

**A FOLLOW-UP STUDY OF CHILDREN  
WHO DEMONSTRATED FEATURES OF  
PERVASIVE DEVELOPMENTAL DISORDER  
AT AGE 3-5 YEARS BUT DID NOT FULFIL  
CRITERIA FOR AUTISM**

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### **A FOLLOW-UP STUDY OF CHILDREN WHO DEMONSTRATED FEATURES OF PERVASIVE DEVELOPMENTAL DISORDER AT AGE 3-5 YEARS BUT DID NOT FULFIL CRITERIA FOR AUTISM**

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\*\*\*\*\*



## ABSTRACT

This follow-up study attempted to trace the development of symptoms in a cohort of children who, at age 3-5 years, showed behavioural features suggestive of a pervasive developmental disorder (PDD) but did not qualify for a diagnosis of childhood autism. Case notes were reviewed and retrospective data pertaining to an assessment completed in the preschool period were extracted. This information was then compared to data collected as part of a follow-up assessment, conducted on average 4 years after the initial evaluation.

The characteristics presented by the sample at each timepoint were examined, to evaluate the continuity of skills and behaviours over time. Inferential statistics were then used to explore the associations between variables, both within and across time. At follow-up, the sample were assessed to have a range of intellectual abilities and widespread language impairments. Communication difficulties, social relationship problems, behavioural disturbance and high levels of autistic symptomatology also featured strongly. Estimates of intellectual and language functioning were found to be relatively stable over time. In addition to early non-verbal and receptive language abilities, preschool social communication skills were found to be related to aspects of follow-up status. The overall pattern of difficulties suggested this group to have a range of significant needs, on the basis of which it was concluded that their autistic features had not dissipated with age.

## **1. INTRODUCTION**

This opening chapter introduces the concepts and issues that are central to the present study. The relevant literature is comprehensively reviewed, a background against which the aims and objectives of this investigation are presented.

### **1.1 The concept of autism and autistic spectrum disorder**

The condition of autism was first formally recognised and assigned a name in a paper published by Leo Kanner (1943). He gave an account of 11 children with resembling characteristics, considered distinct from other clinically defined groups. Kanner described his subjects as exhibiting an “autistic disturbance of affective contact”. This is not to say that individuals had not manifested features of the disorder prior to Kanner’s report, with several historical and legendary figures quoted as having been potential cases in retrospect (Frith, 1989). Victor the ‘Wild Boy of Aveyron’ (Itard, 1801) is one such example.

Over the years, autism has been widely researched. It is proposed to be one of the best validated child psychiatric disorders (Bailey, Phillips & Rutter, 1996), on the basis that there is broad agreement concerning the core clinical features, general consensus regarding the fundamental cognitive deficits and wide acceptance of an organic origin. A plethora of work has been undertaken in an attempt to identify aetiological factors and devise effective approaches to treatment, yet autism continues to both intrigue and baffle those who encounter it as part of their personal or professional life. As Schreibman (1988, p.13) remarks “autism has proven to be a most difficult puzzle indeed” and throughout its relatively short history, this complex, multifaceted syndrome has been

surrounded by controversy. A recently published report (Department of Health, 1998) concluded that “there is much more to be learnt about this serious disorder”.

The diagnostic criteria for childhood autism provided in the current edition of the International Classification of Diseases (ICD-10) published by the World Health Organisation (WHO, 1993) are outlined in Table 1. In brief definition, autism is a neurodevelopmental disorder, characterised by a combination of impairments in social interaction, communication and imagination/ behaviour, with an onset before the age of 3. Males are more commonly affected than females. Labels such as “symbiotic psychosis” and “childhood schizophrenia” have been applied in the past to describe similar patterns of disturbance. Estimates of the prevalence of autism cited in epidemiological studies differ according to the sampling procedures adopted and how inclusive a definition is used. Although such a degree of variability renders figures unreliable, the prevalence rate of classic cases is often quoted as 4 to 5 cases per 10,000 individuals (Lotter, 1966).

Amongst the many novel ideas that have emerged over the course of time, a significant shift in thinking about autism occurred in the late 1970s, early 1980s. In an epidemiological survey involving a population of learning disabled children, Wing and Gould (1979) found a marked tendency for social, communication and behavioural abnormalities to cluster together. Furthermore, this ‘triad’ of impairments was noted to occur not only in children identified as having typical autism, but also in a wider socially impaired group, who did not qualify for such a diagnosis. These findings brought into question the usefulness of conceptualising autism as a discrete entity and forwarded the idea of a continuum of severity.

**Table 1. ICD-10 (WHO, 1993) Diagnostic Criteria for Childhood Autism**

<p><b>A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas:</b></p> <ul style="list-style-type: none"><li>(1) receptive or expressive language as used in social communication;</li><li>(2) the development of selective social attachments or of reciprocal social interaction;</li><li>(3) functional or symbolic play.</li></ul> <p><b>B. A total of at least six symptoms from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3):</b></p> <ul style="list-style-type: none"><li>(1) Qualitative abnormalities in reciprocal social interaction are manifest in at least two of the following areas:<ul style="list-style-type: none"><li>(a) failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction;</li><li>(b) failure to develop (in a manner appropriate to mental age and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;</li><li>(c) lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context; or a weak integration of social, emotional and communicative behaviours;</li><li>(d) lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g. a lack of showing, bringing or pointing out to other people objects of interest to the individual).</li></ul></li><li>(2) Qualitative abnormalities in communication are manifest in at least one of the following areas:<ul style="list-style-type: none"><li>(a) a delay in, or total lack of, development of spoken language that is not accompanied by an attempt to compensate through the use of gesture or mime as an alternative mode of communication (often preceded by a lack of communicative babbling);</li><li>(b) relative failure to initiate or sustain conversational interchange (at whatever level of language skills is present), in which there is reciprocal responsiveness to the communications of the other person;</li><li>(c) stereotyped or repetitive use of language or idiosyncratic use of words or phrases;</li><li>(d) lack of varied or spontaneous make-believe play or (when young) social imitative play.</li></ul></li></ul>
--

cont/d...

**Table 1 cont/d....**

<p>(3) Restricted, repetitive and stereotyped patterns of behaviour, interests and activities are manifest in at least one of the following areas:</p> <ul style="list-style-type: none"><li>(a) an encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in their content or focus;</li><li>(b) apparently compulsive adherence to specific, non-functional routines or rituals;</li><li>(c) stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting or complex whole body movements;</li><li>(d) preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface or the noise or vibration that they generate).</li></ul> <p>C. The clinical picture is not attributable to the other varieties of pervasive developmental disorder: specific developmental disorder of receptive language with secondary socio-emotional problems; reactive attachment disorder or disinhibited attachment disorder; mental retardation with some associated emotional or behavioural disorder; schizophrenia of unusually early onset; and Rett's syndrome.</p>
--

Evidence in support of this proposal was provided in population based studies in Sweden (Gillberg, 1984; Steffenburg & Gillberg, 1986), which documented the existence of autistic-like conditions in addition to 'nuclear' cases. Similarly, family and twin studies have identified a range of cognitive and/or social abnormalities in non-autistic monozygotic and dizygotic cotwins (Bailey, Le Couteur, Gottesman, Bolton, Simonoff, Yuzda & Rutter, 1995) and first degree relatives of autistic probands (Bolton, Macdonald, Pickles, Rios, Goode, Crowson, Bailey & Rutter, 1994). These identified impairments are referred to as a "broader autism phenotype" and are held to be a genetically influenced lesser variant of the disorder.

In response to these developments, growing consideration has been given to the notion that the classic description outlined by Kanner forms part of a wider spectrum of

disorders. The increased recognition that individuals who exhibit features of autism form a very heterogeneous group has led to a broadening of the concept. Thus, although Kanner's seminal article continues to exert a powerful influence and his original criteria have emerged almost unchanged, he effectively forced "thinking onto very narrow paths" (Gillberg, 1992).

The changes in understanding and development of ideas about autism and related disorders are reflected in the series of revisions of the international classification systems published by the aforementioned World Health Organisation (WHO) and the American Psychiatric Association (APA). Specific criteria for the diagnosis of autism were first listed in the 3rd edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III, APA, 1980), classified under the umbrella term *Pervasive Developmental Disorders* (PDD). This broad category, which has been retained in subsequent editions of ICD and DSM, recognises a group of disorders sharing similar features, the prototypical and most severe variant being childhood autism (also referred to as autistic disorder). Of all the developmental disorders, PDDs are considered to be among the more extreme, with severe abnormalities that are a pervasive feature in all situations and a pattern of deviation that crosses several areas of functioning, as opposed to an isolated delay in one domain.

Diagnostic criteria have been progressively refined, such that in the current edition of ICD-10, several subtypes are subsumed under the PDD rubric in an attempt to improve differentiation within the spectrum and limit heterogeneity. In addition to childhood autism, seven other PDD categories are listed: atypical autism; Rett's syndrome; other childhood disintegrative disorder; overactive disorder associated with mental retardation

and stereotyped movements; Asperger's syndrome; other pervasive developmental disorder; pervasive developmental disorder, unspecified.

The title *Autistic Spectrum Disorders* (ASD) is often used synonymously with PDD, to refer to the full range of conditions involving autistic symptomatology (Gillberg & Gillberg, 1989), and occasionally is applied in a more restrictive context to refer solely to non-autistic forms of PDD (Rutter & Schopler, 1992; Szatmari, 1992). Estimates of ASD prevalence range between 0.14% (Nordin & Gillberg, 1996) and 0.21 % (Wing & Gould, 1979), again depending on how broad a definition is adopted.

For the purpose of consistency and to eliminate any confusion arising from the varying use of terminology in the literature, the following definitions will be applied herein: the acronym *PDD* will be used to refer to the whole spectrum of conditions subsumed under the title of Pervasive Developmental Disorders in ICD-10, as listed above (i.e. including childhood autism). Conversely, the term *ASD* will be used to refer collectively to nonautistic forms of PDD (i.e. those conditions that do not fulfil criteria for childhood autism, yet are characterised by qualitatively similar symptoms). It is also important to note that whilst studies referring to both to DSM and ICD are cited, the latter classification system was employed for the purpose of this study.

## 1.2 The boundaries of the spectrum: classification and diagnostic issues

Although the idea of a spectrum disorder is useful in conceptualising the range of clinical features possible in PDD, a major difficulty lies in defining boundaries. As stated by Wing and Atwood (1987, p. 12) "nature never draws a line without smudging it". Clear distinctions and precise definitions are lacking, with typical autism shading into

other conditions in the absence of sharp borderlines. Such a situation engenders a sense of confusion that has invited clarification, attempts at which continue.

Criticisms relating to the nosology of PDD have long been apparent (Cohen, Volkmar & Paul, 1986; Dahl, Cohen & Provenca, 1986). The benefits and shortfalls of diagnostic schemes have been addressed, suggestions for modifications to criteria have been made, and the inadequacies of definitions have been well documented. With the advent of changes to the classification systems, crucial questions regarding the comparability of cohorts diagnosed at different points in time have been raised. The extent of alteration in PDD criteria between the publication of DSM-III and DSM-III-R (APA, 1987) serves as one example that has prompted investigation, with studies concluding that the latter operated a more inclusive definition of autism, resulting in a significant increase in the number of individuals diagnosed (Hertzog, Snow, New & Shapiro, 1990; Volkmar, Bregman, Cohen & Cicchetti, 1988). Amidst such difficulties, concomitant changes in terminology associated with the evolution of ideas about PDD serve to add to the chaos.

In spite of the fact that there is general agreement on the broad domains of abnormality that characterise PDD, the relationship between autism and PDD remains a matter of debate. Formal diagnostic systems conceptualise PDD as consisting of a bounded autistic core with other non-core groups, which contrasts with the notion of a spectrum of autistic conditions lying along a continuum, as suggested by developmental research. Moreover, consideration has been given to the idea that PDD encompasses two main autistic groups, categorised according to level of functioning (i.e. high versus low). Waterhouse, Morris, Allen, Dunn, Fein, Feinstein, Rapin and Wing (1996) recently



addressed this subject, challenging the assumptions that have previously been made. They presented findings in support of an entirely new proposal, with two overlapping autistic subgroups differentiated by functioning level that together form a larger continuum. Arguments in favour of each of these different proposals continue to be offered.

Attempts to meaningfully subclassify children with PDD comprise several models, based on cognitive profiles (Fein, Waterhouse, Lucci & Snyder, 1985), organic features (Cohen, Paul & Volkmar, 1987) and clinical presentation (Allen, 1988). Perhaps the most widely adopted of these systems is that which is commonly referred to as *Wing's subtypes*, first introduced by Wing and Gould (1979), who classified children according to the quality of their social interaction. Three categories were suggested: *aloof* (individuals who are indifferent to or actively avoid interaction); *passive* (individuals who passively accept social interaction but do not spontaneously seek it); *active but odd* (individuals who initiate social interaction, but interact in an odd or eccentric fashion). The reliability, validity and utility of this method of subtyping have been investigated (Volkmar, Cohen, Bregman, Hooks & Stevenson, 1989) and empirical support for the subgroupings has been provided in studies involving both young and older samples (Gillberg & Steffenburg, 1987; Waterhouse et al, 1996). This approach is considered potentially useful to the study of an essential diagnostic feature of autistic disorder.

In response to all the effort invested in identifying more homogeneous groups and in preparation for the publication of DSM-IV (APA, 1994), Szatmari (1992) conducted a literature review in an attempt to assess the taxonomic validity of various ASD subtypes. He cited 20 available papers on the subject, concluding that evidence for the internal and

external validity was limited and somewhat weak, although 3 subgroups could be distinguished from autism on clinical grounds: a low functioning atypical group, a high functioning atypical group and Asperger's syndrome. Eaves, Ho and Eaves (1994) made a further attempt to clarify diagnostic issues, employing factor analytic techniques to comprehend the heterogeneity of PDDs. Strong support for the validity of at least 4 types of autism was presented, including a typically autistic group, a low functioning one, a high-functioning one and a hard-to-diagnose group, (with mild-moderate retardation and a family history of learning difficulties). Both of the aforementioned publications stress the need to take such work further and examine differences in aetiology, course and outcome between PDD subtypes.

Although there is as yet no evidence to answer questions regarding the importance and usefulness of differentiating between PDD subtypes, several authors have examined how well the recently introduced criteria are able to draw such distinctions. Early indications of the potential difficulties in reliably putting into practice the new system of classification were apparent in the DSM-IV autism/PDD field trial (Volkmar, Klin, Siegel et al 1994), in which there was a disappointingly low level of agreement between raters whose task was to differentiate between autism and other forms of PDD. In a study designed to evaluate whether the PDD subgroups included in DSM-IV and ICD-10 can be confirmed by other well established diagnostic instruments, Sponheim (1996) reported an interesting pattern of findings. Specifically, although a significant difference between childhood autism and all other types of PDD was detected, differentiation between certain subgroups listed under the PDD rubric (e.g. Asperger's syndrome versus atypical autism) proved difficult.

Similar problems associated with judgements about which PDD subgroup an individual belongs to were highlighted by Mahoney, Szatmari, MacLean, Bryson, Bartolucci, Walter, Jones and Zwigenbaum (1998), in their analysis of the reliability and validity of DSM-IV criteria. This well designed study gave consideration to the fact that there is always some degree of error in making a diagnosis of PDD (in the absence of a "golden standard") and several different methods of evaluation were employed to reduce the impact of confounding influences. It was found that DSM-IV criteria satisfactorily distinguished PDD from non-PDD cases, and autism from Asperger's disorder, but particular difficulties in the ability to identify atypical autism were suggested by comparatively poor reliability and validity estimates. In light of these and similar results, the adequacy of DSM-IV to diagnose milder variants of autism has been questioned, although the majority of professionals espouse the view that it is an ideal tool for diagnosing classic forms of the condition.

Tentative solutions to this problem have been forwarded by Tanguay, Robertson and Derrick (1998), as part of a preliminary investigation into the utility of a dimensional classification approach to PDDs. A standardised, diagnostic instrument used to diagnose autism was administered to a sample of 63 subjects with PDD. Items representing social communication behaviours were extracted and factor analysed, yielding three factors; labelled Affective Reciprocity, Joint Attention and Theory of Mind. Scores on each identified factor were then correlated with scores on the three DSM-IV domains of impairment. The 3 factors correlated highly with the impaired social interaction domain (coefficients of .724 and above), moderately with the impaired communication domain (coefficients ranging from .343 to .536) and most poorly with the restricted-repetitive-

stereotyped domain (coefficients between .176 and .343). If social communication deficits are core to understanding autism, as has often been suggested, then these results prompt the following alterations in thinking to be considered.

In scrutinising the items listed under the communication impairment domain of DSM-IV, Tanguay et al differentiate between those concerning social communication and those relating to semantic/syntactic language (i.e. vocabulary and grammar). Given that some individuals with PDD, namely those diagnosed with Asperger's syndrome, evidence no difficulties with regards to the latter area of functioning, it is suggested that poor semantic/syntactic skills should be viewed as impairments that are often comorbid with autism, rather than integral features. On the basis of such an argument, it is suggested that autistic individuals who demonstrate difficulties with vocabulary and grammar should be diagnosed as having both autism and a developmental language disorder. The implications of such a proposal (one of which might be the dissolution of the Asperger's category) deserve careful consideration.

The second matter arising from Tanguay et al's findings relates to the necessity for individuals with PDD to demonstrate symptoms from the third domain (i.e. restricted, repetitive, stereotyped behaviours). Although the results of the analysis indicate that these characteristics do not correlate well with the social communication factors, the figures are likely to have been confounded. This is due to the fact that 27% of the sample were diagnosed within the category of 'PDD not otherwise specified', a large proportion of whom were described as having marked abnormalities in the impaired social interaction and communication domains of DSM-IV, but not in the restricted, repetitive, stereotyped domain. The low level of correlation between the factors and the restricted-repetitive-

stereotyped domain could therefore have been predicted to some extent. With this in mind, the findings must be viewed with caution, as must the utility of a classification system based on social communication behaviours, which awaits further investigation.

In addition to arbitrary boundaries within the autistic continuum, a degree of overlap with disorders classified outside of the spectrum has been observed, with several studies attesting the concurrence of PDD and other childhood conditions. One cluster of children who often show evidence of autistic-like conditions are those diagnosed with deficits in attention, motor control and perception, whom Gillberg (1983) argued as having a milder variant of the disorder. A much larger group of children, who have been noted because of problems of over inclusion in studies of autism (Lord, 1995) are those with severe learning disabilities/communication disorders. Children with mental retardation, especially those falling at the lowest end of the range, share a number of behavioural characteristics with children diagnosed as having PDD (Haracopos & Kelstrup, 1978; Wing & Gould, 1979). Nordin and Gillberg (1996) looked further into this and reported an ASD prevalence rate of 14 % within a target population of Swedish children with physical and/or mental disabilities. On a similar note, studies drawing comparisons between samples of children with a language disorder and those with PDD have often found features in common, that extend beyond the language impairments that are central to both conditions. The nature of the relationship between language disorder and PDD has attracted much attention and is explored in more detail in Section 1.4 below.

In view of the above complications, clinical decisions regarding the necessary and sufficient features required for diagnosis are far from straightforward. This may be particularly true for younger children, who are often given tentative diagnoses or are

simply described as having autistic traits, features or tendencies, usually in conjunction with learning disabilities or a language disorder. Although assessment during infancy and preschool years is notably difficult, early identification offers opportunities to secure much needed support services and forward plan for educational provision. The benefits of early intervention have been widely documented (Lovaas, 1987; Rogers, 1996; Rogers & Lewis, 1988), although further research is needed to build on the evidence collected to date. In particular, investigations of responses to treatment across diagnostic labels that display degrees of similarity are called for, given that the importance of differential diagnosis principally rests upon whether different recommendations are required for these conditions.

Alongside the problems associated with defining boundaries and early identification arises a further diagnostic consideration, relating to the developmental context and the fact that the clinical presentation changes across time. In addition to evidence indicating that features of autism can become both more or less pronounced with age (Eaves & Ho, 1996), it has been also suggested that different diagnoses may be applied to the same individual at different points in time (Gillberg & Coleman, 1992; Gonzalez, Alpert, Shay, Campbell & Small, 1992). Eisenmajer, Prior, Leekam, Wing, Gould, Welham and Ong (1996) draw attention to these considerations, remarking on “the dilemma of affixing discrete diagnostic categories to potentially ‘fluid’ states.”

The stability of early PDD diagnoses has been examined in a recent prospective study by Cox, Klein, Charman, Baird, Baron-Cohen, Swettenham, Drew and Wheelwright (in press), involving a sample of children identified as having autism and other PDDs who were assessed at the ages of 20 and 42 months. Although clinical

diagnosis of autism was found to be stable and reasonably sensitive, some children initially considered as either clinically normal or as having a language disorder or general developmental delay were subsequently diagnosed with PDD or Asperger's syndrome. Sensitivity to these conditions in the early years has thereby been questioned.

In a similar vein, Stone, Lee, Ashford, Brissie, Hepburn, Coonrod and Weiss (1999) examined the reliability and stability of autism diagnoses in a sample of under 3s. Evidence for the reliable identification of PDD was strong, whilst the ability to specify diagnostic category (autism versus PDD-not otherwise specified) was shown to be poor, a pattern that is in line with those reported with older samples (e.g. Volkmar et al, 1994). The fact that the majority of children remained on the PDD spectrum at follow-up was taken to suggest that the stability of diagnosis is high over time, at least when a broad view is adopted.

Ultimately, classification and diagnostic issues aside, the fundamental concern in clinical practice must be to assess an individual's needs comprehensively and accurately, so that appropriate health/social/educational services can be offered. Nevertheless, the search for better definition continues, particularly with respect to those conditions that fall outside of the parameters of autism yet lie within the PDD spectrum (i.e. the ASDs).

### 1.3 Non-autistic forms of pervasive developmental disorder

In comparison to the vast amount of literature devoted to autism, ASDs have received considerably less attention. Individuals who present with symptoms phenomenologically similar to those found in autism have been ascribed various labels, such as atypical PDD and PDD-not otherwise specified, as well as the previously

mentioned category names given in ICD-10. Such variant conditions have been recognised for some time and gradually incorporated into the diagnostic manuals. The degree to which they have been the focus of study varies according to subtype.

Since Wing's (1981) seminal article giving a clinical account of Asperger's syndrome, there has been an increasing trend in the use of this diagnosis, which has stimulated research on the topic. In particular, several authors have examined the similarities and differences between autism and Asperger's syndrome, given that the exact nature of the relationship is not fully understood (Eisenmajer et al, 1996; Szatmari, Archer, Fisman, Streiner & Wilson, 1995). Attention has also been given to reviewing Rett's syndrome and disintegrative disorder (Tsai, 1992; Volkmar & Cohen, 1989), both of which have a characteristic profile and course that distinguishes them from autism.

These references aside, there is a distinct lack of literature pertaining to autistic spectrum subtypes. This is particularly true for 'sub-threshold' categories such as atypical autism and PDD unspecified, reserved to describe those individuals who meet some but not all the criteria for autism. Individuals fitting such descriptions are said to be relatively common and likely to be more familiar to professionals than those with more classical PDD diagnoses. Repeated recommendations for more systematic investigation involving children with these milder, yet clinically handicapping conditions have been made (Cohen, Paul & Volkmar, 1986; Rutter & Schopler, 1987).

Essentially, diagnoses such as atypical autism are negative definitions, in that they are assigned when criteria for other specified conditions are not fulfilled, but the general description for a pervasive developmental disorder seems applicable. Children given such labels represent a mixed, varied group of individuals (Greenspan, 1992), who belong



within the PDD category. They demonstrate 'atypicality' in terms of age of onset or range, severity or degree of symptomatology.

ICD-10 diagnostic criteria for atypical autism are listed in Table 2. The criteria are considered rather vague, in that there are no precise guidelines for the boundaries and the cut-offs for reaching threshold are arbitrary and unreliable. It is extremely difficult for clinicians and researchers alike to decide the point at which to consider symptoms as too few or too mild to constitute a form of PDD. Factors such as these inevitably lead to inconsistent use of the concept and ambiguous decisions regarding qualifications for a diagnosis. Furthermore, the menu-like system adopted in current classification schemes allows for a variety of possible combinations of behaviours within each of the three defining categories of impairment, resulting in a range of different profiles of symptoms. Such a degree of heterogeneity, taken together with the difficulties with consistent application of the diagnostic criteria, present a particular challenge to researchers wishing to study this population of atypical individuals. This point is well illustrated in the literature.

Mahoney et al (1998) reported an unacceptably high false-negative error rate in clinicians' classification of children with atypical autism, a significant proportion of which were misdiagnosed as having autism. In hypothesising about possible reasons underlying the poor reliability and validity of the criteria for atypical autism, attention was drawn to the relative newness of the criteria and the need to accrue experience in accurate operationalisation. Elaboration and refinement of the diagnostic criteria, as suggested by Mayes, Volkmar, Hooks and Cicchetti (1993) and many others would be a useful starting point in helping to solve some of these problems.

**Table 2. ICD-10 (WHO, 1993) Diagnostic Criteria for Atypical Autism:**

- A. Abnormal or impaired development is evident at or after the age of 3 years (criteria as for autism except for age of manifestation).
- B. There are qualitative abnormalities in reciprocal social interaction or in communication, or restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. (Criteria as for autism except that it is unnecessary to meet the criteria for number of areas of abnormality).
- C. The disorder does not meet the diagnostic criteria for autism.

Autism may be atypical in either age of onset or symptomatology; the two types are differentiated with a fifth character for research purposes. Syndromes that are atypical for both in both respects should be coded under 'atypicality in both age of onset and symptomatology'.

Atypicality in age of onset

- A. The disorder does not meet criterion A for autism; that is abnormal or impaired development is evident only after the age of 3 years.
- B. The disorder meets criteria for B and C for autism.

Atypicality in symptomatology

- A. The disorder meets criterion A for autism; that is abnormal or impaired development is evident before the age of 3 years.
- B. There are qualitative abnormalities in reciprocal social interactions or in communications, or restricted, repetitive, and stereotyped patterns of behaviour, interests and activities. (Criteria as for autism except that it is unnecessary to meet the criteria for number of areas of abnormality).
- C. The disorder meets criterion C for autism.
- D. The disorder does not fully meet criterion B for autism.

Atypicality in both age of onset and symptomatology

- A. The disorder does not meet criterion A for autism; that is, abnormal or impaired development is evident only at or after the age of 3 years.
- B. There are qualitative abnormalities in reciprocal social interactions or in communications, or restricted, repetitive, and stereotyped patterns of behaviour, interests and activities. (Criteria as for autism except that it is unnecessary to meet the criteria for number of areas of abnormality).
- C. The disorder meets criterion C for autism.
- D. The disorder does not fully meet criterion B for autism.

A comprehensive literature search yielded only a handful of studies that focus exclusively on populations of atypical children, although small numbers have sometimes been included in examinations of wider spectrum conditions. The task of identifying relevant papers is compounded by the changes in diagnostic terminology that have taken place over the period of years since the concept of PDD was first introduced. It is likely that studies focusing on 'atypical children' prior to the publication of ICD-10 and DSM-IV include a very mixed population of individuals whose difficulties seem to lie 'somewhere' along the autistic spectrum. In spite of this, it is considered worthwhile to review the findings produced to date.

Levine and Demb (1987) described the characteristics of a small sample of preschool children diagnosed as having atypical PDD, outlining disturbances in a number of basic psychological functions, which were evident from an early age. Uneven cognitive profiles were reported, with most of the children having higher performance skills and/or language deficits. Prominent clinical features included difficulties socially interacting with parents, other adults and peers (indexed by variable relatedness), a history of delayed and/or deviant speech and language, and ritualistic behaviours. Also highlighted were high anxiety, affective disturbance, communicative styles suggestive of a thinking disorder, hyperactivity, a short attention span and delayed motor skills. Interestingly, a range of diagnostic possibilities were considered for some subjects, with a minority fulfilling criteria for more than one disorder. In response to the extreme variability found in the sample, the authors described the group as having "Jekyll and Hyde" personalities.

Fisher, Burd and Kerbeshian (1987) examined a range of clinical features associated with PDD diagnoses in a cohort of children from a stable, geographically defined area

(North Dakota), of whom 61% were labelled as having atypical PDD. Multiple diagnoses were reported for the atypical sample, the two most common of which were attention deficit disorder with hyperactivity and Tourette disorder. Assessment of cognitive skills revealed that three quarters of the atypical subjects obtained scores in the learning disability range, with the remainder functioning at a borderline level or within normal limits. The mean receptive language quotient was found to be significantly higher than the mean expressive language quotient, both of which were found to be significantly lower than mean IQ score. Compared to individuals diagnosed with infantile autism, children with atypical PDD showed greater variability in IQ scores, less pronounced impairments in social relatedness, and significantly higher receptive and expressive language abilities. Similar between group differences were outlined by Volkmar, Cohen, Hoshino, Rende and Paul (1988), who in addition found atypical cases to have a somewhat later reported age of onset, a high male: female ratio (6:1) and an increased likelihood of excessive anxiety/general affective disturbance. With regards to social functioning and with respect to the aforementioned Wing subtypes, two studies have given evidence suggesting that less severe or atypical forms of autism are most likely to be classified in the 'active but odd' group (Volkmar et al, 1989; Waterhouse et al, 1996).

Sparrow, Rescorla, Provence, Condon, Goudreau and Cicchetti (1986) contrasted the behaviours displayed by a small sample of atypical children (diagnosed prior to the advent of DSM-III) in comparison to normal controls. When assessed during preschool years, significant differences in gross motor, fine motor and global developmental quotients were found, with normals achieving higher scores across the board. A later evaluation at school age revealed marked between group differences in communication,

socialisation and overall adaptive functioning, again with normals demonstrating superior skills. These findings are examined in the context of the clinical literature and it is suggested that atypical children can be differentiated from both autistic children at the one extreme and normal peers at the other. However, questions about the degree of similarity between conditions that show some, but not all, of the features of autism remain to be fully investigated. In this regard, the association between language disorder and PDD is frequently the focus of debate.

#### 1.4 The relationship between pervasive developmental disorder and language disorder

Children presenting with marked difficulties in language acquisition that cannot be explained by an acquired lesion, mental retardation, socio-emotional disturbance or hearing impairment are described as having *specific developmental language disorders (SDLD)*. Such disorders are reported to be more prevalent in males (Bartak, Rutter & Cox, 1975). Conceptualisation of these conditions has varied over the years, during which time these individuals have been labelled as suffering from aphasia or dysphasia. More recently, the diverse nature of this group of conditions has received broad recognition, such that various systems for subtyping have been proposed.

Based on clinical observations, Rapin and Allen (1983) and Bishop and Rosenbloom (1987) each devised a taxonomy of developmental language disorders. These frameworks for classification expanded upon the simple distinction between receptive and expressive language, paying attention to components such as syntax and phonology (concerning language form), semantics and pragmatics (concerning language content and use). This shift towards a linguistic approach to classification was accompanied by an increased

interest in more qualitative aspects, with children's language being understood in terms of its immaturity or deviance.

Diagnostic categories currently employed in ICD-10 include expressive language disorder, receptive language disorder, specific speech articulation disorder, acquired aphasia with epilepsy (Landau-Kleffner syndrome), other developmental disorders of speech and language, and developmental disorder of speech and language, unspecified. In contrast to "slow speaking" children, who simply represent the extreme of normal variation, children with specific developmental disorders of speech and language have a clinically significant disorder, which is accompanied by a range of other problems. Common consequences to their language delay include scholastic difficulties, abnormal interpersonal relationships, emotional problems and behavioural disturbance.

It is not unreasonable to expect that children who experience difficulties mastering language may develop some secondary social problems. Lord and Pickles (1996) recognised that expressive language is related to social, non-verbal communication strategies and suggested the need for a broader conceptualisation of communication handicap within preschool children (autistic and non-autistic) with developmental delays. Research has demonstrated that preschool children with language impairments participate in proportionately fewer interactions compared to normal controls (Hadley & Rice, 1991; Rice, Sell & Hadley, 1991). They are frequently noted as being less responsive and less able to maintain a conversation, with limited discourse skills placing them at risk for social exchanges with peers. A variety of studies involving normally developing, mentally retarded and hearing-impaired children attest to the link between

communication skills and social status (Guralnick, 1990; Hazen & Black, 1989; Vandell & George, 1981).

Given the above, some of the features that accompany language disorder bear resemblance to the characteristics of PDD. For example, children with severe forms of receptive language impairment may be somewhat delayed in their social development, may echo language they do not understand and may show somewhat restricted interest patterns. Children with language impairments and those with PDD have also both been described as passive conversationalists who lack initiative in interacting with others (Willemsen-Swinkels, Buitelaar & van Engeland, 1997). In recognition that there is some degree of overlap in features, ICD-10 criteria for expressive and receptive language disorder (provided in Tables 3 and 4 respectively) list PDD as an exclusion diagnosis.

**Table 3. ICD-10 (WHO, 1993) Diagnostic Criteria for Expressive Language Disorder:**

- |   |
|---|
| <ul style="list-style-type: none"><li>A. Expressive language skills, as assessed on standardised tests, are below the two standard deviations limit for the child's age.</li><li>B. Expressive language skills are at least 1 standard deviation below non-verbal IQ as assessed on standardised tests.</li><li>C. Receptive language skills are, as assessed on standardised tests, are within 2 standard deviations limit for the child's age.</li><li>D. Use and understanding of non-verbal communication and imaginative language functions are within the normal range.</li><li>E. There are no neurological, sensory, or physical impairments that directly affect use of spoken language, nor is there a pervasive developmental disorder.</li><li>F. <i>Most commonly used exclusion clause.</i> Non-verbal IQ is below 70 on a standardised test.</li></ul> |
|---|

**Table 4. ICD-10 (WHO, 1993) Diagnostic Criteria for Receptive Language Disorder:**

- |  |
|--|
| <p>A. Language comprehension, as assessed on standardised tests, is below the 2 standard deviations limit for the child's age.</p> <p>B. Receptive language skills are at least 1 standard deviation below non-verbal IQ as assessed on standardised tests.</p> <p>C. There are no neurological, sensory or physical impairments that directly affect receptive language, nor is there a pervasive developmental disorder.</p> <p>D. <i>Most commonly used exclusion criteria.</i> Non-verbal IQ is below 70 on a standardised test.</p> |
|--|

Konstantareas and Beitchman (1997) devoted an entire chapter to discussing the comorbidity of PDD and SLD, but these ideas are far from new. Churchill (1972) was one of the earliest to pass comment on the association between autism and language disorders, shortly after which, Bartak and colleagues undertook a series of comparative studies, in an attempt to clarify the relationship between the two conditions (Bartak et al, 1975; Bartak, Rutter & Cox, 1977; Cantwell, Baker & Rutter, 1978). They recruited a sample of boys with severe difficulties understanding language, who were sub-divided into three groups: (a) an autistic group; (b) a dysphasic group; (c) a mixed group, who showed some autistic features, but were considered atypical/partial manifestations. The fact that the majority of their sample could be defined as falling within the first two of these groups was taken as evidence to suggest that severe receptive language problems can exist in an uncomplicated form (i.e. without the accompanying social and behavioural abnormalities characteristic of autism). However, the need to include a third group (c) for a small number of intermediate cases who were not easily classified as autistic or



dysphasic stressed the difficulties in drawing an exact boundary between the two categories.

In contrasting the nature of the difficulties in the autistic and dysphasic groups, Bartak et al (1975) found the former to have more severe and extensive communication problems, involving deviance as well as delay, and less functional usage. Marked social and behavioural differences were detected between the groups, with the autistic subjects showing less maturity and more disturbance on these counts respectively. A critical difference between the two groups was their level of receptive language ability, with the autistic boys having a mean receptive language age of 3 years 8 months, compared to 4 years 8 months in the dysphasic boys.

Although helpful in discerning some features that differentiate autism and developmental receptive language disorders, the study simultaneously identified a pattern of commonalties. Some of the dysphasic subjects displayed echolalia and pronominal reversal, as well as a tendency to respond inconsistently to sounds in the pre-verbal stage. Deviant/deficient babble was common to both the autistic and dysphasic groups, who were also found to be similar in their acquisition of language and other milestones. Additionally, a history of speech and/or language disorder was reported in over a quarter of the families of the children in each group (which is higher than the incidence in the general population). Lastly, with regards to obsessional and ritualistic features, similarities in attachment to odd objects and resistance to change were found among both groups, further contributing to the small area of apparent overlap.

In response to this collection of findings, Rutter (1978) concluded that while there are major differences in the severity, range and nature of language and behavioural

problems between “infantile autism” and “developmental receptive aphasia”, it is not easy to draw a sharp boundary. As Wing (1976) aptly said: “If children with these problems could be arranged in an orderly series, starting from the most autistic child at one end and extending to the child who most clearly had nothing but a developmental receptive speech disorder at the other, to say where the dividing line should be drawn would need the judgement of Solomon” (Wing, 1976, p.18).

While many children with language disorders do not exhibit extensive social, behavioural and emotional abnormalities, the literature suggests that a small proportion display autistic features in conjunction with their language difficulties, whilst clearly not fulfilling diagnostic criteria for autism (Bishop, 1989). The question of whether these individuals should be identified as within the autistic spectrum remains open. One particular group of children around whom such discussions often centre are those labelled as having *semantic-pragmatic syndrome* (Rapin & Allen, 1983). Bishop and Rosenbloom (1987, p. 32) are of the opinion that this disorder represents “a set of behaviours that are loosely associated, which shade into autism at one extreme and normality at the other”. However, in the absence of a clear definition and given that no diagnostic criteria have been specified for this profile, a detailed discussion of this condition will not be pursued here (see Brook & Bowler, 1992 for a review).

In clinical practice, differential diagnosis of PDD and SLDL can sometimes prove tricky, as clearly demonstrated in a fictional scenario described by Bishop (1989) of a preschooler who is given four different labels by members of one multidisciplinary team. Particularly at young ages, it can be difficult to clearly distinguish a developmental pattern in which there is a receptive language delay with additional delays in social skills

and imaginative play, from a pervasive developmental disorder, where language delay is common and primary problems lead to impairments in social communication, interaction and imagination. In the former, social skills would be expected to follow the development of language ability, but follow-up studies have shown a pattern of differential outcome, whereby social problems sometimes remain despite improved language skills (Cantwell, Baker, Rutter & Mahwood, 1989). These findings have called into question the traditional view that socio-emotional problems develop purely in response to language handicaps, thus fuelling interest in the association between PDD and SLDL.

Mayes et al (1993) devised a study to investigate which clinical features differentiate PDD-NOS from autism and language disorder, appreciating that in the case of younger children presenting with patterns of delay/deviance in social relatedness, decisions about diagnosis can be complex. A initial pool of 80 clinically relevant items was compiled from various sources (classification manuals and scales used to assess behaviour), from which 24 were selected on the basis that they had reasonable inter-rater reliability and discriminated between the different diagnostic groups. The items concerned with the degree of socialisation and relatedness distinguished PDD-NOS from autism, with the former group showing less severe disturbance. Comparisons between children with a language disorder and PDD-NOS revealed the latter to have more difficulties with social relatedness and more need for routines and order. Overall, a smaller number of items distinguished PDD-NOS from autism than PDD-NOS from language disorder. Whilst recognising the limitations of their study, the authors are encouraged by their findings and emphasise the importance of attempting to define PDD-NOS more specifically.

All in all, the need for more definitive work to increase understanding of the relationship between PDD and SDDL is emphasised. As will be discussed in the following sections, there are a limited number of follow-up studies of PDD and SDDL populations. In addition, there is a paucity of comparative, longitudinal research involving individuals with both conditions. Such a situation renders it difficult to make judgements about the overlap in symptomatology and the changes in psychological functioning that evolve over time.

### 1.5 Follow-up and outcome studies of autism and autistic spectrum disorders

Studies documenting follow-up status of children with autism and ASD are few and far between. Systematic empirical evidence charting the course of these disorders and identifying early predictors of later status is notably lacking. With regards to classic autism, considerable variation in outcome has been reported and with respect to ASD, further longitudinal work is required to elaborate on the few findings produced to date. There are frequent calls in the literature to extend these lines of investigation.

Lotter (1978) first reviewed autism follow-up studies published up until the mid 1970s, of which he considered just eight out of a total of twenty-one to be worthwhile for the purpose of studying outcome. Taken together, the findings were seen to be rather variable, with reports of some individuals who made minimal social and academic progress and tales of others who did comparatively well. Overall, prognosis tended to be less than good, with two-thirds classed as having a poor outcome (defined as “severe handicap, no independent social progress”) or a very poor outcome (defined as “unable to lead any kind of independent existence”). Just 8 % of cases aged 16 and over were in

employment or attending college. Higher IQs and presence of communicative speech in early years were identified as being associated with a better outcome, thus held as potential predictors of later status. Although Lotter's review represented a useful attempt to collate the findings with respect to outcome in autism, his ability to complete the task successfully was hampered by the numerous methodological flaws of the studies he surveyed.

Gillberg (1991) conducted a review of more recent studies in the field, presenting his findings in subsections based on the extent of 'recovery'. He concluded that the majority of studies report a small percentage of cases who appear to make a fair/substantial degree of progress, the most encouraging results having been found in high functioning individuals with autism (Szatmari, Bartolucci, Bremner, Bond & Rich, 1989; Venter, Lord & Schopler, 1992). Nonetheless, other population based studies have provided evidence indicating that over half of children with autistic spectrum conditions remain extremely handicapped in adolescence/early adult life (Gillberg & Steffenburg, 1987). The precursors to this outcome were consistent with those previously delineated by Lotter (1978); almost all individuals with an IQ below 50 and lack of communicative speech before the age of 5-6 years were identified as likely to have a less than favourable outcome with regards to social functioning and have little chance of leading an independent life. The aggravation of symptoms during puberty, either on a temporary or permanent basis, receives special comment from Gillberg, who suggests this may be partially due to the increase in demands, (particularly in the social domain), that accompany this stage of life. He identifies adolescence as a critical period in autism and concludes his paper with a call for detailed longitudinal follow-up data.

Ballaban-Gil, Rapin, Tuchman and Shinnar (1996) echo these sentiments, highlighting the need to follow-up individuals with autistic disorder into adult life. They argue that improvement may take place beyond the adolescent period, although even those regarded as having the best outcomes continue to have persisting abnormalities in later years. In reporting the findings from their follow-up study, Ballaban-Gil and her colleagues report a mixed pattern of results, some of which confirm the handicapping effects of autism identified in previous work, others of which provide hope of slightly better outcomes for younger individuals in the future. In considering the amount of research conducted into outcome in autism, an illuminating statistic is quoted: the number of autistic individuals included in studies that have published outcome data is less than 500 in total.

The most up-to-date, comprehensive review concerned with the long term course of autistic spectrum disorders is provided by Nordin and Gillberg (1998). In discussing the pattern of symptoms in childhood, the possibility of overlap between autism, other communication disorders and global mental retardation in young children is highlighted. It is said that autistic spectrum impairments may not become apparent in those with normal intellectual abilities until the age of 6-8 years or later, the worst scenario being when there is a failure to ever recognise the underlying developmental disorder in children who present as atypical. "For individuals with normal or near-normal intellectual ability, a diffuse notion of 'something wrong' might lead to more suffering than would a straightforward outline of objective deficits and abilities".

Nordin and Gillberg usefully review how the characteristics of individuals in each of Wing's subtypes might alter in adulthood. For the aloof group, features of 'autistic

aloneness' may become less apparent in later years, when problems may arise if demands are made upon them. Individuals in the passive group may be able to engage in selective social activities without appearing too odd, if reciprocity is not demanded. However, changes of routine are noted as potential causes of distress to adults in this subtype, causing behavioural reactions that sharply contrast with their usual passive nature. Finally, the active but odd group is described as being very dissimilar to the other groups, bar their lack of reciprocity which is common to all. As adults, they have a tendency to approach others and either physically touch them (if mute) or bombard them with repetitive questions. The possibility of changing from one style of social interaction to another over time is mentioned, the most typical passage being from the aloof group to either of the other groups.

As in previous review articles of outcome, Nordin and Gillberg give consideration to factors such as prognosis and mortality, in addition to focusing upon the difficulties encountered during adolescence. Seven years on from Gillberg's (1991) call for further research into outcome, the continued need for prospective, longitudinal studies of children with PDD is highlighted once more. With this in mind, it is recommended that for the most part, a cautious approach must be maintained when discussing outcome with the parents of individuals with autism, especially in the case of younger children with whom there is no certain way of knowing how things will develop over time.

Few studies have examined the evolution of autistic characteristics or investigated how initial diagnosis/changes in diagnoses are related to outcome. In light of this, Eaves and Ho (1996) followed 76 children with representative PDDs through childhood, focusing on changes in diagnosis, cognitive functioning and behavioural features over

time. A comparison between evaluations made at two different points in time (early childhood and early adolescence) revealed a mixed pattern of improvement and deterioration.

13% of subjects reportedly received a diagnosis reflecting milder autism on the second assessment occasion, whilst in 18%, autism became more pronounced. With regards to changes in IQ, just over a third of subjects evidenced a rise and approximately a quarter showed a fall. Of these, only a minority (9% and 5% in verbal and performance domains, respectively) showed an increase or decrease in their IQ score that was felt significant enough to have an impact on their education or functioning. IQ was therefore seen to be fairly stable. Age related trends aside, autistic traits were also found to be generally stable, the most improvements being seen in areas such as narrow interests, rigidity and sensory disturbance. The observed stability of social deficits over time, as previously reported by Freeman, Rahbar, Ritvo, Bice, Yokota and Ritvo (1991), lends further support to the hypothesis that such difficulties persist despite relatively good language and cognitive abilities.

Sigman's (1998) paper devoted to change and continuity in the development of children with autism is a valuable source of reference, providing a comprehensive review of studies examining the course of autistic disorder. The importance of adopting a developmental perspective is stressed and the author writes from the basic premise that early development has consequences for later development. Studies that afford insight into the stability of characteristics over time and identify early predictors of later abilities are surveyed. Although a range of relevant publications are cited, many comments are based on data from a 8/9 year follow-up study (Sigman & Ruskin, 1999), involving a



cross-section of subjects (normally developing children and children with autism, Down's syndrome and heterogeneous developmental delays). An exhaustive review of Sigman's paper is not feasible here, although needless to say the most relevant aspects can be briefly summarised as follows.

In examining the stability of diagnosis over time, Sigman cites evidence to suggest that most children who are considered classically autistic in their early years continue to demonstrate all the features of the disorder in later childhood/adolescence, whilst making the point that such continuity may not equally apply to individuals who suffer from milder forms of the condition. A related issue which Sigman briefly touches upon concerns reported changes in the pattern of presenting symptoms over time (e.g. the finding that younger children display more stereotypic behaviours than older children), studies of which are in need of replication.

In turning to examine stability of IQ, Sigman addresses questions relating to the accuracy of assessments conducted at a young age and changes in scores over time. With respect to the first question, test-retest reliability estimates in a sample of 3-5 year olds were not found to markedly differ between a group of autistic children and other groups with alternative diagnoses, all of whom were participated in an initial assessment and a repeat evaluation 1 year later. In response to the second question, correlations between IQ scores measured at different ages are reported to be as satisfactory for individuals with autism as for typically developing, behaviourally disordered and learning disabled populations (Lord & Schopler, 1989b). Examination of changes in scores at an individual level revealed that although the mean IQ in a group of autistic individuals did not change substantially, both significant increases and decreases in scores were observed for a

number of children in the sample. These findings are in line with the pattern of IQ changes reported by Eaves and Ho (1996), although neither article speculates on the meaning of such results.

In examining the stability of language skills over time, a little over half of the children with autism were noted to have achieved a receptive language equivalent of 2 years at follow-up, having not had this level of understanding when initially assessed. Despite finding that early IQ estimates were not predictive of later language gains, improvements in intelligence over time were accompanied by substantial increases in language skills.

Having reviewed the stability of characteristics over time, Sigman proceeds to consider the precursors to improvements in cognitive, language and social functioning. In short, she concludes that achievements in the early years are important predictors of later gains. Children who are generally more communicative (non-verbally), more likely to react to other's attempts to focus their attention on an object and more responsive to other's emotions in early years are reported to make the best progress with regards to language and prosocial behaviour. The influence of these factors is independent of intellectual ability, although both language and intelligence contribute to a child's degree of social competence, both concurrently and predictively. Having established such links between early and later accomplishments, Sigman stresses the need to further understanding and devise appropriate interventions.

When viewed collectively, it can be seen that the vast majority of outcome studies have involved samples of typically autistic individuals, with only a minority including milder variant conditions. Gillberg and Steffenburg's (1987) population-based follow-up

study suggested that, within a group of cases defined as having a poor/very poor outcome, children diagnosed with infantile autism tended to have more favourable outcomes than those identified as having “other childhood psychoses” (said to include autistic-like conditions). Szatmari, Bartolucci and Bremner (1989a) examined outcome in a group of children with Asperger’s syndrome, finding them to have more psychiatric symptoms and to have spent less time in special education compared to a group with high-functioning autism.

Few longitudinal studies have focused exclusively upon less severe, atypical forms of autistic disorder, such that only two examples were identified in trawling the literature. Sparrow et al (1986) followed-up cohort of 11 “atypical” children, who were argued as distinct from individuals diagnosed with high-functioning autism or Asperger’s syndrome. Evaluations were completed during early years (mean age 4.1 years) and at a later stage (mean age 10.4 years), the results of which were presented above in describing how atypical children differ relative to normal controls. The study provides crucial evidence to suggest that the pattern of impairments in communication, socialisation and behaviour identified in preschool atypical children remain a feature in later childhood years.

In a 5 year follow-up study comprising a group of 18 preschool children diagnosed as having atypical PDD, Demb and Weintraub (1989) revealed similar findings to Sparrow and her colleagues with respect to the persistence of emotional, social and cognitive difficulties. All the participants of this study were noted as having required some form of therapeutic input and a subset were reported to have a variety of other symptoms at follow-up, characteristic of anxiety, depressive and schizophrenic disorders.

## 1.6 Follow-up and outcome studies of language disorder

The lack of research undertaken to study the long-term course of language disorders has often received criticism. In a similar way to PDD, a variety of outcomes have been reported for children with SLD. More information is needed in relation to the longer term course of different types of speech and/or language difficulty, the trajectory being likely to differ according to the nature of the impairment (Beitchman, Brownlie, Inglis, Wild, Matthews, Schacter, Kroll, Martin, Ferguson & Lancee, 1994). Furthermore, there is a need to focus on community samples, since much of the available data in this field relate to findings from studies of clinical populations. Paul and Cohen (1984) cite 5 papers reporting follow-up data on speech/language disorders, finding fault with the fact that mixed populations were often used, such that the inclusion of mildly impaired subjects is likely to have skewed the results. All in all, the issue of outcome in relation to developmental language disorders warrants further investigation.

In response to numerous calls for clinicians to assess preschoolers who have failed to develop age-appropriate language skills and in recognising the difficulty in predicting the outcome of delayed language acquisition, Allen and Rapin (1980) examined the potential prognostic value of a range of verbal and non-verbal behaviours. Twenty-one children with developmental language disabilities were assessed every six months over a period of three years, using videotaped recordings of play sessions to allow retrospective and prospective examinations to be carried out. In addition to identifying factors that proved unhelpful in predicting communicative competence, a series of strong predictors of language proficiency were identified. Onset of communicative language before 4 years of age, functional use of language and a modulated activity level were among the items

related to a good outcome. Alternatively, impoverished play, a history of loss or stagnation of skills and limited understanding of connected discourse were associated with a poorer prognosis. In the absence of a detailed breakdown of the types of language difficulties experienced by this likely heterogeneous group of subjects, it is difficult to draw any firm conclusions from this study. More fruitful information on outcome of developmental language disorders can be gained from the recent literature.

Rutter, Mahwood and Howlin (1992) wrote a chapter on language delay and social development, providing an overview of the literature on outcome of SLDL. In reviewing the work of Bishop and colleagues (Bishop & Edmundson, 1987a, b; Bishop & Adams, 1989), features that have been found to predict 'good' and 'poor' outcomes (at age 8 years of age) for severely language disordered preschoolers are listed. Namely, those who progress to near normal levels of language functioning showed either a pure phonological impairment or mild deficits spanning a small variety of language functions early on. Alternatively, those who continue to experience difficulties with language and experience scholastic problems demonstrated more severe and broad language impairments (involving receptive deficits) in younger years, when they also showed associated perceptuomotor abnormalities.

Beitchman et al (1994) reported on the stability of speech and/or language impairments in an epidemiological sample of 5 year olds, examining the continuity of deficits at two different points in time. At the simplest level of analysis, it was found that nearly three quarters of children who were classified as having a speech and/or language impairment at time 1 continued to have speech and/or language difficulties when later re-assessed. This figure is consistent with other estimates of the degree to which these

deficits persist (Baker & Cantwell, 1987; Bishop & Edmundson, 1987a; Stark, Bernstein, Condino, Bender, Tallal & Catts, 1984).

### 1.7 Longitudinal studies comparing pervasive developmental disorder and language disorder

As outlined above, there are some overlapping features between pervasive developmental disorder and language disorder, yet the degree to which they show a comparable developmental course remains largely unexplored. Studies directly comparing the sequelae of these disorders are small in number, in spite of the fact that there are still many issues to be resolved. Increased understanding of the conceptual relationship between PDD and SLDL awaits further research to build upon those tentative conclusions suggested in the comparative studies conducted to date.

Paul, Cohen and Caparulo (1983) published a longitudinal study on a sample of twenty eight developmentally language disordered individuals, reporting separately on those considered to have a simple form of aphasia (characterised by well developed social, non-verbal communication and play skills) and those who demonstrated features of autism in addition to their language difficulties. The former group were labelled as having a 'developmental language disorder' (DL), whilst the latter were said to have an 'atypical developmental language disorder' (ADLD). Although the sample as a whole was language disordered, the study makes direct comparisons between individuals who demonstrated concomitant signs of autism with those who did not, thus warranting its discussion in this section.

The authors present data relating to the status of the subjects when they were assessed at a mean age of 6.5 years, reporting several findings consistent with other studies. The question of changes in characteristics over time is then addressed and it was hypothesised that individuals with a relative strength in comprehension would fare better than their counterparts whose level of language understanding was as limited as production. The DLD and ADLD groups were therefore sub-divided into those where expressive language skills were in line with receptive abilities and those for whom comprehension presented less of a problem. The pattern of progress in social, behavioural and language domains was then reported accordingly, briefly summarised as follows.

Improvements in language abilities varied across all subgroups, the best expressive language gains being made in the DLD group, with comprehension in advance of their production capacities. Behaviour problems continued to be manifest by all subjects in later years, with minimal improvement noted. Finally and most interestingly, with regards to progress in social functioning, the findings suggested that comprehension status was a key factor in predicting improvement, irrespective of IQ level. The study implicates the discrepancy between expressive and receptive language abilities to be potentially important prognostic information. This is seen as a useful starting point in attempting to understand factors contributing to differential outcome for individuals with disordered language.

Subsequent to this, Paul and Cohen (1984) reported outcome data for a proportion of the original sample enlisted in Paul et al's study (1983) who were followed through adolescence. On this occasion, the DLD group comprised 11 subjects, whilst the ADLD group contained 9. All subjects were assessed on a battery of measures, including

evaluations of language skills, cognitive abilities and behaviour. Hyperactivity was commonly reported in parental questionnaires, to the extent that just over half of all participants scored above the normal cut-off. For the small number of subjects for whom performance IQ was available, scores were not found to significantly change for the sample as a whole over time, a finding that is in contrast with suggestions of decrease over time forwarded elsewhere (Eisenson, 1972). Positive results were presented in relation to growth in receptive and expressive language for the entire sample over time, with progress commensurate with age increment in the former and progress in advance of growth in age in the latter.

At follow-up, blind raters reliably assigned subjects to the diagnostic categories they had been originally classified within, indicating that social-communication skills remained relatively stable across time. Characteristics of the ADLD group included “oddities of communication, failure of communicative intent, language deficits and social withdrawal”. On the basis of these features, it is the author’s opinion that they would not be easily distinguished from adolescents diagnosed autistic in their early years.

One suggestion that arises out of the data is that early social competence is a good predictor of later social and communicative development. This prompts the recommendation that intervention with preschoolers who demonstrate both language and social impairments should target social-communicative skills, even if social deficits are mild in comparison to those shown by typically autistic individuals. The importance of such input is underscored when considering the evidence that suggests outcomes for children with social deficits, whether they be of mild or severe degree, appear quite similar in later years. The fact that the picture in adolescence does not appear to vary



much whether a child shows clear autism or a very mild form of the condition lends further support to the notion of a spectrum disorder.

Further arguments relating to the centrality of social deficits are put forward by Cantwell et al (1989), who set out to investigate the differential stability of symptoms over time in a PDD sample compared to a SLD sample. In this regard, follow-up data on the sample of autistic and dysphasic children who participated in Bartak and colleague's original series of studies published in the 1970s are presented. The two groups of boys were aged 6-11 years at follow-up, which took place 2 to 3 years after their initial evaluation. The same standardised investigator-based interview was used on both assessment occasions, to facilitate comparisons over time. The main areas of functioning covered by this measure are language development, social skills, stereotyped/repetitive behaviours and disruptive public behaviour.

Overall, autistic subjects were rated as having a poorer outcome in all the areas of functioning assessed compared to those with a receptive language disorder. Although both groups initially displayed similar levels of expressive language functioning, the boys with autism evidenced less progress over time, in addition to retaining their deviant features. This finding was felt to be striking given that the sample was relatively high functioning (all with IQs above 70). There was a tendency for dysphasic children who had displayed repetitive stereotyped behaviours in earlier years to show less evidence of them at follow-up, although just over a quarter did continue to demonstrate difficulties in this regard. Furthermore, a change in the distribution of children displaying disruptive public behaviours was noted, such that at follow-up, a higher percentage of autistic

subjects were categorised as showing more acceptable behaviours than dysphasic subjects, the reverse having been found at the time of the first assessment.

Last but not means least are the findings in respect of social deficits. Although it might be expected that socio-emotional problems associated with language difficulties would be more extreme in the early years (when language problems are at their worst), this piece of research suggests the opposite. 50% of the dysphasic subjects were classified as having problems with peer relations in middle childhood, compared to 35% at initial assessment. Lack of friends, poor group participation, failure to approach other children and failure to show sympathy were quoted as examples of the kinds of problems encountered by this group at follow-up. These findings raise the possibility that difficulties in these areas do not simply remain stable across time, but may actually become increasingly apparent with age. The fact that social deficits persisted in spite of improved language skills casts some doubt on their being secondary to language difficulties. It is said that “perhaps....in some cases, the social problems constitute a more basic part of the development disorder”. This hypothesis requires further investigation.

Rutter et al (1992) report further on the status of Cantwell et al’s (1989) sample in a unique study examining the parallels and contrasts between individuals with autism and those with language disorders in early adult life. They describe the former group as showing higher levels of continuing handicap in language, communication, daily living skills, scholastic attainment, socio-emotional expressiveness and social relationships compared to the latter. This does not imply of course that those with receptive language problems were free of abnormalities, as they too showed evidence of persisting language and social impairments. By way of conclusion, the authors remind the reader that

although language difficulties are the most obvious in individuals with SLD, their handicaps extend beyond this domain. What remains uncertain however is the mechanism underlying the difficulties that persist long after language had improved.

In summary, the above studies report a mixture of results in comparing these two groups of children over time. Some factors relating to differential outcome have been identified and evidence to suggest that some children with SLD appear more autistic-like in later years has been provided. However, the key issue that remains is whether these children were misdiagnosed at initial assessment or whether they have developed a different set of features over time. More evidence is required before such questions can be answered with any degree of certainty.

### 1.8 Aims of the present study; research questions

Although continual research into PDD has been successful in supplying the answers to a large number of questions, it has prompted investigation into many more. The above literature review conveys the need for clarity on issues relating to diagnosis, classification and the extent of overlap with related disorders. Especially, more longitudinal research is required to furnish the field with valuable information on outcome. By charting the trajectory of symptoms in children with autistic spectrum and related conditions, some of the nosological issues highlighted above might begin to be resolved.

Numerous questions remain unanswered in relation to the longer-term status of children who do not qualify for a diagnosis of autism, yet fit the general description for PDD at a young age. What happens to these individuals as they mature? In some cases, do autistic features dissipate as language skills improve, which might suggest that early

abnormalities were associated with a specific developmental language disorder rather than a more pervasive underlying disorder of social communication? Do the factors that predict a good outcome in children with autism (i.e. language and IQ) hold the same prognostic significance for those with milder forms of the condition?

In light of such questions, the present study reports on the follow-up status of a cohort of children who showed evidence of PDD in the preschool period (3-5 years), but did not qualify for a diagnosis of childhood autism. The study aims to describe the characteristics of the sample at age 6-10 years and identify which impairments prevail. An attempt is also made at investigating which early factors predict outcome at follow-up.

The study is the first of its kind since the advent of ICD-10/DSM-IV to focus exclusively on following-up a cohort of preschool children who demonstrated some features of PDD, but did not meet diagnostic criteria for autism. The investigation represents an attempt to better understand the course of development in these individuals and identify early markers for differential outcomes. Accruing such information will ultimately increase clinician's abilities to be more accurate about prognosis. It will also allow them to better inform parents and other clinicians about the meaning of a diagnosis. In this way, it is clear that the present study is a clinically driven venture, although the findings will be potentially of great interest to practitioners and researchers alike.

Specifically, the study intends to address the following series of questions:

- (i) What characteristics do children who did not qualify for a diagnosis of autism yet fitted the general description for PDD in preschool years present with in middle childhood?
- (ii) To what extent are early estimates of language and intellectual ability associated with language skills, IQ and behaviour at follow-up?
- (iii) To what extent are other early aspects of behaviour associated with language skills, IQ and behaviour at follow-up?

## **2. METHOD**

This section describes the present study sample, outlining how subjects were selected. The procedures used are then detailed and an explanation is given of the methods used to gather and record information at each stage of the project. Finally, an overview of the statistical techniques used in subsequent data analysis is provided.

### **2.1 Subjects**

A list of all children seen for a diagnostic assessment at the Newcomen Centre, Guy's Hospital, London, during the period 1993 to 1995 (Time 1) was compiled through an examination of clinic appointment books. This initial search yielded a total number of 692 cases, 227 of which were selected on the basis that they were between aged 3 and 5 years at the time of their assessment. Case notes were reviewed by hand, as a result of which 102 children were excluded. Reasons for exclusion included a diagnosis of childhood autism, a diagnosis of attention deficit disorder (in which there are often associated social problems) or a non-verbal IQ below 50 (which makes judgements about social functioning very difficult). A further 79 children had to be dropped from further consideration, because their case notes were unavailable for inspection; 49 were logged as 'missing' and 30 had been converted to microfiche format and stored in a distant location. Besides the practical difficulties associated with accessing the latter, the information contained on microfiche was considered to be of limited clinical use, as only typed material from the case notes (not hand written notes) was included.

The remaining 46 files belonged to children labelled as having a pervasive developmental disorder or a language disorder with additional social impairment, all of

whom were earmarked for further examination. None of these children satisfied ICD-10 criteria for childhood autism or Asperger's syndrome at Time 1; they did however all fit the general description for PDD. In the absence of a clear lower cut-off for this category of disorder, clinicians did not feel able to reliably state that all the children fulfilled diagnostic criteria for PDD. In addition, clinicians were unable to reliably discriminate between those who were labelled PDD and those who were said to have a language disorder with additional social difficulties, decisions about labelling having essentially been made on the basis of factors such as parental views and educational needs.

From the potential pool of 46 children from which to recruit to the present study, 7 families were lost to follow-up (4 were untraceable and 3 had moved abroad), 2 families refused to take part and 1 family was not contacted due to extensive involvement in another research study. Of the remaining 36 children, 30 were seen for a follow-up assessment in 1998/1999 (Time 2). Time factors precluded the other 6 children from being offered an opportunity to take part.

The follow-up sample comprised 4 girls and 26 boys, a sex ratio that is consistent with figures quoted in other studies (Volkmar et al, 1988). 28 out of the 30 children were ethnic Caucasian, 1 was Asian and 1 was Black-Caribbean. Mean age at Time 1 was 49.4 months (range 31-67, SD 8.9) and at Time 2 was 100.7 months (range 75-125, SD 11.8). The mean time elapsed between Times 1 and 2 was 51.3 months (range 35-69, SD 9.8).

## 2.2 Procedure

The study took part in two stages, the first of which involved a retrospective analysis of children's case notes and the second of which encompassed conducting a follow-up assessment. A detailed description of each stage now follows.

## Stage 1

At Time 1, all the children were assessed by the same Consultant Community Paediatrician, who has extensive knowledge in the field of developmental disabilities. Members of the Clinical Psychology and Speech & Language Therapy Departments were also involved in each comprehensive, multidisciplinary evaluation. Retrospective data pertaining to the assessment conducted at Time 1 were extracted from the case notes/clinical reports and recorded as follows:

### *(i) Details of language and cognitive functioning*

IQ and language levels have consistently been reported as strongly related to outcome in follow-up studies of children with autism. This would suggest that they are also likely to have some long-term influence in milder variant conditions. To examine this hypothesis, the results of standardised assessments of language and non-verbal IQ conducted at Time 1 were extracted from the notes. Given the range in ability level of the children, several different assessment instruments were used to assess intellectual and language skills. Cognitive measures included the Wechsler Preschool and Primary Scale of Intelligence, revised edition (WPPSI-R, Wechsler, 1992a), the Kaufman Assessment Battery for Children (1983), the Leiter International Performance Scale (1952), the Stanford Binet Intelligence Scale, 4th edition (Thorndike, Hagen & Sattler, 1986) and the Snijders-Oomen (1976). Language measures included the Preschool Clinical Evaluation of Language Fundamentals (Preschool-CELF, Wiig, Secord & Semel, 1992), the Reynell Developmental Language Scales (1985) and the Preschool Language Scales (Zimmerman, Steiner & Pond, 1991). For the purpose of data analysis, it was necessary



to convert scores on these measures to a common metric: a standard score for cognitive tests and a z score for language tests.

Scores obtained on cognitive tests were available for only a proportion of the sample. In situations where a standard score could not be located in the case notes, descriptive information regarding the level of intellectual/non-verbal functioning was often available in the form of an explicit statement in clinical reports. Subjects' IQ was therefore recorded as interval data (where a standard score was available) and/or ordinal data, using the following classification scheme: 'average or above' range (including all those with a score standard score of 90 and over, or a statement to this effect); 'low average' range (including all those with a score between 80 and 89, or a statement to this effect); 'borderline' range (including those with a standard score between 70 and 79, or a statement to this effect); 'disability' range (including all those with a standard score below 70, or a statement to this effect).

In a similar vein, scores obtained on tests of receptive and expressive language were available for only a proportion of subjects, although once again, descriptive information regarding level of functioning in these areas was often available. Expressive and receptive language levels were recorded as interval data (where it was possible to compute a z score) and/or ordinal data, according to a classification scheme based on the same principles as those used for IQ: 'average and above' range (including those with a score of -0.67 standard deviations and above, or a statement to this effect); 'low average' range (including those with a score between -1.33 and -0.68 standard deviations, or a statement to this effect); 'borderline' range (including those with a score between -2 and -1.34 standard deviations, or a statement to this effect); 'disability' range (including those

with a score less than -2 standard deviations, or a statement to this effect). Information about language milestones was also extracted, noting whether single words were used before the age of 24 months and whether phrase speech developed by the age of 36 months.

*(ii) Third axis behaviours (restricted, repetitive, stereotyped behaviours)*

This class of behaviours have traditionally been the subject of less research than social communication behaviours (Rutter, 1996). It has been suggested that these behaviours are less evident in individuals with milder variants of autism and may therefore not be necessary when diagnosing PDD (Tanguay et al, 1998). With these issues in mind, axis three behaviours detailed in the case notes were coded according to their type and severity. The consistency with which such behaviours were recorded was relatively high, perhaps because these features are by definition more notably abnormal.

Four categories of behaviour were rated on a 'none', 'mild' or 'marked' basis (coded 0, 1 and 2 respectively): restricted, repetitive patterns and interests (including unusual preoccupations); routines and rituals; mannerisms; preoccupation with part-objects (including unusual sensory interests). The criteria used to determine degree of severity for each of these categories are outlined in Appendix 1. An axis 3 composite score was computed by summing the severity ratings across the 4 categories; this was only done in cases where it was possible to assign ratings to all 4 categories. Although it is recognised that qualitative information is lost in this method, it does nonetheless provide some insight regarding overall axis 3 pathology. The creation of this composite variable also allowed subjects to be classified into 2 groups, according to whether they obtained a high or low score (the cut-off determined by the median value).

*(iii) Social dysfunction*

It has been suggested in the literature that the nature of social dysfunction displayed in early years may alter with age (Wing & Atwood, 1987). To investigate this further, case notes were reviewed and a clinical judgement was made about the type of social dysfunction evidenced by each child. Subjects were assigned to one of Wing's subtypes: 'active but odd'; 'passive'; 'aloof'. Detailed descriptions of each are provided in Appendix 2.

*(iv) Excessive anxiety*

The multidisciplinary team hypothesised that excessive anxiety might have some bearing on outcome and reference to this in the case notes was therefore recorded. A distinction was drawn between anxiety which results from behaviours traditionally associated with autism (e.g. anxiety in relation to ritualistic behaviours) and more generalised anxiety (e.g. anxious about being the focus of attention, worries about school, signs of extreme insecurity). Examples of the latter only were taken to indicate the presence of excessive anxiety. Information regarding anxiety was coded on a 'present' or 'absent' basis.

*(v) Overactivity*

The multidisciplinary team hypothesised that overactivity might be related to outcome and reference to such behaviour was therefore extracted from the case notes. A distinction was made between children described as overactive and those who were noted as being boisterous or physically energetic. Examples of the former only were taken to indicate the presence of overactivity. Information regarding overactivity was recorded on a 'present' or 'absent' basis.

*(vi) Social communication behaviours*

Having extracted all the above information, it was felt that some key aspects of behaviour that are taken into consideration when making a diagnosis of PDD had not been captured. Namely, data relating to deficits in social communication was missing, and although the centrality of such problems continues to be questioned, the concept is held to be useful in describing the problems of individuals with autism (Mundy & Sigman, 1989). It was therefore considered worthwhile to attempt to extract information regarding social communication behaviours from the case notes. This was carried out as follows.

The Paediatrician who initially assessed all the children in the present study sample made clinical judgements about the severity of social communication difficulties at Time 1, whilst remaining blind to their follow-up status. Such decisions were made on the basis of the Paediatrician's own notes and from the information she was able to recall about each child's presentation at initial assessment. Global ratings ('good' / 'some' / 'poor' - coded 0, 1, 2 respectively) were assigned on 5 dimensions of social communication behaviour: social motivation (a judgement about whether the child seems motivated to be like others, as evidenced in their awareness of others and copying behaviour); social affective behaviours (a judgement about the extent to which the child is affectionate, offers comfort, shares and greets other people); prosocial peer behaviour (a judgement about the extent of the child's interest in other people and their ability to join in group activities); social communication (a judgement about the extent to which the child points to and shows objects to others to express interest, shares pleasure and asks about others' interests and ideas); non-verbal communication (a judgement about

the extent to which the child makes appropriate use of gesture, eye contact and facial expression). A social communication composite score was computed by summing the severity ratings across the 5 dimensions; this was only done in cases where it was possible to assign ratings to all 5 dimensions.

The difficulties inherent in retrospectively rating a child's behaviour on the basis of subjective, summary judgements written in the case notes, raises questions concerning reliability. This issue was addressed by having one person rate all 30 sets of case notes and a second person blind rate a percentage of them ( $n = 14$ , 48.3%) on items (ii), (iii), (iv) and (v) above. Such a procedure allowed estimates of inter-rater reliability to be calculated. Item (vi) was not rated by two persons independently, given that the Paediatrician who had originally assessed each child completed the ratings.

## Stage 2

Families were traced for the purpose of follow-up. Initial contact was established by sending an introductory letter, which briefly outlined the study and invited families to take part (Appendix 3). They were then telephoned approximately two weeks later, on the proviso that they had not returned a prepaid card to indicate they did not wish to be contacted. Appointments for home visits were arranged and a series of questionnaires (details of which are given below) were sent out, together with an information sheet/consent form for the study (Appendix 4).

All visits were carried out by a pair of professionals: a Clinical Psychologist in Training and a Specialist Speech and Language Therapist. Due to the wide geographic location of subjects and the fact that each visit lasted approximately 2.5 hours, it was only

feasible to see one or two families in one day. Each professional spent time with the child individually, administering standardised tests of cognitive and language ability: the Wechsler Intelligence Scale for Children, 3rd edition UK (WISC-III<sup>UK</sup> full version, Wechsler, 1992b) and the Clinical Evaluation of Language Fundamentals, revised edition (CELF-R full version, Semel, Wiig & Secord, 1987). It should be noted that one child experienced difficulty completing these measures and therefore, the WPPSI-R and the Preschool-CELF were administered as alternatives. Also, 6 subjects had completed a CELF-R within the preceding 6 months as part of a local speech and language therapy assessment. Although this precluded the test from being repeated, the results were made available to the present study for the purpose of analysis.

In addition to seeing each child, some time was spent with parents. The questionnaires were reviewed, and information about current symptoms and educational needs and provision was gathered. A written summary of the results of the standardised assessment was provided to the family in due course (an example of which is given in Appendix 5). Following each visit, subjects were rated on a selection of the variables used when retrospectively rating subjects at Time 1: axis 3 behaviours, social dysfunction, excessive anxiety and overactivity. Ratings on these items were completed as previously described, with 15 (50.0 %) of randomly selected case notes being blind rated by a second person.

### 2.3 Design

This non-experimental study uses both descriptive and correlational designs. Details of the follow-up status of the sample are provided and associations between variables, both within and across time, are explored.

## 2.4 Measures

The following battery of instruments, covering several areas of functioning were employed to examine the follow-up status of the sample:

*(i) Wechsler Intelligence Scale for Children, 3rd edition UK*

The WISC-III<sup>UK</sup> (Wechsler, 1992b) is a standardised, individually administered instrument used to assess intellectual functioning. It is one of the most widely used tests of cognitive ability, that yields verbal IQ (VIQ), non-verbal IQ (PIQ) and full scale IQ (FSIQ) scores.

*(ii) Clinical Evaluation of Language Fundamentals, revised edition*

The CELF-R (Semel et al, 1987) is a standardised, individually administered test, designed for the identification, diagnosis and follow-up evaluation of language skill deficits in school-aged children. It is a commonly used clinical tool, which gives Expressive, Receptive and Total Language scores.

*(iii) Children's Communication Checklist (Appendix 6)*

The CCC (Bishop, 1998) is a recently devised measure of communication impairment, which was developed in response to increasing recognition that conventional forms of language assessment were poor at identifying semantic-pragmatic problems. In the interests of obtaining a qualitative picture of the profile of communicative difficulties in children with language impairments, the checklist covers not only semantic and pragmatic abnormalities, but also includes items relating to other aspects of speech and language, social relationships, interests, attention and gross motor skills. In the validation study using information collected from teachers and speech therapists (Bishop, 1998), reported measures of internal consistency for two raters across all subscales were

between .73 and .88 (mean .82), whilst inter-rater reliability across subscales was between .62 and .83 (mean .70). For the purpose of this study, the checklist was completed by parents, the reliability of which has yet to be studied. Data regarding groups of language impaired children have been published by Bishop (1998), but information on autistic children's performance on the CCC are in preparation.

The CCC consists of 70 items, grouped into 9 subscales: speech output (intelligibility and fluency); syntax; inappropriate initiation; coherence; stereotyped conversation; use of conversational context; conversational rapport; social relationships; interests. Respondents are asked to judge whether each statement 'does not apply' (scored 0), 'somewhat applies' (scored 1) or 'definitely applies' (scored 2), with an additional option of 'unable to judge'. Statements describing a child's strengths are scored positively and those describing weaknesses are scored negatively. The total score for each subscale is calculated by summing all the appropriate items, to which 30 is added to ensure that all figures are positive for the purpose of analysis. In cases where items are omitted or coded 'unable to judge', scores can be prorated provided they do not constitute more than one fifth of the items in a subscale. A pragmatic composite score can be computed by summing the total for the inappropriate initiation, coherence, stereotyped conversation, use of context and rapport subscales.

*(iv) Strengths and Difficulties Questionnaire (Appendix 7)*

The SDQ (Goodman, 1997) is a recently developed brief screening questionnaire, that examines general behavioural disturbance. In line with recent trends that have tended to focus on children's strengths in addition to their difficulties, this measure provides balanced coverage of behaviours, emotions and relationships. The SDQ correlates well



with the Rutter questionnaires, for which there are strong psychometric properties (Elander & Rutter, 1996). Correlations range between .78 on the emotional symptoms score (parental report) to .92 on the total deviance/difficulties score (teacher report). The ability of the SDQ to distinguish between psychiatric and non-psychiatric samples compared well to that of the Rutter questionnaires, the area under the Receiver Operating Characteristic (ROC) curves being .87 for the parent version of both measures and .85 for the former and .84 for the latter on teacher versions (sensitivity or specificity estimates are not provided).

The SDQ was designed for use with individuals ranging from 4-16 years, with both a self-report version and an informant-rated version for parents and teachers to complete. For the purpose of the present study, the SDQ was administered to parents only. The SDQ lists 25 attributes (10 strengths, 14 difficulties, 1 'neutral' item), which respondents rate as 'not true', 'somewhat true' or 'certainly true'. Scores in 5 dimensions can then be calculated: conduct problems, emotional symptoms, hyperactivity, peer relationships and prosocial behaviour. A total difficulties score is computed by adding all items contained in the first 4 of these 5 domains. Provisional bandings derived from research conducted on the SDQ to date are provided, use of which depends on the sample characteristics. For the purpose of the present study, the 'abnormal' banding is employed.

*(v) Autism Screening Questionnaire (Appendix 8)*

The ASQ (designed by Rutter & Lord, with preliminary analyses by Berument, Rutter, Lord, Pickles & Bailey, in press) is a novel screening questionnaire, based on the concepts and behaviours underlying other well established instruments used to detect possible autism. It is based on current diagnostic criteria for autism and designed to be

completed by primary caregivers of individuals of all ages who are suspected as having a pervasive developmental disorder. The psychometric properties of the scale appear reasonable, with a reportedly high internal consistency for the total scale ( $\alpha = .90$ ). Receiver Operating Characteristic Analyses suggest the ability of the ASQ is to discriminate between PDD and non PDD diagnoses is high (sensitivity = .88, specificity = .65), although it is noted that the differentiation of autism from other PDD was less successful (sensitivity = .79, specificity = .51).

The ASQ comprises 40 items on reciprocal social interaction, language, communication and repetitive/stereotyped patterns of behaviour. In addition, one question refers to self-injurious behaviour and another asks about current language functioning. The first 20 items refer to lifetime manifestations of behaviour, whereas the latter half focuses specifically on the period when the child was aged between 4 and 5 years (as this is considered to be the period when most prototypical autistic behaviours are apparent). The questionnaire is available in two different versions, for those under and over the age of 6 years. Due to the age of the follow-up sample in the present study, only the latter version was required in this instance.

The respondent rates each item on a 'yes' or 'no' basis, with a score of 1 assigned for the presence of abnormal behaviour. The range of possible total scores for a verbal individual is 0 to 39 (the current language level item being excluded from this calculation). Preliminary analyses of the ASQ (Berument et al, in press) has suggested that cut-off scores of 14 or more differentiate PDD (including autism) from other diagnoses, whilst a higher cut-off of 21 is required to separate autism from other PDD.

## 2.5 Statistical analysis

All data were cast in a suitable form for entry into SPSS (Version 7.5 for Windows). Having checked the data set for transcription errors, an examination of variables to be used in subsequent analyses was carried out. This preliminary step involved studying the distributions of continuous variables, by way of visual inspection and statistical procedure. Those variables identified as having a Skewness or Kurtosis value greater than  $\pm 1.96$  were transformed using the logarithmic function. Five variables necessitated such a procedure: Time 1 receptive language scores; Time 1 expressive language scores; prorated speech subscale scores on the CCC; Time 2 expressive language scores; Time 2 total language scores.

Standard descriptive statistics were employed to examine the characteristics of the sample at initial evaluation and follow-up. In situations where subjects were placed into categories or where groups were formed on the basis of individual's scores on outcome measures, some between subject comparisons to be made in the form of independent t tests and one way analysis of variance. Such procedures are kept to a minimum however, due to the small size of the sample. Changes occurring between Times 1 and 2 were explored, involving the use of paired t tests and nonparametric statistics to examine the significance of any change. Associations between measures, both within and across time, were then computed, mainly by way of correlational analyses. As a matter of course, scatterplots were inspected prior to running correlations, both to check for outliers and observe the degree of linear association. Finally, regression methods were employed to determine which variables at initial assessment predicted characteristics at

follow-up, part of which involved analysis of the residuals to confirm that errors of prediction were normally distributed.

## **2.6 Ethics and Consent**

Ethical approval for this study was granted by Guy's Research Ethics Committee (Appendix 9). Participants were provided with written information about the study, detailing its purpose and what was entailed. Following this, they gave informed consent for their involvement by signing a form devised to specification for this purpose.

## **2.7 Funding**

This study was supported in part by the University of London Central Research Fund and the Graduate School Research Projects & Conference Funds.

### **3. RESULTS**

This chapter presents the result of the investigation. Findings are organised into 5 sections: (i) presentation of data relating to the initial assessment; (ii) presentation of the data relating to the follow-up assessment; (iii) comparisons between data from initial and follow-up assessments; (iv) associations between characteristics, within and across time; (v) predictive factors.

#### **3.1 Characteristics at Time 1**

##### **Representativeness of the sample**

In an attempt to assess the representativeness of the follow-up sample, comparisons were made with the group of children who fulfilled inclusion criteria but were not seen for an assessment at Time 2 (referred to herein as the potential group). Differences in age, IQ and language functioning at initial evaluation were examined. At Time 1, the mean age of the 30 children in the follow-up sample was 49.4 months (SD 8.9), while the mean age of the 16 children in the potential group was 51.9 months (SD 11.4). The age difference was not shown to be significant ( $t(44) = .81, p = .41$ ).

Comparing the mean PIQ for each group revealed a discrepancy of 12 points: 102.7 (SD 17.1) for the follow-up sample versus 90.0 (SD 21.0) for the potential group. An independent samples t-test demonstrated that this difference was not significant ( $t(30) = -1.77, p = .09$ ). However, the number of subjects for whom a PIQ estimate was available in each group was low ( $n = 23$  for the follow-up sample and  $n = 9$  for the potential group); the difference may have been found to be significant if a higher number of subjects had been included.

The number of children in each group with expressive and receptive language estimates was also low. The mean expressive language  $z$  score for the follow-up sample was -2.0 ( $n = 14$ , SD 1.3) compared to -2.3 ( $n = 5$ , SD 0.8) for the potential group, and the mean receptive language  $z$  score for the follow-up sample was -2.1 ( $n = 23$ , SD 1.2) compared to -1.9 ( $n = 5$ , SD 1.0) for the potential group. On both counts, the difference failed to reach significance ( $t(17) = -.56$ ,  $p = .59$  for expressive language;  $t(26) = .61$ ,  $p = .54$  for receptive language).

### Intellectual and language functioning

Table 5 shows the distribution of intellectual and language functioning across categories at Time 1 for the subjects who participated in the present study. A performance IQ only is quoted, given that the tests administered as part of the initial assessment were largely measures of non-verbal ability. The distribution of PIQ estimates reveals that the sample was assessed as relatively high functioning at Time 1, with approximately three quarters of subjects classified within the 'average or above' category. Conversely, levels of expressive and receptive language functioning at initial assessment were rather poor, with 77.8 % and 78.5 % of children respectively classified below the 'low average' range. The group as a whole was therefore clearly language disordered at Time 1, given their level of intellectual ability.

Information about language milestones was available for a proportion of the sample ( $n = 22$  for single words and  $n = 21$  for phrase speech). 10 children (45.5%) did not use single words by their second birthday, while 12 (54.5 %) were successful in

achieving this milestone. 9 children (42.9%) developed phrase speech before the age of 36 months, while 12 (57.1 %) did not.

**Table 5.** Classification of performance IQ and language functioning at Time 1

	Average/Above <i>n</i> (%)	Low Average <i>n</i> (%)	Borderline <i>n</i> (%)	Disability <i>n</i> (%)
Performance IQ	23 (76.7)	4 (13.3)	2 (6.7)	1 (3.3)
Expressive Language <sup>a</sup>	4 (14.8)	2 (7.4)	6 (22.2)	15 (55.6)
Receptive Language <sup>b</sup>	2 (7.1)	4 (14.3)	9 (32.1)	13 (46.4)

<sup>a</sup> data not available for 3 subjects; <sup>b</sup> data not available for 2 subjects

Ratings of social dysfunction, third axis behaviours, excessive anxiety, overactivity and social communication behaviours.

Kappa statistics were derived to assess the accuracy with which information regarding social dysfunction, excessive anxiety and overactivity could be extracted from the case notes. Inter-rater reliability estimates were found to vary depending on the characteristic under investigation. Total agreement was found in relation to excessive anxiety ( $\kappa = 1.00, p < .001$ ), in contrast to the moderate but significant measure of agreement demonstrated for overactivity ratings ( $\kappa = .44, p < .05$ ). The coefficient for Wing subtype was intermediate ( $\kappa = .78, p < .001$ ). Intraclass correlation estimates (Shrout & Fleiss Model 3, Raters Fixed) were computed for third axis behaviour ratings,

ranging between .63 for restricted, repetitive patterns and interests and .77 for routines and rituals (mean .71,  $p < .01$  in all cases). On the basis of these statistics, it was decided that those variables for which there was agreement below the standard of .60 would be dropped from further consideration. Overactivity ratings were therefore discounted.

Retrospective ratings, based on the information available in the case notes, were assigned to 29 subjects. The distribution of the sample according to Wing's subtype was as follows: 41.4 % ( $n = 12$ ) were classified as active but odd; 48.3 % ( $n = 14$ ) were considered passive; 10.3 % ( $n = 3$ ) were categorised as aloof. Details of third axis behaviour ratings are presented in Table 6.

**Table 6.** Severity ratings on four categories of third axis behaviours at Time 1

	None <i>n</i> (%)	Mild <i>n</i> (%)	Marked <i>n</i> (%)
Restricted, repetitive patterns and interests	3 (10.3)	13 (44.8)	13 (44.8)
Routines and rituals	14 (48.3)	7 (24.1)	8 (27.6)
Mannerisms	19 (65.5)	7 (24.1)	3 (10.3)
Pre-occupation with part-objects	18 (62.1)	7 (24.1)	4 (13.8)

It can be seen that restricted, repetitive patterns and interests were the most commonly endorsed category, with 89.6 % of subjects showing some evidence of



abnormality. In contrast, the remaining categories were less characteristic, with 48.3 %, 65.5 % and 62.1 % rated as showing no evidence of routines and rituals, mannerisms or preoccupation with part objects respectively. The mean axis 3 composite score was 3.1 (SD 1.8, range 0 to 6). Only a minority of subjects ( $n = 5$ , 17.2 %) showed evidence of excessive anxiety. As a group, these children were older than their non-anxious counterparts ( $t(27) = -2.60, p < .05$ ).

The Paediatrician's ratings of social communication skills are presented in Table 7, that shows the distribution of subjects who fell at each level of severity (i.e. 'poor' versus 'some' versus 'good') across the five specified dimensions of behaviour.

**Table 7. Social communication behaviour ratings at Time 1**

	'Poor' <i>n</i> (%)	'Some' <i>n</i> (%)	'Good' <i>n</i> (%)
Social motivation <sup>a</sup>	19 (76.0)	6 (24.0)	0
Social-affective behaviour <sup>b</sup>	6 (21.4)	18 (64.3)	4 (14.3)
Prosocial peer behaviour <sup>b</sup>	11 (39.3)	15 (53.6)	2 (7.1)
Social communication <sup>b</sup>	4 (14.3)	24 (85.7)	0
Non-verbal communication <sup>b</sup>	12 (42.9)	13 (46.4)	3 (10.7)

<sup>a</sup>  $n = 25$ ; <sup>b</sup>  $n = 28$ .

Deficits in these areas featured strongly overall; none of the children were classified as having ‘good’ social motivation or social communication at initial assessment and few were rated at this level on social affective behaviours, prosocial peer behaviour and non-verbal communication. The mean social communication composite score was 3.2 ( $n = 25$ , SD 1.7, range 1 to 8).

As a precursor to later examinations of the association between characteristics at initial and follow-up assessments, it was important at this stage to check whether subjects categorised into groups at Time 1 (on the basis of language milestones, social dysfunction, excessive anxiety and social communication) significantly differed in IQ or language functioning. Between subject analyses found no such differences. It was therefore concluded that any differences identified between these groups at Time 2 were not simply attributable to differences in intellectual or language status at Time 1.

### **3.2 Characteristics at Time 2**

#### **Intellectual and language functioning**

A detailed breakdown of individual subtest and summary IQ mean scores obtained on the WISC-III<sup>UK</sup> is given in Table 8. Examination of the test profile reveals a low-level performance on the Comprehension subtest and a superior performance on the Object Assembly and Block Design subtests. A detailed analysis of the sample’s performance on the CELF-R is given in Table 9, which shows the mean score on the Formulated Sentences subtest to be relatively poor, whilst the mean score on the Sentence Assembly subtest is relatively good.

**Table 8.** Mean, standard deviation and range of individual subtest scaled scores and summary IQ scores on the WISC-III<sup>UK</sup> at Time 2.

	Mean	SD	Range
Information (V)	7.5	3.4	2-15
Similarities (V)	7.0	4.5	1-16
Arithmetic (V)	5.6	3.7	1-14
Vocabulary (V)	6.1	3.5	1-15
Comprehension (V)	3.3	3.0	1-11
Picture Completion (P)	7.9	3.5	1-15
Coding (P)	7.2	3.2	2-16
Picture Arrangement (P)	7.7	4.2	1-18
Block Design (P)	8.7	3.9	1-17
Object Assembly (P)	8.8	2.9	1-13
Verbal IQ	76.1	16.9	52-112
Performance IQ	87.0	17.3	50-132
Full Scale IQ	79.0	15.8	49-119

*Note.* Data based on 29 subjects to whom WISC-III<sup>UK</sup> administered

(V) denotes verbal subtests; (P) denotes performance subtests

**Table 9.** Mean, standard deviation and range of individual subtest standard scores and summary language standard scores on the CELF-R at Time 2

	Mean	SD	Range
Linguistic Concepts (R) <sup>a</sup>	6.6	3.4	3 - 13
Sentence Structure (R) <sup>b</sup>	6.9	2.9	3 - 13
Oral Direction (R) <sup>c</sup>	6.9	2.7	3 - 13
Word Classes (R) <sup>d</sup>	7.0	2.2	4 - 13
Semantic Relationships (R) <sup>e</sup>	6.5	2.8	3 - 13
Word Structure (E) <sup>a</sup>	6.7	4.1	3 - 16
Formulated Sentences (E) <sup>o</sup>	4.7	2.5	3 - 15
Recalling Sentences (E) <sup>o</sup>	5.9	2.8	3 - 15
Sentence Assembly (E) <sup>f</sup>	8.6	2.0	6 - 13
Expressive Language <sup>c</sup>	74.4	18.1	50 - 143
Receptive Language <sup>c</sup>	78.3	15.2	50 - 115
Total Language <sup>c</sup>	74.5	17.1	50 - 132

*Note.* Data based on 29 subjects to whom the CELF-R was administered.

(R) denotes receptive subtests; (E) denotes expressive subtests.

<sup>a</sup>  $n = 10$ ; <sup>b</sup>  $n = 9$ ; <sup>c</sup>  $n = 29$ ; <sup>d</sup>  $n = 20$ ; <sup>e</sup>  $n = 18$ ; <sup>f</sup>  $n = 19$  (the number of subjects varies because different combinations of subtests are administered to children of different ages)

Scores on standardised assessments at follow-up were classified into the categories used at Time 1, to enable the distribution of intellectual and language functioning to be examined (Table 10). In terms of the former, between a third to a half of subjects fell below the 'low average' range on all three summary IQ estimates of the WISC-III<sup>UK</sup>: 53.3 % for VIQ; 30.0 % for PIQ; 50.0 % for FSIQ. The number of subjects who fell within the 'disability' category for VIQ is more than twice the number for PIQ (12 versus 5), with the reverse pattern occurring in the 'average or above' category (6 for VIQ versus 12 for PIQ). Taken together, these findings would suggest that a larger proportion of the sample evidenced deficits in verbal skills than non-verbal abilities. In terms of overall level of intellectual functioning (as indexed by FSIQ), a significant minority of children were assessed as severely delayed, with 30.0 % of subjects falling within the 'disability' range.

Moving on to examine the classification of language ability at Time 2, it can be seen that over half of the sample were estimated to be functioning below the 'low average' range in both the expressive and receptive domains (63.3 % and 66.6 % respectively). A little over a third of subjects were estimated to have total language skills falling within the 'disability' range, demonstrating a marked degree of impairment in a significant minority of the sample. An appreciation of the level of language difficulty can also be gained by examining the age equivalents yielded by the CELF-R relative to chronological age. 7 subjects (23.3 %) were estimated to have an age equivalent of less than 60 months at a mean chronological age of 96.4 months (SD 11.5), whilst the remaining 23 children obtained a mean age equivalent of 80.4 months (SD 14.6) at a mean chronological age of 102.0 months (SD 11.8).

**Table 10. Classification of IQ and language functioning at Time 2**

	Average/Above <i>n</i> (%)	Low Average <i>n</i> (%)	Borderline <i>n</i> (%)	Disability <i>n</i> (%)
Verbal IQ	6 (20.0)	8 (26.7)	4 (13.3)	12 (40.0)
Performance IQ	12 (40.0)	9 (30.0)	4 (13.3)	5 (16.7)
Full Scale IQ	4 (13.3)	11 (36.7)	6 (20.0)	9 (30.0)
Expressive Language	2 (6.7)	9 (30.0)	9 (30.0)	10 (33.3)
Receptive Language	7 (23.3)	3 (10.0)	10 (33.3)	10 (33.3)
Total Language	5 (16.7)	5 (16.7)	9 (30.0)	11 (36.7)

**Questionnaire data*****Children's Communication Checklist***

The total number of missing items was 5 (0.3 % of all responses) and the total number of items rated unable to judge was 44 (2.2 % of all responses). Only those subscale scores that could be prorated according to the specified rule were included in analyses, meaning that the number of questionnaires on which statistics were based varies. Table 11 compares the mean scores for the present study sample to those reported by Bishop (1998), who studied 3 groups of children attending language units.

**Table 11.** Mean, standard deviation and range of CCC subscale scores and pragmatic composite score for the present study sample at Time 2, compared to mean scores quoted by Bishop (1998).

	<u>Present study sample</u>			<u>Bishop (1998) sample</u>		
	Mean	SD	Range	SP plus Mean	SP pure Mean	SLI Mean
Speech <sup>a</sup>	27.7	4.3	16 - 32	30.1	30.6	26.5
Syntax <sup>a</sup>	29.6	2.4	24 - 32	30.3	29.2	28.7
Inappropriate Initiation <sup>b</sup>	23.0	3.3	18 - 30	25.0	25.9	28.0
Coherence <sup>a</sup>	26.3	3.8	20 - 35	23.6	25.5	28.7
Stereotyped Conversation <sup>a</sup>	21.9	3.9	14 - 29	21.4	23.9	27.5
Use of Conversational Context <sup>c</sup>	22.5	3.7	17 - 30	22.3	24.2	28.5
Conversational Rapport <sup>a</sup>	24.1	3.3	18 - 30	25.0	29.1	31.0
Social relationships <sup>d</sup>	25.8	4.0	17 - 34	25.3	28.9	29.9
Interests <sup>d</sup>	28.7	2.6	24 - 34	28.3	30.8	31.8
<b>Pragmatic composite <sup>e</sup></b>	<b>120.0</b>	<b>13.1</b>	<b>86 - 162</b>	<b>119.6</b>	<b>129.8</b>	<b>143.2</b>

<sup>a</sup> *n* = 29; <sup>b</sup> *n* = 26; <sup>c</sup> *n* = 28; <sup>d</sup> *n* = 28; <sup>e</sup> *n* = 25.

Bishop's groups included children identified as having semantic pragmatic disorder with PDD features (called the SP plus group); children identified as having semantic pragmatic disorder in the absence of PDD features (named the SP pure group); children not regarded as having either semantic pragmatic disorder or any kind of PDD, but who had some other kind of communication impairment (entitled the SLI group). Table 11 shows that the present study sample means most closely resembled those in the SP plus group, except on the speech, syntax and coherence subscales.

### *Strengths and Difficulties Questionnaire*

Some indication of the level of general behavioural disturbance in the follow-up sample is given in Table 12, that shows the percentage of children who scored within the 'abnormal' banding on each dimension of the SDQ.

**Table 12.** Percentage of subjects scoring above the abnormal cut-off on dimensions of the SDQ at Time 2.

	Above abnormal cut-off (%)
Prosocial behaviour	36.7
Hyperactivity	63.3
Emotional symptoms	40.0
Conduct problems	40.0
Peer problems	80.0
Total difficulties	73.3



Peer problems were identified as the most prevalent difficulty, followed by hyperactivity. Less than half of the sample obtained a score within the abnormal banding on emotional symptoms or conduct problems, while approximately a third achieved a prosocial behaviour score within this range. Overall, a high level of general behavioural disturbance was indicated in a majority of the sample, with just under three quarters of subjects obtaining a total difficulties score within the abnormal banding.

### *Autism Screening Questionnaire*

The mean score on the ASQ was 21.8 (SD 7.5, range 6 to 35), a value that falls at the cut-off proposed to differentiate autism from other pervasive developmental disorders. When subjects were classified according to the suggested cut-offs, 13.3 % ( $n = 4$ ) subjects scored below 14 (the threshold for PDD), while 30.0 % ( $n = 9$ ) scored between 14 and 21 (the threshold for autism). The remaining 17 subjects (56.7 %) fell above the cut-off for autism, indicating a high level of autistic behaviours in more than half of the follow-up sample.

The sample was separated into two groups according to whether ASQ scores were above or below the autism cut-off. Children scoring below the autism threshold were younger than those falling above the cut-off ( $t(28) = -2.60, p < .05$ ), but performance on standardised tests of intellectual and language functioning at follow-up did not differentiate the groups (Table 13).

**Table 13.** Mean (standard deviation) age, IQ and language scores for subjects above and below the autism cut-off on the ASQ.

	Below autism cut-off on the ASQ ( <i>n</i> = 13)	Above autism cut-off on the ASQ ( <i>n</i> = 17)
Age in months	105.1 (9.6)	94.9 (12.1)
Verbal IQ <sup>a</sup>	78.6 (18.3)	72.4 (17.0)
Performance IQ <sup>a</sup>	85.2 (16.3)	86.4 (19.8)
Full Scale IQ <sup>a</sup>	79.5 (17.2)	76.7 (16.8)
Expressive Language <sup>a</sup>	80.2 (23.3)	68.5 (11.8)
Receptive Language <sup>a</sup>	80.1 (18.0)	75.3 (14.0)
Total Language <sup>a</sup>	79.3 (20.9)	69.4 (13.2)

<sup>a</sup>*p* = n.s.

Between group differences on questionnaires administered at the follow-up assessment were examined (Table 14). On the CCC, the difference in means reached significance on 5 subscales: coherence, stereotyped conversation, use of conversational context, conversational rapport and social relationships. In each of these cases, subjects with low to moderate levels of autistic behaviour (i.e. those scoring below the autism threshold) obtained significantly higher scores (indicating better developed skills) than those with higher levels of symptomatology. Not listed in the table are the mean pragmatic composite scores: 128.9 (SD 9.0) for low ASQ scorers and 113.0 (SD 11.5) for

high ASQ scorers, a difference that was also found to be significant ( $t(23) = 3.76, p = .001$ ).

**Table 14.** Mean (standard deviation) CCC and SDQ scores for subjects above and below the autism cut-off.

		Below autism cut-off on the ASQ ( $n = 13$ )	Above autism cut-off on the ASQ ( $n = 17$ )
CCC subscale:	Speech	26.8 (4.9)	28.4 (3.8)
	Syntax	29.8 (2.6)	29.5 (2.4)
	Inappropriate initiation	23.5 (3.5)	22.6 (3.3)
	Coherence <sup>a</sup>	27.9 (3.9)	25.1 (3.4)
	Stereotyped conversation <sup>a</sup>	23.7 (4.0)	20.6 (3.4)
	Use of conversational context <sup>c</sup>	25.1 (3.2)	20.6 (2.9)
	Conversational rapport <sup>b</sup>	27.0 (2.1)	23.4 (3.2)
	Social relationships <sup>a</sup>	27.7 (4.6)	24.4 (2.8)
	Interests	29.4 (3.0)	28.1 (2.3)
SDQ dimension:	Prosocial behaviour	6.2 (2.3)	5.0 (2.4)
	Hyperactivity	5.8 (3.4)	7.5 (2.2)
	Emotional symptoms	4.1 (2.6)	4.5 (2.6)
	Conduct problems	2.2 (2.1)	3.4 (2.3)
	Peer problems	4.5 (2.3)	5.2 (1.7)
	Total difficulties	16.5 (7.1)	20.5 (4.5)

<sup>a</sup> $p < .05$ ; <sup>b</sup> $p < .01$ ; <sup>c</sup> $p = .001$

Turning to compare mean scores for the ASQ groups on the dimensions of the SDQ, independent t tests demonstrated no significant differences. However, a consistent pattern of results was observed, whereby individuals scoring 21+ on the ASQ obtained slightly higher scores on the 'difficulties' dimensions (hyperactivity, emotional symptoms, conduct and peer problems) and a marginally lower score on the 'strengths' dimension (prosocial behaviour) than subjects who scored below 21.

#### Ratings of social dysfunction, third axis behaviours, excessive anxiety and overactivity

The degree to which two people agreed in their ratings of subjects was examined as before and a similar pattern of agreement was found; inter-rater reliability estimates were best for excessive anxiety ( $\kappa = .85, p < .01$ ), poorest for activity level ( $\kappa = .33, p = .09$ ) and intermediate for Wing subtype ( $\kappa = .63, p < .01$ ). Intraclass correlation estimates on axis 3 behaviour ratings ranged between .73 for routines and rituals and .84 for each of the other three categories (mean .81,  $p < .01$  in all cases). The same rule as was applied previously was used, whereby variables with agreement below .60 were dropped from further consideration. Again, this led to overactivity ratings being discounted.

All 30 subjects were rated according to Wing's subtypes at Time 2: 80.0 % of children ( $n = 24$ ) were classified as active but odd and 20.0 % ( $n = 6$ ) were placed within the passive category. Comparisons between the two found the passive group to be younger ( $t(28) = 2.29, p < .05$ ) and have a higher PIQ at follow-up ( $t(28) = -2.60, p < .05$ ) compared to the active but odd sample. There were however no significant differences between them in relation to any of the other follow-up measures.

Although an attempt was made at rating the entire sample on axis 3 behaviours at Time 2, it was not always possible to do so on the basis of the information collected. Table 15 presents the data on those subjects whom it was possible to rate. Restricted, repetitive patterns and interests was shown to be the category with the highest percentage of 'positive' ratings, with 90.0 % of subjects showing a mild or marked level of abnormality. Routines and rituals closely followed, with 86.2 % of children displaying these characteristics to a varying degree. The mean axis 3 composite at follow-up was 3.5 ( $n = 24$ , SD 1.7, range 1 to 7). High and low axis 3 composite scorers ( $n = 12$  in each group) were found to differ significantly in their pragmatic abilities, the former group evidencing more difficulties than the latter ( $t(23) = 2.73, p < .05$ ). Otherwise, no significant differences on measures of outcome were detected.

**Table 15.** Severity ratings on four categories of third axis behaviours at Time 2

	None <i>n</i> (%)	Mild <i>n</i> (%)	Marked <i>n</i> (%)
Restricted, repetitive patterns and interests <sup>a</sup>	3 (10.0)	15 (50.0)	12 (40.0)
Routines and rituals <sup>b</sup>	4 (13.8)	17 (58.6)	8 (27.6)
Mannerisms <sup>c</sup>	15 (55.6)	8 (29.6)	4 (14.8)
Pre-occupation with part-objects <sup>d</sup>	15 (62.5)	7 (29.2)	2 (8.3)

<sup>a</sup>  $n = 30$ ; <sup>b</sup>  $n = 29$ ; <sup>c</sup>  $n = 27$ ; <sup>d</sup>  $n = 24$

9 children (31.0 %) were considered to display excessive anxiety at Time 2. As a group, they were found to differ from 'non-anxious' subjects only in terms of having higher levels of emotional symptoms, as measured on the SDQ ( $t(27) = -3.03, p < .01$ ).

### Parental concerns

Ongoing difficulties with language and problems associated with abnormal behaviours were often discussed during interviews with parents, details of which have been given above. The most commonly reported problem of all however related to social impairment. None of the children were considered to have developed 'true friendships' characterised by reciprocal interaction. Some were attempting to make friends but finding it difficult to form relationships, whereas others were described as "loners" who were largely content to play by themselves. Some of the older subjects were expressing increasing awareness of their difficulties and asking why they are different to their peers. In those cases where parents were at the stage of making decisions regarding a suitable secondary education placement, social problems were felt to be paramount, with issues such as vulnerability to bullying coming to the fore.

### Educational provision

15 children were attending specialist educational facilities at follow-up, whilst 15 were receiving extra support in a mainstream provision. Of those subjects in the former group, 10 were attending language units, 3 were attending schools for children with moderate learning disabilities and 2 were attending autistic units. 3 of the 15 children attending mainstream facilities were in private schools. 28 (93.0 %) subjects were

reported to have a statement of special educational needs, 19 of whom were also receiving speech therapy.

Comparisons of subjects attending mainstream versus specialist facilities on standardised assessments of intellectual and language functioning showed that children in specialist education facilities have the poorest language skills and the lowest intellectual abilities. The differences between the groups were found to be significant with respect to VIQ, FSIQ, expressive, receptive and total language scores (Table 16). Mainstream attenders were more skilled in pragmatics than the group of children attending specialist facilities ( $t(27) = 4.37, p < .01$ ), but the two groups did not significantly differ with respect to the other measures administered at follow-up.

**Table 16.** Mean (standard deviation) IQ and language scores for subjects in mainstream and specialist educational facilities.

	Mainstream education facility ( <i>n</i> = 15)	Specialist education facility ( <i>n</i> = 15)
Verbal IQ <sup>a</sup>	87.7 (13.4)	62.5 (10.9)
Performance IQ	90.2 (17.7)	81.5 (18.0)
Full Scale IQ <sup>a</sup>	87.3 (14.7)	68.5 (13.3)
Expressive Language <sup>a</sup>	85.3 (17.5)	61.8 (9.8)
Receptive Language <sup>a</sup>	87.0 (13.3)	67.7 (11.8)
Total Language <sup>a</sup>	85.1 (15.2)	62.3 (10.6)

<sup>a</sup> $p < .001$

### 3.3 Comparisons between characteristics at Times 1 and 2

#### Intellectual and language functioning

The mean PIQ at initial assessment (102.7, SD 17.1) was compared to the mean PIQ at follow-up (85.3, SD 19.7) for the subset of individuals for whom a PIQ score was available at both timepoints ( $n = 23$ ). A paired t-test demonstrated this difference over time was significant ( $t(22) = 4.24, p < .001$ ). At the categorical level, changes in classification of PIQ over time are best shown in the form of a crosstabulation, presented in Table 17.

**Table 17.** Changes in classification of performance IQ functioning over time.

Time 1:	Time 2:				Total <i>n</i> (%)
	Average/Above <i>n</i> (%)	Low Average <i>n</i> (%)	Borderline <i>n</i> (%)	Disability <i>n</i> (%)	
Average/Above <i>n</i> (%)	10 (33.3)	7 (23.3)	3 (10.0)	3 (10.0)	23 (76.7)
Low Average <i>n</i> (%)	2 (6.7)	1 (3.3)	1 (3.3)	0	4 (13.3)
Borderline <i>n</i> (%)	0	1 (3.3)	0	1 (3.3)	2 (5.7)
Disability <i>n</i> (%)	0	0	0	1 (3.3)	1 (3.3)
<b>Total</b> <i>n</i> (%)	12 (40.0)	9 (30.0)	4 (13.3)	5 (16.7)	30 (100.0)



The shaded area of the table highlights those subjects considered to show a relatively stable PIQ across times 1 and 2, defined here as those who fall within the same category on both assessment occasions or who shift just one category up or down. (This definition of stability is adopted in light of measurement error and the use of different tests at different ages, issues that are explored in depth in the Discussion).

It was found that 80.0 % ( $n = 24$ ) of the sample demonstrated this degree of stability, whilst the residual group of children showed a negative shift in PIQ, moving 2 or 3 categories down from their original classification (i.e. from the 'average or above' range at Time 1 to the 'borderline' or 'disability' range at Time 2). Further investigation of the 6 subjects in question showed they did not differ significantly from the rest of the sample in age, IQ or language at initial assessment or in autistic symptomatology (as measured by the ASQ at Time 2).

The increase/decrease in the number of IQ points over time was calculated in cases where scores were available at both timepoints ( $n = 23$ ). The subset of individuals whose PIQ was stable across Times 1 and 2 evidenced a mean decrease in 11.6 points in PIQ ( $n = 18$ , SD 17.9), whilst those subjects who shifted down 2 or more categories between initial and follow-up assessments evidenced a mean decrease of 38.4 points ( $n = 5$ , SD 0.8). There are several considerations to take into account before drawing conclusions about this apparent downward trend, all of which are covered in the Discussion.

Expressive and receptive language standard scores at follow-up were converted into z scores for the purpose of comparison with Time 1 estimates. With regards to expressive language ability, the mean at Time 1 (-2.0, SD 1.3) was compared to the mean

at Time 2 (-1.6, SD 1.5) for the subset of individuals for whom a score was available at both timepoints ( $n = 14$ ). A paired  $t$  test suggested the change over time was significant ( $t(13) = -2.41, p < .05$ ). Table 18 outlines how the classification of expressive language functioning at Time 1 differed at Time 2, with the shaded area highlighting those subjects demonstrating a high degree of stability (as defined above).

**Table 18.** Changes in classification of expressive language functioning over time

Time 1:	Time 2:				Total <i>n</i> (%)
	Average/ Above <i>n</i> (%)	Low Average <i>n</i> (%)	Borderline <i>n</i> (%)	Disability <i>n</i> (%)	
Average/Above <i>n</i> (%)	1 (3.7)	2 (7.4)	1 (3.7)	0	4 (14.8)
Low Average <i>n</i> (%)	1 (3.7)	1 (3.7)	0	0	2 (7.4)
Borderline <i>n</i> (%)	0	4 (14.8)	0	2 (7.4)	6 (22.2)
Disability <i>n</i> (%)	0	1 (3.7)	6 (22.2)	8 (29.6)	15 (55.6)
Total <i>n</i> (%)	2 (7.4)	8 (29.6)	7 (25.9)	10 (37.0)	27 (100.0)

The table shows that 92.6 % of subjects ( $n = 25$ ) demonstrated the specified degree of stability. Of the two outstanding individuals, one showed a positive shift (transferring from the 'disability' range at Time 1 to the 'low average' range at Time 2), whilst the other evidenced a negative shift (moving from the 'average or above' category at initial assessment to the 'borderline' category at follow-up).

The increase/decrease in expressive language  $z$  score between Times 1 and 2 was calculated in the small number of cases where a score was available at both timepoints ( $n = 14$ ). The subset of subjects who demonstrated stability in expressive language skills over time evidenced a mean increase of 0.4 in their  $z$  value ( $n = 13$ , SD 0.6). The child who transferred from the 'disability' range at initial assessment to the 'low average' range at follow-up, evidenced an increase of 1.3 in their  $z$  value. It was not possible to calculate the decrease in  $z$  value for the child who shifted down 2 categories between Times 1 and 2 because a  $z$  score at initial assessment was unavailable.

Broadly similar findings were found in relation to receptive language ability over time. The mean score at Time 1 (-2.1, SD 1.2) was compared to the mean at Time 2 (-1.5, SD 1.2) for the subset of individuals for whom a score was available at both timepoints ( $n = 23$ ). A Wilcoxon signed ranks test revealed the degree of improvement in receptive language to be significant ( $Z = -2.50$ ,  $p = .013$ ). The pattern of category change is detailed in Table 19, where it can be seen that 78.6 % of subjects ( $n = 22$ ) demonstrated the specified degree of stability. 5 of the 6 outstanding children evidenced a positive shift in receptive language category, moving from the 'disability' and 'borderline' ranges at Time 1 to within the 'average or above' classification at Time 2. Further investigation of these five children showed them not to significantly differ from the other subjects in age,

IQ or language at initial assessment or in autistic symptomatology (as measured by the ASQ at Time 2).

**Table 19. Changes in classification of receptive language functioning over time**

Time 1:	Time 2:				Total <i>n</i> (%)
	Average/Above <i>n</i> (%)	Low Average <i>n</i> (%)	Borderline <i>n</i> (%)	Disability <i>n</i> (%)	
Average/Above <i>n</i> (%)	1 (3.6)	0	1 (3.6)	0	2 (7.1)
Low Average <i>n</i> (%)	1 (3.6)	1 (3.6)	2 (7.1)	0	4 (14.3)
Borderline <i>n</i> (%)	3 (10.7)	1 (3.6)	3 (10.7)	2 (7.1)	9 (32.1)
Disability <i>n</i> (%)	2 (7.1)	0	3 (10.7)	8 (28.6)	13 (46.4)
Total <i>n</i> (%)	7 (25.0)	2 (7.1)	9 (32.1)	10 (35.7)	28 (100.0)

The increase/decrease in receptive language *z* score between Times 1 and 2 was calculated in cases where a score was available at both timepoints ( $n = 23$ ). The subset of individuals who demonstrated stability in receptive language skills over time evidenced a mean increase of 0.3 in their *z* value ( $n = 19$ , SD 0.8). Those subjects who shifted up two or more categories evidenced a mean increase of 2.0 in their *z* value ( $n = 4$ , SD 0.6).

Ratings of social dysfunction, third axis behaviours and excessive anxiety.

Nonparametric statistics were used to investigate the significance of change in ratings from Time 1 to Time 2. Table 20 shows how Wing subtype classifications altered over time. The shaded area of the table shows those subjects who demonstrated stability in their social typology (55.2 %). All those children rated as 'active but odd' at Time 1 were rated in the same category at Time 2. In contrast, only 28.6 % of children considered 'passive' at initial assessment were rated in the same category at follow-up, 71.4 % being characterised as 'active but odd' at Time 2. Finally, all 3 subjects who were initially classed as 'aloof' transferred into the other categories at follow-up.

**Table 20.** Changes in Wing subtype ratings over time

Time 1:	Time 2:		
	Active But Odd <i>n</i> (%)	Passive <i>n</i> (%)	Aloof <i>n</i> (%)
Active But Odd <i>n</i> (%)	12 (41.3)	0	0
Passive <i>n</i> (%)	10 (34.5)	4 (13.8)	0
Aloof <i>n</i> (%)	1 (3.4)	2 (6.9)	0

*Note.* Data based on 29 subjects for whom Wing subtype ratings were available at both Times 1 and 2.

Overall, there appears to have been a tendency for those children who were less likely to initiate social contact at Time 1 to become more interactive in later years. A series of McNemar tests showed the change in Wing subtype over time to be significant when comparing the active but odd group with the passive and aloof groups combined (binomial  $p < .001$ ), and when comparing the passive group to the active but odd group and passive groups combined (binomial  $p < .05$ ). In contrast, the change in subtype was not significant when comparing the aloof group with the active but odd and passive groups combined (binomial  $p = .25$ ).

Changes in severity ratings of axis 3 behaviour ratings across time were examined by a Wilcoxon signed ranks test. Within the routines and rituals category, ratings were found to be significantly higher at follow-up than at initial assessment ( $Z = -2.06$ ,  $p < .05$ ), whilst the other three categories demonstrated change to lesser degrees.

3 of the 5 children rated as excessively anxious at initial assessment were rated as still showing this trait at follow-up. Furthermore, 6 subjects who were not rated as having excessive anxiety initially were felt to display signs when re-assessed. The degree of change in this variable over time was found not to be statistically significant (McNemar test, binomial  $p = .29$ ).

### **3.4 Associations between characteristics**

#### **Within time**

*Time 1:* Pearson correlation coefficients were derived to test the associations between characteristics at initial assessment (Table 21). PIQ showed a low correlation with both expressive and receptive language scores, a finding that suggests cognitive

skills did not account for the severity of language delay seen at Time 1. The two language domains were highly positively correlated to each other however, indicating the sample to have receptive skills largely in line with their expressive abilities. The association between language scores and axis 3 behaviours was found to be modest but significant, the negative correlation indicating that lower expressive and receptive skills were associated with higher degrees of abnormality. PIQ was also negatively correlated with axis 3 behaviours, albeit non-significantly. Social communication behaviours (where a higher composite score indicates better developed skills) were positively correlated with IQ and language at very low levels, but significantly negatively correlated with axis 3 behaviours.

**Table 21.** Pearson correlation coefficients and *p* values for characteristics at Time 1.

	PIQ	Expressive	Receptive	Axis 3	Soc. com
PIQ	-	.12 <sup>a</sup>	.04 <sup>b</sup>	-.25 <sup>c</sup>	.06 <sup>d</sup>
Expressive	-	-	.80 <sup>**e</sup>	-.56 <sup>*f</sup>	.14 <sup>f</sup>
Receptive	-	-	-	-.44 <sup>*g</sup>	.04 <sup>g</sup>
Axis 3	-	-	-	-	-.51 <sup>*h</sup>

Soc. com = social communication

\*\*  $p < .001$ ; \*  $p < .05$  (two-tailed)

<sup>a</sup>  $n = 11$ ; <sup>b</sup>  $n = 18$ ; <sup>c</sup>  $n = 22$ ; <sup>d</sup>  $n = 19$ ; <sup>e</sup>  $n = 14$ ; <sup>f</sup>  $n = 13$ ; <sup>g</sup>  $n = 20$ ; <sup>h</sup>  $n = 24$ .

*Time 2:* The matrix of correlations among characteristics measured at follow-up is shown in Table 22. In contrast to the findings at Time 1, PIQ was significantly correlated with language skills at follow-up (including VIQ). In general, lower IQ and language abilities were related to higher levels of deviance, as indicated by the consistent pattern of negative correlations with the ASQ/SDQ-total difficulties/axis 3 behaviours, and positive correlations with the CCC pragmatic composite/CCC social relationships subscale/SDQ-prosocial behaviour (where lower scores indicate greater difficulties). The very low positive correlation between PIQ and ASQ, plus the low negative correlation between PIQ and SDQ-prosocial behaviour score are two exceptions to this 'rule'. Given that third axis behaviours are core components of autistic symptomatology, it is not surprising to see that the pattern of correlations in the last column of the table mirrors those seen in relation to the ASQ.

As suggested in previous between-subjects analyses, higher levels of autistic symptomatology were associated with more problems with pragmatics, more difficulties with social relationships, more behavioural disturbance and lower levels of prosocial behaviour. The high positive correlation between the two CCC estimates suggests a strong relationship between pragmatic skills and social relationship problems, each of which also showed a high association with behavioural disturbance.



**Table 22.** Pearson correlation coefficients and *p* values for characteristics at Time 2.

	VIQ	PIQ	FSIQ	Express	Recept	ASQ	CCC-pc	CCC-sr	SDQ-td	SDQ-pr	Axis 3
VIQ	-	.55*** <sup>a</sup>	.90*** <sup>a</sup>	.82*** <sup>a</sup>	.77*** <sup>a</sup>	-.28 <sup>a</sup>	.25 <sup>b</sup>	.13 <sup>c</sup>	-.30 <sup>a</sup>	.25 <sup>a</sup>	-.14 <sup>d</sup>
PIQ	-	-	.86*** <sup>a</sup>	.37** <sup>a</sup>	.64*** <sup>a</sup>	.04 <sup>a</sup>	.16 <sup>b</sup>	.13 <sup>c</sup>	-.20 <sup>a</sup>	-.11 <sup>a</sup>	-.10 <sup>d</sup>
FSIQ	-	-	-	.69*** <sup>a</sup>	.81*** <sup>a</sup>	-.15 <sup>a</sup>	.24 <sup>b</sup>	.14 <sup>c</sup>	-.29 <sup>a</sup>	.09 <sup>a</sup>	-.14 <sup>d</sup>
Express	-	-	-	-	.84*** <sup>a</sup>	-.41** <sup>a</sup>	.19 <sup>b</sup>	.18 <sup>c</sup>	-.31 <sup>a</sup>	.29 <sup>a</sup>	-.29 <sup>d</sup>
Recept	-	-	-	-	-	-.22 <sup>a</sup>	.13 <sup>b</sup>	.24 <sup>c</sup>	-.30 <sup>a</sup>	.06 <sup>a</sup>	-.13 <sup>d</sup>
ASQ	-	-	-	-	-	-	-.72*** <sup>b</sup>	-.49** <sup>c</sup>	.56*** <sup>a</sup>	-.42** <sup>a</sup>	.44* <sup>d</sup>
CCC-pc	-	-	-	-	-	-	-	.75*** <sup>b</sup>	-.70*** <sup>b</sup>	.33 <sup>b</sup>	-.50* <sup>e</sup>
CCC-sr	-	-	-	-	-	-	-	-	-.77*** <sup>c</sup>	.17 <sup>c</sup>	-.52* <sup>f</sup>
SDQ-td	-	-	-	-	-	-	-	-	-	-.43** <sup>a</sup>	.24 <sup>d</sup>
SDQ-pr	-	-	-	-	-	-	-	-	-	-	-.17 <sup>d</sup>

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Express = expressive language; Recept = receptive language; CCC-pc = pragmatic composite; CCC-sr = social relationships; SDQ-td = total difficulties; SDQ-pr = prosocial behaviour

\*\*\*  $p < .001$ ; \*\*  $p < .01$ ; \*  $p < .05$  (two-tailed)

<sup>a</sup>  $n = 30$ ; <sup>b</sup>  $n = 25$ ; <sup>c</sup>  $n = 28$ ; <sup>d</sup>  $n = 24$ ; <sup>e</sup>  $n = 21$ ; <sup>f</sup>  $n = 23$ .

Across time

Table 23 shows the correlations among characteristics at initial and follow-up assessment.

**Table 23.** Pearson correlation coefficient and *p* values for characteristics at Time 1 and 2

Time 2:	Time 1:				
	PIQ	Expressive	Receptive	Axis 3	Soc. com
VIQ	.56*** <sup>a</sup>	.69** <sup>b</sup>	.57*** <sup>a</sup>	-.31 <sup>c</sup>	-.02 <sup>d</sup>
PIQ	.44** <sup>a</sup>	.10 <sup>b</sup>	.18 <sup>a</sup>	-.13 <sup>c</sup>	-.15 <sup>d</sup>
FSIQ	.58*** <sup>a</sup>	.47 <sup>b</sup>	.44 <sup>a</sup>	-.26 <sup>c</sup>	-.08 <sup>d</sup>
Expressive	.41 <sup>a</sup>	.79*** <sup>b</sup>	.69*** <sup>a</sup>	-.40* <sup>c</sup>	.07 <sup>d</sup>
Receptive	.49** <sup>a</sup>	.64* <sup>b</sup>	.58*** <sup>a</sup>	-.25 <sup>c</sup>	-.14 <sup>d</sup>
ASQ	.06 <sup>a</sup>	-.64* <sup>b</sup>	-.53*** <sup>a</sup>	.46* <sup>c</sup>	-.32 <sup>d</sup>
CCC-pc	-.10 <sup>a</sup>	.52 <sup>f</sup>	.54* <sup>e</sup>	-.39 <sup>g</sup>	.32 <sup>h</sup>
CCC-sr	-.06 <sup>a</sup>	.24 <sup>j</sup>	.30 <sup>h</sup>	-.21 <sup>k</sup>	.39 <sup>a</sup>
SDQ-td	-.10 <sup>a</sup>	-.38 <sup>b</sup>	-.20 <sup>a</sup>	.24 <sup>c</sup>	-.43* <sup>d</sup>
SDQ-pr	.09 <sup>a</sup>	.03 <sup>b</sup>	.10 <sup>a</sup>	-.19 <sup>c</sup>	.46* <sup>d</sup>
Axis3	-.40* <sup>l</sup>	.04 <sup>j</sup>	-.31 <sup>m</sup>	.63*** <sup>a</sup>	-.40 <sup>i</sup>

CCC-pc = pragmatic composite score; CCC-sr = social relationships score; SDQ-td = total difficulties score; SDQ-pr = prosocial behaviour; Soc. com = social communication

\*\*\*  $p < .001$ ; \*\*  $p < .01$ ; \*  $p < .05$  (two-tailed)

<sup>a</sup>  $n = 23$ ; <sup>b</sup>  $n = 14$ ; <sup>c</sup>  $n = 29$ ; <sup>d</sup>  $n = 25$ ; <sup>e</sup>  $n = 19$ ; <sup>f</sup>  $n = 10$ ; <sup>g</sup>  $n = 24$ ; <sup>h</sup>  $n = 21$ ; <sup>i</sup>  $n = 22$ ; <sup>j</sup>  $n = 12$ ;

<sup>k</sup>  $n = 27$ ; <sup>l</sup>  $n = 20$ ; <sup>m</sup>  $n = 18$ .

As highlighted in the crosstabulation tables previously presented, IQ and language scores were seen to be relatively stable over time. Expressive language showed the highest degree of stability, followed by receptive language and then PIQ. It is noted that while PIQ at Time 1 correlates significantly with IQ and language estimates at Time 2, expressive and receptive abilities at Time 1 correlate only with estimates of language ability (including VIQ) at Time 2.

PIQ at initial assessment had a very low correlation with the majority of the measures at follow-up, except for axis 3 behaviours, with which there was a modest but significant negative correlation. Lower language abilities at Time 1 were generally found to be associated with greater deviance at Time 2, as shown by the consistent pattern of negative correlations with the ASQ/SDQ-total difficulties and positive correlations with the CCC pragmatic composite/CCC social relationships subscale/SDQ-prosocial behaviour. Only three out of twelve correlations were significant, however.

Broadly speaking, the correlational data suggested that higher axis 3 behaviours at Time 1 were related to lower intellectual and language abilities at Time 2, as well as higher levels of autistic symptomatology, more difficulties with pragmatic aspects of communication, greater problems with social relationships, increased behavioural disturbance and lower levels of prosocial behaviour. The correlations only reached significance in relation to expressive language and ASQ. The high correlation between the axis 3 behaviour composite scores at both assessments suggested these features were relatively stable over time. Social communication behaviours at Time 1 had low negative correlations with IQ estimates at Time 2 and showed the same inverse relationship with receptive (but not expressive) language. In addition, there was a suggestion that better

developed social communication abilities at initial assessment were associated with lower levels of autistic symptomatology, superior skills in pragmatics, fewer problems with social relationships, less pronounced axis 3 behaviours, reduced behavioural disturbance and a higher degree of prosocial behaviour at follow-up. The correlations only reached significance in the latter two cases.

A series of one way analysis of variance tests were conducted, to examine whether subjects classified into groups at Time 1 (according to their language milestones, social dysfunction, excessive anxiety and social communication) differed on any of the measures taken at Time 2. The only significant findings were that children grouped on the basis of their social affective behaviour skills differed in terms of expressive language abilities, autistic symptomatology, behavioural disturbance and prosocial behaviour (Table 24). The eta-squared values suggest that approximately one fifth of the variance in expressive language, one third of the variance in ASQ score, one fifth of the variance in SDQ total difficulties score and two fifths of the variance in SDQ prosocial behaviour score at Time 2 can be attributed to the severity of social affective behaviours at Time 1. The suggestions arising from this finding were not analysed any further (i.e. they were not included in the regression analyses detailed below), because two of the three groups contained very small numbers of subjects ( $n = 6$  in the 'poor' group and  $n = 4$  in the 'good' group).

**Table 24.** One way analysis of variance showing differences between social affective behaviour groups on expressive language, ASQ and SDQ scores.

	'Poor' Mean (SD) <i>n</i> = 6	'Some' Mean (SD) <i>n</i> = 18	'Good' Mean (SD) <i>n</i> = 4	<i>F</i> (d.f.)	<i>p</i>	eta <sup>2</sup>	Bonferroni post-hoc comparisons
Expressive language	75.5 (7.7)	70.4 (12.6)	96.8 (33.2)	3.69 (2, 25)	.04	.21	good > some*
ASQ	23.3 (6.5)	23.7 (6.5)	10.8 (4.4)	7.18 (2, 25)	.003	.37	poor > good* some > good**
SDQ-td	22.5 (3.6)	18.9 (5.5)	12.8 (8.6)	3.56 (2, 25)	.04	.22	poor > good *
SDQ-pr	4.0 (1.7)	5.5 (2.1)	9.0 (0.8)	8.70 (2, 25)	.001	.41	good > poor*** good > some*

SDQ-td = total difficulties score; SDQ-pr = prosocial behaviour

\*\*\* *p* < .001; \*\* *p* < .01; \* *p* < .05

### **3.5 Factors at initial assessment which predict outcome**

In order to further investigate the significant relationships suggested by the above across time correlations, a selective number of multiple regressions were carried out, taking into account the need to control for certain factors. The results are given in Table 25, that reports the overall effect of the independent variables entered into the regression equation (the collective effect) and the independent effect of the Time 1 factor in question. The latter statistic demonstrates the extent to which a particular factor at initial assessment significantly predicts a particular factor at Time 2, over and above the influence of the other variables (the control factors).

Seven associations were examined, of which five were demonstrated as significant. PIQ, receptive language and social communication behaviours at Time 1 were found to independently predict some characteristics at follow-up. Specifically, PIQ predicted the extent of axis 3 abnormalities, receptive language predicted difficulties in pragmatics and the degree of autistic symptomatology, while social communication behaviours predicted levels of behavioural disturbance and prosocial behaviour. It should be noted that in three of these cases, a significant independent effect was found in spite of the fact that the overall regression was not significant. These supposedly contradictory results (likely to be due to sampling error) call for caution in interpreting the statistics.

**Table 25. Multiple regression analysis examining the predictive role of factors at Time 1**

Time 1 Factor (IV)	Control factors (IV)	Time 2 factor (DV)	Collective effect			Independent effect of Time 1 factor		
			R <sup>2</sup>	F (d.f.)	p	R <sup>2</sup> change	F change	Sig. F change
PIQ	FSIQ at Time 2; Total language at Time 2; axis 3 at Time 1	Axis 3	.50	3.48 (4, 14)	.036	.17	4.73	.047
Expressive Language	FSIQ at Time 2; Total language at Time 2	ASQ	.47	2.95 (3, 10)	.085	.10	1.82	.207
Receptive Language	FSIQ at Time 2; Total language at Time 2	ASQ	.32	3.04 (3, 19)	.054	.20	5.68	.028
Receptive Language	FSIQ at Time 2; Total language at Time 2	CCC-pc	.33	2.46 (3, 15)	.103	.30	6.60	.021
Axis 3	FSIQ at Time 2; Total language at Time 2; axis 3 at Time 2	ASQ	.31	1.99 (4, 18)	.140	.03	0.78	.390
Soc. com Behaviours	FSIQ at Time 2; Total language at Time 2	SDQ-td	.33	3.50 (3, 21)	.033	.21	6.53	.018
Soc. com Behaviours	FSIQ at Time 2; Total language at Time 2	SDQ-pr	.23	2.07 (3, 21)	.135	.21	5.57	.028

CCC-pc = pragmatic composite; SDQ-td = total difficulties; SDQ-pr = prosocial behaviour; Soc. com = social communication

## **4. DISCUSSION**

This final chapter draws together the findings of the present study and discusses their interpretation in light of the available literature. Suggestions emerging from the data are discussed and explanations to account for the pattern of results are put forward. As a starting point, the rationale behind this investigation is revisited and the main findings are summarised. In response to the research questions posed at the outset, the characteristics of the sample are described, variations over time are examined and longitudinal associations are explored. Following this, attention is paid to the limitations of the project and consideration is given to the implications for both research and clinical practice. In closing, the merits of the present study are underscored and the benefits of extending this line of investigation are emphasised.

### **4.1 Rationale for the present study and summary of the main findings**

In contrast to the number of studies focusing on autism, milder manifestations of the condition have received little attention. This is in spite of the fact that the notion of a spectrum of disorders has earned increasing recognition over recent years. Explanations to account for this relative dearth of research often centre upon the lack of clarity regarding diagnostic criteria. The fact is, however, that clinicians are regularly faced with the difficult task of assessing preschool children with impaired communication and social skills, who do not meet criteria for autism. To date, fundamental questions about the subsequent development of these individuals remain largely unanswered.

In light of this, the present study represents an attempt to trace the development of a cohort of 30 children who displayed characteristics consonant with PDD in early years



but did not qualify for a diagnosis of autism. A suitable sample of subjects was identified and information relating to an assessment completed in the preschool period was extracted from the case notes. A follow-up assessment was then conducted, on average 4 years after the initial evaluation. The main purpose of the investigation was to outline the characteristics of the sample at follow-up and examine the predictive role of IQ, language and other aspects of behaviour at initial assessment.

The results of the follow-up assessment can be summarised as follows. Subject's cognitive skills were found to span from the average to the disability range, with more marked deficits in the verbal as opposed to the non-verbal domain. Language impairments were widespread, with two thirds of subjects classified as having expressive or receptive abilities below the average range. As a whole, the sample's communication difficulties were seen to be on a par with a group of language-impaired children previously reported in the literature. In terms of behavioural disturbance, overall levels were seen to be high, the most prevalent areas of difficulty being in problems with peers and hyperactivity.

High levels of autistic symptomatology were found in a significant number of subjects, who as a group demonstrated more difficulties with the pragmatic aspects of communication and with social relationships than those subjects with lower levels of autistic symptomatology. Social impairments were frequently reported as the focus of parent's concerns, often arising within the context of discussions about future educational placements. Information about current provision revealed half the children to be attending specialist facilities and half to be receiving extra support in a mainstream

environment. The vast majority of subjects had a statement of special educational needs and two thirds were also receiving speech and language therapy.

With information relating to assessments conducted at two different timepoints, it was possible to explore variations in characteristics across time. Estimates of cognitive and language functioning were observed to be reasonably stable from preschool age through to middle childhood, though the change in mean scores suggested a trend towards deterioration in the former (due to measurement error, as explained below) and improvement in the latter over time. A subset of children transferred from one social subtype to another, appearing more interactive at Time 2 compared to Time 1. Third axis behaviours were found to be relatively stable features across time, with some suggestion that routines and rituals become more manifest with age. A slight increase in the prevalence of excessive anxiety was also recognised.

The degree of association between characteristics at initial and follow-up assessment suggested that in addition to IQ and language, there might be other aspects of behaviour at initial assessment that relate to follow-up status. The prognostic value of these factors was investigated, leading to the identification of three significant independent predictors of characteristics at follow-up: performance IQ, receptive language and social communication behaviours. The first of these variables predicted behavioural abnormalities in the third domain; the second predicted difficulties in pragmatic aspects of communication and the degree of autistic symptomatology; the third predicted overall levels of behavioural disturbance and prosocial behaviour. There was some suggestion that social affective behaviours at Time 1 might have a particular relationship with levels of autistic symptomatology, as measured at Time 2.

#### 4.2 Characteristics of the sample at follow-up

Collectively, the information gathered during the course of follow-up assessments with this cohort of children suggests they are a group of individuals with significant needs. On standardised assessments of intellectual and language functioning, a substantial proportion of subjects obtained scores in the borderline range and below. Furthermore, an appreciable number of children evidenced high levels of communication impairment, social deficits, behavioural disturbance and autistic symptomatology. The fact that the vast majority of the sample had a statement of special educational needs is taken as evidence to corroborate the extent of these children's difficulties.

In what way do the difficulties presented by these children compare with those shown by atypical and autistic populations reported in the literature? With respect to atypical children, the very limited data available comes from papers that were published in the 1980's, since which time revised editions of the classification manuals have been published, leading to significant changes in thinking and practice (Volkmar et al, 1988). Bearing this in mind, some comparisons with the existing literature will now be made. Although the conclusions drawn appear obvious on occasions, it should be remembered that children who are not diagnosed autistic yet show features of PDD have not been widely studied and this study's primary purpose was to document what kinds of difficulties they present with in middle childhood, with no prior assumptions made.

The mean VIQ, PIQ and FSIQ scores obtained by the present study sample at age 6-10 years are considerably lower than those achieved by a group of similarly aged 'atypical' children investigated by Sparrow et al in 1986 (76 versus 111; 87 versus 108; 79 versus 110 respectively). Since both were administered revised versions of the

Wechsler Scales, the discrepancies are most likely accountable to different sampling procedures. At a classificatory level, the distribution of subjects across PIQ categories in this investigation bears resemblance to the IQ distributions previously reported for children with atypical PDD (Fisher et al, 1987; Levine & Demb, 1987). However, differences in the ages of the subjects, the standardised tests used and the classification systems adopted across these studies render it difficult to make direct comparisons.

It is considered more informative to examine the profile of subtest scores obtained by the present study sample on the WISC-III<sup>UK</sup> in light of what is known about how autistic children fare on this measure (Happé, 1994, summarises the previous studies). Some degree of consistency can be observed, in that performance on the Comprehension subtest (in which subjects are asked questions regarding social rules and concepts) was poor and performance on the Block Design subtest (in which subjects are required to reproduce geometric designs using 3 dimensional coloured blocks) was relatively good. Attempts to understand these characteristic 'peaks and troughs' in autistic individuals' performances have drawn connections with the primary psychological deficits that have been proposed in autism. These include a lack of mentalising ability (commonly referred to as theory of mind) and a piece-meal processing style (commonly referred to as weak central coherence). Comparing the results of this investigation to the existing literature that details how autistic children perform on the Wechsler Scales, it might therefore be hypothesised that individuals who are not autistic yet show features of PDD share the same psychological deficits as those who receive a diagnosis of autism. Further investigation is necessary to test the extent of such a proposal.

Expressive and receptive language impairments were found to be widespread in the present study sample at follow-up. With respect to the receptive domain, this finding contrasts with Sparrow et al's (1986) report that atypical individuals have receptive skills within the average to above average range. Additionally, the high degree of correlation observed between expressive and receptive abilities appears at odds with Fisher et al's (1987) finding that children with atypical PDD have significantly better developed receptive than expressive skills.

Unlike the Wechsler Scales, there are no studies detailing how children with autism perform on the CELF-R, although some attempt can be made to understand the present study sample's profile of scores in light of what is known about the specific kinds of language difficulties experienced by autistic individuals. The relatively high score on the Sentence Assembly subtest for example (in which a set of jumbled up words are presented that have to be re-arranged into the correct order) could be due to strengths in reading and in the application of 'rules'. On the other hand, the relatively low score obtained on the Formulated Sentences subtest (in which a word is given and the subject has to put it into a sentence) could reflect the difficulties autistic children have in generating language.

The present study sample obtained scores on the CCC that closely matched those achieved by the 'SP plus' group reported by Bishop (1998). An interesting question that arises from these findings is whether children labelled as having 'SP plus' and those considered to have mild forms of PDD are in fact one and the same. Brook and Bowler (1992) reviewed the literature on both conditions, providing evidence to suggest some degree of behavioural overlap in the pattern of impairments reported. A more definite

answer to the question of whether it is meaningful to assigning these different labels awaits longitudinal comparative studies, to determine the degree to which the two disorders have a similar course and outcome.

There are as yet no data on normal and autistic children's performance on the CCC, thus precluding any full conclusions from being drawn about the extent of this sample's communication difficulties. At this stage, the following broad statements can only be made. As borne out in the low social relationships subscale score, the present study sample were reported to experience difficulties interacting with others, which were not associated with their level of intellectual or language functioning. These kinds of difficulties are likely to place these children at increased risk for bullying and social isolation, as highlighted by those parents who were deliberating the transition to secondary education. Even those children with the best outcomes (i.e. those with higher intellectual and language skills, lower levels of autistic symptomatology and better developed pragmatic abilities) evidenced social deficits, which Wing (1988) strongly argued as being core.

The low pragmatic composite score obtained by the present study sample is in line with previous studies providing evidence that it is the functional use of language that is disordered in individuals with autism (Cantwell et al, 1978). By extrapolation, it might also be suggested that children with features of PDD who are not autistic will have deficient joint attention skills, that have been found to be characteristic in individuals with autism (Loveland & Landry, 1986).

A strong association was found between children's ability to interact with others and their abilities to use language in a socially appropriate way. Of course, correlation

does not imply causation, but it seems reasonable to understand this relationship as being reciprocal; children who do not use language in a communicative manner have more difficulties interacting with others, and difficulties in forming and maintaining friendships lead to less opportunities to develop pragmatic skills. The significant relationship observed between CCC pragmatic composite and ASQ scores is consistent with Rutter's (1978) suggestion that the more autistic an individual's language (measured here in terms of ability to use it in an interpersonal context), the more autistic their behaviour.

The overall level of behavioural disturbance in the present study sample, as measured by the SDQ, was found to be high. On the basis of this, it is reasonable to deduce that there are concomitant difficulties with management. As would be expected in children who evidence social impairment, peer problems were identified as the most prevalent difficulty. Hyperactivity was also a relatively common problem, consistent with other studies of children with PDD (Fisher et al, 1987; Levine & Demb, 1987). The finding that only a third of subjects showed 'abnormally' low levels of prosocial behaviour might suggest that children with milder variants of PDD are better at understanding the needs of others compared to those who are diagnosed as autistic. As mentioned previously, this is an avenue for further investigation. However, the pattern of results on the SDQ must be viewed with caution, given that the measure was developed for use with the general child psychiatric population and may not be sensitive to the difficulties of autistic children.

Behavioural difficulties were found to be related to scores on the ASQ, indicating that the higher the level of autistic behaviour, the greater the degree of general

behavioural disturbance. In considering whether particular aspects of autistic behaviour are more strongly related to non-specific behavioural problems than others, the high correlations between the SDQ-total difficulties score and the CCC-pragmatic composite/ social relationships subscale scores would suggest that social communication impairments may be key.

The finding that just over half of the sample evidenced high levels of autistic symptomatology, as measured by the ASQ, showed that a significant proportion of subjects demonstrated extensive behavioural features of autism. To illustrate this point further, the mean score for the present study sample (21.8) did not fall far short of the mean figure of 23.08 quoted by Berument et al (in press), for 83 individuals (age range 4.01 to 40.03 years) who met criteria for autism on a diagnostic instrument (the Autism Diagnostic Interview-Revised: Lord, Rutter & Le Couteur, 1994). Despite the age difference between the two groups, it is striking that the present study sample scored as highly as a group of autistic individuals, who one would presume were selected for inclusion in the ASQ validation study because of their classical presentation.

In light of such significant levels of overall pathology, it becomes clear that this group of children require a good degree of support, both within the school and home environment. In the former context, statutory involvement of the local educational authority had been necessary in the vast majority of cases, but with respect to the latter, ongoing support and advice for families, (regarding management issues for example), was largely lacking. Perhaps this is because the needs of children with ASD are misconstrued as insignificant, in comparison to the difficulties shown by more typically autistic individuals. The results of this investigation provide evidence to the contrary, and



it is hoped that in outlining the range and severity of the impairments shown by the present study sample, alterations in thinking will be prompted.

In some respects, a more positive outcome at age 6-10 years might have been predicted for the present study sample on the basis of their characteristics at initial assessment. At Time 1, these children's language skills were markedly delayed and thus, they would be expected to show some secondary features that overlap with behaviours characteristic of PDD (Willemsen-Swinkels et al, 1997). In conceptualising their difficulties in this way, one might predict that the additional features would dissipate as the children develop greater communicative function; the adage "he/she will grow out of it" comes to mind. However, the results of the current investigation largely suggest that this not the case and, in line with Cantwell et al (1989), some doubt is cast on the notion that the social deficits observed at Time 1 are simply a consequence of language difficulties.

#### 4.3 Variations over time

Information regarding the continuity of skills and behaviours across time was gained by contrasting the data collected at initial assessment with that obtained at follow-up. Such comparisons were of course limited to those variables that were measured at both timepoints. These included IQ, language, social dysfunction, third axis behaviours and excessive anxiety, each of which will now be considered in turn.

In terms of intellectual functioning, direct comparison of the PIQ estimates from Time 1 and Time 2 suggested a tendency towards a decline in scores over time. It is difficult to determine the extent to which this fall in IQ represents a true deterioration in

skills or an artefact of the measures employed. In attempting to shed some light on this issue, there are several points deserving consideration.

Firstly, there was a strong bias towards using the Leiter International Performance Scale in the initial clinical assessment, with 17 out of 30 children administered this measure. The Leiter requires few verbal instructions and on early items, repeated demonstrations can be given. For younger children, the test consists of simple matching tasks involving visual stimuli. On the other hand, the Wechsler Scale administered at Time 2 is a rather more language-dependent test (even on Performance items), that examines abstract problem solving skills. Although Shah and Holmes (1985) found that Leiter scores were significantly correlated (.82,  $p < .01$ ) with Wechsler PIQ scores in a sample of autistic children, this finding was based on test scores obtained at the same point in time. A longitudinal design was adopted by Lord and Schopler (1989a), who examined the role of test selection in the stability of intelligence scores in young autistic children. Here, it was suggested that IQ decreased as a function of the use of WISC in later years, compared with scores obtained on the Leiter in earlier years. In light of this, the apparent fall in PIQ score over time seen in the present study is thought to reflect the change in measure between Times 1 and 2, although the increasing complexity of the test tasks at higher age levels might also be a contributing factor.

In examining the continuity of expressive and receptive language skills over time, both estimates were relatively stable, a finding that is in keeping with other studies (Sigman & Ruskin, 1999). Intervention is likely to have played a role in this achievement. A subset of children showed greater advancement in their skills, whilst the mean change in score for the majority of the group suggested only a slight improvement

in scores over time. Overall, language impairments persisted, as has been previously demonstrated (Beitchman et al, 1994). Although a change in language measure occurred between Time 1 and Time 2, in most cases (12 out of 14 for expressive language and 15 out of 23 for receptive language) the estimates came from preschool and school aged versions of the same test (i.e. the CELF). The impact of such a change in instrument was considered minimal in comparison to the problems with IQ measurement detailed above.

The finding that just under half of the subjects in the current investigation were classified within a different social subtype at Time 2 compared to Time 1 lends some support to the notion that Wing's categories might be related to developmental level. In this respect, it has been suggested that aloof children may become more socially interactive with age (Wing & Atwood, 1987), a theory that in this study also seemed to apply to some of the subjects who were rated as passive at initial assessment. More specifically, a subset of children transferred into the active but odd category at follow-up, therefore seeming to show increased motivation to interact and make more social approaches (albeit not always for entirely appropriate reasons) as they grew older. Although this can be couched as progress, it has to be appreciated that these children's abilities to socially interact still remained qualitatively different from the norm at Time 2. These findings provoke interesting questions about changes in social functioning over time. However, further work to examine the reliability/validity of the Wing subtype scheme is thought to be required before attempting to investigate the mechanisms involved in these apparent changes in social behaviour.

The information recorded in relation to third axis behaviours in the present study sample revealed that they were present in a significant number of subjects, both in the

preschool period and in later years. Consideration was given to how this picture fits with Tanguay et al's (1998) suggestion to "wave the requirement" that individuals with "PDD-NOS" manifest at least one symptom from the third axis. Given that very few children showed no evidence of axis 3 behaviours at either Time 1 or Time 2, one might conclude that the present study findings conflict with Tanguay et al's proposal. Attention must however be paid to the fact that a significant number of subjects were rated as showing evidence of axis 3 behaviours at a 'mild' level, which may not be sufficient in severity to meet ICD-10 criteria in the third domain.

Restricted, repetitive patterns and interests were the most prevalent type of third axis behaviour at both timepoints, with some suggestion that routines and rituals become more pronounced with age. These features are similar to those described for individuals with Asperger's syndrome (Szatmari et al, 1989). On the other hand, motor and sensory mannerisms appeared least characteristic at each of the assessment occasions, perhaps implying that they are more of a prevailing feature in individuals with classic forms of autistic disorder. This idea receives partial support from Cox et al (in press), who found hand/finger and complex mannerisms in a higher percentage of children with autism than PDD at 42 months, although these authors found unusual sensory interests to only feature in the PDD group. At 20 months of age, both groups had tended to display less abnormality in the third domain, which suggested that these behaviours might emerge over time.

As yet, there appears to be no consensus on the developmental course of third axis behaviours nor have any definitive conclusions been made about the extent to which they are involved in milder manifestations of autistic conditions. The association

between repetitive activities/behavioural rigidity and social/communicative impairments also invites clarification (Charman et al, in press). Focusing attention on such issues will help to refine clinical diagnosis of conditions within the PDD spectrum and might well prove useful in furthering understanding of the underlying pathology in autism (Cox et al, in press).

Excessive anxiety was identified as more common at Time 2, compared to Time 1. Possible reasons why this was so could be that as these children grow older, they are inevitably exposed to a wider variety of new and confusing experiences which they find hard to make sense of. Thus, their level of anxiety is seen to increase. The issue of high anxiety in autistic individuals has received comment from Wing (1996) and has also been noted as a trait in children with atypical PDD (Demb & Weintraub, 1989; Levine & Demb, 1987). However, it is difficult to gauge whether the same set of features is being described, as these authors do not specifically define the behaviours that constitute a high level/excessive anxiety.

Given that the ASQ (or an equivalent measure of autistic symptomatology) was not administered at Time 1, it is not possible to state whether the sample's pattern of autistic behaviours has altered with age or whether features autism became any more or less pronounced over time. The finding that those scoring above the autism threshold on the ASQ were older than those scoring below the cut-off might reflect a change in symptomatology with age. It could however be due the fact that these children find it difficult to cope with the increasing demands that are made of them (particularly socially) as they grow older and consequently, their impairments become more apparent.

Sigman (1998) emphasises the need to view changes within such a developmental context.

Related to this point is the issue of whether a change in diagnosis might have occurred, as has been reported in other studies (e.g. Eaves & Ho, 1996, where children diagnosed with PDD-NOS in early childhood were re-diagnosed as having autistic disorder in later childhood). In the absence of a full diagnostic assessment, this question eludes an answer. What can be said however is that the overall pattern of scores obtained on the questionnaires administered at follow-up appeared consistent with what is known about the kinds of difficulties shown by children with autism and ASD. As Wing (1988) strongly argued, social deficits were seen as a key area of difficulty.

Added to this was the clinical impression of both the professionals who assessed each of the children in the present study sample, who felt that all the subjects showed the triad of impairments that characterise PDD, albeit varying in kind and severity. Although a full diagnostic assessment was not carried out, in several cases, it was felt highly likely that the children would fulfil criteria for childhood autism. This raises the question of whether in some individuals, prototypical autistic behaviours are not at their most apparent at age 3-5 years.

#### 4.4 Longitudinal associations

The correlational data found in this study were found to fit with the generally accepted view that IQ and language are related to outcome (as measured by standardised tests of IQ and language, questionnaires assessing levels of autistic symptomatology, communication and behavioural disturbance, and clinical ratings of aspects of

behaviour). In addition, the findings also suggested that other aspects of behaviour might be associated with follow-up status. The importance of understanding the predictive significance of each of these factors is crucial, if professionals are to be more definitive in responding to parents prognostic questions.

Consistent with other studies that have investigated the stability of IQ over time (Lord & Schopler, 1989b), non-verbal skills were seen to remain relatively stable as the children grew older. The stability ( $r = .44$ ) was found to be slightly lower than that quoted by Lord & Schopler (1989a) in their use of the Leiter and the Wechsler Scale at two different timepoints ( $r = .51$ ). PIQ at initial assessment was seen to be associated with language status at follow-up, in contrast with Sigman and Ruskin (1999) who claimed that early assessment of intelligence was not predictive of later language skills.

The other variable with which PIQ at Time 1 significantly correlated at Time 2 was third axis behaviours, whereby those with a lower IQ manifested more evidence of abnormality. This would suggest that there is some variation in third axis behaviours as a function of non-verbal IQ, as has been suggested to be the case in autistic children (Campbell, Locascio, Choroco, Spencer, Malone, Kafantaris & Overall, 1990). The results of the regression analysis revealed that PIQ at Time 1 had a significant effect on axis 3 behaviours at Time 2 independent of the control factors. This would suggest that early non-verbal ability is a good indicator of later abnormalities in behaviour.

Turning to examine the stability of expressive and receptive language, both were correlated well across time, with a higher and more significant relationship found for the former compared to the latter (i.e.  $r = .79, p < .001$  and  $r = .59, p < .01$  respectively). These statistics compare favourably with that reported for Sigman and Ruskin's (1999)

autistic sample ( $r = .56$ ), who also found that early language skills were associated with later language abilities. Estimates of expressive and receptive language at initial assessment were also found to inversely relate to the level of autistic symptomatology at follow-up, which is to be expected given that language impairments are a central feature in PDD. However, given the degree of overlap between early and later language abilities, it was necessary to examine the effect of language at Time 1 independently of language at Time 2.

The regression analysis gave an interesting result, in that receptive but not expressive language at initial assessment was identified to make a significant contribution to the variance in ASQ score independent of other factors measured at follow-up. Furthermore, receptive language at Time 1 was also found to be a significant independent predictor of difficulties with pragmatic aspects of communication at Time 2. On the basis of these figures, it is proposed that a comprehensive assessment of receptive language abilities in the preschool years might yield clinical information that holds broad prognostic significance. Altogether, the data suggested that preschool estimates of IQ and language were associated with a range of characteristics at follow-up, not all of which were the same. The finding that expressive and receptive language relate to different factors at follow-up deserves further investigation.

Over and above these estimates of functioning, an attempt was made to investigate the predictive role of aspects of behaviour at initial assessment. In the first instance, third axis behaviours at Time 1 were examined in relation to the degree of autistic symptomatology at Time 2. An exclusive relationship between the two variables



was not demonstrated in the regression analysis, suggesting that early abnormalities of behaviour alone are not good indicators of later levels of autistic behaviour.

Conversely, social communication skills at Time 1 were found to have a significant independent effect on strengths and difficulties in behaviour at Time 2. Children who demonstrated a higher degree of motivation to interact with others, more emotional responsiveness and better developed non-verbal communication at age 3-5 years were likely to have fewer general behaviour problems at age 6-10 years. In line with Sigman and Ruskin (1999), early achievements in social communication also predicted later levels of prosocial behaviour. The present study failed to replicate these author's finding that social communication behaviours predicted later gains in language, which might be attributed to the fact that Sigman and Ruskin adopted a more systematic approach to measuring these types of behaviours.

The suggestions made by both studies are certainly worth following up in more detail, to identify whether particular clusters of behaviour have more of an influence than others. In the present study for example, there was some suggestion that one particular aspect of social communication, namely the 'social affective behaviours' might be related to later levels of autistic symptomatology. To recap, this dimension of social communication behaviours involved judgements about the extent to which a child showed affection, offered comfort, shared and greeted others. Perhaps those children who display these features early on, (often leading parents to say things like "he/she can't be autistic because he/she gives me cuddles"), make more long-term gains in other areas of functioning. It would prove invaluable if behaviours holding such positive prognostic significance could be identified.

#### 4.5 Methodological weaknesses

There are a number of factors that serve to limit the conclusions that can be drawn from the present study findings. The difficulties inherent in carrying out clinical follow-up studies, particularly those that are retrospective in design are well documented. The methodological flaws of the particular study will now be addressed. With the benefit of hindsight, several suggestions for improving the study are made.

The technique of retrospective case note review is recognised as problematic. Interview notes and observations recorded as part of a routine clinical assessment represent just a proportion of the available information. The data are likely to reflect clinical concerns and it cannot be assumed that failure to document details of particular behaviours implies that they were absent. When the children in the present study were seen for a clinical assessment some years ago, clinicians did not of course have this research purpose in mind and data were therefore not consistently recorded in sufficient detail to allow all those variables of potential interest to be extracted. In this way, the possibilities afforded by the present study were considerably constrained. Additionally, problems concerning missing data are likely to be encountered.

The information gathered as part of the follow-up assessment makes extensive use of one source of information: parental report. Whilst the value in obtaining parent's views of their child's difficulties is not denied, this method of assessment is prone to subjective interpretation and may be influenced by the knowledge that parents have acquired regarding the prototypical features of their child's disorder. The data are therefore likely to be biased in some way. Some consideration was given to the limits of using questionnaires, by providing parents with an opportunity to clarify items they were

unsure about. The interviewer briefly reviewed the answers to all the items alongside the parent, in order to confirm understanding and check that the correct response had been endorsed.

Parents were not only asked to rate their child's current behaviour, but also to recall aspects of their early history. The accuracy with which they are able to remember detailed information from 4 years previously has to be questioned. Supplementation of self-report data is recommended. Time permitting, information from independent sources can be compared and observation schedules can be completed for the purpose of consistency. It is also advisable to use a semi-structured format when interviewing parents about their child's difficulties, in order to ensure that all the relevant areas of information are covered.

The questionnaire measures selected for the purpose of this study were chosen not only for their coverage, but also for their ease and brevity of administration. In the case of the CCC, the SDQ and the ASQ, these are relatively newly developed instruments, meaning that detailed information regarding their use with diverse clinical groups was not available. This placed the study at somewhat of a disadvantage, serving to limit the conclusions that were able to be drawn about the meaning of the data. As explained above, the use of the WISC-III<sup>UK</sup> at follow-up also presented some difficulties when interpreting the data, although it was considered to be the optimum choice, given that parents' agreement to take part in the study was contingent on the provision of clinically/educationally relevant feedback about their child.

The next critique relates to the degree of 'objectivity' in the information collected as part of this investigation. Three levels can be delineated: psychometric data, clinical

judgement data for which a degree of reliability was determined, and clinical judgement data for which no reliability was determined. Given the relative lack of standardised data available at Time 1, it was considered worthwhile to attempt to extract as much information from the case notes as was practically possible, part of which included the Paediatrician's efforts at rating social communication behaviours. This method is recognised as being far from ideal and needless to say the results should be interpreted with caution.

The preferred technique would of course have been the employment of standardised measures at both timepoints. Such instruments are advantageous because they give more adequate descriptions of the extent of a child's delay/deviance, in addition to being more reliable and objective. Three suggested measures that could have been usefully included in this investigation include the Autism Diagnostic Interview - Revised (ADI-R, Lord et al, 1994), the Autism Diagnostic Observation Schedule (ADOS, Lord, Rutter, Goode, Heemsbergen, Jordan, Mahwood & Schopler, 1989) and the Vineland Adaptive Behaviour Scales (VABS, Sparrow, Balla & Cicchetti, 1984).

The ADI-R is seen as an invaluable tool for eliciting examples of behaviour from parents that are key to a diagnosis of autism and providing comprehensive coverage of all the relevant features. The ADOS is a semi-structured assessment, in which the examiner is able to directly observe and code a range of social and communicative behaviours identified as being associated with autism. The VABS examines several areas of behaviour (communication, daily living skills, socialisation) and has proven useful in delineating the difficulties experienced by children with PDD (Sparrow & Cicchetti, 1985). This is not to say that standardised instruments are free from difficulty. For

example, the ADI-R was found to have only moderate sensitivity in diagnosing autism at very young ages, with less sensitivity still for related PDDs (Cox et al, in press).

Although the follow-up sample is bigger in size than those in previous studies reporting exclusively on 'atypical' populations (e.g.  $n = 18$  in Demb & Weintraub, 1989;  $n = 11$  in Sparrow et al, 1986), research on a larger scale is required before general conclusions can be made. A further factor that restricts the degree of generalisability of the current findings relates to selection bias, a topic that Szatmari and Streiner (1996) devote an entire paper to discussing. All the participants were recruited from the same setting, a tertiary service that by definition is likely to receive referrals of children with the more marked difficulties or the most puzzling array of symptoms. In this regard, the chances of producing more positive findings with regards to improvement over time are limited, as the service is biased towards seeing children with more complex needs. Ideally, in future prospective studies, subjects are recruited from various sources and care would be taken to ensure that they are representative of the population under investigation.

With all of these considerable limitations in mind, extreme caution must be exercised in accepting the results of the present study. At this stage, the findings are best treated as hypotheses requiring further investigation, some ideas for which will now be presented.

#### 4.6 Research and clinical implications

Whilst it would be premature to draw any firm conclusions on the basis of this one study alone, attention is now turned to the implications of the current investigation.

Further avenues for research will be considered first, following which the clinical issues will be discussed.

This study is by no means an end in itself. The results require both replication and extension if we are to learn more about individuals who are clearly not autistic, but appear to lie within the same spectrum of disorders. Ideally, such investigations should be prospective, longitudinal and population based in design (Nordin & Gillberg, 1998). Areas for future enquiry arising from the present study have already been mentioned in the context of discussing the results. To recapitulate, these include calls to: (i) investigate the extent to which individuals with milder forms of autism share the same deficits as autistic individuals (ii) evaluate the differences between children diagnosed as having semantic-pragmatic disorder and those diagnosed as having PDD; (iii) extend work on the reliability/validity of Wing's social subtype classification scheme; (iv) clarify the centrality of third axis behaviours in lesser variant conditions; (v) examine the predictive role of early social communication behaviours.

The value of focusing research efforts in these areas is two-fold. Firstly, such investigations will help to shed more light on the points of divergence and convergence between autism, ASDs and related conditions not only with regards to clinical features, but also in relation to outcome, thus enabling some of the nosological queries surrounding these disorders to be resolved. Secondly, identification of early markers for differential outcome will enhance clinicians' abilities to comment on prognosis and recommend the most appropriate targets for intervention.

At present, there lies a fundamental problem in deciding on an appropriate threshold for judging autistic symptomatology, as demonstrated by the fact that clinicians

experience difficulties in reliably diagnosing atypical forms of autism (Mahoney et al, 1998; Volkmar et al, 1994). The issue of differential diagnosis has been shown to be particularly problematic in very young children (Cox et al, in press). Therefore, attempts to better define the differences between conditions in which there are some but not all of the features of autism are strongly encouraged. The primary aim of such efforts should be to yield information that would help improve clinicians' abilities to differentiate between these disorders.

Above all, at the risk of repeating what has been said many times before, there is a continued need for more longitudinal work involving children with the whole range of conditions on the PDD spectrum. Nordin and Gillberg (1998) spell out the importance of outcome studies as "tools" that can further improve professionals' abilities to offer realistic and practical support to families, through the identification of most typical trends in development. They emphasize their significance in providing incentives for long-term management and in delineating factors associated with differential course and outcome.

In thinking about how the suggestions made by the present study might inform and advance clinical practice, a number of issues come to light. The first and most important message derives from the finding that this group of children were found to have a significant range of needs at follow-up; this evidence strongly suggests that when features of PDD are identified in the early years, the fact that they are not considered sufficient in number or severity to warrant a diagnosis of autism should not be taken as an indication to dismiss their impact in the future. Secondly, if specific clusters of behaviour in the preschool years are found to be predictive of later characteristics, then

they should be systemically measured, preferably through the routine administration of standardised instruments.

#### 4.7 Concluding remarks

In summary, this study has shown that a cohort of children who were not diagnosed as having autism at age 3-5 years yet showed features consonant with PDD, continued to have significant needs at age 6-10 years. The findings strongly suggest that the social and imaginative impairments evidenced in early years were not simply a consequence of delayed language skills. Early estimates of IQ and language were identified as associates of later aspects of presentation, in addition to which, other characteristics were seen to have a role in predicting not only general aspects of behaviour, but also those more specific to autism. Although only tentative conclusions can be drawn from these findings, the study is considered to have been a valuable undertaking in its attempt to begin investigating the answers to some worthwhile questions. In this way, it is held as a useful pilot project from which to learn and build upon. Also, it is hoped to have provided suggestions for other fruitful lines of enquiry.

In recent years, there has been an increase in the use of the term ASD in clinics throughout the United Kingdom. The number of referrals of individuals recognised as being mildly affected by autism is expanding. Given that little is known about the course of these conditions and how they relate to each other, further research is justified. If the advances in our understanding of autism over the years are anything to go by, then there is reason to be optimistic that our knowledge of related conditions will similarly blossom.

The more we understand about the differing nature of impairments shown by



individuals who display some but not all of the features of autism, the more we will be in a position to help. Whilst coping admirably in managing and supporting their children, who at times can be quite difficult and demanding, the clinicians who conducted this study were of the opinion that parents could usefully be offered further professional guidance and advice. Ten years ago, Demb and Weintraub (1989) suggested that “there may be as yet many unexplored paths along the spectrum of developmental disorders”. This study demonstrates how this statement continues to be relevant today.

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APPENDIX 1

**CRITERIA FOR RATING SEVERITY OF AXIS 3 BEHAVIOURS**

## **CRITERIA FOR RATING SEVERITY OF AXIS 3 BEHAVIOURS**

### **1. Restricted, repetitive patterns and interests (including unusual preoccupations)**

#### **Mild**

Evidence of some flexibility  
Wider range of interests/curiosity developing  
Transitory  
Some awareness of behaviour as 'odd' (re: preoccupations)

#### **Marked**

Activities/interests largely limited or very restricted  
Affects more than one area (e.g. play, eating...)  
Longstanding feature of behaviour  
Difficulties if interfered with (e.g. lines of cars)

### **2. Routines and rituals (includes verbal and behavioural rituals)**

#### **Mild**

Causes some difficulties, but manageable  
Only occur in a particular context (e.g. school but not home)  
Slight tendency  
Only in phases/featured much more in the past  
Evidence of some flexibility

#### **Marked**

Regular feature of behaviour  
Longstanding  
Considerable difficulties if not adhered to (anger, upset...)

### **3. Mannerisms**

#### **Mild**

One type described  
Only occur in a specific context  
Not a regular feature

**CRITERIA FOR RATING SEVERITY OF AXIS 3 BEHAVIOURS  
(CONTINUED)**

**3. Mannerisms (continued)**

**Marked**

More than one type described (e.g. hand flapping, complex body movements...)  
Occur in different contexts  
Longstanding feature of behaviour

**4. Preoccupation with part-objects/non-functional elements (includes unusual sensory interests)**

**Mild**

Not a regular feature  
Only one example given  
Can be distracted

**Marked**

More than one example given  
Regular feature of behaviour  
Longstanding



APPENDIX 2

**DETAILED DESCRIPTIONS OF WING SUBTYPES**

## **DETAILED DESCRIPTIONS OF WING SUBTYPES**

### **The aloof group**

“Those who are socially aloof behave as though other people did not exist. They do not come when they are called, they do not respond to their name, their faces may be empty of expression except when they experience the extremes of anger, distress or joy, they look through or past you, just occasionally giving you a quick sideways glance, they may pull away if you touch them, they do not put their arms around you if you cuddle them and they may walk past you (or over you, if you are sitting on the floor) without pausing in their stride.

If they want something they cannot reach they grab you by the back of your hand or arm, not placing their hand inside yours or looking up at you, and pull you along to use your hand to reach the object they desire or to carry out an action for them such as turning the handle of a door. Once the object is obtained, you are ignored again.

They show no interest or sympathy if you are in pain or distress. They seem cut off, in a world of their own, completely absorbed in their own aimless activities. However, as children, most of them do respond to rough and tumble play. When tickled, swung round, rolled on the floor or chased around they may laugh with delight and show great pleasure. They may even look into your eyes and indicate that they want you to continue. In these situations, the children seem happy and sociable, as if nothing is wrong. The moment the game is finished, the child becomes aloof once more.

In childhood, the social impairment is particularly noticeable in contrast to other children of the same age. In normal development, interest in other children is evident very early on, well before school age.

## **DETAILED DESCRIPTIONS OF WING SUBTYPES (CONTINUED)**

### **The aloof group (continued)**

Young children with autistic disorders in the aloof group are indifferent to or alarmed by their companions in play group, or nursery school. Even if they will accept their sisters or brothers, they do not interact with children outside the family. The adults who continue to be aloof have no interest in their peers. If they want something, they approach whoever is in charge, though how, despite their social impairments, they unerringly identify the senior person is an unresolved mystery.”

### **The passive group**

“These children or adults are not completely cut off from others. They accept social approaches and do not move away from others but they do not initiate social interaction. They may have poor eye contact, like the aloof group, but are more likely to meet other people’s gaze when reminded to do so. Because, during childhood, they are amenable and willing to do as they are told, other children are often happy to involve them in their play. A passive child makes an ideal baby in a game of mothers and fathers or a patient in a pretend hospital. The problem is, when the game changes, the passive child may be left behind because there is no suitable role for them.

In general, children and adults of this kind have the least behaviour problems of all with autistic disorders. However, some change markedly in adolescence and become disturbed in behaviour.”

## **DETAILED DESCRIPTIONS OF WING SUBTYPES (CONTINUED)**

### **The active but odd group**

“Children and adults of this kind make active approaches to other people, usually those in charge rather than their age peers, but do so in a peculiar one-sided fashion to make demands or to go on and on about their own concerns. They pay no attention to the feelings or needs of the people they talk to. Some have poor eye contact, but the problem is usually timing of making and breaking eye contact rather than avoidance. They often stare too long and hard when talking to, or rather at, others. Their approaches can include physically holding or hugging the other person, often much too tightly. They can become difficult and aggressive if they are not given the attention they demand. In childhood, they may ignore children of their own age or else behave aggressively towards them.

This group tends to present particular problems of diagnosis because the active social approaches cover up the fact that they have no real understanding of how to interact socially with other people.”

**Taken from: Wing, L. (1996).**

**The Autistic Spectrum. A Guide for Parents and Professionals**

**London: Constable**

APPENDIX 3

**INTRODUCTORY LETTER**

**NEWCOMEN CENTRE**  
**Tel: 0171 955 5000 Ext:- 5672**  
**Fax: 0171 955 4950**

**GUY'S & ST. THOMAS'**  
**HOSPITAL TRUST**  
**GUY'S HOSPITAL**  
**ST. THOMAS STREET**  
**LONDON SE1 9RT**  
**Tel: 0171 955 5000**

Dear

You may remember that I met you and your child some years ago for an assessment. We are now trying to improve our own skills by looking again at children that we saw when they were very much younger to gain some idea of the progress that they have made and what difficulties both you as parents and your child are now experiencing. We would be extremely grateful if you felt able to help us with this.

What we would ask you to do is to allow us to visit you at home (this would be our researcher who is a Psychology Graduate accompanied by a very experienced Speech Therapist). They would make an assessment of your child and to help us we would also ask you to fill in a number of questionnaires, about behaviour and any other difficulties which you think are important. We would be happy to provide a brief written report on our assessment results.

We hope that this re-assessment will enable us to be more useful to children and parents in the future. If you would prefer not to be contacted, please would you send back the enclosed pre-paid card otherwise we will get in touch with you with a possible date on which to make a visit.

Yours sincerely

**Dr Gillian Baird**  
**Consultant Developmental Paediatrician**

APPENDIX 4

**CONSENT FORM**

**CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECTS & CLINICAL TRIALS**

**Title of Project:** A follow-up study of children diagnosed with pervasive developmental disorder and language disorder at age 3 to 5 years.

**Principal Investigator:** Dr G. Baird  
**Other Investigator/s**  
**enrolling patients:** V. Slonims & J. Michelotti

**Ethics Committee**  
**Code No:** 98/07/08

**Outline explanation:** We are inviting families to take part in a new project which has recently been set up at Guy's Hospital. We are planning to carry out a follow-up study, which is interested in looking at the ways in which children who were seen at a young age in the clinic at the Newcomen Centre some years ago may have changed over time. In particular, we want to compare children described as having a pervasive developmental disorder (PDD) with those described as having a language disorder (LD). Although the types of difficulties experienced by both these groups are known to show some degree of overlap, the nature of the relationship between them and the changes that occur over the course of development are not completely clear. This study aims to shed light on some of these issues and hopes to increase our knowledge and understanding of the problems associated with making diagnoses in very young children.

The study has essentially been designed in two stages, the second part requires your involvement. In the first instance, your child's file will be retrieved from the medical records department, and researchers working on the study will make note of the information that was collected in the Newcomen Centre clinic some years ago. The next step will involve a pair of researchers arranging a convenient time to visit your home, in order to gather up-to-date information about your child. It is estimated that this visit will last on average 3 to 4 hours, and we realise that this is requiring you to commit a considerable amount of time. You will be asked to complete some questionnaires and we would like to interview you briefly about your child's current situation. In addition, we would like to spend time with your child, which will involve asking them to complete a range of activities which are generally found to be enjoyable, including some puzzles and games. Following the visit, you will be provided with a written summary of your child's performance on the assessment, which we hope will provide some useful feedback about your child's current level of functioning. All the results of this study will remain confidential.

You may withdraw from the study at any stage without necessarily giving a reason for doing so, and this will in no way affect any future care or treatment received. In order for your child to be involved in the study, we need to obtain consent from you on their behalf. For this purpose, we ask that you read and sign the section below. If you have any questions, please feel free to contact one of the researchers working on the study who will be willing to discuss these with you. If you have no objection, we would like to inform your GP that you are taking part in the study.

I (name) \_\_\_\_\_

of (address) \_\_\_\_\_

hereby consent on my child's behalf to their taking part in the above investigation, the nature and purpose of which have been outlined above. I understand that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so and that this will in no way affect the care I receive.

SIGNED (Parent/Guardian) \_\_\_\_\_ Date \_\_\_\_\_



APPENDIX 5

**EXAMPLE OF FEEDBACK REPORT PROVIDED TO PARENTS**

**NEWCOMEN CENTRE**  
**Tel: 0171 955 5000 Ext:- 5672**  
**Fax: 0171 955 4950**

**GUY'S & ST. THOMAS'**  
**HOSPITAL TRUST**  
**GUY'S HOSPITAL**  
**ST. THOMAS STREET**  
**LONDON SE1 9RT**  
**Tel: 0171 955 5000**

X (d.o.b.XX.XX.XX)

X was seen for a follow-up assessment on XX.XX.XX., at chronological age 8 years 3 months. The following measures were administered:

**(i) Wechsler Intelligence Scale for Children – Third Edition (WISC-III<sup>UK</sup>)**

A standardised battery which estimates children's current level of intellectual functioning across Verbal and Performance (non-verbal) domains.

**(ii) Clinical Evaluation of Language Fundamentals – Revised Edition (CELF-R)**

A standardised assessment of children's language skills.

The results of the assessment are summarised below:

SCALE	SUBTEST	STANDARD SCORE (average is 10)
WISC-III <sup>UK</sup> Verbal Scale:	Information	2
	Similarities	1
	Arithmetic	6
	Vocabulary	3
	Comprehension	1
WISC-III <sup>UK</sup> Performance Scale:	Picture Completion	8
	Coding	5
	Picture Arrangement	12
	Block Design	13
	Object Assembly	13

WISC-III <sup>UK</sup> Summary scores: (average is 100)	Verbal IQ	58 (within the range 55-65)
	Performance IQ	101 (within the range 94-108)
	Full Scale IQ	74 (within the range 70-80)

These results suggest that X's verbal skills fall well below the average range, while his non-verbal skills fall within the average range. He performed best on subtests involving him to complete jigsaws and reproduce 2 dimensional geometric patterns from coloured blocks. X experienced most difficulty when asked to consider how paired words are related and when asked questions about social rules/concepts.

## Clinical Evaluation of Language Fundamentals-R

SUBTEST	STANDARD SCORE	PERCENTILE RANK
<b>Receptive language</b>		
Linguistic concepts	5	5
Sentence structure	6	9
Oral Directions	4	2
<b>Expressive language</b>		
Word structure	3	1
Formulated sentences	3	1
Recalling sentences	3	1

The average standard score for each subtest is 10 with a range of 3 points either way marking the range of normal scores; so that 7 is low average and 13 is high average. On the overall scores, 100 is the average score with a normal range of scores between 85 and 115.

CELF-R SUMMARY SCORES	STANDARD SCORES	PERCENTILE RANK
Receptive language score	67	1
Expressive language score	50	1
Total language score	55	1
Age equivalent	< 5 years	

X's overall results reveal significant difficulties with language skills. This was particularly evident on the expressive language subtests where answers were often tangential. However, it is clear that X has difficulty with all levels of language structure including grammatical forms (both at the sentence and word level) and semantics (meaning).

The questionnaires you completed have been most useful in helping us to understand X's current situation. We agree that he continues to show difficulties consistent with autistic spectrum disorder. His behaviour during our visit was somewhat disinhibited and at times inappropriate. He had difficulty conforming to the demands of the tasks presented tending to pursue his own line of thought rather than respond appropriately. You expressed your concern about his future educational provision and we agree that he is likely to need ongoing specialised help in order to ensure continued progress.

We very much enjoyed meeting you and wish you well in the future.

Vicky Slonims  
Specialist Speech and Language Therapist

Janine Michelotti  
Psychologist

cc: GP

APPENDIX 6

**CHILDREN'S COMMUNICATION CHECKLIST**

**Children's Communication Checklist (CCC)**  
**Research version - girls**  
by D.V.M. Bishop

This checklist seeks to improve the assessment and classification of children with communication problems by capturing the impressions of people who see the child on a daily basis. Many aspects of behaviour which are important for understanding children's difficulties are not covered by conventional assessments. The checklist is being developed to see if meaningful and reliable ratings of these behaviours can be made.

---

Child's name or code number: \_\_\_\_\_ Sex \_\_\_\_\_

Date of birth: \_\_\_\_\_ Today's date: \_\_\_\_\_

Your name (person completing the checklist): \_\_\_\_\_

Your relation to the child (i.e. parent, teacher, speech therapist, etc.): \_\_\_\_\_

(For respondents other than parents)

How long have you known this child? \_\_\_\_\_

School attended by child: \_\_\_\_\_

Is child receiving any special educational provision? YES  NO   
If YES, please give further details here:

Has the child ever had a permanent hearing loss diagnosed? YES\*  NO

Has the child any permanent physical handicap or chronic illness? YES\*  NO

Is English the main language spoken at home? YES  NO

\*If YES, please give further details:

---

**INSTRUCTIONS**

This checklist contains a series of statements describing aspects of children's behaviour. For each statement, you are asked to judge whether the statement DOES NOT APPLY, APPLIES SOMEWHAT or DEFINITELY APPLIES. Please tick ONE box per item, choosing the response that, in your judgement, best describes the child named above.

Do not leave any items blank. If you are unable to answer the question, please tick the box labelled "Unable to judge".

**PLEASE FILL IN THE CHECKLIST ON YOUR OWN, DO NOT DISCUSS YOUR ANSWERS WITH ANYONE ELSE.**

The checklist cannot capture every child's behaviour perfectly, so do not worry if you feel that none of the response alternatives is exactly appropriate; tick the one you think comes closest, and, if necessary, add an explanatory comment.

This study will establish whether the checklist is reliable and valid. It may not be! Please do not copy or distribute the checklist to others. If we find it does yield useful information, it will be made more widely available.

does applies definite unable  
 not some-ly to  
 apply what applies judge

1.	people can understand virtually everything she says	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	people have trouble in understanding much of what she says	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	seldom makes any errors in producing speech sounds	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	mispronounces one or two speech sounds but is not difficult to understand; e.g. may say "th" for "s" or "w" for "r".	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	production of speech sounds seems immature, like that of a younger child, e.g. she says things like: "tat" for "cat", or "chimbly" for "chimney", or "bokkle" for "bottle"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	she seems unable to produce several sounds; e.g. might have difficulty in saying "k" or "s", so that "cat" and "sat" are both pronounced as "tat".	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	leaves off beginnings or ends of words, or omits entire syllables (e.g. "bella" for "umbrella")	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	it is much harder to understand her when she is talking in sentences, rather than just producing single words.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	speech is extremely rapid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	seems to have difficulty in constructing the whole of what she wants to say: makes false starts, and repeats whole words and phrases; e.g., might say "can I- can I- can- can I have an - have an icecream".	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	speech is clearly articulated and fluent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	speech is mostly 2 to 3 word phrases such as "me got ball" or "give dolly"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	can produce long and complicated sentences such as: "When we went to the park I had a go on the swings"; "I saw this man standing on the corner"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	does not apply	applies some- what	definite- ly applies	unable to judge
14. tends to leave out words and grammatical endings, producing sentences such as: "I find two dog"; "John go there yesterday" "She got a bag"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. sometimes makes errors on pronouns, e.g. saying "she" rather than "he" or vice versa.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. talks to anyone and everyone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. talks too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. keeps telling people things that they know already	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. talks to herself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. talks repetitively about things that no-one is interested in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. asks questions although she knows the answers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. it is sometimes hard to make sense of what she is saying because it seems illogical or disconnected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. conversation with her can be enjoyable and interesting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. can give an easy-to-follow account of a past event such as a birthday party or holiday	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. can talk clearly about what she plans to do in the future (e.g. tomorrow or next week)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. would have difficulty in explaining to a younger child how to play a simple game such as "snap"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. has difficulty in telling a story, or describing what she has done, in an orderly sequence of events	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. uses terms like "he" or "it" without making it clear what she is talking about.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. doesn't seem to realise the need to explain what she is talking about to someone who doesn't share her experiences; for instance, might talk about "Johnny" without explaining who he is.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. pronounces words in an over-precise manner: accent may sounds rather affected or "put-on", as if child is mimicking a TV personality rather than talking like those around her	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	does not apply	applies some- what	definite- ly applies	unable to judge
31. makes frequent use of expressions such as "by the way", "actually", "you know what?", "as a matter of fact", "well, you know" or "of course"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. will suddenly change the topic of conversation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. often turns the conversation to a favourite theme, rather than following what the other person wants to talk about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. conversation with her tends to go off in unexpected directions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. includes over-precise information in her talk, e.g. will give the exact time or date of an event. For instance, when asked "when did you go on holiday" may say "13th July 1995" rather than "in the summer".	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. has favourite phrases, sentences or longer sequences which she will use a great deal, sometimes in inappropriate situations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. sometimes seems to say things that she does not fully understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. tends to repeat back what others have just said	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. her ability to communicate clearly seems to vary a great deal from one situation to another.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. takes in just one or two words in a sentence, and so often misinterprets what has been said.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. can understand sarcasm (e.g., will be amused rather than confused when someone says "isn't it a lovely day!" when it is pouring with rain).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. tends to be over-literal, sometimes with (unintentionally) humorous results. For instance, a child who was asked "Do you find it hard to get up in the morning" replied "No. You just put one leg out of the bed and then the other and stand up." Another child who was told "watch your hands" when using scissors, proceeded to stare at her fingers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	does not apply	applies some- what	definite- ly applies	unable to judge
43. gets into trouble because she doesn't always understand the rules for polite behaviour, and is regarded by others as rude or strange.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. may say things which are tactless or socially inappropriate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. treats everyone the same way, regardless of social status: e.g. might talk to the head teacher the same way as to another child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. ignores conversational overtures from others (e.g. if asked "what are you making?" the child just continues working as if nothing had happened)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. seldom or never starts up a conversation; does not volunteer information about what has happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. doesn't seem to read facial expressions or tone of voice adequately and may not realise when other people are upset or angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. poor at using facial expression or gestures to convey her feelings; she may look blank when angry, or smile when anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. makes good use of gestures to get her meaning across	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. seldom or never looks at the person she is talking to: seems to actively avoid eye contact	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. tends to look away from the person she is talking to: seems inattentive or preoccupied	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. smiles appropriately when talking to people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
54. is popular with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. has one or two good friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. tends to be babied, teased or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57. is deliberately aggressive to other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. may hurt or upset other children unintentionally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. a loner: neglected by other children, but not disliked	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. perceived as odd by other children and actively avoided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	does not apply	applies some- what	definite- ly applies	unable to judge
61. has difficulty making relations with others because of anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. with familiar adults, she seems inattentive, distant or preoccupied	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. overly keen to interact with adults, lacking the inhibition that most children show with strangers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. uses sophisticated or unusual words; e.g. if asked for animal names might say "aardvark" or "tapir".	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. has a large store of factual information: e.g., may know the names of all the capitals of the world, or the names of many varieties of dinosaurs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. has one or more over-riding specific interests (e.g. computers, dinosaurs), and will prefer doing activities involving this to anything else	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. enjoys watching TV programmes intended for children of her age.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. seems to have no interests: prefers to do nothing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
69. prefers to do things with other children rather than on her own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
70. prefers to be with adults rather than other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX 7

**STRENGTHS AND DIFFICULTIES QUESTIONNAIRE**

## Strengths and Difficulties Questionnaire

For each item, please mark the box Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months or this school year.

Child's Name \_\_\_\_\_

Male/Female

Date of Birth \_\_\_\_\_

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot sit still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks thing out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments or concerns?

APPENDIX 8

**AUTISM SCREENING QUESTIONNAIRE**

**CONFIDENTIAL**

**QUESTIONNAIRE ON BEHAVIOUR AND SOCIAL COMMUNICATION  
FOR PEOPLE AGED SIX AND OVER (G)**

NAME \_\_\_\_\_

DATE OF BIRTH \_\_\_\_\_

TODAY'S DATE \_\_\_\_\_

- |  | <b>YES</b>               | <b>NO</b>                |
|--|--------------------------|--------------------------|
| 1. Is she now able to talk using short phrases or sentences?   | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>If NO, proceed to question 9</b>  |                          |                          |
| 2. Does she ever talk with you just to be friendly (rather than to get something?)   | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Can you now have a to and fro "conversation" with her that involves taking turns or building on what you have said?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Has she ever used odd phrases or said the same thing over and over in almost exactly the same way? That is, either phrases she has heard other people use or the ones that she has made up?             | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Has she ever used socially inappropriate questions or statements? For example, has she ever regularly asked personal questions or made personal comments at awkward times?                              | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Does she ever get her pronouns the wrong way round, i.e. saying you or she for I?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Has she ever used words that she seems to have invented or made up herself, or ever put things in odd, indirect ways, or metaphorical ways of saying things? For example, saying "hot rain" for "steam" | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Has she ever said the same thing over and over in exactly the same way, or insist on you saying the same things over and over again?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Has she ever had things she seemed to have to do in a very particular way or order or rituals that she has to have you to do?   | <input type="checkbox"/> | <input type="checkbox"/> |

- |  | YES                      | NO                       |
|--|--------------------------|--------------------------|
| 10. Does her facial expression usually seem appropriate to the particular situation, as far as you can tell?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Has she ever used your hand like a tool or as if it were part of her own body (e.g. pointing with your finger, putting your hand on a doorknob to get you to open the door)? | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Has she ever had any interests that pre-occupy her and might seem odd to other people (e.g. traffic lights, drainpipes or timetables)?                                       | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Has she ever seemed to be more interested in a certain part of a toy (e.g. spinning the wheel of a car) or an object rather than using the object as it was intended?        | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Had she ever had any special interests that were <u>unusual</u> in their intensity but otherwise appropriate for her age and peer group (e.g. trains and dinosaurs)?         | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Has she ever seemed to be <u>unusually</u> interested in the sight, feel, sound, taste or smell of things or people?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Has she ever had any mannerisms or odd ways of moving her hands or fingers, such as flapping, or moving her fingers in front of her eyes?                                    | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Has she ever had any complicated movements of her whole body, such as spinning or repeatedly bouncing up and down?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Does she ever injure herself deliberately, such as biting her arm or banging her head?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. Does she have any objects that (other than a soft toy or comfort blanket) that she <u>has</u> to carry around with her?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. Does she have any particular friends or a best friend?   | <input type="checkbox"/> | <input type="checkbox"/> |

**For some behaviours, it is most helpful to focus on the time period between the 4<sup>th</sup> and 5<sup>th</sup> birthday. You may find it easier to remember how things were at that time by fixing your mind in relation to key happenings such as starting school, moving house, Christmas time, or any events that are particularly memorable for you as a family.**

- |   | YES                      | NO                       |
|---|--------------------------|--------------------------|
| 21. When she was 4-to-5 did she ever <u>spontaneously</u> copy you (or other people), or what you were doing (such as Hoovering, gardening, mending things)?      | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. When she was 4-to-5 did she ever spontaneously point at things around her just to show you things (not because she wanted them)?                              | <input type="checkbox"/> | <input type="checkbox"/> |
| 23. When she was 4-to-5 did she ever use gestures, other than pointing or pulling your hand, to let you know what she wanted?                                     | <input type="checkbox"/> | <input type="checkbox"/> |
| 24. When she was 4-to-5 did she nod her head to mean "yes"?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 25. When she was 4-to-5 did she shake her head to mean "no"?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 26. When she was 4-to-5 did she usually look at you directly in the face when doing things with you or talking with you?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 27. When she was 4-to-5 did she smile back if someone smiled at her?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 28. When she was 4-to-5 did she ever show you things that interest her to engage your attention?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 29. When she was 4-to-5 did she ever offer to share things other than food with you?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 30. When she was 4-to-5 did she ever seem to want you to join in her enjoyment of something?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 31. When she was 4-to-5 did she ever try to comfort you if you were sad or hurt?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. Between the ages of 4-to-5 when she wanted something or wanted help, did she used to look at you and use gestures with sounds or words to get your attention? | <input type="checkbox"/> | <input type="checkbox"/> |
| 33. Between the ages of 4-to-5 did she show a normal range of facial expression?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 34. When she was 4-to-5 did she ever spontaneously join in and try to copy actions in social games – such as The Mulberrys Bush or The Famer's in His Den?        | <input type="checkbox"/> | <input type="checkbox"/> |



- |   | <b>YES</b>               | <b>NO</b>                |
|---|--------------------------|--------------------------|
| 35. When she was 4-to-5 did she play any pretend games or make-believe games?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 36. When she was 4-to-5 did she seem interested in other children of approximately the same age whom she did not know?  | <input type="checkbox"/> | <input type="checkbox"/> |
| 37. When she was 4-to-5 did she respond positively when another child approached her?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 38. When she was 4-to-5, if you came into a room and started talking to her without calling her name, did she usually look up and pay attention to you?             | <input type="checkbox"/> | <input type="checkbox"/> |
| 39. When she was 4-to-5 did she ever play imaginative games with another child in such a way that you could tell they understood what each other was pretending?    | <input type="checkbox"/> | <input type="checkbox"/> |
| 40. When she was 4-to-5 did she play co-operatively in games that need some form of joining in with a group of other children, such as hide and seek or ball games? | <input type="checkbox"/> | <input type="checkbox"/> |

APPENDIX 9

**ETHICAL APPROVAL**

30 July 1998  
98/07/08

Dr Gillian Baird  
Department of Paediatric Neurology and Disability  
Newcomen Centre  
Guy's Hospital

GUY'S AND ST THOMAS'S  
MEDICAL AND DENTAL SCHOOL

GUY'S RESEARCH ETHICS COMMITTEE  
DEPARTMENT OF NEPHROLOGY &  
TRANSPLANTATION  
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Chairman: Professor S Sacks PhD FF  
Administrator: Mrs Valerie Heard  
Email: v.heard@umds.ac.uk  
s.sacks@umds.ac.uk

Dear Dr Baird

**Re: 98/07/08 A follow-up study of children diagnosed with pervasive developmental disorder or language disorder at age 3 to 5 years**

The Ethics Committee, at its meeting held on Wednesday 29 July 1998 considered your application, including the subject background information and consent form, and approved it subject to receipt of the following:

1. An amended consent form:
  - This requires an invitation to take part in the study
  - Please correct "puzles" to "puzzles" in the 2<sup>nd</sup> paragraph.
  - Add the sentence "If you have no objection, we would like to inform your GP that you are taking part in this study."
  - Add the sentence: "All the results of this study will remain confidential."
2. A copy of the letter which will be sent to parents. This should begin with an introductory statement, such as: "We are following up your child who was previously assessed at this Clinic, so that it is clear how their names were selected ."

Permission is granted on the understanding that:

- i) Any ethical problem arising in the course of the project will be reported to the Committee
- ii) Any change in the protocol or subsequent protocol amendments will be forwarded to the Committee. The principal investigator should see and approve any such changes and this should be indicated in the forwarding letter to the Committee.
- iii) A brief report will be submitted after completion.

Yours sincerely



Steven H Sacks  
Chairman of the Guy's Hospital Research Ethics Committee

The Guy's,  
King's College and  
St Thomas'  
Hospitals' Medical  
and Dental School

Guy's Campus  
Guy's Hospital  
London SE1 9RT

## Guy's Research Ethics Committee

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KING'S  
College  
LONDON  
Founded 1820

University of London

12 October 1998  
98/07/08

Vicky Slonims  
Specialist Speech & Language Therapist  
Department of Paediatric Neurology and Disability  
Newcomen Centre  
Guy's Hospital

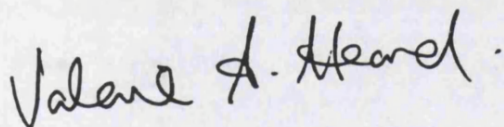
Dear Ms Slonims

**Re: 98/07/08 A follow-up study of children diagnosed with pervasive developmental disorder or language disorder at age 3 to 5 years**

Thank you for your letter of 9 September (received only last week) enclosing the amended consent form and a copy of a letter from Dr Baird. Professor Sacks has seen these and is happy that they meet all the Committee's concerns. The study now has full approval.

For clarity I have marked the consent form **Version 2 dated 09 September 1998**, so that we can identify it against the original.

Yours sincerely



Mrs Valerie Heard  
Ethics Committee Administrator