play, joint attention, goal detection, and imitation. In the area of empathic response, only half of the infants with autism looked at the experimenter during a feigned distress scenario, while nearly all of the infants with Pervasive Developmental Disorder and those with developmental delay noticed the distress, and half of these showed facial concern. Fewer examples of joint attention were observed in the infants with autism compared to those with Pervasive Developmental Disorder and those with developmental delay. The same pattern emerged on the imitation tasks. On the spontaneous play task no infants with autism and only 3 of those with Pervasive Developmental Disorder showed any examples of

pretend play. Half of the infants with developmental delay showed pretend play, however two-thirds of the subjects in all of the groups produced examples of functional play. On the goal-detection tasks, involving measures of imperative or requesting behaviour, only one-third of the infants with autism looked to the experimenter following an ambiguous action by the experimenter while as a group, the infants with Pervasive Developmental Disorder and those with developmental delay produced twice as many looks to the experimenter.

Stone and colleagues (1999) specifically examined the adaptive behaviour patterns of 30 children with autism and 30 children with developmental delay with and without language impairment. Children were aged 23 - 35 months, were individually matched on both mental and chronological age, and in the case of the developmentally delayed control group, excluded those with known aetiologies (e.g. Down syndrome). Parents were interviewed using the Survey Form of the Vineland Adaptive Behavior Scale prior to diagnosis. Analyses revealed differing patterns of adaptive behaviour across the groups. Specifically, differences were found for the Vineland domains of Socialization and Communication with the autism group obtaining significantly lower scores than the delayed group. This result was also obtained when expressive language age and receptive language age were controlled for. The ratio of the Vineland age equivalent to mental age was also calculated (Vineland age equivalent to mental age multiplied by 100). Ratios less than 100 are said to indicate a weakness in adaptive behaviour relative to mental age, while a ratio greater than 100 indicates a strength in adaptive behaviour relative to mental age (Volkmar et al., 1987). Communication and Socialization skills were found to be lower than mental age for both groups, while Daily Living Skills and Motor Skills were found to be higher than mental age for both groups. However, the

autism group were found to have significantly larger adaptive behaviour mental discrepancies for the Communication, Socialization, and Motor Skills domains compared to the developmentally delayed / language impaired children.

In sum, the results of appropriately controlled, contemporaneous studies of early features of autism, reveal a number of behaviours which appear to be unique to children with autism. A range of deficits in reciprocal social interaction and communication have been consistently observed, along with some repetitive behaviours. Deficits in imitation, both spontaneous and pretend play, requesting, and joint attention have also been noted. Other behaviours such as self-injury, food fads, and sensitivity to loud noises have been observed as more common in children with autism compared to comparison groups of developmentally delayed children without autism.

2.2.2.3 Prospective studies

Prospective studies provide an optimal approach to the study of the early features and development of autism and overcome the methodological limitations of the previously described studies. Such studies allow the description of current features and provide information on the development and progression of symptomatology over time.

However, there are a limited number of studies of this nature. The low incidence of autism generally makes such studies unfeasible. Due to this difficulty, the prospective approach is best applied in infants who are at high risk for autism, such as siblings of children with autism, or those demonstrating some early features of the disorder (Stone, 1997).

Despite the difficulties inherent in conducting prospective studies of autism in infants, a number have been undertaken. Researchers have overcome the problem of the low incidence of autism by studying children at genetic risk of autism (Baron-Cohen et al., 1992), those with delayed speech and language (Lord, 1995), and children presenting with early symptoms (Gillberg et al., 1990). A further study has undertaken a prospective screening of all infants within a health region of the United Kingdom (Baron-Cohen et al., 1996; Swettenham, 1996).

One prospective study compared a sample of 41 18 month old children at high genetic risk for autism (all had older siblings with a diagnosis of autism) to a sample of 50 randomly selected 18 month old children (Baron-Cohen et al., 1992). Children were assessed using the Checklist for Autism in Toddlers (CHAT) (Baron-Cohen et al., 1992) and were then reassessed at 30 months of age. It was found that the predictors of a diagnosis of autism at 30 months of age were presenting with two or more of the following behaviours at 18 months of age: (i) lack of pretend play, (ii) lack of protodeclarative pointing (use of the index finger to indicate to another person an object of interest), (iii) lack of social interest, (iv) lack of joint attention, and (v) lack of social play.

Lord (1995) completed a prospective study of the early features of autism with 34 children aged 25 - 35 months who all had delayed speech and language development. All of the children were followed-up 12 - 15 months later, when they were aged 38 - 52 months. At 2 years of age, the children with a diagnosis of autism differed from the other children in terms of their lack of initiative in seeking visual attention, their lack of response to voice, lack of understanding gesture, unusual use of others' bodies, lack of

seeking to share enjoyment, hand and finger mannerisms, and unusual sensory behaviours. A series of behaviours which did not differ significantly between the group with autism and the group without autism at age 2 showed significant differences by 3 years of age. In the area of communication these included instrumental gesture, spontaneous imitation, imaginative play, and social play. In the area of social reciprocity, significantly different rates were reported for social responsiveness, offers comfort, range of facial expressions, inappropriate facial expressions, comes for comfort, direct gaze, and quality of social overtures. In the area of restricted repetitive behaviour significant differences were apparent on the items assessing unusual preoccupations and whole body mannerisms. On all of these items significantly greater prevalence rates, indicative of greater abnormality, were found in the group of children with autism. It is important to note that at both ages, the majority of differences were in the areas of communication and social reciprocity, with relatively few behaviours differing between the groups in the area of repetitive and stereotyped patterns of behaviour and interest.

Deficits in two areas were found to be the best discriminators of autism at 2 years of age in this group of children with delayed speech and language development on both an individual and group basis – directing others' attention and attention to voices, correctly classifying 82.8% of the children, with 2 of the 13 children without autism and 3 of the 16 children with autism incorrectly classified. Of the items from the ADI-R administered at 3 years of age, the item seeks to share own enjoyment was the single best predictor of diagnosis, correctly classifying all children with autism and 10 of the children without autism. Entering the variables in steps revealed 4 other items which

taken together also correctly classified all children. These were use of other's body as a tool, attention to voice, hand and finger mannerisms, and pointing.

Another prospective study involved children presenting with early symptoms of autism. Twenty-eight children received a neuropsychiatric assessment at 8 - 35 months of age and were reassessed at 26 - 150 months (Gillberg et al., 1990). Information on the early features and behaviours of the young children was gathered by questionnaires completed at the time of presentation by 12 of the mothers of the children who received a confirmed diagnosis of autism at follow-up 6 - 13 months later. Abnormalities of play, autistic aloneness, peculiarities of gaze, and hearing were the symptoms most typical of the children with autism. Twelve 'high load' items (items which applied in at least 10 of the 12 cases) were identified from the questionnaire. These consisted of late speech development, does not point to objects, something strange about his/her gaze, late development, does not understand what people say to him/her, difficulties getting eye contact, interested only in certain parts of objects, cannot indicate his/her wishes, indifferent to whether there are people around or not, something the matter before 12 months of age, exceptionally interested in things that move, and does not speak when spoken to.

In a review of this study and a retrospective comparison of early features of children with autism compared to children with developmental delay and children without developmental problems (Dahlgren & Gillberg, 1989), Gillberg, Nordin, and Ehlers (1996) listed 11 items which were consistently identified across both of the studies. These items were: appears to be isolated from surroundings, doesn't smile when expected to, difficulties getting eye contact, doesn't try to attract adult's attention to

own activity, difficulties imitating movements, doesn't play like other children, occupies her/himself only when alone, plays only with hard objects, there is (or has been) a suspicion of deafness, empty gaze, and is overexcited when tickled.

A large-scale prospective population study of autism was conducted in the southeast of England (Baron-Cohen et al., 1996; Swettenham, 1996). This study screened 16,235 children for autism using the Checklist for Autism in Toddlers (CHAT). All of the children were screened by a general practitioner or health visitor at their 18 month developmental checkup. An autism risk group (12 children) was identified along with a developmental delay risk group (44 children). Failure on three key items of the CHAT characterised the children in the autism risk group: (i) protodeclarative pointing (pointing at an object in order to direct another person's attention to the object), (ii) gaze monitoring (turning to look in the same direction in which an adult is looking), and (iii) pretend play. The developmental delay group (without autism) consisted of children who failed either protodeclarative pointing or failed both protodeclarative pointing and pretend play, but passed gaze monitoring. The children who made up the normal group passed all 3 key items: (i) protodeclarative pointing, (ii) gaze monitoring, and (iii) pretend play.

After undergoing a thorough developmental and diagnostic assessment, 10 of the 12 children in the autism risk group received a diagnosis of autism, while the remaining 2 were diagnosed with developmental delay. Twenty-two of the children in the developmental delay group were also assessed; none of them received a diagnosis of autism. Sixteen children were seen from the normal group; none of them were found to have any developmental problems. The 2 children from the autism risk group who were

not found to meet criteria for autism at 18 months of age were seen again at 3 years of age. It is strongly suspected that these 2 children who did not receive a diagnosis of autism at 18 months of age do have an autism spectrum disorder (Swettenham, 1996). All 10 children diagnosed with autism at 18 months of age had their diagnosis confirmed at follow-up at 3.5 years of age.

The entire sample of 16,235 children were followed up at 7 years of age (Baird et al., 2000) in order to provide information on the sensitivity (true positive rate), the probability of having a positive test result among those who have a positive diagnosis (Kraemer, 1992), and specificity (true negative rate), the probability of having a negative test result among those who have a negative diagnosis (Kraemer, 1992), of the CHAT. Children were classified as being at a high risk for autism if they failed protodeclarative pointing (A7 and Biv), gaze monitoring (Bii), and pretend play (A5 and Biii) on an initial and repeated administration of the CHAT. The medium risk for autism group consisted of those children who failed the items relating to protodeclarative pointing (A7 and Biv), but passed at least 1 of the other items (A5, Bii, or Biii).

Using a one-stage administration of the CHAT and both the medium and high risk cut-offs, the CHAT was found to have a sensitivity of 38%, specificity of 98%, and positive predictive value of 4.7%. Of those children identified as having a medium risk of autism who did not receive a clinical diagnosis of autism ($n = 347$), 25 received a diagnosis of a language disorder and 11 diagnoses of other developmental disabilities. Of those identified as having a high risk of autism who did not receive a clinical

diagnosis of autism (n = 27), 4 received a diagnosis of a language disorder and 3 of other developmental disabilities.

Repeating the CHAT one month after the first administration was found to increase the positive predictive value to 75% within the high-risk group. However, while the specificity remained high at 100%, the sensitivity fell to 18%. When an autism spectrum approach (all Pervasive Developmental Disorders) was taken and both the medium and high-risk groups were included, a sensitivity of 21.3% was achieved, along with a specificity of 99.9%, and a positive predictive value of 58.8%.

This prospective screening study has also provided information on a broad range of symptoms which differentiated the groups studied at both 20 months of age, and at follow-up at 42 months (Cox et al., 1999). The children who were diagnosed with autism at 42 months of age and those diagnosed with language disorder at 42 months, were all assessed using the ADI-R at both points in time. Complete data was available for 8 children in the autism group and 9 children in the language disorder group. The items which constitute the ADI-R diagnostic algorithm were examined across these two groups at 20 months and 42 months of age.

At 20 months of age it was found that two of the items from the reciprocal social interaction domain discriminated the children with autism from those with language disorder, namely range of facial expressions and interest in other children. Two items from the communication domain significantly differed between the two groups – point for interest and use of conventional gestures. However, no items from the repetitive

behaviours and stereotyped interests domain differed between the two groups at 20 months of age.

At 42 months of age, two different items from the reciprocal social interaction domain differed significantly across the two groups – seeking to share enjoyment and offering comfort. Two of the same items from the communication domain, point for interest and use of conventional gestures, continued to differentiate the children with autism from those with language disorder, whilst nodding and imaginative play were also significantly different across these two groups. As was the case at 20 months of age, no items from the repetitive behaviours and stereotyped interests domain differed between the two groups at 42 months of age. In all cases the differences reflected greater abnormality in the children with autism.

A range of other behaviours which are not included in the ADI-R diagnostic algorithm but are part of the interview were also examined, namely difficulties with changes in routine, resistance to trivial changes, unusual attachments to objects, negative response to sensory stimuli, unusual fears, problems getting to bed, problems sleeping, tantrums, and feeding problems. No significant differences were found between the two groups for any of these behaviours. Differences in the findings between this study and that by Lord (1995) are attributed to the differences in age, IQ, and sample recruitment (referred versus population screening) across the two studies (Cox et al., 1999).

2.2.3 Summary: Early features and applicability of standard diagnostic criteria

Due to the methodological reasons highlighted previously, those studies comparing the behaviours of young children with autism to those with developmental delay without autism, provide the most reliable information on features and symptoms suggestive of autism in infants and preschool aged children. The majority of these features are in the areas of social interaction and communication.

In the area of reciprocal social interaction, features found to be characteristic of autism include poor social interaction, ignores people, lack of interest in other children, lack of seeking to share enjoyment, lack of social play, uninterested in playing peek-a-boo, failure to develop peer relationships, join in the activities of others, and direct adult's attention to own activities. Other features in the social area include being in his/her own world, preferring aloneness, being indifferent to others, not differentiating between people, lack of attention to voices, failure to show affection and to seek or offer comfort, dislikes social touch and being held, does not follow mother, and a general lack of social responsiveness. Further features in this area characteristic of infants and young children with autism include failure to use eye gaze, body posture, facial expression, and gesture to regulate social interaction, failure to direct the attention of others, failure to hold arms up to be lifted, and no social smile or greeting behaviours.

In the area of communication, autism specific features include a lack of verbal communication, first words spoken late, loss of previously acquired words, lack of babble as an infant, no social chat, problems with comprehension of language and understanding the plots of simple stories, and echolalia. Other features include a lack of

and limited range of appropriate facial expressions, no expression of emotion, no gaze monitoring, no or abnormal eye contact, empty gaze, a lack of pointing to express interest, a lack of smiling at mother or others, smiling with an empty expression, and the unusual use of others' body as a tool. Young children with autism have also been found to be characterised by no use or understanding of gestures, poor imitation, poor imitation of gestures or voice of others, and no nodding or shaking of head.

A small number of features in the area of stereotyped and repetitive routines, behaviours and interests have been identified. These include verbal rituals, hand and finger mannerisms, whole body mannerisms, unusual or repetitive preoccupations and attachments to objects, and bizarre looking at objects, patterns, or movements.

A few features in the areas of play and sensory behaviours have also been identified. These include a lack of spontaneous play, a lack of imitative play, and no imaginative or pretend play. Sensory characteristics include sensitivity to noise, insensitivity to pain or cold, unusual sensory interests, deafness suspected, mouthing of objects, and hypersensitivity to the taste of foods.

A number of other general behavioural features characteristic of infants and young children with autism have also been identified. These include distractibility, behavioural variability, sleep problems, self-injury, food fads, unusual fears, lack of curiosity, lack of response to name, overexcited when tickled, overly quiet, indifferent to animals, having an intelligent-looking face, and running away.

Many studies have observed that a number of diagnostic features typical of older children with autism are less likely to be present in preschool aged children. These include insistence on sameness, distress over change in routines, and adherence to rituals and routines (Dahlgren & Gillberg, 1989; Lord et al., 1994; Stone et al., 1994; Stone et al., 1999), restricted interests and activities (Stone et al., 1994), abnormal seeking of comfort (Stone et al., 1994), unusual attachments to objects (Lord et al., 1994), and impaired conversational skills and abnormal speech production (Stone et al., 1994). A recent review has suggested that a number of DSM-IV (American Psychiatric Association, 1994) criteria for diagnosis and the current diagnostic algorithm may be inappropriate for infants and young children (Rogers, 2001).

A possible explanation for the relative absence or low frequency of these features might be that the child has not yet developed the cognitive skills implicit in the abnormal behaviour. For example it is clearly not possible to assess language abnormality and deviance in children who have not yet acquired speech. Young children have not yet developed object permanence, which is presumably necessary before a child can insist on routines and sameness and have abnormal attachments to objects. It is also difficult to assess peer relationships and interactions in preschool children who generally have limited contact with other young children (Baron-Cohen et al., 1992; Stone et al., 1999).

When assessing young children with autism it is therefore important to recognise that some diagnostic features of autism in older children may not be present, and that their absence does not necessarily exclude the possibility of autism. Lord (1995) has suggested that while it is possible to diagnose autism reliably at the age of 2 years, standard diagnostic criteria may need to be modified in order to take into account the

presentation of autism in very young children. Support for this notion includes the finding that items concerning communication are not useful in differentiating preschool children with autism from children with severely delayed language development (Lord et al., 1993). Further support comes from Lord's (1995) longitudinal study of children with autism from 2 to 3 years of age compared to a group with speech and language delays without autism. At both 2 and 3 years of age the majority of behaviours which differentiated the children with autism from those with speech and language delays were in the areas of communication and social reciprocity. However, there were comparatively fewer behaviours which differentiated these groups at either age in the area of repetitive and stereotyped patterns of behaviour and interests. Similarly, examination of the data provided by the ADI-R at 20 and 42 months of age in a group of children diagnosed with autism and a group diagnosed with language disorder, found that no items in the area of repetitive behaviours and stereotyped patterns differentiated the groups at either point in time (Cox et al., 1999).

Table 2.6 summarises the results of the controlled studies which used comparison groups of children with developmental delay and assessed a broad range of symptoms. When the findings of these studies are categorised according to the 3 main diagnostic groups in DSM-IV (American Psychiatric Association, 1994), it is clear that differentiating features from the categories of communication and social interaction are present. However, only 2 of the 7 studies list differentiating early features in the area of stereotyped behaviours and routines. The relative absence or low frequency in preschool children of some diagnostic features that are seen in older children or adults points to a developmental process in the emergence of symptomatology, with some features perhaps requiring a greater level of maturation (Stone et al., 1999).

Table 2.6

Early Features of Autism: Differentiating Behaviours Relating to Standard DiagnosticCriteria

| Study | Autism (n) | Age of focus | Sex (autism) | Control group (n) | Communication | Social Interaction | Stereotyped Behaviours & Routines |
|--|------------|----------------|--------------|-------------------------------|---------------|--------------------|-----------------------------------|
| (Adrien, Barthelemy et al., 1992) | 39 | 6-48 months | 62% male | 33 dev delay; 17 typical dev | ✓ | ✓ | ✓ |
| (Cox et al., 1999) | 8 | 20 & 42 months | 100% male | 9 language disorder | ✓ | ✓ | |
| (Dahlgren & Gillberg, 1989)* | 26 | 0-24 months | 77% male | 17 dev delay; 22 pop repres | ✓ | ✓ | |
| (Hoshino et al., 1982)* | 85 | ≤ 24 months | 93% male | 150 typical dev, 64 dev delay | ✓ | ✓ | |
| (Lord et al., 1994; Lord et al., 1993) | 25 | 36-59 months | Unk | 25 dev delay | ✓ | ✓ | ✓ |
| (Ohta et al., 1987)* | 141 | unk | 83% male | 33 dev delay | ✓ | ✓ | |
| (Stone & Hogan, 1993) | 58 | 8-66 months | 82% male | 36 dev delay | ✓ | ✓ | |
| (Stone et al., 1999) | 30 | 23-35 months | 83% male | 30 dev delay | ✓ | ✓ | |
| (Vostanis et al., 1998)* | 39 | 12-18 months | Unk | 20 dev delay | ✓ | ✓ | |

dev delay = developmental delay; typical dev = typically developing; pop repres = population representative; unk = unknown, information not provided in article for autism sample;

*retrospective interview

CHAPTER 3

EARLY SCREENING FOR AUTISM

3.1 Screening

The review of the literature has established that it is both desirable and justified to diagnose autism at an earlier age than is currently the practice. Parents usually recognise developmental problems by 2 years of age and indications of the potential efficacy of early intervention (Rogers, 1996) highlight the importance of early diagnosis. It is clearly not possible to clinically assess every child for autism, or even to assess all children with an intellectual disability for autism. A consensus panel has recently provided practice parameters for service providers and professionals, suggesting a dual-level approach to the assessment and diagnosis of autism (Filipek et al., 1999). Level 1 of the recommended approach suggests that primary care providers perform screening for developmental disorders on a routine basis. Autism specific probes covering the areas of socialisation, communication, and behaviour are also provided for practitioners to ask parents. Level 2 involves assessment and diagnosis, performed only by specialists in the evaluation and treatment of autism.

While the report of the consensus panel (Filipek et al., 1999) describes an ideal approach to screening, it acknowledges that we are a long way away from such an ideal standard practice, with fewer than 30% of primary care providers undertaking standardised developmental screening tests (Dworkin, 1992). Screening of at risk children who have developmental problems in order to channel referrals to specialist clinical assessment services for autism is a potential way of ensuring that children who are likely to have autism are referred for specialist diagnostic services at as early an age

as possible. Therefore, the development of a population screening methodology to identify those at risk of autism is required.

Screening can potentially be undertaken through the use of questionnaires, checklists, rating scales, and/or diagnostic interviews or structured observations. Ideally, such an instrument should be capable of screening populations of children and identifying those at risk, thus facilitating clinical diagnostic assessment in a manner allowing for best allocation and use of scarce resources. As screening procedures are usually implemented by health professionals with limited time and who may not be trained in the identification of rare childhood disorders, screening cannot be time consuming, complicated, or require extensive training (Vostanis et al., 1994). A number of potentially useful tools and instruments have already been designed for use in the area of autism and are reviewed for their potential usefulness as a screening tool.

3.2 Historical review of early instruments

The first autism checklist was developed in 1959 (Polan & Spencer, 1959). A 24-item checklist was later developed by Lotter (1966) and used to determine the prevalence of autism among children living in a region of rural England. In 1969, the Nine Diagnostic Points developed by the British Working Party (Creak et al., 1961), were expanded into a 54 item checklist consisting of 14 categories (Clancy, Dugdale, & Rendle-Short, 1969). A number of checklists, questionnaires, and diagnostic interviews and schedules have since followed.

3.3 Checklists, rating scales, and questionnaires

Over the last 40 years, a number of checklists, questionnaires and behavioural rating scales have been developed in the area of autism. These include the Behaviour Rating Instrument for Autistic and Atypical Children (Ruttenberg, Dratman, Fraknoi, & Wenar, 1966), the Rimland Diagnostic Form for Behaviour Disturbed Children (Rimland, 1971), the Behavior Observation Scale (Freeman, Ritvo, Guthrie, Schroth, & Ball, 1978), the Autism Behavior Checklist (Krug, Arick, & Almond, 1980), the Childhood Autism Rating Scale (Schopler, Reichler, DeVellis, & Daly, 1980), the Ritvo-Freeman Real Life Rating Scale (Freeman, Ritvo, Yokota, & Ritvo, 1986), the Behavioral Summarized Evaluation (Barthelemy et al., 1990) and the Infant Behavioral Summarized Evaluation (Adrien, Barthelemy et al., 1992), the Scale of Pervasive Developmental Disorder in Mentally Retarded Persons (Kraijer, 1997), and the Pervasive Developmental Disorders Rating Scale (Eaves, Campbell, & Chambers, 2000). Only one of these is a parent/carer completed instrument (the Rimland Diagnostic Form for Behaviour Disturbed Children), while the remainder are completed by a clinician based upon observation of the child. Checklists such as these are often used as aids in the diagnostic assessment process. As all describe features and symptoms of autism, they are potentially useful as screening tools. A brief summary of each checklist follows, while psychometric properties, training requirements, and potential utility as a screening tool are summarised for each instrument in Table 3.1.

Table 3.1

Checklists, Rating Scales, and Questionnaires in Autism: Psychometric Properties and Suitability for Population Screening

| Instrument | Reliability | | | Validity | | Rated by | Training required | Suitable as population screening tool |
|--|---------------------------|------------------|---------------------------|--------------------|----------------------|-----------|-------------------|---------------------------------------|
| | Interrater | Test retest | Internal consistency | Construct /content | Convergent | | | |
| E-2 Rimland's Form E-2 | - | - | - | Kanner | - | Parent | No | No |
| BRIAAC Behaviour Rating Scale for Autistic and Atypical Children | S-high | - | S- moderate-high | - | - | Clinician | Yes | No |
| BOS Behavior Observation Scale for Autism | I-high | - | - | - | - | Clinician | Yes | No |
| ABC Autism Behavior Checklist | T-variable S-low-good | - | T-high S-low | CARS | - | Clinician | Minimal | No |
| CARS Childhood Autism Rating Scale | T-high S-good | - | T-high | DSM-III-R | RLRS ADI-R ABC | Clinician | Minimal | No |
| RLRS Ritvo-Freeman Real Life Rating Scale | T-high S-good I-low | - | T-high S-moderate-good | - | CARS | Clinician | Yes | No |
| BSE Behavioral Summarized Evaluation | T-high I-low-moderate | - | Factor analysis | - | Rimland's Form E-2 | Clinician | Yes | No |
| IBSE Infant Behavioral Summarized Evaluation | T-high I-low-high | - | Factor analysis | - | - | Clinician | Yes | No |
| FDD-MRS Scale of Pervasive Developmental Disorders | high | high | high | DSM-IV ICD-10 | - | Clinician | Yes | No |
| FDDRS Pervasive Developmental Disorders Rating Scale | - | T-high S-high | T-high S-high | Factor analysis | ABC | Clinician | - | Potentially |

I = item, S = subscale, T = total, high = $\geq .80$, good = .60-.79, moderate = .41-.59, low $\leq .40$

Rimland's Form E-1, and the revised version Form E-2 (Rimland, 1971), was designed to identify Early Infantile Autism as described by Kanner (1943). It is a parent-completed questionnaire which consists of 80 multiple choice questions covering the areas of social interaction and affect, speech, motor and manipulative ability, intelligence and reaction to sensory stimuli, family characteristics, illness development, and physiological and other biological data. A plus point is obtained for each question answered as suggestive of autism, while a minus point scored for each question indicating no autism. A cut-off score of +20 or above is regarded by the author as indicative of classical Early Infantile Autism (Rimland, 1971). Detailed information is lacking as to the derivation of this cut-off score. Criticisms of the E-2 form include its reliance upon retrospective information (Parks, 1983) and it has been observed that it underestimates the severity of a child's handicap (Prior, Boulton, Gajzago, & Perry, 1975). Due to the lack of sound psychometric data on the Rimland Diagnostic Form for Behaviour Disturbed Children, it would be inappropriate as a potential screening instrument.

The Behavior Rating Instrument for Autistic and Atypical Children (BRIAAC) was designed to evaluate autistic children and to measure changes in their behaviour (Ruttenberg et al., 1966). It is made up of four scales; (i) nature and degree of relationship to an adult as a person, (ii) communication, (iii) drive for mastery, and (iv) stage, modulation, and expression of instinctual drives. The BRIAAC also includes three supplementary scales, evaluating intellectual development, speech development, and social skills. Scores on the BRIAAC cannot be summed to produce a total 'autism score' and the scoring procedure has been described as "cumbersome" (Parks, 1988, p.125). The instrument requires a lengthy period of observation (3 hours) and a trained

rater. The lengthy administration time and the need for a trained rater, make the BRIAAC unsuitable for screening purposes.

The Behavior Observation Scale (BOS) (Freeman et al., 1978) was designed for the assessment of autistic children based upon the collection of objective behavioural information. The scale is completed after the child has been observed doing anything he/she wants. The scale consists of 67 behaviours which are rated on a 0 – 3 scale (0 = did not occur to 3 = occurred continuously) during nine three-minute rating intervals. A revised version has been reported which consists of 24 item ratings on 10-second intervals of videotaped unstructured play, although Lord (1997) noted that the authors have indicated that this approach has not been successful. The BOS requires administration by a trained clinician, thus rendering it impractical as a screening instrument.

The Autism Behavior Checklist (ABC) (Krug et al., 1980) is one of the components of the Autism Screening Instrument for Educational Planning (ASIEP). It was originally designed to be used in schools to measure the level of autistic behaviour in children (Krug et al., 1980). The ABC consists of 57 items, which are grouped into five subscales on the basis of face validity; (i) sensory, (ii) relating, (iii) body and object use, (iv) language, and (v) social interaction and self help. A score is calculated based upon a rater's dichotomous scoring of the weighted items. Ranges are provided which suggest that scores of 67 and above indicate a high level of autism, while scores under 53 indicate a low probability of autism.

Use of the suggested cutoffs on the ABC has been shown to provide significant levels of misclassification (Nordin & Gillberg, 1996; Volkmar et al., 1988; Wadden, Bryson, & Rodger, 1991) and factor analysis has not supported the five subscale structure of the checklist (Wadden et al., 1991). A study of 104 children with autism and 32 children with other disorders frequently confused with autism, has found the ABC to have a sensitivity of 77%, specificity of 91%, and overall correct classification rate of 80% (Eaves et al., 2000). It has been suggested that the ABC has limitations as a diagnostic instrument (Lord, 1997). The ABC requires a clinician who is very familiar with the child's behaviour to complete the checklist. This, along with some concerns regarding the psychometric properties of the ABC, make it unsuitable as a potential screening instrument.

The CARS (Schopler et al., 1980) has been described as the "strongest, best documented, and most widely used rating scale for behaviors associated with autism" (Lord, 1997, p. 473). The CARS is made up of 15 scales; (i) impairment in human relations, (ii) imitation, (iii) inappropriate affect, (iv) bizarre use of body movement and persistence of stereotypes, (v) peculiarities in relating to nonhuman objects, (vi) resistance to environmental change, (vii) peculiarities of visual responsiveness, (viii) peculiarities of auditory responsiveness, (ix) near receptor responsiveness, (x) anxiety reaction, (xi) verbal communication, (xii) nonverbal communication, (xiii) activity level, (xiv) intellectual functioning, and (xv) general impressions. Each scale or item is given a score ranging from normal to severely abnormal (1 = behaviour within normal range for child's age, to 4 = severely abnormal behaviour) based upon direct observation of the child by a clinician trained in its use. Total scores can range from 15

to 60. A cutoff score of 30 or above is said to be indicative of a diagnosis of autism (Schopler et al., 1980).

The CARS is reported to be able to discriminate between autistic and intellectually disabled children without autism (Teal & Wiebe, 1986). Although the CARS is one of the most widely used autism rating instruments it is important to note that its development was prior to current diagnostic frameworks (that is DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organisation, 1992)), thus limiting its use as a diagnostic tool (Lord, 1997). Like the ABC, the CARS needs to be completed by a clinician who is very familiar with the behaviour of the child and is therefore not suitable for screening purposes.

The RLRS (Freeman et al., 1986) was developed in order to assess the effects of behavioural treatment in autism. The development of the RLRS was based upon the BOS (Freeman et al., 1978). The scale consists of 47 behaviours, which have been grouped into five subscales on the basis of face validity; (i) sensory-motor, (ii) social relationship to people, (iii) affectual responses, (iv) sensory responses, and (v) language. The scale is completed after observing the person for at least 30 minutes in a natural setting. Each behaviour is rated on a scale ranging from 0 (never demonstrates the target behaviour) to 3 (target behaviour is seen almost always). A total score and subscale scores can be calculated, although no cutoff scores are provided, emphasising the fact that it was not designed for diagnosis or screening. Observers can be trained to administer the scale in three training sessions (Freeman et al., 1986).

It has been suggested that the RLRS has limited use as a tool for classification of subjects or patients (Lord, 1997), as evidenced in the aims of the development of the instrument. The RLRS is completed by a trained rater after a period of observation, thus making it impractical as a screening instrument.

The Behavioral Summarized Evaluation (BSE) (Barthelemy et al., 1990) and the Infant Behavioral Summarized Evaluation (IBSE) (Adrien, Barthelemy et al., 1992) are both French rating scales developed to measure the severity of behaviour problems in children with autism involved in intervention studies. The BSE was designed for use with older children and adults and consists of 20 items. Each item is scored on a scale of 0 to 4 (0 = the problem is never observed, to 4 = the problem is always observed) after five days of observation by a trained staff rater who is with the child on a daily basis. Factor analysis produced six factors, with two main factors accounting for 43.7% of the total variance. Nine items have recently been added to the BSE, resulting in the Revised Behavior Summarized Evaluation Scale (BSE-R) (Barthelemy et al., 1997). Factor analysis of the BSE-R produced two factors which accounted for 48.6% of the total variance (Barthelemy et al., 1997). Receiver Operating Characteristics analysis resulted in a cutoff score of 27 which provided reasonable sensitivity and specificity (Barthelemy et al., 1997).

The Infant Behavioral Summarized Evaluation (IBSE) (Adrien, Barthelemy et al., 1992) was adapted from the BSE in order to assess the behaviours of young children with autism. This was accomplished by adding 13 items to the original 20 items of the BSE and is scored in the same way. Factor analysis produced two main factors which accounted for 59.4% of the total variance, of which one factor (19 items, labelled

'Autism') accounted for 50.1% of the variance (Adrien, Barthelemy et al., 1992).

Discriminant function analysis demonstrated that this factor was able to correctly classify intellectually disabled children as with or without autism with good accuracy (Adrien, Barthelemy et al., 1992). The authors therefore established a new 19 item version of the IBSE for use with children aged 6 months to 4 years (Adrien, Barthelemy et al., 1992). The authors emphasise that neither the BSE nor the IBSE is intended for use as a diagnostic tool (Adrien, Barthelemy et al., 1992). Both the BSE and the IBSE are completed by a rater after a period of observation, thus limiting its usefulness as a screening instrument.

The Scale of Pervasive Developmental Disorder in Mentally Retarded Persons (PDD-MRS) (Kraijer, 1997) was designed to detect Pervasive Developmental Disorders in people with intellectual disability aged 2 - 55 years. The PDD-MRS consists of 12 items, which are differentially weighted. The items are scored as present or absent during an assessment time period of the last 2 - 6 months. The scale is completed by a professional based upon observations, structured parent interview, and other sources of information such as teachers and other professionals. Scores of 0 - 6 indicate non-PDD, 7 - 9 Doubtful, and a score of 10 - 19 is said to be indicative of PDD.

High sensitivity and specificity has been reported for the PDD-MRS (94.4% and 92.7% respectively). However, the PDD-MRS screens for Pervasive Developmental Disorders in general, and not specifically for autism. This scale is completed on the basis of a range of information, including parent interview, thus making it impractical as a screening instrument.

The Pervasive Developmental Disorders Rating Scale (PDDRS) (Eaves et al., 2000) consists of 51 items, which were developed based upon the existing classic and research literature on autism, DSM-III-R (American Psychiatric Association, 1987) criteria, existing instruments, and clinical files of children with autism. The PDDRS is typically completed by health professionals or teachers. It has three subscales, which were derived through the factor analysis of 500 completed scales, and a total score. Subscale 1, Arousal, includes items dealing with autistic aloneness, sensory stimulation, and fascination for objects. Subscale 2, Affect, includes items regarding aggression, fear, anxiety, and distorted affect, while subscale 3, Cognition, examines speech and language, skill development, and savant behaviour. Items are rated on a 5-point Likert scale. A cut-off score has been set at one standard deviation below the mean for the total score and Arousal subscale; both scores must be equal to or greater than the cut-off.

In a sample of 104 children with autism and 32 children with disorders often confused with autism (e.g. Asperger's Disorder, Childhood Disintegrative Disorder, mental retardation, PDD NOS), the PDDRS has been shown to have an overall classification accuracy of 88%, with a sensitivity of 88%, and specificity of 88% (Eaves et al., 2000). The PDDRS is potentially a useful screening tool, however it still requires a health professional to administer.

As summarised in Table 3.1, problems with the psychometric properties (information not provided or inadequate) of a number of the checklists and questionnaires render them inappropriate as population screening tools. As a minimum, the majority of these checklists and questionnaire require a professional to administer them and a significant

number require training. Ideally, a population screening tool would not require a professional to administer it, but rather be able to be completed by parents or carers.

3.4 Diagnostic observation schedules and interviews

A number of interviews and diagnostic schedules have been developed to elicit autism specific information about behaviour and development. These include the Handicaps, Behaviour, and Skills Schedule (Wing & Gould, 1978), the Diagnostic Interview for Social and Communication Disorders (Gould, 1999; Wing, Gould, Leekham, Libby, & Larcombe, 1997), the Autism Diagnostic Interview (Le Couteur et al., 1989; Lord et al., 1994), the Autism Diagnostic Observation Schedule (Lord, Rutter, DiLavore, & Risi, 1999), and the Parent Interview for Autism (Stone & Hogan, 1993). These instruments have been developed to elicit information required to make a diagnosis and thus require a clinician to administer them and, in most cases, a considerable amount of time. These characteristics significantly limit their usefulness as screening tools, rather they are more appropriately used in the diagnostic process after a child has been identified through a screening procedure. However, these instruments may prove useful in providing the basis for creating a screening tool. Each instrument is briefly described, while psychometric properties and training requirements are summarised in Table 3.2.

Table 3.2

Diagnostic Observation Schedules and Interviews in Autism: Psychometric Properties and Suitability for Population Screening

| Instrument | Reliability | | | Validity | | Completed by | Training required | Suitability as a population screening tool |
|---|----------------------------------|-------------------------------|-------------------------------|---------------------|------------|--------------|-------------------|--|
| | Interrater | Test retest | Internal consistency | Construct / content | Convergent | | | |
| HBS Handicaps, Behaviour, and Skills Schedule | S – good high | – | – | – | – | Clinician | Yes | No |
| DISCO Diagnostic Interview for Social and Communication Disorders | – | – | – | – | – | Clinician | Yes | No |
| ADI-R Autism Diagnostic Interview-Revised | T – high I – high | high | S – good-high | DSM-IV ICD-10 | CARS | Clinician | Yes | No |
| ADOS Autism Diagnostic Observation Schedule | T – high S – high I – high | S – good-high | good-high | DSM-IV ICD-10 | – | Clinician | Yes | No |
| PIA Parent Interview for Autism | – | T – high S – moderate-high | T – high S – moderate-high | DSM-III-R | CARS | Clinician | Yes | No |

I = item, S = subscale, T = total, high = $\geq .80$, good = .60-.79, moderate = .41-.59, low $\leq .40$

The Handicaps, Behaviour, and Skills (HBS) Schedule was not designed as a diagnostic instrument but rather as a "framework for eliciting, systematically, clinical information to be used in conjunction with appropriate psychological tests for assessment and diagnosis" (Wing & Gould, 1978, p. 81). The schedule is a structured interview with parents or caregivers and requires a trained administrator. It consists of 42 sections, each of which deal with a type of developmental skill as well as 21 sections assessing abnormal behaviours. The schedule takes several hours to administer, and results in a profile of developmental skills and abnormal behaviours.

The HBS Schedule has recently been redeveloped and revised, resulting in the Diagnostic Interview for Social and Communication Disorders (DISCO) (Gould, 1999; Wing et al., 1997). The DISCO is a semi-structured interview, which collects information on a wide range of behaviours and developmental skills across the entire 'autism spectrum'. The DISCO consists of 8 sections: (i) general information such as identifying data, family history, perinatal history, and medical history, (ii) development in the first 2 years of life, (iii) self-care skills, independence, memory, visuo-spatial skills, academic skills, communication, social interaction, imitation, and imagination, (iv) repetitive activities and odd responses to sensory stimuli, (v) emotions, (vi) behaviour affecting other people and sleep disturbances, (vii) quality of social interaction, (viii) behaviour leading to problems with the law, inappropriate sexual behaviour, psychiatric disorders, and catatonia. The interview takes up to 3 hours to administer (J. Gould, personal communication, December 4, 1997). Diagnostic algorithms have been written for a total of 6 classification systems, including DSM-III-R (American Psychiatric Association, 1987), DSM-IV (American Psychiatric Association, 1994), and ICD-10 (World Health Organisation, 1993). Training in the use

of the instrument is necessary (Gould, 1999). No information on the psychometric properties of the DISCO has yet been published.

The Autism Diagnostic Interview (ADI and ADI-R) (Le Couteur et al., 1989; Lord et al., 1994) is a semi-structured diagnostic interview for use with the parents or caregivers of people with autism. The interview focuses upon three main areas: (i) quality of reciprocal social interaction, (ii) communication and language, and (iii) repetitive, restricted and stereotyped patterns of behaviour. This instrument requires the interviewer to be highly trained and experienced (Le Couteur et al., 1989). The ADI-R is a revision of the ADI, and is shorter, reorganised, and modified in order to be used with children from 18 months of age into adulthood. It produces an algorithm which is linked to ICD-10 (World Health Organisation, 1992) and DSM-IV (American Psychiatric Association, 1994) diagnostic criteria. It is possible to administer the ADI-R in 90 minutes (Lord et al., 1994).

The Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 1999) is a semi-structured, standardised assessment of communication, social interaction, and play. It provides a series of standardised contexts in which the child's social, communication and repetitive, stereotyped behaviours can be observed. It has been designed to assist in the diagnosis of autism and pervasive developmental disorders and is suggested as a complementary instrument to the ADI-R (Lord et al., 1999). Standardised toys and activities are used to present opportunities for social and communicative interaction with the examiner. During these activities, observation of the child notes the absence or presence of behaviours of interest.

The ADOS can be used to assess toddlers, children, and adults, ranging from nonverbal to verbally fluent. It takes approximately 30-45 minutes to administer. Subtotal scores are generated for the domains of Communication, Qualitative Impairments in Reciprocal Social Interaction, Imagination / Creativity, and Restricted, Repetitive Behaviors and Interests. A diagnostic algorithm consistent with DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organisation, 1993) clinical diagnoses is also generated which provides cut-off scores for autism and Autism Spectrum Disorder within the Communication and Reciprocal Social Interaction subtotals, as well as the Communication plus Social total score.

High levels of sensitivity and specificity have been reported for the ADOS using the established diagnostic cut-off scores (Lord et al., 1999). It has been suggested that the ADOS may be particularly useful in the diagnosis of very young children or low functioning children (Lord & Risi, 1998). As with the ADI-R, training is required in the use of the ADOS.

The PIA (Stone & Hogari, 1993) is a structured parent interview for the gathering of autism diagnostic information in young children. The PIA consists of 118 items, which assess behaviour in the following dimensions: (i) social relating, (ii) affective responses, (iii) motor imitation, (iv) peer interactions, (v) object play, (vi) imaginative play, (vii) language understanding, (viii) nonverbal communication, (ix) motoric behaviours, (x) sensory responses, and (xi) need for sameness. Discriminant function analysis has demonstrated that 4 dimensions of the PIA correctly predicted group membership of 78% of the children with autism and mental retardation groups, correctly classifying 86% of the children with autism and 63% of the children with mental retardation. The

PIA does not yet have a cut-off for a diagnosis of autism and to date has only been used in research (W. Stone, personal communication, April 19, 1999).

Due to the lengthy administration time of such interviews, in their current formats they do not lend themselves to screening methodologies. This is to be expected when one considers that they are designed to assist with the gathering of detailed information in order to facilitate the diagnostic process.

3.5 Current screening instruments

The need for screening instruments in autism has been identified (Lord & Risi, 1998). Although a number of pre-existing checklists and rating scales have been assessed for their efficacy in differentiating autism from other disorders, only a few instruments have been designed with this goal specifically in mind. These include the Checklist for Autism in Toddlers (Baron-Cohen et al., 1992; Baron-Cohen et al., 1996), the Autism Screening Questionnaire (Berument, Rutter, Lord, Pickles, & Bailey, 1999), the Screening Tool for Autism in Two-year olds (STAT) (Stone, Coonrod, & Ousley, 2000), and the Pervasive Developmental Disorder Screening Test (PDDST).

The PDDST has been designed to be used with children aged 2 - 3 years. It is a parent completed questionnaire, consisting of 72 items. To the best of this author's knowledge, there are no published evaluations of the PDDST. This review will therefore not include this instrument.

One instrument, the Developmental Behaviour Checklist (Einfeld & Tonge, 1992), although not designed as a screening tool for autism, has been demonstrated to have

potential as a screening instrument in children and adolescents with intellectually disability. Both the Autism Screening Questionnaire and the Developmental Behaviour Checklist are parent/carer completed instruments, while half of the Checklist for Autism in Toddlers is completed by the parent or carer while the other half is completed by a clinician. The Screening Tool for Autism in Two-year olds is a clinician completed assessment. Of these instruments, only the Checklist for Autism in Toddlers and the Screening Tool for Autism in Two-year olds have been specifically evaluated as screening tools in very young children.

3.5.1 Autism Screening Questionnaire (ASQ)

The Autism Screening Questionnaire (ASQ) was developed as a screening tool for autism (Berument et al., 1999). It consists of 40 questions which were based on the ADI-R (Lord et al., 1994). The questionnaire is completed by parents and includes questions on reciprocal social interaction, language and communication, repetitive and stereotyped patterns of behaviour, and a question on self-injurious behaviour and current language functioning. There are two versions of the questionnaire, one designed for children aged less than 6 years, and one for children aged 6 years and above. The ASQ has been shown to correlate highly with the ADI-R domain and total scores (Berument et al., 1999), reflecting the source of its items. Statistically significant differences were found between a group of individuals with Pervasive Developmental Disorders (autism, atypical autism, Asperger Syndrome, Rett Syndrome and Fragile X Syndrome without autism) and a group with non-Pervasive Developmental Disorder diagnoses (mental retardation, language delay, conduct disorder, and other clinical diagnoses) on 33 of the 40 items of the ASQ (Berument et al., 1999). Factor analysis produced a 4-factor solution, explaining 42.4% of the total variance, which mostly

coincided with the social and repetitive stereotyped behaviour domains of the ADI-R. The communication domain items were divided into two factors, one reflecting communication deficits and the other abnormal language features. Some of the communication domain items also loaded onto the social factor.

Receiver Operating Characteristics analyses found that the ASQ was able to differentiate between Pervasive Developmental Disorder and non-Pervasive Developmental Disorder (Area Under the Curve = 0.862, sensitivity = 0.85, specificity = 0.75, positive predictive value = 0.93, negative predictive value = 0.55), and autism and mental retardation (Area Under the Curve = 0.916, sensitivity = 0.96, specificity = 0.67), and autism and non-Pervasive Developmental Disorder diagnoses other than mental retardation (Area Under the Curve = 0.944, sensitivity = 0.96, specificity = 0.80). However, in the case of the group with mental retardation, it is important to note that the sample size consisted of only 15 individuals. Further analyses using the domain scores concluded that the total score provides the most satisfactory differentiation (Berument et al., 1999).

The ASQ appears to be a promising potential screening tool for a range of Pervasive Developmental Disorders (including autism, Fragile X Syndrome, and Rett Syndrome). However, further work is needed in terms of its psychometric properties, particularly with young children if it is to be used effectively as a screening tool. No information on the psychometric properties was provided for the separate versions of the questionnaire and the data were based upon a sample with a very broad age range (4 – 40 years). It is therefore unclear how the ASQ performs in differentiating children under 6 years of age with autism specifically, from those with developmental delay. It is also important to

note that the parents who completed the questionnaire had already received the diagnosis of autism for their children and had also undergone assessment with the ADI-R. As the authors note, it is possible that this may have attuned them to the relevant behaviours of their child and the item content of the questionnaire (Berument et al., 1999). Further work is needed to establish the efficacy of the ASQ in differentiating young children with autism from those with developmental delay without autism before it can be recommended as a population screening tool.

3.5.2 Developmental Behaviour Checklist (DBC-P)

The Developmental Behaviour Checklist (Primary carer version DBC-P) (Einfeld & Tonge, 1992, 1995) is a parent or carer completed checklist designed to measure behavioural and emotional disturbance in children and adolescents with intellectual disability. The DBC-P has been standardised on a representative sample of children and adolescents aged 4 - 18 years with intellectual disability in Australia. The checklist consists of 96 items which are scored on a 0 - 2 rating scale, where 0 = 'not true as far as you know', 1 = 'somewhat or sometimes true', and 2 = 'very true or often true'. Parents are asked to rate the items in terms of their child's behaviour in the past 6 months. A total score (Total Behaviour Problems Score) can be calculated along with scores on 6 factor analytically derived subscales (Disruptive, Self-Absorbed, Communication Disturbance, Anxiety, Social Relating, and Antisocial). A cut-off score for psychiatric 'caseness' has also been derived which reliably identifies those children with clinically significant levels of behavioural and emotional disturbance (Einfeld & Tonge, 1996).

The DBC-P has well established psychometric properties (Einfeld & Tonge, 1992) (see chapter 4, section 4.3.1 for details). The DBC-P has also been evaluated in terms of its ability to distinguish between children and adolescents with autism and those with intellectual disability without autism (Brereton, 1999). It was found that 29 items of the DBC-P best discriminated between the group with autism and those with intellectual disability without autism. On the basis of Receiver Operating Characteristics (ROC) analysis, it was demonstrated that this Developmental Behaviour Checklist Autism Screening Algorithm (DBC-ASA) is a sensitive screening tool for autism in intellectually disabled children and adolescents (aged 4 - 18 years), with an Area Under the Curve of 0.80, sensitivity of 0.86, and specificity of 0.69.

Strong psychometric properties and the ability to differentiate between children with autism and intellectual disability and children with intellectual disability without autism, identify the DBC-P as a potential population screening instrument for autism. The fact that the DBC-P does not require a clinician to administer it, but is rather completed by parents in a short period of time, thus saving on valuable clinician time further supports its utility as a screening tool.

3.5.3 Checklist for Autism in Toddlers (CHAT)

The Checklist for Autism in Toddlers (CHAT) (Baron-Cohen et al., 1992; Baron-Cohen et al., 1996; Swettenham, 1996) was developed to identify children at risk of autism at 18 months of age. The CHAT has been designed to be used by general practitioners or health visitors at a child's 18 month checkup. It identifies those children who require a full diagnostic assessment. The CHAT consists of two sections. Section A contains nine questions (yes / no answers) which the clinician asks the parent. Areas that are

covered include enjoyment of rough and tumble play, social interest in other children, motor development (climbing), social play, pretend play, pointing to ask, pointing to indicate interest, functional play ability, and showing and joint attention (Swettenham, 1996). Section B consists of five observations of behaviours / skills made by the clinician as present or not. These items cover eye contact, gaze monitoring (following another's point), pretend play, production of a protodeclarative gesture (pointing to show an object), and a rough indicator of general development (ability to build a block tower) (Swettenham, 1996). The CHAT can be completed by an experienced clinician in approximately 10 minutes. The CHAT has been shown to be able to distinguish between children with autism, developmental delay, and normal children (Baron-Cohen et al., 1996), and it has been demonstrated to be a useful screening tool (Baron-Cohen et al., 1996; Swettenham, 1996).

Three key items from the CHAT have been identified as carrying a high risk for autism when they are not present in children at 18 months of age. They are: (i)

Protodeclarative Pointing (PDP) - pointing at an object in order to direct the attention of another person to that object, pointing to indicate; (ii) Gaze Monitoring (GM) - turning to look in the same direction that an adult is looking in; (iii) Pretend Play (PP) - play involving object-substitution, and/or the attribution of absent properties to objects or situations (Baron-Cohen et al., 1996). Protodeclarative pointing and gaze monitoring are usually present by 9 - 14 months of age, and pretend play is usually present by 14 months of age (Baron-Cohen et al., 1996). These three concepts are assessed by items A5 and A7 in the parent section (section A) of the CHAT and Bii, Biii, and Biv on the clinician section (section B). Failure on these five items identifies a child at high risk of

autism. Children at medium risk for autism failed protodeclarative pointing (A7 and Biv), but passed at least one of A5, Bii, or Biii.

As discussed previously (see section 2.2.2.3), the long term follow-up study has established that using a one-stage administration of the CHAT and both the medium and high risk cut-offs, the CHAT has a sensitivity of 38%, specificity of 98%, and positive predictive value of only 4.7% (Baird et al., 2000). Repeating the CHAT one month after the first administration, increased the positive predictive value to 75% within the high-risk group, but while the specificity remained high at 100%, the sensitivity fell to 18%.

In addition to problems of low sensitivity, concerns have been expressed regarding the final sample of children on whom the CHAT was tested (Lord, 1997). Specifically, it has been noted that there was a higher proportion of children with autism who did not have intellectual disability than would be expected based on epidemiological research on the prevalence of autism. This has implications for screening tools in that the fundamental task is in distinguishing those with developmental delay from those with autism, rather than identifying those with autism from those without developmental delay (Lord, 1997). The fact that a clinician is required to administer the CHAT also limits its utility as a screening tool. Data on the reliability of the CHAT is also needed (Baird et al., 2000).

3.5.4 Screening Tool for Autism in Two-year olds (STAT)

The Screening Tool for Autism in Two-year olds (STAT) (Stone et al., 2000) has been designed for use in children 24 - 35 months of age and consists of 12 items assessing 3

areas of behaviour, namely imitation, play, and communication (Stone et al., 2000).

The STAT is an interactional assessment, requires a trained clinician to administer, and takes approximately 20 minutes to complete. A development sample of 40 children (7 with autism and 33 with nonautistic developmental disorders) aged 27 to 35 months was used to establish the scoring algorithm for the STAT (Stone et al., 2000). A further sample of 33 children (12 with autism and 21 with nonautistic developmental disorders) aged 24 to 35 months was used to validate the screening algorithm. It was found that the algorithm correctly identified 100% of the children with autism and 91% of the nonautistic children in the development sample. Application of the algorithm to the second sample resulted in correct identification of 83% of the autism sample and 86% of the nonautistic sample, with a sensitivity of 0.83 and specificity of 0.86. Although this study provides preliminary support for the efficacy of the STAT, very small sample sizes (only 7 and 12 children with autism respectively in the two samples) warrant caution in the interpretation of the results and necessitate replication with larger samples.

3.6 Summary: Selecting a screening instrument

The need for a reliable autism screening instrument for use with young children has been established (Gray & Tonge, 2001; Lord & Risi, 1998). There are a number of problems with some of the currently available instruments, which preclude their utility as a screening tool. These issues include professional administration required, unevaluated or inadequately assessed psychometric properties (such as the use of small clinical samples, or potentially biased institutional samples) (e.g., Rimland's Form E-2, BRIAAC, ABC, RLRS, PDD-MRS, ASQ), and lengthy administration times (e.g., the HBS schedule, BRIAAC, BSE, IBSE, ADOS, ADI-R, PIA). Other problems include the requirement of extensive training and experience with people with autism in order to

administer the instrument (e.g., the HBS schedule, BOS, BSE, ADOS, ADI-R, PDD-MRS), and non-specific screening (i.e., Pervasive Developmental Disorders in general PDD-MRS and ASQ). A number of these instruments (e.g. the ADI-R, ADOS) are intended as diagnostic tools, and are therefore inappropriate for use as screening instruments.

When considering an instrument as a screening tool, it is important to evaluate it in terms of a number of characteristics. Firstly, as with any instrument, it is important that it be psychometrically sound. If it is to be used as a screening tool, it must be also be able to discriminate between those it is intended to identify and those it is not aimed at identifying, however as it is intended as a screening tool, rather than a diagnostic tool, it is to be expected that some cases will be missed and some will erroneously screen positive. It is essential to consider who is going to administer the screening instrument. Professionals who have limited time and/or are not trained in the identification of rare childhood disorders, are usually those in the best position to implement screening procedures, for example general practitioners, paediatrician, health visitors. It is therefore essential that screening is not time consuming (Vostanis et al., 1994), complicated, and does not require extensive training.

Findings of studies of age of recognition of developmental problems and prospective screening suggest that screening for autism should be concentrated at children aged 18 months (Baron-Cohen et al., 1992; Baron-Cohen et al., 1996; De Giacomo & Fombonne, 1998). It has also been suggested that as it is usually not feasible to screen entire populations of children, screening should be focused on 'at-risk' populations. This could potentially include screening children with a developmental disability, as is

indicated by the high percentage of children who have autism and an intellectual disability. Screening children with language delays may be also useful, due to the consistency with which a delay in language and speech development is cited by parents of children with autism as their primary cause for concern. In the case of very limited resources it may be best to limit screening to those children with a sibling or other relative already diagnosed with autism. Due to the size of a population that would need to be screened in any given region in the first two categories, a screening methodology would need to be implemented within the system of primary health care professionals who conduct regular health checks with young children (i.e., paediatricians, maternal and child health nurses, and general practitioners). A screening methodology would therefore need to be brief, not require extensive training, and require minimal input from the primary care professional administering it and the person scoring it. Ideally, such a tool would be able to be completed by parents, be brief, and enable easy identification of those children requiring referral to specialist assessment.

In terms of these criteria, the DBC-P, the CHAT, and the ASQ could potentially be used for population screening for autism in young children. The CHAT however requires a professional to administer it, whereas the DBC-P and the ASQ are completed by parents. However, the ASQ has not yet clearly demonstrated that it is capable of differentiating between children with autism and those with developmental delay or intellectual disability without autism. Bearing these factors in mind, this study therefore aimed to evaluate the efficacy of the DBC-P as a screening tool for autism in young children with developmental delay.

CHAPTER 4

METHOD

STAGE ONE

4.1 Aims and design

This project aimed to develop a screening tool for autism for use with children with developmental delay aged 18 – 48 months. Previous work has demonstrated that the Developmental Behaviour Checklist (Primary Carer version – DBC-P) is a useful screening tool for autism in young people with intellectual disability aged 4 – 18 years (Brereton, 1999). Stage 1 of this project therefore involved assessing the efficacy of the DBC-P as a screening tool for autism in children with developmental delay aged 18 – 48 months. This involved identifying those items of the DBC-P which differentiated a sample of children with autism and developmental delay from a control group of children with developmental delay who did not have autism.

Stage 2 of this project aimed to evaluate the efficacy of the proposed screening tool developed in Stage 1 of the project. This involved a field trial evaluation of the screening tool. A community sample of young children, aged 18 – 48 months, presenting to early childhood services were screened for the possibility of autism. Independent diagnostic assessments were conducted in order to determine the accuracy of the screening process.

Ethics approval for this project was obtained from the Southern Health Care Network Human Resources and Ethics Committee. Ethics approval was also obtained from the

Ethics Committee of the Department of Human Services (Southern region) for the involvement of Human Services staff and clients in Stage two of this study (see Appendix A for copies of ethics approval).

4.2 Participants

4.2.1 Recruitment procedures

The subjects with autism were obtained from a number of sources including the Monash Autism Programme at Monash Medical Centre (Victoria, Australia), Travancore autism assessment service (Melbourne, Victoria), the New South Wales Autistic Children's Association, Australia, the pervasive developmental disorder specialist assessment services in Geelong (Victoria), and the Murray-Murrumbidgee region of New South Wales, Australia. These sources provide regional assessment and follow-up services for children with autism. Most if not all children with autism in these regions would be seen by these services at least for assessment. The regions cover the broad range of Australian social class, urban and rural communities and ethnic mix. Therefore it is reasonable to assume that the sample obtained was representative of children with autism in Australia, and that there was no specific bias present.

All of the subjects in the autism sample had received a diagnosis of autism by specialists using DSM-IV (American Psychiatric Association, 1994) criteria. However, a further case file review of all subjects was conducted in order to confirm that DSM-IV (American Psychiatric Association, 1994) criteria for Autistic Disorder were met for each subject. Forty-one of these subjects (68.3%) were diagnosed by either one of two clinicians experienced in the assessment and diagnosis of autism, and for whom

interrater reliability has been established. Interrater reliability between these two clinicians (calculated on a sample of 107 cases of Autistic Disorder) has been established as high (Cohen's kappa = 0.95).

The subjects with developmental delay without autism (control group) were recruited through early intervention services in Victoria and New South Wales, Australia. The early intervention services in the Melbourne Southern, Eastern, Northern, and Western health care regions, Gateways Support Services in Geelong, Human Services in Wodonga, and some services in Gippsland, Victoria, Australia were asked to distribute a package to the parents or caregivers of children receiving services who were 4 years of age or under. In New South Wales, early intervention services in Wagga Wagga, Griffith, and Albury distributed packages to the parents of children in receipt of services. The package contained an information sheet inviting them to participate in a project looking at developmental delay in young children, a Developmental Behaviour Checklist (Primary Carer version) to complete, a consent form, and a reply paid envelope. The consent form also requested permission to contact the professional(s), named by the parents, involved in their child's assessment in order to obtain copies of assessment reports. The decision was then left with the parents as to whether they wished to participate or not.

When completed Developmental Behaviour Checklists and consent forms were returned, the professionals involved in the assessment of each child were contacted in order to obtain copies of assessment reports. The files were reviewed for each child in order to confirm that the child was developmentally delayed and that autism was neither diagnosed nor suspected. For cases where there was any doubt about a diagnosis, an

independent file review was conducted by a child psychiatrist experienced in developmental delay and autism. If doubts remained, the case was not included in the study sample. A number of cases of autism were also collected through this survey. If the diagnoses of autism and developmental delay were confirmed by assessment reports and file review, the child was included in the autism sample.

4.2.2 Selection criteria

Children were included in the autism group if the following criteria were met: (i) DSM-IV (American Psychiatric Association, 1994) diagnosis of Autistic Disorder, (ii) Developmental Behaviour Checklist completed by the parent(s) or caregiver(s), (iii) aged 18 - 48 months inclusive at the time the Developmental Behaviour Checklist was completed, and (iv) developmental delay confirmed.

Children were included in the control group if the following criteria were met: (i) no diagnosis (or suspicion) of autism confirmed by clinician and independent file review, (ii) Developmental Behaviour Checklist completed by the parent(s) or caregiver(s), (iii) aged 18 - 48 months inclusive at the time the Developmental Behaviour Checklist was completed, and (iv) developmental delay confirmed.

A diagnosis of developmental delay was established by contacting health professionals involved in the assessment of each potential subject requesting, with signed parental consent, reports of any developmental assessments. This included the use of assessment tools such as the Bayley Scales of Infant Development (Bayley, 1969), Griffiths' Mental Developmental Scales (Griffiths, 1954, 1970), McCarthy Scales of Children's Abilities (McCarthy, 1972), Merrill-Palmer Scale (Ball, Merrifield, & Stott, 1978),

Gesell Developmental Schedule (Ames, Gillespie, Haines, & Ilg, 1979; Gesell, Ilg, & Ames, 1974), Leiter International Performance Scale-Revised (Roid & Miller, 1997), or Psychoeducational Profile-Revised (Schopler, Reichler, Bashford, Lansing, & Marcus, 1990). Developmental delay, that is global cognitive delay or significant language delay, established either through standardised assessment (that is, a score of 2 more standard deviations below the mean on an assessment tool) or assessed as presenting with developmental delay by an experienced paediatrician, was a requirement for inclusion in either the autism or control groups. Children with physical disabilities only were not included in the control group. Confirmation of biological diagnoses, if determined, for example genetic conditions associated with the delayed development, were also confirmed through this process by discussion with the paediatrician and file review.

4.3 Measures

4.3.1 Developmental Behaviour Checklist

The Developmental Behaviour Checklist (Primary carer version) (DBC-P) (Einfeld & Tonge, 1992, 1995) is a 96 item checklist designed to assess behavioural and emotional problems in children with intellectual disability. The checklist is completed by parents or other primary care givers. Parents are asked to rate the items in terms of their child's behaviour in the past 6 months. It has 6 subscales derived by factor analysis: Disruptive, Self-Absorbed, Communication Disturbance, Anxiety, Social Relating, and Antisocial. Each item is scored on a 0 - 2 rating scale, where 0 = 'not true as far as you know', 1 = 'somewhat or sometimes true', and 2 = 'very true or often true'.

The DBC-P has been shown to have high reliability between parents (intraclass correlation = 0.80) (Einfeld & Tonge, 1992). Internal consistency is also high ($\alpha = 0.94$). High correlations between the DBC-P Total Behaviour Problem Score and other, professionally administered, measures of behavioural disturbance in children with intellectual disability have been found, providing evidence of concurrent validity (Einfeld & Tonge, 1992). The DBC-P has also been shown to be able to distinguish psychiatric cases from non cases, thus demonstrating high criterion group validity (Einfeld & Tonge, 1992). Receiver Operating Characteristics analysis has shown the DBC-P to be both sensitive and specific in determining 'casesness' (Area Under the Curve = 92%). The DBC-P has been shown to be able to differentiate children and adolescents with Williams syndrome (Einfeld, Tonge, & Florio, 1997), Prader-Willi syndrome (Einfeld, Smith, Durvasula, Florio, & Tonge, 1999), Fragile X syndrome (Einfeld, Tonge, & Florio, 1994) and autism (Brereton, 1999), from those with intellectual disability.

The DBC-P was used in Stage 1 as a measure of behavioural and emotional disturbance. The DBC-P was completed by the parents of the children with autism and the parents of the children with developmental delay without autism. Although standardised norms for the DBC-P have not been established for children aged less than 4 years, clinical experience of the usefulness of this instrument in this age range by both the author of this study and the authors of the DBC-P (Tonge and Einfeld) led to the trial of its usefulness in this study. Further, normative comparisons were not required for the purposes of this study. The previously described results of a study (Brereton, 1999) using the DBC-P to differentiate between children with autism and children with intellectual disability without autism (see section 3.5.2), supported the use of the DBC-

P for a similar purpose in Stage 1 of this study. See Appendix B for a copy of the DBC-P.

4.4 Analyses

As the Developmental Behaviour Checklist (Primary carer version) (DBC-P) was developed for use in children and adolescents aged 4 - 18 years, it was predicted that some items would be either irrelevant or inappropriate for the age group involved in this study. The first stage of data analysis therefore involved determining which items of the DBC-P were not relevant for the study population. This was accomplished by establishing the frequencies of each item for the entire study group, that is item frequencies were calculated for the autism and control groups as one. Those items which were endorsed by less than 75% of the parents, that is those items that were given a score of zero ('not true as far as you know') in 75% or more cases, were excluded from further analyses. Item 96 of the DBC-P, 'Overall, do you feel your child has problems with feelings or behaviour, in addition to problems with development?', was also excluded from further analyses as it is an item which gives an overall summary of behavioural and emotional disturbance rather than being a descriptor of a specific behaviour.

Univariate logistic regressions were performed to establish which of the remaining items of the DBC-P differentiated the autism and control groups. A confirmatory factor analysis was performed with those items from the univariate logistic regressions which significantly differentiated the two groups. Factor loadings were then used to develop the DBC-P screening algorithm.

Receiver Operating Characteristics (ROC) analysis was used to evaluate the overall performance of the DBC-P algorithm as a screening tool for autism and to determine cut-off points (Hanley & McNeil, 1982; Kraemer, 1992). An ROC curve is generated by calculating the sensitivity and specificity of each observed data value and plotting sensitivity against 1 – specificity (Altman & Bland, 1994c). The area under the ROC curve provides a global assessment of the performance of the test or diagnostic accuracy. The Area Under the Curve (AUC) is equal to the probability that a random subject with the disease (autism) has a higher score on the measurement (DBC-P) than a random subject without the disease (Altman & Bland, 1994c). Sensitivity (proportion of true positives correctly identified by the test) and specificity (proportion of true negatives correctly identified by the test) were both calculated (Altman & Bland, 1994a). Positive predictive values (proportion of subjects with positive test results who are correctly diagnosed) and negative predictive values (proportion of subjects with negative test results who are correctly diagnosed) were also calculated (Altman & Bland, 1994b).

Mplus (Muthén & Muthén, 1998) was used to perform the confirmatory factor analysis. Sensitivity, specificity, efficiency, predictive value of a positive test, and predictive value of negative test were calculated using DAG-STAT (Mackinnon, 2000). All other analyses were performed using SPSS Version 10.0 for Windows (SPSS Inc., 1999).

CHAPTER 5

RESULTS

STAGE ONE

5.1 Sample characteristics

The autism group consisted of 60 children, 49 (81.67%) of whom were male. The mean age was 40.31 months ($SD = 5.96$), with a range of 23 to 48 months. All had received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Autistic Disorder from a reliable assessment service. The developmental delay control group consisted of 60 children, 40 (66.67%) of whom were male. The mean age was 35.92 months ($SD = 7.57$), with a range of 19 to 47 months. The autism group was significantly older than the control group, $t(111.88) = -3.53$, $p = .001$. None of the children in the control group had a diagnosis of autism. All of the children in both groups had received a diagnosis of developmental delay. Table 5.1 summarises the demographic characteristics of the autism and control groups.

Table 5.1

Sample Demographics

| Sample | N | % Male | Mean age (months) | Standard deviation | Age range (months) |
|----------|----|--------|-------------------|--------------------|--------------------|
| Autism | 60 | 81.67% | 40.31 | 5.96 | 23 - 48 |
| Controls | 60 | 66.67% | 35.92 | 7.57 | 19 - 47 |

Where available, information on the reported aetiology of developmental delay in the control group was also recorded. This information was available for 42 subjects and is summarised in Table 5.2

Table 5.2

Control Sample: Reported Aetiology of Developmental Delay

| <u>Diagnosis</u> | <u>n</u> |
|--|----------|
| 9p syndrome | 1 |
| Bardet Biedl syndrome | 1 |
| Cerebral palsy | 3 |
| Congenital brain abnormality – ‘cerebral malformation’ | 1 |
| Cornelia de Lange syndrome | 1 |
| Down syndrome | 13 |
| Extra material on long arm of chromosome 11 | 1 |
| ‘Fetal Valproate effects’ | 1 |
| Fragile X syndrome | 1 |
| Lennox Gestaut syndrome | 1 |
| Neurofibromatosis | 1 |
| Post meningitis hydrocephalus | 1 |
| Prader Willi syndrome | 2 |
| Prematurity - 28 weeks (twins) | 2 |
| Prematurity – 34 weeks | 1 |
| Spina bifida and hydrocephalus | 1 |
| Sturge Weber syndrome | 2 |
| Tetrasomy 18p | 1 |
| Twin | 1 |
| Williams syndrome | 6 |
| Cause not known | 18 |

5.2 Suitability of DBC-P items

In order to determine which items of the DBC-P were not relevant for the age range of the sample, frequencies were run on the total sample for 95 items of the DBC-P. Item 96 was excluded as it is an overall summary item rather than a descriptor of a specific behaviour. Those items which 75% or more of parents / carers indicated were 'not true as far as you know' (a score of zero) were considered neither relevant nor appropriate for the age range under study. Thirty items of the DBC-P were thus excluded from further analyses. The percentage of parents / carers which indicated that the behaviour was present (that is, gave a score of '1' or '2') are provided in Appendix C for each item of the DBC-P. These 65 remaining items (in bold in Appendix C) were included in the univariate logistic regression analyses.

5.3 Univariate logistic regressions

The remaining 65 DBC-P items were each individually entered into a series of univariate logistic regressions. A significance level of less than or equal to .01 was chosen as the criterion for inclusion into the confirmatory factor analysis in order to ensure that only those items which best differentiated the autism and control groups were included. Thirty DBC-P items were found to be significant at the level of $p \leq .01$. These items are listed in Table 5.3. The thirty-five items which did not meet the criterion for inclusion in the confirmatory factor analysis ($p > .01$) are listed in Appendix D.

Table 5.3

Univariate Logistic Regressions: Estimated Coefficients (β), Wald Statistics, p Values,
and Odds Ratios for Items Included in Confirmatory Factor Analysis ($p \leq .01$)

| Item | Item description | β | Wald | p | Odds ratio |
|------|---|---------|--------|------|------------|
| 2 | Avoids eye contact. | 2.567 | 32.661 | .000 | 13.030 |
| 3 | Aloof, in his/her own world | 2.166 | 30.727 | .000 | 8.721 |
| 5 | Arranges objects or routine in a strict order | .977 | 13.201 | .000 | 2.657 |
| 7 | Becomes over-excited | .940 | 11.714 | .001 | 2.560 |
| 14 | Deliberately runs away | .687 | 7.909 | .005 | 1.987 |
| 17 | Doesn't show affection | 1.186 | 9.949 | .002 | 3.275 |
| 18 | Doesn't respond to others' feelings | 1.250 | 20.015 | .000 | 3.492 |
| 22 | Excessively distressed if separated from familiar person | .756 | 7.823 | .005 | 2.130 |
| 25 | Flicks, taps, twirls objects repeatedly | .728 | 7.351 | .007 | 2.071 |
| 26 | Fussy eater or has food fads | 1.004 | 16.209 | .000 | 2.729 |
| 28 | Gets obsessed with an idea or activity | 1.312 | 24.847 | .000 | 3.715 |
| 31 | Has temper tantrums, e.g. stamps feet, slams doors | .772 | 8.395 | .004 | 2.163 |
| 34 | Hums, whines, grunts, squeals or makes other non-speech noises | .976 | 16.137 | .000 | 2.655 |
| 35 | Impatient | 1.093 | 14.443 | .000 | 2.983 |
| 42 | Laughs or giggles for no obvious reason | .937 | 12.748 | .000 | 2.553 |
| 47 | Mood changes rapidly for no apparent reason | 1.042 | 10.820 | .001 | 2.834 |
| 49 | Noisy or boisterous | .861 | 9.160 | .002 | 2.367 |
| 50 | Overactive, restless, unable to sit still | .846 | 12.740 | .000 | 2.331 |
| 56 | Prefers the company of adults or younger children. Doesn't mix with his/her own age group | .983 | 13.292 | .000 | 2.672 |
| 57 | Prefers to do things on his/her own. | 1.694 | 25.709 | .000 | 5.442 |
| 58 | Preoccupied with only one or two particular interests | .962 | 12.810 | .000 | 2.616 |
| 61 | Resists being cuddled, touched or held | .952 | 7.410 | .006 | 2.590 |
| 63 | Repeats the same word or phrase over and over | .669 | 6.715 | .010 | 1.952 |
| 66 | Screams a lot | .986 | 12.417 | .000 | 2.681 |
| 71 | Speaks in whispers, high pitched voice, or other unusual tone or rhythm | .759 | 7.297 | .007 | 2.136 |
| 72 | Switches lights on and off, pours water over and over; or similar repetitive activity | .952 | 14.289 | .000 | 2.591 |
| 74 | Stubborn, disobedient or uncooperative | .921 | 10.447 | .001 | 2.513 |
| 91 | Upset and distressed over small changes in routine or environment | .681 | 7.437 | .006 | 1.975 |
| 94 | Wanders aimlessly | 1.192 | 15.668 | .000 | 3.292 |
| 95 | Whines or complains a lot | .768 | 6.714 | .010 | 2.155 |

5.4 Development of the screening algorithm

Confirmatory factor analysis was used to extract a single common factor from the 30 items of the DBC-P (see Table 5.3) which were found to be significant at the $p \leq .01$ level in the univariate logistic regression analyses. The factor analysis also included the binary group membership ('autism') variable. Loadings of the DBC-P items were permitted to load freely on the common factor, while the loading of the group membership variable was constrained to 1.00. The effect of this constraint is to align the factor with autism. Mplus 2.01 (Muthén & Muthén, 1998) was used to calculate polychoric correlations between the three response point (0, 1, 2) DBC-P items and with the binary variable autism. Polychoric correlations assume that a normally distributed variable underlies each observed variable (Muthén & Muthén, 1998). The use of polychoric correlations ensured that any differences in the proportion of respondents endorsing each of the items did not affect the magnitude of the correlation coefficient (McDonald, 1985; Muthén, 1989).

Mplus 2.01 (Muthén & Muthén, 1998) was used to calculate parameter estimates for the model using the weighted least square estimator with mean and variance-adjusted chi-square test statistic. The adequacy of model fit was assessed by the chi-square statistic (χ^2), the ratio of the chi-square statistic to the degrees of freedom (χ^2 / DF), the Comparative Fit Index (CFI), the Non-Normed Fit Index (NNFI) (Bentler & Bonett, 1980) and the Root Mean Square Error of Approximation (RMSEA) (Browne & Cudeck, 1992). Values of χ^2 / DF below 2 or 3 are regarded as denoting adequate fit (Arbuckle, 1997). Values larger than 0.90 are desirable on the CFI and NNFI. Browne and Cudeck (1992) have suggested that values of the RMSEA below 0.05 are indicative of acceptable model fit.

The following indices reflect the fit of the model to the data: $\chi^2(62) = 142.661$, $\chi^2 / DF = 2.29$, NNFI = 0.92, CFI = 0.88, RMSEA = 0.105. These generally showed that the model provided a satisfactory fit, but as the sole aim of this analysis was to determine the loadings of the items on the autism factor in order to develop a screening algorithm, ways in which fit might be improved are not relevant, and will not be discussed further.

Item loadings are shown in Table 5.4. These loadings can be interpreted as the correlation of DBC-P items with a dimension that can be described as liability to autism. All loadings were substantial in size and significantly greater than zero, reflecting the basis upon which items were chosen for inclusion in the confirmatory factor analysis (significant univariate logistic regressions).

Using a cut point of 0.60 or greater, 17 DBC-P items were selected to create a DBC-P autism screening algorithm. These 17 items and their loadings are described in Table 5.4. The decision regarding a cut point is arbitrary, however it was decided that a cut point of 0.60 produced a sufficiently short screening tool, but retained items which had face validity and were felt to be clinically important in the diagnosis of autism in young children. A cut point of 0.60 was also still relatively conservative, which was deemed appropriate for a screening tool which was still to be further tested.

Table 5.4

Confirmatory Factor Analysis: DBC-P Item Loadings

| Item | | Loading | SE |
|------|---|---------|------|
| 57 | Prefers to do things on his/her own. Tends to be a loner | 0.82 | 0.04 |
| 3 | Aloof, in his/her own world | 0.80 | 0.04 |
| 94 | Wanders aimlessly | 0.75 | 0.06 |
| 2 | Avoids eye contact. Won't look you straight in the eye | 0.74 | 0.05 |
| 28 | Gets obsessed with an idea or activity | 0.71 | 0.06 |
| 58 | Preoccupied with only one or two particular interests | 0.69 | 0.06 |
| 50 | Overactive, restless, unable to sit still | 0.69 | 0.06 |
| 72 | Switches lights on and off, pours water over and over; or similar repetitive activity | 0.66 | 0.07 |
| 34 | Hums, whines, grunts, squeals or makes other non-speech noises | 0.66 | 0.07 |
| 91 | Upset and distressed over small changes in routine or environment | 0.65 | 0.06 |
| 18 | Doesn't respond to others' feelings, e.g. shows no response if a family member is crying | 0.64 | 0.07 |
| 47 | Mood changes rapidly for no apparent reason | 0.64 | 0.07 |
| 66 | Screams a lot | 0.63 | 0.07 |
| 35 | Impatient | 0.62 | 0.07 |
| 42 | Laughs or giggles for no obvious reason | 0.61 | 0.07 |
| 74 | Stubborn, disobedient or uncooperative | 0.60 | 0.07 |
| 17 | Doesn't show affection | 0.60 | 0.07 |
| 49 | Noisy or boisterous | 0.59 | 0.06 |
| 31 | Has temper tantrums, e.g. stamps feet, slams doors | 0.59 | 0.07 |
| 61 | Resists being cuddled, touched or held | 0.58 | 0.07 |
| 95 | Whines or complains a lot | 0.55 | 0.09 |
| 7 | Becomes over-excited | 0.55 | 0.08 |
| 56 | Prefers the company of adults or younger children. Doesn't mix with his/her own age group | 0.54 | 0.08 |
| 14 | Deliberately runs away | 0.54 | 0.08 |
| 26 | Fussy eater or has food fads | 0.49 | 0.08 |
| 25 | Flicks, taps, twirls objects repeatedly | 0.49 | 0.09 |
| 22 | Excessively distressed if separated from familiar person | 0.49 | 0.09 |
| 71 | Speaks in whispers, high pitched voice, or other unusual tone or rhythm | 0.44 | 0.09 |
| 5 | Arranges objects or routine in a strict order | 0.42 | 0.08 |
| 63 | Repeats the same word or phrase over and over | 0.34 | 0.10 |

_____ cut point of ≥ 0.60

Using the item loadings in a weighted screening algorithm produced an autism screening score which ranged from 0 – 25.02. An unweighted screening score was also generated by summing the selected items. This produced a screening score ranging from 0 – 34. Receiver Operating Characteristics (ROC) curves were generated for both the weighted and unweighted screening algorithms in order to evaluate the performance of each of the screening algorithms and assign cut-off scores for screening.

For the ROC curve generated for the weighted 17-item DBC-P screening algorithm an Area Under the Curve (AUC) of 0.874 (SE = 0.032, 95% CI: 0.810 – 0.938) was obtained, indicating good overall performance of the weighted screening algorithm (see Figure 5.1).

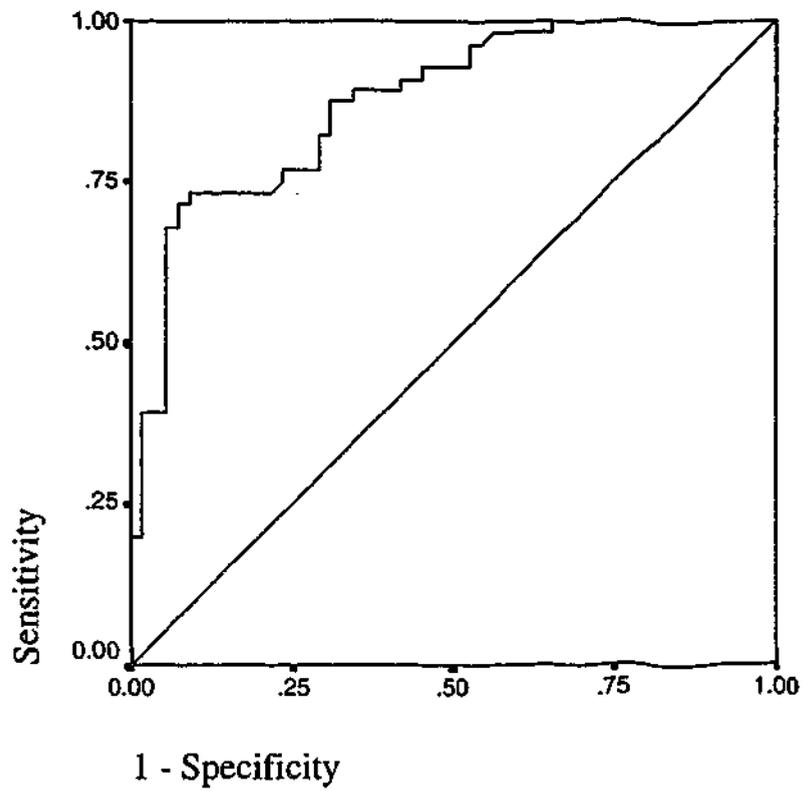


Figure 5.1. Receiver Operating Characteristics curve for the weighted 17-item DBC-P autism screening algorithm.

For the ROC curve generated for the unweighted 17-item DBC-P screening algorithm an AUC of 0.871 (SE = 0.033, 95% CI: 0.806 – 0.936) was obtained, indicating good overall performance of the unweighted screening algorithm (see Figure 5.2).

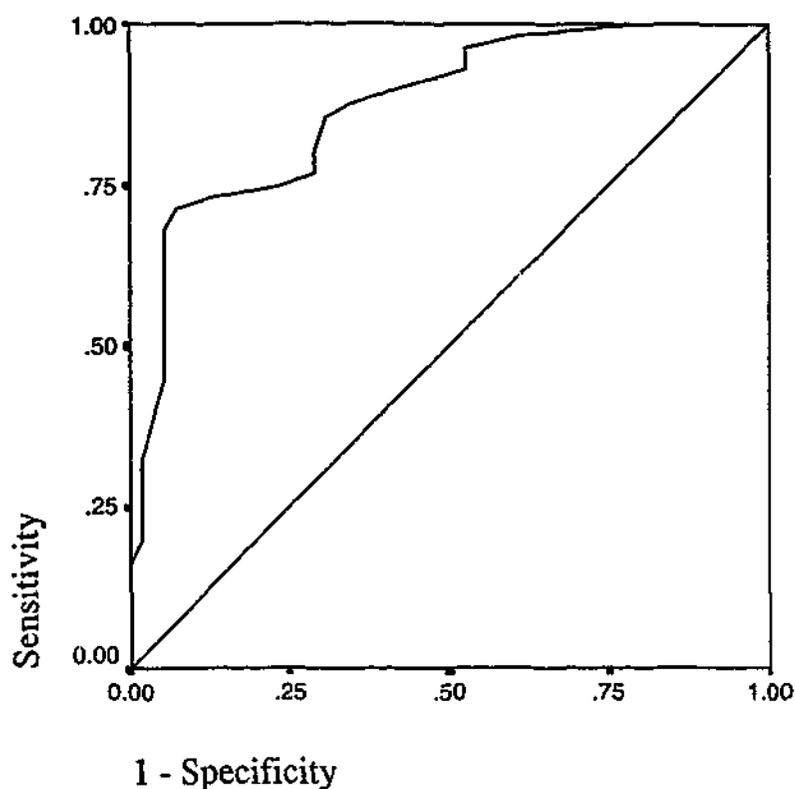


Figure 5.2. Receiver Operating Characteristics curve for the unweighted 17-item DBC-P autism screening algorithm.

The range of potential cut points (see Appendix E) were studied for both the weighted and unweighted screening algorithms. Cut points can vary according to the purpose of the screening. For example, in order to identify all or as many cases of autism as possible, setting the cut point low will maximise sensitivity, although at the expense of specificity. Conversely, if the resources to conduct many assessments with false positives are not available, setting the cut point high will increase the specificity, while reducing the sensitivity. In this study cut points were chosen in order to optimise both sensitivity and specificity. As a field trial was planned, higher sensitivity was favoured, whilst attempting to maintaining specificity as close to 0.70 as possible. Cut-off points were selected for both the weighted and unweighted 17-item screening algorithms. For

the weighted screening algorithm, a cut-off point of greater than or equal to 6.995 was selected and greater than or equal to 10.500 for the unweighted screening algorithm. Sensitivity, specificity, correct classification rate, predictive value of a positive test, and predictive value of a negative test were calculated for both the weighted and unweighted screening algorithms using these cut-off points with 111 subjects (autism = 56 and controls = 55) for whom responses on the 17 algorithm items were available (see Table 5.5).

Table 5.5

Sensitivity, Specificity, Correct Classification Rate, Predictive Value of Positive Test, and Predictive Value of Negative Test for the Weighted (cut-off of ≥ 6.995) and Unweighted (cut-off of ≥ 10.500) 17-Item Screening Algorithms

| | 17-item weighted algorithm (95% <u>CI</u>) | 17-item unweighted algorithm (95% <u>CI</u>) |
|--|---|---|
| Sensitivity | 0.8750 (0.7593 – 0.9482) | 0.8571 (0.7378 – 0.9362) |
| Specificity | 0.6909 (0.5519 – 0.8086) | 0.6909 (0.5515 – 0.8086) |
| Efficiency (correct classification rate) | 0.7838 (0.6956 – 0.8563) | 0.7748 (0.6857 – 0.8486) |
| Predictive value of positive test (PVP) | 0.7424 (0.6199 – 0.8422) | 0.7385 (0.6146 – 0.8397) |
| Predictive value of negative test (PVN) | 0.8444 (0.7054 – 0.9351) | 0.8261 (0.6858 – 0.9218) |

5.5 Summary

The results of Stage 1 of the project indicate that the DBC-P is a potentially useful screening tool for autism in children with developmental delay aged 18 - 48 months. Both a weighted and an unweighted 17-item autism screening algorithm was developed. Both of these screening algorithms performed well. A comparison of the sensitivity, specificity, predictive value of a positive test, and correct classification rates of the two screening algorithms revealed very little differences, with the weighted algorithm performing only marginally better than the unweighted algorithm.

CHAPTER 6

DISCUSSION

STAGE ONE

6.1 Differentiating early features

Thirty items of the DBC-P were found to significantly differentiate the infants and preschool children with autism from those with developmental delay without autism. Behaviours which differed significantly between the children in the areas of social interaction and communication are described in Table 6.1. Behaviours in the area of restricted, repetitive and stereotyped patterns of behaviour, interests and activities, and other significantly differentiating behaviours are described in Table 6.2.

Table 6.1

DBC-P Items Significantly Differentiating the Autism and Developmental Delay

Samples: Social Interaction and Communication

| Social interaction | | Communication | |
|---------------------------------------|---------------------------------------|--|--|
| • Avoids eye contact | • Aloof | • Echolalia | |
| • Doesn't show affection | • Doesn't respond to others' feelings | • Hums, whines, grunts, squeals, makes other non-speech noises | • Speaks in whispers, high pitched voice, other unusual tone or rhythm |
| • Doesn't mix with own age group | • Prefers to do things on own | | |
| • Resists being cuddle, touched, held | | | |

Table 6.2

DBC-P Items Significantly Differentiating the Autism and Developmental Delay

Samples: Restricted, Repetitive, and Stereotyped Patterns of Behaviour, Interests and Activities and Other Behaviours

| Restricted, repetitive & stereotyped patterns of behaviour, interests & activities | | Other behaviours | | |
|---|---|---|---|---|
| <ul style="list-style-type: none"> • Flicks, taps, twirls objects repeatedly • Gets obsessed with an idea or activity | <ul style="list-style-type: none"> • Arranges objects or routine in a strict order • Preoccupied with only one or two particular interests • Switches lights on & off, pours water over & over, or similar repetitive activity | <ul style="list-style-type: none"> • Temper tantrums • Noisy, boisterous • Excessively distressed if separated from familiar person • Stubborn, disobedient • Deliberately runs away | <ul style="list-style-type: none"> • Impatient • Fussy eater, has food fads • Laughs, giggles for no apparent reason • Becomes over excited • Mood changes rapidly | <ul style="list-style-type: none"> • Screams • Wanders aimlessly • Upset, distressed over small changes in routine or environment • Whines, complains • Overactive, restless |

Consistent with other studies focusing on the early identifying features of autism in infants and preschool children, this project identified a number of features in the areas of social interaction and communication which differentiated the children with autism and developmental delay from those with developmental delay without autism. In contrast to a number of studies, this project did find a number of behaviours in the area of restricted, repetitive and stereotyped patterns of behaviour, interests and activities that significantly differentiated the children with autism and the developmentally

delayed children without autism. These included flicking, tapping, twirling objects repeatedly, arranging objects or routines in a strict order, obsessions with ideas or activities, preoccupying interests, and repetitive activities such as switching lights on and off or pouring water over and over.

This inconsistency may be attributable to age differences in the samples studied. In examining the controlled studies which looked at a range of potential differentiating features (see Table 2.6) three of the studies which did not find differences in this area focused on the child's behaviour when they were less than 24 months of age (Dahlgren & Gillberg, 1989; Hoshino et al., 1982; Vostanis et al., 1998). One focused on the broad 8 – 66 months period (Stone & Hogan, 1993), another on 23-35 months (Stone et al., 1999), and in one of these studies the exact age period of focus was unclear (Ohta et al., 1987). These studies thus tended to focus on infants and children for the most part under 24 months of age.

Those studies which did find significantly different behaviours in the area of restricted, repetitive and stereotyped patterns of behaviour, interests and activities concentrated on the 6 – 48 months period (Adrien, Barthelemy et al., 1992) and 36 - 59 months (Lord et al., 1994; Lord et al., 1993). It may be that having older children up to 48 months of age in these studies increases the likelihood of such behaviours being present, which is consistent with the suggestion that these behaviours may not emerge until the third or fourth year of life (Cox et al., 1999). Further support for this view comes from a study which assessed children with autism at two points in time, namely at 20 and 42 months of age. It was found that few children showed any definite abnormality in this area at 20 months, but restricted interests and repetitive behaviours were emerging at 42

months (Cox et al., 1999). The small sample of 8 children in this study warrants caution in interpreting these results.

Another possible explanation for this apparent inconsistency on whether restricted, repetitive and stereotyped patterns of behaviour, interests and activities are present in preschool children with autism may be attributable to the heterogeneity of autism.

Different subgroups of autism have been proposed (e.g. Wing, 1997), and it is possible that such differences are present from the onset of the condition. Thus, some preschool children with autism may demonstrate restricted, repetitive or stereotyped patterns of behaviour, interests and activities from an early age, while others may not present with these behaviours until they are somewhat older. Such differences in early presentation may prove to be a useful way of grouping subtypes of children with autism.

In order to clarify the issue of the presence of behaviours in the area of restricted, repetitive and stereotyped patterns of behaviour, interests and activities in young children with autism, further studies are needed using common measures of assessment across sufficiently large samples of children aged less than 24 months compared to children 36 – 48 months of age. Further study of possible subgroups or subtypes of autism from an early age, in addition to studies of their progress and outcome are also needed in order to identify whether differences in presentation or outcome persist over time.

6.2 Screening algorithm

The results of this study indicate that the DBC-P is a potentially useful screening tool for autism in at risk children aged 18 - 48 months with developmental delay. Both the weighted and unweighted / unit weighted 17-item autism screening algorithms performed well. When screening for the presence of developmental problems in infants and young children sensitivity, specificity, and positive predictive values of 70 – 80% are regarded as acceptable (Aylward, 1997; Glascoe, 1997; Squires, Nickel, & Eisert, 1996). For both the weighted and unweighted autism screening algorithms cut-off points were chosen at which the sensitivities and positive predictive values fell within these recommended rates of acceptability. Cut-off points were chosen in order to optimise both sensitivity and specificity. The second stage of this project involved a field trial of the proposed autism screening algorithm, therefore higher sensitivity was necessary, whilst attempting to maintaining specificity as close to 0.70 as possible. For both the weighted and unweighted autism screening algorithms specificities just under the recommended rate were obtained (0.69), which was deemed acceptable as a high level of sensitivity was achieved.

A comparison of the sensitivity, specificity, predictive value of a positive test, and correct classification rates of the two screening algorithms revealed very few differences, with the weighted algorithm performing only marginally better than the unweighted algorithm. However, in terms of ease of use for clinicians, the unweighted screening algorithm has clear practical advantages over the weighted algorithm. Using the unweighted autism screening algorithm results in scores ranging from 0 – 34. The ROC derived cut-off point at the previously discussed levels of sensitivity and

specificity levels was 10.5. As each item of the DBC-P is scored as a 0, 1, or 2, this results in a cut-off score for a screen positive result of greater than or equal to 11.

No screening tool is diagnostic; it does not ever take the place of an in depth specialist diagnostic assessment, rather it indicates the need for such an assessment. The purpose of this screening tool is to identify those infants and children who are most likely to display symptoms which indicate autism and warrant an assessment. It is equally important to note that a negative screen result does not rule out the possibility of autism. Screening tools should not be used in isolation from the availability of an assessment service. They are a tool which aids the diagnostic process and assists in the early identification of infants and children who may benefit from a referral to a specialist autism assessment service.

6.3 Limitations

There are a number of limitations of Stage 1 of this project, which need to be kept in mind when interpreting the results obtained. The autism screening algorithm was developed using children with developmental delay. Children without cognitive delays with autism (high functioning autism) and typically developing children without autism were not included in the samples from which the differentiating behaviours used in the screening tool were identified. It is possible that the screening tool can identify children without cognitive delays who are at risk for autism, however this has not been tested. It is also possible that such children with autism are more difficult to identify at an early age than those with developmental delay in addition to autism. Such children may present with fewer, different, or additional features that are indicative of autism.

Therefore a further study of the validity of the screening tool is required in non developmentally delayed young children.

A further limitation of Stage 1 of this project relates to a potential response bias.

Although the author is confident that there was no specific bias in the autism sample, it is possible that due to the method of recruitment, nonspecific biases were operating in the control group of children with developmental delay without autism. The parents of children in this group all received information about a study on developmental delay and an invitation to participate from staff of the early intervention service from which their child was receiving services. Parents were not directly contacted and asked to participate by the author of the study. Potential biases in the way in which the information about the study was introduced to parents may have been present, along with a tendency for parents more interested in participating in research projects on developmental delay to respond to the invitation to be involved.

6.4 Field trial evaluation – Developmental Behaviour Checklist Early Screen

Stage 1 of this study provided preliminary support for a subset of 17 items of the DBC-P as a screening tool for autism in infants and young children with developmental delay. However, the full potential of this screening tool can only be assessed via a field trial evaluation. Stage 2 of this study consisted of two evaluations of the proposed screening tool, the Developmental Behaviour Checklist Early Screen (DBC Early Screen) in order to assess its utility and validity.

The first evaluation study of the DBC Early Screen involved its use with children 18 - 48 months of age who were referred to a public specialist autism assessment clinic. The second evaluation study involved the screening of children 18 - 48 months of age who were referred to a regional community health service with suspected developmental delay.

CHAPTER 7

METHOD

STAGE TWO

7.1 Aims and design

The efficacy of the autism screening tool, the Developmental Behaviour Checklist Early Screen (DBC Early Screen) developed in Stage 1 of this project was tested in two independent studies. The first of these studies involved applying the DBC Early Screen to children referred for a specialist autism assessment. The second study consisted of applying the DBC Early Screen to a community sample of children referred with developmental delay.

7.2 Evaluation study one: Autism assessment clinic

The DBC Early Screen was used to screen consecutive referrals to two autism assessment clinics which provide comprehensive assessments for children with developmental and behavioural problems. One of these clinics received referrals from a metropolitan health region of Melbourne in Victoria, Australia (Southern Health Care region). The second of these assessment clinics was located in the Murray-Murrumbidgee region of rural New South Wales, including the regional centres of Albury, Wagga Wagga, Griffith, Deniliquin, and surrounding areas. These clinics were headed by a psychiatrist with expertise in the area of autism assessment. These clinics provide regional assessment and follow-up services for children with autism. Most if not virtually all children with autism in these regions would be seen by these services for assessment. The regions cover the broad range of Australian social class, urban and

rural communities, and ethnic mix. It is thus reasonable to assume that the sample obtained was representative of children with autism in Australia, and that no specific bias was present.

7.2.1 Participants

7.2.1.1 Recruitment procedures

Participants consisted of consecutive referrals of children aged 18 – 48 months with developmental delay referred for assessment at the autism assessment clinics in the previously described areas. The parents or carers of children referred to these clinics completed a Developmental Behaviour Checklist (Primary carer version) (DBC-P) (Einfeld & Tonge, 1992, 1995) prior to the commencement of the assessment session. The 17 items which make up the DBC Early Screen autism screening algorithm were then extracted from the completed DBC after the assessment was complete and after a diagnosis had been made. The clinicians involved in the diagnostic process were thus blind to the results of the autism screen.

The 0 – 2 scores for each of the 17 DBC items were summed to create a total screen score. If the total screen score was greater than or equal to the cut-off score of 11, the subject was classified as a positive screen. If the score was below 11, the subject was classified as a negative screen.

7.2.1.2 Selection criteria

Children were included in the sample if the following criteria were met: (i) aged 18 - 48 months inclusive at the time of assessment, (ii) Developmental Behaviour Checklist completed by the parent(s) or caregiver(s), (iii) developmental delay confirmed.

A diagnosis of developmental delay was established through the multidisciplinary assessment process conducted by the assessment clinics. Developmental level was ascertained through the use of assessment tools such as the Bayley Scales of Infant Development (Bayley, 1969), Griffiths' Mental Developmental Scales (Griffiths, 1954, 1970), McCarthy Scales of Children's Abilities (McCarthy, 1972), Merrill-Palmer Scale (Ball et al., 1978), Leiter International Performance Scale-Revised (Roid & Miller, 1997), or Psychoeducational Profile-Revised (Schopler et al., 1990). Developmental delay, that is global cognitive delay, was established through standardised assessment (that is, a score 2 or more standard deviations below the mean on an assessment tool). Children with physical disabilities only were not included.

7.2.1.3 Diagnostic assessment

All referrals to the clinics received a comprehensive diagnostic assessment. Assessment involved the following components: cognitive / developmental assessment, speech pathology assessment, medical evaluation, and psychiatric evaluation and diagnosis. Diagnoses of autism were made according to DSM-IV (American Psychiatric Association, 1994) criteria for Pervasive Developmental Disorder (Autistic Disorder). All diagnoses were made by the head of the assessment team. This psychiatrist is experienced in the assessment and diagnosis of autism. Interrater reliability between this clinician and another experienced in the assessment and diagnosis of autism

(calculated on a sample of 107 cases of Autistic Disorder) has been established as high (Cohen's kappa = 0.95).

7.3 Evaluation study two: Community sample with developmental delay

The second evaluation of the DBC Early Screen involved screening referrals to a metropolitan region early childhood health service in the southern region of Melbourne, Victoria, Australia. This public health agency (Specialist Children's Services) receives referrals of children aged under 6 years who are suspected of having problems with development. In the Southern health region of Melbourne, this agency is spread between 3 main office sites (Dandenong, Frankston, and Cheltenham). Each site consists of a multidisciplinary team, headed by a team leader. This service provides assessment and intervention services for children and facilitates referrals to specialist assessment and intervention services. This region covers the broad range of Australian social class and ethnic mix, and is predominantly suburban.

There is no other similar service in this region. It is likely that most children with developmental problems in this region would be seen by this service, unless they had had no contact with any medical (general practice or paediatric) or welfare agency.

7.3.1 Participants

7.3.1.1 Recruitment procedures

The screening tool (DBC Early Screen) was distributed to the staff of each Specialist Children's Services office along with information sheets on the project and consent forms (see Appendices F and G respectively for copies of the information sheet and

consent forms). When the staff met with a family referred to Specialist Children's Services the research project was explained to parents of children who met the study inclusion criteria and they were invited to participate. Parents were asked to complete the consent form and the DBC Early Screen. Parents were also given the contact details of the author if they wished to discuss the project further. If parents agreed to participate in the project, they completed the DBC Early Screen before the end of the appointment. At no point was the word autism mentioned. The project was introduced as focusing on the early detection of developmental problems. None of the materials received by parents contained the word autism. The completed DBC Early Screen forms and consent forms were sent to the project office directly following completion.

7.3.1.2 Selection criteria

Children were included in the sample if the following criteria were met: (i) aged 18 - 48 months inclusive at the time of presentation to Specialist Children's Services, (ii) the DBC Early Screen completed by the parent(s) or caregiver(s), and (iii) developmental delay confirmed or suspected. Children with physical disabilities only were not included.

7.3.2 Screening procedure

The completed DBC Early Screen and consent forms were sent to the project office. Two independent research assistants received the completed forms. These research assistants each independently scored the DBC Early Screen forms. Each case was designated as either a screen positive or a screen negative (cut point of greater than or equal to 11 equals points is a positive screen result). If consensus was reached, the data

was entered by one research assistant and then independently checked by the other. Disagreements in scoring were independently rescored until consensus was reached.

The name, date of birth, gender, and contact details of all screen positive and screen negative cases were then given to the author to be contacted and invited to an assessment. The author was not given any information regarding the results of the screening process.

The project clinician (author) contacted the families and invited them to participate in an assessment. In all cases the clinician was blind to the results of the screening, as were the parents of the child. If the parents requested the results of the screen, this was given to them at the end of the assessment process, once a diagnosis had been given.

7.3.3 Measures

The DBC Early Screen was completed for each subject prior to commencing the diagnostic assessment. The Autism Diagnostic Interview-Revised (ADI-R) and Autism Diagnostic Observation Schedule (ADOS) were completed in order to gather information relevant to reaching a DSM-IV (American Psychiatric Association, 1994) diagnosis. The Childhood Autism Rating Scale (CARS) was used to provide further information on autism symptomatology. The DSM-IV (American Psychiatric Association, 1994) diagnosis remained the study gold standard.

The Psychoeducational Profile-Revised (PEP-R) was completed in order to obtain a developmental level for each subject. Where possible, the Reynell Developmental Language Scales were undertaken to assess each subject's receptive and expressive

language ability. The Vineland Adaptive Behavior Scales were used to obtain information on each subject's adaptive behaviour level.

7.3.3.1 Screening

7.3.3.1.1 Developmental Behaviour Checklist Early Screen

The Developmental Behaviour Checklist Early Screen (DBC Early Screen) was developed in Stage 1 of this project. The DBC Early Screen retains the format and 0, 1, 2 scoring system of the Developmental Behaviour Checklist (Primary carer version) (DBC-P) (Einfeld & Tonge, 1992, 1995). The psychometric properties of the DBC-P have been described previously (see section 4.3.1). Like the DBC, the DBC Early Screen is a parent or carer completed instrument.

The DBC Early Screen consists of the 30 items identified in Stage 1 of this study which significantly differentiated the children with autism from those with developmental delay without autism. As described previously (section 5.4), 17 of these items are used to calculate the screen score. The remaining 13 items were retained in the instrument, including the overall item ('Overall, do you feel your child has problems with feelings or behaviour, in addition to problems with development?'), as these items still significantly differentiated the groups and were thought to be clinically useful.

A total screen score was calculated by summing the scores of the 17 items which made up the autism screening algorithm (see Table 7.1 for a listing of these items). As the unweighted screening score performed as well as the weighted version and has practical

advantages over the weighted algorithm, it was used for this field trial. A screen positive cut-off score of 11, as established through Stage 1 of this project, was used.

The DBC Early Screen was completed by parents in all cases. See Appendix H for a copy of the DBC Early Screen.

Table 7.1

The DBC Early Screen: Items Totalled to Calculate the Total Screen Score

| Item | |
|-------------|--|
| 1 | Prefers to do things on his/her own. Tends to be a loner |
| 2 | Aloof, in his/her own world |
| 3 | Wanders aimlessly |
| 4 | Avoids eye contact. Won't look you straight in the eye |
| 5 | Gets obsessed with an idea or activity |
| 6 | Preoccupied with only one or two particular interests |
| 7 | Overactive, restless, unable to sit still |
| 8 | Switches lights on and off, pours water over and over; or similar repetitive activity |
| 9 | Hums, whines, grunts, squeals or makes other non-speech noises |
| 10 | Upset and distressed over small changes in routine or environment |
| 11 | Doesn't respond to others' feelings, e.g. shows no response if a family member is crying |
| 12 | Mood changes rapidly for no apparent reason |
| 13 | Screams a lot |
| 14 | Impatient |
| 15 | Laughs or giggles for no obvious reason |
| 16 | Stubborn, disobedient or uncooperative |
| 17 | Doesn't show affection |

7.3.3.2 Diagnosis

Diagnoses of autism were made according DSM-IV (American Psychiatric Association, 1994) diagnostic criteria for Pervasive Developmental Disorders (Autistic Disorder, PDD NOS). Two standardised assessment tools designed to assist in the assessment of children and adults referred for possible autism and other pervasive developmental disorders, namely the Autism Diagnostic Interview-Revised (Le Couteur et al., 1989; Lord et al., 1994) and the Autism Diagnostic Observation Schedule (Lord et al., 1999), were used to assist with diagnosis. Both of these instruments are discussed in detail later. A clinical diagnosis was made for each subject utilising all information gathered during the assessment process (with the exception of the DBC Early Screen result). Diagnosis was made according to DSM-IV (American Psychiatric Association, 1994) criteria which remained the study gold standard.

Of the 22 cases seen in the second evaluation study, 20 were seen by a psychiatrist experienced in the diagnosis of children with autism. This psychiatrist made a diagnosis independent of that made by the study clinician (author). This was done through observations made during the assessments. This psychiatrist was also blind to the results of the screening process. Of the 20 cases for whom diagnoses were independently made by the 2 clinicians, diagnostic agreement was reached in 19 cases (95% agreement). Of the one case where agreement was not reached, one clinician (author) diagnosed Autistic Disorder, whilst the other diagnosed PDD NOS. After discussion of the case, diagnostic agreement (Autistic Disorder) was reached between the clinicians.

7.3.3.3 Assessment measures

7.3.3.3.1 Autism Diagnostic Interview – Revised

As described previously (section 3.4), the Autism Diagnostic Interview (ADI) (Le Couteur et al., 1989; Lord et al., 1994) is a standardised, semi-structured diagnostic interview for use with the parents or caregivers of people with autism or Asperger's Disorder. The interview consists of 111 items and focuses upon three main areas (i) quality of reciprocal social interaction, (ii) communication and language, and (iii) repetitive, restricted and stereotyped patterns of behaviour. In general items are coded 0 (no evidence of abnormality), 1 (some evidence of abnormality), and 2 (evidence of marked abnormality). It produces an algorithm which is linked to ICD-10 (World Health Organisation, 1992) and DSM-IV (American Psychiatric Association, 1994) diagnostic criteria.

The ADI-R has been shown to have good interrater reliability when used with preschool children (Lord et al., 1994). The algorithm items making up the Reciprocal Social Interaction domain have weighted kappas ranging from 0.64 to 0.89, percentage agreement ranging from 90% to 96%, and intraclass correlations ranging from 0.93 to 0.96. High reliability was also obtained for non algorithm items, with the exception of three items receiving kappas of 0.52 to 0.59, although high levels of percentage agreement were obtained (87 - 96%). For the Communication and Language domain algorithm items kappas ranged from 0.69 to 0.89, mean percentage agreement from 88% to 96%, and intraclass correlations from 0.94 to 0.95. The other, non algorithm items were also generally found to be reliable (Lord et al., 1994). For the algorithm items making up the Repetitive, Restricted and Stereotyped Patterns of Behaviour domain, kappas ranged from 0.64 to 0.86, percentage agreement was above 90% for all

items of this domain (including non algorithm items), and intraclass correlations from 0.93 to 0.95.

Internal consistency was assessed for each domain. A Cronbach's alpha of 0.95 was obtained for the Reciprocal Social Interaction domain, 0.84 for the Communication domain, and 0.69 for the Restricted and Repetitive Behaviours domain. Test-retest reliability was assessed over a 2-3 month period, with a mean percentage agreement of 91%. However the sample size was small (six) and test-retest reliability needs to be examined with a larger sample.

The ADI-R has been shown to be able to differentiate between preschool children with and without autism, with the children with autism demonstrating greater abnormality (higher scores) (Lord et al., 1994). The findings of this study have been discussed previously (see section 2.2.2.2.3). Stability of diagnosis using the ADI-R with preschool children has been found to be good (Cox et al., 1999; Gillberg et al., 1990; Lord, 1995; Stone et al., 1999).

The ADI-R diagnostic algorithm has been shown to be able to discriminate between preschool children with autism and nonverbal, developmentally delayed non autistic preschool children (Lord et al., 1993). There is evidence that the ADI-R is a sensitive diagnostic measure in preschool children, particularly when an autism spectrum approach to diagnosis is used (Cox et al., 1999; Stone et al., 1999). However, the ADI-R has been found to over diagnose autism in young children with severe levels of mental handicap; being unable to differentiate children with autism from children with a mental age under 18 months (Lord et al., 1993). It has been concluded that further

information from direct observation is necessary to diagnose such young children (Lord et al., 1993). Standardised direct observation information is provided by the ADOS (Lord et al., 2000; Lord et al., 1999), which was therefore administered in this study.

In a study of young children with autism, Baron-Cohen and colleagues (1996) used a modified cut-off score for the Repetitive Behaviours and Stereotyped Pattern domain. It was argued that due to the often low frequency or absence of these types of behaviours in infants and young children with autism (Cox et al., 1999; Lord et al., 1994; Rogers, 2001; Stone et al., 1994; Stone et al., 1999) a lower cut-off score (2 rather than 3) was justified. The results of the ADI-R interviews were examined in terms of both the established ADI-R algorithm scoring (Le Couteur et al., 1989; Lord et al., 1994) and the lowered cut-off for the Repetitive Behaviours and Stereotyped Pattern domain.

Training is required in the use of the ADI-R in order to achieve satisfactory reliability (at least 90% agreement on the protocol and algorithm). This reliability is established with an international team of researchers with established reliability. The author has been trained in the use of this interview and has established reliability (90% plus) with an accredited trainer from the University of Chicago.

See Appendix I for a copy of the ADI-R.

7.3.3.3.2 Autism Diagnostic Observational Schedule

As described in section 3.4, the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000; Lord et al., 1999) is a semi-structured, standardised observational

assessment of the child's communication, social interaction, and play. It provides a series of standardised contexts in which the child's social, communication and repetitive, stereotyped behaviours can be observed. It has been designed to assist in the diagnosis of autism and pervasive developmental disorders and is used as a complementary instrument to the ADI-R (Lord et al., 1999). Standardised toys and activities are used to present opportunities for social and communicative interaction with the examiner. During these activities, the absence or presence of the child's behaviours of interest is recorded.

The current version of the ADOS was developed from revisions of the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 1989) and the Pre-Linguistic Autism Diagnostic Observation Schedule (PL-ADOS) (DiLavore, Lord, & Rutter, 1995). It can be used to assess toddlers, children, and adults, ranging from nonverbal to verbally fluent. It consists of four modules, each of which take approximately 30-45 minutes to administer. In assessing a child, one module is chosen, based upon the child's expressive language level. Module 1 is for use with those with a minimum of no speech up to a maximum of simple phrases (less than three words), while Module 4 is used with those who are verbally fluent. Due to the language level of the subjects in this study, Module 1 was used throughout. Discussion of the psychometric properties of the ADOS is therefore limited to this module.

Subtotal scores are generated for the domains of Communication, Qualitative Impairments in Reciprocal Social Interaction, Imagination / Creativity, and Restricted, Repetitive Behaviors and Interests. A diagnostic algorithm consistent with DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organisation,

1993) clinical diagnoses is generated which provides cut-off scores for autism and for other Pervasive Developmental Disorders ('autism spectrum disorders') within the Communication and Reciprocal Social Interaction subtotals, as well as the Communication plus Social total score. Imagination / Creativity and Restricted, Repetitive Behaviors and Interests are not included in the calculation of the algorithm as inadequate time and opportunity is provided to measure such behaviours. Research has also revealed that this domain was not useful in classifying individuals (Lord et al., 1999).

Thorough research has been undertaken by the authors of the ADOS in both the design and investigation of the psychometric properties of this assessment tool. These studies included subjects with autism, PDD NOS, and non Pervasive Developmental Disorders. Reliability and validity was examined for both items and domains scores for each Module, cut-off scores were set, and the sensitivity and specificity of these scores was established (Lord et al., 1999).

Interrater reliability for all items in Module 1 was high. Mean percentage agreement was 91.5% across raters, and all items had greater than 80% agreement. With the exception of items relating to repetitive behaviours ($\kappa = 0.55$) and sensory abnormalities ($\kappa = .057$), all kappas exceeded 0.60. Codings were adjusted for those items with lower kappas, and reliability checks were redone.

Reliability of domain scores was found to be good to excellent (Lord et al., 1999). For the Social domain, intraclass correlations across pairs of raters ranged from 0.88 to 0.97 for separate modules. For the Communication domain the intraclass correlations ranged

from 0.74 to 0.90. For Restricted, Repetitive Behaviors the intraclass correlations ranged from 0.75 to 0.90. For the Social – Communication subtotal used in the algorithm, intraclass correlations ranged from 0.84 to 0.98.

Interrater agreement in diagnostic classification (autism versus non autism spectrum) for the ADOS Module 1 was found to be high – 100%. Good to excellent test-retest reliability has been demonstrated for all of the domains of the ADOS across an average period of 9 months (Lord et al., 1999). The intraclass correlation for the Social domain was 0.78, 0.73 for the Communication domain, 0.59 for Restricted, Repetitive Behaviors, and 0.82 for the Social – Communication algorithm subtotal. Internal consistency was evaluated for each domain using Cronbach's alpha. In the Social domain alphas ranged from 0.86 to 0.91 for each module, 0.74 to 0.84 for the Communication domain, and 0.91 to 0.94 for the Social – Communication algorithm subtotal. For Restricted, Repetitive Behaviors alphas ranging from 0.63 to 0.65 were obtained for Modules 1 and 2.

Receiver Operating Characteristics curves were calculated to assist in determining diagnostic cut-off scores for each of the ADOS modules (Lord et al., 1999). High sensitivity and specificity was obtained for each module at the diagnostic cut-off points. For Module 1 when considering autism versus other conditions (i.e. non autism spectrum), sensitivity was found to be 100% and specificity 100%. When considering autism and autism spectrum disorders versus other conditions, sensitivity was found to be 97% and specificity 94%.

Training in the use of the ADOS is required to achieve reliability (at least 80% agreement on both the protocol and algorithm). This reliability is established with an international team of researchers with established reliability. The author has been trained in the use of this assessment and has established reliability (80% plus) with an accredited trainer from the University of Chicago.

See Appendix J for a copy of the ADOS (Module 1).

7.3.3.3 Psychoeducational Profile – Revised

The Psychoeducational Profile-Revised (PEP-R) (Schopler et al., 1990) is a developmental measure designed specifically for use with children who have autism. It has been designed to overcome the difficulties inherent in tests designed for and normed on typically developing children. Most of the items do not require language. The items do not have to be administered in a predetermined order, and directions are not entirely dependent on the child's receptive language abilities. Items are included which measure skills down to very young age ranges, and flexible administration procedures allow examiners to adjust for behaviour problems. None of the items are timed. The test materials are concrete and interesting to children with autism, and a wide range of developmental levels are addressed (Schopler et al., 1990).

The PEP-R can be used with children from 6 months up to 12 years of age. It consists of two scales - the Developmental Scale and the Behavioral Scale. The Developmental Scale provides information on developmental functioning in seven areas; Imitation, Perception, Fine Motor, Gross Motor, Eye-Hand Integration, Cognitive Performance, and Cognitive Verbal. The Developmental Scale consists of 131 items involving a set

of toys and materials that are presented to the child in structured play activities. The materials are designed to be appealing to children that are difficult to assess and are useful in establishing rapport with children (Schopler et al., 1990). Items are scored as Pass, Fail or Emerging (indicative of some knowledge of what is required, but insufficient knowledge or skill needed to successfully complete the task). A Total Developmental Score and Developmental Quotient can be calculated, along with a profile of the child's strengths and weaknesses in each area assessed relative to standardised age equivalents.

The PEP-R Developmental Scale has been normed on typically developing children aged 1-7 years, providing age equivalents for the children with autism in each developmental area. The PEP-R takes 45 minutes to 1.5 hours to administer. Reliability has been shown to be good (Schopler et al., 1990), the internal consistency of items has been reported as ranging from 0.82 to 0.98 (Steerneman, Muris, Merckelbach, & Willems, 1997), and good interrater reliability has been documented for the developmental items (Muris, Steerneman, & Ratering, 1997). The authors of the instrument report good validity and point out that the items and materials have been empirically tested, eliminating those that have not demonstrated clinical validity (Schopler et al., 1990).

The second scale of the PEP-R is the Behavioral Scale. This scale is used to identify and measure behavioural abnormalities in four areas - Relating & Affect, Play & Interest in Materials, Sensory Responses, and Language. Items on this scale are not norm-referenced. It has been suggested that this scale is useful for diagnostic purposes and assessing changes in behaviour over time (Schopler et al., 1990). This scale of the

PEP-R was not used in this study as the purpose of using the PEP-R was to provide a measure of each subject's developmental level.

See Appendix K for a copy of the PEP-R.

7.3.3.4 Reynell Developmental Language Scales

The Reynell Developmental Language Scales III (RDLS) (Edwards et al., 1985) assesses the language ability of children aged between 18 months and 7 years. It has been standardised on a sample of 1074 typically developing children from both rural and urban settings, and has an established role in the assessment of language in children with autism. The RDLS consists of two scales, the Comprehension Scale (62 items), and the Expressive Scale (62 items). It takes approximately 30 minutes to administer, and utilises a selection of toys, picture books and finger puppets. Equivalent age levels, percentile scores, and standard scores are generated. The RDLS has a mean of 50 and a standard deviation of 10.

The RDLS (both scales) has been shown to be a reliable (reliability coefficients of 0.97 for the Comprehension Scale and 0.96 for the Expressive Scale) and valid measure of the language ability of children (Edwards et al., 1985). The RDLS was administered during assessment to provide a measure of the child's language ability.

See Appendix L for a copy of the RDLS.

7.3.3.5 Vineland Adaptive Behavior Scales

The Vineland Adaptive Behavior Scales (VABS) (Sparrow, Balla, & Cicchetti, 1984) provide a general assessment of adaptive behaviour in daily functioning. It is a semi-structured interview (with parent / caregiver), consisting of 297 items measuring behaviour in 4 domains: Communication, Daily Living Skills, Socialisation, and Motor Skills. An Adaptive Behaviour Composite score is also calculated. The survey form has the additional optional domain of Maladaptive Behavior. Both the domain scores and the Adaptive Behavior Composite have a mean of 100 and a standard deviation of 15. Standard scores, percentile ranks, adaptive levels, and age equivalents are generated. The VABS is suitable for use with individuals from birth to 18 years 11 months of age.

A review of nine adaptive behaviour scales concluded that the VABS had excellent reliability and validity (Harris, Belchic, Blum, & Celiberti, 1994). Internal consistency (split-half reliability) of each of the domains has been reported as high – Communication 0.89, Daily Living Skills 0.90, Socialization 0.86, and Motor Skills 0.83 (Sparrow et al., 1984). Test-retest reliability for each domain has also been established - Communication 0.75, Daily Living Skills 0.72, Socialization 0.62, and Motor Skills 0.78 (Sparrow et al., 1984). Correlations between the VABS and intelligence scales are low, indicating that the adaptive behaviour scales measure different areas of functioning (Harris et al., 1994).

The VABS, excluding the optional Maladaptive Behavior domain, was administered at assessment through interview with the parent(s) or caregiver(s). It was decided that the

types of behaviours described in the Maladaptive Behavior domain were better assessed by other instruments used in this study (e.g., the ADI-R, DBC Early Screen, CARS). The Interview Edition Survey Form (Harris et al., 1994) was used in this study.

See Appendix M for a copy of the Vineland.

7.3.3.3.6 Childhood Autism Rating Scale

The CARS (Schopler et al., 1980), an observational measure of behaviour, is made up of 15 scales; (i) impairment in human relations, (ii) imitation, (iii) inappropriate affect, (iv) bizarre use of body movement and persistence of stereotypes, (v) peculiarities in relating to nonhuman objects, (vi) resistance to environmental change, (vii) peculiarities of visual responsiveness, (viii) peculiarities of auditory responsiveness, (ix) near receptor responsiveness, (x) anxiety reaction, (xi) verbal communication, (xii) nonverbal communication, (xiii) activity level, (xiv) intellectual functioning, and (xv) general impressions. Each scale is rated on a scale ranging from normal to severely abnormal (1 = behaviour within normal range for child's age, to 4 = severely abnormal behaviour) based upon observation of the child. Total scores can range from 15 to 60. A cut-off score of 30 or above is said to be indicative of a diagnosis of autism (Schopler et al., 1980). Concordance between ADI-R diagnoses of autism and CARS diagnoses of autism has been reported (85.7% agreement) (Pilowsky, Yirmiya, Shulman, & Dover, 1998). The CARS has been shown to be able to discriminate between autistic and intellectually disabled children without autism (Teal & Wiebe, 1986) and between intellectually disabled adolescents with and without autism (Garfin, McCallon, & Cox, 1988), although these studies used pre DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organisation, 1992) diagnostic criteria. Good to high

internal consistency (alpha coefficients of .94 and .85) has been reported (Schopler et al., 1980; Sturmey, Matson, & Sevin, 1992), along with average interrater reliability (average reliability of .71 across scales) (Schopler et al., 1980).

The CARS was used to provide further information on autism symptomatology and was completed by the clinician at the end of the child assessment period.

See Appendix N for a copy of the CARS.

7.4 Analyses

7.4.1 Evaluation study one: Autism assessment clinic

The total sample was examined in terms of demographic variables such as age, gender, and the DBC Early Screen scores. The sample was then divided into those who received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Pervasive Developmental Disorder - Autistic Disorder and those who did not. These two samples were examined to establish whether there were any sample differences in terms of age, proportion of males, and the mean DBC Early Screen score.

The screening efficacy of the DBC Early Screen was then evaluated, using a cut-off of 11 for a positive case and comparing this to the clinical DSM-IV diagnostic classification of Autistic Disorder and non Autistic Disorder. Sensitivity (proportion of true positives correctly identified by the test) and specificity (proportion of true negatives correctly identified by the test) were both calculated (Altman & Bland,

1994a). Positive predictive values (proportion of subjects with positive test results who are correctly diagnosed) and negative predictive values (proportion of subjects with negative test results who are correctly diagnosed) were also calculated (Altman & Bland, 1994b).

Sensitivity, specificity, efficiency, predictive value of a positive test, and predictive value of negative test were calculated using DAG-STAT (Mackinnon, 2000). All other analyses were performed using SPSS Version 10.0 for Windows (SPSS Inc., 1999).

7.4.2 Evaluation study two: Community sample with developmental delay

The total sample was examined in terms of demographic variables such as age, gender, and the DBC Early Screen scores. Further information on developmental age, language ability, adaptive behaviour, autism symptomatology, and results of the ADI-R and ADOS assessments was also examined.

The sample was then divided into those who received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Pervasive Developmental Disorder - Autistic Disorder and those who did not. These two samples were examined to establish whether there were any sample differences in terms of age, proportion of males, and the mean DBC Early Screen score. The two samples were also evaluated in terms of developmental age, language ability, adaptive behaviour, autism symptomatology, and results of the ADI-R and ADOS assessments.

The screening efficacy of the DBC Early Screen was then evaluated, using a cut-off of 11 for a positive case and comparing this to the clinical DSM-IV (American Psychiatric Association, 1994) diagnostic classification of Autistic Disorder and non Autistic

Disorder. Sensitivity (proportion of true positives correctly identified by the test) and specificity (proportion of true negatives correctly identified by the test) were both calculated (Altman & Bland, 1994a). Positive predictive values (proportion of subjects with positive test results who are correctly diagnosed) and negative predictive values (proportion of subjects with negative test results who are correctly diagnosed) were also calculated (Altman & Bland, 1994b).

The total sample was also divided into those who received the broader DSM-IV (American Psychiatric Association, 1994) diagnosis of a Pervasive Developmental Disorder and those who did not. These two samples were examined to establish whether there were any sample differences in terms of age, proportion of males, and the mean DBC Early Screen score. The two samples were also evaluated in terms of developmental age, language ability, adaptive behaviour, autism symptomatology, and results of the ADI-R and ADOS assessments.

The screening efficacy of the DBC Early Screen was then evaluated, using a cut-off of 11 for a positive case and comparing this to the clinical DSM-IV (American Psychiatric Association, 1994) broad diagnostic classification of Pervasive Developmental Disorder and non Pervasive Developmental Disorder. Sensitivity and specificity were both calculated. Positive predictive values and negative predictive values were also calculated.

Sensitivity, specificity, efficiency, predictive value of a positive test, and predictive value of negative test were calculated using DAG-STAT (Mackinnon, 2000). All other analyses were performed using SPSS Version 10.0 for Windows (SPSS Inc., 1999).

CHAPTER 8

RESULTS

STAGE TWO

8.1 Evaluation study one: Autism assessment clinic

8.1.1 Sample characteristics

The total sample referred to the clinics for assessment consisted of 38 subjects, 29 (76.3%) of whom were male. The mean age was 39.07 months ($SD = 6.81$), with a range of 23 to 48 months. All of the subjects had a diagnosis of developmental delay confirmed. The DBC Early Screen total scores ranged from 5 to 29, with a mean of 16.92 ($SD = 6.96$). Thirty (78.95%) subjects screened positive (DBC Early Screen total score at or above 11) and 8 (21.05%) screened negative.

8.1.2 Assessment results

As a result of the clinical assessment process, 35 (92.10%) of the children referred received a DSM-IV diagnosis of Autistic Disorder. Of those who did not receive a diagnosis of Autistic Disorder, one was diagnosed with an Expressive Language Disorder and two with Mixed Receptive-Expressive Language Disorder. The age, sex, and the mean DBC Early Screen scores of the two groups are described in Table 8.1.

All of those subjects who did not receive a diagnosis of Autistic Disorder were male, while 26 (74.29%) of those with a diagnosis of Autistic Disorder were male. The ages of those who did not receive a diagnosis of Autistic Disorder ranged from 42 to 48 months, with a mean of 45.82 ($SD = 3.02$) months. The ages of those who did receive a

diagnosis of Autistic Disorder ranged from 23 to 48 months, with a mean of 38.49 ($SD = 6.75$) months. As the skewness of the age distribution in the non Autistic Disorder sample was greater than ± 1.0 (-1.552), a non parametric test was used to examine whether the difference in ages between the two groups was significant (George & Mallery, 2000). Analysis using the Mann-Whitney rank-sum U test revealed that those in the non Autistic Disorder sample were significantly older than those in the Autistic Disorder sample, Mann-Whitney $U = 12.0$, $z = -2.193$, $p < .05$.

Of those who did not receive a diagnosis of autism, the DBC Early Screen scores ranged from 5 to 24, with a mean of 17.67 ($SD = 10.97$). Of those who did receive a diagnosis of autism, the DBC Early Screen scores ranged from 5 to 29, with a mean of 16.86 ($SD = 6.75$). As the skewness of the DBC Early Screen score distribution in the non Autistic Disorder sample was greater than ± 1.0 (-1.732), a non parametric test was used to examine whether the difference in ages between the two groups was significant (George & Mallery, 2000). Analysis using the Mann-Whitney rank-sum U test revealed no differences between the DBC Early Screen scores of the two groups, Mann-Whitney $U = 49.50$, $z = -.163$, ns .

Table 8.1

Demographics and the Mean DBC Early Screen Score by Diagnostic Group

| DSM-IV diagnosis | N | Sex n male | Age in months (SD) | DBC Early Screen score (SD) |
|-----------------------|----|----------------|-----------------------|-----------------------------------|
| Non Autistic Disorder | 3 | 3 (100%) | 45.82 (3.02) | 17.67 (10.97) |
| Autistic Disorder | 35 | 26 (74.29%) | 38.49 (6.75) | 16.86 (6.75) |

8.1.3 Efficacy of the DBC Early Screen

As outlined in Table 8.2, of those who screened positive on the DBC Early Screen, 28 (73.68%) received a diagnosis of Autistic Disorder and 2 (5.26%) did not. Of those who screened negative, 1 (2.63%) did not receive a diagnosis of Autistic Disorder while 7 (18.42%) did. This is described in Figure 8.1. The two false positive cases both obtained DBC Early Screen scores of 24, well above the screen cut-off of 11. One case received a diagnosis of Expressive Language Disorder, whilst the other was diagnosed with Mixed Receptive-Expressive Language Disorder. Both subjects had significant levels of behavioural disturbance; one with high levels of anxiety and obsessional behaviour as a reaction to the subject's experience of domestic violence, and the other with oppositional, defiant behaviour, and high anxiety. Of the 7 false negative cases, one obtained a DBC Early Screen score of 5, 3 obtained a score of 7 on the DBC Early Screen, 2 scored 9, and one scored 10.

This resulted in a sensitivity (proportion of true positives correctly identified by the test) of 0.80 (95% CI: 0.63 – 0.92), specificity (proportion of true negatives correctly identified by the test) of 0.33 (95% CI: 0.01 – 0.91), and efficiency (correct

classification rate) of 0.76 (95% CI: 0.60 – 0.89). A predictive value of a positive test value (proportion of subjects with positive test results who are correctly diagnosed) of 0.93 (95% CI: 0.78 – 0.99) was obtained along with a predictive value of a negative test (proportion of subjects with negative test results who are correctly diagnosed) of 0.13 (95% CI: 0.00 – 0.53). These results are summarised in Table 8.3.

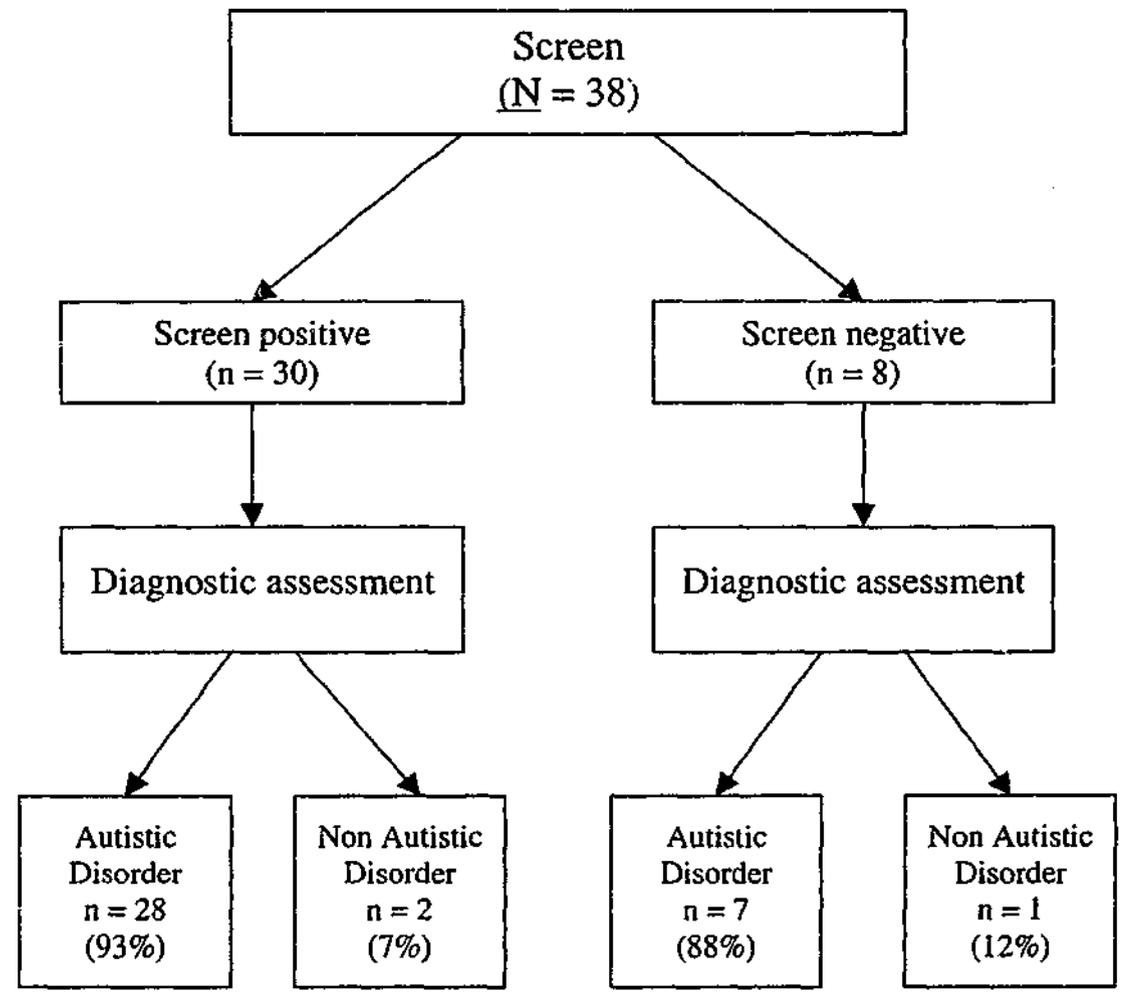


Figure 8.1. DBC Early Screen accuracy in terms of DSM-IV Autistic Disorder diagnosis for evaluation study one

Table 8.2

The DBC Early Screen Result by Diagnostic Group

| DBC Early Screen result | | | |
|--------------------------------|------------------------------|------------------------------|--------------------|
| DSM-IV diagnosis | Positive screen n | Negative screen n | Total n |
| Autistic Disorder | 28 (73.68%) | 7 (18.42%) | 35 |
| Non Autistic Disorder | 2 (5.26%) | 1 (2.63%) | 3 |
| Total | 30 | 8 | 38 |

Table 8.3

Sensitivity, Specificity, Correct Classification Rate, Predictive Value of Positive Test,
and Predictive Value of Negative Test

| | Screen accuracy (CI) |
|--|---------------------------------|
| Sensitivity | 0.80 (0.63 – 0.92) |
| Specificity | 0.33 (0.01 – 0.91) |
| Efficiency (correct classification rate) | 0.76 (0.60 – 0.89) |
| Predictive value of positive test (PVP) | 0.93 (0.78 – 0.99) |
| Predictive value of negative test (PVN) | 0.13 (0.00 – 0.53) |

8.1.4 Summary

In sum, evaluation study one found the DBC Early Screen to have good sensitivity (0.80), good overall classification efficiency (0.76), and very good predictive value of a positive test (0.93). However, specificity was found to be low (0.33). This may have been effected by the low number of non autistic cases in the sample ($n = 3$). This was due to the referral pattern of cases during the study, with a disproportionate number receiving a DSM-IV (American Psychiatric Association, 1994) diagnosis of Autistic Disorder during the period through which the study was conducted. The small number of non autistic cases was not surprising due to the referral patterns to a specialist autism assessment clinic. It is likely that cases referred to a specialist autism assessment clinic will have autism as they have been through a filter of other services prior to being referred to the specialist autism assessment clinic.

8.2 Evaluation study two: Community sample with developmental delay

8.2.1 Total referred sample

8.2.1.1 Sample characteristics

The total sample referred consisted of 22 subjects, 17 (77.3%) of whom were male. At the time of assessment, the mean age of the sample was 40 months ($SD = 6.42$), with a range of 23 to 49 months. The DBC Early Screen total scores ranged from 2 to 31, with a mean of 15.45 ($SD = 7.56$). Fifteen (68.2%) subjects screened positive (DBC Early Screen total score at or above 11) and 7 (31.8%) screened negative.

8.2.1.2 Assessment results

As a result of the assessment process, 19 (86.4%) of the total number of subjects tested in the developmentally delayed range. Twenty-one (95.5%) children tested as having delayed language. Nine children were verbal (40.9%) and 13 were nonverbal (59.1%). Table 8.4 describes the mean, standard deviation, and range of scores obtained by the total referred sample on the Childhood Autism Rating Scale (CARS), Psychoeducational Profile-Revised (PEP-R), Reynell Developmental Language Scales (Reynell), and Vineland Adaptive Behavior Scales (Vineland). A mean score of 34.02 ($SD = 9.55$) was obtained on the CARS, while an average developmental age of 24 months ($SD = 9.70$) was obtained using the PEP-R. A mean age equivalent of 31.90 ($SD = 8.37$) months was obtained on the Comprehension scale of the Reynell for the 12 subjects who were able to complete this assessment, with the remaining 10 subjects scoring less than 21 months. On the Expressive scale of the Reynell an age equivalent of 30.44 months ($SD = 7.89$) was obtained for the 10 subjects able to complete this scale, with the remaining 12 subjects scoring less than 21 months. The Vineland Adaptive Behavior Scales was completed for a total of 19 subjects. A mean Vineland

Adaptive Behavior Composite score of 63.89 (SD = 11.81) was obtained for the total sample referred. On the Vineland Communication domain an age equivalent of 22.40 months (SD = 23.70) was obtained with one subject scoring below 1 month. On the Vineland Daily Living Skills domain an age equivalent of 25.21 months (SD = 12.06) was obtained, while an age equivalent of 60.89 months (SD = 8.20) was obtained for the Socialisation domain. For the Vineland Motor Skills domain an age equivalent of 30.78 months (SD = 12.03) was obtained with one case scoring greater than 71 months.

Table 8.4

Means, Standard Deviations, and Range of Scores on the Childhood Autism Rating Scale, Psychoeducational Profile-Revised (PEP-R), Reynell Developmental Language Scales, and Vineland Adaptive Behavior Scales for the Total Referred Sample

| Assessment | N | Mean (SD) | Range |
|--|----|------------------|---------------------------------|
| Childhood Autism Rating Scale (CARS) | 22 | 34.02 (9.55) | 18.50 - 48.50 |
| PEP-R developmental score | 22 | 53.09 (26.34) | 11 - 97 |
| PEP-R developmental age (months) | 22 | 24.00 (9.70) | 10 - 43 |
| Reynell Comprehension standard score | 12 | 22.58 (19.07) | 0 - 50 |
| Reynell Comprehension age equivalent (months) | 12 | 31.90 (8.37) | 24 - 50 10 cases < 21 months |
| Reynell Expressive standard score | 10 | 23.20 15.02 | 0 - 46 |
| Reynell Expressive age equivalent (months) | 10 | 30.44 (7.89) | 21 - 45 12 cases < 21 months |
| Vineland Communication domain standard score | 19 | 66.11 (18.05) | 48 - 115 |
| Vineland Communication domain age equivalent (months) | 19 | 22.44 (23.70) | 5 - 107 1 case < 1 month |
| Vineland Daily Living Skills domain standard score | 19 | 69.12 (10.91) | 58 - 94 |
| Vineland Daily Living Skills domain age equivalent (months) | 19 | 25.21 (12.06) | 13 - 62 |
| Vineland Socialisation domain standard score | 19 | 60.89 (8.20) | 51 - 81 |
| Vineland Socialisation domain age equivalent (months) | 19 | 15.63 (11.44) | 5 - 53 |
| Vineland Motor Skills domain standard score | 19 | 79.74 (15.02) | 56 - 108 |
| Vineland Motor Skills domain age equivalent (months) | 19 | 30.78 (12.03) | 16 - 71 1 case 71+ months |
| Vineland Adaptive Behavior Composite | 19 | 63.89 (11.81) | 51 - 95 |
| Vineland total age equivalent (average months across all domains) | 19 | 24.63 (14.34) | 11 - 73.25 |

Nine (40.9%) subjects met the ADI-R diagnostic algorithm cut-off criteria for autism, while 13 (59.1%) scored below the cut-off criteria. Table 8.5 describes the scores obtained within each domain of the ADI-R diagnostic algorithm, along with the number of subjects which met the ADI-R diagnostic algorithm cut-off scores for autism. As outlined in this table, 16 (72.7%) subjects met the cut-off criteria for autism in the Reciprocal Social Interaction domain, 16 (72.7%) met the cut-off criteria for autism in the Communication domain, while 11 (50%) met the cut-off criteria for autism in the Repetitive Behaviours & Stereotyped Patterns domain.

Baron-Cohen and colleagues (1996) have used a modified score for the Repetitive Behaviours and Stereotyped Patterns domain, using a cut-off threshold of 2 rather than 3 for young children due to the fact that the research literature has shown that these behaviours are often not seen in young children with autism (see section 2.2.3). As described in Table 8.5, this modified cut-off score resulted in 15 (68.2%) subjects meeting the algorithm criteria for autism for the Repetitive Behaviours and Stereotyped Patterns domain, 4 more than when using a cut-off of 3. This modified cut-off score for the Repetitive Behaviours and Stereotyped Patterns domain resulted in 13 (59.1%) subjects meeting the total ADI-R algorithm criteria for autism, 4 more than when the higher cut-off for the Repetitive Behaviours and Stereotyped Patterns domain was applied.

Table 8.5

ADI-R Algorithm Domain Mean Scores, Standard Deviations, and Cut-Offs for theEntire Sample Referred

| ADI-R algorithm | Mean (SD) | At / above autism cut-off N (%) | Below cut-off N (%) |
|--|-----------------|---------------------------------------|------------------------|
| Reciprocal Social Interaction domain | 14.73 (6.72) | 16 (72.7%) | 6 (27.3%) |
| Communication domain | 10.05 (3.90) | 16 (72.7%) | 6 (27.3%) |
| Repetitive Behaviours & Stereotyped Patterns domain | 3.23 (2.33) | 11 (50%) | 11 (50.0%) |
| ADI-R autism diagnosis* | - | 9 (40.9%) | 13 (59.1%) |
| Repetitive Behaviours & Stereotyped Patterns domain - modified cut-off | 3.23 (2.33) | 15 (68.2%) | 7 (31.8%) |
| ADI-R autism diagnosis using modified repetitive cut-off* | - | 13 (59.1%) | 9 (40.9%) |

*total score for ADI-R algorithm not applicable

Twelve (54.5%) subjects in the sample met the ADOS algorithm cut-off criteria for autism, 6 (27.3%) met the cut-off criteria for an autism spectrum disorder, and 4 (18.2%) scored below the cut-off criteria. Table 8.6 describes the scores obtained within each domain of the ADOS diagnostic algorithm, along with the number of subjects which met the ADOS diagnostic algorithm cut-off scores for autism and autism spectrum disorder. As outlined in this table, 14 (63.6%) subjects met the cut-off criteria

for autism and an additional 4 subjects (18.2%) met the criteria obtained scores which fell within the autism spectrum in the Reciprocal Social Interaction domain. In the Communication domain 16 (72.7%) subjects met the cut-off criteria for autism, whilst an additional 5 (22.7%) fell within the autism spectrum range. For the combined Reciprocal Social Interaction and Communication domain score, 14 (63.6%) subjects met the cut-off criteria for autism and an additional 4 (18.2%) obtained scores which fell within the autism spectrum. Cut-off scores are not generated for the Repetitive Behaviours and Restricted Interests and Play domains (Lord et al., 1999).

8.2.1.3 Assessment summary

The total community referred sample consisted of 22 subjects. Nineteen were confirmed as developmentally delayed, with 21 having delayed language. The mean chronological age was 40 ($SD = 6.42$) months, while the mean developmental age was 24 ($SD = 26.34$) months. An adaptive behaviour mean age equivalent of 24.63 ($SD = 14.34$) months was obtained. Scores on the CARS ranged from 14.50 to 48.50, with a mean of 34.02. Of the 12 subjects able to complete the Reynell Comprehension scale, a mean age equivalent of 31.90 ($SD = 8.37$) months was obtained, with the remaining 10 cases thus scoring below 21 months of age. Similarly, of the 10 cases with sufficient language to complete the Reynell Expressive scale, a mean score of 30.44 ($SD = 7.89$) was obtained, with the remaining 12 cases thus scoring below 21 months of age.

Table 8.6

ADOS Algorithm Domain Mean Scores, Standard Deviations, and Cut-Offs for the
Total Sample Referred

| ADOS algorithm | Mean (SD) | Autism N (%) | Autism spectrum N (%) | Non autism N (%) |
|--|-----------------|-----------------|-----------------------------|---------------------|
| Reciprocal Social Interaction domain | 7.73 (4.13) | 14 (63.6%) | 4 (18.2%) | 4 (18.2%) |
| Communication domain | 5.05 (1.86) | 16 (72.7%) | 5 (22.7%) | 1 (4.5%) |
| Reciprocal Social Interaction + Communication domains | 12.77 (5.76) | 14 (63.6%) | 4 (18.2%) | 4 (18.2%) |
| Repetitive Behaviours & Restricted Interests domain* | 2.00 (1.31) | - | - | - |
| Play* | 3.09 (1.11) | - | - | - |
| ADOS algorithm diagnosis** | - | 14 63.6 | 4 18.2 | 4 18.2 |

*cut-off scores not available for the Repetitive Behaviours & Restricted Interests and Play domains

**total score for ADOS algorithm not applicable

8.2.2 Diagnostic samples: Autistic Disorder and non Autistic Disorder

8.2.2.1 Sample characteristics

The 22 subjects referred for assessment were diagnosed according to DSM-IV criteria (American Psychiatric Association, 1994). Table 8.7 describes the breakdown of DSM-IV (American Psychiatric Association, 1994) clinical diagnoses received (excluding developmental delay / mental retardation as this was a feature of all children referred to the study). For the purposes of this study, the DSM-IV diagnosis is considered the gold standard. Diagnostic differences between the DSM-IV gold standard clinical diagnosis and the diagnostic assignments made by the ADI-R and ADOS algorithms are discussed in section 8.2.2.2. For the purposes of analyses, the sample was divided into those who received a diagnosis of Autistic Disorder ($N = 15$) and those who did not ($N = 7$). The sample was also divided into those who received a diagnosis of a Pervasive Developmental Disorder ($N = 17$) and those who did not ($N = 5$). The Autistic and non Autistic Disorder samples will be examined first.

Table 8.7

DSM-IV Diagnoses for Entire Sample*

| DSM-IV Diagnosis | N (%) |
|---|---------------|
| Autistic Disorder | 15 (68.2%) |
| Asperger's Disorder | 1 (4.5%) |
| PDD NOS | 1 (4.5%) |
| Mixed Receptive-Expressive Language Disorder | 3 (13.6%) |
| Reactive Attachment Disorder | 1 (4.5%) |
| Disruptive Behaviour Disorder Not Otherwise Specified | 1 (4.5%) |
| Total | 22 (100%) |

*Excluding diagnoses or developmental delay/mental retardation (as was a criterion for study entry)

Table 8.8 describes the mean chronological age (in months), developmental age as measured by the PEP-R (in months), total CARS score, and the DBC Early Screen total score for the autistic and non autistic samples. Fifteen out of a total of 22 subjects received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Autistic Disorder.

There was no significant difference between the chronological ages of the two samples, $t(20) = 1.304$, ns, nor in terms of developmental age, $t(20) = 1.192$, ns. Ten (66.67%) subjects in the autistic sample were male, whilst 7 (100%) subjects in the non autistic

sample were male. There was no significant difference in the proportion of males in each of the samples, $\chi^2(1, N=22) = 3.020$, Fisher's Exact Test ns. The Autistic Disorder sample had a higher mean CARS total score than the non Autistic Disorder sample $t(20) = -6.475$, $p \leq .001$. There was no significant difference between the total DBC Early Screen scores of the two samples, $t(20) = -1.507$, ns.

Table 8.8

Mean, Standard Deviation, and Range of Scores for Chronological Age, Developmental Age, Total CARS Score, and the DBC Early Screen Total Score for the Autistic and Non Autistic Samples

| | Autistic Disorder (N=15) | | Non Autistic Disorder (N=7) | |
|---------------------------------|-----------------------------|---------------|--------------------------------|---------------|
| | Mean (SD) | Range | Mean (SD) | Range |
| Chronological age (months) | 38.80 (6.81) | 23 - 49 | 42.57 (5.00) | 34 - 49 |
| Developmental age (months) | 22.33 (9.58) | 10 - 41 | 27.57 (9.64) | 18 - 43 |
| CARS | 39.27 (5.78) | 30.50 - 48.50 | 22.79 (5.02) | 18.50 - 30.00 |
| DBC Early Screen total score | 17.07 (7.49) | 6 - 31 | 12.00 (7.00) | 2 - 23 |

8.2.2.2 Clinical assessment results

As described in Table 8.9, 86.67% of the autistic sample were confirmed as being developmentally delayed (as measured by the PEP-R) while 85.71% of the non autistic sample were confirmed as developmentally delayed. This difference was not

significant, $\chi^2(1, N=22) = .004$, Fisher's Exact Test ns. All of the children with autism were language delayed (as measured by the Reynell Developmental Language Scales), while 85.71% of those without autism had delayed language. This difference was not significant, $\chi^2(1, N=22) = 2.245$, Fisher's Exact Test ns. Eleven (73.33%) of the children with autism were nonverbal, whilst 2 (28.57%) of those without autism were nonverbal. This difference was not significant, $\chi^2(1, N=22) = 3.956$, Fisher's Exact Test ns.

Table 8.9

Proportion of Autistic Disorder and Non Autistic Disorder Samples with Developmental Delay, Language Delay, and Who are Nonverbal

| | Autistic Disorder (N=15) | Non Autistic Disorder (N=7) |
|---------------------|-----------------------------|--------------------------------|
| Developmental delay | 13 delayed (86.67%) | 6 delayed (85.71%) |
| Language delay | 15 delayed (100%) | 6 delayed (85.71%) |
| Verbal ability | 11 nonverbal (73.33%) | 2 nonverbal (28.57%) |

Table 8.10 describes the mean, standard deviation, and range of standard scores for each of the Vineland Adaptive Behavior Scales domains and Adaptive Behavior Composite standard scores for the Autistic Disorder and Non Autistic Disorder samples. One way Analysis of Variance (ANOVA) revealed that the differences in mean standard scores were not significant for the Adaptive Behavior Composite, $F(1, 17) = 2.354$, ns; total

age equivalent, $F(1, 17) = 2.933$, ns; Daily Living Skills, $F(1, 17) = 1.255$, ns; or Motor Skills $F(1, 17) = .009$, ns. The Non Autistic Disorder sample obtained a significantly higher mean Communication standard score, $F(1, 17) = 5.086$, $p \leq .05$, and a significantly higher mean Socialisation standard score $F(1, 17) = 7.104$, $p = .01$.

Table 8.11 describes the mean, standard deviation, and range of the standard scores obtained on the Comprehension and Expressive Scales of the Reynell Developmental Language Scale for the Autistic Disorder and Non Autistic Disorder samples. A total of 12 subjects were able to complete the Comprehension Scale of the Reynell. A one way ANOVA revealed no significant differences between the scores of the two samples, $F(1, 10) = .199$, ns. Ten subjects had sufficient language to complete the Expressive Scale of the Reynell. There was no significant difference between the scores of the two samples, $F(1, 8) = 1.843$, ns.

Table 8.10

Mean, Standard Deviation, and Range of Standard Scores Obtained on the Vineland Adaptive Behavior Scales Domain, Adaptive Behavior Composite, and Total Age Equivalent for the Autistic Disorder and Non Autistic Disorder Samples

| | Autistic Disorder (N=12) | | Non Autistic Disorder (N=7) | |
|-------------------------------|-----------------------------|----------|--------------------------------|---------------|
| | Mean (SD) | Range | Mean (SD) | Range |
| Communication domain | 59.67 (11.46) | 48 - 81 | 77.14 (22.62) | 54 - 115 |
| Daily Living Skills domain | 67.08 (7.50) | 58 - 82 | 72.86 (15.15) | 58 - 94 |
| Socialisation domain | 57.58 (6.17) | 51 - 69 | 66.57 (8.52) | 55 - 81 |
| Motor Skills domain | 80.00 (15.75) | 56 - 105 | 79.29 (14.87) | 63 - 108 |
| Vineland total age equivalent | 20.54 (8.57) | 11 - 39 | 31.64 (19.79) | 14.75 - 73.25 |
| Adaptive Behavior Composite | 60.83 (8.90) | 51 - 76 | 69.14 (14.90) | 53 - 95 |

Table 8.11

Mean, Standard Deviation, and Range of Reynell Developmental Language Scales Comprehension Scale Standard Scores and Expressive Scale Standard Scores for the Autistic Disorder and Non Autistic Disorder Samples

| | Autistic Disorder | | | | Non Autistic Disorder | | | |
|------------------------------|-------------------|-------|-----------|--------|-----------------------|-------|-----------|---------|
| | n | Mean | <u>SD</u> | Range | n | Mean | <u>SD</u> | Range |
| Comprehension standard score | 7 | 20.43 | 17.67 | 9 - 50 | 5 | 25.60 | 22.63 | 9 - 50 |
| Expressive standard score | 6 | 18.17 | 13.09 | 0 - 32 | 4 | 30.75 | 16.26 | 13 - 46 |

As outlined in Table 8.12, 9 (60%) subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed (study gold standard) Autistic Disorder sample met the ADI-R diagnostic algorithm cut-off criteria for autism, while 6 (40%) scored below the cut-off criteria. All of the subjects in the non Autistic Disorder sample fell below the ADI-R diagnostic algorithm cut-off criteria for autism. This difference was significant, $\chi^2(1, N=22) = 7.108$, Fisher's Exact Test $p \leq .05$.

Table 8.12 also describes the scores obtained within each domain which make up the ADI-R diagnostic algorithm, along with the number of subjects which met each of the ADI-R domain diagnostic algorithm cut-off scores for autism. Thirteen (86.7%) subjects in the Autistic Disorder sample met the cut-off criteria for autism in the Reciprocal Social Interaction domain, while 3 (42.9%) subjects in the non Autistic Disorder sample met the cut-off criteria for autism. This difference was significant,

$\chi^2(1, N=22) = 4.618$, Fisher's Exact Test $p = .05$. Thirteen (86.7%) subjects in the Autistic Disorder sample met the cut-off criteria for autism in the Communication domain, while 3 (42.9%) subjects in the non Autistic Disorder sample met the cut-off criteria for autism. This difference was significant $\chi^2(1, N=22) = 4.618$, Fisher's Exact Test $p = .05$. In the Repetitive Behaviours and Stereotyped Patterns domain 10 (66.7%) subjects in the Autistic Disorder sample met the cut-off criteria for autism, and 1 (14.3%) subject in the non Autistic Disorder sample met the cut-off criteria for autism. This difference was not significant, $\chi^2(1, N=22) = 5.238$, Fisher's Exact Test ns.

A modified score for the Repetitive Behaviours and Stereotyped Patterns domain was also calculated, using a cut-off threshold of 2 rather than 3 for young children (Baron-Cohen et al., 1996). As described in Table 8.12, this modified cut-off score resulted in 12 (80.0%) subjects in the Autistic Disorder sample meeting the cut-off criteria for autism for the Repetitive Behaviours and Stereotyped Patterns domain, 2 more than when using a cut-off of 3. As described previously, this was 8 subjects more than in the non Autistic Disorder sample, a difference which was not found to be significant, $\chi^2(1, N=22) = 3.035$, Fisher's Exact Test ns.

This modified cut-off score for the Repetitive Behaviours and Stereotyped Patterns domain resulted in 13 (73.3%) subjects in the Autistic Disorder sample meeting the total ADI-R algorithm criteria for autism, 2 more than when the higher cut-off for the Repetitive Behaviours and Stereotyped Patterns domain was applied and 9 subjects more than in the non Autistic Disorder sample. This difference was not significant, $\chi^2(1, N=22) = 3.956$, Fisher's Exact Test ns.

Table 8.12 also gives the means and standard deviations for the total ADI-R domain scores for both the DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder and non Autistic Disorder samples. As outlined in this table, the Autistic Disorder sample scored higher than the non Autistic Disorder sample in all three domains. A one way ANOVA revealed that these differences were significant for the Reciprocal Social Interaction domain, $F(1, 20) = 13.912, p = .001$, the Communication domain, $F(1, 20) = 7.442, p = .01$, and the Repetitive Behaviours and Stereotyped Patterns domain, $F(1, 20) = 5.202, p \leq .05$.

Table 8.12

ADI-R Algorithm Domain Mean Scores, Standard Deviations, and Cut-Offs for the
Autistic Disorder and Non Autistic Disorder Samples

| ADI-R algorithm | Autistic Disorder (N=15) | | | Non Autistic Disorder (N=7) | | |
|---|-----------------------------|--|---------------------------|--------------------------------|--|---------------------------|
| | Mean (SD) | At / above autism cut-off N (%) | Below cut-off N (%) | Mean (SD) | At / above autism cut-off N (%) | Below cut-off N (%) |
| ADI-R autism diagnosis* | - | 9 (60.0%) | 6 (40.0%) | - | 0 (0%) | 7 (100%) |
| Reciprocal Social Interaction domain | 17.60 (5.83) | 13 (86.7%) | 2 (13.3%) | 8.57 (3.74) | 3 (42.9%) | 4 (57.1%) |
| Communication domain | 11.40 (2.95) | 13 (86.7%) | 2 (13.3%) | 7.14 (4.30) | 3 (42.9%) | 4 (57.1%) |
| Repetitive Behaviours & Stereotyped Patterns domain | 3.93 (2.15) | 10 (66.7%) | 5 (33.3%) | 1.71 (2.06) | 1 (14.3%) | 6 (85.7%) |
| Modified cut-off Repetitive Behaviours & Stereotyped Patterns domain | 3.93 (2.15) | 12 (80.0%) | 3 (20.0%) | 1.71 (2.06) | 3 (42.9%) | 4 (57.1%) |
| Modified repetitive cut- off – ADI-R algorithm total* | - | 11 (73.3%) | 4 (26.7%) | - | 2 (28.6%) | 5 (71.4%) |

*total score for ADI-R algorithm not applicable (Lord et al., 1994)

Table 8.13 describes the scores obtained within each domain of the ADOS diagnostic algorithm, along with the number of subjects which met the overall ADOS diagnostic algorithm cut-off scores for autism and autism spectrum disorder for both the DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder and non Autistic Disorder samples. Thirteen (86.7%) subjects in the Autistic Disorder sample met the overall ADOS algorithm cut-off criteria for autism, 2 (13.3%) met the cut-off criteria for an autism spectrum disorder, and none scored below the cut-off criteria. One (14.3%) subject in the non Autistic Disorder sample met the ADOS algorithm cut-off criteria for autism, 2 (28.6%) met the cut-off criteria for an autism spectrum disorder, and 4 (57.1%) scored below the cut-off criteria. In order to examine the difference between the diagnostic groups, the ADOS algorithm categories of autism and autism spectrum were combined to form one autism spectrum category, in order to overcome the problem of small numbers in each cell. This resulted in all 15 of the subjects in the Autistic Disorder sample falling within the ADOS algorithm category of autism spectrum. Three of the subjects in the non Autistic Disorder sample fell within the autism spectrum range, and 4 remained below the cut-off. This difference was found to be significant, $\chi^2(1, N=22) = 10.476$, Fisher's Exact Test $p \leq .01$.

As outlined in Table 8.13, 13 (86.7%) subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder sample met the ADOS algorithm cut-off criteria for autism in the Reciprocal Social Interaction domain and an additional 2 subjects (13.3%) obtained scores which fell within the autism spectrum. One (14.3%) subject in the non Autistic Disorder sample met the ADOS algorithm cut-off criteria for autism in the Reciprocal Social Interaction domain, 2 (28.6%) met the autism spectrum cut-off criteria, and 4 (57.1%) fell below the autism cut-off. As described previously, in

order to examine the difference between the diagnostic groups, the ADOS algorithm categories of autism and autism spectrum were combined to form one autism spectrum category, in order to overcome the problem of small numbers in each cell. This resulted in all 15 of the subjects in the Autistic Disorder sample falling within the ADOS algorithm category of autism spectrum in the Reciprocal Social Interaction domain. Three of the subjects in the non Autistic Disorder sample fell within the autism spectrum range, and 4 remained below the cut-off. This difference was found to be significant, $\chi^2(1, N=22) = 10.476$, Fisher's Exact Test $p \leq .01$.

In the Communication domain 14 (93.3%) subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder sample met the ADOS algorithm cut-off criteria for autism and one additional subject (6.7%) obtained a score which fell within the autism spectrum. In the non Autistic Disorder sample, 2 (28.6%) subjects met the ADOS algorithm cut-off criteria for autism in the Communication domain, 4 (57.1%) met the autism spectrum cut-off criteria, and one (14.3%) scored below the autism cut-off. As with the ADOS algorithm total and the Reciprocal Social Interaction domain, the ADOS algorithm categories of autism and autism spectrum were combined to form one autism spectrum category, in order to overcome the problem of small numbers in each cell. For the Communication domain, this resulted in all 15 of the subjects in the Autistic Disorder sample falling within the ADOS algorithm category of autism spectrum, and 6 of the subjects in the non Autistic Disorder sample falling within the autism spectrum range and one remaining below the cut-off. This difference was not found to be significant, $\chi^2(1, N=22) = 2.245$, Fisher's Exact Test ns.

For the combined Reciprocal Social Interaction and Communication domain, 13 (86.7%) subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder sample met the ADOS algorithm cut-off criteria for autism, and an additional 2 (13.3%) subjects obtained scores which fell within the autism spectrum. In the non Autistic Disorder sample 1 subject (14.3%) met the ADOS algorithm cut-off criteria for autism in the combined Reciprocal Social Interaction and Communication domain, 2 (28.6%) met the autism spectrum cut-off criteria, and 4 (57.1%) fell below the autism cut-off. In order to examine the difference between the diagnostic groups the ADOS algorithm categories of autism and autism spectrum were combined. This resulted in all 15 of the subjects in the Autistic Disorder sample falling within the ADOS algorithm category of autism spectrum in the combined Reciprocal Social Interaction and Communication domain. Three of the subjects in the non Autistic Disorder sample fell within the autism spectrum range, and 4 remained below the cut-off. This difference was found to be significant, $\chi^2(1, N=22) = 10.476$, Fisher's Exact Test $p \leq .01$. Cut-off scores are not generated for the Repetitive Behaviours and Restricted Interests and Play domains (Lord et al., 1999).

Table 8.13 also provides the means and standard deviations for the ADOS domain scores for both the DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder and non Autistic Disorder samples. As outlined in this table, the Autistic Disorder sample scored higher than the non Autistic Disorder sample in all five domains. A one way ANOVA revealed that these differences between the samples were significant for the Reciprocal Social Interaction domain, $F(1, 20) = 30.265$, $p \leq .001$, the Communication domain, $F(1, 20) = 11.641$, $p \leq .01$, the combined Reciprocal Social Interaction and Communication domains, $F(1, 20) = 26.056$,

$p \leq .001$, the Play domain, $F(1, 20) = 11.124$, $p \leq .01$, and the Repetitive Behaviours and Restricted Interests domain, $F(1, 20) = 7.979$, $p = .01$. A total score for the ADOS algorithm is not generated (Lord et al., 1999).

Table 8.13

ADOS Algorithm Domain Mean Scores, Standard Deviations, and Cut-Offs for the Autistic Disorder and Non Autistic Disorder Samples

| ADOS algorithm | Autistic Disorder (N=15) | | | | Non Autistic Disorder (N=7) | | | |
|---|-----------------------------|-----------------|-----------------------------|------------------------|--------------------------------|-----------------|-----------------------------|------------------------|
| | Mean (SD) | Autism N (%) | Autism spectrum N (%) | Non autism N (%) | Mean (SD) | Autism N (%) | Autism spectrum N (%) | Non autism N (%) |
| Reciprocal Social Interaction domain | 9.87 (2.64) | 13 (86.7%) | 2 (13.3%) | 0 (0%) | 3.14 (2.73) | 1 (14.3%) | 2 (28.6%) | 4 (57.1%) |
| Communication domain | 5.80 (1.37) | 14 (93.3%) | 1 (6.7%) | 0 (0%) | 3.43 (1.81) | 2 (28.6%) | 4 (57.1%) | 1 (14.3%) |
| Reciprocal Social Interaction + Communication domains | 15.67 (3.66) | 13 (86.7%) | 2 (13.3%) | 0 (0%) | 6.57 (4.39) | 1 (14.3%) | 2 (28.6%) | 4 (57.1%) |
| Repetitive Behaviours & Restricted Interests domain* | 2.47 (1.13) | - | - | - | 1.00 (1.15) | - | - | - |
| Play* | 3.53 (0.74) | - | - | - | 2.14 (1.21) | - | - | - |
| ADOS algorithm diagnosis** | - | 13 (86.7%) | 2 (13.3%) | 0 (0%) | - | 1 (14.3%) | 2 (28.6%) | 4 (57.1%) |

*cut-off scores not available for the Repetitive Behaviours & Restricted Interests and Play domains (Lord et al., 1999)

**total score for ADOS algorithm not applicable (Lord et al., 1999)

8.2.2.3 Summary of the results of the clinical assessments

The total sample of 22 was divided into an Autistic Disorder sample and a non Autistic Disorder sample according to DSM-IV (American Psychiatric Association, 1994) diagnoses (the study gold diagnostic standard). Comparison of these two samples revealed no significant chronological age differences, no significant developmental age differences, no significant difference in terms of the proportion of males in each sample. In terms of language ability, there were no significant differences between the two groups in terms of standard scores obtained on the Reynell, nor in the proportion of children in each sample who were nonverbal. The two samples were thus comparable in terms of developmental level.

As would be expected, the Autistic Disorder sample had a significantly higher CARS total score than the non Autistic Disorder sample. In terms of adaptive behaviour, the non Autistic Disorder sample scored significantly higher on the Communication and Socialisation domains of the Vineland Adaptive Behavior Scales.

On the parent interview ADI-R, 9 of the 15 subjects diagnosed with Autistic Disorder (DSM-IV criteria) met the ADI-R algorithm cut-off criteria for autism. Three of the 7 subjects who had been clinically diagnosed without autism met the ADI-R cut-off criteria for autism. This difference between the two samples was significant. The Autistic Disorder sample also scored significantly higher than the non autistic sample on all three domains (Reciprocal Social Interaction, Communication, and Repetitive Behaviours and Stereotyped Patterns) of the ADI-R. Of the 6 subjects who met DSM-IV (American Psychiatric Association, 1994) criteria for Autistic Disorder but who did not meet the ADI-R cut-off criteria, 4 met the cut-off on the ADI-R Reciprocal Social

Interaction domain, 4 met the cut-off on the ADI-R Communication domain, but only 1 met the cut-off criteria on the Repetitive Behaviours and Stereotyped Patterns domain. When Baron-Cohen's modified cut-off for the Repetitive Behaviour and Stereotyped Patterns domain was applied, 3 met the cut-off. Two of these subjects met the ADOS observation assessment cut-off criteria for autism and the remaining 4 scored within the ADOS autism spectrum.

On the ADOS, the observational diagnostic measure used in this study, 13 of the 15 DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder sample met the ADOS diagnostic algorithm cut-off for autism, while the remaining 2 subjects met the ADOS autism spectrum cut-off criteria. Therefore, no subject who received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Autistic Disorder failed to meet ADOS cut-off criteria for an autism spectrum disorder. Of the 7 subjects in the non Autistic Disorder sample, 1 met the ADOS cut-off criteria for autism, 2 met the ADOS cut-off criteria for an autism spectrum disorder, and 4 fell below these cut-off criteria. Compared to the non Autistic Disorder sample, a significantly larger proportion of the DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder sample scored above the ADOS autism spectrum cut-off. The Autistic Disorder sample also scored significantly higher than the non autistic sample in all five domains of the ADOS (Reciprocal Social Interaction, Communication, Reciprocal Social Interaction + Communication, Repetitive Behaviours and Restricted Interests, and Play).

8.2.2.4 Efficacy of the DBC Early Screen

The subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder sample ($N = 15$) obtained a mean DBC Early Screen Score of 17.07 ($SD = 7.49$), with a range of 6 - 31. The non Autistic Disorder sample ($N = 7$) obtained a mean DBC Early Screen Score of 12.00 ($SD = 7.00$), with a range of 2 - 23. This difference was not significant, $t(20) = -1.507$, *ns*.

As described in Table 8.14, of those who screened positive on the DBC Early Screen, 12 (80%) received a diagnosis of Autistic Disorder and 3 (20%) did not. Of those who screened negative, 4 (57.14%) did not receive a diagnosis of Autistic Disorder while 3 (42.86%) did. This is described in Figure 8.2. Of the three false positive cases obtained only one was just above the DBC Early Screen cut-off of 11, with DBC Early Screen scores of 23, 19, and 12. Respectively, these subjects received diagnoses of Asperger's Disorder (DBC Early Screen score of 23), PDD NOS (DBC Early Screen score of 19), and the third (DBC Early Screen score of 12) received a diagnosis of Disruptive Behaviour Disorder Not Otherwise Specified, along with developmental delay. The 3 false negative cases obtained DBC Early Screen scores of 9 and 6 (2 subjects). The parents of all three of these subjects did not feel that anything was wrong with their children other than slightly delayed language. All three subjects tested as developmentally delayed, had speech and language delays, and one was nonverbal. Their chronological ages were 41, 40, and 43 months, with developmental ages of 27, 23, and 29 months respectively. All three scored within the ADOS algorithm autism spectrum category, none met the ADI-R diagnostic algorithm criteria for autism.

The DSM-IV (American Psychiatric Association, 1994) diagnoses (study gold standard) of Autistic Disorder and non Autistic Disorder and the DBC Early Screen scores (positive or negative screen) were compared to establish the efficacy of the DBC Early Screen. This resulted in a sensitivity (proportion of true positives correctly identified by the test) of 0.80 (95% CI: 0.52 – 0.96), specificity (proportion of true negatives correctly identified by the test) of 0.57 (95% CI: 0.18 – 0.90), and efficiency (correct classification rate) of 0.73 (95% CI: 0.50 – 0.89). A predictive value of a positive test (proportion of subjects with positive test results who are correctly diagnosed) of 0.80 (95% CI: 0.52 – 0.96) was obtained along with a predictive value of a negative test (proportion of subjects with negative test results who are correctly diagnosed) of 0.57 (95% CI: 0.18 – 0.90). These results are summarised in Table 8.15.

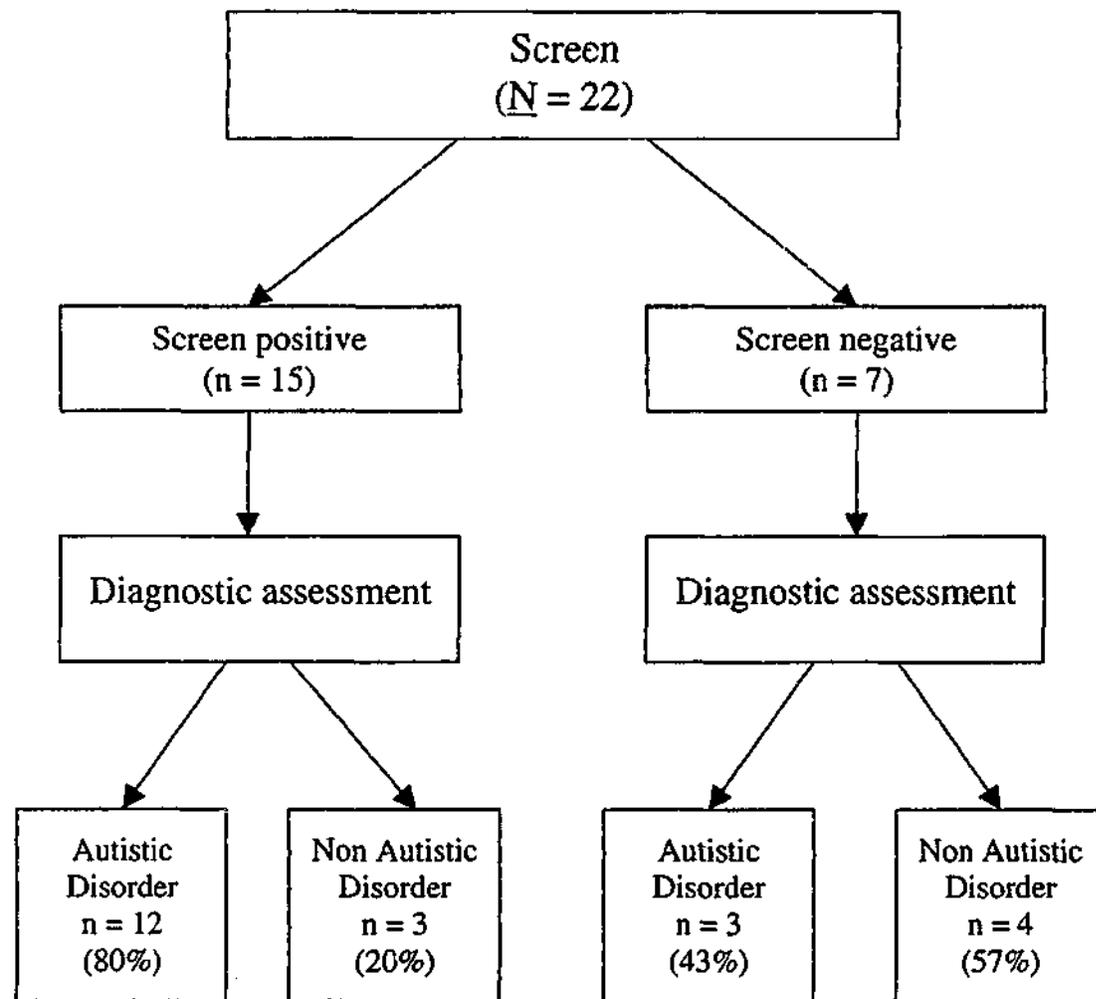


Figure 8.2. DBC Early Screen accuracy in terms of DSM-IV Autistic Disorder diagnosis for evaluation study two

Table 8.14

The DBC Early Screen Result for the Autistic Disorder and Non Autistic Disorder

Samples

| DBC Early Screen result | | | |
|--------------------------------|--------------------------------|--------------------------------|----------------------|
| DSM-IV diagnosis | Positive screen (n) | Negative screen (n) | Total (n) |
| Autistic Disorder | 12 (80.00%) | 3 (42.86%) | 15 |
| Non Autistic Disorder | 3 (20.00%) | 4 (57.14%) | 7 |
| Total | 15 | 7 | 22 |

Table 8.15

The DBC Early Screen Sensitivity, Specificity, Correct Classification Rate, Predictive Value of Positive Test, and Predictive Value of a Negative Test: Autistic Disorder and Non Autistic Disorder Samples

| | Screen accuracy (CI) |
|--|---------------------------------|
| Sensitivity | 0.80 (0.52 – 0.96) |
| Specificity | 0.57 (0.18 – 0.90) |
| Efficiency (correct classification rate) | 0.73 (0.50 – 0.89) |
| Predictive value of positive test (PVP) | 0.80 (0.52 – 0.96) |
| Predictive value of negative test (PVN) | 0.57 (0.18 – 0.90) |

8.2.3 Diagnostic samples: Pervasive Developmental Disorder and non Pervasive Developmental Disorder

8.2.3.1 Sample characteristics

Table 8.16 describes the chronological age (in months), sex, developmental age as measured by the PEP-R (in months), total CARS score, and the DBC Early Screen total score for the Pervasive Developmental Disorder and non Pervasive Developmental Disorder samples. Seventeen out of a total of 22 subjects received a DSM-IV (American Psychiatric Association, 1994) diagnosis within the Pervasive Developmental Disorder category (Autistic Disorder, PDD NOS, or Asperger's Disorder).

There was no significant difference between the chronological ages of the two groups, $t(20) = .866$, *ns*. As the skewness of the developmental age distribution in the non Pervasive Developmental Disorder sample was greater than ± 1.0 (1.344), a non parametric test was used to examine whether the difference in developmental age between the two groups was significant (George & Mallery, 2000). Analysis using the Mann-Whitney rank-sum U test revealed no significant difference between the developmental ages of the two groups, Mann-Whitney $U = 29.50$, $z = -1.021$, *ns*.

Twelve (70.59%) subjects in the autistic group were male, whilst 5 (100%) subjects in the non autistic group were male. There was no significant difference in the proportion of males in each of the groups, $\chi^2(1, N=22) = 1.903$, Fisher's Exact Test *ns*. The Pervasive Developmental Disorder group had a higher mean CARS total score than the non Pervasive Developmental Disorder group $t(19.06) = -11.425$, $p \leq .001$. As the

skewness of the DBC Early Screen total score distribution in the non Pervasive Developmental Disorder sample was greater than ± 1.0 (-1.517), a non parametric test was used to examine whether the difference in the DBC Early Screen scores between the two groups was significant (George & Mallery, 2000). Analysis using the Mann-Whitney rank-sum U test revealed that those in the Pervasive Developmental Disorder sample scored significantly higher on the DBC Early Screen than those in the non Pervasive Developmental Disorder sample, Mann-Whitney $U = 11.500$, $z = -2.432$, $p = .01$.

Table 8.16

Mean, Standard Deviation, and Range for Chronological Age, Developmental Age, CARS Total Score, DBC Early Screen Total Score, and Gender Breakdown for the Pervasive Developmental Disorder and the Non Pervasive Developmental Disorder Samples

| | Pervasive Developmental Disorder (N=17) | | Non Pervasive Developmental Disorder (N=5) | |
|---------------------------------|--|---------------|---|---------------|
| | Mean (SD) | Range | Mean (SD) | Range |
| Chronological age (months) | 39.35 (6.56) | 23 - 49 | 42.20 (6.06) | 34 - 49 |
| Developmental age (months) | 23.06 (9.79) | 10 - 41 | 27.20 (9.68) | 18 - 43 |
| CARS | 38.18 (6.22) | 30.00 - 48.50 | 19.90 (1.19) | 18.50 - 21.50 |
| DBC Early Screen total score | 17.53 (7.16) | 6 - 31 | 8.40 (3.85) | 2 - 12 |

8.2.3.2 Clinical assessment results

As described in Table 8.17, 82.35% of the Pervasive Developmental Disorder sample were confirmed as being developmentally delayed (as measured by the PEP-R) whilst all of the non Pervasive Developmental Disorder sample were confirmed as developmentally delayed. This difference was not significant, $\chi^2(1, N=22) = 1.022$, Fisher's Exact Test ns. Sixteen (94.12%) of those with Pervasive Developmental Disorder were language delayed (as measured by the Reynell Developmental Language Scales), while all of those in the Pervasive Developmental Disorder group had delayed language. This difference was not significant, $\chi^2(1, N=22) = .308$, Fisher's Exact Test ns. Twelve (70.59%) of the children with a Pervasive Developmental Disorder were nonverbal, whilst one (20%) subject without a Pervasive Developmental Disorder was nonverbal. This difference was not significant, $\chi^2(1, N=22) = 4.090$, Fisher's Exact Test ns.

Table 8.18 describes the mean, standard deviation, and range of standard scores on each of the Vineland Adaptive Behavior Scales domains and Adaptive Behavior Composite standard scores for the Pervasive Developmental Disorder and Non Pervasive Developmental Disorder samples. A one way ANOVA revealed differences in mean standard score were not significant for the Adaptive Behavior Composite, $F(1, 17) = .517$, ns, total age equivalent, $F(1, 17) = .054$, ns, Communication, $F(1, 17) = 1.395$, ns, Daily Living Skills, $F(1, 17) = .313$, ns, or Motor Skills $F(1, 17) = .249$, ns. The Non Pervasive Developmental Disorder sample obtained a significantly higher mean Socialisation standard score $F(1, 17) = 7.246$, $p = .01$.

Table 8.17

Proportion of Pervasive Developmental Disorder and Non Pervasive Developmental Disorder Samples With Developmental Delay, Language Delay, and Proportion Nonverbal

| | Pervasive Developmental Disorder (N=17) | Non Pervasive Developmental Disorder (N=5) |
|---------------------|--|---|
| Developmental delay | 14 delayed (82.35%) | 5 delayed (100%) |
| Language delay | 16 delayed (94.12%) | 5 delayed (100%) |
| Verbal ability | 12 nonverbal (70.59%) | 1 nonverbal (20%) |

Table 8.18

Mean, Standard Deviation, and Range of Standard Vineland Adaptive Behavior ScalesDomain Scores, Adaptive Behavior Composite, and Total Age Equivalent for thePervasive Developmental Disorder and Non Pervasive Developmental DisorderSamples

| | Pervasive Developmental Disorder (N=14) | | Non Pervasive Developmental Disorder (N=5) | |
|-------------------------------|--|---------------|---|---------------|
| | Mean (SD) | Range | Mean (SD) | Range |
| Communication domain | 63.21 (18.32) | 48 - 115 | 74.20 (16.25) | 58 - 100 |
| Daily Living Skills domain | 68.36 (10.39) | 58 - 94 | 71.60 (13.24) | 58 - 89 |
| Socialisation domain | 58.29 (6.64) | 51 - 70 | 68.20 (8.32) | 59 - 81 |
| Motor Skills domain | 80.79 (17.08) | 56 - 108 | 76.80 (7.19) | 70 - 86 |
| Vineland total age equivalent | 24.16 (16.19) | 11.00 - 73.25 | 25.95 (8.42) | 14.75 - 34.75 |
| Adaptive Behavior Composite | 62.71 (12.56) | 51 - 95 | 67.20 (9.81) | 57 - 81 |

Table 8.19 describes the means and standard deviations of the standard scores obtained on the Comprehension and Expressive Scales of the Reynell Developmental Language Scale for the Pervasive Developmental Disorder and Pervasive Developmental Disorder samples. A total of 12 subjects were able to complete the Comprehension Scale of the Reynell. A one way ANOVA revealed that there was no difference between the scores of the two samples on the Comprehension scale, $F(1, 10) = .101, ns$. Ten subjects had

sufficient language to complete the Expressive Scale of the Reynell. There was no difference between the scores of the two samples, $F(1, 8) = .104, ns$.

Table 8.19

Means and Standard Deviations of Reynell Developmental Language Scales
Comprehension Scale Standard Scores and Expressive Scale Standard Scores for the
Pervasive Developmental Disorder and Non Pervasive Developmental Disorder
Samples

| | Pervasive Developmental Disorder | | | | Non Pervasive Developmental Disorder | | | |
|-------------------------------------|----------------------------------|-------|-----------|--------|--------------------------------------|-------|-----------|---------|
| | n | Mean | <u>SD</u> | Range | n | Mean | <u>SD</u> | Range |
| Comprehension standard score | 8 | 23.88 | 19.04 | 0 - 48 | 4 | 20.00 | 21.77 | 9 - 50 |
| Expressive standard score | 7 | 22.14 | 15.92 | 0 - 46 | 3 | 25.67 | 15.53 | 13 - 43 |

As outlined in Table 8.20, 9(52.9%) subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed (study gold standard) Pervasive Developmental Disorder sample met the ADI-R diagnostic algorithm cut-off criteria for autism, while 8 (47.1%) scored below the cut-off criteria. All 5 (100%) subjects in the non Pervasive Developmental Disorder sample scored below the ADI-R diagnostic algorithm cut-off criteria for autism. This difference was significant, $\chi^2(1, N=22) = 4.480$, Fisher's Exact Test $p \leq .05$.

Table 8.20 also describes the scores obtained within each domain of the ADI-R diagnostic algorithm, along with the number of subjects which met the ADI-R diagnostic algorithm cut-off scores for autism. Fourteen (82.4%) subjects in the Pervasive Developmental Disorder sample met the cut-off criteria for autism in the Reciprocal Social Interaction domain, while 2 (40%) subjects in the non Pervasive Developmental Disorder sample met the cut-off criteria for autism. This difference was not significant, $\chi^2(1, N=22) = 3.494$, Fisher's Exact Test ns. Fourteen (82.4%) subjects in the Pervasive Developmental Disorder sample met the cut-off criteria for autism in the Communication domain, while 2 (40%) subjects in the non Pervasive Developmental Disorder sample met the cut-off criteria for autism. This difference was not significant $\chi^2(1, N=22) = 3.494$, Fisher's Exact Test ns. In the Repetitive Behaviours and Stereotyped Patterns domain 10 (58.8%) subjects in the Pervasive Developmental Disorder sample met the cut-off criteria for autism, and 1 (20%) subject in the non Pervasive Developmental Disorder sample met the cut-off criteria for autism. This difference was not significant, $\chi^2(1, N=22) = 2.329$, Fisher's Exact Test ns.

A modified score for the Repetitive Behaviours and Stereotyped Patterns domain was also calculated, using a cut-off threshold of 2 rather than 3 for young children (Baron-Cohen et al., 1996). As described in Table 8.20, this modified cut-off score resulted in 13 (76.5%) subjects in the Pervasive Developmental Disorder sample meeting the modified cut-off criteria for autism in the Repetitive Behaviours and Stereotyped Patterns domain, 3 more than when using a cut-off of 3. As outlined in Table 8.20, this was 11 subjects more than in the non Pervasive Developmental Disorder sample, a

difference which was not found to be significant, $\chi^2(1, N=22) = 2.369$, Fisher's Exact Test ns.

This modified cut-off score for the Repetitive Behaviours and Stereotyped Patterns domain resulted in 12 (70.6%) subjects in the Pervasive Developmental Disorder sample meeting the total ADI-R algorithm criteria for autism, 2 more than when the higher cut-off for the Repetitive Behaviours and Stereotyped Patterns domain was applied and 11 subjects more than in the non Pervasive Developmental Disorder sample. This difference was not significant, $\chi^2(1, N=22) = 4.090$, Fisher's Exact Test ns.

Table 8.20 also gives the means and standard deviations for the total ADI-R domain scores for both the DSM-IV (American Psychiatric Association, 1994) diagnosed Pervasive Developmental Disorder and non Pervasive Developmental Disorder samples. As outlined in this table, the Pervasive Developmental Disorder sample scored higher than the non Pervasive Developmental Disorder sample in all three domains. A one way ANOVA revealed that these differences were significant for the Reciprocal Social Interaction domain, $F(1, 20) = 7.516$, $p = .01$, but not for the Communication domain, $F(1, 20) = 2.761$, ns, or the Repetitive Behaviours and Stereotyped Patterns domain, $F(1, 20) = 2.618$, ns.

Table 8.20

ADI-R Algorithm Domain Mean Scores, Standard Deviations, and Cut-Offs for the
Pervasive Developmental Disorder and Non Pervasive Developmental Disorder
Samples

| ADI-R algorithm | Pervasive Developmental Disorder (N=17) | | | Non Pervasive Developmental Disorder (N=5) | | |
|---|--|--|---------------------------|---|--|---------------------------|
| | Mean (SD) | At / above autism cut-off N (%) | Below cut-off N (%) | Mean (SD) | At / above autism cut-off N (%) | Below cut-off N (%) |
| ADI-R autism diagnosis* | - | 9 (52.9%) | 8 (47.1%) | - | 0 (0%) | 5 (100%) |
| Reciprocal Social Interaction domain | 16.59 (6.20) | 14 (82.4%) | 3 (17.6%) | 8.40 (4.34) | 2 (40%) | 3 (60%) |
| Communication domain | 10.76 (3.36) | 14 (82.4%) | 3 (17.6%) | 7.60 (4.98) | 2 (40%) | 3 (60%) |
| Repetitive Behaviours & Stereotyped Patterns domain | 3.65 (2.18) | 10 (58.8%) | 7 (41.2%) | 1.80 (2.49) | 1 (20%) | 4 (80%) |
| Modified cut-off Repetitive Behaviours & Stereotyped Patterns domain | 3.65 (2.18) | 13 (76.5%) | 4 (23.5%) | 1.80 (2.49) | 2 (40%) | 3 (60%) |
| Modified repetitive cut- off - ADI-R algorithm total* | - | 12 (70.6%) | 5 (29.4%) | - | 1 (20%) | 4 (80%) |

*total score for ADI-R algorithm not applicable (Lord et al., 1994)

Table 8.21 describes the scores obtained within each domain of the ADOS diagnostic algorithm, along with the number of subjects which met the ADOS diagnostic algorithm cut-off scores for autism and autism spectrum disorder for both the DSM-IV (American Psychiatric Association, 1994) diagnosed Pervasive Developmental Disorder and non Pervasive Developmental Disorder samples. Fourteen (82.4%) subjects in the Pervasive Developmental Disorder sample met the ADOS algorithm cut-off criteria for autism, 3 (17.6%) met the cut-off criteria for an autism spectrum disorder, and no subject scored below the cut-off criteria. No subjects in the non Pervasive Developmental Disorder sample met the ADOS algorithm cut-off criteria for autism, one (20%) met the cut-off criteria for an autism spectrum disorder, and 4 (80%) scored below the cut-off criteria. To examine the difference between the DSM-IV (American Psychiatric Association, 1994) diagnostic groups, the ADOS algorithm categories of autism and autism spectrum were combined to form one autism spectrum category, in order to overcome the problem of small numbers in each cell. This resulted in all 17 of the subjects in the Pervasive Developmental Disorder sample failing within the ADOS algorithm category of autism spectrum. One of the subjects in the non Pervasive Developmental Disorder sample fell within the autism spectrum range, and 4 remained below the cut-off. This difference was found to be significant $\chi^2(1, N=22) = 16.662$, Fisher's Exact Test $p \leq .001$.

As outlined in Table 8.21, 14 (82.4%) subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed Pervasive Developmental Disorder sample met the ADOS algorithm cut-off criteria for autism in the Reciprocal Social Interaction domain and an additional 3 (17.6%) subjects obtained scores which fell within the autism spectrum. No subjects in the non Pervasive Developmental Disorder sample met the ADOS

algorithm cut-off criteria for autism in the Reciprocal Social Interaction domain, one (20%) met the autism spectrum cut-off criteria, and 4 (80%) fell below the autism cut-off. As described previously, to examine the difference between the diagnostic groups, the ADOS algorithm categories of autism and autism spectrum were combined to form one autism spectrum category, in order to overcome the problem of small numbers in each cell. This resulted in all 17 of the subjects in the Pervasive Developmental Disorder sample falling within the ADOS algorithm category of autism spectrum in the Reciprocal Social Interaction domain. One of the subjects in the non Pervasive Developmental Disorder sample fell within the autism spectrum range, and 4 remained below the cut-off. This difference was found to be significant, $\chi^2(1, N=22) = 16.622$, Fisher's Exact Test $p \leq .001$.

In the Communication domain 16 (94.1%) subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed Pervasive Developmental Disorder sample met the ADOS algorithm cut-off criteria for autism and one additional subject (5.9%) obtained a score which fell within the autism spectrum. In the non Pervasive Developmental Disorder sample, no subject met the ADOS algorithm cut-off criteria for autism in the Communication domain, 4 (80%) met the autism spectrum cut-off criteria, and one (20%) scored below the autism cut-off. As with the ADOS algorithm total and the Reciprocal Social Interaction domain, the ADOS algorithm categories of autism and autism spectrum were combined to form one autism spectrum category, in order to overcome the problem of small numbers in each cell. For the Communication domain, this resulted in all 17 of the subjects in the Pervasive Developmental Disorder sample falling within the ADOS algorithm category of autism spectrum. Four of the subjects in the non Pervasive Developmental Disorder sample fell within the autism spectrum

range, and 1 remained below the cut-off. This difference was not found to be significant, $\chi^2(1, N=22) = 3.562$, Fisher's Exact Test ns.

For the combined Reciprocal Social Interaction and Communication domain, 14 (82.4%) subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed Pervasive Developmental Disorder sample met the ADOS algorithm cut-off criteria for autism and an additional 3 (17.6%) subjects obtained scores which fell within the autism spectrum. In the non Pervasive Developmental Disorder sample no subject met the ADOS algorithm cut-off criteria for autism in the combined Reciprocal Social Interaction and Communication domain, 2 (20%) met the autism spectrum cut-off criteria, and 4 (80%) fell below the autism cut-off. In order to examine the difference between the diagnostic groups the ADOS algorithm categories of autism and autism spectrum were combined. This resulted in all 17 of the subjects in the Pervasive Developmental Disorder sample falling within the ADOS algorithm category of autism spectrum in the combined Reciprocal Social Interaction and Communication domain. One of the subjects in the non Pervasive Developmental Disorder sample fell within the autism spectrum range, and 4 remained below the cut-off. This difference was found to be significant, $\chi^2(1, N=22) = 16.662$ Fisher's Exact Test $p \leq .001$. Cut-off scores are not generated for the Repetitive Behaviours and Restricted Interests and Play domains (Lord et al., 1999).

Table 8.21 also provides the means and standard deviations for the ADOS domain scores for both the DSM-IV (American Psychiatric Association, 1994) diagnosed Pervasive Developmental Disorder and non Pervasive Developmental Disorder samples. As outlined in this table, the Pervasive Developmental Disorder sample

scored higher than the non Pervasive Developmental Disorder sample in all five domains. A one way ANOVA revealed that these differences were significant for the Reciprocal Social Interaction domain, $F(1, 20) = 34.697, p \leq .001$, the Communication domain, $F(1, 20) = 32.731, p \leq .001$, the combined Reciprocal Social Interaction and Communication domains, $F(1, 20) = 42.777, p \leq .001$, the Play domain, $F(1, 20) = 4.966, p \leq .05$, and the Repetitive Behaviours and Restricted Interests domain, $F(1, 20) = 10.878, p \leq .01$. A total score for the ADOS algorithm is not generated (Lord et al., 1999).

Table 8.21

ADOS Algorithm Domain Mean Scores, Standard Deviations, and Cut-Offs for the Pervasive Developmental Disorder and Non Pervasive Developmental Disorder Samples

| ADOS algorithm | Pervasive Developmental Disorder (N=17) | | | | Non Pervasive Developmental Disorder (N=5) | | | |
|---|--|-----------------|-----------------------------|------------------------|---|-----------------|-----------------------------|------------------------|
| | Mean (SD) | Autism N (%) | Autism spectrum N (%) | Non autism N (%) | Mean (SD) | Autism N (%) | Autism spectrum N (%) | Non autism N (%) |
| Reciprocal Social Interaction domain | 9.47 (2.76) | 14 (82.4%) | 3 (17.6%) | 0 (0%) | 1.80 (1.48) | 0 (0%) | 1 (20%) | 4 (80%) |
| Communication domain | 5.82 (1.29) | 16 (94.1%) | 1 (5.9%) | 0 (0%) | 2.40 (.55) | 0 (0%) | 4 (80%) | 1 (20%) |
| Reciprocal Social Interaction + Communication domains | 15.29 (3.62) | 14 (82.4%) | 3 (17.6%) | 0 (0%) | 4.20 (1.79) | 0 (0%) | 1 (20%) | 4 (80%) |
| Repetitive Behaviours & Restricted Interests domain* | 2.41 (1.12) | - | - | - | 0.60 (0.89) | - | - | - |
| Play* | 3.35 (0.93) | - | - | - | 2.20 (1.30) | - | - | - |
| ADOS algorithm diagnosis** | - | 14 (82.4%) | 3 (17.6%) | 0 (0%) | - | 0 (0%) | 1 (20%) | 4 (80%) |

*cut-off scores not available for the Repetitive Behaviours & Restricted Interests and Play domains (Lord et al., 1999)

**total score for ADOS algorithm not applicable (Lord et al., 1999)

8.2.3.3 Summary of the results of the clinical assessments

The total sample of 22 was divided into a Pervasive Developmental Disorder sample (Autistic Disorder, Asperger's Disorder, and PDD NOS) and a non Pervasive Developmental Disorder sample according to DSM-IV (American Psychiatric Association, 1994) diagnoses (the study gold diagnostic standard). Comparison of these two samples revealed no significant chronological age differences, no significant developmental age differences, no significant difference in terms of the proportion of males in each sample. In terms of language ability, there were no significant differences between the two groups in terms of standard scores obtained on the Reynell, nor in the proportion of children in each sample who were nonverbal. The two samples were thus comparable in terms of developmental level.

As would be expected, the Pervasive Developmental Disorder sample had a significantly higher CARS total score than the non Pervasive Developmental Disorder sample. In terms of adaptive behaviour, the non Pervasive Developmental Disorder sample scored significantly higher on the Socialisation domain of the Vineland Adaptive Behavior Scales.

On the parent interview ADI-R, 9 of the 17 subjects diagnosed with a Pervasive Developmental Disorder (DSM-IV criteria) met the ADI-R algorithm cut-off criteria for autism. All of the 5 subjects who had been clinically diagnosed without a Pervasive Developmental Disorder scored below the ADI-R cut-off criteria for autism. This difference between the two samples was significant. The Pervasive Developmental Disorder sample also scored significantly higher than the non Pervasive Developmental Disorder sample on the Reciprocal Social Interaction domain of the ADI-R. Of the 8

subjects who met DSM-IV criteria for a Pervasive Developmental Disorder but who did not meet the ADI-R cut-off criteria, 5 met the cut-off on the ADI-R Reciprocal Social Interaction domain, 5 met the cut-off on the ADI-R Communication domain, but only 1 met the cut-off criteria on the Repetitive Behaviours and Stereotyped Patterns domain. When Baron-Cohen's (Baron-Cohen et al., 1996) modified cut-off for the Repetitive Behaviour and Stereotyped Patterns domain was applied, 4 subjects met the cut-off. Three of these subjects met the ADOS observation assessment cut-off criteria for autism and the remaining 5 scored within the ADOS autism spectrum.

On the ADOS, the observational diagnostic measure used in this study, 14 of the 17 DSM-IV (American Psychiatric Association, 1994) diagnosed Pervasive Developmental Disorder sample met the ADOS diagnostic algorithm cut-off for autism, while the remaining 3 subjects met the ADOS autism spectrum cut-off criteria. Therefore, no subject who received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Pervasive Developmental Disorder failed to meet ADOS cut-off criteria for an autism spectrum disorder. Of the 5 subjects in the non Pervasive Developmental Disorder sample, none met the ADOS cut-off criteria for autism, 1 met the ADOS cut-off criteria for an autism spectrum disorder, and 4 fell below these cut-off criteria. A significantly larger proportion of the DSM-IV (American Psychiatric Association, 1994) diagnosed Pervasive Developmental Disorder sample scored above the ADOS autism spectrum cut-off. The Pervasive Developmental Disorder sample also scored significantly higher than the non Pervasive Developmental Disorder sample in all five domains of the ADOS (Reciprocal Social Interaction, Communication, Reciprocal Social Interaction + Communication, Repetitive Behaviours and Restricted Interests, and Play).

8.2.3.4 Efficacy of the DBC Early Screen

The subjects in the DSM-IV (American Psychiatric Association, 1994) diagnosed Pervasive Developmental Disorder sample ($N = 17$) obtained a mean DBC Early Screen score of 17.53 ($SD = 7.16$), with a range of 6 - 31. The non Pervasive Developmental Disorder sample ($N = 5$) obtained a mean DBC Early Screen Score of 8.40 ($SD = 7.16$), with a range of 2 - 12. As the skewness of the DBC Early Screen Score distribution in the non Pervasive Developmental Disorder sample was greater than ± 1.0 (-1.517), a non parametric test was used to examine whether the difference in ages between the two groups was significant (George & Mallery, 2000). Analysis using the Mann-Whitney rank-sum U test revealed that those in the Pervasive Developmental Disorder sample scored significantly higher than those in the non Disorder sample, Mann-Whitney $U = 11.50$, $z = -2.432$, $p < .01$.

As described in Table 8.22, of those who screened positive on the DBC Early Screen, 14 (93.33%) received a clinical diagnosis within the Pervasive Developmental Disorder category and one subject (6.67%) did not. Of those who screened negative on the DBC Early Screen, 4 (57.14%) did not receive a Pervasive Developmental Disorder diagnosis while 3 (42.6%) did. This is described in Figure 8.3. The one false positive case was the subject who obtained a DBC Early Screen score of 12, only one point above the cut-off of 11. This case was diagnosed with Disruptive Behaviour Disorder Not Otherwise Specified, along with developmental delay. The three false negative cases have previously been described, with DBC Early Screen scores of 9 and 6 (2 subjects). All three subjects tested as developmentally delayed, had speech and language delays, and one was nonverbal.

The DSM-IV (American Psychiatric Association, 1994) diagnoses (study gold standard) falling within the Pervasive Developmental Disorder category and the DBC Early Screen scores (positive or negative screen) were compared to establish the efficacy of the DBC Early Screen. This resulted in a sensitivity (proportion of true positives correctly identified by the test) of 0.82 (95% CI: 0.57 – 0.96), specificity (proportion of true negatives correctly identified by the test) of 0.80 (95% CI: 0.28 – 0.99), and efficiency (correct classification rate) of 0.82 (95% CI: 0.60 – 0.95). A predictive value of a positive test (proportion of subjects with positive test results who are correctly diagnosed) of 0.93 (95% CI: 0.68 – 0.99) was obtained along with a predictive value of a negative test (proportion of subjects with negative test results who are correctly diagnosed) of 0.57 (95% CI: 0.18 – 0.90). These results are summarised in Table 8.23.

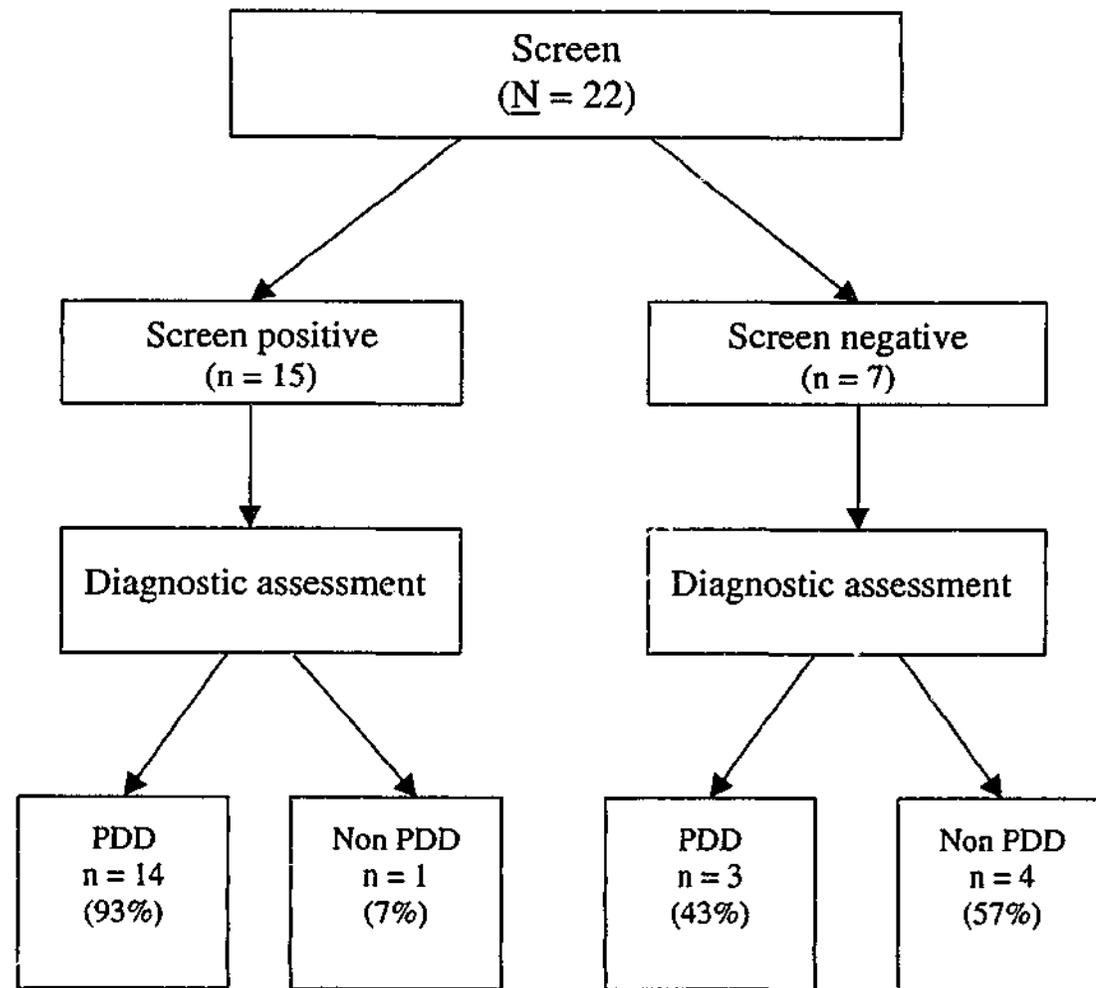


Figure 8.3. DBC Early Screen accuracy in terms of DSM-IV Pervasive Developmental Disorder (PDD) diagnosis for evaluation study two

Table 8.22

The DBC Early Screen Result for the Pervasive Developmental Disorder and Non Pervasive Developmental Disorder Samples

| DBC Early Screen result | | | |
|---|--------------------------------|--------------------------------|----------------------|
| DSM-IV diagnosis | Positive screen (n) | Negative screen (n) | Total (n) |
| Pervasive Developmental Disorder | 14 (93.33%) | 3 (42.6%) | 17 |
| Non Pervasive Developmental Disorder | 1 (6.67%) | 4 (57.14%) | 5 |
| Total | 15 | 7 | 22 |

Table 8.23

The DBC Early Screen Sensitivity, Specificity, Correct Classification Rate, Predictive Value of Positive Test, and Predictive Value of a Negative Test: Pervasive Developmental Disorder and Non Pervasive Developmental Disorder Samples

| | Screen accuracy (CI) |
|---|-------------------------|
| Sensitivity | 0.82 (0.57 – 0.96) |
| Specificity | 0.80 (0.28 – 0.99) |
| Efficiency (correct classification rate) | 0.82 (0.60 – 0.95) |
| Predictive value of positive test (PVP) | 0.93 (0.68 – 0.99) |
| Predictive value of negative test (PVN) | 0.57 (0.18 – 0.90) |

8.2.4 Summary: Screen efficacy

When the total referred community sample ($N = 22$) was divided into DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder and non Autistic Disorder samples, the sensitivity of the DBC Early Screen was good (0.80), specificity was low (0.57), overall classification efficiency of the instrument was good (0.73), and the predictive value of a positive test was also good (0.80).

Due to the low specificity obtained when the DBC Early Screen was examined in terms of an Autistic Disorder diagnosis, the sample was also examined in terms of a Pervasive

Developmental Disorder diagnosis. Again, this resulted in good sensitivity (0.82), good overall classification efficiency (0.82), and excellent predictive value of a positive test (0.93). Notably, specificity was much improved (0.80).

CHAPTER 9

DISCUSSION

STAGE TWO

9.1 Evaluation study one: Autism assessment clinic

The first evaluation of the screening tool (DBC Early Screen) developed in Stage 1 of the study involved 38 consecutive referrals to an assessment clinic. Using the DBC Early Screen, 30 of these subjects screened positive while 8 screened negative. Thirty-five received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Autistic Disorder. Evaluation of the performance of the DBC Early Screen resulted in a sensitivity of 0.80 (95% CI: 0.63-0.92), specificity of 0.33 (95% CI: 0.01-0.91), overall efficiency of 0.76 (95% CI: 0.60-0.89), predictive value of positive test of 0.93 (95% CI: 0.78-0.99), and predictive value of a negative test of 0.13 (95% CI: 0.00-0.53). Whilst sensitivity and overall efficiency remained high, specificity was low, with a large confidence interval as was the predictive value of a negative test.

The sample used in this evaluation, although consecutive referrals, only contained three cases of developmental delay without autism, which may have contributed to the problem of low specificity. There were two false positive cases, each of whom had screen scores of 24; well above the cut-off of 11. One case received a diagnosis of Expressive Language Disorder, whilst the other was diagnosed with Mixed Receptive Expressive Language Disorder. Both of these cases had high levels of behavioural problems, thus necessitating evaluation. As described in Chapter 5, when deciding on a cut-off point for determining caseness for the DBC Early Screen, higher sensitivity was

favoured in order to identify as many cases of autism as possible, knowing that this lower cut-off point would maximise sensitivity, although at the expense of specificity. It was therefore to be expected that specificity would be lower, and that a number of cases who did not have autism would receive diagnostic assessments.

Seven cases diagnosed with Autistic Disorder were missed by the DBC Early Screen. In the case of three of these, their screen scores were only just below the cut-off of 11 (2 received a score of 9 and one of 10). The remaining false negative cases scored 5 (1 case) and 7 (3 cases).

The specialist assessment clinic used in this first evaluation was likely to only be referred cases that other clinics and childhood services expected would have autism. Any cases not having autism would be a difficult case, with high levels of behavioural problems. This referral bias would most likely have contributed to the low specificity and low predictive value of a negative test found in this evaluation.

9.2 Evaluation study two: Community sample with developmental delay

In contrast to the first evaluation, the second evaluation study utilised a community sample with developmental delay, rather than a sample referred to a specialist clinic. It is in this type of population that a screening tool such as the DBC Early Screen would be of most benefit. Twenty-two subjects were involved in this evaluation study. Using the DBC Early Screen, 15 of these subjects screened positive while 7 screened negative. Fifteen received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Autistic Disorder, one case was diagnosed with Asperger's Disorder, and one with PDD NOS. Three subjects received a diagnosis of Mixed Receptive Expressive Language,

one was diagnosed with Reactive Attachment Disorder, and the remaining case received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Disruptive Behaviour Disorder Not Otherwise Specified.

In order to evaluate the performance of the DBC Early Screen, the sample was firstly divided into those who were diagnosed with DSM-IV (American Psychiatric Association, 1994) Autistic Disorder and those who were not. Comparison of the clinical diagnoses made by an experienced clinician blind to the results of the DBC Early Screen resulted in a sensitivity of 0.80 (95% CI: 0.52-0.96), specificity of 0.57 (95% CI: 0.18-0.90), overall efficiency of 0.73 (95% CI: 0.50-0.89), predictive value of positive test of 0.80 (95% CI: 0.52-0.96), and predictive value of a negative test of 0.57 (95% CI: 0.18-0.90). Whilst sensitivity and overall efficiency remained high, specificity, although improved, was still relatively low, with a large confidence interval as was the predictive value of a negative test.

The sample was then divided into those who were diagnosed with a DSM-IV (American Psychiatric Association, 1994) diagnosis of a Pervasive Developmental Disorder (Autistic Disorder, Asperger's Disorder, or PDD NOS) and those who were not. Comparison of the clinical diagnoses made by an experienced clinician blind to the results of the DBC Early Screen resulted in a sensitivity of 0.82 (95% CI: 0.57-0.96), specificity of 0.80 (95% CI: 0.28-0.99), overall efficiency of 0.82 (95% CI: 0.60-0.95), predictive value of positive test of 0.93 (95% CI: 0.68-0.99), and predictive value of a negative test of 0.57 (95% CI: 0.18-0.90). In this case, both sensitivity and specificity were high, although for specificity the confidence interval was still rather large. Overall efficiency and predictive value of a positive test were also high.

When the efficacy of the DBC Early Screen was considered in terms of Autistic Disorder and non Autistic Disorder, and in terms of Pervasive Developmental Disorder and non Pervasive Developmental Disorder, the same three subjects were identified as false negatives. These were three cases of Autistic Disorder which were not identified by the DBC Early Screen. All three of these subjects were developmentally delayed, and all had language delay. They received scores of 9, 6, and 2 on the DBC Early Screen. All three of these subjects scored within the autism spectrum range on the ADOS (Lord et al., 1999) algorithm, but failed to meet the ADI-R (Lord et al., 1994) diagnostic algorithm cut-off. Both the ADI-R (Lord et al., 1994) and the DBC Early Screen rely upon parent report, whereas the ADOS (Lord et al., 1999) is scored using clinician observation and interaction with the child. It is thus possible that these parents were under reporting their child's problems. As is discussed later (see section 9.3.1), the results of a screening tool such as DBC Early Screen will be affected by parents under reporting problems due to either a reluctance to acknowledge problems or a lack of experience of typical child development. Professional observation and follow-up of a child with developmental problems is necessary to determine whether the child would benefit from further assessment, regardless of the result of a screening instrument.

When the sample was divided into Autistic Disorder and non Autistic Disorder, there were no significant differences between the two groups in terms of chronological age, developmental age, proportion of males in each group, receptive and expressive language ability, and proportion of subjects who were nonverbal. The same was true when the sample was divided into Pervasive Developmental Disorder and non Pervasive Developmental Disorder groups. The groups were thus comparable in terms

of developmental level. Therefore the differentiation made between the groups by the DBC Early Screen was independent of any factors relating to the children's level of developmental. There were potential referral biases (see section 9.2.2), although these would have operated for both the autism and non autism samples.

9.2.1 Standardised diagnostic instruments: ADI-R and ADOS

The diagnostic gold standard in this study remained clinical DSM-IV (American Psychiatric Association, 1994) diagnosis made taking into account information from all assessments, including the ADI-R (Lord et al., 1994) and the ADOS (Lord et al., 1999). Information was therefore available to compare the results of the ADI-R (Lord et al., 1994) and ADOS (Lord et al., 1999) diagnostic algorithms with the gold standard clinical diagnosis. These results need to be interpreted with caution in light of the fact that the clinical diagnosis was not made independently of the ADI-R (Lord et al., 1994) or ADOS (Lord et al., 1999) information gathered in this study. For children with developmental ages of less than 18 months, the ADI-R (Lord et al., 1994) has been reported to over diagnose (Lord et al., 1993). In this study the ADI-R tended to under diagnose. It may be that this was a feature of using a parent report measure with parents who are just coming to terms with the fact that their child has developmental delay or delayed language, let alone any other problems. They may tend to under report problems, either because they don't notice them, attributing all behaviour to the child's diagnosis of developmental delay (diagnostic overshadowing), are reluctant to acknowledge that there might be anything additional wrong with their child, or they are inexperienced and do not know what to expect with regards to child development.

Using the ADI-R (Lord et al., 1994), 9 of the 15 subjects diagnosed with DSM-IV (American Psychiatric Association, 1994) Autistic Disorder met the ADI-R (Lord et al., 1994) algorithm cut-off criteria for autism. Three of the 7 subjects who did have a clinical diagnosis of autism, met the ADI-R (Lord et al., 1994) cut-off criteria for autism. Of the 6 subjects who met DSM-IV (American Psychiatric Association, 1994) criteria for Autistic Disorder but who did not meet the ADI-R (Lord et al., 1994) cut-off criteria, 4 met the cut-off on the ADI-R (Lord et al., 1994) Social Interaction domain, 4 met the cut-off on the ADI-R (Lord et al., 1994) Communication domain, but only 1 met the cut-off criteria on the Repetitive Behaviours and Stereotyped Patterns domain. The ADOS (Lord et al., 1999) however, does not rely on parent report. Two of these 6 subjects did meet the ADOS (Lord et al., 1999) observation assessment cut-off criteria for autism and the remaining 4 scored on the ADOS (Lord et al., 1999) autism spectrum.

This observation suggests that the parents of children who later received a DSM-IV (American Psychiatric Association, 1994) diagnosis of Autistic Disorder but did not reach the ADI-R (Lord et al., 1994) algorithm cut-off for autism may have under reported their children's problems. It also shows that these children failed to meet ADI-R (Lord et al., 1994) algorithm criteria for autism due to failing to reach the cut-off criteria on the Repetitive Behaviours and Stereotyped Patterns domain. Lowering the cut-off in this domain as done by Baron-Cohen and colleagues (1996) in a study with young children (aged less than 2 years), did result in 4 more children who had received a clinical DSM-IV (American Psychiatric Association, 1994) diagnosis of autism meeting the cut-off criteria for autism on the ADI-R. As the ADOS (Lord et al., 1999) does not have a cut-off in this domain, this would not have prevented those children

meeting the ADOS (Lord et al., 1999) algorithm cut-off for autism or autism spectrum. As previously discussed (section 2.2.3) low frequencies or the absence of repetitive and stereotyped behaviours are not uncommon in infants and young children with autism (Cox et al., 1999; Lord et al., 1994; Rogers, 2001; Stone et al., 1994; Stone et al., 1999). The findings of this study regarding lower frequencies of repetitive behaviours support those found by other researchers. Therefore it must be remembered that when assessing very young children referred for the possibility of autism, the absence of stereotyped and repetitive behaviours may not necessarily rule out a Pervasive Developmental Disorder.

In the second evaluation study a significantly larger proportion of children in the DSM-IV (American Psychiatric Association, 1994) diagnosed Autistic Disorder group met the ADI-R (Lord et al., 1994) diagnostic algorithm cut-off for autism than in the non autism group. Previous research examining the use of the ADI-R in preschool children aged 2 – 6 years has found it to have high levels of diagnostic agreement with independent clinician diagnoses of DSM-IV (American Psychiatric Association, 1994) Autistic Disorder (Lord et al., 1993). In a sample of 51 children with autism and 43 children with mental retardation or language impairment only 1 child in the autism sample failed to meet the ADI-R cut-off criteria for autism, while 9 children in the control sample were incorrectly classified by the ADI-R as having autism. As to be expected in an in depth clinical interview, these results indicate high sensitivity and specificity (0.98 and 0.79 respectively). Compared to the DBC Early Screen (sensitivity of 0.82 and specificity of 0.80 for a Pervasive Developmental Disorder diagnosis) the sensitivity of DBC Early Screen is not as high as that of the ADI-R, however this is to be expected as the ADI-R is an in depth clinical interview while the DBC Early Screen is a brief parent

completed screening tool designed to identify those children in need of a more in depth assessment. However, somewhat surprisingly, comparable rates of specificity were found. It must be noted however, that in addition to being very different tools designed for different purposes, the sample size in the DBC Early Screen evaluation was smaller ($N = 22$) than that used in the evaluation of the ADI-R in preschool children ($N = 94$).

9.2.2 Limitations

This second evaluation was limited by a small overall sample size, but also by the small number of subjects (five) who did not receive a DSM-IV (American Psychiatric Association, 1994) Pervasive Developmental Disorder diagnosis. As the subjects were referrals from a community service for children with suspected developmental delay, the low number of subjects without a Pervasive Developmental Disorder was beyond the control of the study. The staff of the community service were asked to refer all children suspected of developmental delay, regardless of whether they felt they had symptoms of autism. Despite regularly emphasising this point, there may still have been a tendency for staff to press families to participate if they thought the child might have autism. There may also have been a tendency to refer more difficult cases with high levels of behavioural disturbance, or those where they were unsure of the diagnosis. It is possible that this occurred in some cases, as the staff knew that referral to the project would ensure that the child would receive a comprehensive assessment and appropriate referral and recommendation for services without having to go on a long waiting list. It is also possible that parents over reported their children's behavioural problems, perhaps to get an assessment or simply out of frustration at having been placed on long waiting lists for assessment services. This would have resulted in a sample biased towards autism and high levels of behavioural and

emotional disturbance. This would thus be a sample of children who all required a comprehensive assessment, and would therefore be more likely to screen positive.

9.3 Summary of evaluations of efficacy

The measures of efficacy generated by the original development of the DBC Early Screen and by the two subsequent evaluation studies indicate that this is a potentially useful screening tool for identifying those children who are in need of a comprehensive assessment for Pervasive Developmental Disorders. Table 9.1 summarises the results of the tests of the efficacy of the DBC Early Screen. High sensitivity was maintained throughout, although the specificity improved in the field trial evaluation when the results were interpreted in terms of DSM-IV (American Psychiatric Association, 1994) Pervasive Developmental Disorders compared to non Pervasive Developmental Disorders. Predictive Value of a Positive Test (PVP) remained high throughout.

When screening for developmental problems in infants and young children sensitivity, specificity, and positive predictive values of 70 – 80% are regarded as acceptable (Aylward, 1997; Glascoe, 1997; Squires et al., 1996). Such levels were reached in the second evaluation study. However it is recognised that there is often a trade off in specificity if the sensitivity is high (Aylward, 1997). Over referrals (false positives) are recognised as not being an issue in developmental screening, as such children usually constitute a significant risk group who would benefit from referral to specialist services for assessments which can help to inform and focus intervention (Glascoe, 2001). In the case of the two DBC Early Screen evaluation studies, all false positives were children who required assessment and referral to appropriate services. Therefore, high sensitivity at the expense of slightly lower specificity is a trade off which is worthwhile.

Of more concern are false negatives; cases that have been missed by the screening tool. As previously discussed, there were 7 false negatives in evaluation study one and 3 in evaluation study two. Four of these cases scored only 1-2 points below the DBC Early Screen cut-off of 11. It would therefore be recommended that cases scoring within such a close range of the screening cut-off score be carefully considered before a decision is made as to whether they require further assessment. No screening tool can replace clinical judgement and regardless of the screening score, if it is felt that a child needs further assessment, an appropriate referral for assessment should still be made. One should never rely absolutely on a single test, clinical judgement is still vitally important and no paper and pencil test can replace this.

Table 9.1

Efficacy of the DBC Early Screen: Sensitivity, Specificity, Predictive Value of a Positive Test (PVP), and Predictive Value of a Negative Test (PVN)

| | Sensitivity | Specificity | PVP | PVN |
|--------------------------------------|-------------|-------------|------|------|
| Development (Stage 1) | 0.86 | 0.69 | 0.74 | 0.83 |
| Evaluation 1 (Stage 2) | 0.80 | 0.33 | 0.93 | 0.13 |
| Evaluation 2 (Stage 2) Aut / Non Aut | 0.80 | 0.57 | 0.80 | 0.57 |
| Evaluation 2 (Stage 2) PDD / Non PDD | 0.82 | 0.80 | 0.93 | 0.57 |

PVP = Predictive Value of Positive test, PVN = Predictive Value of Negative test, Aut = Autistic Disorder, PDD = Pervasive Developmental Disorder

9.3.1 Limitations

Further to the limitations of the evaluations of the DBC Early Screen already discussed, it is important to consider the potential limitations of a parent report measure as a screening tool. As previously discussed, such a measure is sensitive to both parental denial and over concern. Parents may under report due to a reluctance to see anything wrong with their child. The concerns of parents have been identified as accurate indicators of developmental problems (Glascoe, Altemeier, & MacLean, 1989) but in the case of Pervasive Developmental Disorders, parents need to accept that there is something wrong with their child's development above and beyond developmental and / or language delays. Glascoe and Dworkin (1995) have identified a number of advantages to using parental report in screening measures. These include eliminating the need for obtaining the cooperation of children in testing, providing a more thorough sampling of skills or behaviours than is usually obtained with direct elicitation measures, and flexibility with means of administration such as interview, parent completing in the waiting room, or completion at home either prior to or between appointments.

The DBC Early Screen was developed and tested using samples of children who were likely to have developmental delay. It is therefore uncertain how it may perform in population screening which would include typically developing children or children with Pervasive Developmental Disorders without global developmental delay.

However, evaluation study two did include one child who received a diagnosis of Asperger's Disorder. In this case, delay was originally suspected, hence the referral to the project, but the child tested within the normal range and had age appropriate language development. This child did screen positive on the DBC Early Screen. There

is now a need to test the DBC Early Screen in populations that include young children without developmental delay.

It is also important to note that screening occurs at a point in time when parents are often at an emotionally vulnerable stage. They are often still adjusting to the fact that their child has developmental delay. As previously discussed, under reporting of problems may be a limitation of a parent completed screening instrument. A clinician should never assume that a lack of concern on the part of a parent or a failure to voice concerns implies normal development. Factors including parenting experience, denial, cultural factors, and the presence of pressing medical issues can all potentially contribute to a reluctance on the part of a parent to voice their concerns (Filipek et al., 1999). Observation and follow-up of a child and the use of sound clinical judgement in regards to when a child may benefit from a more in depth assessment for a Pervasive Developmental Disorder is still paramount and cannot be replaced by any screening test.

9.4 The DBC Early Screen and other screening tools

Table 9.2 compares the studies of the efficacy of the DBC Early Screen and other autism screening tools, namely the Screening Tool for Autism in Two-year olds (STAT) (Stone et al., 2000), the Autism Screening Questionnaire (ASQ) (Berument et al., 1999), the Checklist for Autism in Toddlers (CHAT) (Baird et al., 2000; Baron-Cohen et al., 1992), and the Developmental Behaviour Checklist Autism Screening Algorithm (DBC-ASA) (Brereton, 1999).

While the STAT (Stone et al., 2000) and the DBC (Brereton, 1999) both have adequate sensitivity and specificity, the STAT requires a clinician to administer it and DBC-ASA is for children aged 4 –18 years, in both cases thus limiting the use of these two instruments as screening tools for Pervasive Developmental Disorders in infants and young children. In the case of the DBC-ASA, this is the reason why further study was undertaken to develop a subset of items from the DBC which could constitute a screening tool for younger children. The ASQ (Berument et al., 1999) has good sensitivity and specificity in identifying autism from mental retardation (although the sample is small), but as previously discussed (see section 3.5.1) it has not been tested in children under 4 years of age. The CHAT (Baird et al., 2000; Baron-Cohen et al., 1992) has been shown to have good specificity, particularly if the administration is repeated one month later. However the sensitivity of the CHAT is low. It is important however to remember that the CHAT was used as a population screening test (the only instrument that has been tested in this way, with a 6 year follow-up). It is possible that using the CHAT in a sample of children with developmental delay would produce higher sensitivity. The CHAT does require a clinician in its administration, thus limiting its application in large populations.

This study has shown that the DBC Early Screen has good sensitivity and specificity in terms of identifying cases of Pervasive Developmental Disorder from samples of infants and young children with developmental delay. It takes parents approximately 5 minutes to complete, and is easily scored by hand. Bearing in mind the limitations discussed, this work provides preliminary support for the use of the DBC Early Screen as a screening tool for Pervasive Developmental Disorder in infants and young children with developmental delay in community settings. It could act as a first stage screen, perhaps

then supplemented by clinician completed screens (such as the CHAT) prior to referral for clinical assessment (a scarce resource).

Table 9.2

Screening Instruments: Description and Efficacy

| Instrument | Age | Items | Administration | AUC | Sensitivity | Specificity | PVP | PVN |
|---|--------------------------------------|-------|--------------------|------|-------------|-------------|-------|------|
| Screening Tool for Autism in Two-year olds (STAT) | 24-35 months | 12 | Clinician | - | 0.83 | 0.86 | - | - |
| Autism Screening Questionnaire (ASQ) | less than 6 years, & above 6 years | 40 | Parent | | | | | |
| | Autism from mental retardation | | | 0.92 | 0.96 | 0.67 | - | - |
| | PDD from non PDD | | | 0.86 | 0.85 | 0.75 | 0.93 | 0.55 |
| Checklist for Autism in Toddlers (CHAT) | 18 months | 14 | Parent & Clinician | | | | | |
| | 1 stage administration | | | - | 0.38 | 0.98 | 0.047 | - |
| | Repeat administration after 1 month | | | - | 0.18 | 1.00 | 0.75 | - |
| Developmental Behaviour Checklist (DBC) | 4-18 years | 96 | Parent | 0.80 | 0.86 | 0.69 | - | - |
| DBC Early Screen | 18-48 months | 30 | Parent | | | | | |
| | Development (Stage 1) | | | 0.87 | 0.86 | 0.69 | 0.74 | 0.83 |
| | Evaluation 1 (Stage 2) | | | - | 0.80 | 0.33 | 0.93 | 0.13 |
| | Evaluation 2 (Stage 2) Aut / Non Aut | | | - | 0.80 | 0.57 | 0.80 | 0.57 |
| | Evaluation 2 (Stage 2) PDD / Non PDD | | | - | 0.82 | 0.80 | 0.93 | 0.57 |

AUC = Area Under the Curve, PVP = Predictive Value of Positive test, PVN = Predictive Value of Negative test, Aut = Autistic Disorder, PDD = Pervasive Developmental Disorder

CHAPTER 10

CONCLUSIONS AND FUTURE STUDIES

While this study has developed and undertaken preliminary evaluations of the DBC Early Screen, further work is needed to conclusively establish its efficacy as a screening tool for Pervasive Developmental Disorders in infants and young children with developmental delay. Firstly, it is necessary to undertake a community trial with a larger sample of young children with developmental problems, who are most at risk of autism. Secondly, it would be important to then undertake a larger community field trial to determine how the DBC Early Screen performed in a population including children without developmental delay.

As described in Stage 1 of this study, the items which make up the DBC Early Screen were obtained from the DBC (Einfeld & Tonge, 1992). Although the DBC has been demonstrated to be a reliable and valid parent completed checklist, it would still be useful to examine the reliability of the DBC Early Screen, particularly test retest reliability and interrater (parent – parent) reliability, as the previous reliability studies of the DBC did not include the parents of children aged less than 4 years. Studies comparing the ratings of parents and other carers such as creche staff to those of clinicians on the DBC Early Screen would also prove interesting in terms of examining interrater agreement between parents and others.

The DBC Early Screen consists of the 30 items identified in Stage 1 of this study which significantly differentiated the children with autism from those with developmental delay without autism. As described previously (section 5.4), 17 of these items are used

to calculate the screen score. The remaining 13 items were retained in the instrument, as these items still significantly differentiated the groups and were thought to be clinically useful. Future work might consider whether the addition of any of the 13 items which are not in the screening algorithm, but which were found to significantly differentiate the children with autism from those with developmental delay without autism, improves the sensitivity or specificity of the DBC Early Screen.

Research has demonstrated that some features of autism (repetitive and stereotyped patterns of behaviour) may not be present in young children with autism. It is possible that such behaviours are more likely to be present in children diagnosed with autism aged 3 to 4 years than in children under 2 years of age (see section 6.1). Further work is now needed on examining the presence or absence of these behaviour in children with autism less than 2 years of age, compared to those up to 4 years of age.

The ultimate utility of a screening instrument for autism will depend upon the degree to which paediatricians and other health professionals, such as speech pathologists, who come into contact with infants and young children with developmental delay decide to implement it in their daily practice. Early childhood health services would also need to be convinced of its value and introduce it as part of other population screening policies such as monitoring weight and height. To this end the DBC Early Screen must be shown to have practical utility if it is to be adopted as a screen. Paediatricians and other primary care providers are often reluctant to undertake developmental screening, with fewer than 30% of primary care providers undertaking standardised developmental screening tests (Dworkin, 1992; Rapin, 1995). Research has also indicated that the recognition of children's emotional and behavioural problems by paediatricians is

frequently inaccurate, with many cases missed and not referred on to other services for assessment and intervention (Lavigne et al., 1993). Given the time constraints on the standard paediatric appointment and the apparent reluctance on the part of such primary care physicians to undertake screening tests, a Pervasive Developmental Disorder screening tool must be short and require minimal clinician input. Clearly an ideal tool would be one such as the DBC Early Screen which is short, completed by parents, and can be easily scored. Until a biological marker(s) for autism is found, the use of screening tools by primary care physicians and early childhood professionals is the best method we have for the early identification of children with Pervasive Developmental Disorders. Given the recognised importance of early intervention, both the development and improved use of screening tools is paramount. However, it is apparent that improved professional education and changes in early childhood services policy is required to facilitate a broader use of screening tools by primary care professionals who are likely to be the first to see children at risk of Pervasive Developmental Disorders.

The limitations of screening must also be recognised. The purpose of any screening tool, regardless of its field of use, is to indicate those in need of a more comprehensive assessment (Aylward, 1997). It is important to educate and train primary care physicians in the identification of symptoms of autism in infants and young children and to equip them with screening tools to aid in this process. However, it is equally important to emphasise that while research has shown that the diagnosis of autism in young children is stable, these diagnoses have invariably been made by clinicians experienced in the assessment of infants and young children with autism (Rogers, 2001). A positive screen on a screening instrument such as the DBC Early Screen does

not indicate a diagnosis of a Pervasive Developmental Disorder. Rather, it identifies that child as at risk for a Pervasive Developmental Disorder diagnosis and the need for a specialist assessment. Like any psychological assessment tool, screening tools cannot be used without informed clinical judgement and awareness of the limitations of such tools. Aylward (1997) wisely cautions that while a screening test yields a result, that result still has to be interpreted and followed up with an assessment.

Ultimately, one of the key reasons for early identification of children with Pervasive Developmental Disorders is to provide access to early intervention programmes. The development of tools to aid early diagnosis is therefore in and of itself not sufficient. Unless these children then have access to proven early intervention programmes, the benefits of early diagnosis are potentially wasted.

APPENDICES A - O

APPENDIX A
ETHICS APPROVAL

Monash Medical Centre
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HUMAN RESEARCH & ETHICS COMMITTEE B

DATE 02 JULY, 1998

PROJECT NO. 98053B

PROJECT TITLE Early detection of developmental problems

INVESTIGATOR(S) Prof Bruce Tonge

I.E.C. MEETING DATE 21.05.98

APPROVAL 02.07.1998 – 02.07.2001

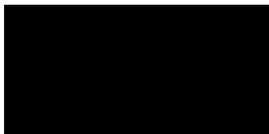
The Principal Investigator is required to notify the Secretary of the Human Research and Ethics Committee of:

1. Any change in protocol and the reason for that change together with an indication of ethical implications (if any)
2. Adverse effects of project on subjects and steps taken to deal with them
3. Any unforeseen events

At the conclusion of the project or every twelve months if the project continues, the Principal Investigator is required to complete and forward an annual report to the Committee.

Annual report forms will be forwarded to the researcher.

SPECIAL CONDITIONS

SIGNED  **DATE** 02 JULY, 1998
Committee Representative

Please quote Project No. and Title for all correspondence

APPENDIX B

DEVELOPMENTAL BEHAVIOUR CHECKLIST – PARENT /

CARER VERSION (DBC-P)

Many of the following behaviours may not apply to the child or teenager in your care. For each item that does describe the person in your care, now or within the past six months, please circle the 2 if the item is very true or often true. Circle 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child circle the 0.

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

If your child is unable to perform an item, circle the 0. For example, if your child has no speech, then for the item "Talks too much or too fast" circle the 0

Underline any you are particularly concerned about

| Office Use Only | Please Circle | | | |
|-----------------|---------------|---|---|---|
| 1. ⑤ | 0 | 1 | 2 | Appears depressed, downcast or unhappy |
| 2. ⑤ | 0 | 1 | 2 | Avoids eye contact. Won't look you straight in the eye. |
| 3. ⑤ | 0 | 1 | 2 | Aloof, in his/her own world. |
| 4. ① | 0 | 1 | 2 | Abusive. Swears at others. |
| 5. | 0 | 1 | 2 | Arranges objects or routine in a strict order. Please describe: _____ |
| 6. ② | 0 | 1 | 2 | Bangs head. |
| 7. ① | 0 | 1 | 2 | Becomes over-excited. |
| 8. | 0 | 1 | 2 | Bites others. |
| 9. | 0 | 1 | 2 | Cannot attend to one activity for any length of time, poor attention span. |
| 10. ② | 0 | 1 | 2 | Chews or mouths objects, or body parts. |
| 11. ④ | 0 | 1 | 2 | Cries easily for no reason, or over small upsets. |
| 12. ④ | 0 | 1 | 2 | Covers ears or is distressed when hears particular sounds. Please describe: _____ |
| 13. ③ | 0 | 1 | 2 | Confuses the use of pronouns e.g. uses "you" instead of "I". |
| 14. ② | 0 | 1 | 2 | Deliberately runs away. |
| 15. ③ | 0 | 1 | 2 | Delusions: has a firmly held belief or idea that can't possibly be true. Please describe: _____ |
| 16. ④ | 0 | 1 | 2 | Distressed about being alone. |
| 17. ⑤ | 0 | 1 | 2 | Doesn't show affection. |
| 18. ⑤ | 0 | 1 | 2 | Doesn't respond to others' feelings, e.g. shows no response if a family member is crying. |
| 19. ④ | 0 | 1 | 2 | Easily distracted from his/her task, e.g. by noises. |
| 20. | 0 | 1 | 2 | Easily led by others. |
| 21. ② | 0 | 1 | 2 | Eats non-food items e.g. dirt, grass, soap. |
| 22. ④ | 0 | 1 | 2 | Excessively distressed if separated from familiar person. |
| 23. ④ | 0 | 1 | 2 | Fears particular things or situations, e.g. the dark or insects. Please describe: _____ |
| 24. ⑤ | 0 | 1 | 2 | Facial twitches or grimaces. |
| 25. ② | 0 | 1 | 2 | Flicks, taps, twirls objects repeatedly. |
| 26. ④ | 0 | 1 | 2 | Fussy eater or has food fads. |
| 27. | 0 | 1 | 2 | Gorges food. Will do anything to get food e.g. takes food out of garbage bins or steals food. |
| 28. | 0 | 1 | 2 | Gets obsessed with an idea or activity. Please describe: _____ |
| 29. | 0 | 1 | 2 | Grinds teeth. |
| 30. ④ | 0 | 1 | 2 | Has nightmares, night terrors or walks in sleep. |

Please be sure you have answered all items
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Subscales

| | | | | | |
|---|---|---|---|---|---|
| ① | ② | ③ | ④ | ⑤ | ⑥ |
| | | | | | |

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true
Underline any you are particularly concerned about

| Office Use Only | Please Circle | | | |
|-----------------|---------------|---|---|--|
| 67. | 0 | 1 | 2 | Sleeps too little. Disrupted sleep. |
| 68. ② | 0 | 1 | 2 | Stares at lights or spinning objects. |
| 69. ⑤ | 0 | 1 | 2 | Sleeps too much. |
| 70. ② | 0 | 1 | 2 | Soils outside toilet though toilet trained. Smears or plays with faeces. |
| 71. ③ | 0 | 1 | 2 | Speaks in whispers, high pitched voice, or other unusual tone or rhythm. |
| 72. ② | 0 | 1 | 2 | Switches lights on and off, pours water over and over; or similar repetitive activity. Please describe: _____ |
| 73. ⑥ | 0 | 1 | 2 | Steals. |
| 74. ① | 0 | 1 | 2 | Stubborn, disobedient or unco-operative. |
| 75. ④ | 0 | 1 | 2 | Shy. |
| 76. ② | 0 | 1 | 2 | Strips off clothes or throws away clothes. |
| 77. ① | 0 | 1 | 2 | Says he/she can do things that he/she is not capable of. |
| 78. | 0 | 1 | 2 | Stands too close to others. |
| 79. | 0 | 1 | 2 | Sees, hears, something which isn't there. Hallucinations. Please describe: _____ |
| 80. ① | 0 | 1 | 2 | Talks about suicide. |
| 81. ③ | 0 | 1 | 2 | Talks too much or too fast. |
| 82. ③ | 0 | 1 | 2 | Talks to self or imaginary people or objects |
| 83. ①⑥ | 0 | 1 | 2 | Tells lies. |
| 84. ③ | 0 | 1 | 2 | Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow. |
| 85. ①④ | 0 | 1 | 2 | Tense, anxious, worried. |
| 86. ①② | 0 | 1 | 2 | Throws or breaks objects. |
| 87. ① | 0 | 1 | 2 | Tries to manipulate or provoke others. |
| 88. ③ | 0 | 1 | 2 | Underreacts to pain. |
| 89. ③ | 0 | 1 | 2 | Unrealistically happy or elated. |
| 90. | 0 | 1 | 2 | Unusual body movements, posture, or way of walking. Please describe: _____ |
| 91. ④ | 0 | 1 | 2 | Upset and distressed over small changes in routine or environment. Please describe: _____ |
| 92. ② | 0 | 1 | 2 | Urinate outside toilet, although toilet trained. |
| 93. ① | 0 | 1 | 2 | Very bossy. |
| 94. ② | 0 | 1 | 2 | Wanders aimlessly. |
| 95. ① | 0 | 1 | 2 | Whines or complains a lot. |
| | | | | Please write in any problems your child has that were not listed above |
| | 0 | 1 | 2 | _____ |
| | 0 | 1 | 2 | _____ |
| | 0 | 1 | 2 | _____ |
| 96. | 0 | 1 | 2 | Overall, do you feel your child has problems with feelings or behaviour, in addition to problems with development? If not, please circle the 0. If so, but they're minor, please circle the 1. If they're major problems, please circle the 2. |

Please be sure you have answered all items

Are there any other comments you would like to make?

THANK YOU

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Subscales

TBPS
[]

| | | | | | |
|-----|-----|-----|-----|-----|-----|
| ① | ② | ③ | ④ | ⑤ | ⑥ |
| [] | [] | [] | [] | [] | [] |

APPENDIX C

DBC-P ITEM FREQUENCIES FOR TOTAL SAMPLE (STAGE 1)

Appendix C

DBC-P Item Frequencies for Total Sample: Percentage of Behaviours Endorsed by

Parents as Present (Score of '1' or '2')

| Item | Item description | Endorsed as present (%) |
|-------------|---|--------------------------------|
| 1 | Appears depressed, downcast or unhappy | 15.0 |
| 2 | Avoids eye contact. Won't look you straight in the eye | 60.0 |
| 3 | Aloof, in his/her own world | 64.2 |
| 4 | Abusive. Swears at others | 8.3 |
| 5 | Arranges objects or routine in a strict order | 50.8 |
| 6 | Bangs head | 27.5 |
| 7 | Becomes over-excited | 60.0 |
| 8 | Bites others | 26.7 |
| 9 | Cannot attend to one activity for any length of time, poor attention span | 80.0 |
| 10 | Chews or mouths objects, or body parts | 55.8 |
| 11 | Cries easily for no reason, or over small upsets | 58.3 |
| 12 | Covers ears or is distressed when hears particular sounds | 50.0 |
| 13 | Confuses the use of pronouns e.g. uses "you" instead of "I" | 16.7 |
| 14 | Deliberately runs away | 55.8 |
| 15 | Delusions: has a firmly held belief or idea that can't possibly be true | 8.3 |
| 16 | Distressed about being alone | 37.5 |
| 17 | Doesn't show affection | 31.7 |
| 18 | Doesn't respond to others' feelings | 45.0 |
| 19 | Easily distracted from his/her task, e.g. by noises | 75.8 |
| 20 | Easily led by others | 49.2 |
| 21 | Eats non-food items | 36.7 |
| 22 | Excessively distressed if separated from familiar person | 47.5 |
| 23 | Fears particular things or situations | 40.0 |
| 24 | Facial twitches or grimaces | 23.3 |
| 25 | Flicks, taps, twirls objects repeatedly | 40.8 |
| 26 | Fussy eater or has food fads | 66.7 |
| 27 | Gorges food. Will do anything to get food | 19.2 |
| 28 | Gets obsessed with an idea or activity | 58.3 |
| 29 | Grinds teeth | 43.3 |
| 30 | Has nightmares, night terrors or walks in sleep | 33.3 |
| 31 | Has temper tantrums, e.g. stamps feet, slams doors | 79.2 |
| 32 | Hides things | 19.2 |
| 33 | Hits self or bites self | 26.7 |
| 34 | Hums, whines, grunts, squeals or makes other non-speech noises | 71.7 |

Appendix C continued

DBC-P Item Frequencies for Total Sample: Percentage of Behaviours Endorsed by Parents as Present (Score of '1' or '2')

| Item | Item description | Endorsed as present (%) |
|-------------|---|--------------------------------|
| 35 | Impatient | 81.7 |
| 36 | Inappropriate sexual activity with another | 3.3 |
| 37 | Impulsive, acts before thinking | 39.2 |
| 38 | Irritable | 51.7 |
| 39 | Jealous | 48.3 |
| 40 | Kicks, hits others | 37.5 |
| 41 | Lacks self-confidence, poor self-esteem | 21.7 |
| 42 | Laughs or giggles for no obvious reason | 48.3 |
| 43 | Lights fires | 1.7 |
| 44 | Likes to hold or play with an unusual object; overly fascinated with something | 51.7 |
| 45 | Loss of appetite | 32.5 |
| 46 | Masturbates or exposes self in public | 7.5 |
| 47 | Mood changes rapidly for no apparent reason | 35.8 |
| 48 | Moves slowly, underactive, does little | 25.8 |
| 49 | Noisy or boisterous | 55.8 |
| 50 | Overactive, restless, unable to sit still | 55.8 |
| 51 | Overaffectionate | 36.7 |
| 52 | Overbreathes, vomits, has headaches or complains of being sick for no physical reason | 10.8 |
| 53 | Overly attention-seeking | 29.2 |
| 54 | Overly interested in looking at, listening to, dismantling mechanical things | 27.5 |
| 55 | Poor sense of danger | 75.8 |
| 56 | Prefers the company of adults or younger children. Doesn't mix with his/her own age group | 49.2 |
| 57 | Prefers to do things on his/her own. Tends to be a loner | 75.8 |
| 58 | Preoccupied with only one or two particular interests | 45.8 |
| 59 | Refuses to go to school, activity centre or workplace | 10.0 |
| 60 | Repeated movements of hands, body, head or face | 43.3 |
| 61 | Resists being cuddled, touched or held | 35.0 |
| 62 | Repeats back what others say like an echo | 44.2 |
| 63 | Repeats the same word or phrase over and over | 43.3 |
| 64 | Smells, tastes, or licks objects | 36.7 |
| 65 | Scratches or picks his/her skin | 19.2 |

Appendix C continued

DBC-P Item Frequencies for Total Sample: Percentage of Behaviours Endorsed by Parents as Present (Score of '1' or '2')

| Item | Item description | Endorsed as present (%) |
|------|---|-------------------------|
| 66 | Screams a lot | 39.2 |
| 67 | Sleeps too little. Disrupted sleep | 43.3 |
| 68 | Stares at lights or spinning objects | 40.0 |
| 69 | Sleeps too much | 12.5 |
| 70 | Soils outside toilet though toilet trained. Smears or plays with faeces | 14.2 |
| 71 | Speaks in whispers, high pitched voice, or other unusual tone or rhythm | 35.0 |
| 72 | Switches lights on and off, pours water; or similar repetitive activity | 56.7 |
| 73 | Steals | 5.0 |
| 74 | Stubborn, disobedient or uncooperative | 68.3 |
| 75 | Shy | 45.8 |
| 76 | Strips off clothes or throws away clothes | 27.5 |
| 77 | Says he/she can do things that he/she is not capable of | 6.7 |
| 78 | Stands too close to others | 17.5 |
| 79 | Sees, hears, something which isn't there. Hallucinations | 5.0 |
| 80 | Talks about suicide | 0.0 |
| 81 | Talks too much or too fast | 4.2 |
| 82 | Talks to self or imaginary people or objects | 16.7 |
| 83 | Tells lies | 1.7 |
| 84 | Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow | 12.5 |
| 85 | Tense, anxious, worried | 17.5 |
| 86 | Throws or breaks objects | 50.0 |
| 87 | Tries to manipulate or provoke others | 15.0 |
| 88 | Under reacts to pain | 37.5 |
| 89 | Unrealistically happy or elated | 18.3 |
| 90 | Unusual body movements, posture, or way of walking | 43.3 |
| 91 | Upset and distressed over small changes in routine or environment | 44.2 |
| 92 | Urinate outside toilet, although toilet trained | 12.5 |
| 93 | Very bossy | 20.0 |
| 94 | Wanders aimlessly | 40.0 |
| 95 | Whines or complains a lot | 34.2 |

* Items in bold retained for further analyses. Remaining items were endorsed as not present by $\geq 75\%$ of parents/carers and excluded from further analyses

APPENDIX D

**UNIVARIATE LOGISTIC REGRESSIONS: ESTIMATED
COEFFICIENTS (β), WALD STATISTICS, p VALUES, AND ODDS
RATIOS FOR ITEMS NOT INCLUDED IN CONFIRMATORY
FACTOR ANALYSIS (STAGE 1)**

Appendix D

Univariate Logistic Regressions: Estimated Coefficients (β), Wald Statistics, p values,
and Odds Ratios for Items Not Included in Confirmatory Factor Analysis ($p > .01$)

| Item | Item description | β | Wald | p | Odds ratio |
|------|--|---------|-------|------|------------|
| 6 | Bangs head | .042 | .021 | .885 | 1.043 |
| 8 | Bites others | .108 | .108 | .743 | 1.114 |
| 9 | Cannot attend to one activity for any length of time, poor attention span | .494 | 3.591 | .058 | 1.639 |
| 10 | Chews or mouths objects, or body parts | .458 | 3.978 | .046 | 1.582 |
| 11 | Cries easily for no reason, or over small upsets | .497 | 4.288 | .038 | 1.644 |
| 12 | Covers ears or is distressed when hears particular sounds | .499 | 4.525 | .033 | 1.647 |
| 16 | Distressed about being alone | .557 | 3.775 | .052 | 1.745 |
| 19 | Easily distracted from his/her task, e.g. by noises | -.153 | .377 | .539 | .858 |
| 20 | Easily led by others | -.602 | 5.629 | .018 | .547 |
| 21 | Eats non-food items | -.116 | .174 | .677 | .890 |
| 23 | Fears particular things or situations | .352 | 1.883 | .170 | 1.422 |
| 29 | Grinds teeth | .209 | .681 | .409 | 1.232 |
| 30 | Has nightmares, night terrors or walks in sleep | -.230 | .448 | .503 | .795 |
| 33 | Hits self or bites self | .725 | 5.050 | .025 | 2.064 |
| 37 | Impulsive, acts before thinking | .601 | 5.270 | .022 | 1.823 |
| 38 | Irritable | .701 | 5.332 | .021 | 2.016 |
| 39 | Jealous | .326 | 1.282 | .257 | 1.386 |
| 40 | Kicks, hits others | .143 | .285 | .593 | 1.154 |
| 44 | Likes to hold or play with an unusual object; overly fascinated with something | .532 | 5.821 | .016 | 1.703 |
| 45 | Loss of appetite | .606 | 3.646 | .056 | 1.833 |
| 48 | Moves slowly, underactive, does little | -.553 | 2.406 | .121 | .575 |
| 51 | Overaffectionate | -.234 | .748 | .387 | .791 |
| 53 | Overly attention-seeking | .325 | 1.110 | .292 | 1.384 |
| 54 | Overly interested in looking at, listening to or dismantling mechanical things | .474 | 2.891 | .089 | 1.607 |
| 55 | Poor sense of danger | .469 | 4.104 | .043 | 1.598 |
| 60 | Repeated movements of hands, body, head, face | .571 | 5.342 | .021 | 1.771 |
| 62 | Repeats back what others say like an echo | .446 | 3.214 | .073 | 1.563 |
| 64 | Smells, tastes, or licks objects | .551 | 4.499 | .034 | 1.735 |
| 67 | Sleeps too little. Disrupted sleep | .430 | 3.310 | .069 | 1.537 |
| 68 | Stares at lights or spinning objects | .664 | 5.750 | .016 | 1.942 |
| 75 | Shy | .263 | .909 | .341 | 1.301 |
| 76 | Strips off clothes or throws away clothes | .682 | 4.825 | .028 | 1.978 |
| 86 | Throws or breaks objects | .305 | 1.202 | .273 | 1.357 |
| 88 | Under reacts to pain | .457 | 2.406 | .121 | 1.580 |
| 90 | Unusual body movements, posture, or way of walking | .243 | 1.124 | .289 | 1.276 |

APPENDIX E

**17-ITEM WEIGHTED AND UNWEIGHTED SCREENING
ALGORITHMS: POTENTIAL CUT POINTS AND THEIR
RESPECTIVE SENSITIVITY AND SPECIFICITY**

Appendix E

17-Item Weighted Screening Algorithm: Potential Cut Points and Their Respective Sensitivity and Specificity

| Positive screen if greater than or equal to | Sensitivity | Specificity |
|--|--------------------|--------------------|
| 5.6300 | .893 | .582 |
| 5.8450 | .893 | .600 |
| 6.0200 | .893 | .618 |
| 6.0600 | .893 | .636 |
| 6.2700 | .893 | .655 |
| 6.6200 | .875 | .655 |
| 6.8800 | .875 | .673 |
| 6.9950 | .875 | .691 |
| 7.2150 | .857 | .691 |
| 7.4950 | .839 | .691 |
| 7.5800 | .821 | .691 |
| 7.6150 | .821 | .709 |
| 7.9200 | .804 | .709 |
| 8.2400 | .786 | .709 |
| 8.3250 | .768 | .709 |

17-Item Unweighted Screening Algorithm: Potential Cut Points and Their Respective Sensitivity and Specificity

| Positive screen if greater than or equal to | Sensitivity | Specificity |
|--|--------------------|--------------------|
| 8.500 | .893 | .600 |
| 9.500 | .875 | .655 |
| 10.500 | .857 | .691 |
| 11.500 | .804 | .709 |
| 12.500 | .768 | .709 |
| 13.500 | .750 | .764 |
| 14.500 | .732 | .873 |
| 15.500 | .714 | .927 |

APPENDIX F

**STAGE 1 – PARENT INFORMATION SHEET (PLAIN LANGUAGE
STATEMENT)**

**STAGE 2 – PARENT INFORMATION SHEET (PLAIN LANGUAGE
STATEMENT)**

xxth xxxxxxx, 1999

Dear Sir/Madam,

I am contacting you regarding a study currently being run by Professor Bruce Tonge and Ms Kylie Gray from Monash University. The focus of this study is the importance of early recognition of developmental difficulties in young children. The aim of this project is to develop a screening package to be used by general practitioners to facilitate early referral to specialist assessment services, thus enabling children to access early intervention services as early as possible.

We have received permission from the early intervention programme that your child attends to invite families to participate in this important study.

Participation simply involves completing the enclosed questionnaire, which focuses on a range of behavioural and emotional difficulties experienced by some children with developmental difficulties. We would also like your permission to contact the professional who completed your child's developmental assessment, in order to obtain the results of that assessment. We have also included a question on diagnosis, specifically whether you have received a diagnosis for your child's developmental difficulties, who gave this diagnosis, and permission to obtain a copy of that professional's report.

Your child will not be individually identified or named in any publication arising from this study and no information that would identify an individual will be released. All information collected as part of this study will remain confidential.

If you wish to support this project, please complete the enclosed questionnaire and consent form regarding your child, and return it in the enclosed reply paid envelope, no stamp is necessary.

Please feel free to call **Kylie Gray** on **(03) 9594 1300** if you wish to discuss this project further.

Thank you for your generous support of our work in the field of early child development.

Yours sincerely,

Kylie Gray
Doctoral candidate

**Centre for Developmental Psychiatry & Psychology
Monash Medical Centre**

**Information sheet
Early detection of developmental problems**

This project is being conducted by Professor Bruce Tonge and Ms Kylie Gray, of the Monash University Centre for Developmental Psychiatry & Psychology at Monash Medical Centre.

Unfortunately there is often a delay before children with developmental problems receive specialist assessment. This delay may cause added distress and burden for the parents and delay the provision of effective early intervention services. We have developed a questionnaire, the Developmental Behaviour Checklist (DBC), which has the potential to screen populations of children with developmental delays and identify those who may benefit from further assessment. These children could then be referred for assessment and receive timely early intervention.

This project proposes to undertake a trial of this screening questionnaire. If the effectiveness of its screening properties are confirmed, its use could then be simply and widely applied in early childhood services leading to earlier assessment and provision of more timely early intervention which is of great benefit to the child.

Parents of children will complete a brief questionnaire about their child's emotions and behaviour. A number of families will then be invited to participate in a more in depth interview about their child's development, which will take place at Monash Medical Centre. Parents will be fully informed if we think their child may have any specific developmental problems and they will be put in touch with the early intervention services in their area. If any specific difficulties or problems are identified, a referral to appropriate services will be arranged. If any parent involved in the project expresses any concerns or needs any help, this will also be arranged.

There is no risk of physical or psychological harm in the study. Drugs are not used in the study.

Parents will be required to provide written consent for their participation. The interview may be videotaped, but only if the parents provide specific written consent. The confidentiality of files and tapes will be safeguarded by the researchers. There will be nothing in any reports of the study that could identify individual children or families. Participation in this project is voluntary. Participants are free to withdraw from the project at any stage.

Should there be any questions about the project or any problems, please do not hesitate to contact:

**Ms Kylie Gray
Centre for Developmental Psychiatry & Psychology
PO Box 1030
CLAYTON STH VIC 3169
Telephone - (03) 9594 1300**

If you have any concerns regarding the conduct of this project, please contact the above person. If you have any further concerns that you do not feel have been addressed, the Complaints Liaison Officer at Monash Medical Centre is available on (03) 9594 2745.

APPENDIX G

STAGE 1 – CONSENT FORM

STAGE 2 – CONSENT FORM

**MONASH UNIVERSITY
CENTRE FOR DEVELOPMENTAL PSYCHIATRY**

I
of

agree to participate in the study regarding

as part of a research project described in an explanatory letter I have read.

In order to confirm any diagnoses and the developmental level of your child, we require copies of the reports from the health professionals who either assessed your child or from whom you sought help (for example: paediatrician, psychologist, speech pathologist, psychiatrist, etc).

We would appreciate it if you would supply us with such copies. If you are unable to, we seek your permission to contact the health professionals you have named below in order to obtain this information.

PLEASE NAME THE HEALTH PROFESSIONAL(S) INVOLVED:

Name(s):

Address:

Name(s):

Address:

To assist with the research program, I agree to Professor Tonge supervising contact, if necessary, with the health professionals named above.

Signed

Date

**MONASH UNIVERSITY, CENTRE FOR DEVELOPMENTAL PSYCHIATRY & PSYCHOLOGY
MONASH MEDICAL CENTRE
CONSENT FORM**

I

of

have been asked to participate in the research project entitled 'Early detection of children with developmental problems' being conducted by Professor B. Tonge and Kylie Gray involving myself and my child,

I give my consent by signing this form on the understanding that the research study will be carried out in a manner conforming with the principles set out by the National Health and Medical Research Council, and further that:

1. I understand the general purposes, methods, demands and benefits and possible risks, inconveniences and discomforts of the study as outlined in the 'Information Sheet' that has been given to me.
2. My participation in the research study is voluntary, and that I am free to withdraw at any time.
3. The confidentiality of my medical history will be safeguarded.
4. I have been given the opportunity to have a member of my family or a friend present while the project was explained.
5. I have been given the opportunity to ask questions in relation to the research study.

Parent's signatures:

Signature

Signature

Witness: I

of

as an independent witness, confirm that the aims and procedures of the study and any risks involved have been explained to the person consenting, whose signatures I witness. In opinion, he/she is acting rationally and voluntarily.

Signature Date

Investigator: I

have fully explained the aims, risks, and procedures of the abovenamed study to the person named herein.

Signature Date

APPENDIX H
DEVELOPMENTAL BEHAVIOUR CHECKLIST EARLY SCREEN
(DBC EARLY SCREEN)

Many of the following behaviours may not apply to the child in your care. For each item that does describe the person in your care, now or within the past six months, please circle the **2** if the item is **very true** or **often true**. Circle **1** if the item is **somewhat** or **sometimes true** of your child. If the item is **not true** of your child circle the **0**.

0 = not true as far as you know 1 = somewhat or sometimes true 2 = very true or often true

If your child is unable to perform an item, circle the **0**. For example, if your child has no speech, then for the item "Repeats the same word or phrase over and over" circle the **0**

Underline any you are particularly concerned about

| Office Use Only | Please Circle | | | |
|-----------------|---------------|---|---|--|
| 1. | 0 | 1 | 2 | Avoids eye contact. Won't look you straight in the eye. |
| 2. | 0 | 1 | 2 | Aloof, in his/her own world. |
| 3. | 0 | 1 | 2 | Arranges objects or routine in a strict order. Please describe: _____ |
| 4. | 0 | 1 | 2 | Becomes over-excited. |
| 5. | 0 | 1 | 2 | Deliberately runs away. |
| 6. | 0 | 1 | 2 | Doesn't show affection. |
| 7. | 0 | 1 | 2 | Excessively distressed if separated from familiar person. |
| 8. | 0 | 1 | 2 | Doesn't respond to others' feelings, e.g. shows no response if a family member is crying. |
| 9. | 0 | 1 | 2 | Flicks, taps, twirls objects repeatedly. |
| 10. | 0 | 1 | 2 | Fussy eater or has food fads. |
| 11. | 0 | 1 | 2 | Gets obsessed with an idea or activity. Please describe: _____ |
| 12. | 0 | 1 | 2 | Has temper tantrums, e.g. stamps feet, slams doors. |
| 13. | 0 | 1 | 2 | Hums, whines, grunts, squeals or makes other non-speech noises. |
| 14. | 0 | 1 | 2 | Impatient. |
| 15. | 0 | 1 | 2 | Laughs or giggles for no obvious reason. |
| 16. | 0 | 1 | 2 | Mood changes rapidly for no apparent reason. |
| 17. | 0 | 1 | 2 | Noisy or boisterous. |
| 18. | 0 | 1 | 2 | Overactive, restless, unable to sit still. |
| 19. | 0 | 1 | 2 | Prefers the company of adults or younger children. Doesn't mix with his/her own age group. |
| 20. | 0 | 1 | 2 | Prefers to do things on his/her own. Tends to be a loner. |
| 21. | 0 | 1 | 2 | Preoccupied with only one or two particular interests. Please describe |
| 22. | 0 | 1 | 2 | Resists being cuddled, touched or held. |
| 23. | 0 | 1 | 2 | Repeats the same word or phrase over and over. |
| 24. | 0 | 1 | 2 | Screams a lot. |
| 25. | 0 | 1 | 2 | Speaks in whispers, high pitched voice, or other unusual tone or rhythm. |
| 26. | 0 | 1 | 2 | Switches lights on and off, pours water over and over; or similar repetitive activity. Please describe: _____ |
| 27. | 0 | 1 | 2 | Stubborn, disobedient or unco-operative. |
| 28. | 0 | 1 | 2 | Upset and distressed over small changes in routine or environment. Please describe: _____ |
| 29. | 0 | 1 | 2 | Wanders aimlessly. |
| 30. | 0 | 1 | 2 | Whines or complains a lot. |
| 31. | 0 | 1 | 2 | Overall, do you feel your child has problems with feelings or behaviour, in addition to problems with development? If not, please circle the 0 . If so, but they're minor, please circle the 1 . If they're major problems, please circle the 2 . |

Please be sure you have answered all items

Are there any other comments you would like to make?

THANK YOU

APPENDIX I

AUTISM DIAGNOSTIC INTERVIEW-REVISED (ADI-R)

July 1995

-Autism Diagnostic Interview - R
Research
(Third Edition).

N.B. COPYRIGHT

Professor Michael Rutter
Dr. Catherine Lord
Dr. Ann LeCouteur

Inquiries regarding the schedule and training on its use may be addressed to:

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or

Professor Michael Rutter
MRC Child Psychiatry Unit
Institute of Psychiatry
De Crespigny Park
London SE5 8AF
England

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INTRODUCTION continued

Name of Proband:

Family ID Number:

| | | | | |
|--|--|--|--|--|
| | | | | |
|--|--|--|--|--|

Individual ID Number of Subject of Interview:

| | |
|--|--|
| | |
|--|--|

Proband Status (Code as relevant for specific study):

Subject's Sex:

0 = male
1 = female

Relationship of Subject to Proband (if different):
(Code as relevant for specific study when ADI is being used for a family study to assess relatives of proband)

Clinical Status:

Month of Interview:

| | |
|--|--|
| | |
|--|--|

Day of Interview:

| | |
|--|--|
| | |
|--|--|

Year of Interview:

| | | | | |
|--|--|--|--|--|
| | | | | |
|--|--|--|--|--|

Subject's Age at Interview (in years):

| | |
|--|--|
| | |
|--|--|

Subject's Month of Birth
(Code 99 if unknown)

| | |
|--|--|
| | |
|--|--|

Subject's Day of Birth:
(Code 99 if unknown)

| | |
|--|--|
| | |
|--|--|

Subject's Year of Birth:
(Code 9999 if unknown)

| | | | | |
|--|--|--|--|--|
| | | | | |
|--|--|--|--|--|

Research Worker:

| | |
|--|--|
| | |
|--|--|

Informant's Name:

Informant:

0 = mother
1 = father
2 = other caregiver
3 = combination

Informant's Telephone Number:

Location and Circumstances of Interview (DESCRIBE)

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INTRODUCTION

The main purpose of this interview, to be administered to the subject's principal caregiver, is to obtain detailed descriptions of those behaviors that are necessary for the differential diagnosis of pervasive developmental disorders (PDD) and especially for the diagnosis of infantile autism. The interview focuses primarily on the key diagnostic characteristics specified in ICD-10 and DSM-III-R; namely those features concerned with developmental delays and deviance in reciprocal social interactions, language, communication and play and on restricted, repetitive and stereotyped behaviors and interests. However, in addition, a variety of other behaviors often associated with PDD are covered, and details are obtained on developmental milestones in the first years. The ADI specifically provides for the assessment of developmental abnormalities that may be associated with any type of specific or general developmental retardation, but which are of particular importance in the differential diagnosis of PDD. A complementary instrument, the Autism Diagnostic Observation Schedule (ADOS), provides data from direct observation of the subject's behavior.

INTERVIEW STYLE

The ADI is an investigator-based interview in which the structuring lies in the details of the predetermined codings for each behavioral item. The interviewer is expected to be fully familiar with the conceptual distinctions involved in each item and with the specific aspects of behavioral information that are necessary in order to decide on each rating. It is up to the interviewer to ensure that all necessary information is obtained for all codings. The interview schedule specifies a variety of screening questions, the purpose of which is to guide the interviewer on the nature of the information obtained and not just to obtain an affirmative or negative response from the informant. The responsibility of deciding when enough questions have been asked is firmly placed on the interviewer. The interviewer's decision is based on whether the behavioral descriptions are adequate for coding and not on whether all the probes have been used. If the coding remains in doubt, the interviewer is expected to consider which further questions would help resolve the doubts, and ask them accordingly.

It is crucial to appreciate that this approach is different from that employed in structured respondent-based interviews. In such interviews, standardized questions are specified and must be asked in the form given, with codings based solely on whether or not the respondent says 'yes' or 'no' to the behaviors in question. Respondent-based interviews rely on all informants interpreting questions in the same way and on their having the conceptual understanding to make the distinctions required. In the ADI, it is up to the interviewer to cross-question until it is clear that the requisite information has been obtained for him/her (the investigator) to make the distinctions required for each coding. 'Yes' or 'no' answers are never coded as such. Rather, behavioral descriptions are coded.

This feature means that there is a heavy emphasis on the need to obtain detailed descriptions of actual behavior. General statements are not acceptable. Instead, informants are asked to give a sequential account of the subject's behavior in actual incidents or episodes. These descriptions should be written down in the schedule, using the blank pages on the left. This serves as a means of checking both on comparability across interviewers and on the extent to which ratings adhere to the specified criteria given for each coding. In addition, it provides the raw material for a reassessment of particular behaviors, if subsequent knowledge indicates that further distinctions have to be made.

INTRODUCTION continued

Throughout the interview, the codings (and, hence, the questions designed to elicit the relevant behaviors) have been devised with the aim of differentiating developmental delay, or impairment in some function, from deviance, or qualitative abnormality in that function. Moreover, each coding seeks to focus on some specific type of deviance rather than on an undifferentiated general abnormality.

Because this type of investigator-based interview relies heavily on skilled interviewing techniques and on the interviewer's detailed knowledge of the conceptual distinctions involved in each coding, it is essential that interviewers receive training in the use of the ADI. Depending on the interviewer's previous experience of clinical interviewing and with the behavioral features that may be associated with PDD, the length of training will vary. Training should involve the viewing of videotaped interviews, together with supervision and discussion of the trainee's own interviews using the ADI, in order to acquire the necessary interviewing skills. Training must also include the coding of videotaped interviews, together with discussion of the codings, in order to learn the concepts and coding conventions.

INTERVIEW FORMAT

The interview consists of six sections. The first part is a general orienting section to obtain background information about the subject and his/her family that is designed to enable the interviewer to better formulate later questions. For example, for many items, it is useful to ask the informant to compare the subject with his/her siblings. However, this requires the interviewer to be aware of the age and sex of siblings and know whether or not they have handicaps. Similarly, it is important for the interviewer to know whether the subject is in any form of residential care and what type of school is attended. This initial section of the interview is designed solely for this orienting purpose and it is not intended to provide comprehensive data on the family.

The second section of the interview covers the early developmental history with questioning on when the parents first became aware that something might be wrong with the subject (and what it was that caused concern at that time) and on various developmental milestones (e.g. walking, toilet training). In seeking to time these milestones (as well as other features in the interview), it is always desirable to personalize the timing by reference to birthdays, Christmas, or key family events (such as holidays or moving house or the time of starting nursery school). People rarely remember happenings by date or age, and the purpose of this personalization is to trigger memories of what the subject was doing at some personally memorable period or occasion.

The next three sections of the interview focus on the subject's behavior in earlier years and currently, with 'current' defined as the 3 months prior to the interview. Each of the three sections addresses, in turn, a different area or combination of areas related to the diagnosis of autism, namely: communication and language, social development and play, and unusual interests and behaviors. The seventh and last section concerns nonspecific behavior difficulties, special abilities, and a few questions to complete the interview.

AGE PERIOD FOR CODINGS:

Because the interview is designed to be applicable across a very wide age range (in terms of both mental age and chronological age), there is a need to define the age period to which ratings apply, and to do so in a way that provides maximum comparability across subjects. This is done in three different ways according to the type of item. First, there is the class of behaviors that indicate qualitative abnormalities that would be deviant at any age. Examples include delayed echolalia, rituals and self-injury. These are coded in terms of CURRENT (meaning the 3-months immediately preceding the interview assessment) and EVER (meaning at any time during the subject's life, including the current time period). Because EVER includes CURRENT, the interviewer needs to check that the EVER coding always indicates at least as much abnormality as that evident on the CURRENT rating.

Second, there is the class of behaviors that are likely to be influenced strongly by maturational level. These would include many aspects of social behavior and communication. Ideally, these would be coded in terms of abnormality in relation to the subject's developmental level. However, accurate quantification of developmental level may not be available at the time of interview and, even when available, for many behaviors valid data on range of normality at different ages are not available. There are two main concerns with respect to this class of behaviors. First, because maturational factors are so influential, older subjects may have outgrown at least some of the grosser impairments; accordingly there is a need to focus on an age period in earlier childhood. Second, young severely retarded subjects may show impairment as a result of developmental delay alone without the need to involve any additional disorder or abnormality; accordingly there is a need to avoid making ratings on the basis of behavior in very early childhood. Experience has shown that the most satisfactory compromise is to code the behavior that was MOST ABNORMAL DURING THE 4.0 TO 5.0 AGE PERIOD; and to code CURRENT behavior. The focus on the fifth year of life does not, of course, mean that autism, or other pervasive developmental disorders, cannot be diagnosed under the age of 4 years. However, it does mean that the diagnosis in very young children has to take very careful account of systematic quantified assessment of different domains of development (including verbal and non-verbal skills). For children aged under 4.0 years, all "MOST ABNORMAL 4.0 TO 5.0" ratings should be coded "8" for not applicable.

Third, there are a few behaviors that either are relevant only during particular age periods (early or late) or which change their quality so markedly with age that early and late childhood cannot be dealt with in the same way. In these cases, specific age restrictions are given for each codings. Examples include direct gaze (item 42), imaginative play (item 63) and friendships (item 69).

DURATION OF TIME FOR CODINGS:

A further concern that applies to all ratings is the duration of time that the behaviors must have been present to be coded. The period specified (with a very few exceptions) is 3 MONTHS. This is because many children show transient abnormalities of types that approximate those that are characteristic of autism (but which probably do not have the same meaning). Accordingly, for abnormal behaviors to be coded as present, they must have lasted at least 3 months.

SUMMARY CODINGS:

In addition to the codings on specific behaviors, there is a small number of summary codings, for example, overall level of language (item 19) and current communicative speech (item 28). For some of these items earlier questioning will have provided all the necessary information, so no specific probes are provided. However, it is the interviewer's responsibility to ensure that sufficient descriptive data to make the codings are available and to ask further questions as necessary.

There is also a different sort of summary coding (items 95-103) that concerns whether or not there has been a loss of skills (regression), meaning a definite loss of previously acquired skills that has lasted at least 3 months. Specific probes are provided, but often it may be quite difficult to differentiate a definite regression from a transitory variation in performance that is related to some immediate situation such as a physical illness or the psychological challenge/stress of a change of school or birth of a sibling. It is up to the interviewer to use initiative in questioning in order to obtain an accurate picture of the manner in which skills were lost, the pattern and duration of change, and the extent to which the change has continued to be progressive.

FORM OF QUESTIONING AND RECORDING

For each section of the interview, there is an initial compulsory probe printed in **bold** typescript. The interviewer should then continue to ask further questions until he/she is able to make the coding for that section or item. In addition to the initial compulsory probe for each section of the interview, there is a variable number of supplementary probes. The interviewer may choose whether or not to make use of these or any other additional questions according to whether they are helpful in clarifying aspects of the behavior under assessment. In making these decisions, the interviewer should be guided by the coding definitions and instructions.

It is the interviewer's responsibility to obtain and record sufficient examples of actual behavior, prior to making each coding decision. A coding should then be made and entered in the relevant box on the schedule, before moving on to the next item of the interview. This ensures that the interviewer is certain that sufficient information has been collected in order to make the coding. Note that, in order to facilitate the choice of questions, some items provide instructions and guidelines for the interviewer. All such instructions are typed in capitals and enclosed in brackets. These instructions are not for the informant.

As already noted, except where explicitly specified to the contrary in the schedule, behaviors must have been present repeatedly or persistently over a period of at least three months in order to be coded as abnormal. A single episode of abnormal behavior should be noted in writing, but ordinarily this would not be regarded as sufficient for coding. However, when the informant is definite and explicit that the behavior was (or is) recurrent, but can give only one actual example, the abnormality should be coded as present. If at any stage during the interview, the informant gives additional information or remembers details that may affect an earlier coding, the interviewer should return to that coding to clarify and alter the score as appropriate. Finally, throughout the interview, the interviewer should take note of any obvious discrepancies between the information given by the informant and other sources of information. These discrepancies should be summarized on the last page of the interview and a 'discrepancy/best estimate' code entered beside the discrepant code in the schedule.

INTRODUCTION continued

At the end of the interview, the interviewer should ensure that all the codings have been made and note his/her impressions of the interview and the circumstances under which it was conducted. Note should also be made as to whether any recording (audio or visual) was made.

APPLICABILITY OF ITEMS

There are various places where decisions have to be taken on whether particular questions are applicable. The general principle is that applicability should be assumed, unless it is clear that the behavior in question could not be shown by the subject. This issue arises most obviously in the section dealing with abnormalities in spoken language. Clearly, there is no point in asking about these if the subject does not have sufficient speech to make the coding. In this case, '8' should be coded.

Because it is desirable for the purposes of the diagnostic algorithm to have a rule on applicability that extends across all communication items, a single code OVERALL LEVEL OF LANGUAGE (item 19) is used to divide subjects into those who are verbal (for whom all communication items apply) and those who are non-verbal (for whom all items on abnormalities of spoken language are treated as non-applicable). For this purpose, VERBAL is defined as "the functional use of spontaneous, echoed or stereotyped language that, on a daily basis, involves phrases of 3 words or more that at least sometimes include a "verb" and is comprehensible to others. (Non-verbal subjects are further sub-divided into SPEAKING AND NON-SPEAKING according to whether or not speech is used on a daily basis with a vocabulary of at least 5 words. This further differentiation is relevant for the applicability of a few specific codings noted in the schedule). This dichotomy into "verbal" and "non-verbal" (although necessary for applicability purposes) is not intended to describe a subject's level of communication, but is just for the purpose of obtaining an algorithm that takes into account the possibility of certain abnormalities. The range of variation in language usage is described by a finer set of sub-divisions within the various codes that concern complexity of language usage.

It should also be noted that "phrases" are defined differently for the coding of age of onset of first use of phrases (item 13). For this coding a phrase is defined as two words that must involve a verb and which must be spontaneous, and not echolalic. It will be appreciated that these definitions are not synonymous with those often employed by psycholinguists; that is because it has been necessary to devise definitions that maximize valid reporting by parents/caregivers (rather than those that are used by experts in the analysis of recorded speech samples).

CODING CONVENTIONS

Many complex behaviors have multiple aspects that are tapped by separate codings. When that is the case, each aspect should be noted by making the relevant codings. For example, when there is ritualistic behavior that has definite evidence of both verbal and behavioral components, these should be reflected in codings of verbal rituals and compulsions/rituals. However, the same aspect of behavior should not be double coded. When there is ambiguity over which coding should be made, it is up to the interviewer to come to a decision on which is the most appropriate.

When making a decision on the coding of individual items, the interviewer should ensure that the described behavior is truly of the type specified in the definition and coding and that it is not simply a secondary consequence of some other more generalized feature (such as high activity or short attention span or aggressiveness).

INTRODUCTION continued

A problem is sometimes posed by uncertainty over whether a particular behavior would have been manifest if the subject had not been on some medication which is thought to have brought it under control. In these instances, the interviewer should not seek to perform that experiment in his/her head. Rather, the behavior, as it occurred, should be coded.

Each item (other than those referring to developmental milestones and the like) is intended to specify some particular type of abnormality (often, but not always, of a kind thought to be associated with PDD). A coding of '2' or '3' should be made when that specified abnormality is present (the 2/3 distinction, when allowed, being made on the basis of its severity). A '1' coding should be made when it is clear that the subject has exhibited behavior of the type specified in the coding, but where it is not severe, frequent, or marked enough to warrant a '2' coding. The '1' coding should not be used to reflect vague, dubious, or uncertain abnormalities; these should be coded '0'. The '0' coding means that the behavior specified in the coding was not present. This does not necessarily imply that the behavior was fully normal, but it does mean that any departures from normality were not of the kind specified in that particular coding.

When a behavior is nonapplicable (as in the nonverbal example given above), '8' should be coded. In general, there are three main circumstances when a coding is nonapplicable: 1) the child's age is outside the range used for coding (e.g., a 3 year old for 'most abnormal 4.0 to 5.0' codings, or an 11 year old for the 'current' rating for 'Imaginative Play with Peers'); 2) the child does not have the level of behavior required to exhibit the abnormality (e.g., a nonverbal child for the language abnormality codings); and 3) the child has never been in the circumstances required to elicit the behavior (e.g., a very isolated preschool child who had never been exposed to other children would be coded '8' on 'Interest in other children'). This last situation is rare and should be invoked only when it is quite clear that there really has been no opportunity.

When it is not known whether a behaviour has occurred (i.e. the interviewer did not question adequately or the informant could not provide the necessary information), '9' should be coded.

In a few instances only, a further coding of '7' is allowable to record that a definite abnormality not of the type specified, but in the general area of that coding, was present.

It is important that the interviewer concentrate on the specifics of each coding in order to avoid any 'halo' effects stemming from preconceptions regarding whether or not the child has some PDD. It is common for severely retarded children to show some abnormalities of the types associated with PDD, even though it is less usual for these children to show these difficulties over a range, pattern and severity sufficient to meet the full diagnostic criteria of PDD. It is this concern to avoid 'halo' effects that has led to a restriction on the use of '7' codings to just some items.

INTRODUCTION continued

The coding conventions may be summarized as follows:

- 0: Behavior of type specified in the coding is/was not present
- 1: Behavior of type specified is/was present in abnormal form (or 'lack of behavior' was present), but not sufficiently severe, frequent or marked to meet the criteria for '2'
- 2: Definite abnormality of the type specified that meets/met the criteria given for that coding
- 3: A more severe manifestation of '2'
- 7: Definite abnormality in the general area of the coding, but not of the type specified
- 8: Not applicable (no opportunity to exhibit the behavior because outside relevant age range, does not have the required level of behavior or because never in circumstances that could elicit the behavior)
- 9: Not known

The coding conventions for developmental items are somewhat different because actual ages are needed. Where the interview schedule requires the coding of an age, this should be recorded in months. If the informant can give only an age range (e.g. 6-9 months or 10-12 weeks); the midpoint should be taken and rounded up to the nearest month (i.e. recording 8 months and 3 months respectively). When no date can be obtained, the following sequence should be used throughout the interview.

- 993: Regression - milestone achieved, but subject then relapsed over a period; e.g. toilet trained, but relapsed and now soils and/or wets regularly
- 994: Milestone never achieved, e.g. never smiled socially, never babbled, never continent of urine or faeces
- 995: Milestone still not reached, e.g. toilet trained, but for less than a year
- 996: Not known, but apparently normal
- 997: Not known, but apparently delayed
- 998: Not applicable for any reason, e.g. physical handicap preventing the attainment of a particular motor milestone
- 999: Not known or not asked

RECORDING BEHAVIORAL DESCRIPTIONS:

Because codings are made by the interviewer on the basis of behavioral descriptions (and NOT on the informant's "yes" or "no" response to particular questions), it is important to have sufficient details written down on the schedule for someone else to be able to check the codings. Accordingly, it is the responsibility of the interviewer to ensure that, for all items, there is a written description of the subject's behavior that is sufficiently detailed for another person to be able to determine what the correct rating should be.

BACKGROUND

(NOTE THROUGHOUT ANY DISCREPANCIES BETWEEN INFORMANT'S DESCRIPTION AND OBSERVER'S KNOWLEDGE FROM OTHER SOURCES, AND SUMMARIZE AT END OF INTERVIEW)

To begin, perhaps you could give me an idea of who's who in the family.

Do you have any other children? Could you tell me their names and ages? Are any of them married? Do any of them have children? Are these all your children? Are any of them adopted or fostered? (IF EITHER PARENT PREVIOUSLY MARRIED) Do you have any children from a previous marriage? Is there anyone in your extended family who has difficulties similar to (child)?

| <u>NAME</u> | <u>DOB</u> | <u>Age</u> | <u>Sex</u> | <u>Marital Status</u> | <u>Children</u> | <u>Parents of children</u> <u>(this marriage, prev.</u> <u>marriage, fostered,</u> <u>adopted, etc.)</u> |
|-------------|------------|------------|------------|-----------------------|-----------------|---|
|-------------|------------|------------|------------|-----------------------|-----------------|---|

BACKGROUND continued

Have any of your children been delayed in their development? or had any special problems for which you sought treatment when they were children (or later)? e.g. medical, surgical, worries about physical or mental handicap, emotional problems.

Did either you or your husband have any developmental difficulties? or special problems for which you received treatment when you were children (or later)? e.g. medical, surgical, worries about physical or mental handicap, emotional problems.

NAME

DOB

Sex

Medical/Social History

SUBJECT'S EDUCATION (SCHOOL AND PRESCHOOL)

(THE PURPOSE OF THESE QUESTIONS IS TO PROVIDE A FRAME OF REFERENCE FOR THE ITEMS THAT FOLLOW)

Now I'd like to ask about what sort of programs, playgroups and schools _____ has attended. Was this a regular playgroup or school? How long did he/she attend? Did he/she need any special help/remedial help? Did he/she have any special problems with reading or spelling? (GO THROUGH SCHOOLS AS APPROPRIATE FOR AGE AND OBTAIN DETAILS OF ATTAINMENTS.) (IF APPROPRIATE) What has he/she done since leaving school?

| <u>School</u> | <u>Type</u> | <u>Dates</u> <u>attended</u> | <u>Additional help required</u> |
|---------------|-------------|---------------------------------|---------------------------------|
|---------------|-------------|---------------------------------|---------------------------------|

MEDICATION (NO CODING NEEDED HERE)

Does _____ take any regular pills or medicines now? (GET DETAILS AND WRITE BELOW)

INTRODUCTORY QUESTIONS

(THE PURPOSE OF THESE FIRST QUESTIONS IS TO PROVIDE A FRAME OF REFERENCE FOR THE ITEMS BELOW)

I'd like to start off by just getting a general picture of _____. Let me just briefly ask you some questions and then we can then come back to some things in more detail once I have got some sense of what _____ is like. Can you tell me a little about _____? Perhaps we could start with what his/her day is like. When is he/she at his/her best? What about the most difficult? How would you describe _____ to me if I had to pick him/her out in a group of other children/young people of his/her age? What kinds of things does he/she do when left to his/her own devices? What is _____'s language like?

1. CURRENT CONCERNS

(SCORE CONCERNS IN ORDER OF PRIORITY BELOW)

Do you have any serious concerns about _____'s behavior or development now? What are they? (RANK ORDER ALL MAJOR CONCERNS, IF POSSIBLE)

(CODE THE MOST MAJOR CURRENT CONCERN IN THE BOX LABELLED 'A'. OTHER CONCERNS SHOULD BE CODED, IN ORDER OF PRIORITY AS MUCH AS POSSIBLE, IN BOXES 'B' TO 'D'. IF THERE ARE MORE THAN FOUR MAJOR CONCERNS, CODE ONLY THE FOUR WITH THE HIGHEST PRIORITY IN THE PERCEPTION OF THE INFORMANT. IF THERE ARE FEWER THAN FOUR MAJOR CONCERNS, LEAVE THE BOXES BLANK. IN EACH CASE, DETAILS OF THE CONCERNS SHOULD BE SPECIFIED IN WRITING.)

- 0 = no concern, parental or professional
- 1 = delay/deviance in development of speech and/or expressive language (include possible deafness, failure to respond to sounds or does not seem to understand what is said)
- 2 = medical problems (such as seizures) or delay in milestones other than language (may include lack of physical growth, motor development, toilet training or being "slow")
- 3 = lack of interest in or abnormality/oddity in social or emotional response to people (may include specific difficulties in playing with other children or "in world of his/her own" or general social incompetence)
- 4 = behavior difficulty not specific to autism (e.g., sleeping or eating problems, generally high activity level, wandering, aggressive or destructive behavior)
- 5 = autistic-type behaviors (e.g. hand or finger mannerisms; unusual attachments; extreme difficulties with change; highly repetitious, nonfunctional behaviors; unusual or no appropriate play with objects)
- 6 = possible lack of ability to live independently or happily (include difficulties finding a job, looking after him/herself etc.)
- 7 = concerns not directly associated with subject's behavior or development (e.g. family problems or dispute over care or schooling or concerns over financial compensation)
- 8 = professionals worried; parents not
- 9 = N/K or not asked

A:

B:

C:

D:

ONSET OF SYMPTOMS

Can we now go back to talk about _____'s early years?

2. AGE (IN MONTHS) WHEN PARENTS FIRST NOTICED THAT SOMETHING IS NOT QUITE RIGHT IN LANGUAGE, RELATIONSHIPS OR BEHAVIOUR

(CONCERNS ON STRICTLY MEDICAL ISSUES, SUCH AS PREGNANCY COMPLICATIONS OR PROBLEMS IN BREATHING IN THE NEONATAL PERIOD OR THE PRESENCE OF DOWN'S SYNDROME ARE NOT RELEVANT FOR THIS CODING. NEVERTHELESS, NOTE SUCH INFORMATION AS IT IS RELEVANT FOR AN OVERALL ASSESSMENT)

First, I'd like to ask a little about _____'s early development. How old was _____ when you first wondered if there might be something not quite right with his/her development?

Note: If parents express age in weeks, code to nearest month. Similarly, if an age range is given, e.g. 3-4 months, take midpoint and round up to nearest month. As far as possible, try to code an actual age rather than 996, etc.

Three empty boxes for coding age.

- 991 = parents not concerned, though child was referred by professional
992 = parents have been worried since birth, e.g. if baby premature or very ill at birth
996 = can't recall, but before 3 years
997 = can't recall, but 3 years or later
998 = N/A
999 = N/K or not asked

3. FIRST SYMPTOMS TO AROUSE PARENTAL CONCERN

What was it that gave you concern at that time? (ELICIT DETAILS OF SYMPTOMS FIRST CAUSING PARENTAL CONCERN. SCORE CONCERNS IN ORDER OF PRIORITY)

- 0 = no concern, parent or professional
1 = delay/deviance in speech and/or expressive language (include possible deafness, failure to respond to sounds or does not seem to understand what is said)
2 = medical problems (such as seizures) or delay in milestones other than language (may include lack of physical growth, motor development, toilet training or being "slow")
3 = lack of interest in or abnormality/oddity in social or emotional response to people (may include specific difficulties in playing with other children or "in world of his/her own" or general social incompetence)
4 = behavior difficulty not specific to autism (e.g. sleeping or eating problems, generally high activity level, wandering, aggressive or destructive behavior)
5 = autistic-type behaviors (e.g. hand or finger mannerisms; unusual attachments; extreme difficulties with change; highly repetitious, nonfunctional behaviors; unusual or no appropriate play with objects)
6 = possible lack of ability to live independently or happily (include difficulties finding a job, looking after him/herself etc.)
7 = concerns not directly associated with subject's behavior or development (e.g. family problems or dispute over care or schooling or financial compensation)
8 = professionals worried; parents not
9 = N/K or not asked

Four vertical boxes labeled A, B, C, and D for rating concerns.

EARLY DEVELOPMENT continued

ONSET OF SYMPTOMS continued

4. AGE (IN MONTHS) WHEN PARENTS FIRST SOUGHT ADVICE

When did you first see someone (such as your family doctor or GP) about this?

Note: If parents express age in weeks, code to nearest month. Similarly, if an age range is given, e.g. 3-4 months, take midpoint and round up to nearest month. As far as possible, try to code an actual age rather than 996, etc.

| | | |
|--|--|--|
| | | |
|--|--|--|

- 991 = parents not concerned, though child was referred by professional
- 992 = parents have been worried since birth, e.g. if baby premature or very ill at birth
- 996 = can't recall, but before 3 years
- 997 = can't recall, but 3 years or later
- 998 = N/A
- 999 = N/K or not asked

DIAGNOSIS (NO CODING NEEDED HERE)

Did anyone ever say that _____ had a medical problem or give you a medical diagnosis for him/her? (GET DETAILS AND WRITE BELOW)

5. ONSET AS PERCEIVED WITH HINDSIGHT

(THE PURPOSE OF THIS ITEM IS TO RECORD THE EARLIEST POINT IN THE CHILD'S DEVELOPMENT THAT ANYTHING UNUSUAL MAY HAVE OCCURRED, ACCORDING TO THE CAREGIVER'S BEST JUDGMENT WITH HINDSIGHT)

Looking back with hindsight, when do you think he/she first showed any problems or difficulties in development or behavior? Do you think that everything was fully alright before then? (CODE CAREGIVER'S JUDGMENT)

- 0 = problems present in first 12 months
- 1 = problems not present before 12 months, but were noted at/or before 24 months
- 2 = problems not present before 24 months, but were noted at/or before 36 months
- 3 = problems not present before 36 months, but were noted at/or before 4 years
- 4 = problems not present before 4 years, but were noted at/or before 5 years
- 5 = problems not present before 5 years, but were noted at/or before 6 years
- 6 = problems not present before 6 years, but were noted at a later date (SPECIFY:)
- 7 = child always 'different' but differences were not perceived by parents as any kind of abnormality
- 8 = no problems were noted by parents
- 9 = N/K or not asked

| |
|--|
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EARLY DEVELOPMENT continued

TOILET TRAINING

(PROBE FOR THE POSSIBILITY THAT EACH SET OF HABITS MAY HAVE BEEN SUBSEQUENTLY LOST AND RELEARNED. NOTE AGES FOR BOTH, BUT CODE RELEARNING. DO NOT CODE ISOLATED ACCIDENTS WITH AN UNDERSTANDABLE EXPLANATION, E.G., SUBJECT UNWELL, HAD A HIGH TEMPERATURE, RESPONDING TO A CHANGE OF ENVIRONMENT, OR ACUTE DISTRESS)

How has toilet training gone?

8. ACQUISITION OF BLADDER CONTROL: DAYTIME

Is _____ dry during the day? How old was he/she when this was first achieved? When was he/she first dry for 12 months without accidents?

(Code the age of last bladder accident before clear 12 month period. Exclude soiling accidents. Code months when milestone first reached.)

| | | |
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| | | |
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- 993 = successfully toilet trained for a period of 12 months, but has relapsed and now regularly wets
- 994 = never achieved continence
- 995 = still not reached, i.e. continent, but for period of less than 12 months
- 996 = not known, but apparently delayed
- 997 = not applicable
- 999 = N/K or not asked

9. ACQUISITION OF BLADDER CONTROL: NIGHT

Is _____ dry at night? How old was he/she when he/she first remained dry at night? When was he/she first dry for 12 months without an accident?

(Code the age of last bladder accident before clear 12 month period. Exclude soiling accidents. Code months when milestone first reached.)

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- 993 = successfully toilet trained for a period of 12 months, but has relapsed and now regularly wets
- 994 = never achieved continence
- 995 = still not reached, i.e. continent, but for period of less than 12 months
- 996 = not known, but apparently delayed
- 997 = not applicable
- 999 = N/K or not asked

10. ACQUISITION OF BOWEL CONTROL

Does _____ soil himself/herself at all (with his/her bowel movements)? How old was he/she when he/she first got full control of his/her bowels? When was he/she first continent for 12 months without an accident? (CODE ACCIDENTS INVOLVING BOTH WETTING AND SOILING HERE)

(Code the age of last bowel accident Before clear 12 month period. Code in months of age when continence achieved)

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- 993 = successfully toilet trained for a period of 12 months; but has relapsed and now regularly soils
- 994 = never achieved continence
- 995 = still not reached, i.e. continent, but for period of less than 12 months
- 996 = not known, but apparently normal
- 997 = not known, but apparently delayed
- 998 = not applicable
- 999 = N/K or not asked

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0 -
1 -
2 -
3 -
8 -
9 -

COMMUNICATION

Now I'd like to talk about _____'s language development and the kinds of things children do before they learn to talk. What is _____'s language like now? Has he/she learned to talk yet? (ADAPT INITIAL PROBES TO WHAT IS ALREADY KNOWN ABOUT SUBJECT'S LEVEL OF LANGUAGE AND OBTAIN DESCRIPTION TO AID THE WORDING OF LATER QUESTIONS)

11. USE OF OTHER'S BODY TO COMMUNICATE

(THE EMPHASIS IS ON THE ABNORMAL USE OF ANOTHER PERSON AS A KIND OF EXTENSION OF THE SUBJECT'S ARM OR BODY. FOR EXAMPLE THE USE OF ANOTHER PERSON'S HAND TO POINT, TOUCH AN OBJECT OR PERFORM A TASK SUCH AS TURNING A DOOR KNOB TO OPEN A DOOR, UNSCREWING A BOTTLE TOP OR LID OR MANIPULATING A ZIP-FASTENING OR BUTTONS. THIS BEHAVIOR WILL PROBABLY TAKE PLACE WITHOUT ANY PRIOR ATTEMPT TO COMMUNICATE THE NEED OR REQUEST USING OTHER SOUNDS OR GESTURE. THUS, THE PHYSICAL CONTACT IS NOT TO INITIATE A SOCIAL APPROACH BUT RATHER TO FACILITATE THE COMPLETION OF THE TASK)

How does _____ usually let you know s/he wants something? (If subject uses speech now; ask: How did s/he let you know before s/he was able to use words?) Did/does s/he ever show you what s/he wants by taking your hand or wrist or some other part of your body? What exactly does s/he do? What does s/he do when you are brought to the object wanted? Does s/he ever use your hand as if it were a tool or an extension of his/her own arm (such as pointing with your hand or getting your hand to turn a door knob)? Does s/he look at you when doing this? Does s/he combine taking your hand with trying to communicate with sounds or words? When does s/he do this? Does s/he try to communicate first by sounds or gesture?

- 0 = no use of other's body to communicate, except in situations where other strategies have not worked (e.g. when parent conversing with someone and subject cannot get his/her attention)
- 1 = occasional placement of hands on objects or use of it as a tool or to point, but some combination with other modes of communication (merely taking someone's hand to lead them places should be coded '0')
- 2 = occasional placement of other's hand or use of other's hand as a tool or to demonstrate 'for' the subject without integration with other modes of communication
- 3 = regular use of other's hand as a tool or to gesture 'for' the subject
- 6 = little or no spontaneous communication
- 9 = N/K or not asked

CURRENT

EVER

(NOTE: SPEECH, THAT IS, VOCABULARY OF AT LEAST 5 WORDS, OF WHICH AT LEAST ONE SHOULD BE USED DAILY; OTHERWISE TREAT SUBJECT AS NON-SPEAKING)

12. AGE OF FIRST SINGLE WORDS (IF EVER USED)

(MEANINGFULLY REFERS TO WORDS USED REPEATEDLY AND CONSISTENTLY FOR THE PURPOSE OF COMMUNICATION WITH REFERENCE TO A PARTICULAR CONCEPT, OBJECT OR EVENT. DO NOT CODE "MUMMY" AND "DADDY"; INCLUDE ANY OTHER SPONTANEOUS PHONOLOGICALLY CONSISTENT SOUNDS APPROXIMATING REAL WORDS IN LANGUAGE OF FAMILY, AND USED REPEATEDLY WITH MEANING)

How old was he/she when he/she first used words meaningfully apart from "mama" and "dada"? What were his/her first words? How did he/she show that he/she knew their meaning? (GET EXAMPLES) Did _____ ever use these words to refer to anything else or as sounds that didn't seem to have any specific meaning?

AGE OF FIRST SINGLE WORDS (Code in months)
Age first used (normal < 24 months)

| | | |
|--|--|--|
| | | |
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- 993 = had some words, then lost
- 994 = milestone not reached
- 996 = not known, but apparently normal
- 997 = not known, but apparently delayed
- 999 = N/K or not asked

13. AGE OF FIRST PHRASES (IF EVER USED)

(FOR THE PURPOSES OF THIS CODE, A PHRASE MUST CONSIST OF 2 WORDS, ONE OF WHICH MUST BE A VERB. DO NOT CODE ATTRIBUTE-NOUN COMBINATIONS NOR ECHOLALIC SPEECH NOR PHRASES THAT MIGHT HAVE BEEN LEARNED AS A SINGLE WORD TO CONVEY A SINGLE MEANING, E.G. "SEE YOU" (MEANING GOODBYE) - NOTE THAT THIS DEFINITION DIFFERS FROM WHAT IS REGARDED AS VERBAL FOR ITEM 19 'OVERALL LEVEL OF LANGUAGE' LATER IN INTERVIEW ON PAGE 27)

How old was he/she when he/she first said something that involved putting words together meaningfully, i.e. using 2 or 3 word phrases? What did he/she say? What about phrases including a verb? (GET EXAMPLES)

AGE OF FIRST PHRASES (Code in months)
Age first used (normal < 33 months)

| | | |
|--|--|--|
| | | |
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- 993 = had some phrases, then lost
- 994 = milestone not reached
- 996 = not known, but apparently normal
- 997 = not known, but apparently delayed
- 999 = N/K or not asked

14. ARTICULATION/PRONUNCIATION

(SCORE ONLY FOR SUBJECTS AGE 4 YEARS OR OLDER. ARTICULATION REFERS TO THE ENUNCIATION OF THE SOUNDS OF LANGUAGE)

What is his/her pronunciation like? Are there any words or sounds he/she doesn't get quite right? What are they? Do other people understand him/her easily? What about people outside the family? What was his/her articulation like when he/she reached his/her fifth birthday? What errors did he/she make at the time? (NOTE EXAMPLES) Could a stranger understand him/her? (GET DETAILS OF DIFFICULTIES WITH ARTICULATION)

- | | | |
|-----|---|--------------------------|
| 0 = | understood by anybody, i.e. clear enunciation of most sounds, but may include a few consonant omissions or substitutions | CURRENT |
| 1 = | understood better by family than others because of difficulty with some sounds, but mostly comprehensible to strangers at first encounter | <input type="checkbox"/> |
| 2 = | definite articulation difficulties such that some words are very difficult for strangers to understand until they get to know him/her | AT AGE 5.0 |
| 3 = | strangers find speech almost impossible to understand or parents have significant difficulties understanding because of articulation | <input type="checkbox"/> |
| 8 = | N/A | |
| 9 = | N/K or not asked | |

15. COMPLEXITY OF NON-ECHOED UTTERANCES

(THIS ITEM REFERS TO SEMANTIC AND GRAMMATICAL COMPLEXITY WITHIN A SENTENCE IN NON-ECHOED UTTERANCES. IT IS OFTEN HELPFUL TO ASK PARENTS/CAREGIVERS TO RECALL A PARTICULAR CONVERSATION WITH THE SUBJECT SUCH AS ON THE WAY TO THE APPOINTMENT OR DURING A RECENT MEAL)

Now when he/she speaks, what sort of combinations of words or sentences does he/she use? What is the average length do you think? (1 word, 2 words, 6 words - or what?) What about when he/she is not echoing? Can _____ make different kinds of sentences, such as questions, commands and negatives? Can _____ link two ideas together in one sentence by using "but" or "if"? (NOTE EXAMPLES) What about when he/she was five years old?

- | | | |
|-----|--|--------------------------|
| 0 = | uses a range of grammatical constructions and an extensive vocabulary (as seen in most normally-developing 4 to 5 year-olds). May make occasional errors in some advanced constructions, but with little interference with communication | CURRENT |
| 1 = | extensive vocabulary and a range of grammatical structures, but somewhat limited in flexibility and variety and/or with frequent grammatical errors or omissions | <input type="checkbox"/> |
| 2 = | significant proportion of utterances that follow simple grammatical rules (such as word endings to indicate tense), but constructions markedly limited in variety and complexity | AT AGE 5.0 |
| 3 = | non-echoed utterances predominantly simple phrases | <input type="checkbox"/> |
| 4 = | non-echoed utterances predominantly single words | |
| 8 = | N/A | |
| 9 = | N/K or not asked | |

16. SOCIAL VOCALIZATION/"CHAT"

(THE EMPHASIS IN DEFINING SOCIAL VOCALIZATION/CHAT IS, FOR ALL SUBJECTS, WHETHER OR NOT THEY VOCALIZE WITH PEOPLE JUST TO BE FRIENDLY OR SOCIAL RATHER THAN TO EXPRESS THEIR NEEDS OR GIVE SOME INFORMATION. THE FOCUS OF THIS QUESTION IS SOCIAL APPROACH, NOT SOCIAL RECIPROCITY, WHICH IS DEALT WITH IN QUESTION 20)

FOR SUBJECTS WITHOUT PHRASE SPEECH

When children are babbling or just beginning to talk, they sometimes seem to be making sounds just to be friendly and sociable, rather than because they want something. Would _____ do this? Does he/she talk or make sounds as if to make "comments" or to get you to continue talking to him/her? If you talk to him/her, does he/she try to answer or join in as if it were a conversation? When children are starting to talk, often they chatter away following their parents around, even though they know only a few words. Was _____ ever like that? I mean, did he/she ever talk or make sounds just to be social?

FOR SUBJECTS WITH PHRASE SPEECH:

When people talk, sometimes it is to get something or find out about something, but sometimes it seems mainly just to be with someone - sort of "small talk". Would _____ ever talk with you just to participate in some form of conversation? What about when he/she was 4 to 5?

- 0 = vocalizes or chats with clear social quality of talking/vocalization to be friendly or to express interest, rather than to make needs known
- 1 = some social use of vocalization or speech in response to caregiver or to get attention with no other obvious motivation, but limited in frequency or vocal quality or range of contexts
- 2 = uses some sounds or speech to alert caregiver to immediate needs or wants, but no or little purely 'social' use of vocalization
- 3 = no or very limited social use of sounds or speech
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

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17. IMMEDIATE ECHOLALIA

(THE REPETITION OF WORDS/PHRASES JUST SPOKEN BY SOMEONE ELSE)

(IF SUBJECT HAS ANY SPEECH ASK) Many children, when learning to talk, repeat words they hear people say. Does _____ ever repeat the last word or two of what you say or does he/she ever repeat back whole phrases in the same intonation you said it? Can you give me an example? Has he/she ever done this?

- 0 = rarely or never echoes/echoed words or phrases
- 1 = occasionally echoes/echoed words or phrases
- 2 = echoes/echoed words or phrases regularly, but some productive language as well (can be stereotyped)
- 3 = speech largely consists/consisted of immediate echolalia
- 8 = not enough speech to code
- 9 = N/K or not asked

CURRENT

EVER

18. STEREOTYPED UTTERANCES AND DELAYED ECHOLALIA

(THESE ARE DEFINED AS THE NON-HALLUCINATORY USE OF REPETITIVE SPEECH PATTERNS THAT ARE CLEARLY ODD IN TERMS OF EITHER STEREOTYPED CONTENT OR THEIR NON-SOCIAL USAGE, OR BOTH. THESE INCLUDE PHRASES THAT ARE INTERSPERSED INTO MORE NORMAL SPEECH, SELF-COMMENTARY ON THE PERSON'S OWN ACTIONS, A REPETITIVE RE-RUN OF EMOTIVE OR UPSETTING INTERCHANGES OR ROUTINIZED PHRASES USED OUT OF APPROPRIATE CONTEXT. DO NOT INCLUDE THE REPETITIONS THAT OFTEN OCCUR WITH NORMAL CHILDREN AS PART OF PLAY WHEN PHRASE SPEECH IS JUST BECOMING WELL ESTABLISHED, OR FOR REASSURANCE)

(IF SUBJECT HAS ANY SPEECH ASK) Has he/she ever tended to use rather odd phrases or say the same thing over and over in almost exactly the same way? That is, either phrases he/she has heard other people use or ones he/she has made up? (e.g. "Its bad to bite your wrist"; "Does this look like a traffic light"; "Say its alright now") Does he/she tend to talk to him/herself in this way when doing something on their own, or when upset about something that has happened during the day? Does he/she use the phrase appropriately or not to mean anything in particular or as part of a conversation with him/herself? Can you give me some examples? What about when he/she was younger? Does he/she ever give a running commentary on what he/she is doing? Did he/she ever do this more often?

- 0 = rarely or never uses/used stereotyped phrases
- 1 = speech tends/tended to be more repetitive than most subjects at the same level of complexity, but not stereotyped in an odd or unusual way; or occasional stereotyped utterances, but consistent productive language as well
- 2 = often uses/used stereotyped utterances with or without productive language as well
- 3 = speech almost exclusively stereotyped utterances
- 8 = N/A
- 9 = N/K or not asked

CURRENT

EVER

19. OVERALL LEVEL OF LANGUAGE

(THIS IS A SUMMARY CODE CONCERNING WHETHER SUBJECT USES AT LEAST 3 WORD PHRASES; INCLUDING BOTH SPONTANEOUS SPEECH AND/OR ECHOED OR STEREOTYPED SPEECH SO LONG AS THEY ARE USED FUNCTIONALLY)

(FOR SUBJECTS WHO ARE NON-SPEAKING AND NEVER HAD ANY SPEECH AND WHO SCORE '1' OR '2' ON OVERALL LEVEL OF LANGUAGE, SCORE '8' ON ITEMS 20 TO 28 BELOW, AND PROCEED TO ITEM 29)

(FOR SUBJECTS WHO DID HAVE SOME LANGUAGE AT AGE 4.0 TO 5.0 BUT ARE CURRENTLY NON-VERBAL, SCORE 8 ON 'CURRENT' FOR ITEMS 20 TO 28 BUT SCORE AS APPROPRIATE FOR 'MOST ABNORMAL 4.0-5.0'. FOR SUBJECTS WHO HAD LANGUAGE EARLIER BUT LOST IT BY AGE 4.0 TO 5.0, CODE 8 ON 'MOST ABNORMAL 4.0 TO 5.0' BUT NOTE DETAILS ABOUT THE LANGUAGE THEY HAD)

(FOR SUBJECTS WHOSE OVERALL LEVEL OF LANGUAGE IS CODED '0', PROCEED TO ITEM 20 BELOW)

- 0 = functional use of spontaneous, echoed or stereotyped language that, on a daily basis, involves phrases of 3 words or more that at least sometimes include a verb and is comprehensible to other people CURRENT
- 1 = no functional use of three word phrases in spontaneous, echoed or stereotyped speech, but uses speech on a daily basis with at least 5 different words in the last month
- 2 = fewer than 5 words total and/or speech not used on a daily basis

20. RECIPROCAL CONVERSATION (AT WHATEVER VERBAL LEVEL OF COMPLEXITY POSSIBLE)

(THE EMPHASIS IS ON THE ABILITY TO FACILITATE THE FLOW OF CONVERSATION, IE TO BUILD ON THE OTHER PERSON'S RESPONSES RATHER THAN THE SUBJECT'S ABILITY TO TALK/CHAT)

Can you have a 'conversation' with _____? That is, if you say something to him/her, without asking a direct question, what will _____ usually do? Will he/she say something? Will he/she ever ask you a question or build on what you have said in such a way that he/she adds something new to what you have said, so that the conversation will continue? In other words, will he/she converse in a to and fro way on topics that you have introduced? Can he/she also bring up appropriate topics? What about when _____ was 4 to 5?

- 0 = conversation flows including both offering information and building on other person's response in a manner that leads to ongoing dialogue CURRENT
- 1 = occasional reciprocal conversation, but less frequent than normal or limited in flexibility or topics
- 2 = little or no reciprocal conversation; others find it difficult to build a conversation even if there is apparent positive or social talk by subject; subject fails to follow anyone else's conversation topic; may ask or answer questions but not as part of a single interchange MOST ABNORMAL
4.0 - 5.0
- 3 = very little spontaneous speech
- 8 = subjects scoring '1' or '2' on item 19 Overall Level of Language OR N/A
- 9 = N/K or not asked

21. TALK EXPRESSING INTEREST IN OTHERS

(THE EMPHASIS IS ON THE SUBJECT'S SPONTANEOUS EXPRESSION OF INTEREST IN SOMEONE ELSE'S ACTIVITIES, IDEAS, OR ATTITUDES, THE INTEREST BEING SHOWN IN AN INTERACTIVE WAY AS PART OF A CONVERSATION)

Does he/she ever ask questions as part of a conversation? What are they like? Does he/she ever ask questions about you and how you feel? Will _____ talk on a topic you're interested in? Does he/she try to participate in your ideas or interests? For example, does _____ ever ask how your day has been, or how you're feeling, or about what you've been doing? Does he/she seem really interested in hearing about topics of interest to you, or are the questions just part of routines or interests of his/hers? How about with people outside the family? What about when _____ was 4 to 5?

- 0 = at whatever level of complexity is possible, asks a variety of different questions in conversation that indicate a spontaneous interest in listener's life
- 1 = asks some questions concerning listener, but limited in frequency, spontaneity or range
- 2 = questions concerning listener most often are limited to routines or preoccupations
- 3 = no questions concerning listener
- 8 = subjects scoring '1' or '2' on item 19 Overall Level of Language, or no questions OR N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

22. INAPPROPRIATE QUESTIONS OR STATEMENTS

(THE FOCUS IS ON SOCIALLY INAPPROPRIATE UTTERANCES THAT REFLECT A LACK OF UNDERSTANDING OF THE SOCIAL IMPACT OF SUCH COMMENTS OR A DISREGARD OF IT. THESE MAY CONSIST OF UTTERANCES THAT ARE INTRINSICALLY ODD (EG HOW TALL WAS MR BROWN WHEN HE WAS 2?) OR UTTERANCES THAT ARE INAPPROPRIATE BECAUSE OF THEIR PERSONAL NATURE OR IN RELATION TO THE SITUATION. REPETITION MAY CONTRIBUTE TO THE ODDNESS BUT IT IS NOT SUFFICIENT IN ITSELF)

Are there times when _____ uses socially inappropriate questions or statements? For example, does he/she regularly ask personal questions or make personal comments at awkward times? (GET EXAMPLES) Was this ever a problem in the past?

- 0 = no or very rare questions/statements inappropriate to conversation on setting
- 1 = uses some questions/statements regardless of situation. Questions or statements are slightly inappropriate and may be repetitious, but are not usually very odd or highly embarrassing
- 2 = frequent use of questions/statements that are odd and/or obviously inappropriate to the situation
- 8 = subjects scoring '1' or '2' on item 19 Overall Level of Language
- 9 = N/K or not asked

CURRENT

EVER

Now I want ask about the quality of _____'s speech.

23. PRONOMINAL REVERSAL

(THE EMPHASIS IS ON THE CONSISTENT ABNORMAL CONFUSION OF PRONOUNS BETWEEN FIRST AND SECOND OR THIRD PERSON. IT DOES NOT INCLUDE "I/ME" CONFUSION AS THIS IS OFTEN A SUBCULTURALLY ACCEPTABLE USAGE)

Has _____ ever got his personal pronouns the wrong way round? For example, has _____ ever mixed up "you" and "I"? What about saying "he" or "she" instead of "I"? For example, saying "You want a drink", instead of "I want a drink" or "He is hungry" instead of "I am hungry" (NOTE EXAMPLES). IF YES, When using "you" or "he/she" instead of "I", how does he/she say it? For example, does his/her statement have the intonation of a question? What about when _____ was younger?

- 0 = no confusion between 1st and 2nd or 3rd person after phrase speech with pronoun use established
- 1 = refers/referred to self by name instead of "I" after phrase speech established, but no persistent "you/he/she - I" confusion
- 2 = "you-I" or "he/she-I" confusion after phrase speech established, but "you" or "he/she" not used with intonation of a question
- 3 = "you-I" or "he/she-I" confusion with intonation of a question when "you" or "he/she" is used for "I"
- 7 = other types of pronominal confusion (other than me/I), such as "he/you"
- 8 = subjects scoring '1' or '2' on item 19 Overall Level of Language, or no pronouns
- 9 = N/K or not asked

CURRENT

EVER

24. NEOLOGISMS/IDIOSYNCRATIC LANGUAGE

(NEOLOGISMS MUST BE NON-WORDS AND OBVIOUSLY PECULIAR, E.G. "PLIN" FOR A FREE-FALLING PIECE OF PAPER OR FABRIC; "MASHUDA" FOR TRIANGLES)

(IDIOSYNCRATIC REFERS TO REAL WORDS AND/OR PHRASES USED OR COMBINED BY THE SUBJECT IN A WAY THAT HE/SHE COULD NOT HAVE HEARD. THESE ARE USED TO CONVEY SPECIFIC MEANINGS; THEY DO NOT INCLUDE CONVENTIONAL METAPHORS. DIFFERENTIATE UNUSUAL OR TRULY IDIOSYNCRATIC USAGES FROM ORDINARY CHILDISH REFERENCES TO OBJECTS ACCORDING TO THEIR FUNCTION OR AS PART OF A SHARED GAME OR JOKE)

Does he/she ever use words that he/she seems to have invented or made up himself/herself?

Does _____ ever put things in odd, indirect ways ... or have 'idiosyncratic' ways of saying things, such as saying "hot rain" for "steam" or referring to his/her grandmother by her age? Would he/she ever then take this one step further and refer to other women as "55"? Can you give me some examples? Did he/she ever use these sorts of odd words or phrases in the past? (GET EXAMPLES AND PROMPT AS NECESSARY)

- | | | |
|-----|--|--------------------------|
| 0 = | no use of neologisms or idiosyncratic language | CURRENT |
| 1 = | occasional use of neologisms and/or "idiosyncratic" words and phrases used consistently over a period of time | <input type="checkbox"/> |
| 2 = | regular use of neologisms and/or "idiosyncratic" ways of saying things, including generalization of unusual term to referents beyond the example that may have fostered the initial idiosyncratic word or phrase | <input type="checkbox"/> |
| 8 = | subjects scoring '1' or '2' on item 19 Overall Level of Language | EVER |
| 9 = | N/K or not asked | <input type="checkbox"/> |

25. VERBAL RITUALS

(WHEN DECIDING WHETHER VERBAL RITUALS ARE PRESENT, FOCUS ON THE DEGREE OF PREDICTABILITY OF THE CONTEXT AND SEQUENCE, AS WELL AS THE COMPULSIVE QUALITY OF THE SPEECH. THE EMPHASIS IS ON THE FIXED SEQUENCES OF UTTERANCES THAT ARE SAID "AS IF" THE SUBJECT FEELS PRESSURE TO COMPLETE THEM IN A PARTICULAR ORDER. THE SUBJECT IS IMPOSING AN ORDER ON WHAT HE/SHE SAYS AND MAY, IN ADDITION, POSE SIMILAR RESTRICTIONS ON THE VERBAL RESPONSES/UTTERANCES OF OTHERS)

Does he/she ever say the same thing over and over in exactly the same way or insist on you saying the same things over and over again? Does he/she ever keep saying the same thing until you reply in a certain way? What happens if you interrupt him/her or refuse to comply? Was this ever a problem in the past? (GET-DETAILS)

- 0 = none
- 1 = tendency to say things in ritualized way or to require others to do so, but no indication that this is compulsive, and readily stops if asked to do so
- 2 = subject has to say one or more things in a special way. Rituals may intrude on family life. May involve other family members and some distress at interruption. May cause some disturbance or minor reorganization of family life that can be tolerated by most families as for '2', but with marked difficulty to control and marked intrusiveness on family life. Family members involved to a degree that causes definite social impairment, disruption or prevention of some family activities. Serious distress at any attempted interruption
- 8 = subjects scoring '1' or '2' on item 19 Overall Level of Language
- 9 = N/K or not asked

CURRENT

EVER

26. INTONATION/VOLUME/RHYTHM/RATE

(THIS ITEM REFERS TO UNUSUAL QUALITIES OF PROSODY AND/OR THE PARA-LINGUISTIC SOUND OF THE SUBJECT'S SPEECH AS EVIDENCED IN INTONATION, VOLUME, RHYTHM AND RATE. DO NOT SCORE USE OF COLLOQUIAL PHRASES OR INVECTIVES HERE)

Is there anything unusual about the way he/she speaks? That is, is his/her speech of normal volume or is it consistently too loud or too quiet? What about the rate and rhythm of his/her speech? What about the intonation or pitch? Does he/she ever repeat whole sentences or monologues in exactly the same tone of voice in which he/she first heard them? (GET DETAILS) What about in the past?

- 0 = normal, appropriately varying intonation, reasonable volume and normal rate of speech, with regular rhythm coordinated with breathing
- 1 = speech that shows one or other of the abnormalities listed under '2', but not obviously peculiar and no interference with intelligibility
- 2 = speech that is clearly abnormal in terms of any or all of the following:
 - (i) odd intonation or inappropriate pitch and stress;
 - (ii) markedly flat and toneless or mechanical speech;
 - (iii) consistently abnormal volume that lacks modulation;
 - (iv) inappropriate, poorly modulated rate or rhythm (either unusually slow or halting or unusually rapid or jerky) to a degree that creates some interference with intelligibility
- 3 = speech that is frequently obviously peculiar or difficult to understand because of abnormalities of type specified under '2'
- 7 = stutter or stammer
- 8 = subjects scoring '1' or '2' on item 19 Overall Level of Language
- 9 = N/K or not asked

CURRENT

EVER

27. VOCAL EXPRESSION

(THE EMPHASIS IS ON THE VARIETY AND RANGE OF DIFFERENT FEELINGS THAT THE SUBJECT CAN CONVEY SOLELY IN THE TONE OF HIS/HER VOICE AS PART OF A COMMUNICATIVE ACT)

Can you tell how he/she is feeling from his/her tone of voice without listening to the words he/she says? How subtle are the differences? Could you tell when he/she is puzzled, interested or irritated? If he/she was talking on the telephone, would you have any idea with whom they were talking if you didn't know who it was? (ie, if it was a friend, grandmother or teacher). Could someone else tell who didn't know him/her well? (GET DETAILS) What about in the past; was it ever difficult?

- 0 = normal tonal expressiveness CURRENT
 - 1 = some tonal expressiveness, but limited in range
 - 2 = vocal expressiveness limited to odd or unusual changes in tone or pitch
 - 3 = little or no tonal expression
 - 8 = subjects scoring '1' or '2' on item 19 Overall Level of Language
 - 9 = N/K or not asked EVER
-

28. CURRENT COMMUNICATIVE SPEECH

(THIS IS A SUMMARY CODE TO ASSESS HOW WELL THE SUBJECT USES HIS/HER LANGUAGE TO COMMUNICATE)

How does _____ now use the words he/she has? In what sort of situation does he/she "talk" the most? Does he/she call you by name or use words to direct your attention? (GET EXAMPLES OF COMMUNICATIVE USE OF WORDS) Does he/she ever tell you about things that are not present (e.g. about something that happened a while ago or about something he/she is looking forward to)? What about when he/she was 5 years of age?

- 0 = speech, at whatever level attained, used frequently and communicatively in a variety of contexts, including some reference to events not present (Do not include requests here) CURRENT
- 1 = some communicative use of words (i.e. words used regularly to communicate, with or without an abnormal element), but somewhat restricted in frequency or contexts
- 2 = some spontaneous words and/or echolalic language, but with limited communicative use AT 5.0 YEARS
- 3 = little or no communicative language (i.e. including exclusively non-communicative echolalia), though subject has some language
- 8 = subjects scoring '1' or '2' on item 19 Overall Level of Language (or under 5 years of age for 5.0 year coding)
- 9 = N/K or not asked

Now we are going to turn to some other aspects of behavior.

29. SPONTANEOUS IMITATION OF ACTIONS (CHILDREN AGED UNDER 10.0 YEARS)

(THE EMPHASIS IS ON THE SPONTANEOUS IMITATION OF A VARIED RANGE OF NON-TAUGHT, INDIVIDUAL BEHAVIORS, ACTIONS OR CHARACTERISTICS OF ANOTHER PERSON. EXCLUDE IMITATION OF TV/FILM CHARACTERS)

What about _____ imitating you or other people in the family? How about when you are not trying to get him/her to do so? Does he/she copy something you have done, but using a 'pretend' object (such as mowing the lawn with some toy vehicle)? Is the imitation only at the time you are doing whatever it is or does the copying form part of his/her play at other times? How varied are the things he/she imitates? Does the imitation ever involve some personal characteristic, such as the way you walk or gesture or the way you hold something? (GET EXAMPLES. DO NOT CODE ELICITED OR VOCAL IMITATION HERE.) What about when _____ was 4 to 5 years old?

- 0 = has spontaneously imitated a varied range of non-taught actions, at least some of which are incorporated into play outside the context of the observed behavior of the imitated person
 - 1 = some indication of spontaneous imitation that goes beyond copying a frequent use of an object, but not of sufficient flexibility or number to meet the criteria for '0'
 - 2 = spontaneous imitation limited to a few familiar routines that are not incorporated into play. Includes frequent appropriate use of an object probably learned through imitation (eg, mowing lawn with a toy mower)
 - 3 = very rare or no spontaneous imitation
 - 8 = N/A
 - 9 = N/K or not asked
- CURRENT
(UNDER AGE 10.0)
-
- MOST ABNORMAL
4.0 - 5.0
-

30. POINTING TO EXPRESS INTEREST

(CODE FOR EVIDENCE OF POINTING USED AS SPONTANEOUS COMMUNICATION TO EXPRESS INTEREST OR TO SHOW SOMETHING, RATHER THAN AS A MEANS OF OBTAINING SOME OBJECT. IT MUST BE SOCIAL AND INITIATED BY THE SUBJECT. POINTING MUST BE DIRECTED AT SOMETHING AT SOME DISTANCE WITHIN A BROAD VISUAL CONTEXT. POINTING AT BOOKS OR POINTING AS A LEARNED RESPONSE TO QUESTIONS IS CODED SEPARATELY FROM SPONTANEOUS POINTING. FOR FULL CREDIT, POINTING MUST INVOLVE COORDINATED EYE GAZE WITH THE OTHER PERSON, AS DESCRIBED BELOW)

Does he/she ever spontaneously point at things around him/her? With a finger or sort of a hand extended, like reaching? In what circumstances? Does he/she ever point at things at a distance, such as out a window at home or in a car or bus? You know how if I wanted to get you to look at something, I might first look at it, then look at you, then point and look at the object again, then look back at you to see if you understood. Can _____ do this? What about when _____ was 4 to 5 years old?

- 0 = spontaneously points at objects at a distance with finger to express interest, using coordinated eye gaze in order to communicate
- 1 = makes some attempt to express interest by pointing, but with limited flexibility and/or lack of coordination (e.g. uses arm or points with finger, but without consistent coordination with eye gaze)
- 2 = does not spontaneously attempt to point to express interest, but sometimes points when prompted and/or expresses interest, in other ways
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL

4.0 - 5.0

31. CONVENTIONAL/INSTRUMENTAL GESTURES

(INSTRUMENTAL GESTURES ARE SPONTANEOUS, CULTURALLY APPROPRIATE, DELIBERATE HAND OR ARM MOVEMENTS THAT CONVEY A MESSAGE BY THEIR FORM AS A SOCIAL SIGNAL. EXCLUDE PURELY EMOTIONAL SIGNALS (SUCH AS HANDS TO FACE IN EMBARRASSMENT OR SHRINKING WITH FEAR), DEMONSTRATIONS, AND TOUCHING OR PULLING SOMEONE TO GAIN THEIR ATTENTION OR SHOW THEM SOMETHING. ALSO EXCLUDE MANNERISMS SUCH AS TOUCHING THE FACE OR SCRATCHING. ALL GESTURES MUST BE/HAVE BEEN USED OVER A PERIOD OF 3 OR MORE MONTHS TO BE SCORED. OFTEN IT IS USEFUL IN HELPING PARENTS TO REMEMBER GESTURES TO FOCUS ON HOW THE SUBJECT DIRECTED THEIR ATTENTION OR USED GESTURE WHEN OTHER MODES OF COMMUNICATION WERE NOT CLEAR OR SUCCESSFUL)

Does _____ wave good bye? When does this happen? Does he/she ever use other common gestures, such as blowing a kiss, clapping for a job well done, putting a finger to his/her lips to mean 'be quiet' or shaking a finger for "bad"? Does he/she ever use gestures, other than pointing or holding arms up to be lifted, to let you know what he/she wants? Does he/she use gestures when he/she is trying to get you to help him/her or to get your attention (for example, beckoning to someone, or putting out a hand with his/her palm extended to ask that you give him/her something)? What about when _____ was 4 to 5 years old?

- 0 = appropriate and spontaneous use of a variety of conventional or instrumental gestures
- 1 = spontaneous use of conventional or instrumental gestures, but limited in range and/or contexts
- 2 = inconsistent spontaneous use, and/or use of elicited or well-rehearsed simple conventional or instrumental gestures only
- 3 = no use of conventional or instrumental gestures
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

Note: Subjects who have been taught signing and who use instrumental signs only in the teaching context should be scored '2'. If the taught signs are used spontaneously with some variety and creativity for instrumental purposes, however, code '0' or '1' as appropriate

32. NODDING

(THIS ITEM IS INTENDED TO DETERMINE IF THE SUBJECT CURRENTLY OR EVER USED THE CONVENTIONAL GESTURE OF HEAD NODDING TO COMMUNICATE 'YES'. NODDING SHOULD HAVE OCCURRED IN SEVERAL DIFFERENT SITUATIONS BUT MAY HAVE DECREASED IN FREQUENCY AS THE SUBJECT LEARNED TO SPEAK)

Does _____ nod his/her head to mean "yes"? What about when he/she was 4 to 5 years old? (GET DETAILS)

- 0 = yes, consistently; nods spontaneously
- 1 = sometimes
- 2 = no
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

33. HEAD SHAKING

(THIS ITEM IS INTENDED TO DETERMINE IF THE SUBJECT CURRENTLY OR EVER USED THE CONVENTIONAL GESTURE OF HEAD SHAKING TO COMMUNICATE 'NO'. HEAD SHAKING SHOULD HAVE OCCURRED IN SEVERAL DIFFERENT SITUATIONS, BUT MAY HAVE DECREASED IN FREQUENCY AS THE SUBJECT LEARNED TO SPEAK)

Does _____ shake his/her head to mean "no"? What about when he/she was 4 to 5 years old? (GET DETAILS)

- 0 = yes, consistently, shakes head spontaneously
- 1 = sometimes
- 2 = no
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

34. ATTENTION TO VOICE

FOR SUBJECTS AGED 5.0 YEARS OR OLDER, PROBE FOR THE 4.0 - 5.0 YEAR PERIOD

(THE FOCUS IS ON WHETHER THE SUBJECT SHOWS AN ALERTING RESPONSE WHEN SPOKEN TO AND NOT WHETHER THEY COMPLY WITH WHAT IS SAID. THE ALERTING RESPONSE SHOULD CONSIST OF AN AUTOMATIC LOOKING TO THE SOUND, TOGETHER WITH AN APPROPRIATE FACIAL EXPRESSION AND SHOULD OCCUR WITHOUT THE NEED FOR EXTRA STEPS SUCH AS CALLING THE SUBJECT'S NAME OR STANDING VERY CLOSE)

If you come into a room and start talking to _____, without calling his/her name what does he/she do? I mean when you say something pleasant rather than when you're trying to get him/her to do something. Does he/she look up and pay attention to you? How does he/she respond? How about to other people? Do you need to say his/her name or catch his/her eye first or could you just say something that he/she might not even be that interested in, such as "Oh no, it's raining," or "My goodness, what a lot of toys!" What did _____ he/she do when he/she was 4 to 5 years old? (GET DETAILS)

- 0 = usually looks up and pays attention when spoken to in a positive manner in contexts other than to do something that he/she may not want to do
- 1 = does not consistently appear to pay attention (e.g. might look up briefly, but little sustained attention), but sometimes responds to what was said or responds on occasion only to firm, loud voice
- 2 = usually does not look up or pay attention when spoken to, and does not respond to what is said. Or responds to his/her name only or when his/her attention is caught very deliberately
- 3 = rarely responds, although hearing normal
- 8 = N/A
- 9 = N/K or not asked

CURRENT
(UNDER AGE 5.0)

MOST ABNORMAL
4.0 - 5.0

34A. COMPREHENSION OF SIMPLE LANGUAGE

How much language do you think _____ understands if you don't gesture? What about when he/she can't tell from the situation what is going to happen? For example, can you send him/her into another room to get something like his/her shoes or blanket? What about your purse or a book? Could you ask him/her to put them somewhere, other than the usual place? Could he/she deliver a simple message? Could he/she follow an instruction with an "if" and a "then"? Does he/she understand if you "no" without gesturing or raising your voice? How about "yes" or "okay"? How about names of favourite foods or toys or people in you family? Do you think he/she understands 10 words? 50? What about at age 4 or 5?

- 0 = can usually perform an unexpected action with an unexpected object or could place an object, other than something to be used by self (such as boots or a toy), in an unexpected location in a different room ("put the keys on the kitchen table")
- 1 = can usually get an object, other than something for self or something highly contextualized, from another room ("Get the keys from the kitchen table"), but cannot usually carry out a new action on this object or put it in a 'new' place
- 2 = understands many words (more than 50), including "yes", names of familiar people, toys, or foods, but does not meet criteria for '0' or '1'
- 3 = understands fewer than 50 words, but some comprehension of "no", names of a few favourite objects, foods, or people, or words within familiar routines
- 4 = little or no comprehension of words, even in context

CURRENT

MOST ABNORMAL
4.0 - 5.0

35. CONCERNS ABOUT HEARING

(THIS ITEM IS TO ESTABLISH WHETHER ANYONE (PARENTS OR PROFESSIONALS) EXPRESSED CONCERN ABOUT POSSIBLE DEAFNESS BECAUSE OF FAILURE TO RESPOND TO SOUNDS, AND NOT BECAUSE TESTING WAS DONE AS A ROUTINE)

Has anyone ever thought _____ might be deaf or have a hearing problem? What made them say this? Is this still a concern? Does he/she respond to noises like a door bell or look up when an aeroplane flies overhead? What about to other noises that come from things he/she can't see?

- 0 = deafness not suspected
- 1 = parents certain child was not deaf, but deafness queried by others or tested automatically as part of assessment
- 2 = deafness queried by parents (and possibly professionals as well)
- 8 = N/A (e.g. actually deaf)
- 9 = N/K or not asked

EVER

36. UNDUE GENERAL SENSITIVITY TO NOISE

(THE FOCUS NEEDS TO BE THE PREDICTABLE GENERALLY INCREASED SENSITIVITY TO EVERYDAY SOUNDS SUCH AS HOUSEHOLD APPLIANCES OR TRAFFIC RATHER THAN A REACTION TO A SUDDEN, HARSH OR UNEXPECTED NOISE SUCH AS THUNDER OR A LOUDSPEAKER. DO NOT INCLUDE IDIOSYNCRATIC RESPONSES TO HIGHLY SPECIFIC SOUNDS; THESE ARE COVERED BY ITEM 78)

Has he/she ever seemed oversensitive to noise? Has he/she ever deliberately and regularly put his/her hands over his/her ears in response to ordinary sounds? Does he/she do this now? To what kinds of sounds? Have you ever had to adjust what you do because _____ was so upset by noises? (NOTE - TO SCORE, MORE THAN ONE OCCURRENCE IS REQUIRED, HOWEVER CLEARLY IT IS REMEMBERED)

- 0 = no
- 1 = slight only: somewhat sensitive to loud sounds such as the vacuum cleaner, motorbikes or other appliances
- 2 = yes: definite sensitivity to noises that are not distressing to most other people, the sensitivity being accompanied by a clear behavioral change (such as avoidance, hands over ears, or crying)
- 3 = yes, to the extent that subject's distress/disturbance in relation to certain noises interfered with family or household routines
- 9 = N/K or not asked

RECURRENT

EVER

37/41. LEVEL OF COMMUNICATIVE LANGUAGE BEFORE LOSS/LOSS OF LANGUAGE SKILLS AFTER ACQUISITION

(DEFINITION OF LOSS: NO ELICITED IMITATION OF WORDS, USAGE OF WORDS TO COMMUNICATE OR SPONTANEOUS VERBALIZATIONS, AFTER HAVING HAD AT LEAST ONE OF THESE SKILLS ON A DAILY BASIS FOR AT LEAST 3 MONTHS, WITH AT LEAST 5 DIFFERENT WORDS OTHER THAN "MAMA" AND "DADA" USED REGULARLY)

Were you ever concerned that _____ might have lost language skills during the first years of his/her life? Was there ever a time that he/she stopped speaking for some months after having learned to talk?

IF NO, CODE "8"

IF YES:

What happened? How old was he/she when this occurred? How much language did he/she have before losing it? What was _____ able to say or do before the change occurred? (PROBE RE: NUMBER OF MEANINGFUL WORDS, SPONTANEOUS USAGE, ATTEMPTS TO COMMUNICATE. NOTE DETAILS AND CODE LEVEL OF COMMUNICATIVE LANGUAGE BEFORE LOSS. CONTINUE TO PROBE TO ASCERTAIN NATURE AND TYPE OF LANGUAGE SKILLS LOST. CODE AS SEPARATE SCORES.) When did he/she begin to regain some speech?

37. LEVEL OF COMMUNICATIVE LANGUAGE BEFORE LOSS

- 0 = daily, spontaneous and meaningful speech used communicatively, with at least 5 different words used at some point before change (and any of the other skills listed below)
- 1 = occasional and/or fewer than 5 words used spontaneously and communicatively (alone or in combination with imitative abilities)
- 2 = produced speech or sounds upon request (may or may not have also spontaneously imitated)
- 3 = spontaneous imitations of vocalization (without ever having any completely spontaneous speech), with no elicited imitation or spontaneous communicative speech
- 8 = no change or loss
- 9 = N/K or not asked

EVER

LOSS OF LANGUAGE SKILLS AFTER ACQUISITION

(Score each of the following abilities the subject had and then lost for at least 3 months)

- 0 = no definite loss
- 1 = probable loss of specified skill
- 2 = definite loss of specified skill
- 8 = insufficient language to show change in quality
- 9 = N/K or not asked

38. SPONTANEOUS, MEANINGFUL COMMUNICATIVE SPEECH (AT SOME LEVEL)

EVER

39. WORDS USED SPONTANEOUSLY, BUT WITHOUT CLEAR COMMUNICATIVE INTENT

EVER

40. SIMPLE SYNTAX

EVER

41. ARTICULATION

EVER

SOCIAL DEVELOPMENT AND PLAY

Thank you. That has given me a clear idea about his/her speech; now can we talk about how he/she got on with people when he/she was little?

42. DIRECT GAZE

(DIRECT GAZE INCLUDES BOTH THE SUBJECT'S USE OF DIRECT EYE GAZE TO COMMUNICATE AND HIS/HER RESPONSE TO OTHERS' ATTEMPTS TO 'CATCH' HIS/HER EYE)

FOR SUBJECTS UNDER 4.0 YEARS:

Does _____ look at you directly in the face when doing things with you or talking with you? Can you catch his/her eye? Does he/she sometimes watch you as you walk into the room? Does he/she look back and forth to your face as other children would? What about with others?

FOR SUBJECTS OVER 4.0 YEARS:

When _____ was 4 to 5 years of age, did he look at you directly in the face when doing things with you or talking with you? Could you catch his/her eye? Did he/she sometimes watch you as you walked into the room? Would he/she have looked back and forth to your face as other children would? What about with others?

- 0 = normal reciprocal direct gaze used to communicate across a range of situations and people
- 1 = definite direct gaze, but only of brief duration or not consistent during social interactions
- 2 = uncertain/occasional direct gaze, or gaze rarely used during social interactions
- 3 = unusual or odd use of gaze
- 8 = N/A
- 9 = N/K or not asked

CURRENT

(UNDER
4.0)

MOST ABNORMAL

4.0 - 5.0

43. SOCIAL SMILING

(SOCIAL SMILING IS DEFINED AS SPONTANEOUS SMILING DIRECTED AT A VARIETY OF PEOPLE, INCLUDING SMILING BACK AT SOMEONE SMILING AT HIM/HER, SMILING DURING AN APPROACH, AND IN RESPONSE TO WHAT SOMEONE DOES OR SAYS TO HIM/HER)

When _____ is approaching someone to get them to do something or to talk to them, does he/she smile in greeting? What about when he/she sees you for the first time when you've been out? Or when meeting someone he/she knows? If he/she is not smiling first, what does he/she do if someone else smiles at him/her? Or say something nice to him/her? What about at age 4-5?

- 0 = regularly predictable social smiles in response to the smiles of a variety of people, besides parent/caregiver
- 1 = some evidence of reciprocal social smiling, but not sufficient to score '0'
- 2 = some evidence of smiling while looking at people, but generally not reciprocal. Code here if only smiles are to parent/caregiver or only when requested to do so or if occurs in odd situations or odd ways
- 3 = little or no smiling at people, though may smile at other things
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL

4.0 - 5.0

SOCIAL DEVELOPMENT AND PLAY continued

44. GREETING

(THE FOCUS OF THIS ITEM IS ON THE SUBJECT'S SOCIO-EMOTIONAL GREETING RESPONSE TO REUNION IN EVERYDAY SITUATIONS WITH SOMEONE WHOM HE/SHE KNOWS WELL)

Can we talk about this in a bit more detail? How does he/she greet you when you come back from being out? (For example, by going to the door or running to be picked up, or by smiling and saying, e.g. "mama" or "dada" or your name while looking at you?) Could you tell, even from across a room or the garden, that he/she was happy to see you or do you have to go right up to him/her or wait until he/she came right up to you? Does he/she greet relatives whom he/she knows when they come to visit? What about when he/she was 4 or 5? (CODE FOR EVIDENCE OF SOCIAL RESPONSE, NOT RESPONSE TO DOOR BELL OR SOUND OF CAR OR SIGHT OF SHOPPING)

- 0 = shows clearcut pleasure and full range of vocal and non-verbal socioemotional behaviors in greeting people of whom he/she is fond
- 1 = some spontaneous greeting, but rather reduced in frequency, consistency, flexibility or quality (not unusual)
- 2 = unusual spontaneous greeting or limited social response unless prompted or responds only to non-social aspects of arrival (e.g., child goes out and gets in car to depart when father gets home)
- 3 = little or no greeting
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

45. SHOWING AND DIRECTING ATTENTION

(THE PURPOSE OF THIS ITEM IS TO DETERMINE WHETHER, HOW AND WHY THE SUBJECT DIRECTS OTHERS' ATTENTION TO TOYS OR OBJECTS IN WHICH HE/SHE IS INTERESTED. THE FOCUS IS ON SPONTANEOUS DIRECTING OF ATTENTION PURELY TO SHARE INTEREST)

Does he/she ever show you things that interest him/her? For example, would he/she bring a new toy for you to see or call your attention to something he/she is playing with or making? What sorts of things are these? Does this ever happen for things that aren't part of his/her special interests and aren't things he/she needs you for? What about when _____ was 4 to 5?

- 0 = regular showing of objects by bringing things to parent/caregiver and directing his/her attention, with no manifest motive other than sharing
- 1 = possible showing as described above, but not sufficiently frequent or of purely communicative quality to meet criteria for '0'
- 2 = some bringing things to parent/caregiver and/or showing, but associated with preoccupations, food or need for help
- 3 = rare or no social approaches of this type
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

46. OFFERING TO SHARE

(THIS ITEM CONCERNS UNPROMPTED, NON-ROUTINE OFFERS TO SHARE A RANGE OF DIFFERENT OBJECTS WITH OTHER PEOPLE)

Does _____ ever offer to share things, that is, food or toys or favourite objects, with you? How about with other children? Does he/she do this on his/her own or do you need to suggest it? How often would this happen? What about when _____ was 4-5? (BE SURE TO DIFFERENTIATE CLEAR, SPONTANEOUS OFFERS TO SHARE FROM RESPONSES TO PROMPTING AND FROM RELINQUISHING THINGS IF ANOTHER CHILD TRIES TO TAKE THEM; PROBES FOR OLDER CHILDREN OR ADULTS COULD INCLUDE SHARING A PEN, PENCIL OR CRAYONS, NAPKINS, SPACE ON A BENCH OR COUCH, A BLANKET OR GETTING A CUP OF TEA OR A DRINK)

- 0 = frequent, spontaneous and varied offers to share different sorts of objects (e.g. food, toys, comforters) with other people CURRENT
- 1 = some spontaneous offers to share, but limited in number of contexts or frequency (must be more than food)
- 2 = will sometimes share if requested, but not spontaneously, or spontaneous sharing of food only
- 3 = no sharing MOST ABNORMAL
- 8 = N/A 4.0 - 5.0
- 9 = N/K or not asked

47. SEEKING TO SHARE HIS/HER ENJOYMENT WITH OTHERS

(THE AIM OF THIS ITEM IS TO DETERMINE WHETHER THE SUBJECT ATTEMPTS TO SHARE HIS/HER ENJOYMENT OF THINGS THAT GIVE HIM/HER PLEASURE WITH OTHERS, WITH NO OTHER APPARENT MOTIVE BUT SHARING)

What kinds of things might make him/her excited and happy? How does he/she show these feelings? Does _____ ever seem to want you to share in his/her enjoyment of something? Has he/she tried to share these feelings with you? For example, if he/she has built something or sees something he/she particularly likes, will he/she let you know about his/her excitement by smiling or talking or making noises? What about when _____ was 4-5 years old?

- 0 = frequent attempts across a variety of contexts to direct several other people's attention to things that he/she enjoys or has done well (must be more than one parent) CURRENT
- 1 = some attempts to share enjoyment, but limited in number or variety or spontaneity, or lacking clear quality of shared pleasure
- 2 = few or no attempts to share enjoyment
- 8 = N/A MOST ABNORMAL
- 9 = N/K or not asked 4.0 - 5.0

48. SHARING OTHERS' PLEASURE AND EXCITEMENT

(THE FOCUS OF THIS ITEM IS ON WHETHER AND HOW THE SUBJECT RESPONDS TO OTHERS' PLEASURE AND EXCITEMENT; THAT IS, WHETHER HE/SHE SHARES THE PLEASANT FEELINGS AND JOINS IN THE EXCITEMENT OR PLAYFULNESS)

Does he/she share other people's pleasure/excitement? Is there a 'playful' quality in the way he/she reacts to special events or occasions? For example, does he/she share the excitement when it's someone else's birthday? What if a favourite sports team won on television and everyone in your house was excited? Did _____ ever clap when you clapped or laugh when you laughed? What about when _____ was 4-5? (GET EXAMPLES. DO NOT CODE RESPONSE TO PHYSICAL CONTACT SUCH AS TICKLING)

- | | |
|---|--|
| <p>0 = shows pleasure, has 'playful' quality, able to share other people's excitement</p> <p>1 = takes part and excited; may imitate simple expressions of affect (e.g. laughing), but dubious or limited sharing of other people's feelings</p> <p>2 = behavior clearly lacks 'playful' quality of shared enjoyment; doesn't share other people's excitement</p> <p>3 = little or no awareness of others' pleasure and excitement</p> <p>8 = N/A</p> <p>9 = N/K or not asked</p> | <p>CURRENT</p> <p><input type="checkbox"/></p> <p>MOST ABNORMAL</p> <p>4.0 - 5.0</p> <p><input type="checkbox"/></p> |
|---|--|

49. OFFERS COMFORT

(OFFERING COMFORT IS DEFINED AS A SPONTANEOUS UNPROMPTED GESTURE, TOUCH, VOCALIZATION OR OFFER OF AN OBJECT (E.G. BLANKET) AND CHANGE IN FACIAL EXPRESSION DIRECTED TO SOMEONE WHO IS SAD, ILL OR HURT IN AN ATTEMPT TO HELP HIM/HER FEEL BETTER)

Does _____ ever try to comfort you if you are sad, hurt or ill? What does he/she do if you are crying or if you have hurt yourself? Would his/her facial expression change as he/she does this? What about with his/her brother or sister? Does he/she show comfort in more than one situation? Do people have to show that they are upset in an exaggerated fashion to elicit comfort? What about when he/she was 4-5? (CODE ONLY IF OFFERS OF COMFORT ARE SPONTANEOUSLY INITIATED BY THE SUBJECT)

- | | |
|--|--|
| <p>0 = flexibly and spontaneously offers comfort in a range of circumstances and several different ways, for example, by gesture or touching or vocalization or offers of objects (e.g. blanket). Must include change in facial expression</p> <p>1 = partial response (e.g. stands nearby and looks concerned) or indirect physical approach (e.g. comes to sit in lap, but with no clear attempt to comfort) or, <u>only</u> offers comfort in response to exaggerated expression (e.g. to pretend crying) or in one routine situation (e.g. baby sister when hungry)</p> <p>2 = rarely offers comfort or only in odd ways</p> <p>3 = never offered comfort to others</p> <p>8 = N/A</p> <p>9 = N/K or not asked</p> | <p>CURRENT</p> <p><input type="checkbox"/></p> <p>MOST ABNORMAL</p> <p>4.0 - 5.0</p> <p><input type="checkbox"/></p> |
|--|--|

SOCIAL DEVELOPMENT AND PLAY continued

50. COMING FOR COMFORT

(THE FOCUS HERE IS ON WHETHER AND, IF SO, HOW THE SUBJECT SEEKS COMFORT IF HE/SHE IS HURT WITH A MINOR INJURY. THE EMPHASIS IS ON WHAT THE SUBJECT DOES ON HIS/HER OWN, BEFORE ANYONE MAY BE AWARE HE/SHE IS HURT)

Has he/she ever come to you or your husband/wife (or main caregiver) for comfort if he/she was hurt? Or do you have to go to him/her? Has he/she ever hurt himself/herself and you didn't know because he/she didn't cry or come to get you? Is he/she comforted if you pick him/her up, give him/her a kiss or offer reassurance in other ways? (GET DETAILS. SCORE ONLY IF APPROACH FOR COMFORT IS SPONTANEOUS, NOT ELICITED) How about when he/she was 4 or 5?

- 0 = makes affectionate use of contact with parents/caregiver for comfort
- 1 = somewhat reduced or slightly odd seeking of parents/caregiver for comfort or reassurance
- 2 = little or inappropriate use of parents as source of comfort. May respond to parents' comforting, but without seeking it
- 3 = no use of physical contact or proximity with parents/caregiver for comfort
- 8 = N/A
- 9 = N/K or not asked or ten years or over

CURRENT
(UNDER AGE 10
YEARS)

MOST ABNORMAL
4.0 - 5.0

51. QUALITY OF SOCIAL OVERTURES

(THE FOCUS OF THIS ITEM IS ON THE QUALITY OF SOCIAL INTENTIONALITY WHEN SEEKING HELP, NOT ON THE NUMBER OF CONTEXTS IN WHICH SUCH APPROACHES OCCUR. CODE ONLY IF SUBJECT CONSISTENTLY, DURING HIGHLY MOTIVATED APPROACHES (SUCH AS ASKING FOR HELP) MAKES SOME SORT OF VOCALIZATION THAT IS INTEGRATED WITH HIS/HER OTHER BEHAVIOURS INCLUDING EYE GAZE, WITH HIS/HER ATTENTION DIRECTED TO THE OBJECT AND THE OTHER PERSON. CODE TYPICAL MOTIVATED OVERTURES, NOT BEST)

When he/she wants something or wants help, how does he/she try to get your attention? Does he/she point, give objects to you, or come and get you when he/she needs help? Does he/she look at the object or you? Does he/she ever use gestures or movements with sounds or words to get your attention? If you didn't understand at first, what would _____ do? Does he/she look at you and then talk or make a sound? What about when he/she was 4 to 5? (GET EXAMPLES) Does he/she show interest in other people or any other activities? How does he/she show his/her interest, or get other people's attention? How often would he/she do this? (CODE ACCORDING TO MAJORITY OF OVERTURES)

- 0 = consistently uses coordinated eye gaze with accompanying vocalization in typical situations where motivated to communicate
- 1 = may use eye gaze or vocalization, but poorly or rarely integrated
- 2 = rarely shows well coordinated focused social intentionality involving eye gaze and/or vocalization, or carried out in odd ways
- 3 = no coordination of eye gaze and vocalization
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

52. RANGE OF FACIAL EXPRESSION USED TO COMMUNICATE

(THE FOCUS HERE IS ON FACIAL EXPRESSIONS USED TO COMMUNICATE, NOT JUST THOSE ASSOCIATED WITH THE EXPERIENCE OF EMOTIONS. A NORMAL RANGE OF EMOTIONS, EVEN IN A VERY YOUNG CHILD, WOULD BE EXPECTED TO INCLUDE SEVERAL MORE SUBTLE FACIAL EXPRESSIONS USED COMMUNICATIVELY, INCLUDING SURPRISE, GUILT, DISGUST, INTEREST, AMUSEMENT AND EMBARRASSMENT, AS WELL AS JOY, ANGER, FEAR AND PAIN)

Does _____ show a normal range of facial expression? For example, does he/she frown or pout or look embarrassed as well as laugh or cry? Can he/she look guilty..... or surprised..... or amused? Can you tell by his/her face when he/she is afraid or disgusted? Does he/she have the same range of facial expressions as other children? What about when he/she was 4 to 5? (GET EXAMPLES)

- | | | |
|-----|--|--------------------------|
| 0 = | full range of facial expression | CURRENT |
| 1 = | somewhat limited facial expression; may be rather stilted, exaggerated, in manner | <input type="checkbox"/> |
| 2 = | markedly limited range of facial expressions or tendency to have just one facial expression (e.g. happy) for all circumstances | |
| 3 = | facial expression shows little or no indication of emotion of any kind | MOST ABNORMAL |
| 8 = | N/A | 4.0 - 5.0 |
| 9 = | N/K or not asked | <input type="checkbox"/> |

53. INAPPROPRIATE FACIAL EXPRESSION

(INAPPROPRIATE FACIAL EXPRESSIONS ARE THOSE THAT INDICATE EMOTIONS INCONGRUENT WITH THE SITUATION, SUCH AS LAUGHING WHEN SOMEONE IS UPSET OR HURT OR LAUGHING OR CRYING FOR NO DISCERNABLE REASON)

Does his/her facial expression usually seem appropriate to the particular situation as far as you can tell? Does he/she ever laugh or smile in situations that do not seem funny to most people or when you do not understand what it is he/she finds amusing? Did this ever occur in the past? (NOTE EXAMPLES)

- | | | |
|-----|--|--------------------------|
| 0 = | facial expressions almost always appropriate to mood, situation and context | CURRENT |
| 1 = | some slight or occasional inappropriateness or oddness | <input type="checkbox"/> |
| 2 = | expressions obviously inappropriate in several different situations (SPECIFY) | |
| 8 = | almost no variation in facial expression, appropriate or inappropriate, as in coding of '3' in item 52 | EVER |
| 9 = | N/K or not asked | <input type="checkbox"/> |

SOCIAL DEVELOPMENT AND PLAY continued

54. ARMS UP TO BE LIFTED

(NOTE: FOR CHILDREN UNDER 4.0 YEARS, ONLY THE "CURRENT" CODING IS APPLICABLE; FOR THOSE AGED 4.0 YEARS OR OLDER ONLY THE "MOST ABNORMAL 4.0 - 5.0 YEARS" IS APPLICABLE. THE FOCUS OF THE ITEM IS ON WHETHER THE SUBJECT AS A YOUNG CHILD SPONTANEOUSLY INDICATED A WISH TO BE PICKED UP BY RAISING HIS/HER ARMS AS AN ANTICIPATORY GESTURE)

FOR SUBJECTS UNDER 4.0 YEARS

Does _____ put up his/her arms to be lifted? Does he/she do this spontaneously or only when you put your arms out?

FOR SUBJECTS OVER 4.0 YEARS

When _____ was 4 to 5 years of age, did he/she put up his/her arms to be lifted? Did he/she do this spontaneously or only when you put your arms out? (CODE '0' FOR SUBJECTS WHO SHOWED NORMAL PUTTING UP OF ARMS TO BE LIFTED WHEN UNDER 4.0 YEARS, BUT WHERE THIS DIMINISHED IN A NORMAL WAY WITH INCREASING AGE SO THAT LITTLE OR NO PUTTING UP OF ARMS BETWEEN 4.0 AND 5.0 YEARS)

- 0 = normal gestures to be lifted
- 1 = occasional use of anticipatory gestures to be lifted
- 2 = responds to parents' indication of intention to pick up by extending arms, but does not anticipate spontaneously
- 3 = little or no appropriate social anticipatory gestures
- 8 = N/A
- 9 = N/K or not asked

CURRENT
(UNDER 4.0)

MOST ABNORMAL
4.0 - 5.0

55. AFFECTION

(AFFECTION IS DEFINED AS THE SPONTANEOUS POSITIVE EXPRESSION OF LOVE OR CARING DIRECTED TO A SPECIFIC PERSON AND SHOWN THROUGH TOUCHING, SEEKING PROXIMITY, OFFERS OF GIFTS OR VOCALIZATION ACCOMPANIED BY AN APPROPRIATE FACIAL EXPRESSION)

How affectionate is he/she? In what situation is _____ affectionate? How does he/she show it? (GET EXAMPLES) Does he/she come up to give you a hug or does he/she show affection in some other way? What about when he/she was 4 or 5? (DIFFERENTIATE BETWEEN SPONTANEOUS AFFECTION AND ELICITED)

Note: All ratings should be as judged by interviewer on basis of descriptions obtained and not on informant's inference

- 0 = normal range of spontaneous affectionate behaviour to several different people
- 1 = some spontaneous affection, but with questionable reciprocity and limited in context or person (only parents), i.e. less demonstrative than normal
- 2 = little or no spontaneous affection, but some response
- 3 = aloof, 'cold'; no affection with caregiver, even as a response
- 7 = indiscriminately affectionate to familiar and unfamiliar people
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

56. SOCIAL DISINHIBITION (SUBJECTS AGED 4.0 OR OLDER)

(SOCIAL DISINHIBITION REFERS TO BEHAVIOR THAT IS NOT APPROPRIATELY MODULATED ACCORDING TO THE SOCIAL EXPECTATIONS IN THE CHILD'S/SUBJECT'S SOCIO-CULTURAL ENVIRONMENT. SUCH DISINHIBITION MAY ARISE FROM A VARIETY OF CAUSES, BUT THE AIM HERE IS TO ASK ABOUT THAT WHICH ARISES FROM A LACK OF AWARENESS OF SOCIAL CUES. CODE INAPPROPRIATE QUESTIONS OR STATEMENTS IN QUESTION 22, NOT HERE)

As they grow up, children ordinarily learn that they need to behave differently in different social situations. For example, they are usually more shy or reserved with people that they do not know very well or in certain situations such as church. Does _____ vary in his/her behavior according to whom he/she is with or where he/she is? Is he/she ever cheeky or rude or even inappropriately friendly to strangers? Does he/she ever ask impertinent or personal questions of people he/she has just met? Does he/she seem aware of social cues or social rules? Is he/she more socially naive than other children/people (that is, unable to understand what one should say or do in particular social situations)? Does he/she ever approach or touch strangers inappropriately? How does he/she do if you visit a friend's home? (GET EXAMPLES) Was this ever a problem (after _____ was 4), in a way that it would not have been for other children that age?

Note: All ratings should be as judged by interviewer on basis of descriptions obtained and not on informant's inference

- 0 = normal social inhibition
- 1 = occasional cheekiness or disinhibition more than others at same developmental level, but not to the extent of embarrassment. Somewhat socially naive or imperceptive for developmental level
- 2 = definite lack of appreciation of social cues, contexts or requirements. Definitely lacks normal social inhibitions and sometimes behaves in socially embarrassing ways. Fails to modulate behavior according to social context
- 3 = marked social disinhibition. Appears unaware of social cues and social requirements so that behavior frequently embarrassing or inappropriate
- 8 = N/A
- 9 = N/K or not asked

CURRENT
(AGE 4.0 AND ABOVE)

MOST ABNORMAL
4.0-5.0

SOCIAL DEVELOPMENT AND PLAY continued

57. APPROPRIATENESS OF SOCIAL RESPONSES

(THE FOCUS OF THIS ITEM IS ON HOW THE SUBJECT RESPONDS WHEN ADULTS, OTHER THAN PARENTS ATTEMPT TO INTERACT WITH HIM/HER IN EVERYDAY, BUT NON-ROUTINE SITUATIONS)

Now can we turn to how _____ responds to what other people say or do? Does he/she consistently respond to the approaches of others in familiar situations? How does he/she respond if a friend of yours whom he/she doesn't know well approaches and speaks to him/her? What about someone he/she really likes? How does he/she respond if someone unfamiliar (such as at church or in a shop) appropriately talks to him/her or tries to attract his/her attention? Does he/she look directly at him/her? Does he/she smile or show pleasure? Would he/she show other reactions such as interest or tentativeness? (GET EXAMPLES. PROBE TO DETERMINE CONSISTENCY AND CIRCUMSTANCES. IF THE CHILD SOUNDS SHY, SEEK FURTHER EXAMPLES OF PEOPLE WHO ARE MORE FAMILIAR) What about when he/she was 4 to 5 years of age?

- 0 = appropriate response to overtures by familiar and unfamiliar adults
- 1 = some clear positive responses and interactions, but not consistent
- 2 = responds to parents/caregiver and others in familiar settings but responses are stereotyped and/or inappropriate or very limited
- 3 = little or no interest in, or response to people, except parents/caregiver or very familiar significant others
- 5 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

58. SOCIAL ANXIETY/AVOIDANCE

(THE FOCUS IS ON MARKED ANXIETY IN ORDINARY SOCIAL SITUATIONS, OF A DEGREE THAT IS ASSOCIATED WITH AVOIDANCE BEHAVIOR IN THE SITUATION (SUCH AS LOOKING DOWN))

Does _____ seem markedly anxious when meeting people he/she doesn't know very well? For example, would he/she tend to look down or avoid meeting their gaze? IF YES: How does he/she show it? Does it vary according to whom he/she is with? Does he/she respond appropriately to the other person apart from avoiding meeting their gaze? In what way? What about when he/she was 4 to 5 years of age?

- 0 = appropriate social use of mutual gaze with social selectivity and level of anxiety within limits expected for situation and age
- 1 = selective avoidance of mutual gaze or other indicators of social anxiety with some social engagement/responsivity, ie falling short of criteria for '2'
- 2 = definite avoidance of mutual gaze with unfamiliar people and/or in unfamiliar social situations. Must be associated with some other indications of anxiety regarding social involvement (such as lowering of head, twisting of hands etc). Occurs in conjunction with some appropriate social engagement and responsivity, and selectivity in this behavior so that less anxious in familiar social situation or with familiar people
- 7 = lack, or abnormal quality of, mutual social gaze without clear evidence of anxiety and/or without some appropriate social engagement and responsivity OR largely oblivious to the social situation
- 6 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

SOCIAL DEVELOPMENT AND PLAY continued

(NOTE: ITEMS 59 AND 60 FOR CHILDREN UNDER 4.0 YEARS, ONLY THE "CURRENT" CODING IS APPLICABLE; FOR THOSE AGED 4.0 YEARS OR OLDER, ONLY THE "MOST ABNORMAL 4.0 - 5.0 YEARS" IS APPLICABLE. CODE '0' FOR OLDER SUBJECTS WHO SHOWED NORMAL USE OF PARENT(S)/CAREGIVERS AS SECURE BASE AND/OR DEFINITE EXPRESSION OF DISTRESS ON SEPARATION WHEN UNDER 4.0 YEARS BUT WHERE THIS HAS DIMINISHED IN A NORMAL WAY WITH INCREASING AGE SO THAT LITTLE EVIDENCE BETWEEN 4 AND 5 YEARS)

59. SECURE BASE

(THE PURPOSE OF THIS ITEM IS TO DETERMINE IF THE SUBJECT USES CAREGIVERS AS A 'BASE' FROM WHICH HE/SHE CAN EXPLORE. TWO ASPECTS OF THE SUBJECT'S BEHAVIOR ARE IMPORTANT: 1) THE SUBJECT'S AWARENESS OF THE CAREGIVER'S LOCATION AND ATTENTION TO IT, AS EVIDENCED BY SEEKING PROXIMITY AND CHECKING BACK, AND 2) THE SUBJECT'S ABILITY TO THEN GO ON TO INTERACT OR EXPLORE IN A NEW SITUATION)

FOR SUBJECTS UNDER 4.0 YEARS:

When _____ is playing, does he/she ever 'check back' to see where you are when he/she is playing in another room - as if to make sure that everything is alright? What about if you're together in a park or playground? Does he/she ever come back to you from time to time to make sure he/she knows where you are? Do you ever worry about his/her wandering off? How does he/she react if a stranger comes right up and tries to talk to him?

FOR SUBJECTS OVER 4.0 YEARS:

When _____ was 4 to 5 years old, did he/she tend to 'check back' to see where you were when he/she was playing in another room - as if to make sure that everything was alright? What about if you were together in a park or playground? Did he/she come back to you from time to time to make sure he/she knew where you were? Did you ever worry about his/her wandering off? Did he/she ever 'check back' when younger than 4?

- 0 = uses parent(s)/caregiver as secure base, indicated by seeking proximity when approached by stranger and checking in when in a new situation, but, once settled, being able to interact or explore
- 1 = occasionally uses parent(s)/caregiver as a secure base, but with less frequency, spontaneity or more narrow range of contexts than '0'
- 2 = seek parent(s)/caregiver primarily to avoid other social contact or out of fear; no use of parental/caregiver's proximity to explore or interact
- 3 = no seeking of parent(s)/caregiver in new situations
- 7 = excessively clingy across a variety of situations
- 8 = N/A
- 9 = N/K or not asked

CURRENT
(UNDER 4.0)

MOST ABNORMAL
4.0 - 5.0

60. SEPARATION ANXIETY

(SEPARATION ANXIETY REFERS TO THE OVERT EXPRESSION OF DISTRESS UPON SEPARATION AND PLEASURE UPON REUNION TYPICALLY SEEN IN INFANTS AND TODDLERS. IF THE CHILD HAD A CLEAR PERIOD OF SEPARATION ANXIETY OVER SEVERAL MONTHS WHEN HE/SHE WAS YOUNGER, USE THE LOWEST CODE APPLICABLE DURING THAT TIME, EVEN FOR MOST ABNORMAL 4.0 - 5.0. THIS RATING REQUIRES DISTRESS OVER SEPARATION FROM PARENT/MAIN CAREGIVER AND NOT JUST DISTRESS OVER CHANGE OF SITUATION)

FOR SUBJECTS UNDER 4.0 YEARS:

Has _____ had a clinging, mummyish phase? I mean, when he/she didn't seem to want to leave you. (IF YES) When was that? Did he/she mind if you went out, leaving him/her with a relative or babysitter? What did he/she do? What about if you just went into another room? Was there ever a time when he/she would get upset about this? How old was he/she? (NB. IF NORMAL SEPARATION ANXIETY SHOWS BEFORE AGE 4 YEARS, CODE '0' FOR MOST ABNORMAL 4.0 TO 5.0)

FOR SUBJECTS OVER 4.0 YEARS:

When _____ was 4 to 5 years or before, did he/she go through a clinging, mummyish phase? (PROBE AS ABOVE, BUT FOR THE 4.0 - 5.0 YEAR PERIOD)

(N.B. IF NORMAL SEPARATION ANXIETY SHOWS BEFORE AGE 4 YEARS; CODE '0' FOR MOST ABNORMAL 4.0 TO 5.0)

- 0 = definite expression of appropriate distress on separation
- 1 = behavior indicates some awareness of separation, but not of normal intensity or quality
- 2 = little or no apparent reaction to separation
- 7 = no evidence of discrimination between parents/caregiver and other adults
- 8 = N/A
- 9 = N/K or not asked

CURRENT
(UNDER 4.0)

MOST ABNORMAL
4.0 - 5.0

NOW I'D LIKE TO TALK ABOUT THE WAY _____ PLAYS AND THE KINDS OF THINGS HE/SHE IS INTERESTED IN.

FAVOURITE ACTIVITIES/TOYS

If _____ could choose anything he/she likes to do, what are his/her favourite activities? How about favourite toys or any other kinds of objects? (CODE ACTIVITIES AND TOYS SEPARATELY, AND RECORD AS MANY AS POSSIBLE)

FAVOURITE ACTIVITIES

FAVOURITE TOYS/OBJECTS

61. INITIATION OF APPROPRIATE ACTIVITIES

(THIS ITEM CONCERNS HOW THE SUBJECT SPONTANEOUSLY KEEPS HIMSELF/HERSELF OCCUPIED AND INVOLVED IN A RANGE OF NON-ODD AND NON-REPETITIVE ACTIVITIES WHEN NOT SUPERVISED OR DIRECTED)

How good is _____ at organizing his/her own play or activities without your help? That is, does he/she find things to do without your directing him/her? What kind of things does he/she do if left to his/her own devices? (GET EXAMPLES) What about when he/she was 4 to 5 years old?

- 0 = able to spontaneously take up a range of appropriate activities, which may include pretend play if age appropriate, without prompting
- 1 = spontaneously initiates a limited range of appropriate activities
- 2 = engages in passive, but appropriate, activity, such as TV or radio
- 3 = does nothing or engages in repetitive activity or motor stereotypes only
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL

4.0 - 5.0

SOCIAL DEVELOPMENT AND PLAY continued

62. CURIOSITY

(CURIOSITY REFERS TO THE SUBJECT'S INTEREST IN INVESTIGATING OR FINDING OUT ABOUT THINGS IN HIS/HER ENVIRONMENT. THIS INTEREST SHOULD GO BEYOND SIMPLE SENSORY EXPLORATION TO WANTING MORE INFORMATION ABOUT HOW SOMETHING WORKS OR WHAT IT DOES ETC)

Is _____ interested in things around him/her? What happens when you show _____ a new toy or book? How does he/she react? Is he/she usually interested in it right away or does it take him/her a while (or never)? What do you have to do to get him/her interested in it? Is _____ interested in how things work? What sorts of things capture his/her interest? What about when _____ was 4 to 5? (GET EXAMPLES. PROBE IN TERMS OF SUBJECT'S DEVELOPMENTAL LEVEL, NOT CHRONOLOGICAL AGE)

- 0 = usually attends to new toys or objects when first presented with them; appears interested in and inquisitive about his/her environment CURRENT
- 1 = some curiosity or interest in new things, but limited in frequency or context
- 2 = little curiosity or interest in new things unless strongly encouraged or accompanied by demonstrations, though may have abnormal preoccupations with particular features MOST ABNORMAL
4.0 - 5.0
- 3 = little or no spontaneous exploration of environment
- 8 = N/A
- 9 = N/K or not asked

63. IMAGINATIVE PLAY

(FOR SUBJECTS AGED 10.0 YEARS OR OLDER, PROBE FOR THE 4.0 - 5.0 YEAR PERIOD)

(IMAGINATION IS DEFINED AS PRETEND PLAY THAT INVOLVES THE FORMATION OF MENTAL IMAGES OF THINGS NOT PRESENT. THE FOCUS HERE IS ON THE CHILD'S CREATIVE AND VARIED USE OF ACTIONS OR OBJECTS IN PLAY TO REPRESENT HIS/HER OWN IDEAS)

(As a child) does he/she play any pretend games? Does he/she play with toy tea sets or dolls or action figures or cars? (GET EXAMPLES) Does she/he drink the tea/push the car/kiss the stuffed animal? Has he/she ever given the doll a drink or the action figure a ride in the car? Has he/she ever used the doll/action figure as the initiator --- so that the doll pours and serves the tea or the action figure walks to the car and gets in it? Does he/she ever 'talk' to his/her dolls or animals? Does he/she ever make them talk or make noises? Does this type of play vary from day to day? Has he/she ever made up a sort of story or sequence (e.g. with the toy cars racing each other, being parked in a garage or going to Granny's house)? What about at age 4-5? (GET EXAMPLES)

- 0 = variety of pretend play, including use of dolls/animals/toys as self-initiating agents CURRENT
- 1 = some pretend play including actions directed to dolls or cars etc., but limited in variety and/or frequency (UNDER
10.0)
- 2 = occasional, spontaneous pretend actions and/or highly repetitive (that may be frequent) pretend play and/or only play that has been taught by others MOST ABNORMAL
4.0 - 5.0
- 3 = no pretend play
- 8 = N/A
- 9 = N/K or not asked

SOCIAL DEVELOPMENT AND PLAY continued

64. IMAGINATIVE PLAY WITH PEERS

(FOR SUBJECTS AGED 10.0 YEARS OR OLDER, PROBE FOR THE 4.0 - 5.0 YEAR PERIOD)

(THE FOCUS HERE IS ON THE SPONTANEOUS, CREATIVE SHARING OF IMAGINATION AMONG CHILDREN, BOTH OF THE SUBJECT'S IDEAS AND THOSE OF OTHER CHILDREN. THE LEVEL OF IMAGINATION MAY BE SIMPLE SO LONG AS IT IS SOCIALLY INTERACTIVE, SPONTANEOUS AND VARIED. IF THE SUBJECT'S ONLY PLAY IS WITH SIBLINGS, BE PARTICULARLY CAREFUL TO DIFFERENTIATE WELL-PRACTISED ROUTINES FROM SPONTANEOUS, FLEXIBLE PLAY AND TO DIFFERENTIATE PLAY THAT IS HIGHLY STRUCTURED FOR THE SUBJECT BY THE SIBLING FROM PLAY IN WHICH HE/SHE SHOWS SOME INITIATIVE)

Does _____ ever play imaginative games with someone else? Do they seem to understand what each other is pretending? How can you tell? Can you give me an example? Does _____ ever take the lead in this play? Or does he/she mostly follow the other person's ideas? What about at age 4 to 5?

- 0 - imaginative, cooperative play with other children, where the subject both takes the lead and follows another child in spontaneous, pretend activities
- 1 - some participation in pretend play with another child, but not truly reciprocal and/or pretending is very limited in variety
- 2 - some play with other children, but little or no pretending
- 3 - no play with other children or no pretend play even on own
- 8 - N/A
- 9 - N/K or not asked

CURRENT
(UNDER
10.0)

MOST ABNORMAL
4.0 - 5.0

65. IMITATIVE SOCIAL PLAY

(NOTE: ITEMS 65 - 68 INCLUSIVE, FOR CHILDREN UNDER 4.0 YEARS, ONLY THE "CURRENT" CODING IS APPLICABLE; FOR THOSE AGED 10.0 YEARS OR OLDER, ONLY THE "MOST ABNORMAL 4.0 - 5.0" YEARS IS APPLICABLE. THE FOCUS OF THIS ITEM IS ON THE CHILD'S RECIPROCAL PARTICIPATION AS BOTH LEADER AND FOLLOWER IN EARLY SOCIAL GAMES THAT REQUIRE IMITATION AND COORDINATION OF SIMPLE ACTIONS. DO NOT COUNT BALL GAMES)

As a young child, did _____ enter into the spirit of social games such as Going Round the Mulberry Bush or Ring Around the Rosie? That is, did he/she spontaneously join in and try to copy the various actions? What about teasing games such as the "I'm going to get you!" sort, or having your fingers walking towards him/her? What about with other familiar adults? How did he/she join in the to-and-fro? Can he/she play peek-a-boo? How do you play it? How about pat-a-cake? Simon Says? What about at age 4 to 5?

- 0 - normal social play, including clear evidence that the child initiates and responds to simple infant social games and can take both parts
- 1 - some reciprocal to-and-fro social play, but limited in amount, duration or contexts in which shown (e.g. only plays peek-a-boo or pat-a-cake with parents/caregiver)
- 2 - little reciprocal to-and-fro social play (e.g. plays peek-a-boo or pat-a-cake in a limited way only, but not reciprocal)
- 3 - no evidence of to-and-fro social play
- 8 - N/A
- 9 - N/K or not asked

CURRENT
(UNDER
10.0)

MOST ABNORMAL
4.0 - 5.0

SOCIAL DEVELOPMENT AND PLAY continued

66. INTEREST IN CHILDREN

(FOR SUBJECTS AGED 10.0 YEARS OR OLDER, PROBE FOR THE 4.0 - 5.0 YEAR PERIOD)

(THE FOCUS HERE IS ON THE SUBJECT'S INTEREST IN WATCHING AND INTERACTING WITH OTHER CHILDREN OF THE SAME AGE)

What does _____ think about other children of approximately the same age whom he/she does not know? Is he/she interested in them? What does he/she do when another child comes to your house or he/she sees a child in another familiar situation (e.g. church, playgroup)? What about when _____ was 4 to 5? (CODE IN RELATION TO CHILDREN OF APPROXIMATELY THE SAME AGE WHOM THE SUBJECT DOES NOT KNOW. DO NOT CODE INTEREST IN BABIES HERE)

- | | | |
|-----|--|----------------------------|
| 0 = | often watches other children. Sometimes makes a clear effort to approach them or get their attention | CURRENT (UNDER 10.0) |
| 1 = | usually watches other children or indicates interest in them to parent/caregiver in some way (e.g. by pointing, vocalizing or trying to imitate what they are doing, but no attempt to seek them out) or approaches other children without trying to get their attention | <input type="checkbox"/> |
| 2 = | occasionally watches other children, but almost never tries to approach them /or to direct parent's/caregiver's attention to them or to copy them | MOST ABNORMAL 4.0 - 5.0 |
| 3 = | shows no, or almost no, interest in other children | <input type="checkbox"/> |
| 8 = | N/A | |
| 9 = | N/K or not asked | |

67. RESPONSE TO APPROACHES OF OTHER CHILDREN

(FOR SUBJECTS AGED 10.0 YEARS OR OLDER, PROBE FOR THE 4.0 - 5.0 YEAR PERIOD)

(THE AIM HERE IS TO DETERMINE HOW THE SUBJECT RESPONDS WHEN OTHER CHILDREN APPROACH HIM/HER AND WHETHER THIS RESPONSE CONSTITUTES AN EFFORT TO KEEP AN INTERACTION GOING)

What about if another child approaches him/her? Does he/she behave differently with _____ (SIBLING) or with a child he/she has seen many times before? Does the other child's age make a difference? Does he/she ever actively avoid other children? What about at age 4 to 5? (CODE IN RELATION TO PEERS AND OLDER CHILDREN; DO NOT INCLUDE RESPONSES TO BABIES)

- | | | |
|-----|---|----------------------------|
| 0 = | generally responsive to other children's approaches, although may be hesitant initially if other children are too rough or intrusive. Sometimes makes a clear effort to keep an interaction going with a child, other than a sibling, by gesturing, vocalizing, offering and object etc | CURRENT (UNDER 10.0) |
| 1 = | sometimes responsive to other children's approaches, but response is limited, somewhat unpredictable, or only to a sibling or a very familiar child | <input type="checkbox"/> |
| 2 = | rarely or never responds to the approach of even a familiar child (although may show interest in nonapproaching children or babies) | MOST ABNORMAL 4.0 - 5.0 |
| 3 = | consistently and persistently avoids approaches of other children | <input type="checkbox"/> |
| 8 = | N/A | |
| 9 = | N/K or not asked | |

SOCIAL DEVELOPMENT AND PLAY continued

68. GROUP PLAY WITH PEERS

DON'T CODE FOR CHILDREN
L 4 YEARS OF AGE

(FOR SUBJECTS AGED 10.0 YEARS OR OLDER, PROBE FOR THE 4.0 - 5.0 YEAR PERIOD)
(THE FOCUS IS ON THE SUBJECT'S PARTICIPATION IN GROUPS OF OTHER CHILDREN IN SPONTANEOUS GAMES OR ACTIVITIES. CO-OPERATION MUST INVOLVE THE SUBJECT ATTENDING TO HIS/HER PEERS AND MODIFYING HIS/HER BEHAVIOR IN A WAY THAT CLEARLY DEMONSTRATES SPONTANEOUS, FLEXIBLE, INTERACTIVE PLAY. CHASING AND BALL GAMES SHOULD BE INCLUDED ONLY IF SPONTANEOUS, FLEXIBLE AND INTERACTIVE. NOTE PREVIOUS COMMENTS REGARDING CARE IN INTERPRETING PLAY WITH SIBLINGS)

How does _____ play with other children/subjects of his/her own age when there are more than two together? What is their play like? Is _____ different with children or others outside your immediate family? Does _____ play cooperatively in games that need some form of joining in - such as musical games or hide and seek or ball games? (GIVE EXAMPLES AS APPROPRIATE FOR MENTAL AGE LEVEL). Would he/she initiate such games? Or actively seek to join in? Can he/she take different parts in these games (like being chased or doing the chasing or hiding and looking for the other person)? What about when _____ was 4 to 5?

- 0 = actively seeks and plays cooperatively in several different groups (3 or more participants) in a variety of activities or situations CURRENT (UNDER 10.0)
- 1 = some cooperative play, but of insufficient initiative, flexibility, frequency and/or variety to score '0'
- 2 = enjoys 'parallel' active play (such as jumping in turn on a trampoline or falling down together during Ring-Around-the-Rose), but little or no cooperative play MOST ABNORMAL 4.0 - 5.0
- 3 = no play that involves participation in groups of other children, though may chase or play catch
- 8 = N/A
- 9 = N/K or not asked

69. FRIENDSHIPS (SUBJECTS AGED 5.0 YEARS AND OLDER)

(FOR THE PURPOSE OF THIS ITEM, FRIENDSHIP IS DEFINED AS A SELECTIVE, RECIPROCAL RELATIONSHIP BETWEEN TWO PERSONS OF APPROXIMATELY THE SAME AGE WHO SEEK EACH OTHER'S COMPANY AND SHARE ACTIVITIES AND INTERESTS)

Does he/she have any particular friends or a best friend? In what way does he/she show that they are his/her friends? Do you know the names of any of his/her friends? Does he/she see any of them outside of school, like around the neighbourhood or in another social setting (e.g. clubs)? Does he/she ever go out with them such as to the cinema/theatre/concerts? Do they share interests? (PROBE AS APPROPRIATE AND NOTE EXAMPLES) Are his/her relationships with others normal? (IF NOT), In what way abnormal? (FOCUS ON SUBJECT'S DEVELOPMENTAL LEVEL, i.e., MENTAL AGE, NOT CHRONOLOGICAL AGE) Was it the same in the past, or did he/she have fewer/more friends when he/she was younger?

- 0 = one or more relationships with person in approximately own age group with whom shares non-stereotyped activities of personal variety, seen outside prearranged group (such as club), and with whom there is definite reciprocity and mutual responsiveness CURRENT (AGE 5.0 OR OLDER)
- 1 = one or more relationships that involve some personal shared activities outside a prearranged situation with some initiative taken by subject, but limited in terms of restricted interests (e.g. model railways) or less than normal responsiveness/reciprocity MOST ABNORMAL 10.0 - 15.0
- 2 = people with whom subject has some kind of personal relationship involving seeking of contact, but only in group situation (such as club, Church, etc.) or in place of school or work
- 3 = no peer relationships that involve selectivity and sharing
- 8 = not known because serious lack of opportunity for peer contact or outside specific age group
- 9 = N/K or not asked

INTERESTS AND BEHAVIORS

(NOTE: FOR ITEMS 70 - 79 AND ITEMS 81 AND 84, 'INTERFERENCE WITH' REFERS TO DIFFICULTIES FOR THE FAMILY, AND 'SOCIAL IMPAIRMENT' REFERS TO SUBJECT'S OWN LIMITATION OR HANDICAP AS A RESULT OF THE AMOUNT OF TIME SPENT IN ABNORMAL ACTIVITY. NOTE THAT ALL BEHAVIORS EXCEPT AGGRESSION MUST HAVE OCCURRED OVER A 3 MONTH PERIOD TO BE CODED. THROUGHOUT THIS SECTION, ITEMS 70 - 83, IT IS IMPORTANT TO ENSURE THAT EXAMPLES FOR CURRENT AND EVER CODINGS ARE OBTAINED, WHERE SPECIFIED)

(NOTE: INTERVIEWERS SHOULD ADAPT THE WORDING OF QUESTIONS AS APPROPRIATE FOR THE AGE AND DEVELOPMENTAL LEVEL OF THE SUBJECT. NOTE THAT 'CIRCUMSCRIBED INTERESTS' USUALLY APPLIES ONLY TO OLDER, MORE ABLE SUBJECTS)

70. CIRCUMSCRIBED INTERESTS (SUBJECTS AGED 4.0 YEARS AND OLDER)

(A CIRCUMSCRIBED INTEREST IS DEFINED AS A PURSUIT THAT DIFFERS FROM ORDINARY HOBBIES IN ITS INTENSITY; ITS CIRCUMSCRIBED NATURE (THAT IS, IT MAY INVOLVE A HIGH LEVEL OF EXPERTISE, BUT THIS REMAINS UNUSUALLY FOCUSED AND NOT DEVELOPED INTO A BROADER CONTEXT OF KNOWLEDGE); ITS NON-SOCIAL QUALITY (IT MAY BE SHARED WITH ANOTHER INDIVIDUAL WITH A SIMILAR CIRCUMSCRIBED INTEREST BUT NOT AS PART OF A SPECIALIZED CLUB OR ASSOCIATION); AND ITS RELATIVE NON-PROGRESSION OR DEVELOPMENT OVER TIME (THAT IS, THE INTEREST PERSISTS, BUT DOES NOT FORM THE BASIS OF A BUILDING UP OF SHARED OR USED EXPERTISE). IT DIFFERS FROM AN "UNUSUAL PREOCCUPATION" IN THAT IT LACKS PECULIAR OR ODD CONTENT. CIRCUMSCRIBED INTERESTS ARE UNUSUAL IN THEIR QUALITIES (AS ABOVE) BUT NOT IN THEIR CONTENT)

Does he/she have any special hobbies/interests that are unusual in their intensity? How long has he/she had this interest? In what way is it unusual? Has it developed or changed at all over time? Does he/she share the interest with other people? In what way? Does it (the interest) seem at all compulsive? What happens if you interrupt him/her? Does it interfere with his/her doing things? Have there been any special interests in the past? (GET DETAILS)

FOR ITEMS 70 - 79, 81 AND 84

Code 2 involves some disturbance or reorganization of family life that can be tolerated by most families OR involves some interference with subject participating in other activities.

Code 3 requires major disruption or prevention of some family activities OR disruption or prevention of activities by the subject

CIRCUMSCRIBED INTERESTS (MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

- 0 = no circumscribed interest
- 1 = special interest(s) of unusual degree, but not definitely intrusive into or constraining of the subject's or family's other activities
- 2 = definite circumscribed interest(s) that do not cause substantial interference with social functioning, but which do constrain or intrude upon subject's or family's other activities
- 3 = definite circumscribed interest(s) that cause definite social impairment
- 8 = N/A
- 9 = N/K or not asked

CURRENT
(AGE 4.0 AND ABOVE)

EVER

71. UNUSUAL PREOCCUPATIONS

(AN UNUSUAL PREOCCUPATION IS DEFINED AS AN INTEREST THAT IS ODD OR PECULIAR IN QUALITY, THAT IS UNUSUAL IN ITS INTENSITY AND LACK OF SOCIAL FEATURES, AND WHICH IS REPETITIVE OR STEREOTYPED IN ONE OR MORE OF ITS FEATURES OR ELEMENTS)

I have asked about special hobbies, but are there also unusual or peculiar interests - I mean ones that preoccupy him/her... even when the focus of interest is not physically present and that might seem odd to other people? For example, is he/she unusually interested in things like metal objects, traffic lights, street signs or toilets? How much does he talk about them? Does this interest influence how he/she behaves? How long has it lasted? Does this interfere with his/her other activities or with family life? Are there things that you do differently as a family because of this interest? How much of a problem is it for the family? Was there ever anything like this in the past?

UNUSUAL PREOCCUPATIONS (MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

- 0 = none
- 1 = unusual preoccupation(s) of significant activities of family life OR do not cause social impairment of the subject
- 2 = definite, repetitive preoccupation that intrudes into family life, but does not disrupt it significantly OR definite, repetitive preoccupation(s) that do not cause substantial interference with social functioning, but which do constrain or intrude upon subject's other activities
- 3 = definite preoccupation(s) that causes substantial interference OR social impairment and severely limit the subject's other activities
- 9 = N/K or not asked

CURRENT

EVER

72. REPETITIVE USE OF OBJECTS OR INTEREST IN PARTS OF OBJECTS

(THIS ITEM IS DEFINED AS ACTIONS OF A STEREOTYPED OR REPETITIVE NATURE THAT ARE NON-FUNCTIONAL AND WHICH INVOLVE A FOCUS EITHER ON PARTS OF OBJECTS OR ON A USAGE OF AN OBJECT THAT IS CLEARLY SEPARATE FROM THAT WHICH IS ORDINARILY ACCEPTED)

How does he/she play with his/her toys or things around the house? (GET EXAMPLES) Will he/she play with the whole toy or does he/she seem to be more interested in a certain part of the toy (e.g. spinning the wheels of a car or opening and shutting its door), rather than using it as it was intended? Are there particular kinds of objects he/she really likes? Does he/she ever collect or gather together certain sorts of objects? What does he/she do with them? Does he/she ever line things up or do the same thing over and over with them, such as drop things from the same distance? Do these activities change over time or are they exactly the same? Has he/she ever used objects in these ways in the past?

REPETITIVE USE OF OBJECTS OR INTERESTS IN PARTS OF OBJECTS (MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

- 0 = little or no repetitive use of object
- 1 = some repetitive use of objects (e.g. shaking strings or spinning things) or interest in parts or very specific types of objects (such as turning wheels or dials or collecting bits of paper), but in conjunction with several other activities and does not cause social impairment
- 2 = play limited to highly stereotypic use of objects or attention to specific parts or types of objects, but which does not constrain or intrude upon subject's other activities
- 3 = play linked to highly stereotypic use of objects to an extent that prevents or seriously interferes with other activities
- 7 = interested in "infant" toys, such as music boxes or rattles, but play is with a variety of objects and not in a highly stereotypic fashion
- 8 = no play with objects
- 9 = N/K or not asked

CURRENT

EVER

73. DIFFICULTIES WITH MINOR CHANGES IN SUBJECT'S OWN ROUTINES OR PERSONAL ENVIRONMENT

(THIS ITEM CONCERNS MARKED, EXTREME REACTIONS TO A VARIETY OF MINOR CHANGES IN HOW OR WHERE OR WHEN THE SUBJECT CARRIES OUT DAILY ACTIVITIES. THESE CHANGES MUST BE MINOR. NOT INCLUDED WOULD BE MOVING HOUSE OR CHANGING SCHOOL OR A MAJOR TRANSITION THAT WOULD BE EXPECTED TO AFFECT ANY SUBJECT. THE EMPHASIS FOR THIS ITEM IS ON AN UNUSUAL DEGREE OF UPSET AND/OR INSISTENCE ON MAINTAINING THE ORIGINAL CONDITION IF A MINOR ASPECT OF THE SUBJECT'S ROUTINE IS CHANGED)

Is _____ bothered by minor changes in his/her routine? Or in the way his/her personal things are arranged? For example, does it bother him/her to switch from one pair of mittens or gloves to another or from winter to summer clothing (e.g. long sleeves to short sleeves)? How about changes in schedule? Does it make a difference _____ if you bathe him/her or he/she takes a bath 15 minutes earlier or later than usual or gets dressed before breakfast or after, if this broke his/her routine? What does happen? Do minor changes in eating routines, such as where the salt and pepper are on the table or where food is placed on his/her plate, cause any difficulty? Was this ever a problem in the past? (PROBE FOR DETAILS AND NOTE EXAMPLES)

DIFFICULTIES WITH MINOR CHANGES IN SUBJECT'S OWN ROUTINES OR PERSONAL ENVIRONMENT CURRENT
(MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

- 0 = none
- 1 = unusually negative reaction to minor changes in subject's own routines, but with no serious distress and little or no interference in family life
- 2 = definite, unusual reactions to minor changes in subject's own routines, causing resistance or distress and/or family goes to unusual lengths to avoid changing minor aspects of subject's routines or to prepare subject for minor changes, but without substantial interference in family life
- 3 = definite, unusual and marked resistance to minor changes in subject's own routines, with substantial interference with or impairment of family activities
- 9 = N/K or not asked

EVER

74. RESISTANCE TO TRIVIAL CHANGES IN THE ENVIRONMENT (NOT DIRECTLY AFFECTING THE SUBJECT)

(THIS ITEM CONCERNS THE SUBJECT'S MARKED DIFFICULTY WITH MINOR OR TRIVIAL CHANGES IN ASPECTS OF THE ENVIRONMENT THAT HAVE NO DIRECT EFFECT ON HIM/HER, FOR EXAMPLE, THE POSITION OF ORNAMENTS, THE ORIENTATION OF THE TELEPHONE, CLOTHES WORN BY PEOPLE OTHER THAN SUBJECT. THE EMPHASIS IS ON THE SUBJECT'S UNUSUAL NEGATIVE REACTION TO THESE TRIVIAL CHANGES THAT DO NOT HAVE DIRECT BEARING ON THE SUBJECT)

How does _____ react to changes about the house, or to changes in small details of his/her environment or surroundings? For example, how does he/she react to a change in someone else's daily routine, or how the furniture is arranged, or if you wore glasses or a hat? Does he/she get distressed? What about when he/she was younger? Was this ever a problem in the past? (IF THIS IS/WAS A PROBLEM, PROBE FOR DETAILS AND NOTE EXAMPLES)

RESISTANCE TO TRIVIAL CHANGES IN THE ENVIRONMENT
(MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

- 0 = none
- 1 = unusually negative reaction to trivial changes in the environment, but with no serious distress and little or no interference in family life
- 2 = definite, unusual reactions to trivial changes in the environment, causing marked distress and/or family goes to unusual lengths to avoid trivial changes in the environment or to prepare subject for such trivial changes, but without substantial interference in family life
- 3 = definite, unusual and marked resistance to trivial changes in the environment, with substantial interference with or impairment of family activities
- 9 = N/K or not asked

RECURRENT

EVER

75. COMPULSIONS/RITUALS

(THE EMPHASIS IN DEFINING COMPULSION/RITUALS IS ON FIXED SEQUENCES THAT ARE PERFORMED "AS IF" THE SUBJECT FEELS PRESSURE TO COMPLETE THEM IN A PARTICULAR ORDER. COMPULSIONS MAY ALSO INCLUDE HAVING TO PLACE PARTICULAR OBJECTS IN EXACT POSITIONS OR RELATIONSHIPS IN SPACE, SUCH AS OPENING ALL DOORS AT A CERTAIN ANGLE OR TURNING ALL LIGHTS OFF. A COMPULSION WITH LIGHTS DIFFERS FROM REPETITIVE USE OF OBJECTS SCORED ABOVE IN THAT THE SUBJECT INSISTS THAT SEVERAL LIGHTS MUST REMAIN OFF, RATHER THAN CARRY OUT A REPETITIVE ACTION OF FLICKING LIGHTS OFF AND ON. RITUALS DIFFER FROM DIFFICULTIES WITH CHANGES AS DESCRIBED BELOW IN THAT THEY HAVE SEQUENCE AND BECAUSE, IN A RITUAL OR COMPULSION, THE SUBJECT IS IMPOSING AN ORDER ON EVENTS, RATHER THAN RESPONDING TO A PERCEIVED CHANGE. THUS, A SUBJECT WHO NEEDS TO LAY HIS/HER NAPKIN OUT FLAT AND PLACE HIS/HER SPOON ON IT BEFORE HE/SHE WILL EAT, COULD BE SCORED AS HAVING A RITUAL; WHEREAS A SUBJECT WHO IS UPSET IF HE/SHE IS GIVEN A DIFFERENT NAPKIN WOULD BE CODED ABOVE UNDER DIFFICULTIES WITH MINOR CHANGES IN SUBJECT'S OWN ROUTINE)

Are there things that _____ seems to have to do in a very particular way or order; that is, rituals that he/she has to do or has to have you do? Like touching particular things or putting things in special places before going on to do something else? How does he/she react if he/she is unable to complete the whole sequence of his/her activity or is disrupted during the course of his/her actions? (GET DETAILS AND EXAMPLES) Was this ever a problem in the past? (PROBE AS APPROPRIATE, USING PROMPTS OR A BRIEF DEMONSTRATION, IF NECESSARY)

COMPULSIONS/RITUALS (MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

CURRENT

- 0 = none
- 1 = some activities with unusually fixed sequences, but no activity that appears compulsive in quality
- 2 = one or more activities that subject has to perform in a special way. Subject appears to be under pressure or becomes anxious if activity disrupted and/or family goes to unusual lengths to avoid interrupting ritual or to make sure subject is forewarned if it is necessary to interrupt him/her. Compulsive quality present, but little interference with family life or social impairment
- 3 = one or more activities that subject has to perform in a special way. Subject appears to be under marked pressure or becomes extremely anxious or distressed if activity disrupted. Degree of compulsive quality intrudes in family life or causes definite social impairment to subject
- 9 = N/K or not asked

EVER

76. UNUSUAL ATTACHMENT TO OBJECTS

(AN ATTACHMENT IS DEFINED AS AN UNUSUAL INTEREST AND DEPENDENCE ON A PARTICULAR OBJECT THAT THE SUBJECT CARRIES AROUND WITH HIM/HER, MAY TAKE TO BED, OR USES AS A COMFORTER. THE FOCUS HERE IS ON ATTACHMENTS TO UNUSUAL OBJECTS, I.E., NOT THE SOFT, CUDDLY BLANKETS OR STUFFED TOYS USED BY MOST CHILDREN. THE STRENGTH OF THE ATTACHMENT IS DETERMINED BY HOW DIFFICULT IT IS FOR THE SUBJECT TO SEPARATE FROM THE OBJECT AND WHETHER ITS POSSESSION INTRUDES IN THE SUBJECT'S OR FAMILY'S LIFE. THE BEHAVIOR OF AN UNUSUAL ATTACHMENT MUST HAVE LASTED 3 MONTHS, BUT THIS MAY OR MAY NOT HAVE INVOLVED THE SAME OBJECT THROUGHOUT)

Does _____ have anything to which he/she is particularly attached and that he/she likes to carry around with him/her? What is it like? Is it something like a teddy or blanket or is it something more unusual like a piece of pipe, a clothes peg or a stone? (GET EXAMPLES) What does he/she do with it? If asked to put it down, will he/she do so? Does he/she take it to bed? What happens if it is taken away or if it gets mislaid? What about when he/she was younger? Has he/she ever been particularly attached to anything?

UNUSUAL ATTACHMENTS TO OBJECTS (MUST HAVE GONE ON FOR AT LEAST 3 MONTHS) CURRENT

- | | | |
|-----|---|-----------------------------------|
| 0 = | no attachment or attachment only to cuddly object used as comforter | <input type="checkbox"/> |
| 1 = | some attachment to slightly unusual object, such as piece of paper or soft brush, or several similar interchangeable objects, but puts down if asked to do so and can tolerate separation from it. No interference with activities | <input type="checkbox"/> |
| 2 = | attachment to an unusual object associated with significant distress on separation and/or caregivers try to ensure object always readily available for subject because of anticipated distress, occasional interference with activities | NEVER <input type="checkbox"/> |
| 3 = | attachment so intrusive that it prevents many everyday activities | |
| 6 = | attached to soother/comforter or blanket or other usual object beyond age 5 and/or so intensely that interferes with social functioning or activities (if has also had an unusual attachment, code that instead) | |
| 7 = | series of short-lasting (1 - 3 days) attachments to unusual objects or groups of objects, replaced by new attachment to different kind of unusual object also for short time | |
| 9 = | N/K or not asked | |

77. UNUSUAL SENSORY INTERESTS

(UNUSUAL SENSORY INTERESTS ARE DEFINED AS UNUSUALLY STRONG OR REPEATED REACTIONS OR SEEKING OF STIMULATIONS FROM THE BASIC SENSATIONS OF SIGHT, TOUCH, SOUND, TASTE OR SMELL DISSOCIATED FROM MEANING. THE FOCUS IS ON THE EXTENT TO WHICH THE ABNORMAL INTEREST DISTURBS OR REPLACES 'NORMAL USE' OF THE OBJECT)

Does he/she seem particularly interested in the sight, feel, sound, taste or smell of things or people? For example; does he/she tend to sniff toys, objects or people inappropriately? Or is he/she unusually concerned with the feel or texture of things? Or does he/she tend to peer at or look at things for long periods of time? Or does he/she touch things to his/her lips or tongue to see how they feel? How long has he/she been interested in this? (GET EXAMPLES - SPECIFY: AUDITORY, VISUAL, OLFACTORY, TACTILE) Has there ever been a time when he/she seemed particularly interested in any of these sorts of sensations? (NOTE EXAMPLES)

UNUSUAL SENSORY INTERESTS (MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

- 0 = none
- 1 = shows one or two unusual interests regularly
- 2 = unusual sensory interest that takes up a major amount of time or prevents or limits alternative use of that material in its ordinary function
- 9 = N/K or not asked

CURRENT

EVER

78. ABNORMAL IDIOSYNCRATIC NEGATIVE RESPONSE TO SPECIFIC SENSORY STIMULI

(DEFINITION: TO MEET THE CRITERIA FOR SCORING, THE SUBJECT'S RESPONSE MUST BE PREDICTABLE AND SPECIFIC TO SOME IDENTIFIABLE AND PARTICULAR SENSORY STIMULUS (OR GROUP OF STIMULI); IT MUST INVOLVE SOME FORM OF NEGATIVE, EMOTIONAL REACTION OTHER THAN FEAR (OFTEN IT INVOLVES ANGER OR MARKED IRRITATION), AND THE RESPONSE MUST BE IDIOSYNCRATIC. THUS, GENERAL DISTRESS IN RELATION TO VERY LOUD NOISES IS EXCLUDED. NEGATIVE REACTIONS TO ENVIRONMENTAL CHANGE ARE ALSO EXCLUDED (SEE ITEMS 73 AND 74)

Does _____ ever get unusually upset or irritated by particular sounds such as people coughing or a baby crying? (N.B. TAKE CARE TO DIFFERENTIATE FROM A FEAR REACTION) What does he/she do? How does he/she show that he/she is upset? Do you think he/she is afraid or is it more like anger or irritation? Is it just one particular sort of sound? Does _____ ever react in an unusual, but predictable, way to other sensations (such as tastes or smells or the sight or feel of things)? For example, does he/she react to the sight of something like earrings or men with beards? How long has this gone on? Was this ever a problem in the past? (GET EXAMPLES)

ABNORMAL IDIOSYNCRATIC NEGATIVE RESPONSE TO SPECIFIC SENSORY STIMULI

(MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

- 0 - none
- 1 - predictable, abnormal, idiosyncratic negative response to one or more specific stimuli, but reaction mild and/or controllable so that does not give rise to avoidance or to any interference with ordinary life
- 2 - some intrusion into ordinary activities so that there are occasional tantrums/disturbances and/or attempts by family to avoid subject being exposed to specific stimulus; however, no substantial interference with general pattern of family life
- 3 - predictable abnormal idiosyncratic negative response to one or more specific stimuli that causes substantial interference with family life or which totally, or almost totally, prevents some activity
- 9 - N/K or not asked

CURRENT

EVER

79. UNUSUAL FEARS

(THE FOCUS HERE IS ON THE STRENGTH OF THE SUBJECT'S FRIGHTENED REACTION TO SOMETHING NOT USUALLY CONSIDERED FRIGHTENING TO HIS/HER (MENTAL) AGE GROUP. THE EXTENT TO WHICH THE FEAR INTERFERES WITH ORDINARY ACTIVITIES OR FAMILY LIFE PROVIDES A MEASURE OF SEVERITY)

Is _____ very afraid of any particular things? What are they? (GET DETAILS) How frightened is he/she? What do you have to do to help him/her cope with this? Do you have any idea how this fear developed? How long has it gone on? Do you ever have to rearrange what you do because of this fear? Have you ever described him/her as exceptionally fearless? Did _____ ever have fears like this in the past?

UNUSUAL FEARS (MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

CURRENT

- 0 = none or only fears typical of age group (e.g. fears the dark)
- 1 = predictable strong fear response to one or more specific stimulus, but reaction mild and/or controllable so that does not give rise to avoidance or to any interference with ordinary life
- 2 = at least one unusual fear with some intrusion into ordinary activities so that there are occasional tantrums/disturbances and/or attempts by family to avoid stimuli that might cause interference with the general pattern of family life
- 3 = predictable unusual fear in reaction to one or more specific stimuli that causes substantial interference with family life or which totally, or almost totally, prevents some activity
- 7 = unusually unafraid or fearless
- 9 = N/K or not asked

EVER

80. HYPERVENTILATION

(HYPERVENTILATION INVOLVES EPISODES OF RAPID, DEEP, REPETITIVE BREATHING IN SITUATIONS OTHER THAN THOSE ELICITING PANIC)

Does he/she ever breathe in deeply with repeated rapid breaths? Does he/she ever sound as if he/she is gasping for air over and over within a period of a few seconds?

- 0 = none
- 1 = occasional
- 2 = frequent hyperventilating
- 9 = N/K or not asked

CURRENT

EVER

81. HAND AND FINGER MANNERISMS

(AUTISTIC HAND AND FINGER MANNERISMS TYPICALLY INVOLVE RAPID, VOLUNTARY REPETITIOUS MOVEMENTS OF THE FINGERS, OFTEN, BUT NOT ALWAYS WITHIN THE LINE OF THE SUBJECT'S VISION. DO NOT INCLUDE NAIL BITING, HAIR TWISTING OR THUMB SUCKING. CLAPPING IS NOT A HAND MANNERISM NOR ARE THE NONSPECIFIC OVERFLOW MOVEMENTS SEEN IN INFANTS AND TODDLERS WHEN THEY ARE EXCITED. IF HAND AND FINGER MANNERISMS ONLY OCCUR DURING WHOLE BODY MOVEMENTS, CODE ON QUESTION 82 ONLY)

Does _____ have any mannerisms or odd ways of moving his/her hands or fingers? Such as twisting or flicking his/her fingers in front of his/her eyes? Do they interfere with getting _____ to do other things? In what way? What happens if you try to get him/her to stop? Are there any particular circumstances in which he/she does this more than in others? (GET DETAILS) Did he/she ever show any of these types of mannerisms or odd movements in the past? (NOTE EXAMPLES)

HAND AND FINGER MANNERISMS (MUST HAVE GONE ON FOR AT LEAST 3 MONTHS)

- 0 = none
- 1 = occasional only or type not as clearly specified as for rating of '2'
- 2 = definite, frequent hand mannerisms and/or finger flicking/twisting, but no interference with other activities or distress if interrupted
- 3 = marked mannerisms of type specified; associated with social impairment or distress when interrupted or is seldom interrupted because of concern about subject's reaction
- 8 = N/A (e.g. physically disabled)
- 9 = N/K or not asked

CURRENT

EVER

INTERESTS AND BEHAVIORS continued

82. MID-LINE HAND MOVEMENTS

(THESE MOVEMENTS ARE THOSE THAT OCCUR IN THE MIDDLE OF THE SUBJECT'S BODY AND USUALLY INVOLVE BOTH HANDS MOVING IN SIMILAR WAYS)

Does he/she have any particular ways of moving his/her hands in front of his/her body, for example, hand wringing or turning the hands from side to side together as if washing them?

MID-LINE HAND MOVEMENTS

- 0 = none
- 1 = occasional only or type not as clearly specified as for a rating of '2'
- 2 = definite abnormal wringing hand movements mainly in the mid-line
- 9 = N/K or not asked

CURRENT

EVER

83. LOSS OF PURPOSIVE HAND USE

(THE FOCUS OF THIS ITEM IS ON A LOSS OF THE ABILITY TO CARRY OUT SIMPLE DIRECTED ACTIONS WITH THE HANDS AFTER A PERIOD OF SEVERAL MONTHS DURING WHICH THE SUBJECT COULD CARRY OUT SUCH ACTIONS. DEVELOPMENTALLY APPROPRIATE EXAMPLES OF PURPOSIVE HAND USE INCLUDE VERY SIMPLE ACTIVITIES SUCH AS DELIBERATELY BANGING OBJECTS, HOLDING A SPOON OR FOOD, STACKING OR LINING UP OBJECTS OR TOYS)

Is his/her grip OK? Does his/her grip feel firm? Can he/she use his/her hands to carry out an activity that he/she likes to do? Can you give me some examples?

IF NO - Was there ever a time (for at least 3 months) when _____ could do things with his/her hands like this? How long ago was that? What could he/she do?

LOSS OF PURPOSIVE HAND USE

- 0 = no loss
- 1 = possible loss of some purposive hand movements
- 2 = definite loss of purposive hand movements
- 3 = never had purposive hand movements
- 9 = N/K or not asked

CURRENT

EVER

84. OTHER COMPLEX MANNERISMS OR STEREOTYPED BODY MOVEMENTS
(DO NOT INCLUDE ISOLATED ROCKING)

(THE FOCUS HERE IS ON COMPLEX, STEREOTYPIC, VOLUNTARY WHOLE BODY MOVEMENTS, SUCH AS POSTURING OR ARM WAVING WHILE ROCKING UP TO TIPTOES AND THE DEGREE TO WHICH IT INTRUDES ON THE SUBJECT'S DAILY LIFE)

Does he/she have any complicated movements of his/her whole body, such as spinning or repeatedly bouncing up and down or arm waving while rocking? Do they interfere at all with getting... to do other things? In what way? What happens if you try to get him to stop? (GET DETAILS) In the past, did he/she have any of these movements? (NOTE EXAMPLES. CODE ROCKING HERE IF IT INVOLVES ARM OR HEAD MOVEMENTS AS WELL)

- 0 = none
- 1 = occasional only
- 2 = definite, frequent other mannerisms or stereotypies, but will stop without distress if interrupted
- 3 = marked mannerisms associated with social impairment
- 9 = N/K or not asked

CURRENT

EVER

85. ROCKING

(CODE ANY RAPID RHYTHMIC ROCKING HERE, UNLESS IT INVOLVES OTHER MOVEMENTS AND IS CODED ABOVE)

Has he/she ever rocked? Does he/she do this now? What happens when you try to get him/her to stop? (GET EXAMPLES, INCLUDING AMOUNT OF TIME SPENT AND THE FORM THE ROCKING TAKES/TOOK) Was this ever a problem in the past?

- 0 = no rocking
- 1 = minimal rocking, e.g. when tired or upset, or for very short times in only one situation (e.g. before bed or in car seat (< 5 minutes, less than once a day)
- 2 = regular periods of rocking in more than one context, but can stop if distracted or interrupted
- 3 = frequent rocking across multiple situations
- 9 = N/K or not asked

CURRENT

EVER

GENERAL BEHAVIORS

86. GAIT

(THE FOCUS IS ON UNUSUAL WAYS OF WALKING, PARTICULARLY TIPTOEING OR BOUNCING, THAT ARE NOT CLEARLY ASSOCIATED WITH PHYSICAL HANDICAP)

Is there anything unusual about the way _____ walks; e.g. bouncing, exaggeration of toe-heel, up on toes? (GET DESCRIPTION) Do you think other people notice it? Has there ever been anything unusual? How did he/she walk when he/she was 4 to 5? (DO NOT CODE BROAD-BASED IMMATURE OR CLUMSY GAIT)

- 0 = normal
- 1 = somewhat unusual
- 2 = definitely odd gait, e.g. toe-walking or abnormal bouncing
- 3 = gait sufficiently odd to be noticed by others outside family or teachers
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

87. SCOLIOSIS/WEAKNESS OF BACK

(SCOLIOSIS IS CURVATURE OF THE SPINE, USUALLY SUSPECTED IN LATER CHILDHOOD OR ADOLESCENCE)

Has _____ any problems with his/her posture such as weakness of the back or difficulty in keeping an upright posture (ie keeping head and chest up)? When did this occur? (NOTE DETAILS)

- 0 = normal
- 1 = possible scoliosis or weakness of back but not required investigation or treatment such as physiotherapy
- 2 = definite scoliosis, investigated and requiring treatment such as physiotherapy
- 8 = N/A
- 9 = N/K or not asked

CURRENT

GENERAL BEHAVIORS continued

88. GROSS-MOTOR CO-ORDINATION

(GROSS MOTOR SKILLS ARE THOSE REQUIRING MOVEMENTS OF THE ARMS, LEGS OR WHOLE BODY)

Is _____ agile or clumsy in how he/she uses his/her arms and legs and whole body? (ASK IN TERMS OF AGE-APPROPRIATE GROSS MOTOR ACTIVITIES SUCH AS THROWING OR CATCHING OR KICKING A BALL, CLIMBING, OR RIDING A BICYCLE OR TRICYCLE. GET DESCRIPTION. CLIMBING WITHOUT ANY OTHER ACTIVITY IS NOT SUFFICIENT FOR FULL CREDIT) What about when he/she was 4 to 5? Has this changed over the years?

- 0 = normal
- 1 = limited gross motor skills, but not definitely abnormally clumsy
- 2 = definitely unusually clumsy
- 8 = N/A
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

89. FINE MOTOR COORDINATION

(FINE MOTOR SKILLS ARE THOSE THAT INVOLVE JUST THE HANDS AND FINGERS)

How well can he/she use his/her hands and fingers to make things or to fit things together? How about at 4 - 5? (ASK IN TERMS OF AGE-APPROPRIATE ACTIVITIES SUCH AS LEGO, WRITING OR MANIPULATING SMALL OBJECTS. GET DESCRIPTION)

- 0 = normal
- 1 = limited fine motor skills, but not definitely abnormally clumsy in hand use
- 2 = definitely unusually clumsy in hand use
- 8 = N/A (i.e. known neurological or orthopaedic condition that affects motor control)
- 9 = N/K or not asked

CURRENT

MOST ABNORMAL
4.0 - 5.0

GENERAL BEHAVIORS continued

90. SELF INJURY

(SELF-INJURY IS A DELIBERATE SELF-DIRECTED AGGRESSIVE ACT, EG BITING THE WRIST, BANGING THE HEAD, THAT RESULTS IN TISSUE DAMAGE THAT OCCURS OVER A PERIOD OF AT LEAST 3 MONTHS)

Does _____ ever injure himself/herself deliberately, such as by biting his/her arm or banging his/her head or anything else like this? (GET DETAILS) Was this ever a problem in the past?

- 0 = non.
- 1 = slightly only: e.g. occasionally bites own hand/arm when annoyed, pulls hair or slaps face. No substantial tissue damage CURRENT
- 2 = definitely present: e.g. actual bruising or callousing, repeated headbanging, hairpulling, biting associated with definite tissue damage (do not count picking of spots)
- 3 = definite self injury with serious damage, e.g. skull fracture, eye injury, etc EVER
- 9 = N/K or not asked

91. OVERACTIVITY AT HOME AND ELSEWHERE

(THE FOCUS IS ON THE LEVEL AND FREQUENCY OF HIGH ACTIVITY, THE EXTENT TO WHICH IT OCCURS IN A VARIETY OF SITUATIONS AND THE DEGREE TO WHICH THE SUBJECT AND HIS/HER FAMILY'S LIVES ARE IMPAIRED)

Some people seem to find it hard to sit down for any length of time - for instance at mealtime or when watching TV or while travelling on a bus.

Does _____ find it difficult to sit still? Does he/she tend to rush around? Is he/she always on the go? (OBTAIN A DESCRIPTION OF RELEVANT SITUATIONS AND OF SUBJECT'S BEHAVIOR) (FOCUS ON THE BEHAVIOR THAT IS MOST INAPPROPRIATE FOR THE SUBJECT'S MENTAL AGE)

IF YES:

- Is he/she in and out of his/her chair at mealtimes?
- Can he/she remain seated throughout if told to do so?
- What about when you take him/her out, like on a bus or to church?
- What happens at home when he/she is doing whatever he/she likes and when there is no particular expectation to stay in one place?
- What happens in situations outside home, for example, at school or in your friends' homes or in public places?
- Has anyone ever remarked to you or complained about his/her activity level?

Was this ever a problem in the past?

- 0 = rarely a problem, able to remain seated if expected to do so
- 1 = gets up and moves about a great deal when expected to stay still; responds to requests to return, but soon out of seat again CURRENT
- 2 = hardly ever sits down; almost always on the move; overactivity occurs even when allowed to do what he/she wants; family is able to cope and subject able to carry out some activities but many/serious complaints and/or reports that overactivity definitely interferes with social/work activities EVER
- 3 = overactivity is so pervasive and significant that family is severely affected and/or subject is severely impaired
- 9 = N/K or not asked

GENERAL BEHAVIORS continued

92. FAINTS/FITS/BLACKOUTS

(THE FOCUS IS ON EPISODES INVOLVING AN UNEXPLAINED CHANGE IN LEVEL OF CONSCIOUSNESS WITH OR WITHOUT FALLING OR JERKING MOVEMENTS OF THE LIMBS)

Has _____ ever fainted or had a fit/seizure/convulsion? Has he/she ever had medicine to control fits? (IF YES, PROBE FOR FURTHER DETAILS INCLUDING AGE OF ONSET, HOW OFTEN 'FITS' OCCURRED, A CLEAR DESCRIPTION OF 'FITS' AND WHETHER THEY REQUIRED INVESTIGATION AND TREATMENT, INCLUDING PAST AND CURRENT MEDICATION AND/OR HOSPITAL ADMISSION)

- 0 = none
 - 1 = history of attacks that might be epileptic, but diagnosis not established
 - 2 = definite diagnosis of epilepsy
 - 7 = febrile convulsions only, with no continuing daily medication outside the period of fever
 - 9 = N/K or not asked
- RECURRENT
- NEVER

93. AGE WHEN ABNORMALITY FIRST EVIDENT

(IF IT IS ALREADY CLEAR THAT BEHAVIOR ABNORMAL BY AGE 3 YEARS, QUESTION ONLY ON EARLIER AGES IN ORDER TO ASSESS PROBABLE TIME THAT ABNORMALITIES FIRST EVIDENT. IF ACCOUNT SO FAR SUGGESTS SUBJECT NORMAL UP TO 3 YEARS, FOCUS FIRST ON AGE 3 YEARS IN ORDER TO DETERMINE IF DEVELOPMENT DEFINITELY NORMAL AT THAT AGE, AND THEN EXPLORE EARLIER AGES. THIS CODING IS MADE ON THE INTERVIEWER'S JUDGMENT USING ALL AVAILABLE INFORMATION FROM THE INTERVIEW)

When we started talking about _____, I asked you when you thought that he/she first showed any difficulties in development or behavior. You said that you thought / / / (CODE RECORDED item 2). I'd like now just to check back on those early years. Could you tell what _____ was like about the time of his/her third birthday? What was his/her play like? What toys did he/she play with? Any pretend games? How was his/her talking then? What about looking after him/her self? Feeding? Toileting? Dressing? What were his/her relationships with other children like? Working back again just to check - what about at age 1 years and 2 years?

- 0 = development in the first three years of life clearly normal in quality and within normal limits for social, adaptational, language, self-help, and motor milestones. No behavioral problems of a type that might indicate developmental delay or deviance
 - 1 = development possibly within normal limits during first 3 years, but uncertainty because of either the quality of behavior or the level of skills
 - 2 = development probably abnormal by the age of 3 years, as indicated by developmental delay or deviance, but not of a degree or type that is definitely incompatible with normality
 - 3 = development definitely abnormal in the first 3 years, but quality of behavior/social relationships/communications not unambiguously autistic at that age
 - 4 = development definitely abnormal in the first 3 years and quality of behavior/social relationships/communications strongly indicative of autism at that age
 - 9 = N/K or not asked
-

94. INTERVIEWER'S JUDGMENT ON AGE WHEN DEVELOPMENTAL ABNORMALITIES PROBABLY FIRST MANIFEST (CODE IN MONTHS)

GENERAL BEHAVIORS continued

95/103. LOSS OF SKILLS / LOSS OF SKILLS ASSOCIATED WITH PHYSICAL ILLNESS

(LOSS, AS DEFINED IN THIS CODING, MEANS THAT A SKILL HAVING BEEN PREVIOUSLY AT A NORMAL LEVEL, AND ESTABLISHED SO THAT IT WAS MANIFEST SPONTANEOUSLY AND CONSISTENTLY OVER A PERIOD OF AT LEAST 3 MONTHS WAS LOST SUBSTANTIALLY OR COMPLETELY FOR A PERIOD OF AT LEAST 3 MONTHS)

I asked you earlier about possible loss of language skills and hand movements. I'd like to go back now to ask about possible losses in other skills. Has there ever been a period when _____ seemed to get markedly worse or dropped further behind in his/her development? When was this? What skills did _____ lose? Did it affect his/her toileting? or understanding of language? or use of speech? or play? or ability to look after him/her self? or co-ordination? posture or walking? What about skills in manipulating objects? What about school-type skills? (DO NOT INCLUDE VARIATIONS IN USE OF SKILLS AT TIMES OF WORSENING BEHAVIOR IF SUBJECT CLEARLY RECOVERS, I.E. IF LOSS IS PART OF A MORE GENERAL PATTERN OF UPS AND DOWNS. LOSS MUST BE CONSISTENT OVER A PERIOD OF AT LEAST 3 MONTHS. NOTE AGE OF SUBJECT WHEN LOSS OF SKILLS OCCURRED)

IF YES: Was there any suggestion that the loss of skills was associated with a physical illness? (IF NO LOSS, CODE 8 FOR LOSS OF SKILLS ASSOCIATED WITH PHYSICAL ILLNESS)

(IF LOSS OF SKILLS, PROCEED TO NEXT ITEM; IF NO LOSS SKIP TO ITEM 104)

95. LOSS OF SKILLS (FOR AT LEAST 3 MONTHS)

- 0 = no consistent loss of skills (although behavior may vary at times)
- 1 = probable loss of skill, but of a degree that falls short of specified criteria
- 2 = account of definite loss of skills over a period of time
- 8 = N/A through age
- 9 = N/K or not asked

BEFORE AGE 5.0

AFTER AGE 5.0

96. LOSS OF SKILLS (ASSOCIATED WITH PHYSICAL ILLNESS)

- 0 = loss of skills, but insignificant physical symptoms, e.g. rash or post-inoculation fever
- 1 = loss of skill associated with symptoms that cannot be taken as clear evidence of meningeal or encephalitic origin, e.g. high fever with ear infection
- 2 = loss of skills associated with clinical evidence of meningeal or encephalitic involvement, e.g. stupor, coma and/or fits
- 8 = no loss of skills noted or N/A through age
- 9 = N/K or not asked

BEFORE AGE 5.0

AFTER AGE 5.0

CODE AREAS OF LOSS ON NEXT PAGE

GENERAL BEHAVIORS continued

AREA OF LOSS (Code 0 if none, 1 if possible, 2 if definite)

BEFORE AGE 5.0 AFTER AGE 5.0

97. COMMUNICATION

98. SOCIAL INTEREST AND RESPONSIVENESS

99. PLAY AND IMAGINATION

100. ADAPTIVE SKILLS

101. PREACADEMIC, ACADEMIC OR VOCATIONAL SKILLS

102. MOTOR SKILLS

103. AGE WHEN MAIN LOSS OF SKILL FIRST APPARENT

(Code age in months)

998 = no loss of skills at either "1" or "2" level

| | | |
|--|--|--|
| | | |
|--|--|--|

GENERAL BEHAVIORS continued

104. PROGRESSIVE DETERIORATION

(LOSS OF SKILLS, AS PREVIOUSLY DEFINED, THAT GOES ON INCREASING IN SEVERITY FOR A PERIOD OF AT LEAST 2 YEARS)

IF LOSS OF SKILLS: Has _____'s development started moving ahead again? How long did the period of getting worse seem to go on? Is he/she back to the point where he/she was at his/her best before there was the set back?

- 0 = development now moving ahead appropriately in relation to the level of handicap
- 1 = development at a plateau, without definite improvement or worsening
- 2 = deterioration definitely still continuing with regard to at least one of the domains specified under loss of skills, but one or more of other at plateau or even improving somewhat
- 3 = deterioration definitely continuing in all, or nearly all domains
- 8 = not applicable (no loss of skills)

105. DURATION OF PERIOD OF DETERIORATION

(CODE IN MONTHS UP TO THE BEGINNING OF THE PLATEAU OR IMPROVEMENT, WHICHEVER IS THE EARLIER)

Can you estimate the duration of this period of deterioration?

CODE IN MONTHS UP TO THE BEGINNING OF PLATEAU OR IMPROVEMENT (whichever is the earlier)

- 995 = DETERIORATION CONTINUING
- 998 = NO DETERIORATION
- 999 = NOT KNOWN

| | | |
|--|--|--|
| | | |
|--|--|--|

106/111. SPECIAL SKILLS (FOR ALL SUBJECTS)

(PROBE AS APPROPRIATE TO THE SUBJECT'S LEVEL OF FUNCTIONING AND GET DETAILS OF LEVEL AND PATTERN OF SKILLS, AS WELL AS EXTENT THAT ANY SKILL INVOLVES MEANING AND INTERPRETATION AND CAN BE APPLIED IN DAY-TO-DAY SITUATIONS. DESCRIBE IN DETAIL. FOR ALL ITEMS ON THIS PAGE, CODE FOR CURRENT AND EVER)

Does _____ have any special skills? Are there any things that he/she seems to be unusually good at, either currently or at any time in the past? (GET DETAILS AND EXAMPLES) Are these skills related to one of his/her special interests or unusual preoccupations?

Is _____ particularly good with shapes - as in puzzles or jigsaws? Has this ever been a particular ability?

What about his/her memory? Was it ever exceptional?

Does he/she have particular musical skills? In the past?

Is he/she unusually good at drawing? Was he/she in the past?

How about reading? In the past?

What about computations? In the past?

(THROUGHOUT THIS SECTION, THE FOCUS SHOULD BE ON A PARTICULAR SKILL OR ABILITY. ONCE A DECISION HAS BEEN MADE ABOUT THE PRESENCE OR ABSENCE OF A SKILL, THE NEXT ASSESSMENT NEEDS TO BE IN RELATION TO HOW THIS SKILL COMPARES WITH THE SUBJECT'S OVERALL LEVEL OF FUNCTIONING AND HOW THIS WOULD COMPARE WITH THE GENERAL POPULATION. FOR EXAMPLE, A MENTALLY RETARDED CHILD WHO COULD MULTIPLY THREE FIGURE NUMBERS IN HIS HEAD, BUT WHO COULD NOT APPLY THIS COMPUTATIONAL SKILL, WOULD SCORE '3'. IF HE COULD APPLY THE SKILL IN REAL LIFE SITUATIONS, HE WOULD SCORE '4'. IF HIS COMPUTATIONAL SKILL WAS AVERAGE BY POPULATION NORMS, BUT WELL ABOVE HIS MENTAL AGE, THIS WOULD SCORE '2')

CODE SPECIAL SKILLS ON NEXT PAGE

GENERAL BEHAVIORS continued

106/111. SPECIAL ISOLATED SKILLS continued

- 0 = no outstanding skills/knowledge in relation to overall level of ability, whether high or low
- 1 = isolated skill/knowledge, commented upon by others, but not much above subject's own general level of functioning
- 2 = isolated skill/knowledge that is definitely out of keeping with subject's general level of ability, but not above general population norms
- 3 = isolated skill/knowledge that is definitely above the subject's general level of ability and above the general population normal level, but is not used functionally or meaningfully to any marked extent (e.g. a preschool child who can read without comprehension or a calendrical calculator would be scored here)
- 4 = isolated skill/knowledge that is above the subject's general level and above the normal population level of ability and is used meaningfully (i.e. genuine talent or ability used adaptively such as performing music for others' enjoyment or participating in age-appropriate children's hobbies such as model-building or computer programming) and recognized by peers as having exceptional skill
- 8 = not applicable (e.g. reading in a nonverbal subject)
- 9 = N/K or not asked

CURRENT EVER

106. VISUOSPATIAL ABILITY (i.e. in puzzles, jigsaws, shapes, patterns, etc.)

VISUOSPATIAL

| | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|

107. MEMORY SKILL (accurate memory for detail, as of dates or timetables)

MEMORY

| | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|

108. MUSICAL ABILITY (recognition, composition, absolute pitch or performance)

MUSIC

| | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|

109. DRAWING SKILL (unusually skilled use of perspective or creative approach)

DRAWING

| | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|

110. READING ABILITY (e.g. early sight reading)

READING

| | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|

111. COMPUTATIONAL ABILITY (e.g. mental arithmetic)

COMPUTATION

| | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
|--------------------------|--------------------------|

OVERALL ASSESSMENT (NO CODING REQUIRED)

Are there any other aspects of _____'s behavior that particularly concern you? (PROBE ONLY IF POSSIBLY RELEVANT TO ANY OF SPECIFIED CODINGS OR TO DIFFERENTIAL DIAGNOSIS OF AUTISM) Is there anything else you would like to tell me about that we haven't covered?

IMPRESSIONS AND CIRCUMSTANCES OF INTERVIEW (DESCRIBE):
(NOTE WHETHER AUDIO/VIDEO RECORDING MADE)

SUMMARY OF ANY DISCREPANCIES BETWEEN INFORMANT DESCRIPTION AND OBSERVER INFORMATION:

Name

Qual

B1:

B2:

B3:

B4:

Tot:

| Name of Child | DOB | DOE | CA (y-m) | Therapist |
|---------------|-----|-----|----------|-----------|
|---------------|-----|-----|----------|-----------|

Proposed ADI-R Algorithm for ICD-10
 For Research Form of ADI
 (revised December, 1996)

(Use current for children under age 4 and most abnormal
 4-5 for others except where otherwise noted)

(Convert 3s from the protocol to 2s)

Qualitative Impairments in Reciprocal Social Interaction

B1: Failure to use nonverbal behaviors to regulate social interaction

| | | |
|-----------------------------|------|-------|
| Direct gaze | (42) | _____ |
| Social smiling | (43) | _____ |
| Range of facial expressions | (52) | _____ |

Total B1 _____

B2: Failure to develop peer relationships

| | | |
|--|---------|-------|
| Imaginative play with peers (over 4 yrs. only) | (64) | _____ |
| Interest in children | (66) | _____ |
| Response to other children's approaches | (67) | _____ |
| Group play with peers (CA 4 - 10 yrs.) | | |
| or | | |
| Friends (CA 10 - 15 yrs.) | (68/69) | _____ |

Total B2 _____

B3: Lack of shared enjoyment

| | | |
|--|------|-------|
| Showing and directing attention | (45) | _____ |
| Offering to share | (46) | _____ |
| Seeking to share own enjoyment with others | (47) | _____ |

Total B3 _____

B4: Lack of socioemotional reciprocity

| | | |
|---|------|-------|
| Use of other's body (Score Ever) | (11) | _____ |
| Offers comfort | (49) | _____ |
| Quality of social overtures | (51) | _____ |
| Inappropriate facial expressions (Score Ever) | (53) | _____ |
| Appropriateness of social response | (57) | _____ |

Total B4 _____

Total B = B1 + B2 + B3 + B4 (Cutoff = 10) _____

Proposed ADI Algorithms for ICD-10 (cont.)

Communication

All Subjects

C1: Lack of, or delay in, spoken language and failure to compensate through gesture

- Pointing to express interest (30) _____
- Conventional instrumental gestures (31) _____
- Nodding (32) _____
- Headshaking (33) _____

Total C1 _____

C4: Lack of varied spontaneous make-believe or social imitative play

- Spontaneous imitation of actions (29) _____
- Imaginative play (63) _____
- Imitative social play (65) _____

Total C4 _____

Verbal Subjects (overall level of language (19) = 0)

C2V: Relative failure to initiate or sustain conversational interchange

- Social Chat (Score Current) (16) _____
- Reciprocal conversation (Score Current) (20) _____

Total C2V _____

C3V: Stereotyped, repetitive or idiosyncratic speech

- Stereotyped utterances (Score Ever) (18) _____
- Inappropriate questions (Score Ever) (22) _____
- Pronominal reversal (Score Ever) (23) _____
- Neologisms/idiosyncratic language (Score Ever) (24) _____

Total C3V _____

Verbal Total: C1 + C4 + C2V + C3V (Cutoff = 8) _____

Nonverbal Children (overall level of language (19) = 1 or 2)

Nonverbal Total: C1 + C4 (Cutoff = 7) _____

Proposed ADI Algorithm for ICD-10 (cont.)

Repetitive Behaviors and Stereotyped Patterns

(Score Ever for these items)

D1: Encompassing preoccupation or circumscribed pattern of interest

| | | |
|--|------|-------|
| Circumscribed interests (4 years and over) | (70) | _____ |
| Unusual preoccupations | (71) | _____ |

D2: Apparently compulsive adherences to nonfunctional routines or rituals

| | | |
|---------------------|------|-------|
| Verbal rituals | (25) | _____ |
| Compulsions/rituals | (75) | _____ |

D3: Stereotyped and repetitive motor mannerisms

| | | | |
|---------------------------|--------------|-------|-------|
| Hand and finger movements | (81) | | _____ |
| OR | Score Higher | | |
| Complex mannerisms | (84) | | _____ |

D4: Preoccupations with part of objects or non-functional elements of materials

| | | | |
|---------------------------|--------------|-------|-------|
| Repetitive use of objects | (72) | | _____ |
| OR | Score Higher | | |
| Unusual sensory interests | (77) | | _____ |

D Total = D1 + D2 + D3 + D4 (Cutoff = 3) _____

Abnormality of development evident at or before 36 months

| | | |
|---|--------------|-------|
| Age parents first noticed (if <36 months, score 1) | (2) | _____ |
| Age when abnormality first evident (if coded 3 or 4, score 1) | (93) | _____ |
| Interviewer's judgment on age manifest (if <36 months, score 1) | (94) | _____ |
| Age at first single words (if >24 months, score 1) | (12) | _____ |
| Age at first phrases (if >36 months, score 1) | (13) | _____ |
| | (Cutoff = 1) | _____ |

APPENDIX J
AUTISM DIAGNOSTIC OBSERVATION SCHEDULE (ADOS) –
MODULE 1

Name of Child: _____ Date of Testing: _____

Scorer: _____ Administrator: _____

MODULE 1

Pre-Verbal/Single Words

ADOS

Observation/Coding

1. Free Play
2. Response to Name
3. Response to Joint Attention
4. Bubble Play
5. Anticipation of a Routine with Objects
6. Responsive Social Smile
7. Anticipation of a Social Routine
8. Functional and Symbolic Imitation
9. Birthday Party
10. Snack

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1 2 3 4 5 6 7 8 9

Name of Child: _____

Date of Testing: _____

2. Response to Name

Focus of Observations: The goal of this observation is to observe the consistency of a child's response to a hierarchy of auditory stimuli from 1) the examiner calling his name, to 2) a parent calling his name, to 3) the parent making a familiar noise or calling in a way that implies physical contact (e.g., "I'm gonna get you!"), to 4) touching him. The focus of observation is both on the sounds that the examiner or parent needs to make to get the child's attention and how the child responds.

3. Response to Joint Attention

Focus of Observations: The focus of observation is on whether the child follows a shift in gaze alone or follows a shift in gaze when accompanied by a point.

4. Bubble Play

Focus of Observations: This task provides a context for observation of the child's affect, initiation of joint attention, shared enjoyment, requesting and motor behavior during the bubbles.

5. Anticipation of a Routine with Objects

Focus of Observation: This task provides another context for observation of the child's affect and initiation of joint attention and shared enjoyment, requesting and motor behavior during the activity.

6. Responsive Social Smile

Focus of Observations: The goal in this observation is to observe the consistency of a child's smile in response to 1) the examiner's smiling, 2) a parent smiling, 3) a parent smiling and making a familiar noise or calling in a way that implies physical contact (e.g., "I'm gonna get you!") or 4) being touched.

Name of Child: _____

Date of Testing: _____

7. Anticipation of a Social Routine

Focus of Observations: The focus of observations is on the child's affect and attempts to initiate the repetition of the routine, particularly on the social directedness of the child's behaviors and the extent to which he integrates gaze, facial expression, vocalization and gesture in actions directed to the examiner or a parent.

8. Functional and Symbolic Imitation

Focus of Observations: The focus of observation is on the child's use of miniature objects and a placeholder in imitation of familiar actions, including whether these acts are carried out with social awareness and shared enjoyment.

Strategies Used for Joint Referencing

_____ point with index finger

_____ open-handed reach

_____ other gesture *specify:*

_____ vocalization:

_____ words

_____ non-verbal

_____ eye contact:

_____ alone

_____ with vocalization

_____ with point

Object(s) Referenced

_____ mechanical animal

_____ balloon

_____ bubbles

_____ other *specify:*

Name of Child: _____

Date of Testing: _____

9. Birthday Party

Focus of Observations: The focus of observation is on the child's interest and ability to join in the "script" of a doll's birthday party. Attention should be directed to whether the child treats the doll as a representation of an animate being, whether he spontaneously contributes to the enactment of the party or, if not, whether he will imitate the examiner's actions spontaneously or participate when requested or directed to do so.

10. Snack

Focus of Observations: This task provides the opportunity to observe whether and, if so, how, a child indicates a preference and requests food in a familiar context. Attention is directed to how the child uses gaze, gesture, reaching, facial expression and vocalization to communicate a request to the examiner.

Strategies Used for Requests:

_____ points with index finger _____ open-handed reach _____ pulls adult's hand toward object
 _____ eye contact _____ uses adult's hand as a tool _____ hands item to adult
 _____ other gesture *specify:*
 _____ vocalization: _____ words _____ non-verbal

Activities Requested:

_____ animal _____ balloon
 _____ bubbles _____ social routine: _____
 _____ other *specify:*

Coding - Module 1

The overall ratings below should be made on the basis of the child's behavior throughout the entire scale. If the child's behavior changes in quality after an adaptation period, ratings should be based on the period after the behavior stabilizes. The scales should be completed immediately after the assessment. The ratings are organized according to five main groupings: A. Language and Communication, B. Reciprocal Social Interaction, C. Play, D. Stereotyped Behaviors and Restricted Interests, E. Other Abnormal Behaviors.

A. LANGUAGE AND COMMUNICATION (unless stated otherwise, code absolutely, not in comparison to developmental level or estimated expressive language skills)

1. Overall Level of Non-echoed Language (This is a code for the complexity of spontaneous expressive language produced during the session. Code the majority of utterances, not the most complex.)

- 0 = regular use of utterances with two or more words.
 1 = occasional phrases only; mostly single words.
 2 = recognizable single words only; must use at least five different words during session.
 3 = at least one word or word approximation, but fewer than five words used during session.
 8 = no words or word approximations.

2. Frequency of Vocalization Directed To Others (This is a code for the amount of socially-directed vocalization.)

- 0 = directs vocalizations to parent/caregiver or examiner in a variety of contexts. Must include chatting or vocalizing to be friendly or to express interest as well as to make needs known.
 1 = directs vocalizations to parent/caregiver or examiner consistently in one context OR directs vocalizations to parent/caregiver or examiner infrequently across a variety of contexts.
 2 = directs an occasional vocalization to parent/caregiver or examiner inconsistently in a limited number of contexts. May include whining or crying due to frustration.
 3 = vocalizations almost never appear to be directed to parent/caregiver or examiner OR rarely or never vocalizes.

3. Intonation of Vocalizations or Verbalizations (This is a general code that applies to all vocalizations or verbalizations, including crying and whining.)

- 0 = normal, appropriately varying intonation, with no peculiar or odd intonation.
 1 = little variation in pitch and tone; rather flat or exaggerated, or occasional peculiar intonation.
 2 = odd intonation or inappropriate pitch and stress and/or markedly flat and toneless mechanical vocalizations or an odd cry and few other vocalizations.
 8 = N/A, insufficient vocalizations for assessment of intonation; includes presence of normal cry and few other vocalizations.

4. Immediate Echolia (Immediate echolia is defined as repetitions of the speech of the parent/caregiver or examiner that immediately follow the adult's last statement or series of statements. This should not include repetitions that are a lead-in to a response to the examiner or that are used as a memory device in specific tasks.)

- 0 = rarely or never repeats the adult's speech.
 1 = occasional echoing.
 2 = echoing words and phrases regularly, but some spontaneous language (it can be stereotyped).
 3 = speech largely consists of immediate echolia.
 8 = language too limited to judge.

5. **Stereotyped/Idiosyncratic Words or Phrases** (This code includes delayed echolalia or other highly repetitive utterances with consistent intonation patterns. These words or phrases can be intended meaningfully and can be appropriate to conversation at some level. The focus is on the stereotyped or idiosyncratic quality of the phrasing or unusual use of words and/or their arbitrary association with a particular meaning. Neologisms should be coded here. Score relative to expressive language level.)

-
- 0 = rarely or never uses stereotyped or idiosyncratic words or phrases.
 - 1 = use of words or phrases tends to be more repetitive than most children at the same level of complexity, but not obviously odd. OR occasional stereotyped utterances or use of odd words or use of phrases in an unusual way, with other flexible spontaneous language as well.
 - 2 = often uses stereotyped utterances or odd words or phrases with some other language.
 - 3 = phrases almost exclusively odd or stereotyped utterances.
 - 8 = N/A, no phrase speech.

6. **Use of Other's Body to Communicate** (The focus of this item is on the use of another person's body as a tool. It requires movement of a limb or a part of someone else's body without a previous or concurrent attempt to direct his/her attention using gaze.)

-
- 0 = no use of adult's body to communicate, except in situations where other strategies have not worked (e.g., when the adults are conversing and the child cannot get their attention) and in conjunction with coordinated gaze.)
 - 1 = takes adult's hand and leads him/her places without coordinated gaze, but no placement of hand on objects and no use of it as a tool or to point.
 - 2 = placement of adult's hand or other body part on object or movement of adult's hand when it is holding an object or use of adult's hand or other body part as a tool or to gesture "for" the child (such as pointing).
 - 8 = little or no spontaneous communication.

7. **Pointing** (This code describes socially-directed pointing including for the purpose of requesting and/or for shared attention. Distal implies not touching and not close to touching [e.g., more than about 2 inches/5 cm away].)

-
- 0 = points with index finger to show visually-directed referencing (coordinated gaze to object and person) of distal objects in at least two contexts.
 - 1 = uses a point to reference objects, but without sufficient flexibility or frequency to meet criteria for a "0" (e.g., only one point as described in "0" or absence of coordinated eye gaze with distal point, though may vocalize.) Or produces an approximation of a point rather than an index finger point. Or coordinates only a point to a picture or other nearby objects including touching points, with gaze or vocalization. Or points to a person or self only.
 - 2 = points only when close to or actually touching an object and without coordinated eye gaze or vocalization.
 - 3 = does not point to objects in any way.

8. **Gestures** (This code includes use of any kind of conventional, emotional or descriptive gestures other than pointing. Gestures may be conventional or idiosyncratic but must be communicative. They cannot involve moving someone else's body and do not include mannerisms. Acting out routines may be coded if this is carried out in a way that is communicative, spontaneous, and appropriate. Odd gestures should not be included in coding at all unless they are the only appropriate gestures that occur.)

-
- 0 = spontaneous use of at least two different gestures of any type (descriptive, conventional, emotional or instrumental, excluding pointing); at least one used more than once. (Gestures may be conventional or not, but must be communicative.)
 - 1 = spontaneous use of descriptive, conventional, instrumental or emotional gestures, but exaggerated, or limited in range and/or contexts (e.g., only one or used only once each).
 - 2 = no spontaneous use of descriptive, conventional, instrumental or emotional gestures or inappropriate use only.
 - 8 = N/A (e.g., limited by severe motor difficulties).

B. RECIPROCAL SOCIAL INTERACTION (Unless stated otherwise, code absolutely, not in comparison to developmental level or expressive language level.)

1. **Unusual Eye Contact** (This code distinguishes clear, flexible, socially-modulated, appropriate gaze that is used for a variety of purposes, from gaze that is limited in flexibility, appropriateness or contexts. If the child is shy initially and his gaze changes markedly and consistently as he becomes more comfortable, do not code earlier aspects. However, if eye contact never improves, coding must be on what is observed, even if the child seems "shy".)

- 0 = appropriate gaze with subtle changes meshed with other communication.
 2 = uses poorly socially modulated eye contact to initiate, terminate or regulate social interaction.

2. **Responsive Social Smile** (This rating codes the child's facial response to a smile and/or playful verbal interaction by the examiner or parent/caregiver. To be coded here, the child's smile must be in response to another person rather than to an action.)

- 0 = smiles immediately to one of the first two smiles of the examiner and/or parent/caregiver. This must be a clear change from non-smiling to a fully responsive smile. The press cannot include saying, "Give me a smile."
 1 = delayed or partial smile, or smiles fully or partially only after more than two smiles by the parent/caregiver or the examiner OR smiles only in response to a specific request (e.g., "Give me a smile").
 2 = smiles fully or partially at an adult only after being tickled or touched in some way, or in response to a repeated action with a physical component (even if the child is not actually touched).
 3 = does not smile in response to another person.

3. **Facial Expressions Directed to Others** (This rating should indicate whether the child's facial expressions are directed toward another person for the purpose of communicating affect. Facial expressions that are directed toward objects or that are undirected are not rated here. Code appropriate facial expressions if they occur, even if there are also odd expressions.)

- 0 = directs a range of appropriate facial expressions toward parent/caregiver or examiner in order to communicate affect.
 1 = some direction of facial expressions to examiner and/or parent/caregiver (e.g., directs only expressions indicating emotional extremes to others, or occasionally directs wider range of expressions). A child who has a limited range of facial expressions or who only has slightly unusual facial expressions but directs most of his facial expressions to another person may be scored here.
 2 = rarely or never directs appropriate facial expressions to adults.

4. **Integration of Gaze and Other Behaviors during Social Overtures** (The focus of this item is on the quality of the child's attempts to initiate interaction, particularly the integration of gaze with other behaviors, not the frequency of such attempts. Should include attempts to get help or other highly motivated approaches. Rate the majority of these attempts, not the best.)

- 0 = effectively uses eye contact with words or vocalizations or gestures to communicate social intention.
 1 = uses eye contact and vocalization independently of each other to communicate social intention (i.e., uses both eye contact and other strategies at different times, but does not coordinate them with each other).
 2 = uses either eye contact or vocalization to communicate social intention.
 3 = uses neither eye contact nor vocalization to communicate social intention OR no social overtures.

5. **Shared Enjoyment in Interaction** (Code the child's social response during any of the activities or presses. This code should not be used to indicate the child's general emotional state during the interview. The rating applies to the child's ability to indicate pleasure to the examiner, not just to interact or respond.)

- 0 = shows definite appropriate pleasure with the examiner during more than one activity. Must include pleasure in at least one activity that is not purely physical (e.g., tickling) in nature.
- 1 = shows some appropriate pleasure in the examiner's actions during more than one activity, or shows definite pleasure directed to the examiner during one interaction (may be physical in nature).
- 2 = shows little or no expressed pleasure in interaction with the examiner. May show pleasure in own actions, in interaction with a parent, or in the available toys.

6. **Response to Name** (This rating codes the child's response to hearing his name called during a specific press. A full response is defined as orienting to and making eye contact with the examiner who calls his name. The number of presses is specified because of the increased likelihood that the child will look if provided many opportunities.)

- 0 = looks toward the examiner and makes eye contact immediately on at least one of the first two clear presses made by the examiner (i.e., name only is called).
- 1 = looks toward the parent/caregiver and makes eye contact immediately for first or second press or responds to either the third or fourth press of name only by the examiner.
- 2 = does not make eye contact with an adult after his name is called in six attempts, but shifts gaze briefly (no eye contact) in six attempts OR looks at least once when an interesting or familiar vocalization or verbalization is made (e.g., tongue clucking; "I'm gonna get you").
- 3 = does not look toward adult after any purely verbal or vocal attempt to get attention.

7. **Requesting** (Requesting is defined as a conventional indication through gesture, vocalization, facial expression or other means of the child's desire for a particular action or object. This can include requests for a social routine, balloon, bunny, bubbles or other objects or events, as long as they are not part of a routine from home and are related to a specific event or object. It does not include a general desire to be held. If the child uses more than one strategy to request different objects or activities, code the highest (i.e., closest to "0") level request. Do NOT include the child's request for snack items or a request to leave the room in this code.)

- 0 = exhibits appropriate integration of eye contact and at least one behavior (e.g., vocalization, gesture or handing an object to an adult) to request bubbles, the switch-operated animal, object routine or social routine. Must include eye contact with an adult and a definite indication of wanting the adult to do or give something (e.g., by persisting in the request if the adult pauses before responding). This does not include physically pulling or placing the examiner's hand to an object or to himself.
- 1 = uses one or more behavior(s) listed above to request the animal, bubbles and/or a routine without integrating eye contact and other behavior(s), such as vocalization or gesture or handing an object without looking at an adult, or looking at an adult without another behavior. It does not include physically pulling the examiner's hand to an object or to himself. It includes very brief requests, as in "0," but without persistence.
- 2 = does not directly request as specified in "0" or "1", but uses some physical means to request at least one action as part of a routine (e.g., pulls the examiner's hand to an object or to himself).
- 3 = may participate in routine(s) or try to activate an object by vocalizing, banging or other actions (e.g., blowing) without looking at or vocalizing to the adult for help, but does not request as specified above.

8. **Giving** (This code describes handing objects to another person across a range of contexts, including sharing and getting help. It does not require eye contact but does imply independent, spontaneous release of the object.)

- 0 = spontaneously gives toys or objects to other people in a variety of contexts throughout the ADOS-G, including giving toys, food or pretend food for the purpose of sharing.
- 1 = gives objects to other people for the purpose of getting help (e.g., in operating toys or opening food containers) or as part of a routine.
- 2 = rarely or never gives anything to another person.

9. **Showing** (Showing is defined as deliberately orienting or placing an object where it can be seen by another person with no identifiable purpose of getting help or participating in a routine. For full credit, it requires eye contact but not vocalization.)

- 0 = spontaneously shows toys or objects throughout the ADOS-G by holding them up or placing them in front of adults and using eye contact with or without vocalization.
- 1 = shows toys or objects in a partial or inconsistent manner, (e.g., holds them up and/or places them in front of adults without coordinated eye contact, looks from an object in his hands to an adult without clearly orienting it toward the adult, or shows objects as in "0" on one occasion only).
- 2 = does not show objects to another person.

10. **Spontaneous Initiation of Joint Attention** (This rating codes the child's attempts to draw an adult's attention to objects that neither of them is touching and that is not for the purpose of requesting.)

- 0 = uses clearly integrated eye contact to reference an object that is out of reach by looking at the object, at an adult and back to the object. Eye contact may be coordinated with pointing and/or vocalization. One clear example of an attempt to draw an adult's attention to an object (i.e., more than just referencing) is sufficient for a "0".
- 1 = partially references an object that is clearly out of reach. May spontaneously look and point to the object and/or vocalize, but does not coordinate either of these with looking at an adult, or may look at an object and then an adult or point to an adult but not look back at the object.
- 2 = no approximation of spontaneous initiation of joint attention in order to reference an object that is out of reach.

11. **Response to Joint Attention** (This rating codes the child's response to the examiner's use of gaze and/or pointing in order to direct his attention to a distant object. The codes should not be affected by the child's understanding of language [i.e., the child must follow the direction of the examiner's gaze or point, but does not have to understand what was said].)

- 0 = uses the orientation of the examiner's eyes and face as a cue to look toward the target, without a point. The child must follow the examiner's gaze and turn his face or eyes in the direction of the target after watching the examiner do so; he may or may not actually catch sight of the target.
- 1 = responds to a point by looking at or toward the target.
- 2 = looks at the target when it is activated or placed directly in front of him, but does not make use of the gaze or point in order to locate the target from a distance.
- 3 = no interest or awareness of the target; if it is not possible to get the child's attention in order to direct it in five attempts, code here.

12. **Quality of Social Overtures** (This is a summary code that focuses on the quality of the participant's attempts to initiate social interaction. NOT on the frequency of such attempts. Special attention should be given to the form of the overtures and their appropriateness to the social context. Code the majority of overtures, not the best.)

- 0 = *effectively uses nonverbal and verbal vocal means to make clear social overtures to the parents or examiner that are appropriate to immediate contexts.*
- 1 = *slightly unusual quality of social overtures. Code here if overtures are restricted to personal demands or related to strong interests, but with some attempt to involve the parents or examiner in the interest.*
- 2 = *overtures often lack integration into context AND/OR social quality AND/OR some clearly inappropriate overtures.*
- 3 = *negligible social overtures of any kind.*

C. **PLAY** (Code absolutely)

1. **Functional Play with Objects** (This code describes appropriate use of toys or miniatures as they are intended. Code all play with a doll under Imaginative Play below. Exclude responses to directions from a parent /caregiver or examiner.)

- 0 = *spontaneously plays with a variety of toys in a conventional manner, including construction with manipulatives (e.g., blocks) and/or appropriate play with miniatures (e.g., telephone, truck, dishes). Do not code imitations or pushing the car here.*
- 1 = *some spontaneous functional play with at least one miniature. Does not include pushing the car or using a construction toy.*
- 2 = *plays appropriately with cause and effect toys and/or construction toys only and/or pushing the car; may include imitating a demonstration or imitating more representational play with other toys.*
- 3 = *no play with toys or only stereotyped play with toys.*

2. **Imagination** (This code describes flexible, creative use of objects in a representational manner that goes beyond the physical properties of the materials, e.g., beyond placing toy spoons on toy plates. Any use of the doll should be coded here, as specified.)

- 0 = *spontaneous use of a doll or other object as an independent agent or uses objects to represent objects (e.g., using a block to give the doll a drink).*
- 1 = *spontaneous pretend play with a doll (e.g., feeding, hugging or giving a drink) or other objects, but no use of a doll or other toy as an independent agent or placeholder.*
- 2 = *imitates pretend play as described in "1" or imitation with a placeholder; no spontaneous pretend play.*
- 3 = *no pretend play.*

D. STEREOTYPED BEHAVIOR AND RESTRICTED INTERESTS (code all items below without reference to developmental level or estimated language age unless otherwise specified)

- 1. Unusual Sensory Interest In Play Material/Person** (Code interest in or unusual response to sensory aspects of toys or surroundings. If the child has a preoccupation that is based on a sensory interest, this may be coded here as one unusual sensory interest. For example, if he shows an interest in table legs for long periods of time, this is coded under repetitive and stereotyped behaviors; if he is interested in table legs and he likes to look at them as shown by his peering at them and tilting his head, it should be coded under repetitive and stereotyped behaviors if it is a persistent behavior, but may also be coded here as a "1" because of the sensory component involved. If the child likes to look at table legs, the corners of the room, the doors on the Poppin' Pals and the slats of the window blinds, but does not become overly preoccupied with any of them, he should receive a "2" for unusual sensory interests and a "0" for repetitive interests and stereotyped behaviors. Mouthing is not coded in Module 1.)

- 0 = *no sniffing, repetitive touching, feeling of texture, licking or biting (not mouthing), interest in the repetition of or unusually strong reactions to certain sounds, or unusual or prolonged visual examination.*
- 1 = *occasional unusual sensory interests or responses. (OR not as clear as specified for a rating of "2".)*
- 2 = *definite interest in nonfunctional elements of play materials or sensory examination of self or others on more than one occasion or persistent unusual sensory response to several materials or events.*

SPECIFY:

- 2. Hand and Finger and Other Complex Mannerisms** (Code unusual and/or repetitive movements or posturing of the hands and fingers, arms or whole body. Clapping is not coded in Module 1. Do not include body rocking unless it involves more than the torso. Finger tapping, nail biting, hair twisting or thumb sucking are also not coded here. Children do not have to watch the movements of their fingers or hands in order to be coded here.)

- 0 = *none.*
- 1 = *very brief or rare hand and finger mannerisms or complex mannerisms or mannerisms not as clear as specified for a rating of "2".*
- 2 = *definite finger flicking twisting and/or hand or other mannerisms or stereotypies.*

SPECIFY:

- 3. Self-Injurious Behavior** (Code any behaviors that involve any kind of aggressive act to self, even if not clearly harmful.)

- 0 = *no attempts to harm self.*
- 1 = *rare and/or dubious self-injury (e.g., at least once bites at own hand or arm, pulls own hair, slaps own face or hangs head).*
- 2 = *self-injury definitely present (e.g., more than one example of head-banging, face slapping, hair pulling or self-biting.)*

4. **Unusually Repetitive Interest or Stereotyped Behaviors** (Code any unusually repetitive or stereotyped behaviors including preoccupation with unusual objects or activities such as table legs or watches; repetitive non-functional use of toys such as spinning wheels or lining things up or flicking the doll's eyes for more than 2 or 3 seconds; repetitive actions such as hanging objects or putting fingers in ears; and insistence on unusual routines or ritualized behaviors such as specific ways of touching or moving objects or insistence on having an adult act in a specific way.)

- 0 = no repetitive or stereotyped behaviors during the ADOS-G.
- 1 = an interest or behavior that is repetitive or stereotyped to an unusual degree, including an intense interest in a particular toy or object, a definite interest in an unusual object or activity (odd for the child's level of motor skill), an unusually routinized activity, frequent repetitive use of objects, or a clear interest in a part of an object. This interest or behavior occurs in conjunction with several other activities, and does not prevent the child from completing any ADOS-G activities.
- 2 = repetitive or stereotyped interests and/or behaviors, as described above, form a substantial minority of the child's interests and spontaneous behaviors. These interests and behaviors may interfere with the child's ability to complete the ADOS-G activities, but it is possible for the child's attention to be directed to other objects or activities at least momentarily. If necessary to remove the objects from the room, code here.
- 3 = repetitive or stereotyped interests and/or behaviors, as described above, form the majority of the child's interests. OR attempts to direct the child to other objects or activities are met with resistance and/or distress.

SPECIFY UNUSUAL PREOCCUPATIONS, RITUALS, REPETITIVE BEHAVIORS:

E. **OTHER ABNORMAL BEHAVIORS** (Code absolutely unless otherwise stated.)

1. **Overactivity** (This item is coded in term of expectations for remaining still and/or seated based on general developmental level.)

- 0 = sits or stands still appropriately when expected to do so during the assessment.
- 1 = sits briefly or stands still when expected to do so (e.g., during the symbolic imitation task, the birthday party) for activities besides snack. Often fidgets or moves about or gets up out of his seat, but is not obviously restless or unusually fidgety. Difficulties in the assessment are not principally due to overactivity.
- 2 = hardly remains still at all (not counting the snack). May move around the room in a way that is difficult to interrupt; the level of activity disrupts the assessment.
- 7 = underactive.

2. **Tantrums, Aggression, Negative or Disruptive Behavior** (This code includes any form of anger or disruption beyond communication of mild frustration or whining.)

- 0 = not upset, disruptive, negative, destructive or aggressive during ADOS-G.
- 1 = occasional display of mild upset, anger, aggression, negativism or disruptive behavior to parent-caregiver or examiner.
- 2 = shows marked or repeated negativism, temper tantrums or more significant aggression; e.g., hitting, tantrumming, biting others. Loud screaming is included here.

3. **Anxiety** (Anxiety includes initial wariness, as well as more obvious signs of worry or concern.)

- 0 = no obvious anxiety (such as trembling or jumpiness).
- 1 = mild signs of anxiety especially at the beginning of the interview or marked anxiety only in response to a specific request or to one particular toy or task.
- 2 = marked anxiety in response to more than one toy or task or several times during the session.

Name of Child _____ DOB _____ DOE _____ CA _____ Examiner _____

ADOS-G Module 1

Proposed ADOS-G Algorithm for DSM-IV/ICD-10 Autism
(Convert 3s from the protocol to 2s. Treat all numbers other than 0-3 as 0.)

| | | |
|--|--------------|-------|
| Communication | | |
| Frequency of Vocalization Directed to Others | (A-2) | _____ |
| Stereotyped/Idiosyncratic Words or Phrases | (A-5) | _____ |
| Use of Other's Body to Communicate | (A-6) | _____ |
| Pointing | (A-7) | _____ |
| Gestures | (A-8) | _____ |
| Communication (Autism cut-off = 4; Autism spectrum cut-off = 2) | Total | _____ |
| Qualitative Impairments in Reciprocal Social Interaction | | |
| Unusual Eye Contact | (B-1) | _____ |
| Facial Expressions Directed to Others | (B-3) | _____ |
| Shared Enjoyment in Interaction | (B-5) | _____ |
| Showing | (B-9) | _____ |
| Spontaneous Initiation of Joint Attention | (B-10) | _____ |
| Response to Joint Attention | (B-11) | _____ |
| Quality of Social Overtures | (B-12) | _____ |
| Social (Autism cut-off = 7; Autism spectrum cut-off = 4) | Total | _____ |
| Communication+Social (Autism cut-off = 12; Autism spectrum cut-off = 7) | Total | _____ |

| | | |
|------------------------------|--------------|-------|
| Play | | |
| Functional Play with Objects | (C-1) | _____ |
| Imagination/Creativity | (C-2) | _____ |
| Play | Total | _____ |

Stereotyped Behaviors and Restricted Interests

| | | |
|---|--------------|-------|
| Unusual Sensory Interest in Play Material/Person | (D-1) | _____ |
| Hand and Finger and Other Complex Mannerisms | (D-2) | _____ |
| Unusually Repetitive Interests or Stereotyped Behaviors | (D-4) | _____ |
| Stereotyped Behaviors and Restricted Interests | Total | _____ |

Diagnosis

ADOS-G Classification: _____

Overall Diagnosis: _____

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APPENDIX K

PSYCHOEDUCATIONAL PROFILE – REVISED (PEP-R)

PSYCHOEDUCATIONAL PROFILE REVISED

PEP-R Summary Sheet

| Year Month Day |
|-------------------|
| Date of Test |
| Date of Birth |
| Chronological Age |

| Behavioral Scale | A | M | S |
|------------------|---|---|---|
| Relating (R) | | | |
| Materials (M) | | | |
| Sensory (S) | | | |
| Language (L) | | | |

| Developmental Scale | P | E | F |
|---------------------|---|---|---|
| Imitation (I) | | | |
| Perception (P) | | | |
| Fine Motor (FM) | | | |
| Gross Motor (GM) | | | |
| Eye-Hand (EH) | | | |
| Performance (CP) | | | |
| Verbal (CV) | | | |
| Developmental Score | | | |
| Developmental Age | | | |

| | |
|------------|----------------|
| Name | Classroom |
| Sex Case # | School |
| Examiner | Town or County |

Physical Description

Significant Limitations

Behavioral Observations

Spontaneous Communication Sample

PEP-R Score Sheet 1

Bubbles

1. Unscrews Lid on Jar
2. Blows Bubbles
3. Visually Tracks Movement
4. Visual Pursuit Across Midline

| Behavioral | | | |
|------------|---|---|---|
| R | M | S | L |
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| Developmental | | | | | | |
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| I | P | FM | GM | EH | CP | CV |
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Tactile Blocks

5. Examines Tactile Blocks (A/M/S)

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Kaleidoscope

6. Manipulates Kaleidoscope
7. Displays Eye Dominance

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Call Bell

8. Taps Call Bell Twice

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Clay and Dowels

9. Pokes with Finger
10. Grasps Dowel (score P if 12 = P)
11. Rolls Clay
12. Makes Clay Bowl

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Cat and Dog Puppets and Objects (spoon, cup, toothbrush, tissue)

13. Manipulates Puppet
14. Imitates Animal Sounds
15. Imitates Actions with Objects (3)
16. Points to Puppet's Body Parts (eye, nose, ear, mouth) (3)
17. Points to Own Body Parts (eye, nose, ear, mouth) (3)
18. Complex Play Interaction (story) (score F if 13 = F)

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| P | | | | | | | |
| E | | | | | | | |
| F | | | | | | | |

PEP-R Score Sheet 2

Behavioral

Developmental

Geometric Form Board

19. Indicates Correct Slots (3)

20. Fits Shapes into Slots (3)

21. Expressively Identifies Shapes (3)

22. Receptively Identifies Shapes (3)

Objects Form Board

(umbrella, chick, butterfly, pear)

23. Completes Form Board

24. Crosses Midline to Get Puzzle Pieces

Size Form Board (mittens)

25. Indicates Slots by Size

26. Fits Pieces into Slots by Size

27. Expressively Identifies Big and Little

28. Receptively Identifies Big and Little

Interlocking Kitten Puzzle

29. Indicates Placement of Puzzle Pieces (score F if 23 = F)

30. Interlocks Puzzle Pieces (score F if 23 = F)

Cow Puzzle

31. Completes Cow Puzzle (score F if 23 = F)

Colored Disks and Blocks

32. Matches Blocks with Disks (5)

33. Expressively Labels Colors (5)

34. Receptively Labels Colors (5)

Clapper

35. Hears and Orients to Sound of Clapper

36. Reacts to Sound of Clapper (A/M/S)

| R | M | S | L |
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| P | | | | | | | |
| E | | | | | | | |
| F | | | | | | | |

PEP-R Score Sheet 3

Physical Activity

- 37. Walks Alone
- 38. Claps Hands
- 39. Stands on One Foot (score F if 37 = F)
- 40. Jumps Up and Down on Both Feet (score F if 37 = F or E)
- 41. Imitates Gross Motor Movements (raise arm, touch nose, touch nose and raise other arm)
- 42. Touches Thumb to Fingers in Sequence

Ball

- 43. Catches Ball (1 of 3)
- 44. Throws Ball (1 of 3)
- 45. Kicks Ball (1 of 3)
- 46. Displays Foot Dominance
- 47. Carries Ball (4 steps) (score F if 37 = F)
- 48. Pushes Ball (score P if 44 = P)

Stairs

- 49. Climbs Stairs Using Alternating Feet (score F if 37 = F)

Chair

- 50. Climbs into Chair

Wheeled Walker

- 51. Pushes Self in Walker

Towel or Cup and Favored Toy

- 52. Social Baby Games (score P if 18 = P)
- 53. Finds Hidden Object (score P if 108 = P)

Mirror

- 54. Reacts to Own Reflection in Mirror (A/M/S)

Physical Contact

- 55. Reacts to Physical Contact (A/M/S)

Behavioral

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PEP-R Score Sheet 4

Behavioral

Developmental

Tickling

56. Reacts to Being Tickled (A/M/S)

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Whistle

57. Hears and Orients to Sound of Whistle

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58. Reacts to Sound of Whistle (A/M/S)

Gestures

59. Responds to Gestures

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Cup and Juice

60. Drinks from Cup

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Jar and Favored Object

61. Gestures for Help

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Beads, Heavy String, Spindle

62. Reacts to String (A/M/S)

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63. Strings Beads (1)

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64. Swings Beads on String

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65. Takes Beads off Pipe Cleaner (6)

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66. Threads Beads on Spindle (3) (score P if 63 = P)

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67. Uses Hands Cooperatively

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68. Transfers Objects from Hand to Hand

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Identification

69. What's Your Name?

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70. Are You a Boy or a Girl?

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Child's Writing Book

71. Scribbles Spontaneously

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72. Displays Hand Dominance

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PEP-R Score Sheet 5

Child's Writing Book, Continued

- 73. Copies Vertical Line (1 of 3) (score F if 71 = F)
- 74. Copies Circle (1 of 3) (score F if 71 = F)
- 75. Copies Square (1 of 3) (score F if 73 = F)
- 76. Copies Triangle (1 of 3) (score F if 73 = F)
- 77. Copies Diamond (1 of 3) (score F if 73 = F)
- 78. Colors in Lines (score F if 71 = F)
- 79. Traces Shapes (score P if 74-77 = P or E)

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Alphabet Lotto Card

- 80. Matches Letters (9)
- 81. Expressively Identifies Letters (9)
- 82. Receptively Identifies Letters (9)
- 83. Copies Letters (7) (score F if 73 = F)
- 84. Draws a Person (score F if 73 = F)
- 85. Writes First Name (score F if 83 = F)

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Paper and Scissors

- 86. Cuts Paper with Scissors

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Pouch with 5 Objects

- 87. Identifies and Hands Objects (4) (may need visual samples)
- 88. Identifies Objects by Touch (4) (no visual samples)

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Felt Board and Pieces

- 89. Makes Boy out of Felt Pieces

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Unstructured Play

- 90. Plays Alone (A/M/S)
- 91. Initiation of Social Interaction (A/M/S)
- 92. Response to Examiner's Voice (A/M/S)

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PEP-R Score Sheet 6

Small Blocks and Box

- 93. Stacks Blocks (8)
- 94. Puts Block in Box
- 95. Counts 2 and 7 Blocks
- 96. Receptively Counts 2 and 6 Blocks

Behavioral

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Developmental

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Cup and Blocks

- 97. Carries Out 2-Step Direction

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Blocks, Checkers, Containers

- 98. 2-Way Sort (6) (score F if 94 = F)
- 99. Drop in Bucket (score P if 98 = P or E)

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Digit Imitation

- 100. Repeats 2 and 3 Digits
- 101. Repeats 2 and 3 Digits 1st trial: 7-9, 2-4-1
2nd trial: 5-3, 5-7-9
- 102. Repeats 4 and 5 Digits (score F if 100 = F)
- 103. Repeats 4 and 5 Digits 1st trial: 5-8-6-1, 3-2-9-4-8
2nd trial: 7-1-4-2, 7-4-8-3-1

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Rote Counting

- 104. Counts Aloud (1-10)

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Number Cards

- 105. Expressively Identifies Numbers (10)

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Adding and Subtracting

- 106. Solves Second-Person Problems (2)
(score F if 95 = F)
- 107. Solves Third-Person Problems (2)
(score F if 95 = F)

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PEP-R Score Sheet 7

3 Cups and Candy

108. Finds Candy Under Cup (2) (score F if 53 = F or E)

109. Uses Pincer Grasp

Function Cards

110. Pantomimes Use of Objects (5)

Handbell

111. Hears and Orients to Sound of Handbell

112. Reacts to Sound of Handbell (A/M/S)

Handbell, Clapper, Spoon

113. Imitates with Noisemakers (3)

Category Cards

114. Sorts Cards by Color or Shape (12)
(score F if 32 = F or E)

Matching Cards and Objects

115. Matches Objects to Pictures (5)

116. Names Objects (5)

117. Gives Objects on Request (3)

118. Demonstrates Functions of Objects (4)

Light Switch

119. Flips Light Switch

Language Book

120. Shows Interest in Book

121. Receptively Identifies Pictures (14)

122. Expressively Identifies Pictures (14)

Repeats Sounds, Words, and Sentences

123. Repeats Sounds (3) (mmm, ba-ba, pa-ta, la-la)

124. Repeats Words (2) (up, cook, baby)

Behavioral

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PEP-R Score Sheet 8

Repeats Sounds, Words, and Sentences, Continued

125. Repeats Short Sentences or Phrases (2)
(score F if 124 = F)

126. Repeats Simple Sentences (2)
(score F if 125 = F or E)

127. Repeats Complex Sentences (2)
(score F if 126 = F or E)

Box, Puppet, Cup, Chair, Ball

128. Responds to Verbal Directions (4)

Imitation

129. Responds to Imitation of Own Actions
(score P if 41 = P)

130. Responds to Imitation of Own Sounds
(score P if 124 = P)

Commands

131. Responds to Simple Commands (3)

Child's Use of Language

132. Uses 2-Word Phrases (3)

133. Uses 4- or 5-Word Phrase (1)

134. Uses Plurals (2)

135. Uses Pronouns (1)

Language Book

136. Reads Short Words (3)

137. Reads Short Sentence (1) (score F if 136 = F or E)

138. Reads with Few Errors (score F if 137 = F or E)

139. Reads with Comprehension (2)
(score F if 137 = F or E)

140. Reads and Follows Directions
(score F if 137 = F or E)

Finished Box

141. Anticipates Routines

Waves

142. Waves Bye-Bye (score P if 41 = P)

Pinch

143. Reaction to Pinch (A/M/S)

Behavioral

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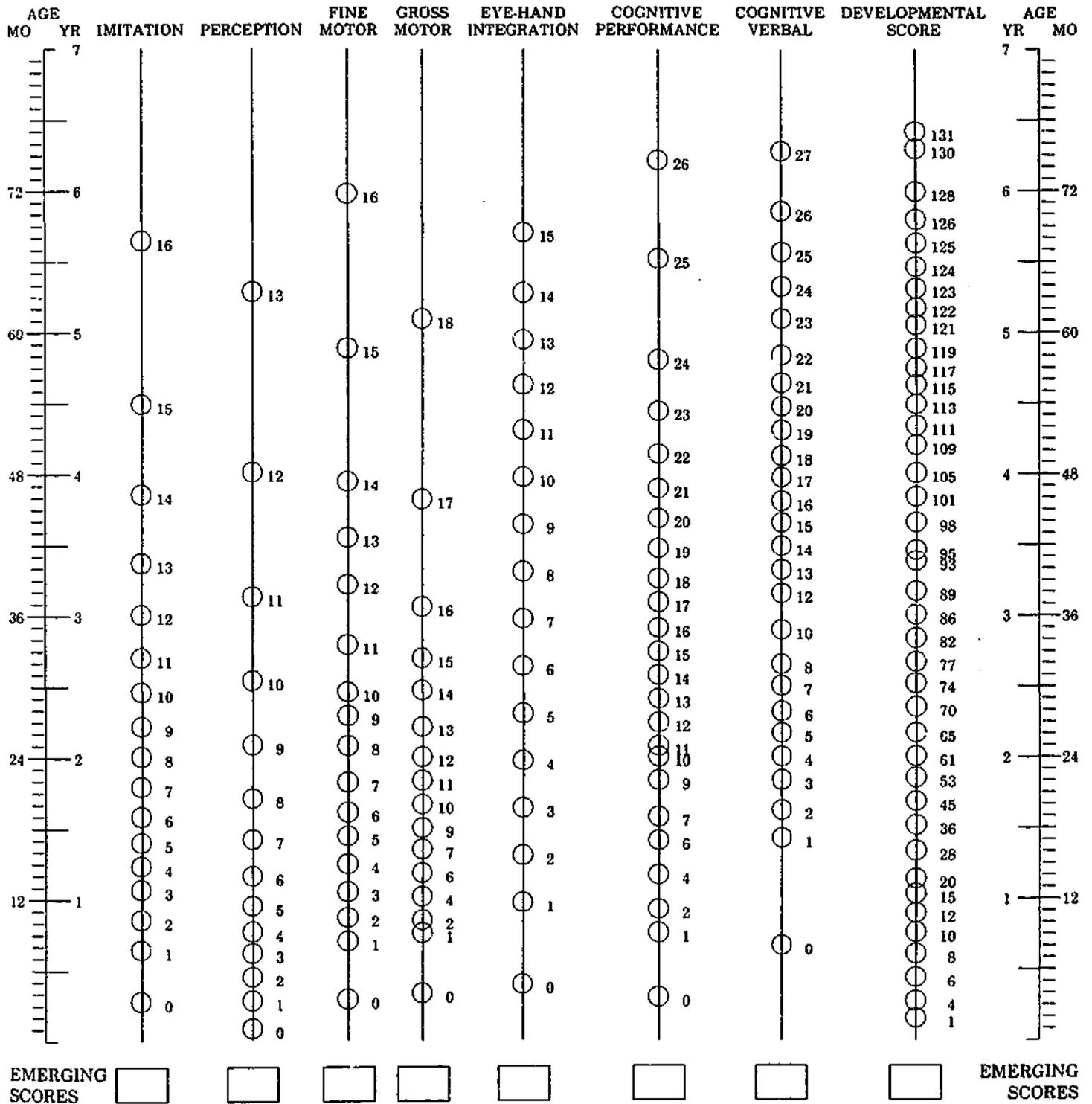
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PEP-R DEVELOPMENTAL SCALE PROFILE

Name _____ Case # _____

Date of Test _____ Date of Birth _____ Chronological Age _____

Mark the point on each scale that represents the number of Ps (passes) scored in that Developmental area. In the Developmental Score column, mark the point that represents the total number of Ps for all seven Developmental areas. (Where a number is missing in the scale, mark the next lowest point on the scale.) In the box at the bottom of each column, record the total E (emerging) scores for that Developmental area. These Emerging scores reflect the child's readiness to learn new skills and indicate appropriate starting points for educational programming.



EMERGING SCORES

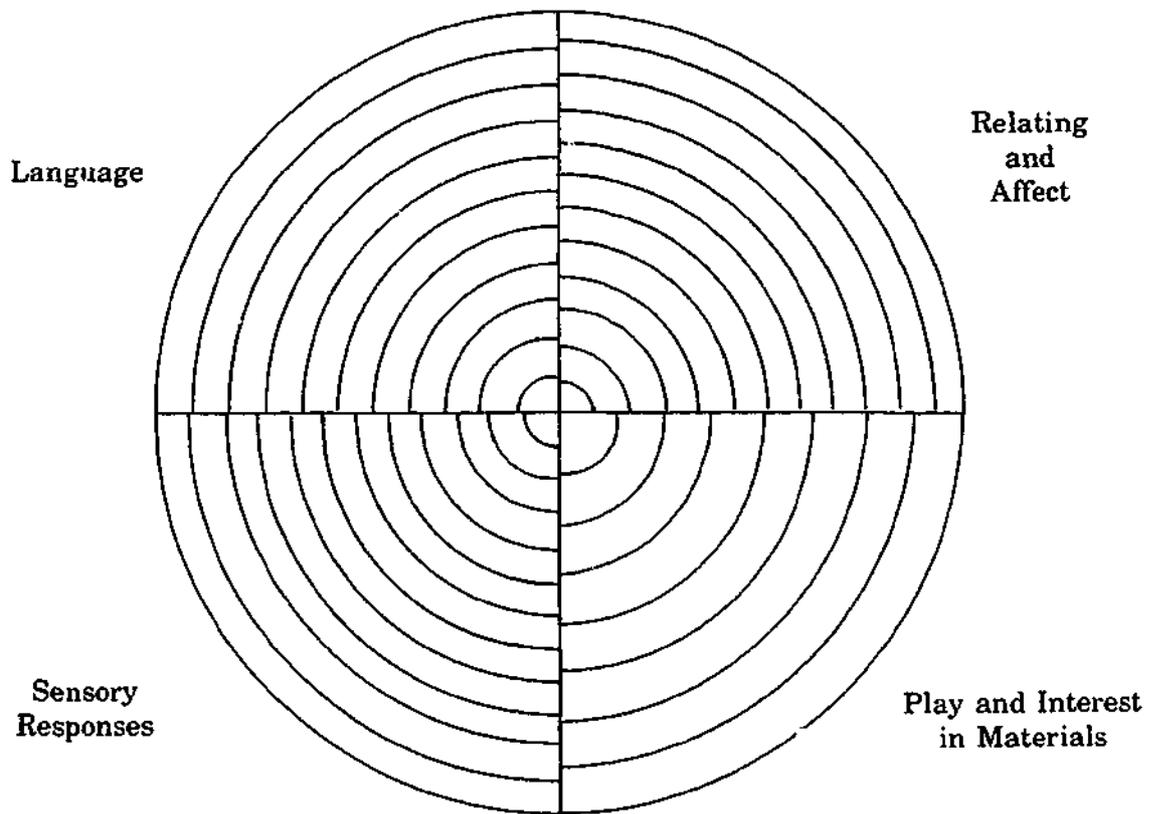
EMERGING SCORES

PEP-R BEHAVIORAL SCALE PROFILE

Name _____ Case # _____

Date of Test _____ Date of Birth _____ Chronological Age _____

Starting at the center of the circle, blacken the number of rings corresponding to the number of items scored S (severe) in each Behavioral area. Lightly shade the number of items scored M (mild) in the respective Behavioral areas. Leave any remaining rings blank.



Additional copies of this form (#1493)
may be ordered from:



8700 Shoal Creek Boulevard
Austin, Texas 78757

APPENDIX L

REYNELL DEVELOPMENTAL LANGUAGE SCALES

Record Booklet

Comprehension & Expressive Scales

RIDS

The Reynell Developmental Language Scales III
The University of Reading Edition

Name: _____ (M/F): _____

Date of birth: _____ Date of testing: 1st session: _____
2nd session: _____

School/Nursery: _____

Tester: _____

| Percentile score | | Standard score | | CA* | | Raw score | | Age equivalent | |
|------------------|-----|----------------|-----|-----|-----|-----------|-----|----------------|-----|
| 1st | 2nd | 1st | 2nd | 1st | 2nd | 1st | 2nd | 1st | 2nd |

Comprehension

Expressive

Comments

*Chronological age



| | | Comments | Score |
|--|--|----------|-------|
| Ai | SINGLE WORDS (<i>teddy, brush, cup, sock, doll, purse</i>)* | | |
| Where's the... | | | |
| 1 |  | teddy | |
| 2 |  | brush | |
| 3 |  | cup | |
| 4 |  | sock | |
| 5 |  | doll | |
| 6 |  | purse | |
| Aii | SINGLE WORDS (<i>apple, keys, chair, fish, cheese, table, watch, horse, bath</i>) | | |
| Where's the... | | | |
| 7 |  | apple | |
| 8 |  | keys | |
| 9 |  | chair | |
| 10 |  | fish | |
| 11 |  | cheese | |
| 12 |  | table | |
| 13 |  | watch | |
| 14 |  | horse | |
| 15 |  | bath | |
| Comprehension Scale: Section A Score (max. 15) | | | |

| | | | |
|---|---|----------------------------------|--|
| B | RELATING TWO NAMED OBJECTS (<i>teddy, bed, keys, box, apple, chair</i>) | | |
| 16 |  | Put teddy on the bed. | |
| 17 |  | Put the keys in the box. | |
| 18 |  | Give me the apple and the teddy. | |
| 19 |  | Put the apple on the bed. | |
| 20 |  | Give me the bed and the chair. | |
| 21 |  | Put the keys on the bed. | |
| Comprehension Scale: Section B Score (max. 6) | | | |

| | | | |
|---|---|-------------------|--|
| C | AGENTS AND ACTIONS (<i>rabbit, teddy</i>) | | |
| 22 |  | Make teddy sit. | |
| 23 |  | Make rabbit jump. | |
| 24 |  | Make teddy walk. | |
| Comprehension Scale: Section C Score (max. 3) | | | |

*Toys required for each section are shown in brackets.

2 Illegal photocopying is theft and may result in prosecution.

| | | Comments | Score |
|---|---|----------------------------|-------|
| D | CLAUSAL CONSTITUENTS (<i>teddy, rabbit, box, bed</i>) | | |
| 25 |  | Make teddy push the box. | |
| 26 |  | Make rabbit push the bed. | |
| 27 |  | Make teddy touch the bed. | |
| 28 |  | Make teddy sit on the box. | |
| Comprehension Scale: Section D Score (max. 4) | | | |

| | | | |
|---|---|---------------------------|--|
| E | ATTRIBUTES (<i>picture book</i>) | | |
| 29 |  | Show me the red car. | |
| 30 |  | Show me the blue box. | |
| 31 |  | Show me the sad cat. | |
| 32 |  | Show me the little clown. | |
| Comprehension Scale: Section E Score (max. 4) | | | |

| | | | |
|---|---|--|--|
| F | NOUN PHRASES (<i>pencils, buttons, cup, box</i>) | | |
| 33 |  | Put the longest red pencil in the box. | |
| 34 |  | Put all the white buttons in the cup. | |
| 35 |  | Which pencil has been put away ? | |
| 36 |  | Take two buttons out of the cup. | |
| 37 |  | Which red pencil has not been put away ? | |
| Comprehension Scale: Section F Score (max. 5) | | | |

| | | | |
|---|---|----------------------------------|--|
| G | LOCATIVE RELATIONS (<i>teddy, truck</i>) | | |
| 38 |  | Put teddy on top of the truck. | |
| 39 |  | Put teddy next to the truck. | |
| 40 |  | Put teddy under the truck. | |
| 41 |  | Put teddy behind the truck. | |
| 42 |  | Put teddy in front of the truck. | |
| Comprehension Scale: Section G Score (max. 5) | | | |

| | | | |
|---|---|---|--|
| H | VERBS AND THEMATIC ROLE ASSIGNMENT (<i>picture book</i>) | | |
| Show me: | | | |
| 43 |  | the girl's splashing the boy. (a b c d) | |
| 44 |  | the boy's carrying an elephant. (a b c d) | |
| 45 |  | the police car's chasing the red lorry. (a b c d) | |
| 46 |  | the baby's pushing the mummy. (a b c d) | |
| 47 |  | the bird's watching the girl. (a b c d) | |
| Comprehension Scale: Section H Score (max. 5) | | | |

Comprehension Scale

| | | Comments | Score |
|---|---|---|-------|
| I | VOCABULARY AND COMPLEX GRAMMAR (<i>picture book</i>) | | |
| | Show me: | | |
| 48 | <input type="checkbox"/> | the sheep was pushed. (a b c d) | |
| 49 | <input type="checkbox"/> | the bull was chased. (a b c d) | |
| 50 | <input type="checkbox"/> | the girl who is wearing a hat is running. (a b c d) | |
| 51 | <input type="checkbox"/> | which horse is not outside the field. (a b c d) | |
| 52 | <input type="checkbox"/> | the car is furthest away. (a b c d) | |
| 53 | <input type="checkbox"/> | the boy followed the policeman who was fat. (a b c d) | |
| 54 | <input type="checkbox"/> | all the girls except one are eating. (a b c d) | |
| Comprehension Scale: Section I Score (max. 7) | | | |

| | | | |
|---|--|---|--|
| J | INFERENCE (<i>picture book</i>) | | |
| 55 | <input type="checkbox"/> | Who's being naughty? | |
| 56 | <input type="checkbox"/> | Who is too young to eat food here? | |
| 57 | <input type="checkbox"/> | Who might not be able to have any food? | |
| 58 | <input type="checkbox"/> | Who will get their food very soon? | |
| 59 | <input type="checkbox"/> | Who is feeling very upset? | |
| 60 | <input type="checkbox"/> | Who will have to wait a long time for their food? | |
| 61 | <input type="checkbox"/> | Who doesn't come here to buy food? | |
| 62 | <input type="checkbox"/> | Whose daughter is having a birthday party? | |
| Comprehension Scale: Section J Score (max. 8) | | | |

| | | | |
|--|--|--|--|
| Comprehension Scale: Total Score (Sections A-J, max. 62) | | | |
|--|--|--|--|



Toy(s) required to administer this item Picture(s) required to administer this item

All toys required for each section are shown in brackets

| Stimulus (Target) | | Response | Score |
|--|---|------------------------|-------|
| A SINGLE WORDS (<i>doll, chair, apple, ball, spoon, teddy, sock, keys, duck, cup</i>) | | | |
| 1 |  | What's this? (doll) | |
| 2 |  | What's this? (chair) | |
| 3 |  | What's this? (apple) | |
| 4 |  | What's this? (ball) | |
| 5 |  | What's this? (spoon) | |
| 6 |  | What's this? (teddy) | |
| 7 |  | What's this? (sock) | |
| 8 |  | What are these? (keys) | |
| 9 |  | What's this? (duck) | |
| 10 |  | What's this? (cup) | |
| Expressive Scale: Section A Score (max. 10) | | | |

| | | | |
|--|---|---|--|
| Bi VERBS (<i>teddy, bed, apple, chair, truck, sponge</i>) | | | |
| |  | I'm going to make teddy do things. You tell me what he's doing. <i>Example: Look, teddy's dancing. What's teddy doing?</i> Teddy's... | |
| 11 |  | Look, teddy's jumping on the bed. What's teddy doing? Teddy's... (jump/ing) | |
| 12 |  | Now what's teddy doing? Teddy's... (eat/ing) | |
| 13 |  | What's teddy doing? Teddy's... (sit/ing) | |
| 14 |  | What's teddy doing? Teddy's... (wash/ing truck) | |
| Bii PHRASES (<i>picture book</i>) | | | |
| |  | Here is a plate and here is a cup. This time there is a big key in the picture. | |
| 15 |  | You tell me where the key is. (on the plate) | |
| |  | Here is a big cat; here is a small cat. Here is a happy teddy and here is a sad teddy. I'm going to show you one of the pictures. | |
| 16 |  | You tell me which one it is. (happy teddy) | |
| Expressive Scale: Section B Score (max. 6) | | | |

Expressive Scale

| Stimulus (Target) | Response | Score |
|--|----------|-------|
| Ci INFLECTIONS - PLURALS (picture book) | | |
| <input type="checkbox"/> <input type="checkbox"/> Example: Here is one cat. Here is another cat; so now there are two... | | |
| 17 <input type="checkbox"/> <input type="checkbox"/> (bananas) | | |
| 18 <input type="checkbox"/> <input type="checkbox"/> (balloons) | | |
| 19 <input type="checkbox"/> <input type="checkbox"/> (hats) | | |
| 20 <input type="checkbox"/> <input type="checkbox"/> (books) | | |
| 21 <input type="checkbox"/> <input type="checkbox"/> (cows) | | |
| 22 <input type="checkbox"/> <input type="checkbox"/> (buses) | | |
| Cii INFLECTIONS - THIRD PERSON (picture book) | | |
| <input type="checkbox"/> <input type="checkbox"/> Example: Every day this lady dances. What does she do every day? She... NB If no response, prompt with: What does he/she do every day/week? | | |
| 23 <input type="checkbox"/> <input type="checkbox"/> Every day I eat dinner, every day you eat dinner. Every day he... (eats) | | |
| 24 <input type="checkbox"/> <input type="checkbox"/> Look at this girl. Every day she... (runs) | | |
| 25 <input type="checkbox"/> <input type="checkbox"/> Here's another girl. Every day she... (reads) | | |
| 26 <input type="checkbox"/> <input type="checkbox"/> Every week I wash my car. Look at the lady. Every week she... (washes) | | |
| Ciii INFLECTIONS - PAST TENSE (picture book) | | |
| <input type="checkbox"/> <input type="checkbox"/> Example: Now I'm going to tell you about some things that happened yesterday. Yesterday these children painted. What did they do yesterday? They... NB Prompt with: Yesterday she/he... | | |
| 27 <input type="checkbox"/> <input type="checkbox"/> This baby cries a lot. Yesterday he... (cried) | | |
| 28 <input type="checkbox"/> <input type="checkbox"/> This lady likes walking. Yesterday she... (walked) | | |
| Expressive Scale: Section C Score (max. 12) | | |

| Stimulus (S) | Target (T) | Response (R) | Score |
|--|---|--------------|-------|
| D 3 AND 4 CLAUSAL (teddy, rabbit, flag, apple, table, bed, blue car, red car, bricks, truck, knife) | | | |
| | Now the toys are going to do some things and I want you to tell me about them. | | |
| 29  | (S) Teddy's waving the flag. Now you tell me what's happening. (T) Teddy's waving the flag. (R) | | |
| 30  | (S) Tell me what's happening now. (T) Teddy's eating the apple. (R) | | |

| Stimulus (S) | Target (T) | Response (R) | Score |
|--|---|--------------|-------|
| D 3 AND 4 CLAUSAL ELEMENTS | | | |
| 31  | (S) Teddy is hiding under the table. Tell me what's happening. (T) Teddy's hiding under the table. (R) | | |
| 32  | (S) Tell me what's happening now. (T) Teddy's sitting on the bed. (R) | | |
| 33  | (S) Teddy's giving a blue car to rabbit. Tell me what's happening. (T) Teddy's giving a blue car to rabbit. (R) | | |
| 34  | (S) Tell me what's happening now. (T) Rabbit's giving a red car to teddy. (R) | | |
| 35  | (S) Teddy's loading the bricks on the truck. Tell me what's happening. (T) Teddy's loading the bricks on the truck. (R) | | |
| 36  | (S) Tell me what's happening now. (T) Teddy's putting the knife under the bed. (R) | | |
| 37  | (S) Rabbit's giving teddy a red brick. Tell me what's happening. (T) Rabbit's giving teddy a red brick. (R) | | |
| 38  | (S) Tell me what's happening now. (T) Teddy's giving rabbit a red car. (R) | | |
| Expressive Scale: Section D Score (max. 10) | | | |

| Ei COMPLEX STRUCTURES: IMITATION (no equipment required) | | | |
|---|--|--|--|
| | I want you to say exactly what I say. <i>Example:</i> I like days when the sun shines. | | |
| 39 | (S/T) The girl who won the competition was given a prize. (R) | | |
| 40 | (S/T) The mother cuddled the baby who had been crying. (R) | | |
| 41 | (S/T) There wasn't any light on so they couldn't have been in. (R) | | |
| 42 | (S/T) After mummy had built the dolls' house, daddy painted it. (R) | | |
| 43 | (S/T) If you asked Andrew to help you, I think he probably would. (R) | | |
| 44 | (S/T) Tina wasn't tired even though she had been working all day. (R) | | |
| 45 | (S/T) If they hadn't gone to the park, they wouldn't have seen the lion that was there. (R) | | |
| 46 | (S/T) While you were out, your friend who likes dinosaurs came round to the house. (R) | | |

Expressive Scale

| Stimulus (S) | Target (T) | Response (R) | Score |
|---|---|--|-------|
| Eii CORRECTION OF ERRORS (horse finger puppet) | | | |
| |  | Horsie can't say things properly. You listen and then tell me what he should say. <i>Example:</i> Horsie says, 'I tired.' He should say, 'I am tired.' Let's try one. Horsie says, 'He jump over the gate.' He should say, '...' | |
| 47 |  | (S) The man drives car. (T) The man drives (determiner) car. (R) | |
| 48 |  | (S) The boy eating apples. (T) The boy is eating [or other acceptable verb form] apples. (R) | |
| 49 |  | (S) The lion attack the man. (T) The lion attacks [or other acceptable verb form] the man. (R) | |
| Eiii COMPLEX STRUCTURES: UTTERANCE COMPLETION (picture book) | | | |
| 50 |  | Look at the picture first. This boy is washing the car for his mum but he really wants to play football. I'll begin the story and you finish it. (S) Although... (T)...he really wanted to play football, the boy/he had to wash the/his mum's car. (R) | |
| 51 |  | Look at the pictures first. You can see a clown. He's fallen over and he's crying. I'll begin the story and you finish it. (S) The clown who... (T)...fell over is crying. [or other acceptable VP+VP] (R) | |
| 52 |  | Look at the pictures first. A boy has left a gate open. The sheep are in the road. I'll begin the story and you finish it. (S) If the boy hadn't... (T)...left the gate open, then the sheep wouldn't have escaped. [or other acceptable completion of first conditional clause and additional main clause] (R) | |
| Expressive Scale: Section E Score (max. 14) | | | |
| F AUXILIARIES - NEGATIVES, QUESTIONS, TAGS (both finger puppets) | | | |
| |  | <i>Example:</i> Horsie says, 'My brother goes to school.' Panda says, 'My brother doesn't go to school.' Let's try one. You have Panda. Horsie says, 'My aunty watches television.' Panda says, '...' | |
| 53 |  | (S) Horsie says, 'My sister can run fast.' (T) My sister can't run fast. [aux + neg] (R) | |
| 54 |  | (S) Horsie says, 'Mum likes swimming.' (T) Mum doesn't like swimming. [aux + neg] (R) | |
| |  | <i>Example:</i> Horsie says, 'I can have my breakfast.' Panda says, 'Can I have my breakfast?' Let's try one. Horsie says, 'I like playing the recorder.' Panda says, 'Do...' | |
| 55 |  | (S) Horsie says, 'I can ride a bicycle.' (T) Can I ride a bicycle? [subject/aux inversion; pronoun substitute permitted I/you] (R) | |

| Stimulus (S) | Target (T) | Response (R) | Score |
|---|---|--------------|-------|
| F AUXILIARIES - NEGATIVES, QUESTIONS, TAGS | | | |
| 56 |  (S) Horsie says, 'I saw the postman.' (T) Did I see the postman? [subject/aux inversion; pronoun substitute permitted I/you] (R) | | |
| 57 |  (S) Horsie says, 'The ice-cream van comes every day.' (T) Does the ice-cream van come every day? [subject/aux inversion] (R) | | |
| 58 |  (S) Horsie says, 'They are helping the lady.' (T) Are they helping the lady? [subject/aux inversion] (R) | | |
| 59 |  (S) Horsie says, 'I ate my dinner quickly.' (T) Did I eat my dinner quickly? [subject/aux inversion; pronoun substitute permitted I/you] (R) | | |
| 60 |  (S) Horsie says, 'The boy are playing football.' (T) Are the boys playing football? [subject/aux inversion] (R) | | |
| |  <i>Example:</i> Horsie says, 'I couldn't see the cat.' Panda says, 'I couldn't see the cat, could I?' Let's try one. Horsie says, 'She likes to dance and sing.' Panda says, '...' | | |
| 61 |  (S) Horsie says, 'We wouldn't make a noise.' (T) We wouldn't make a noise, would we? [positive aspect + modal + pronoun] (R) | | |
| 62 |  (S) Horsie says, 'The boy wants to go out.' (T) The boy wants to go out, doesn't he? [negative aspect + modal + pronoun] (R) | | |
| Expressive Scale: Section F Score (max. 10) | | | |

Expressive Scale: Total Score (Sections A-F, max. 62)



Toy(s) required to administer this item Picture(s) required to administer this item



Finger puppet(s) required to administer this item. All toys required for each section are shown in brackets.



NFER-NELSON
Health & Social Care
INFORMING YOUR DECISIONS

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APPENDIX M

VINELAND ADAPTIVE BEHAVIOR SCALES

Record Booklet

ABOUT THE INDIVIDUAL:

Name _____ Sex _____
Home address _____
Telephone _____ Grade _____
School or other facility _____
Present classification or diagnosis _____
Race (if pertinent) _____
Socioeconomic background (if pertinent) _____
Other pertinent information _____

AGE: **YEAR** **MONTH** **DAY**

Interview date _____

Birth date _____

Chronological age _____

Age used for starting points _____

Type (circle one). chronological mental social

ABOUT THE RESPONDENT:

Name _____ Sex _____
Relationship to individual _____

ABOUT THE INTERVIEWER:

Name _____ Sex _____
Position _____

DATA FROM OTHER TESTS:

Intelligence _____

Achievement _____

Adaptive behavior _____

Other _____

REASON FOR THE INTERVIEW: _____

BEFORE BEGINNING ADMINISTRATION, READ THE INSTRUCTIONS IN THE MANUAL CAREFULLY.

General Directions: In each adaptive behavior domain, begin scoring with the item designated for the individual's age. Score each item 2, 1, 0, N, or DK, according to the scoring criteria in the manual (Appendix C). Record each score in this booklet in the designated box. Establish a *basal* of seven consecutive items scored 2 and a *ceiling* of seven consecutive items scored 0 for each domain. (For reference when totaling scores, the highest possible sums are printed in the upper right corner of the sum boxes.)

COMMUNICATION DOMAIN

ITEM 2 Yes, usually
 1 Sometimes or partially
 0 No, never
 SCORES N No opportunity
 DK Don't know

- <1 1. Turns eyes and head toward sound.
- 2. Listens at least momentarily when spoken to by caregiver.
- 3. Smiles in response to presence of caregiver.
- 4. Smiles in response to presence of familiar person other than caregiver.
- 5. Raises arms when caregiver says, "Come here" or "Up."
- 6. Demonstrates understanding of the meaning of "no."
- 7. Imitates sounds of adults immediately after hearing them.
- 8. Demonstrates understanding of the meaning of at least 10 words.
- 1 9. Gestures appropriately to indicate "yes," "no," and "I want."
- 10. Listens attentively to instructions.
- 11. Demonstrates understanding of the meaning of "yes" or "okay."
- 12. Follows instructions requiring an action and an object.
- 13. Points accurately to at least one major body part when asked.
- 14. Uses first names or nicknames of siblings, friends, or peers, or states their names when asked.
- 15. Uses phrases containing a noun and a verb, or two nouns.
- 16. Names at least 20 familiar objects without being asked.
DO NOT SCORE 1.
- 17. Listens to a story for at least five minutes.
- 18. Indicates preference when offered a choice.
- 2 19. Says at least 50 recognizable words. DO NOT SCORE 1.
- 20. Spontaneously relates experiences in simple terms.
- 21. Delivers a simple message.
- 22. Uses sentences of four or more words.
- 23. Points accurately to all body parts when asked. DO NOT SCORE 1.
- 24. Says at least 100 recognizable words. DO NOT SCORE 1.
- 25. Speaks in full sentences.
- 26. Uses "a" and "the" in phrases or sentences.
- 27. Follows instructions in "if-then" form
- 28. States own first and last name when asked
- 29. Asks questions beginning with "what," "where," "who," "why," and "when." DO NOT SCORE 1.
- 3,4 30. States which of two objects not present is bigger.
- 31. Relates experiences in detail when asked.
- 32. Uses either "behind" or "between" as a preposition in a phrase.
- 33. Uses "around" as a preposition in a phrase.

| | | | |
|----|--------------------------|--------------------------|---------|
| | RECEPTIVE | EXPRESSIVE | WRITTEN |
| 1 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 2 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 3 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 4 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 5 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 6 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 7 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 8 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 9 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 10 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 11 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 12 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 13 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 14 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 15 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 16 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 17 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 18 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 19 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 20 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 21 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 22 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 23 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 24 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 25 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 26 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 27 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 28 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 29 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 30 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 31 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 32 | <input type="checkbox"/> | <input type="checkbox"/> | |
| 33 | <input type="checkbox"/> | <input type="checkbox"/> | |

Count items before basal as 2, items after ceiling as 0

24 42 0

Sum of 2s, 1s, 0s page 2

RECEPTIVE

EXPRESSIVE

WRITTEN

ITEM 2 Yes, usually
 1 Sometimes or partially
 0 No, never
 SCORES N No opportunity
 DK Don't know

- 34. Uses phrases or sentences containing "but" and "or."
- 35. Articulates clearly, without sound substitutions.
- 36. Tells popular story, fairy tale, lengthy joke, or television show plot.
- 37. Recites all letters of the alphabet from memory.
- 38. Reads at least three common signs.
- 39. States month and day of birthday when asked.
- 40. Uses irregular plurals.
- 41. Prints or writes own first and last name.
- 42. States telephone number when asked. N MAY BE SCORED.
- 43. States complete home address, including city and state, when asked.
- 44. Reads at least 10 words silently or aloud.
- 45. Prints or writes at least 10 words from memory.
- 46. Expresses ideas in more than one way, without assistance.
- 47. Reads simple stories aloud.
- 48. Prints or writes simple sentences of three or four words.
- 49. Attends to school or public lecture more than 15 minutes.
- 50. Reads on own initiative.
- 51. Reads books of at least second-grade level.
- 52. Arranges items or words alphabetically by first letter.
- 53. Prints or writes short notes or messages.
- 54. Gives complex directions to others.
- 55. Writes beginning letters. DO NOT SCORE 1.
- 56. Reads books of at least fourth-grade level.
- 57. Writes in cursive most of the time. DO NOT SCORE 1.
- 58. Uses a dictionary.
- 59. Uses the table of contents in reading materials.
- 60. Writes reports or compositions. DO NOT SCORE 1.
- 61. Addresses envelopes completely.
- 62. Uses the index in reading materials.
- 63. Reads adult newspaper stories. N MAY BE SCORED.
- 64. Has realistic long-range goals and describes in detail plans to achieve them.
- 65. Writes advanced letters.
- 66. Reads adult newspaper or magazine stories each week. N MAY BE SCORED.
- 67. Writes business letters. DO NOT SCORE 1.

| | RECEPTIVE | EXPRESSIVE | WRITTEN |
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Count items before basal as 2, items after ceiling as 0.

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Sum of 2s, 1s, 0s page 3
 Sum of 2s, 1s, 0s page 2
 Number of Ns pages 2 and 3
 Number of DKs pages 2 and 3
SUBDOMAIN RAW SCORE
 (Add rows 1—4 above)

| | |
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| RECEPTIVE | |
| EXPRESSIVE | |
| WRITTEN | |

COMMUNICATION DOMAIN

DAILY LIVING SKILLS DOMAIN

ITEM SCORES
 2 Yes, usually
 1 Sometimes or partially
 0 No, never
 N No opportunity
 DK Don't know

- <1 1. Indicates anticipation of feeding on seeing bottle, breast, or food.
- 2. Opens mouth when spoon with food is presented.
- 3. Removes food from spoon with mouth.
- 4. Sucks or chews on crackers.
- 5. Eats solid food.
- 1 6. Drinks from cup or glass unassisted.
- 7. Feeds self with spoon.
- 8. Demonstrates understanding that hot things are dangerous.
- 9. Indicates wet or soiled pants or diaper by pointing, vocalizing, or pulling at diaper.
- 10. Sucks from straw.
- 11. Willingly allows caregiver to wipe nose.
- 12. Feeds self with fork.
- 13. Removes front-opening coat, sweater, or shirt without assistance.
- 2 14. Feeds self with spoon without spilling.
- 15. Demonstrates interest in changing clothes when very wet or muddy.
- 16. Urinates in toilet or potty-chair.
- 17. Bathes self with assistance.
- 18. Defecates in toilet or potty-chair.
- 19. Asks to use toilet.
- 20. Puts on "pull-up" garments with elastic waistbands.
- 21. Demonstrates understanding of the function of money.
- 22. Puts possessions away when asked.
- 3 23. Is toilet-trained during the night.
- 24. Gets drink of water from tap unassisted.
- 25. Brushes teeth without assistance.
DO NOT SCORE 1.
- 26. Demonstrates understanding of the function of a clock, either standard or digital.
- 27. Helps with extra chores when asked.
- 28. Washes and dries face without assistance.
- 29. Puts shoes on correct feet without assistance.
- 30. Answers the telephone appropriately.
N MAY BE SCORED.
- 31. Dresses self completely, except for tying shoelaces.
- 4 32. Summons to the telephone the person receiving a call, or indicates that the person is not available. N MAY BE SCORED.
- 33. Sets table with assistance.

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Count items before basal as 2, items after ceiling as 0.

Sum of 2s, 1s, 0s page 4

PERSONAL

DOMESTIC

COMMUNITY

ITEM 2 Yes, usually
 1 Sometimes or partially
 SCORES 0 No, never
 N No opportunity
 DK Don't know

1. Looks at face of caregiver.
2. Responds to voice of caregiver or another person.
3. Distinguishes caregiver from others.
4. Shows interest in novel objects or new people.
5. Expresses two or more recognizable emotions such as pleasure, sadness, fear, or distress.
6. Shows anticipation of being picked up by caregiver.
7. Shows affection toward familiar people.
8. Shows interest in children or peers other than siblings.
9. Reaches for familiar person.
10. Plays with toy or other object alone or with others.
11. Plays very simple interaction games with others.
12. Uses common household objects for play.
13. Shows interest in activities of others.
14. Imitates simple adult movements, such as clapping hands or waving good-bye, in response to a model.
15. Laughs or smiles appropriately in response to positive statements.
16. Addresses at least two familiar people by name.
17. Shows desire to please caregiver.
18. Participates in at least one game or activity with others.
19. Imitates a relatively complex task several hours after it was performed by another.
20. Imitates adult phrases heard on previous occasions.
21. Engages in elaborate make-believe activities, alone or with others.
22. Shows a preference for some friends over others.
23. Says "please" when asking for something.
24. Labels happiness, sadness, fear, and anger in self.
25. Identifies people by characteristics other than name, when asked.
26. Shares toys or possessions without being told to do so.
27. Names one or more favorite television programs when asked, and tells on what days and channels the programs are shown.
N MAY BE SCORED.
28. Follows rules in simple games without being reminded.
29. Has a preferred friend of either sex.
30. Follows school or facility rules.
31. Responds verbally and positively to good fortune of others.
32. Apologizes for unintentional mistakes.
33. Has a group of friends.
34. Follows community rules.
35. Plays more than one board or card game requiring skill and decision making.
36. Does not talk with food in mouth.
37. Has a best friend of the same sex.

INTERPERSONAL RELATIONSHIPS
 PLAY & LEISURE TIME
 GAMING SKILLS

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Count items before basal as 2, items after ceiling as 0.

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Sum of 2s, 1s, 0s page 7

INTERPERSONAL RELATIONSHIPS

PLAY & LEISURE TIME

SOCIALIZATION DOMAIN

SOCIALIZATION DOMAIN

ITEM SCORES
 2 Yes, usually
 1 Sometimes or partially
 0 No, never
 N No opportunity
 DK Don't know

- 38. Responds appropriately when introduced to strangers.
- 7, 8 39. Makes or buys small gifts for caregiver or family member on major holidays, on own initiative.
- 40. Keeps secrets or confidences for more than one day.
- 41. Returns borrowed toys, possessions, or money to peers, or returns borrowed books to library.
- 42. Ends conversations appropriately.
- v 43. Follows time limits set by caregiver.
- 44. Refrains from asking questions or making statements that might embarrass or hurt others.
- 45. Controls anger or hurt feelings when denied own way.
- 46. Keeps secrets or confidences for as long as appropriate.
- 10, 11 47. Uses appropriate table manners without being told.
DO NOT SCORE 1.
- 48. Watches television or listens to radio for information about a particular area of interest. N MAY BE SCORED.
- 49. Goes to evening school or facility events with friends, when accompanied by an adult. N MAY BE SCORED.
- 50. Independently weighs consequences of actions before making decisions.
- 51. Apologizes for mistakes or errors in judgment.
- 12, 13, 14 52. Remembers birthdays or anniversaries of immediate family members and special friends.
- 53. Initiates conversations on topics of particular interest to others.
- 54. Has a hobby.
- 55. Repays money borrowed from caregiver.
- 15 to 18+ 56. Responds to hints or indirect cues in conversation.
- 57. Participates in nonschool sports. N MAY BE SCORED.
- 58. Watches television or listens to radio for practical, day-to-day information. N MAY BE SCORED.
- 59. Makes and keeps appointments.
- 60. Watches television or listens to radio for news independently. N MAY BE SCORED.
- 61. Goes to evening school or facility events with friends, without adult supervision. N MAY BE SCORED.
- 62. Goes to evening nonschool or nonfacility events with friends, without adult supervision.
- 63. Belongs to older adolescent organized club, interest group, or social or service organization.
- 64. Goes with one person of opposite sex to party or public event where many people are present.
- 65. Goes on double or triple dates.
- 66. Goes on single dates.

INTERPERSONAL RELATIONSHIPS
 PLAY & LEISURE TIME
 COPING SKILLS

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Count items before basal as 2, items after ceiling as 0.

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Sum of 2s, 1s, 0s page 8
 Sum of 2s, 1s, 0s page 7
 Number of Ns pages 7 and 8
 Number of DKs pages 7 and 8
SUBDOMAIN RAW SCORE
 (Add rows 1—4 above)

ITEM SCORES
 2 Yes, usually
 1 Sometimes or partially
 0 No, never
 N No opportunity
 DK Don't know

Note: The Motor Skills domain is for individuals 5-11:30 or under, and optional for older individuals for whom a motor deficit is suspected (see Chapters 4 and 5 in the manual for procedures for administering and scoring the Motor Skills domain for individuals 6:0-0 or older)

1. Holds head erect for at least 15 seconds without assistance when held vertically in caregiver's arms.
2. Sits supported for at least one minute.
3. Picks up small object with hands, in any way.
4. Transfers object from one hand to the other.
5. Picks up small object with thumb and fingers.
6. Raises self to sitting position and maintains position unsupported for at least one minute.
7. Crawls across floor on hands and knees, without stomach touching floor.
8. Opens doors that require only pushing or pulling.
9. Rolls ball while sitting.
10. Walks as primary means of getting around.
11. Climbs both in and out of bed or steady adult chair.
12. Climbs on low play equipment.
13. Marks with pencil, crayon, or chalk on appropriate writing surface.
14. Walks up stairs, putting both feet on each step.
15. Walks down stairs, forward, putting both feet on each step.
16. Runs smoothly, with changes in speed and direction.
17. Opens doors by turning and pulling doorknobs.
18. Jumps over small object.
19. Screws and unscrews lid of jar.
20. Pedals tricycle or other three-wheeled vehicle for at least six feet. N MAY BE SCORED.
21. Hops on one foot at least once, while holding on to another person or stable object, without falling.
22. Builds three-dimensional structures, with at least five blocks.
23. Opens and closes scissors with one hand.
24. Walks down stairs with alternating feet, without assistance.
25. Climbs on high play equipment.
26. Cuts across a piece of paper with scissors.
27. Hops forward on one foot at least three times without losing balance. DO NOT SCORE 1.
28. Completes non-inset puzzle of at least six pieces. DO NOT SCORE 1.
29. Draws more than one recognizable form with pencils or crayons.
30. Cuts paper along a line with scissors.
31. Uses eraser without tearing paper.
32. Hops forward on one foot with ease. DO NOT SCORE 1.
33. Unlocks key locks.
34. Cuts out complex items with scissors.
35. Catches small ball thrown from a distance of 10 feet, even if moving is necessary to catch it.
36. Rides bicycle without training wheels, without falling. N MAY BE SCORED.

GROSS FINE

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COMMENTS

Count items before basal as 2, items after ceiling as 0.

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Sum of 2s, 1s, 0s page 9
 Number of Ns page 9
 Number of DKs page 9

SUBDOMAIN RAW SCORE
 (Add rows 1-3 above)

GROSS

FINE

MOTOR SKILLS DOMAIN

MALADAPTIVE BEHAVIOR DOMAIN

Note: The Maladaptive Behavior domain is for individuals 5-0-0 or older. Administration is optional.

ITEM SCORES
 2 Yes, usually
 1 Sometimes or partially
 0 No, never
 DO NOT SCORE N OR DK.

PART 1

1. Sucks thumb or fingers.
2. Is overly dependent.
3. Withdraws.
4. Wets bed.
5. Exhibits an eating disturbance.
6. Exhibits a sleep disturbance.
7. Bites fingernails.
8. Avoids school or work.
9. Exhibits extreme anxiety.
10. Exhibits tics.
11. Cries or laughs too easily.
12. Has poor eye contact.
13. Exhibits excessive unhappiness.
14. Grinds teeth during day or night.
15. Is too impulsive.
16. Has poor concentration and attention.
17. Is overly active.
18. Has temper tantrums.
19. Is negativistic or defiant.
20. Teases or bullies.
21. Shows lack of consideration.
22. Lies, cheats, or steals.
23. Is too physically aggressive.
24. Swears in inappropriate situations.
25. Runs away.
26. Is stubborn or sullen.
27. Is truant from school or work.

A. PART 1 RAW SCORE
 (Sum of 2s, 1s, 0s Part 1)

PART 2

Note: Part 2 is for individuals who will be compared only with supplementary norm groups.

28. Engages in inappropriate sexual behavior.
29. Has excessive or peculiar preoccupations with objects or activities.
30. Expresses thoughts that are not sensible.
31. Exhibits extremely peculiar mannerisms or habits.
32. Displays behaviors that are self-injurious.
33. Intentionally destroys own or another's property.
34. Uses bizarre speech.
35. Is unaware of what is happening in immediate surroundings.
36. Rocks back and forth when sitting or standing.

B. Sum of 2s, 1s, 0s Part 2
PARTS 1 AND 2 RAW SCORE
 (Add A and B)

ABOUT THE INTERVIEW:

Respondent's estimate of the individual's functioning

Language used in the interview

Special characteristics of the individual

Estimate of rapport established with the respondent

Estimate of the respondent's accuracy

General observations

Vineland Adaptive Behavior Scales: INTERVIEW EDITION Survey Form

Individual's name _____ Chronological age _____
 Date of interview _____ Supplementary norm group (if applicable) _____

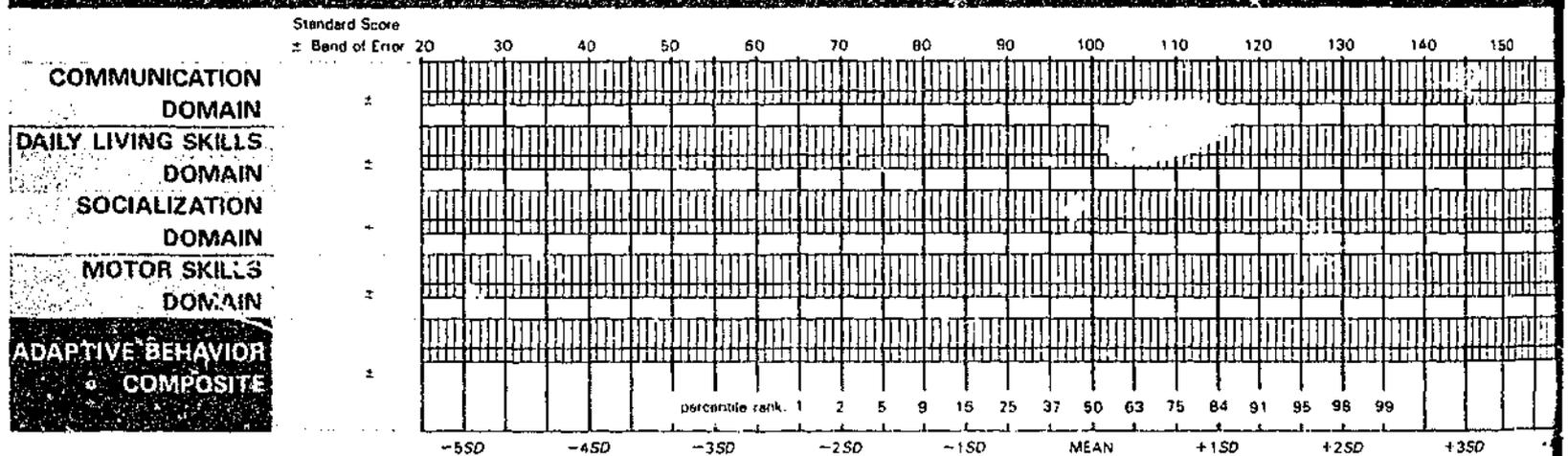
Before beginning the score summary, read Chapter 5 in the manual.

SCORE SUMMARY

| SUBDOMAIN | Raw Score | Standard Score $\bar{X}=100$ $SD=15$ Tables B.1 and B.2 | Band of Error % Confidence Table B.3 | National %ile Rank Table B.4 | Stenche Table B.4 | Supplementary Norm Group %ile Rank Table B.5 | Adaptive Level Tables B.6 and B.8 | Supplementary Norm Group Adaptive Level Tables B.7 and B.9 | Age Equivalent Tables B.10 and B.11 |
|---------------------------------------|-----------|--|--|---------------------------------|----------------------|---|--------------------------------------|---|--|
| Receptive | | | | | | | | | |
| Expressive | | | | | | | | | |
| Written | | | | | | | | | |
| COMMUNICATION DOMAIN SUM | | | | | | | | | |
| Personal | | | | | | | | | |
| Domestic | | | | | | | | | |
| Community | | | | | | | | | |
| DAILY LIVING SKILLS DOMAIN SUM | | | | | | | | | |
| Interpersonal Relationships | | | | | | | | | |
| Play and Leisure Time | | | | | | | | | |
| Coping Skills | | | | | | | | | |
| SUM | | | | | | | | | |
| (For ages 5-11-30) | | | | | | | | | |
| Gross | | | | | | | | | |
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| MOTOR SKILLS DOMAIN SUM | | | | | | | | | |
| | | SUM OF DOMAIN STANDARD SCORES | | | | | | | |
| ADAPTIVE BEHAVIOR COMPOSITE | | | | | | | | | |

(See Chapter 5 in the manual to graph scores.)

SCORE PROFILE



OPTIONAL MALADAPTIVE BEHAVIOR DOMAIN (Administer for ages 5-0-0 and older)

Raw Score _____ Maladaptive Level: Table 9.12
 Supplementary Norm Group Maladaptive Level: Table 9.13

Part 1 _____
 Parts 1 and 2 _____

Additional interpretive information (see Chapters 7 and 6 in the manual)

Recommendations

APPENDIX N
CHILDHOOD AUTISM RATING SCALE

Age
Equivalent
Tables B.10
and B.11

150

350 +4
Norm Group
Level- Table B.13

Printed on
recycled paper

Directions: For each category, use the space provided below each scale for taking notes concerning the behaviors relevant to each scale. After you have finished observing the child, rate the behaviors relevant to each item of the scale. For each item, circle the number which corresponds

to the statement that best describes the child. You may indicate the child is between two descriptions by using ratings of 1.5, 2.5, or 3.5. Abbreviated rating criteria are presented for each scale. See chapter 2 of the Manual for detailed rating criteria.

I. RELATING TO PEOPLE

No evidence of difficulty or abnormality in relating to people • The child's behavior is appropriate for his or her age. Some shyness, fussiness, or annoyance at being told what to do may be observed, but not to an atypical degree.

Mildly abnormal relationships • The child may avoid looking the adult in the eye, avoid the adult or become fussy if interaction is forced, be excessively shy, not be as responsive to the adult as is typical, or cling to parents somewhat more than most children of the same age.

Moderately abnormal relationships • The child shows aloofness (seems unaware of adult) at times. Persistent and forceful attempts are necessary to get the child's attention at times. Minimal contact is initiated by the child.

Severely abnormal relationships • The child is consistently aloof or unaware of what the adult is doing. He or she almost never responds or initiates contact with the adult. Only the most persistent attempts to get the child's attention have any effect.

Observations:

II. IMITATION

Appropriate imitation • The child can imitate sounds, words, and movements which are appropriate for his or her skill level.

Mildly abnormal imitation • The child imitates simple behaviors such as clapping or single verbal sounds most of the time; occasionally, imitates only after prodding or after a delay.

Moderately abnormal imitation • The child imitates only part of the time and requires a great deal of persistence and help from the adult; frequently imitates only after a delay.

Severely abnormal imitation • The child rarely or never imitates sounds, words, or movements even with prodding and assistance from the adult.

Observations:

III. EMOTIONAL RESPONSE

1 Age-appropriate and situation-appropriate emotional responses • The child shows the appropriate type and degree of emotional response as indicated by a change in facial expression, posture, and manner.

1.5
2 Mildly abnormal emotional responses • The child occasionally displays somewhat inappropriate type or degree of emotional reactions. Reactions are sometimes unrelated to the objects or events surrounding them.

2.5
3 Moderately abnormal emotional responses • The child shows definite signs of inappropriate type and/or degree of emotional response. Reactions may be quite inhibited or excessive and unrelated to the situation; may grimace, laugh, or become rigid even though no apparent emotion-producing objects or events are present.

3.5
4 Severely abnormal emotional responses • Responses are seldom appropriate to the situation; once the child gets in a certain mood, it is very difficult to change the mood. Conversely, the child may show widely different emotions when nothing has changed.

Observations:

IV. BODY USE

1 Age appropriate body use • The child moves with the same ease, agility, and coordination of a normal child of the same age.

1.5
2 Mildly abnormal body use • Some minor peculiarities may be present, such as clumsiness, repetitive movements, poor coordination, or the rare appearance of more unusual movements.

2.5
3 Moderately abnormal body use • Behaviors that are clearly strange or unusual for a child of this age may include strange finger movements, peculiar finger or body posturing, staring or nicking at the body, self-directed aggression, rocking, spinning, finger-wiggling, or toe-walking.

3.5
4 Severely abnormal body use • Intense or frequent movements of the type listed above are signs of severely abnormal body use. These behaviors may persist despite attempts to discourage them or involve the child in other activities.

Observations:

V. OBJECT USE

- 1 Appropriate use of, and interest in, toys and other objects • The child shows normal interest in toys and other objects appropriate for his or her skill level and uses these toys in an appropriate manner.
- 1.5
- 2 Mildly inappropriate interest in, or use of, toys and other objects • The child may show atypical interest in a toy or play with it in an inappropriately childish way (e.g., banging or sucking on the toy).
- 2.5
- 3 Moderately inappropriate interest in, or use of, toys and other objects • The child may show little interest in toys or other objects, or may be preoccupied with using an object or toy in some strange way. He or she may focus on some insignificant part of a toy, become fascinated with light reflecting off the object, repetitively move some part of the object, or play with one object exclusively.
- 3.5
- 4 Severely inappropriate interest in, or use of, toys or other objects • The child may engage in the same behaviors as above, with greater frequency and intensity. The child is difficult to distract when engaged in these inappropriate activities.

Observations:

VI. ADAPTATION TO CHANGE

- 1 Age appropriate response to change • While the child may notice or comment on changes in routine, he or she accepts these changes without undue distress.
- 1.5
- 2 Mildly abnormal adaptation to change • When an adult tries to change tasks the child may continue the same activity or use the same materials.
- 2.5
- 3 Moderately abnormal adaptation to change • The child actively resists changes in routine, tries to continue the old activity, and is difficult to distract. He or she may become angry and unhappy when an established routine is altered.
- 3.5
- 4 Severely abnormal adaptation to change • The child shows severe reactions to change. If a change is forced, he or she may become extremely angry or uncooperative and respond with tantrums.

Observations:

VII. VISUAL RESPONSE

- 1 Age appropriate visual response • The child's visual behavior is normal and appropriate for that age. Vision is used together with other senses as a way to explore a new object.
- 1.5
- 2 Mildly abnormal visual response • The child must be occasionally reminded to look at objects. The child may be more interested in looking at mirrors or lighting than peers, may occasionally stare off into space, or may also avoid looking people in the eye.
- 2.5
- 3 Moderately abnormal visual response • The child must be reminded frequently to look at what he or she is doing. He or she may stare into space, avoid looking people in the eye, look at objects from an unusual angle, or hold objects very close to the eyes.
- 3.5
- 4 Severely abnormal visual response • The child consistently avoids looking at people or certain objects and may show extreme forms of other visual peculiarities described above.

Observations:

VIII. LISTENING RESPONSE

- 1 Age appropriate listening response • The child's listening behavior is normal and appropriate for age. Listening is used together with other senses.
- 1.5
- 2 Mildly abnormal listening response • There may be some lack of response, or mild overreaction to certain sounds. Responses to sounds may be delayed, and sound may need repetition to catch the child's attention. The child may be distracted by extraneous sounds.
- 2.5
- 3 Moderately abnormal listening response • The child's responses to sounds vary; often ignores a sound the first few times it is made; may be startled or cover ears when hearing some everyday sounds.
- 3.5
- 4 Severely abnormal listening response • The child overreacts and/or underreacts to sounds to an extremely marked degree, regardless of the type of sound.

Observations:

IX. TASTE, SMELL, AND TOUCH RESPONSE AND USE

- 1 Normal use of, and response to, taste, smell, and touch • The child explores new objects in an age appropriate manner, generally by feeling and looking. Taste or smell may be used when appropriate. When reacting to minor, everyday pain, the child expresses discomfort but does not overreact.
- 1.5
- 2 Mildly abnormal use of, and response to, taste, smell, and touch • The child may persist in putting objects in his or her mouth; may smell or taste inedible objects. May ignore or overreact to mild pain that a normal child would express as discomfort.
- 2.5
- 3 Moderately abnormal use of, and response to, taste, smell, and touch • The child may be moderately preoccupied with touching, smelling, or tasting objects or people. The child may either react too much or too little.
- 3.5
- 4 Severely abnormal use of, and response to, taste, smell, and touch • The child is preoccupied with smelling, tasting, or feeling objects more for the sensation than for normal exploration or use of the objects. The child may completely ignore pain or react very strongly to slight discomfort.

Observations:

X. FEAR OR NERVOUSNESS

- 1 Normal fear or nervousness • The child's behavior is appropriate both to the situation and to his or her age.
- 1.5
- 2 Mildly abnormal fear or nervousness • The child occasionally shows too much or too little fear or nervousness compared to the reaction of a normal child of the same age in a similar situation.
- 2.5
- 3 Moderately abnormal fear or nervousness • The child shows either quite a bit more or quite a bit less fear than is typical even for a younger child in a similar situation.
- 3.5
- 4 Severely abnormal fear or nervousness • Fears persist even after repeated experience with harmless events or objects. It is extremely difficult to calm or comfort the child. The child may, conversely, fail to show appropriate regard for hazards which other children of the same age avoid.

Observations:

XI. VERBAL COMMUNICATION

Normal verbal communication, age and situation appropriate.

Mildly abnormal verbal communication • Speech shows overall retardation. Most speech is meaningful; however, some echolalia or pronoun reversal may occur. Some peculiar words or jargon may be used occasionally.

Moderately abnormal verbal communication • Speech may be absent. When present, verbal communication may be a mixture of some meaningful speech and the peculiar speech such as jargon, echolalia, or pronoun reversal. Peculiarities in meaningful speech include excessive questioning or preoccupation with particular topics.

Severely abnormal verbal communication • Meaningful speech is not used. The child may make infantile squeals, weird or animal-like sounds, complex noises approximating speech, or may show persistent, bizarre use of some recognizable words or phrases.

Observations:

XII. NONVERBAL COMMUNICATION

Normal use of nonverbal communication, age and situation appropriate.

Mildly abnormal use of nonverbal communication • Immature use of nonverbal communication; may only point vaguely, or reach for what he or she wants, in situations where same-age child may point or gesture more specifically to indicate what he or she wants.

Moderately abnormal use of nonverbal communication • The child is generally unable to express needs or desires nonverbally, and cannot understand the nonverbal communication of others.

Severely abnormal use of nonverbal communication • The child only uses bizarre or peculiar gestures which have no apparent meaning, and shows no awareness of the meanings associated with the gestures or facial expressions of others.

Observations:

XIII. ACTIVITY LEVEL

1 Normal activity level for age and circumstances • The child is neither more active nor less active than a normal child of the same age in a similar situation.

1.5
2 Mildly abnormal activity level • The child may either be mildly restless or somewhat "lazy" and slow moving at times. The child's activity level interferes only slightly with his or her performance.

2.5
3 Moderately abnormal activity level • The child may be quite active and difficult to restrain. He or she may have boundless energy and may not go to sleep readily at night. Conversely, the child may be quite lethargic, and need a great deal of prodding to get him or her to move about.

3.5
4 Severely abnormal activity level • The child exhibits extremes of activity or inactivity and may even shift from one extreme to the other.

Observations:

XIV. LEVEL AND CONSISTENCY OF INTELLECTUAL RESPONSE

1 Intelligence is normal and reasonably consistent across various areas • The child is as intelligent as typical children of the same age and does not have any unusual intellectual skills or problems.

1.5
2 Mildly abnormal intellectual functioning • The child is not as smart as typical children of the same age; skills appear fairly evenly retarded across all areas.

2.5
3 Moderately abnormal intellectual functioning • In general, the child is not as smart as typical children of the same age; however, the child may function nearly normally in one or more intellectual areas.

3.5
4 Severely abnormal intellectual functioning • While the child generally is not as smart as the typical child of his age, he or she may function even better than the normal child of the same age in one or more areas.

Observations:

XV. GENERAL IMPRESSIONS

1 No autism • The child shows none of the symptoms characteristic of autism.

1.5
2 Mild autism • The child shows only a few symptoms or only a mild degree of autism.

2.5
3 Moderate autism • The child shows a number of symptoms or a moderate degree of autism.

3.5
4 Severe autism • The child shows many symptoms or an extreme degree of autism.

Observations:

APPENDIX O

SUPPORTING PUBLICATION

Are there early features of autism in infants and preschool children?

Review Article

Are there early features of autism in infants and preschool children?

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Abstract: Autism is characterized by impairments in three areas: (i) reciprocal social interaction; (ii) communication; and (iii) repetitive and stereotyped patterns of interest and behaviour. Despite the finding that parents notice abnormalities and problems with their child's development at a very early age, research shows that diagnoses are often made at an age beyond that recommended for the commencement of early intervention. This paper reviews the range of studies that have sought to elucidate the early features of autism in young, preschool children. Impairments in the capacity for reciprocal social interaction involving preverbal, verbal and non-verbal communication, and play and symbolic behaviour are the key features indicative of autism in infants and preschool children.

Key words: autistic disorder; behaviour; children; infants.

AUTISM

A DSM-IV¹ or ICD-10² diagnosis of autism requires impairment in three areas of development: (i) social interaction; (ii) communication; and (iii) restricted, repetitive and stereotyped patterns of behaviour, interests and activities, and onset must be before the age of 3 years. Taking into account variations in definition and methodology, the best available prevalence estimate for autism in children is 5 per 10 000.³ The male to female ratio is within the range of 3–4 males to 1 female.⁴ The rate of intellectual disability in autism is 75–80%,^{4,5} with the majority in the moderate to severe range.^{1,6} Although the precise aetiology remains unknown, autism is recognized as a neurobiological condition involving central nervous system dysfunction^{7,8} most likely with a genetic basis involving multiple, interacting genes.^{9–11}

AGE OF RECOGNITION AND DIAGNOSIS

The onset of autism is within the first 30 months of life;^{12–14} however, the majority of parents suspect problems with their child's development before 24 months of age (Table 1). Despite this, the age at which children are first diagnosed with autism is usually at least 2 years later (Table 1). The optimal age for the commencement of early intervention is less than 4 years of age,^{15,16} therefore the delay in diagnosis is preventing some children from receiving the benefits of early intervention.

Language delay and speech problems are the symptoms that initially cause parents the most concern.^{17–22} Abnormalities in

social development such as being indifferent to or upset by social approaches, rituals, stereotypies, sleeping problems, feeding problems, motor delay, emotional problems, medical problems and a lack of imaginative play are also reported as early concerns.^{19,22} A number of these concerns may not be specific to autism but relate to general developmental delay.^{17,23} Deficits in social relating and responsiveness are usually not detected by developmental screening until 18 months of age.²³

Potential reasons for diagnostic delay

The diagnostic criteria for autism relating to social and communicative development require time to emerge and may therefore be difficult to assess in preschool children.^{24,25} For example, a follow-up study found that a number of behaviours which differentiated children with autism from children with specific speech and language delays without autism, were more prevalent in children with autism at 3 years of age than at 2 years of age.²⁶ These included abnormalities in understanding gesture, sharing enjoyment, greeting, social reciprocity and directing attention, all of which showed higher rates in those children with autism. Similarly, in young children autism symptoms may change, develop or present only intermittently.²⁷ For example, a number of behaviours have been shown to decrease in prevalence in children with autism from age 2 to age 3, including abnormalities in the use of another's body as a tool, interest in children and unusual sensory behaviours.²⁶

The differentiation of children with autism with a mental age of less than 18 months from non-verbal children with

Table 1 Age of parental recognition of problems with development and age of diagnosis

| Study | N | Age of recognition of problems | Age of diagnosis |
|---|------|--------------------------------|--|
| Baranek, 1999 | 11 | Mean of 13.86 months | Mean = 2.71 years |
| De Giacomo & Fombonne, 1998 | 80 | Mean of 19.1 months | |
| Fombonne, 1995 | 49 | Mean age of 13 months | |
| Frith & Soares, 1993 | 173 | 65% before 24 months | 0-3 years - 30% 3-5 years - 46% 6+ years - 24% Mean = 6.11 years |
| Howlin & Moore, 1997 | 1294 | Mean age of 20.3 months | |
| Ohta, Nagai, Hara & Sasaki, 1987 | 129 | 57% between 18 and 30 months | |
| Ornitz, Guthrie & Farley, 1977 | 74 | 50% by 12 months of age | |
| Rescorla, 1986 | 274 | Before 30 months of age | |
| Short & Schopler, 1988 | 1800 | Mean of 20 months | |
| Siegel, Pliner, Eschler & Elliott, 1988 | 51 | By 18 months of age | Mean = 4.5 years Young group mean = 3.63 years Older group mean = 6.89 years |
| Smith, Chung & Vostanis, 1994 | 127 | Before the age of 18 months | |
| Volkmar, Cohen & Paul, 1986 | 50 | Mean of 18 months | |
| Volkmar <i>et al.</i> , 1994 | 454 | Mean of 12.7 months | |

developmental delay without autism^{28,29} or from those with language impairment,³⁰ is difficult and may result in misdiagnosis or a decision to wait.^{28,31} The relative rarity of the condition combined with a lack of specialized training of primary health-care professionals and a lack of specialist services contribute to the delay in diagnosis.^{24,27,32,33} There are few standardized assessment procedures or autism screening measures designed for use with young children.^{32,33} Delay in diagnosis has also been attributed to a reluctance to apply the diagnosis in preschool children due to concerns over unduly alarming parents or labelling children prematurely.³⁰ The fear of litigation if a diagnosis is proven to be incorrect may also be a contributing factor.

Stability of early diagnosis

Despite the difficulties of diagnosing autism in preschool children and the concerns inherent in diagnosing in early childhood, a number of studies have shown that the diagnosis of autism in children aged less than 3 years remains stable.^{26,34-38} It has been shown that the symptoms of autism can be reliably assessed by 18 months of age,^{26,39,40} allowing for a diagnosis to be made by a specialist clinician. It has recently been stressed that evaluations should only be undertaken by professionals who have specific expertise in the assessment and treatment of autism.⁴¹

ARE THERE ANY RELIABLE EARLY IDENTIFYING FEATURES OF AUTISM?

The answer to this question has been sought through individual case studies, analyses of home movies, retrospective parental reports and prospective studies. In the case of some of these studies, the findings must be regarded with caution. A number were not controlled in any way; that is, did not compare the early behaviour of autistic children with any other children. These studies of the early development of children with autism provide some indications of the early features of this disorder, although, in light of the lack of control data, it is impossible to conclude whether the features described as early indicators of

autism are unique or specific to autism. Other studies have only used typically developing children and infants as a basis for comparison. Due to the high rate of intellectual disability in children with autism, this results in a set of differentiating features, which may simply be a function of developmental delay rather than features unique to autism. Due to these methodological shortcomings, only those studies utilizing appropriate control groups will be discussed in the present review.

Studies of home movies and retrospective surveys of early features

Retrospective studies and one home movie study have been done comparing the early features of children with autism with those of developmentally delayed children without autism.^{20,25,42-45} These studies have identified a range of behaviours unique to children with autism, which are included in Tables 2 and 3.

Retrospective information is likely to be unreliable, but asking parents of very young autistic children to recall more recent behaviours is one way of minimizing this problem. Labelling a child as autistic may also influence parental recall as they interpret their child's early behaviour within the current diagnostic framework and acquired knowledge of the disorder. Gillberg comments that parental retrospective observations are dependent upon factors such as the degree of parent alertness in observing abnormalities in their child's development, parental age, social circumstances, educational level, personality, intelligence, the presence/absence of age peers and parental mental health.¹² Error is therefore potentially inherent in any methodology that relies upon retrospective parental recall.

Controlled observational studies

Controlled child observations, assessments and parental interviews of very young children already diagnosed with autism avoid some of the problems of retrospective studies.^{28,31,46-49} Such research has revealed a number of early features of

Table 2 Features of autism in infants and preschool children: Social interaction and communication

| Social Interaction | Communication |
|---|--|
| <ul style="list-style-type: none"> • Poor social interaction • Lack of interest in other children • Lack of seeking to share own enjoyment • Failure to develop peer relations • Failure to join in activities of others • Failure to direct adult's attention to own activity • Does not direct the attention of others • Does not hold arms up to be lifted • Does not show affection • Does not seek or offer comfort • Dislikes social touch and being held • Lack of social responsiveness | <ul style="list-style-type: none"> • Ignores people • Lack of social play • Being in own world • Prefers aloneness • Indifferent to others • Does not differentiate between people • Lack of attention to voices • No social smile • Lack of eye contact • Lack of gesture • Lack of facial expression • No greeting behaviours |
| | <ul style="list-style-type: none"> • Lack of verbal communication • No social chat • Lack/limited range of facial expressions • No/abnormal eye contact, empty gaze • No or 'empty' smiling • Loss of previously acquired words • Problems with language comprehension • Does not express emotion • Poor imitation • Use of others' body as a tool • Lack of infant babble • Echolalia • No gaze monitoring • No pointing to express interest • No use or understanding of gestures |

Table 3 Features of autism in infants and preschool children: Stereotyped and repetitive routines, behaviours and interests, play and sensory behaviours, and other behaviours

| Stereotyped & repetitive routines, behaviours and interests | Play & Sensory | Other behaviours |
|---|--|--|
| <ul style="list-style-type: none"> • Verbal rituals • Hand & finger mannerisms • Whole body mannerisms • Unusual/repetitive preoccupations • Unusual/repetitive attachments to objects | <ul style="list-style-type: none"> • Lack of spontaneous play • Lack of imitative play • No pretend play • Sensitivity to noise • Insensitivity to pain/cold • Unusual sensory interests • Deafness suspected • Mouthing of objects • Unusual looking at objects/patterns/movements | <ul style="list-style-type: none"> • Distractibility • Behavioural variability • Sleep problems • Self-injury • Food fads • Unusual fears • Lack of curiosity • Lack of response to name • Running away • Overly quiet • Indifferent to animals • Having an intelligent-looking face • Overexcited when tickled |

preschool children with autism, which are included in Tables 2 and 3.

The results of appropriately controlled studies of the early features of autism reveal a number of behaviours indicative of autism in young children and which, when considered together, point to the diagnosis. These early symptoms of autism indicate a range of deficits in reciprocal social interaction and communication, repetitive behaviours, deficits in imitation, spontaneous and pretend play, requesting, joint attention and an increased likelihood of other behaviours such as self-injury, food fads and sensitivity to loud noises.

Prospective studies

Prospective studies would provide the ideal approach to the study of the early features and development of autism but the low incidence of autism generally makes them unfeasible. A number of investigators have overcome this problem by studying children at genetic risk of autism,²⁴ those with delayed speech and language,²⁶ and children presenting with early symptoms.³⁶ A prospective screening of all infants within a health region of the United Kingdom has also been undertaken.^{35,38}

One prospective study compared 41 18-month-old children at genetic risk for autism with 50 randomly selected 18-month-old children.²⁴ Children were assessed using the Checklist for Autism in Toddlers (CHAT)²⁴ and then reassessed at 30 months of age. It was found that the predictors of a diagnosis of autism at 30 months of age were the presence of two or more of the following behaviours at 18 months: (i) lack of pretend play; (ii) lack of protodeclarative pointing (pointing to an object in order to direct another person's attention); (iii) lack of social interest; (iv) lack of joint attention; and (v) lack of social play.

Lord completed a prospective study of the early features of autism with 34 children who all had delayed speech and language development.²⁶ All the children were assessed initially at age 2 and followed up at 3 years of age. At age 2 the children with autism differed from the other children in terms of their lack of initiative in seeking visual attention, lack of response to voice, lack of understanding gesture, unusual use of others' bodies, lack of seeking to share enjoyment, hand and finger mannerisms and unusual sensory behaviours. At age 3 the children with autism differed from the other children in terms of deficits in instrumental gesture, spontaneous imitation, imaginative play, social play, social responsiveness, direct gaze, were less likely to seek/offer comfort and had abnormal facial expression, preoccupations and whole body mannerisms.

Table 4 Features of children with autism that differentiate them from children with language disorder at 20 and 42 months of age using the Autism Diagnostic Interview-Revised (ADI-R)

| Age | ADI-R items | | |
|-----------|---|---|---|
| | Reciprocal social interaction | Communication | Repetitive behaviours & stereotyped interests |
| 20 months | <ul style="list-style-type: none"> • Limited range of facial expressions • Lack of interest in other children | <ul style="list-style-type: none"> • Lack of pointing to express interest • Limited use of conventional gestures | No items |
| 42 months | <ul style="list-style-type: none"> • Lack of seeking to share enjoyment • Lack of offering comfort | <ul style="list-style-type: none"> • Lack of pointing to express interest • Limited use of conventional gestures • Lack of nodding • Lack of imaginative play | No items |

Another prospective study involved 12 children presenting with early symptoms of autism who were assessed at 8–35 months of age and reassessed at 26–150 months.³⁶ A behavioural questionnaire completed by mothers at the time of presentation found that abnormalities of play, social interaction, peculiarities of gaze and auditory inattention were typical of the children with autism. In at least 10 of the 12 cases late speech development, lack of pointing, poor comprehension, an interest in parts of objects, lack of interest in people, extreme interest in things that move and commencement of problems before 12 months of age were also noted.

A large-scale prospective population study conducted in the United Kingdom screened 16 000 children by using the CHAT at their 18-month general practitioner or health visitor developmental check-up.^{35,38} An autism risk group (12 children) was identified along with a developmental delay risk group (44 children). Failure on three key items of the CHAT characterized the autism risk group: (i) protodeclarative pointing; (ii) gaze monitoring (turning to look in the same direction in which an adult is looking); and (iii) pretend play. The developmental delay group (without autism) consisted of children who failed protodeclarative pointing or failed protodeclarative pointing and pretend play, but had developed gaze monitoring.

Following clinical assessment, 10 of the 12 children in the autism risk group received a diagnosis of autism, whereas the remaining two were diagnosed with developmental delay. Twenty-two of the children in the developmental delay group were also assessed; none of them received a diagnosis of autism. Sixteen children were selected from the normal group and none of them were found to have any developmental problems. The two children from the autism risk group who did not meet criteria for autism at 18 months of age were seen again at 3 years of age and are thought to have an autism spectrum disorder.³⁸ All 10 children diagnosed with autism at 18 months of age had their diagnosis confirmed at 3.5 years of age. The entire sample of 16 000 children are being re-screened in order to establish the rate of false negatives.³⁸

The CHAT screening study has also provided information on a range of symptoms that differentiated the groups studied at both 20 months of age and at follow-up at 42 months.³⁹ The children who were diagnosed with autism at 42 months and those diagnosed with language disorder at 42 months, were all assessed using the Autism Diagnostic Interview-Revised (ADI-R)⁴⁷ at both points in time. Complete data were available for eight children in the autism group and nine children in the language disorder group. The items which constitute the ADI-R⁴⁷ diagnostic algorithm were examined across these two groups at 20 months and 42 months of age (Table 4).

APPLICABILITY OF STANDARD DIAGNOSTIC CRITERIA

A number of studies have observed that some diagnostic features that are typical of older children with autism are infrequently present in preschool-aged children. These include insistence on sameness, distress over change in routines and adherence to rituals and routines,^{37,43,47,50} restricted interests and activities,⁵⁰ abnormal seeking of comfort,⁵⁰ unusual attachments to objects,⁴⁷ impaired conversational skills and abnormal speech production.⁵⁰

It seems reasonable to assume that the skills necessary to demonstrate abnormalities in these areas have not yet developed in young children with autism. It is clearly difficult to assess language abnormality and deviance in children who have not yet acquired speech. It is also difficult to assess peer relationships and interactions in preschool children who have limited contact with other young children.^{24,37}

When assessing young children with autism it is therefore important to recognize that some diagnostic features of autism in older children may not be present, and that their absence does not necessarily exclude the possibility of autism. Lord has suggested that while it is possible to diagnose autism reliably at the age of 2 years, standard diagnostic criteria may need to be modified in order to take into account the presentation of autism in very young children.²⁶

Support for this notion includes the finding that items concerning communication are not useful in differentiating preschool children with autism from children with severely delayed language development.²³ Further support comes from Lord's longitudinal study of children with autism and children with speech and language delays without autism.²⁶ At both the ages of 2 and 3 years, the majority of behaviours that differentiated the groups of children were in the areas of communication and social reciprocity. There were comparatively less behaviours differentiating these groups at either age in the area of repetitive and stereotyped patterns of behaviour and interests. Similarly, another study that examined data provided by the ADI-R⁴⁷ at 20 and 42 months of age in children diagnosed with autism and a group diagnosed with language disorder, found no items in the area of repetitive behaviours and stereotyped patterns that differentiated the groups at either point in time.⁴⁰

Table 5 summarizes the results of a number of studies that compared a broad range of symptoms in children with autism to children with developmental delay. All of these studies specify the presence of diagnostic features of impaired communication and social interaction, although only two of the

Table 5. Early features of autism: Presence of behaviours relating to standard diagnostic criteria

| Study | Autism (n) | Comparison groups (n) | Age | Method | Communication | Social interaction | Stereotyped behaviours & routines |
|--|------------|--|--|--|---------------|--------------------|-----------------------------------|
| Adrien <i>et al.</i> 1992 | 39 | 33 Developmental delay; 17 typically developing | 6-48 months | Vidiotape observation | ✓ | ✓ | ✓ |
| Cox <i>et al.</i> 1999 | 8 | 9 Language disorder | 20 months | Current parent interview | ✓ | ✓ | |
| Dahlgren & Gillberg 1989 | 26 | 17 Developmental delay; 22 population representative | 7-22 years | Retrospective parent questionnaire (1-24 months focus) | ✓ | ✓ | |
| Hoshino <i>et al.</i> 1982 | 85 | 150 Typically developing; 64 developmental delay | 36-82 months | Retrospective (1-24 months focus) | ✓ | ✓ | |
| Lord <i>et al.</i> 1994; Lord <i>et al.</i> 1993 | 25 | 25 Developmental delay | Autism 46.76 months, controls 44.72 months | Current parent interview | ✓ | ✓ | ✓ |
| Ohta <i>et al.</i> 1987 | 141 | 33 Developmental delay | 1-12 years | Retrospective questionnaire | ✓ | ✓ | |
| Stone & Hogan 1993 | 58 | 36 Developmental delay | Autism 38.6 months, controls 42.1 months | Current parent interview | ✓ | ✓ | |
| Vostanis <i>et al.</i> 1998 | 39 | 20 Developmental delay | 2-15 years | Retrospective (12-18 months focus) | ✓ | ✓ | |

seven studies add early features of stereotyped behaviours and routines.

The relative absence in preschool children of ritualised, stereotyped behaviours that are seen in older children or adults might point to a developmental process in the emergence of symptomatology. Obsessional features may require a greater level of maturation (e.g. in language and cognition) and therefore emerge later as a sign of developmental progression. Therefore, a better understanding of the early features of autism may illuminate our knowledge of the primacy of deficits in autism.

SUMMARY AND CONCLUSIONS

Studies that compare the behaviours of young children with autism to those with developmental delay without autism and prospective studies have provided the best information on the features and symptoms indicative of autism in preschool-aged children. The majority of these features are in the areas of impaired reciprocal social interaction and verbal and non-verbal communication (Table 2). Stereotyped and repetitive routines, behaviours and interests, lack of pretend play and perceptual sensitivities also point to the possibility of the diagnosis (Table 3) but are not necessarily present in young children. Clearly a child presenting with deficits in the area of reciprocal social interaction and/or impairments in verbal or non-verbal communication and play behaviour, as manifest by symptoms described in Tables 2 and 3, needs to be considered for referral for specialist assessment for autism. The absence of stereotyped and repetitive routines, behaviours and interests does not exclude the possibility of autism in young children and infants.

The identification of these early indicators will hopefully assist in lowering the age at which autism is diagnosed and facilitate the earliest possible commencement of intervention. However, the full benefits of early diagnosis can only be recognized if family support and early intervention is provided promptly. Current research has paved the way for the development of autism screening tools, such as the CHAT. Research examining the feasibility and accuracy of early childhood screening for children at risk of autism is now needed.

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CHAPTER 11

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