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Erratum
Volume 6 Issue 3 - September 2002
Temperament and Character in Adults with Asperger Syndrome

The authors wish to point out the following erratum:

‘Table 3 One-sample t-tests for the TCI variables in index cases (n = 20, d.f. = 19) compared with the mean t-score of 50 in the reference population’. The figures within the brackets should be (n = 31, d.f. = 30).

Henrik Soderstrom

AIMS AND SCOPE
Autism provides a major forum for research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders.

The aims of the journal are twofold: 1. to encourage research into practice in the field of autism spectrum disorders; 2. to encourage theoretical and academic researchers to consider the implications of their findings for practice. Articles will include substantive research reports as well as smaller-scale action research and case studies. Critical reviews of theoretical and experimental work, and its relevance to intervention and provision, will also be a core feature of the journal.
This is the beginning of the journal’s 7th year. Since the time of our first issue the number of submissions to the journal has increased steadily, both in quantity and quality. We have attempted to keep to our original remit of publishing articles that, whilst being of potential practical value to readers, are backed up by adequate research data. We have also attempted to include work from countries across the world. This issue, we believe, provides a good example of how those aims have been met. The articles come from England, Scotland, America, Israel and Sweden. The issues covered include diagnosis, autistic symptomatology, and social functioning.

The article by Stone and her colleagues describes the Parent Interview for Autism–Clinical Version (PIA–CV), designed to measure symptom severity across a wide range of behavioural domains. Of particular interest is the fact that the research presented indicates that this may be a potentially important tool for making diagnoses in very young children, as the authors report significant group differences in social communication skills between 2-year-old children with autism, and a developmentally matched sample. Given the emphasis on early intervention for children with autism, the development of reliable diagnostic instruments that can be used with very young children is clearly of major importance. The data also indicate that the PIA–CV may be helpful in monitoring changes and improvements in children who are involved in therapy, and possibly, too, to compare the effectiveness of different therapies. Although the authors note that, so far, the instrument has only been used to investigate differences between groups of children, and is not designed to provide individual diagnoses, its potential applications, both in the field of research and clinical practice, are considerable.

Exploring another area related to diagnosis, Brogan and Knussen examine the responses of parents to the diagnosis of an autistic spectrum disorder for their child. Although it is sometimes argued that ‘labelling’ of young children is not helpful, either for them or their parents, this study of children aged from 3 years upwards, indicates that amongst the parents interviewed, the majority found the diagnosis to be helpful, and in many cases diagnosis resulted in the provision of follow-up help and support. The way in which the diagnosis was given, however, was also very important, with parent satisfaction at the way in which the disclosure was made correlating with many other variables. In line with other studies in this area,
the results indicate that professionals can do much to influence parents’ experience of disclosure; they can ensure that parents feel supported, respected and informed or, conversely, they can leave parents feeling confused, angry, distressed and humiliated. The aim of all professionals should be the improvement of disclosure practices, as diagnosis can be the gateway to appropriate health, education and social provision and help to ensure that both the child and his/her family have access to the services they need as early and as smoothly as possible.

The final article concerning diagnostic issues examines how well early diagnosis of autism stands the test of time. Moore and Goodson, a psychologist and speech and language therapist working in the South of England, found diagnosis based on the Autism Diagnostic Interview (ADI–R) to be very stable over time, although there are some changes in the profile of symptoms. Thus, as has been noted in previous reports, routines and rituals may not be particularly evident in very young (2-year-old) children, and are more likely to be observed amongst 3- to 4-year-old children.

While some professionals are still reluctant, despite all the evidence, to assign specific diagnoses to young children with autism, even more are sceptical about the value of psychometric assessments. It is often claimed that these are irrelevant, or unreliable for this group of children, because of their particular difficulties in language and social communication. However, again, research belies such claims. It is clear that IQ data, if obtained from instruments that are appropriate to the child’s developmental level, are reliable, but that patterns of cognitive functioning do tend to change with age. For example, whereas verbal IQ tends to be low, relative to non-verbal IQ, during the preschool years, as time goes on and children develop better language skills, this gap tends to close. Within verbal and non-verbal domains there are also particular profiles of skills and difficulties that have important implications for teaching. The study by Mayes and Calhoun examines various aspects of ability profiles in children with autism, according to age and IQ, and although the data are cross-sectional rather than longitudinal, and therefore do not allow an examination of individual change, it appears that in the early school years (age 3 to 8) IQ scores tend to increase, but thereafter become more stable. The reason for these changes in the early years still requires greater explanation, but it is an important finding and one that needs to be taken account of by those claiming that specific intervention programmes have had a positive impact on IQ. Clearly there are variables other than therapy that may result in changes in IQ over time and hence this is a crucial area for future research.

The final two articles focus on social interactions in people with autism. Bauminger and Shulman report the results of their research on maternal...
perceptions of friendship amongst typically developing children and high-functioning children with autism. Although the authors note the need for a more direct, observational study of friendships amongst children with autism, the present research indicates that those who are high functioning can develop relationships with their peers, although the nature and quality of these friendships does tend to differ from those of typically developing children. In particular, mothers of children with autism were more involved in forging and maintaining close friendships, and the degree of environmental structure required in order to facilitate interactions was also greater. Nevertheless, it was clear that children could develop friendships, both with other children with difficulties, and with their typically developing peers. ‘Non-mixed’ interactions (i.e. with other children with disabilities) tended to be more common at school, whereas ‘mixed’ friendships mostly developed at home, with children in the neighbourhood. The most common factor relating to the development of friendships was a shared interest in particular topics. This is further evidence of the important role that the special interests or skills associated with autism can play in fostering wider social interactions and increasing the chances of social inclusion.

The final article, by Engström et al. in Sweden, moves on from children to study social outcomes in adults. The findings are mixed, with the numbers of individuals rated as having a good outcome being lower than in some other follow-up studies, but with fewer cases being identified as having a poor or very poor outcome. The article illustrates the variability of findings amongst follow-up studies of adults with autism, although some of the findings – for example the numbers of people in regular work, or making long-term relationships – are fairly typical. The individuals in this study had a higher rate of psychiatric morbidity than is generally reported but, since data on cognitive and linguistic abilities are limited, it is not clear how far these findings can be generalized to other groups of individuals with autism. However, the finding that almost 90 percent had either a good or fair outcome is encouraging, and may indicate that the future, at least for higher functioning individuals within the autistic spectrum, may be improving over time.
The development and maintenance of friendship in high-functioning children with autism

Maternal perceptions

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ABSTRACT The current study investigated mothers' perceptions of the development of friendship in high-functioning children with autism and in typically developing children. Fourteen mothers in each group (autism, typical) completed the Childhood Friendship Survey regarding their children's friendships. Main results indicated that both groups (autism and typical) tended to have same-gender and same-age friendships. However, friendships of children with autism differ compared with typical children's friendships on number of friends, friendship duration, frequency of meetings, and type of activities. Half of the friendships in the autism group were mixed (friendship with a typically developing child). Mixed differed from non-mixed friendships in that mixed pairs met and played mostly at home, whereas non-mixed pairs met and played at school. Factors contributing to the development and formation of friendship in each group are discussed.

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KEYWORDS friendship; high-functioning autism; maternal perception

A unified definition of friendship, accepted by all researchers, does not yet exist. However, most researchers tend to perceive friendship as a close, intimate affective tie between children that is based on reciprocal and stable (6 months and above) social interactions with a peer (e.g. Buhrmester, 1990; Dunn, 1993; Hartup, 1992; Howes, 1983). Friendship is a significant social experience for children, enabling them to develop and practice fundamental prosocial behaviors, such as mutual caring, emotional support, empathy, liking, intimacy, and sharing. Yet, at the same time, friendship requires certain skills such as the ability to compromise, the
capacity to understand and consider another child's perspective, emotional regulation capabilities, and efficient strategies for conflict resolution (Asher et al., 1996; Buhrmester, 1996; Hartup and Sancilio, 1986; Howes, 1996; Newcomb and Bagwell, 1996). Recent research on social information processing has stressed that the quality of children's peer relationships will have an influence on each stage in the processing of social situations, and that a close peer friendship will motivate a child to embark on more complex social information processing and to take into consideration the friend's point of view on the situation (Lemerise and Arsenio, 2000). Thus, friendship requires social skills; but, at the same time, the experience of friendship helps in developing these skills. Furthermore, the formation of friendship involves interrelations in all areas of development including cognitive and linguistic abilities, symbolic thinking, emotional understanding and expressiveness, and representational capacities (Dunn, 1993; Hartup, 1996; Hartup and Sancilio, 1986; Howes, 1992; Parker and Gottman, 1989). The lack of friendship is correlated with later adjustment problems (Parker et al., 1995).

Children with autism frequently have difficulties establishing friendships. A failure to develop peer relationships appropriate to developmental level is a diagnostic criterion for these children (DSM-IV: American Psychiatric Association, 1994). Furthermore, different theoretical approaches to these children's social-emotional deficits have also led to pessimistic predictions regarding the feasibility of friendship in children with autism. The affective view of social-emotional deficits in autism predicts difficulties in developing affective closeness and intimacy with a friend, which are considered to be essential functions of typical friendship (Hobson, 1993; Kanner, 1943; Wimpory et al., 2000). The theory of mind view of the core deficit in autism - emphasizing the child's difficulty in understanding that other people have different thoughts, desires, and feelings - predicts crucial difficulties in the reciprocity and empathic prosocial behaviors (e.g. comforting, caring, complimenting, listening) necessary for friendship development (Waterhouse and Fein, 1997).

Despite consensus that friendship constitutes a major area of difficulty for children with autism, recent empirical evidence suggests that friendship is an actual experience at least for high-functioning children with autism, who reported having at least one best friend and whose reports were verified by their mothers (Bauminger and Kasari, 2000). The potential for such a complex social experience as friendship seems to correspond with other higher social-emotional capabilities of high-functioning children with autism, as compared with their lower-functioning counterparts with autism. For example, the former are more likely to initiate social behaviors in peer interaction, reveal higher sensitivity and responsiveness
to social bids, and understand a larger repertoire of emotions that includes complex affects such as pride or embarrassment (Bacon et al., 1998; Kasari et al., 2001; Sigman and Ruskin, 1999; Stone and Caro-Martinez, 1990).

Moreover, friendship may be a particularly advantageous social framework for the development of social skills in high-functioning children with autism. It offers a one-on-one social experience with a familiar peer whose benefits include continuity over time; greater predictability owing to the fact that children learn to know one another's interests and to develop shared play routines; and a more ongoing, secure, and structured social experience in which to practice social activities, feelings, and skills such as cooperation, social initiation, play skills, taking another person's perspective, and sharing (see review in Bauminger and Kasari, 2001). However, friendship is an overlooked area of research in autism; therefore, we know very little about its development in these children.

The challenging nature of friendship for children with autism, due primarily to the aforementioned key problematic prosocial, affective, and reciprocal behaviors, implies that these children will need help in the development and maintenance of this type of peer relationship. One important source of support for these children's formation and maintenance of friendships may lie in their parents' ongoing support and guidance. Parents may also offer crucial information on their child's friendship formation process, by virtue of their access to the child's relationships outside educational and clinical settings (e.g. in the neighborhood). In Stone and Lemanek (1990), parents' reports on the social deficits of their young children with autism were consistent with the findings of experimental investigations on this age group (e.g. lack of peer and imaginative play; lack of imitation skills) substantiating parents' reliability as an information source about their children with autism. Wimpory and colleagues (2000) also investigated parents' reports on the social engagement of their pre-diagnosed youngsters with autism. Although parents were not aware of their child's diagnosis (thus could not be influenced by their knowledge), they could accurately delineate specific abnormalities in their children's ability to form person-to-person non-verbal communication and interpersonal contact and in triadic person-person-object interactions, which differentiated the autism sample from a control group of children with developmental delays. In addition, parents' perceptions of emotional expressiveness among their children with autism (at younger and older ages) have corroborated the body of recent empirical findings asserting evidence of emotional reactions in these children (Capps et al., 1993). Likewise, several recent studies have emphasized the importance of empirically examining parents' perceptions in diverse domains related to autism such as inclusion (Kasari et al., 1999), sleep problems (Schreck and Mulick,
2000), and developmental regression (Davidovitch et al., 2000). In spite of the acknowledgment of parents’ potential major role as informants about the different social abilities and experiences of their children with autism, a paucity exists in empirical investigations of parental perceptions concerning these children’s friendships. The current study, examining mothers’ perceptions of friendship in high-functioning children with autism, undertook to narrow this gap in the literature.

This study explored several aspects of the process via which friendships are developed and maintained in autism, as reported by mothers. These aspects included whether friendship is indeed an actual relationship for high-functioning children with autism; what helps these relationships begin and persist; how stable and continuous the relationships are; who the friends are; and what type of mutual activities they experience. The current study had three aims: (1) to examine mothers’ perceptions of the differences between friendship in high-functioning children with autism and typically developing children in respect of the number of friends, friend’s disability status (typical development or special education), age of best friend, gender of best friend, friendship duration, frequency of meetings, and types of activities; (2) to describe the characteristics of non-mixed friendships (between a child with autism and another child in special education) and mixed friendships (between a child with autism and a typical peer) in high-functioning children with autism; and (3) to identify factors that may contribute to the development and maintenance of friendship in children.

**Method**

**Participants**

The current sample comprised mothers of 28 children: 14 high-functioning children with autism and 14 children with typical development (two girls, 12 boys each). Children with autism were matched to the group of typically developing children on chronological age, full-scale IQ determined by the WISC–R (Wechsler, 1974), gender, and maternal education (see Table 1).

Mean chronological age was 10.45 years (SD = 2.57, range 8.25–17.10) for the children with autism and 11.72 years (SD = 2.70, range 8.66–16.50) for the typically developing children. Mean full-scale IQ score as measured on the WISC–R was 88.36 (SD = 14.81) for the children with autism and 96.64 (SD = 6.54) for the typically developing group. Children with autism were recruited through the Special Education Department in the Israeli Ministry of Education. All (but one) of the children in the autism sample were included in regular schools, in special
education classes, and spent several hours per day in regular classes on an individual basis. Thus, the majority of children with autism had opportunities to meet with typically developing children as well as with another child having atypical development. Typical children were recruited from local public schools.

Prior to participation in this study, all of the children with autism had been diagnosed by a licensed psychologist not associated with the current study. All children met the criteria for autistic disorder described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994), including (1) onset prior to 36 months of age; (2) qualitative impairment in social interaction; (3) qualitative impairment in communication (e.g. deficits or abnormalities in language development or deficits in play, particularly symbolic play); and (4) restricted and repetitive stereotyped behaviors, which may include bizarre responses to various aspects of the environment, such as resistance to change.

The Autism Diagnostic Interview–Revised (ADI–R: Lord et al., 1994)

### Table 1  Sample characteristics

<table>
<thead>
<tr>
<th></th>
<th>Autism (n = 14)</th>
<th>Typical (n = 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's chronological age (years, months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>10.45 (2.57)</td>
<td>11.72 (2.70)</td>
</tr>
<tr>
<td>Range</td>
<td>8.25–17.10</td>
<td>8.66–16.50</td>
</tr>
<tr>
<td>Child's full-scale IQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>88.36 (14.81)</td>
<td>96.64 (6.54)</td>
</tr>
<tr>
<td>Range</td>
<td>71–117</td>
<td>83–106</td>
</tr>
<tr>
<td>Child's verbal IQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>86.79 (12.86)</td>
<td>94.64 (5.51)</td>
</tr>
<tr>
<td>Range</td>
<td>73–120</td>
<td>87–104</td>
</tr>
<tr>
<td>Child's performance IQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>92.29 (17.81)</td>
<td>99.79 (10.9)</td>
</tr>
<tr>
<td>Range</td>
<td>71–131</td>
<td>82–118</td>
</tr>
<tr>
<td>Child's gender: male/female</td>
<td>12/2</td>
<td>12/2</td>
</tr>
<tr>
<td>Mother's education:a, b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>6.64 (1.39)</td>
<td>5.71 (1.43)</td>
</tr>
<tr>
<td>Mother's chronological age (years, months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>45.04 (7.24)</td>
<td>44.68 (5.90)</td>
</tr>
<tr>
<td>Range</td>
<td>33.75–56.00</td>
<td>34.66–53.66</td>
</tr>
</tbody>
</table>

* No significant differences between groups on children's chronological age, performance IQ, full-scale IQ, or gender, or on mothers' education or chronological age. IQ scores are based on the WISC–R.

b Mother's education was calculated according to a 1–8 scale (1 = less than 7th grade; 2 = junior high graduate; 3 = some high school; 4 = high school graduate; 5 = some college; 6 = special training after high school; 7 = college graduate; 8 = graduate school/professional training).

< *p* < 0.05.
was administered to the parents of the children by the authors of this article to verify diagnosis and to provide additional information about the children's developmental histories. The ADI–R focuses on meeting criteria for autism in three main areas: reciprocal social interaction; communication and language; and repetitive, restrictive, and stereotyped behaviors. The child also needs to show evidence of developmental delay or deviation prior to the age of 36 months. All 14 children met criteria for autism on all four ADI–R domains.

As seen in Table 1, the 14 mothers of children with autism ranged in age from 33.75 to 56.00 years (mean = 45.04, SD = 7.24). Two mothers (14.3 percent) had a high school education or less, four mothers (28.6 percent) had vocational or technical training, and eight mothers (57.1 percent) had a college or advanced degree. The 14 mothers of children with typical development ranged in age from 34.66 to 53.66 (mean = 44.68, SD = 5.90). Their educational level was distributed as follows: two mothers (14.3 percent) had a high school education or less, nine mothers (64.3 percent) had vocational or technical training, and three mothers (21.4 percent) had a college or advanced degree. The two groups of mothers did not significantly differ in chronological age or educational level.

Measures
Buysse's (1991) parents' Early Childhood Friendship Survey was used as a framework for asking mothers about their children's friendship. The Buysse (1991) survey consists of closed and open-ended questions evaluating the nature, development, and maintenance of friendship in typical children and in children with atypical development. The survey includes three sections. Section 1 consists of 19 questions that address the child's mutual friendships (characterized by a mutual interest in spending time or playing together), such as, 'Does your child currently have one friend who, in turn, thinks of your child as a friend?' (yes/ no); 'Where do they meet?' (school/ home/ both); 'Does this friend have a disability?' (yes/ no); 'How long have the children been friends?' (months); 'What helped this friendship to start?'; 'What can parents or teachers do to help the formation of friendship?' Section 2 includes unilateral friendship in which the target child initiates interactions with a peer who does not reciprocate; and section 3 includes unilateral friendship in which the target child does not reciprocate to a peer who initiates. Each mother in the current study reported at least one mutual friendship for her child. Also, the majority of mothers of the older children, in both groups, commented that they could not reliably report on their children's unilateral connections; thus these two sections (section 2 and 3) were excluded from the analyses.
Procedure
Children in the current study were part of a more extensive project examining social-emotional aspects in high-functioning children with autism. As part of this project three meetings were held with each child, two at school and one at home. The home visits were conducted by the first author. During these home visits with the child, mothers completed several questionnaires, including the Friendship Survey and a demographic questionnaire.

Results
Between-group differences on friendship
The study’s first aim was to examine differences between the two groups of mothers’ perceptions of their children’s friendships, comparing the friendships of high-functioning children with autism and the friendships of typically developing children. A set of t-test analyses was executed to examine group (autism and typical) differences on number of friends, friendship duration, and frequency of meetings. All three analyses were significant. Mothers of children with typical development perceived their children as having more friends ($t(26) = 2.33, p < 0.05$), for a longer time ($t(26) = 2.36, p < 0.05$), and with more frequent meetings ($t(26) = 3.52, p < 0.01$) compared with mothers of high-functioning children with autism (see Table 2 for means, SDs, and ranges).

Table 2  Friendship characteristics in high-functioning children with autism and in typically developing children

<table>
<thead>
<tr>
<th>Friendship categories</th>
<th>Autism</th>
<th>Typical</th>
<th>Group differences</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>t</td>
</tr>
<tr>
<td>Number of friends</td>
<td>2.50 (1.16)</td>
<td>4.00 (2.08)</td>
<td>2.33</td>
</tr>
<tr>
<td>1–5</td>
<td></td>
<td>1–7</td>
<td></td>
</tr>
<tr>
<td>Friendship duration (months)</td>
<td>21.80 (19.96)</td>
<td>44.57 (30.02)</td>
<td>2.36</td>
</tr>
<tr>
<td>6–72</td>
<td></td>
<td>6–120</td>
<td></td>
</tr>
<tr>
<td>Frequency of meetings</td>
<td>2.79 (2.01)</td>
<td>5.38 (1.80)</td>
<td>3.52</td>
</tr>
<tr>
<td>1–8</td>
<td></td>
<td>3–8</td>
<td></td>
</tr>
</tbody>
</table>

Note: friendship meeting frequency was calculated on an eight-point scale ranging from 1 to 8: 1 = meeting less than once a week, and 2–8 representing meeting frequency during the week (i.e. 2 = once a week; 3 = twice a week; . . . ; 8 = seven times a week).
Next, the two groups were compared on the friend’s age and disability status (typical development or special education). The majority of children in both groups (64 percent in the autism group and 93 percent in the typically developing group) had friends in their own age range (within one year), with a non-significant Fisher exact test. In the group of children with autism, four children had younger friends (1 year younger or below), and one child had an older friend (1 year older or more). Among the typically developing children, only one child had a younger friend. In terms of the friend’s disability status, high-functioning children with autism were significantly more likely to choose another child with special needs as a friend, compared with typically developing children (50 versus 7 percent, respectively). Fisher’s exact test yielded significant group differences, \( p < 0.05 \). In addition, the majority of friendships in both groups were also same-gender friendships. Only one of the mothers with typically developing children identified a mixed-gender friendship, and only two mothers of children with autism identified mixed-gender friendships.

Last, we asked the mothers to describe the types of activities in which their children were involved when they met. The most frequent activities among friends reported by the mothers of children with autism were: playing board games (eight pairs); watching TV or video together (seven pairs), and playing on the computer (six pairs). Activities reported by these mothers in lower frequencies included talking together (also by telephone) or playing ball games (basketball or football) (three pairs for each activity), as well as pretend play or eating together (two pairs for each activity). The following activities appeared among mothers’ reports only once: playing at the private family swimming pool, running together in the room for no particular reason, doing artwork where each child worked on a separate project, going out together in the company of parents, playing hide and seek, riding bikes, climbing trees, and playing with plastic building blocks.

The most frequent activity among friends reported by the mothers of children with typical development was playing ball games (basketball and football) (11 pairs). ‘Going out’ activities, such as going to the movies, going to the mall to ‘hang out’ with other children or to shop, and attending parties or other peer activities (e.g. an evening bonfire) together were cited by half the mothers (seven pairs). Other relatively frequent activities in the typical group were spending time on the computer (five pairs) and watching TV or pretend play (four pairs for each activity). Activities with very low frequency were studying together (three pairs), as well as talking, telling jokes, and eating together (two pairs in each activity). Activities that appeared only once were: drawing, riding on a skateboard, looking for and taking care of cats, selling objects, sleeping together, playing hide and seek, and running away from school.
Altogether, two activities – play on the computer and watching TV – were reported at relatively high frequencies by mothers in both groups. On the other hand, typically developing children frequently played different ball games and went out together with their friends, whereas children with autism frequently played board games with their friends.

In summary, according to mothers' perceptions, friends in both groups (typical and autism) tended to be of the same gender and age as the target child. However, friendships among children with autism were found to differ from typically developing children's friendships on their number of friends, friendship duration, and the frequency of meetings. Also, children with autism were significantly more likely to form a friendship with another child having a disability and were involved in different activities with their friends, as compared with the typically developing children.

**Within-group differences on mixed and non-mixed friendship**

The study's second aim was to examine the characteristics of 'mixed' friendships between a child with autism and a typically developing peer, and the characteristics of 'non-mixed' friendships between a child with autism and another child having a disability. Owing to the fact that only seven children with autism were in each group (mixed and non-mixed), only descriptive analyses were performed for each friendship type.

With regard to the seven non-mixed friendships reported for the high-functioning children with autism, five children were friends with another child who had a pervasive developmental disorder (PDD) or high-functioning autism, one child had a friend with cerebral palsy and a normal IQ, and one child had a friend with mild mental retardation (MR). The latter was the only non-mixed friendship of mixed gender: between the boy with autism and a female friend with MR. In terms of the friends' ages in these non-mixed relationships, two children with autism were more than a year older than their PDD and MR friends, and one child with autism was younger than his friend with PDD. The mean duration of non-mixed friendships was 19.6 months (SD = 16.9, range: 6–48 months). Four non-mixed pairs played both at school and at home, and three pairs played only at school.

With regard to the seven mixed friendships reported between the high-functioning children with autism and typically developing friends, one friend was the non-biological brother of the child with autism, and one friend was the child of the mother's best friend. Two typical friends were significantly younger than the child with autism (2 years and 8 months; 1 year and 3 months). Also, one mixed-gender friendship was reported: a female with autism had a typical male friend. In terms of the duration of friendship, mean duration for the mixed friendships was 24 months (SD
Five pairs played only at home, and two pairs played both at home and at school.

The most frequent joint activity reported for non-mixed friendships was playing board games (in six out of the seven pairs). Talking together (also by telephone) was reported for three different non-mixed pairs. Playing on the computer and watching video and/or TV were each reported for two different non-mixed pairs. Playing pretend play, playing ball games, running in the room for no particular reason, and going out with the company of parents each appeared very seldom (only once).

The most frequent activity reported by mothers for their children’s mixed friendships with typically developing peers was watching video and/or TV together, appearing in five out of the seven mixed pairs. Four mixed pairs played on the computer, and two pairs each played board games, ate together, and played ball games. Pretend play, playing at the private family swimming pool, doing separate artwork projects, playing hide and seek, riding bikes, climbing trees, and playing with building blocks each appeared only once.

In sum, non-mixed pairs mainly played board games, whereas mixed pairs tended to watch video and/or TV and play on the computer together.

Factors contributing to the formation of friendship in children

The third aim of the current study was to identify the factors that contributed to the development and maintenance of friendship in children according to mothers’ perceptions. Three main questions in the Friendship Survey were analyzed: (1) ‘How did your child's friendship start?’, (2) ‘What helped this friendship begin and persist?’, and (3) ‘How can parents/teachers help in the formation and maintenance of friendship?’

Children with autism

In terms of the first question – how this friendship started – all seven mothers who reported non-mixed friendships for their children with autism noted that studying in the same class and spending time in after-school activities contributed to the formation of their children's friendships. Out of the seven mothers who reported mixed friendships for their children with autism, four noted that the friendships started based on contacts formed between both parents, and three stated that the friendships started because both children studied in the same class or were enrolled in the same kindergarten when they were younger. In addition, three mothers provided additional factors that also contributed to their children’s mixed friendship: one mother had noted that her son’s relationship in a 'Big Brother' program had developed into a friendship (with the help of contact between the parents); one mother emphasized the children’s common
interests in the computer and in animated film; and one mother noted her child's strong desire for friends.

Mothers' responses to the second question - 'What helped this friendship begin and persist?' - were as follows. Among the seven mothers who reported non-mixed friendships for their children with autism, two said that the friends' same level of functioning and of social activity was important. Several answers appeared only once: mutual interest; the characteristics of the friend (i.e. high social expressiveness); the characteristics of the child with autism (i.e. friendliness and expression of high social interest); close proximity; the older age of the child with autism, thus enabling his ability to be more dominant in the relationship; and help from the teacher. One mother said she did not know.

Among the seven mothers who reported mixed friendships for their children with autism, three emphasized the typical friend's characteristics, such as warmth, openness, responsiveness, and kindness. Other responses included common areas of interest, e.g. computers (three mothers); parental involvement and contact with the friend's parents (three mothers); close proximity (two mothers); and the friend's small size, thus the child with autism does not feel threatened by him (one mother).

All 14 mothers said that their child's development and maintenance of friendship was highly dependent on their ongoing support. Mothers provided several suggestions regarding the ways they could help their child with autism in forming and maintaining friendship: (1) providing opportunities for her child to meet with other children and arranging continuous ongoing meetings after school; (2) helping her child with autism to find an 'appropriate' friend and encouraging her child to initiate contact with this friend; (3) supporting the ongoing process of friendship by physically bringing the friend over and taking her child to the friend's house; by helping the children find shared activities; and by taking the children to fun activities, such as to see a movie or eat a pizza; and (4) initiating contact with the friend's parents (some also noted that they became friends owing to their children's mutual interest).

Mothers also identified several ways in which teachers can contribute to the formation of friendship in children with autism. Mothers suggested that teachers can: (1) identify potential pairs in class who share common areas of interest, or who demonstrate mutual interest in one another; (2) arrange shared activities for the 'identified pairs' to experience, such as working together on shared projects; (3) incorporate conversations on friendship (e.g. what a friend is, why we need friends, how we choose friends, what we can do with friends) within the didactic program; (4) teach skills that facilitate the child's social competence and social understanding; (5) inform parents about the potential friendships that have been
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identified in class; (6) help in creating open communication between parents of both children; and (7) help in finding strategies for conflict resolution between friends. Lastly, mothers pinpointed cooperation, shared efforts, and open communication between parents and teachers as key factors in the development of friendship in these children.

In summary, five factors were identified by the mothers of the children with autism as contributing to their child's ability to form friendship:

1. The characteristics of the friend. In non-mixed friendship, mothers emphasized the importance of a similar level of functioning, and the social expressiveness and sensitivity of the friend. In mixed friendship, the typical friend's characteristics (e.g. openness, responsiveness, warmth) were considered as important.
2. A high level of social interest and social activity in the child with autism.
3. Close proximity, such as studying in the same class and/or living in close proximity (neighbors).
4. Shared areas of interest (such as computer games).
5. Active support from the parents and the child's teacher.

Typically developing children

Regarding the first question, 13 of the mothers of typically developing children reported that their children's friendships had started at school or even in kindergarten for several children. One mother said that their love of football connected her son and his friend. Three types of responses were provided to the second question, concerning what helped this friendship begin and persist: (1) shared areas of interest, similar style, and chemistry, reported by nine of the mothers; (2) close proximity, reported by five mothers; and (3) the kindness of the friend, reported by five mothers. In terms of how parents and/or teachers can facilitate the development and maintenance of friendship, seven mothers stated that they cannot help or do not want to get involved or to interfere with their child's social relationships. For example, one mother said: 'It depends only on the children themselves.' Four mothers said that parents can encourage their child to meet with a friend after school; two mothers suggested that parents can bring their child to a friend's house; and one mother said that parents can invite the friend's parents on shared outings.

Six mothers of typically developing children suggested ways in which teachers can foster the formation of friendships: two mothers recommended that the teacher sit the two children together; two mothers suggested that the teacher should arrange shared after-school activities for the children; and two mothers emphasized cooperation between home and school, for example, where the teacher notifies the parents about the
children’s interest in one another. In summary, in contrast to mothers of children with autism, mothers of typically developing children reported less responsibility for and less involvement in their children’s friendship. It seems that the major difference between the two groups of children (autism and typical) lies in the fact that friendship in children with typical development may be formed more spontaneously, and the friends are not heavily dependent on mediation of the children’s close social environment, whereas in children with autism the support from the environment appears crucial for the development and maintenance of peer friendships.

Discussion

The current study sought to gain insight into the formation and maintenance of friendship among high-functioning children with autism, through the perspectives of their mothers. Although the question of whether intimate friendship is possible in autism remains debatable, children with autism and their mothers reported that they do have friends (Bauminger and Kasari, 2000). Based on mother reports in the current study, children with autism do indeed have at least one mutual friendship. However, it seems that very rarely do these friendships emerge spontaneously and persist without the help and mediation of others in the child’s close social environment, such as parents and teachers, in contrast to the case of typically developing children. All mothers of children with autism emphasized that their own support in the creation and maintenance of their children’s friendship was crucial, whereas only half of the mothers of typically developing children thought so. Other differences were notable between the groups with autism and typical development: children with autism had less stable friendships, met their friends less often, and were involved in different activities with their friend. Activities preferred by children with autism and their friends were more structured (i.e. board games), providing clear, explicitly stated rules and/or activities that do not require high levels of social exchange. In contrast, typically developing friends preferred activities with a high level of social engagement (i.e. ball games or going out together).

Different types of friendships for the child with autism were seen to emerge through different circumstances. Children with autism were reported as having both typical and atypical children as their friends. Yet, it appears that the majority of non-mixed friendships were struck up at school, with other children having a disability who attended the same class or school setting, whereas most mixed friendships commenced at home, with typical peers from the neighborhood, or with children somehow connected to the family. Perhaps non-mixed friendships can be formed more
spontaneously via natural opportunities for social interaction in school, whilst mixed friendships with a typical peer need more support from the child’s social environment (e.g. parents). Nevertheless, mixed and non-mixed friendships seemed to share several commonalities, such as a similar duration and similar percentages of same-gender friendships and similarity friendships.

Mothers of children with autism identified various characteristics of the partner in their children’s friendships. It seems that a typically developing child’s kindheartedness and humanity are important factors in his or her ability to form a friendship with a child with autism. In terms of non-mixed friendship, the two children’s similarity in level of functioning and the level of social expressiveness exhibited by the friend who has a disability were cited. For mothers in both samples (autism and typical), shared areas of interest, close proximity, and the characteristics of the friends were considered to be chief contributors to the formation of friendship.

One limitation of the current study is its reliance on a single source of information to investigate friendship in children with autism. Parents are considered to be important informants regarding early childhood friendship and friendship in children with special needs (Buysse, 1991; Guralnick et al., 1995). Studies suggest a high correspondence between caregiver perceptions of friendship and other methods of measuring friendships (Buysse, 1993; Roopnarine and Field, 1984; Rubenstein and Howes, 1976). In the current study, albeit the fact that half of the mothers in the typical sample thought that they could not (or did not need to) help their children in the formation of friendship, they still provided a thorough description of their children’s mutual friendships. Moreover, mothers of children with autism were very much involved in their children’s friendships; therefore, it is reasonable to assume that their reports furnish important insights into the nature of these friendships. Yet, parents may report more mutual friendships in children with disabilities than noted by the teacher’s or child’s report (Bauminger and Kasari, 2000). One explanation for the parent-teacher gap is inherently related to the unique characteristics of friendship in children with disabilities. Owing to the fact that friendships may develop only or mostly in the child’s home (as found in the current study for mixed friendships), teachers may not know about these relationships. In terms of the parent-child gap in friendship reports, children with autism exhibit perceptions of friends that differ from typical children’s (Bauminger and Kasari, 2000; Hobson, 1993). Thus, it is difficult to rely solely on the self-reports of children with autism. It is, of course, imperative to conduct direct observations on these children’s friendships. Indeed, it seems that a more qualitative study design that observes these children’s behaviors and listens to their conversations with friends can
significantly promote our understanding of the nature of friendship in autism (Meyer et al., 1998).

Finally, the current article adds to the study on friendships in autism by providing parental perspective on these friendships. Findings of the current study verified data collected based on children's self-report (Bauminger and Kasari, 2000) which noted that high-functioning children with autism do have friends. Mothers in the current study took our understanding a step further to the understanding of the process of formation and maintenance of friendship in these children. Thus, a more integral, multiple source examination of childhood friendship in high-functioning children with autism is gathered. According to maternal report, friendship is an actual social experience for children with autism, although it may differ in quality from that of typically developing children. The role of the environment is crucial to the development and maintenance of friendship in high-functioning children with autism.

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References
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BAUMINGER & SHULMAN: MATERNAL PERCEPTIONS


The disclosure of a diagnosis of an autistic spectrum disorder

Determinants of satisfaction in a sample of Scottish parents

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ABSTRACT Satisfaction with disclosure of the diagnosis of an autistic spectrum disorder was investigated using a self-report questionnaire completed by 126 parents. On a rating of satisfaction, 55 percent indicated that they were satisfied or very satisfied with the disclosure. Parents were more likely to be satisfied if they gave positive ratings to the manner of the professional and the quality of the information provided; if they had been given written information and the opportunity to ask questions; and if their early suspicions had been accepted by professionals. These factors were combined into a global index of satisfaction; those gaining higher scores were more likely to have been given the diagnosis of Asperger syndrome (as opposed to autism), to have had a definite diagnosis, and to have children who were not currently in an educational placement. These results underline the importance of the interaction between parent and professional during the disclosure interview.

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KEYWORDS diagnosis; disclosure; parents; satisfaction

Introduction

A substantial body of literature exists on the disclosure of childhood disability, but little has been published relating specifically to a diagnosis of an autistic spectrum disorder. The aim of the present study was to examine the factors associated with parental satisfaction with such a disclosure.

Recent guidelines for good practice in the disclosure of disability tend to have a number of features in common, stressing particularly the importance
of the manner of the professional during the disclosure interview, and the way in which information can be given most effectively (e.g. Cunningham et al., 1984; Lingam and Newton, 1996). In line with such guidelines, Sloper and Turner (1993) found that mothers who were more satisfied with a disclosure of a diagnosis of severe physical disability rated the professional's manner more highly, and they felt that they had been given enough information and the opportunity to ask questions. Overall, 37 percent of their sample were satisfied or very satisfied with the way the news of their child's disability had been broken to them. A more recent study by Baird et al. (2000) found that three-quarters of mothers of children with cerebral palsy were satisfied or very satisfied with the structure and manner of telling, but satisfaction with the information content was lower (54 percent).

Ensuring that parents are satisfied with a disclosure of a diagnosis of an autistic spectrum disorder may be more problematic from the outset. First of all, children with autistic spectrum disorders tend to be diagnosed at a later age than children with other disabilities, such that the majority of parents do not receive a diagnosis until the child is around 5 or 6 years of age on average (Howlin and Asgharian, 1999; Howlin and Moore, 1997). Further, there may be a delay in the region of 2 to 4 years between parents' first suspicions of a problem and the final diagnosis (Howlin and Moore, 1997; Smith et al., 1994). Good practice would dictate that parents be told about their child's condition as soon as possible (Lingam and Newton, 1996) and delays in disclosure, in terms of the child's age and delays in the process, have been linked to parental dissatisfaction (Baird et al., 2000; Howlin and Moore, 1997; Quine and Pahl, 1986; 1987). Second, the diagnosis itself may be relatively vague (e.g. 'autistic features'); again, there is evidence to suggest that satisfaction with disclosure is greater when a clear-cut or specific diagnosis can be provided for the child's disability (Howlin and Moore, 1997; Quine and Pahl, 1987).

The aim of the study presented here was to investigate the determinants of parental satisfaction with the disclosure interview of a diagnosis of an autistic spectrum disorder, using a self-report questionnaire based on the instrument used by Sloper and Turner (1993). It was hypothesized that more satisfied parents would have children diagnosed at a younger age and diagnosed more recently, and that they would have experienced shorter delays between referrals and significant points on the pathway to diagnosis. It was also hypothesized that parents of children with a specific diagnosis (e.g. 'autism') would be more satisfied than parents of those given a relatively vague diagnosis (e.g. 'autistic tendencies'). Finally, it was hypothesized that those who gave positive ratings both to the professional's manner during the disclosure, and to the quality of the information, would express more satisfaction.
Method

Sample
Participants were drawn from the population of mothers and fathers of children with autistic spectrum disorders (including Asperger syndrome) living in Scotland. Four groups of potential participants were identified from the records of three hospitals in Scotland (identified here as ‘A’, ‘B’ and ‘C’) and one voluntary organization. Overall, 212 children were identified and a total of 334 questionnaires were sent out to mothers and fathers. (Two of the hospitals were able to identify single-parent families before the distribution of questionnaires.) The overall parental response rate was 38 percent (N = 126), with individual response rates of 32 percent (Hospital A), 56 percent (Hospital B), 36 percent (Hospital C), and 100 percent (the voluntary organization). Thirty pairs of parents were identified: thus data were available on 96 children, representing 45 percent of the possible number of children identified by the hospitals. Details are provided in Table 1.

Of the 126 participants, 73 percent were mothers and 27 percent were fathers. Fifteen mothers were single parents (12 percent) and there were no lone fathers. Of the 96 children included in this study, 85 percent were male. The age of each child at the time of data collection was calculated as the age on 31 December 1996: ages ranged from 39 months to 206 months with a mean of 86 months (SD = 35.8 months). The mean age of the child at the point of diagnosis was 55 months (SD = 31 months), ranging from 14 months to 180 months: 53 percent of the children had been diagnosed by the age of 48 months. Ninety-one percent of the children had been diagnosed within the 5 years prior to data collection. From parental reports, 77 percent of the children had been given a diagnosis of autism, 16 percent had received a diagnosis of Asperger syndrome, and the remainder had been given a diagnosis which included autistic features or tendencies. Notably, parents did not report diagnoses of ‘autistic spectrum disorder’ or ‘pervasive developmental disorder’, perhaps suggesting professional preference for certain terms at that time (Bennett, 1996) and/or parental interpretation and usage of diagnostic terminology. A significant difference was found between the hospitals with regard to diagnosis: Hospital C gave no diagnoses of Asperger syndrome, and gave more diagnoses of autistic features or tendencies than would be expected ($\chi^2(6) = 26.76, p < 0.001$).

Procedure
A letter was sent to each parent inviting participation in the project. Parents who agreed to participate were sent the questionnaire package by post. Approximately 8 weeks after the distribution of the questionnaire, parents
Table 1  Details of eligible and actual sample, by source (numbers of children identified by each hospital and a voluntary organization); numbers of single parents and couples identified prior to contact; numbers of initial contacts made with parents; numbers of refusals and envelopes returned ‘unknown’; numbers of questionnaires sent out and numbers returned; and numbers of returns by family composition. Note that Hospital B did not provide initial details of family composition

<table>
<thead>
<tr>
<th>Hospital</th>
<th>No. children identified</th>
<th>No. single parents</th>
<th>No. couples</th>
<th>No. initial contact</th>
<th>No. refusals</th>
<th>No. ‘unknown’</th>
<th>No. quest. sent out</th>
<th>No. returned</th>
<th>No. single parents returned</th>
<th>No. returns by both mother and father</th>
<th>No. children returned</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>102</td>
<td>13a</td>
<td>87a</td>
<td>190</td>
<td>3</td>
<td>8</td>
<td>179</td>
<td>58</td>
<td>8</td>
<td>14</td>
<td>44</td>
</tr>
<tr>
<td>B</td>
<td>25</td>
<td>–</td>
<td>–</td>
<td>50</td>
<td>21</td>
<td>4</td>
<td>25</td>
<td>14</td>
<td>1</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>C</td>
<td>74</td>
<td>12</td>
<td>62a</td>
<td>136</td>
<td>6</td>
<td>11</td>
<td>119</td>
<td>43</td>
<td>6</td>
<td>12</td>
<td>31</td>
</tr>
<tr>
<td>Vol.</td>
<td>11</td>
<td>–</td>
<td>–</td>
<td>11</td>
<td>0</td>
<td>0</td>
<td>11</td>
<td>11</td>
<td>0</td>
<td>4</td>
<td>7</td>
</tr>
</tbody>
</table>

*a* Includes one case of twins.
were issued with a reminder letter. Data collection took place during the winter of 1996.

Measures
The self-report questionnaire used in the current study was adapted from an interview schedule and a self-report questionnaire developed by Sloper and Turner (1993). It was clearly stated in the questionnaire that the term ‘autism’ would be used to refer to all subgroupings within the spectrum of autistic disorders, including Asperger syndrome. The final questionnaire covered a wide range of topics: only those relating to the current investigation are reported here.

Satisfaction with disclosure  Parents were asked to rate their satisfaction on the way the news of their child’s disorder was broken to them. Ratings were measured using a five-point scale from ‘very dissatisfied’ to ‘very satisfied’. An index of satisfaction was calculated following preliminary investigation of the relationships between the satisfaction rating and the descriptor variables (see ‘Results’).

Disclosure and time/delay variables  A rating of the quality of the information given at the time of diagnosis was obtained by summing responses to four items, each rated on a five-point scale: understanding of the information; the amount of information given; the degree of technicality of the information; and the ease with which the information was remembered. Similarly, a rating of the professional’s behaviour or manner was obtained by summing responses to five items, each rated on a five-point scale: sympathetic manner; understanding of the parent’s concern; good communicator; evasive/direct; and was/was not approachable and open to questions.

Other disclosure variables included the hospital involved; whether the parent had had suspicions before diagnosis; age of child when the parent first suspected that something was wrong with their child; time/delay details about the process of assessment and diagnosis (delays between first suspicions and tentative diagnosis, i.e. told that autism was likely; between tentative and firm diagnosis; and between first suspicions and firm diagnosis); and time since the diagnosis. Structural aspects of the disclosure were also considered, such as which professional(s) gave the diagnosis; where the parents were told; whether they were together/who was present; whether the child was present; nature of the diagnosis (definite/tentative); whether written information was given; whether help was offered on how to tell other family members; opportunities available to ask questions at the time of disclosure or at a follow-up meeting; and whether they were put in touch with other parents of children with autism.
Parent and child variables  Variables relating to the parent included age and sex; the number of siblings and the number of children living in the parental home; occupation and hours worked; whether a single parent; and partner's occupation (if applicable). Variables relating to the child included current age; age at the time of diagnosis; sex; diagnosis; educational placement; and measures of ability and disability (e.g. ability to walk, feed him/herself, go to the toilet alone, communicate with peers, understand language, and awareness of him/herself) (adapted from a behaviour problems questionnaire developed by Cunningham et al., 1986).

Results

Twenty percent of the sample indicated that they were very satisfied with the disclosure interview, 35 percent that they were satisfied, 33 percent that they were neither satisfied nor dissatisfied, 7 percent that they were dissatisfied, and 6 percent that they were very dissatisfied. Thus 55 percent of the sample indicated that they were satisfied or very satisfied with the disclosure interview. Given the small proportion of responses at the lower end of the scale, the categories of ‘very dissatisfied’ and ‘dissatisfied’ were merged for the purposes of further analysis. The analysis was therefore based on four categories of satisfaction: very satisfied; satisfied; mid-point; and dissatisfied/very dissatisfied.

The relationships between the single-item rating of satisfaction and the descriptor variables (disclosure, parent and child variables) were examined using chi-square analysis or one-way analysis of variance. Where appropriate, variables were corrected for skew prior to analysis. Missing data (from blank questionnaire items) were not reconstructed. Tables 2 and 3 provide descriptive statistics for all variables, and relationships with the single-item rating of satisfaction. Where both parents had completed a questionnaire for the same child, only maternal responses were used in analysis.

Parents giving a more positive rating of satisfaction gained higher (more positive) scores on the measure of the quality of the information given at the time of diagnosis ($F(3, 87) = 18.96, p < 0.001$) and on the measure of the professional's manner ($F(3, 88) = 14.72, p < 0.001$). They were more likely to indicate that their first suspicions (that there was something wrong with their child) had been accepted by professionals ($\chi^2(3) = 12.57, p < 0.01, N = 79$); they were also more likely to have received written information at the time of disclosure ($\chi^2(3) = 13.58, p < 0.01, N = 93$), and were more likely to have been given the opportunity to ask questions of the professional who was breaking the news ($\chi^2(3) = 22.69, p < 0.001, N = 90$). At the 5 percent level, a significant relationship was
Table 2  Descriptive statistics for continuous variables, and relationship with the rating of satisfaction F. Note that all had possible N of 96

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (SD)</th>
<th>Range</th>
<th>Relationship with satisfaction (F)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rating of disclosure information</td>
<td>14.2 (4.2)</td>
<td>4–20</td>
<td>18.96***</td>
</tr>
<tr>
<td>Rating of disclosure manner</td>
<td>20.6 (4.8)</td>
<td>7–25</td>
<td>14.72***</td>
</tr>
<tr>
<td>Age of child at first suspicions</td>
<td>24 (12.6)</td>
<td>1–72</td>
<td>1.52</td>
</tr>
<tr>
<td>Age of child when told that autism likely</td>
<td>52.3 (31.9)</td>
<td>14–182</td>
<td>0.15</td>
</tr>
<tr>
<td>Age of child at diagnosis</td>
<td>55 (31.2)</td>
<td>14–182</td>
<td>0.28</td>
</tr>
<tr>
<td>Delay between first suspicions and autism likely</td>
<td>30.5 (29.4)</td>
<td>1–127</td>
<td>0.19</td>
</tr>
<tr>
<td>Delay between autism likely and diagnosis</td>
<td>9.7 (6.3)</td>
<td>2–24</td>
<td>0.74</td>
</tr>
<tr>
<td>Total delay period</td>
<td>33.1 (28.6)</td>
<td>0–152</td>
<td>0.34</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>29.5 (22.9)</td>
<td>0–101</td>
<td>3.09*</td>
</tr>
<tr>
<td>Child age at time of study</td>
<td>86 (35.8)</td>
<td>39–206</td>
<td>2.61</td>
</tr>
<tr>
<td>Child abilities score</td>
<td>8 (1.61)</td>
<td>6–12</td>
<td>0.73</td>
</tr>
</tbody>
</table>

* p < 0.05, *** p < 0.001.

a Corrected for skew prior to analysis.

Table 3  Descriptive statistics for categorical variables, and relationship with the rating of satisfaction (χ²). Note that all had possible N of 96

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>% (N) (max. N = 96)</th>
<th>Relationship with satisfaction (χ²) (max. N = 96)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family variables</td>
<td></td>
<td></td>
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<tr>
<td>Sex of parent</td>
<td>Mother</td>
<td>96 (92)</td>
<td>3.97</td>
</tr>
<tr>
<td>Age of parent</td>
<td>Under 30</td>
<td>10 (10)</td>
<td>5.55</td>
</tr>
<tr>
<td></td>
<td>30–39</td>
<td>69 (66)</td>
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</tr>
<tr>
<td></td>
<td>40+</td>
<td>21 (20)</td>
<td></td>
</tr>
<tr>
<td>Parent employed</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Social class</td>
<td>I and II</td>
<td>49 (47)</td>
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<tr>
<td></td>
<td>III</td>
<td>18 (17)</td>
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<td></td>
<td>IV and V</td>
<td>7 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
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<td></td>
<td>Unemployed</td>
<td>22 (21)</td>
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<tr>
<td>Partner employed</td>
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<tr>
<td>Single mother</td>
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<td>77 (73)</td>
<td>1.01</td>
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<tr>
<td>No. other children</td>
<td>0</td>
<td>11.5 (11)</td>
<td>8.66</td>
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<tr>
<td></td>
<td>1</td>
<td>52 (50)</td>
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</tr>
<tr>
<td></td>
<td>2</td>
<td>25 (24)</td>
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<td>3+</td>
<td>11.5 (11)</td>
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<td>1</td>
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<td>2+</td>
<td>38 (36)</td>
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### Table 3 continued

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>% (N) (max. N = 96)</th>
<th>Relationship with satisfaction (χ²) (max. N = 96)</th>
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<tr>
<td><strong>Child variables</strong></td>
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<tr>
<td>Sex</td>
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<td></td>
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<td>Mainstream</td>
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<td>Special unit</td>
<td>11 (11)</td>
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<tr>
<td></td>
<td>Residential</td>
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<td>Diagnosis</td>
<td>Autism</td>
<td>77 (74)</td>
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<tr>
<td></td>
<td>Asperger</td>
<td>16 (15)</td>
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<tr>
<td></td>
<td>Autistic features</td>
<td>7 (7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>or tendencies</td>
<td></td>
<td></td>
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<tr>
<td>Disclosure variables</td>
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<tr>
<td>Hospital</td>
<td>Hospital A</td>
<td>46 (44)</td>
<td>14.27</td>
</tr>
<tr>
<td></td>
<td>Hospital B</td>
<td>15 (14)</td>
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</tr>
<tr>
<td></td>
<td>Hospital C</td>
<td>32 (31)</td>
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</tr>
<tr>
<td></td>
<td>Voluntary</td>
<td>7 (7)</td>
<td></td>
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<tr>
<td>Suspicions before disclosure</td>
<td></td>
<td>91 (87)</td>
<td>2.95</td>
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<tr>
<td>Suspicions accepted by</td>
<td></td>
<td>56 (45 of 81)</td>
<td>12.57**</td>
</tr>
<tr>
<td>professional</td>
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<tr>
<td>Alone at disclosure</td>
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<td>26 (24)</td>
<td>3.44</td>
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<tr>
<td>Child present at disclosure</td>
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<td>55 (52)</td>
<td>4.40</td>
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<td>Wanted child present</td>
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<td>5 (2 of 40)</td>
<td>6.81</td>
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<td>Profession of discloser</td>
<td>Psychiatrist</td>
<td>40 (38)</td>
<td>11.96</td>
</tr>
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<td></td>
<td>Psychologist</td>
<td>25 (23)</td>
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<td></td>
<td>Paediatrician</td>
<td>21 (20)</td>
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</tr>
<tr>
<td></td>
<td>Other</td>
<td>14 (13)</td>
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<tr>
<td>Location of disclosure</td>
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<td>86 (80)</td>
<td>2.65</td>
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<tr>
<td>Written info. provided</td>
<td></td>
<td>30 (29)</td>
<td>13.58**</td>
</tr>
<tr>
<td>Opp. to ask questions</td>
<td></td>
<td>71 (66)</td>
<td>22.69***</td>
</tr>
<tr>
<td>Opp. for later contact</td>
<td></td>
<td>84 (80)</td>
<td>5.50</td>
</tr>
<tr>
<td>Offered help on telling family</td>
<td></td>
<td>8 (8)</td>
<td>0.34</td>
</tr>
<tr>
<td>Provision of follow-up</td>
<td></td>
<td>65 (58)</td>
<td>4.80</td>
</tr>
<tr>
<td>Info. provided from others</td>
<td></td>
<td>57 (54)</td>
<td>7.55</td>
</tr>
<tr>
<td>afterwards</td>
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<td></td>
<td></td>
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<tr>
<td>Put in touch with other</td>
<td></td>
<td>35 (33)</td>
<td>3.15</td>
</tr>
<tr>
<td>parents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wanted contact with others</td>
<td></td>
<td>56 (33 of 59)</td>
<td>1.36</td>
</tr>
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</table>

* **p < 0.01, ***p < 0.001*

*a Social class (HMSO, 1990) based on paternal occupation (if respondent is the mother and if the father is present/in employment). Otherwise based on maternal occupation.*
found between satisfaction and the time since diagnosis ($F(3, 83) = 3.09, p < 0.05$), such that those with children more recently diagnosed were more satisfied. No other significant relationships were found between the time/delay variables (the age of the child at first suspicions, tentative diagnosis and firm diagnosis, and the periods of delay between each of these points) and the rating of satisfaction.

An index of satisfaction was created by taking the mean of the scores for descriptor variables demonstrating statistically significant associations with the rating of satisfaction with the disclosure (including the rating itself): suspicions accepted by professionals, the opportunity to ask questions at disclosure, the total score for the quality of information, and the total score for the manner of the professional. The index was created for two reasons: first, it was hoped that this would illuminate factors associated with satisfaction with the disclosure process as a whole; and second, it was hoped that the index would provide a more reliable measure of satisfaction in statistical terms. In order to reduce the number of missing values, the mean score was included if one or two scores were missing. The mean value for the satisfaction index was 8.68 (SD = 1.88, range 3.00–13.33).

Relationships between the satisfaction index and the descriptor variables were examined using one-way analysis of variance or regression, focusing on the variables related to current investigation. Again, the analysis was based on 96 responses, with maternal scores used in cases where scores from both parents were available. The results are displayed in Table 4. Scores on the satisfaction index varied according to the diagnosis and the extent to which parents perceived the diagnosis to be definite or tentative. Thus parents of children with a diagnosis of autism and parents of children with a diagnosis of autistic characteristics had significantly lower scores on the satisfaction index than parents of children with a diagnosis of Asperger syndrome. Further, parents who stated that their child’s diagnosis was definite gained higher scores on the satisfaction index than parents who stated that the diagnosis was tentative or not definite. Finally, parents whose child was not in an educational placement gained higher scores on the satisfaction index than parents of children in an educational placement. There were no significant associations between the satisfaction index and any other of the parent, child, or time/delay variables.

A hierarchical multiple regression analysis was conducted with scores on the satisfaction index as the dependent variable; the independent variables were hospital (included as a control); diagnosis; whether the diagnosis was definite; and whether the child was in an educational placement. Variables were entered into the equation in that order. The first two variables were dummy coded: the reference categories were the voluntary organization (as opposed to Hospitals A, B or C), and a diagnosis of Asperger
syndrome (as opposed to autism or autistic tendencies/features). The other two variables both comprised two categories: the diagnosis was definite or tentative, and the child was or was not in an educational placement. Prior to this analysis, the relationships among the independent variables were examined using chi-square analysis, and no problems of confounding were noted. The results are displayed in Table 5, including $R^2$, change in $R^2$, final $\beta$, the final $F$-value and the significance of the final $F$.

The variables accounted for 25 percent of the variance of the satisfaction index (19 percent adjusted) ($F(7, 87) = 4.23, p < 0.001$). Three variables were significant in the final equation: diagnosis, whether the diagnosis was definite or tentative, and educational placement. When hospital was

- Hospital 2.23
- Age of child at first suspicions $r = -0.04$
- Age of child when told autism likely (tentative) $r = -0.12$
- Delay between first suspicions and tentative $r = -0.14$
- Delay between tentative and firm diagnosis $r = -0.13$
- Total delay period $r = 0.09$
- Time since diagnosis $r = -0.18$
- Sex 0.08
- Age at time of study $r = -0.07$
- Age of child at diagnosis $r = -0.04$
- Total ability score $r = -0.10$
- Diagnosis 3.72*
- Definite diagnosis 6.34*
- Child in educational placement 4.66*
- Sex 1.45
- Age 0.16
- Employment 0.16
- Social class 0.82
- Partner in employment 0.01
- Single parenthood 0.00
- No. other children 0.04
- No. other children at home 0.64

* $p < 0.05$. 

Table 4  Relationship between scores on the satisfaction and descriptor variables (disclosure, time/delay, child and parental variables) (F-value or r-value and significance level)
accounted for, parents of children with a diagnosis of Asperger syndrome gained higher scores on the satisfaction index than parents of children with a diagnosis of autism. When both of these factors were controlled, parents receiving a definite diagnosis gained higher scores on the satisfaction index than those receiving a tentative diagnosis. Finally, parents whose child was not in an educational placement gained higher satisfaction scores than other parents.

To determine whether the significance levels of diagnosis and educational placement were due to age, sex of the child, ability or time since diagnosis, a second analysis was conducted controlling for these variables. The results are shown in Table 5. Note that degrees of freedom were reduced in the second analysis owing to missing data on the control variables ($F(11, 75) = 3.09, \ p < 0.002$). This time, parents of children with Asperger syndrome gained higher satisfaction scores than parents of children in both other diagnostic categories. The significance levels of both definite diagnosis and educational placement were reduced to just over 5 percent. It was concluded that the relationships between satisfaction and diagnosis, definite
diagnosis and educational placement were not due to the effects of the child's age, sex or abilities, or the time since diagnosis. Interestingly, in this analysis, parents recruited through the voluntary agency were more satisfied, at the 5 percent level, than those recruited through Hospital B.

As noted above, the sample contained 30 couples, or parents of the same child. Scores for the satisfaction rating and satisfaction index were compared across couples. On the satisfaction rating, 12 couples gained the same score and a further 13 were one point either side of each other. No significant difference was found ($\chi^2(6) = 3.29$). On the satisfaction index, five couples gained the same score. Mothers tended to have higher satisfaction index scores than fathers (mean = 9.0, SD = 1.7 and mean = 8.9, SD = 1.4 respectively), but this difference was not significant ($t(29) = -0.46$).

Discussion

This study revealed relatively high levels of parental satisfaction with disclosure of an autistic spectrum disorder: more than half of the participants were satisfied or very satisfied with the disclosure, compared with 37 percent of Soper and Turner's (1993) sample of mothers of children with severe physical disability. The results also contrast with the findings of a recent survey of satisfaction with the process of diagnosing autistic spectrum disorders in the UK (Howlin and Moore, 1997) in which only 35 percent of parents (and only 23 percent of Scottish parents) expressed a degree of satisfaction with the process. However, the latter discrepancy may be related to a difference between satisfaction with the process of diagnosis and satisfaction with the disclosure per se. While the findings of the current study suggest that the disclosure of a diagnosis of an autistic spectrum disorder need not be a negative experience for parents, the proportion of dissatisfied parents must serve to warn against complacency and these results highlight the factors associated with variation in satisfaction which are open to intervention.

As predicted, parents giving a more positive satisfaction rating were more positive about the manner of the professional during the disclosure interview and about the quality of the information given at that time (including the provision of written information and being given the opportunity to ask questions). They also felt that their first suspicions had been accepted by the professionals; this is an important finding as recent studies report that the vast majority of parents of children with autistic spectrum disorders are worried about their child's behaviour before professionals become aware of a problem (Howlin and Moore, 1997; Smith et al., 1994).
Overall, these results are clearly consistent with those reported by Sloper and Turner (1993), and underline the overwhelming importance to parents of what they are told by professionals and the way in which the interview is conducted. When these factors were combined with the rating of satisfaction to form a global index of satisfaction, factors more specific to the diagnosis of an autistic spectrum disorder were highlighted: with recruitment hospital controlled, those gaining higher scores on the index were parents of a child diagnosed with Asperger syndrome (rather than autism), and parents with a definite (rather than tentative) diagnosis. In addition, those with a higher score on the satisfaction index had a child who was not in an educational placement. These findings were not attributable to the child’s age, sex or abilities, or the time since diagnosis.

The issues surrounding diagnosis, including the clarity or certainty of diagnosis and prognosis, are complex. In the current study, no attempt was made to match parents’ reports of diagnosis, or indeed the extent to which the diagnosis was definite, with hospital records. However, while figures from some studies would suggest that Asperger syndrome was under-represented in this study (Ehlers and Gillberg, 1993; Kadesjo et al., 1999), pooled data from recent autism surveys indicate that on average the number of children with autism is five times higher than for Asperger syndrome (Fombonne, 2001). Current difficulties with prevalence estimation may be related to relatively recent entry of Asperger syndrome into international classification systems (e.g. ICD-10: World Health Organization, 1992), absence of epidemiological research on this disorder (Fombonne, 2001), and continuing confusion for professionals surrounding the diagnostic criteria for Asperger syndrome (Wing, 1999). There is also evidence of low levels of autism awareness and lack of diagnostic expertise among health professionals in this field (Brogan, 2000; 2001).

Contrary to expectations, satisfaction was not related to any of the variables associated with the age of the child at various stages in the process of diagnosis, or to either of the periods of delay (between first suspicions and likely diagnosis, and between likely and final diagnosis). Ninety percent of the parents reported that they had had suspicions that something was wrong with their child prior to the diagnosis; the average length of time between those first suspicions and the final diagnosis was approximately 3 years, ranging from no delay at all to 12.7 years. It is possible that some parents may have been relieved in the end to have their suspicions finally confirmed, an interpretation consistent with the finding that parents who felt that their first suspicions had been accepted by professionals were more satisfied with the disclosure. Parents may be more able to withstand the lengthy process of assessment if they feel that their opinions, observations and fears are taken seriously by the professionals, and if they feel that their knowledge and
understanding of the child is respected. One other finding is worthy of note: parents of children who were not in an educational placement were more satisfied than other parents, and their children were clearly younger. This result is unlikely to be related to the educational placement itself and was not found to be related to the age of the child, or the time since diagnosis.

A number of limitations to the study must be acknowledged. The first and second relate to the sample. The parental response rate was low, at 38 percent. It is possible, therefore, that the findings will not generalize to the target population. However, it should be noted that 45 percent of the children identified by the hospitals were represented in the sample. One of the factors affecting return rate was that both mothers and fathers of the same child were asked to return separate questionnaires about their experience of the disclosure; typically, studies of this sort rely mainly on maternal reports since the mother is usually the main caregiver (e.g. Howlin and Moore, 1997; Smith et al., 1994). Some of the fathers who were sent questionnaires may not have been present at the disclosure interview; 27 percent of participants (all mothers) indicated that they attended the disclosure interview on their own. In addition, it was not always possible to determine from hospital records whether or not the parents lived together, and some records were clearly out of date.

While socio-economic status was not related to satisfaction with disclosure, a skew towards over-representation of the higher socio-economic classes was observed in the sample and this may have influenced the results. Social class bias has been noted by many theorists in this field, including Kanner (1943; 1954), Eisenberg and Kanner (1956), and Schopler et al. (1979), and may be explained in terms of factors affecting referral and diagnosis (Wing, 1980).

In the multiple regression analysis of scores on the satisfaction index, a large proportion of the variance remained unexplained. This was not unexpected given that the index took account of the factors (such as professional manner) which were highly related to the single-item rating of satisfaction, but suggested that other factors may have been influential. Since Sloper and Turner (1993) found no significant relationships between satisfaction and factors reflecting parental individual differences (e.g. locus of control, neuroticism, social desirability, or ways of coping) it is reasonable to posit that the remaining variance could be accounted for by factors relating to the professionals and the hospitals involved in the process of assessment, diagnosis and disclosure.

In conclusion, the majority of parents expressed satisfaction with the disclosure of their child's disability by professionals. It is clear from the results of this and other studies that professionals can do much to influence parents' experience of disclosure; they can ensure that parents feel
supported, respected and informed, or, conversely, they can leave parents feeling confused, angry, distressed and humiliated. Professionals are moving towards better practice in disclosure; ideally disclosure of the diagnosis is the gateway to appropriate health, education and social provision and the aim is to ensure that the child and the family access the services that they need as quickly and as smoothly as possible. Although in this study delays in the diagnostic process were not significantly related to satisfaction, lengthy delays often mean that children and their families do not get the support they require during this difficult period. Continuing emphasis must be placed on ensuring that children with autistic spectrum disorders are identified and diagnosed as early as possible, and that disclosure practice continues to improve.

References


Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism

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ABSTRACT This study reports on psychosocial functioning in Swedish adults with Asperger syndrome (AS) or high-functioning autism (HFA). A systematically selected sample of patients and relatives was interviewed concerning their psychosocial situation. The majority was living independently. All persons but one were unemployed. None was married and none had children. Only a few had some kind of partner. Most persons needed a high level of public and/or private support. The overall adjustment was rated good in 12 percent, fair in 75 percent and poor in 12 percent. Adult persons with AS/HFA have extensive need for support from their families and/or society. This information is important in order to provide adequate interventions that are in accordance with the expressed needs of the individuals themselves.

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KEYWORDS Asperger syndrome; autism; long-term course; outcome

Introduction

The recognition of adults with Asperger syndrome (AS) or high-functioning autism (HFA) in Sweden has increased considerably in recent years. Before 1980, very few people, either children or adults, were given these diagnoses. Although Asperger described the condition in 1944, interest in his writings had to await ‘rediscovery’ by Wing (1981) who coined the term ‘Asperger syndrome’. The term ‘high-functioning autism’ was first used by DeMyer et al. (1981), but has not yet achieved unanimous definition.

A number of follow-up studies of children with autism have been
published during recent years, but few studies have specifically addressed the more able individuals with AS/HFA. In most studies available, it is not possible to distinguish clearly between individuals with high-functioning autism and those with Asperger syndrome. It is also not yet clear if AS or HFA represent distinct conditions (Gillberg, 1998; Howlin, 2000). This is mainly due to insufficient diagnostic information and because the diagnostic criteria for Asperger syndrome are frequently used inconsistently (Szatmari, 1998).

There is a number of studies regarding outcome in people with autism. Kanner (1971) reported about individuals he had first seen as children. In this sample of 96 individuals, 11 had jobs and seven had their own homes. The vast majority, however, was described as 'did not fare well in adulthood'. By contrast, in his first paper on autistic psychopathy Asperger (1944) suggested that the outcome in high-functioning autism was often 'remarkably good'. It is thus obvious that outcome in autistic conditions may vary considerably.

It has been pointed out (Nordin and Gillberg, 1998) that outcome studies should, at best, be prospective, longitudinal and population based. There are today few, if any, outcome studies that meet these requirements. A certain knowledge, however, does emerge from follow-up studies of clinical samples.

In general, studies on autism have shown a poor or very poor outcome in 60–75 percent of the cases followed up to early adulthood. A good outcome, defined as near-normal or normal social life and acceptable functioning in school or work, has been found only in 5–15 percent of cases (Nordin and Gillberg, 1998).

In a recent review (Howlin, 2000), the current knowledge concerning outcome in adult life for more able individuals with HFA or AS is presented. The conclusion of this review is that there are individuals with HFA/AS who do succeed well as adults, but such achievements rarely come easily. The six studies that are most closely examined (Goode et al., 1999; Howlin, 2000; Larsen and Mouridsen, 1997; Rumsey et al., 1985; Szatmari et al., 1989; Venter et al., 1992;) give extremely variable results concerning social functioning. The proportion with college or university education varies across studies from 7 to 50 percent; the proportion in work ranges from 5 to 44 percent; the proportion living independently from 16 to 50 percent; and rates of psychiatric disturbance from 9 to 89 percent. The majority of psychiatric diagnoses are depressive disorders, but some cases of schizophrenia were also found.

Howlin (2000) tries to compile an outcome rating across studies based on information on independent living, jobs, education etc. A good outcome is then found in 16 to 44 percent of the cases, a fair outcome in 10 to 56
percent and a poor or very poor outcome in 0 to 74 percent. It is obvious that the variation between studies is extremely large. Most studies show, however, a considerably better outcome in individuals with AS/HFA compared with autism in general.

It is not possible to draw any clear conclusions about the reasons for the large differences between studies, but differences in assessment measures and selection biases probably play a major role. However, differences in geographical areas and differences regarding interventions may also be part of the explanation.

From Scandinavia there is, to our knowledge, only one study concerning adults with AS/HFA (Larsen and Mouridsen, 1997). In this study, nine individuals with autism were compared with nine with Asperger syndrome. The average age was 36.5 and 29.1 years respectively. The composition of the studied sample was very unusual in several aspects. The majority of the cases had been admitted to psychiatric hospitals, many with ‘massive psychiatric illness’. The authors themselves also point out that the diagnostic differentiation between AS and autism may be unreliable.

The group with autism showed, as expected, a much poorer outcome than did the group with Asperger syndrome. In the AS group, five of the nine had their own homes and lived independently or with minimal help. Four were or had been married, with six children in total; one was living with a partner. Eight had attended school. Only one, however, had a regular job, six others were in some kind of sheltered job. Overall, seven of the nine individuals with AS were assessed as having a good or fair outcome and only two as having a poor outcome.

In summary, the current knowledge of psychosocial functioning of adult people with AS/HFA is insufficient and highly contingent on selection procedures.

The purpose of this study was to examine the psychosocial functioning of adult people with known diagnoses of AS/HFA in Örebro County, Sweden. We also wanted to describe their need for help of different kinds and how these needs were met from the family and/or from the public health sector.

**Participants**

The sample was recruited from Örebro County, which is located in central Sweden and has 274,000 inhabitants. An inventory was made from a scrutiny of the files at all clinics within psychiatry and habilitation in Örebro County in the year 1998. The health sector in Sweden is almost completely public, especially so in this area. The psychiatric health service comprises four clinics in the county.
The term 'habilitation' is used in Sweden for health services to certain groups of individuals with severe and long-standing disabilities. A special law (LSS) defines the groups that are entitled to the special services that are provided by habilitation. Individuals with autistic disorders are always entitled to habilitation. The term 'habilitation' refers to interventions made to develop functions that have never been present, which may be compared to the term 'rehabilitation' which aims at regaining functions that have been lost by disease, trauma etc. All four habilitation teams for adults in Örebro County participated in the study.

The inventory was made through a survey to all teams in psychiatry and habilitation. The inclusion criteria for selection were:

- over 18 years of age
- a DSM-IV diagnosis of autism with normal or above intelligence (IQ > 70) verified by WAIS (Wechsler Adult Intelligence Scale) or similar cognitive assessments; or a DSM-IV diagnosis of Asperger syndrome
- residency in Örebro County.

The diagnosis had to be confirmed by a psychiatrist as well as a psychologist, both trained in diagnostic procedures for autistic syndromes.

A total of 42 individuals with AS/HFA was found in this inventory, which yields a known prevalence of 0.19 cases per 1000 adults > 18 years of age.

Methods

The study was conducted in two phases. In the first phase, the professional responsible for each person with AS/HFA completed a questionnaire concerning the psychosocial functioning of the person. The questionnaire aimed at getting information about socio-demographic factors, psychosocial functioning, the use of health care and social support.

In the second phase, a subsample was selected for further interviewing. This subsample was chosen systematically to get a wide variation regarding important background factors. Thus, the subsample was chosen to include people of different ages, of both sexes, and with AS as well as HFA diagnosis. It was considered preferable to conduct a smaller number of in-depth interviews rather than a large number of short interviews.

The individuals in this subsample were then asked to participate in an interview. All people asked except one participated in the study. The sample therefore consisted of 16 individuals. The interview was in most cases carried out by home visits. The interviews were semi-structured using a modified form of the Camberwell Assessment of Needs (CAN-S) (Phelan et al., 1995). CAN-S is an assessment scale which is designed to describe
how the needs of a person with disability are satisfied. This scale was developed in the so-called PRiSM project (Psychiatric Research in Service Measurement) at the Maudsley Hospital in London. It is translated into many languages, including Swedish.

To further increase our knowledge about the individuals, a close relative or other significant person was interviewed with a similar schedule. Three individuals did not give approval for this, and in one case the parents were both dead. Altogether, we interviewed 12 people; 10 parents, one sister and one former partner.

All interviews were conducted by two of the authors (LE and BE), who have many years of experience working with children and adults with autistic disorders. One of the interviewers conducted the interview while the other took notes. The interviews most often lasted 1-2 hours each.

The level of support was assessed in respect of both public and private support. Since there are no standardized measures on the psychosocial outcome in autism, we used the following assessments scales.

Public support was graded:

- none = no public support
- low = advice and support from habilitation; regular home-help service
- moderate = continuous home support; sheltered job; job assistant; regular support from psychiatry and/ or habilitation
- high = supported living; group home or institution; daycentre; personal assistant.

Private support was graded:

- none = no contact with family
- low = normal or near normal contact with parents, siblings and other relatives; support and practical assistance from time to time
- moderate = regular practical assistance at home; daily contact by phone or physically; help with local authorities
- high = extensive help with social contacts and employment sites; total control of economic affairs; lives with relatives from time to time.

The overall social adjustment was assessed using the criteria suggested by Lotter (1978):

- good outcome = normal or near normal social life and satisfactory functioning at school or work
- fair outcome = some social and educational progress despite significant or even marked abnormalities in behaviour or interpersonal relationships
- poor outcome = severe handicap, no independent progress
- very poor outcome = unable to lead any kind of independent existence.
The two interviewers made the ratings independently. The agreement between the raters was above 90 percent. In cases of different ratings, all three authors reviewed the situation in order to reach a unanimous assessment.

Results

Demographics
In the whole sample, the sex distribution was 24 men (57 percent) and 18 women (43 percent). The ages ranged from 18 to 49 years with a mean age of 30.8 years (SD 8.0). Half of the sample was born in the 1970s. Thirty-two individuals had a diagnosis of Asperger syndrome (76 percent) and 10 a diagnosis of high-functioning autism (24 percent).

In the subsample that was studied more closely, the sex distribution was nine men (56 percent) and seven women (44 percent), thus closely resembling the whole sample. The age ranged from 23 to 46 years of age with a mean age of 31.4 years (SD 7.7). There were 10 individuals with Asperger syndrome (63 percent) and six individuals with high-functioning autism (37 percent).

The subsample was therefore representative concerning age and sex but the diagnostic proportions were somewhat skewed towards fewer cases with AS than in the larger sample.

In the subsample, eight were in their twenties, five in their thirties and three in their forties.

Diagnosis
The age at the time of diagnosis varied considerably. Only two individuals were diagnosed as children (0–12 years); four were diagnosed as adolescents (13–17 years), six in early adulthood (18–30 years) and four in middle adulthood (31–41 years). The HFA group were all diagnosed between 4 and 20 years of age (mean age 13.5 years) whereas the AS group were more spread over ages from 15 to 41 years of age (mean age 28 years).

Family
None of the 16 cases were married and none had children. Five had some form of relation with a partner and one cohabited from time to time. Four of these were women and two men.

Living
Nine of the individuals had their own homes, but in several of these cases with high levels of support, from the public sector and/or the family. Only one with minimal extra support.
| No. | Born year | Sex | Diagnosis | Year of diagnosis | Occupation          | Providing            | Marital status | Partner | Children | Residence | Public support | Private support | Outcome |
|-----|-----------|-----|-----------|------------------|---------------------|---------------------|-----------------|----------|----------|-----------|------------|----------------|----------------|---------|
| 1   | 1960      | F   | AS        | 1996             | Sheltered job       | Temp. dis. pension  | Not married     | Yes      | 0        | Apartment | High       | High           | Fair           | Fair    |
| 2   | 1974      | M   | AS        | 1994             | Daycentre           | Disability pension  | Not married     | Yes      | 0        | Group home | High       | Low            | Poor           | Poor    |
| 3   | 1966      | F   | AS        | 1995             | Daycentre           | Temp. dis. pension  | Not married     | No       | 0        | Apartment | High       | Moderate       | Fair           | Fair    |
| 4   | 1970      | M   | AS        | 1992             | None                | Disability pension  | Not married     | No       | 0        | Group home | High       | Moderate       | Fair           | Fair    |
| 5   | 1968      | M   | A         | 1975             | Sheltered job       | Salary subsidy      | Not married     | No       | 0        | Apartment | Moderate   | High           | Fair           | Fair    |
| 6   | 1952      | F   | AS        | 1993             | None                | Disability pension  | Not married     | Yes      | 0        | Group home | High       | None           | Fair           | Fair    |
| 7   | 1960      | M   | AS        | 1997             | None                | Temp. dis. pension  | Not married     | No       | 0        | Hospital  | High       | Moderate       | Fair           | Fair    |
| 8   | 1955      | M   | A         | ?                | Daycentre           | Disability pension  | Not married     | No       | 0        | Apartment | High       | None           | Fair           | Fair    |
| 9   | 1975      | M   | AS        | 1991             | None                | Social welfare      | Not married     | No       | 0        | Apartment | Low        | Moderate       | Fair           | Fair    |
| 10  | 1972      | F   | A         | 1987             | Daycentre           | Temp. dis. pension  | Not married     | Yes      | 0        | Group home | High       | Low            | Fair           | Fair    |
| 11  | 1975      | M   | AS        | 1990             | Studies             | Temp. dis. pension  | Not married     | Yes      | 0        | Parents   | Low        | High           | Good           | Good    |
| 12  | 1975      | F   | A         | 1990             | Sheltered job       | Disability pension  | Not married     | Yes      | 0        | Group home | High       | Low            | Fair           | Fair    |
| 13  | 1965      | M   | A         | 1985             | None                | Disability pension  | Not married     | No       | 0        | Apartment | High       | Low            | Poor           | Poor    |
| 14  | 1970      | F   | A         | 1974             | Daycentre           | Temp. dis. pension  | Not married     | No       | 0        | Apartment | High       | Moderate       | Fair           | Fair    |
| 15  | 1957      | M   | AS        | 1996             | Regular job         | Salary              | Not married     | No       | 0        | Apartment | High       | Low            | Good           | Good    |
| 16  | 1972      | F   | AS        | 1997             | None                | Temp. dis. pension  | Not married     | No       | 0        | Apartment | Low        | Moderate       | Fair           | Fair    |

Temp. dis. pension = temporary disability pension.
Work
In this group, only one had a regular paid job as an inspector in a factory. Three had sheltered employment, one was employed by a relative, one had state-provided employment and one worked although he had a pension. Five were enrolled in a day centre where other people with disabilities, such as severe learning disability, also took part. Six did not have an occupation at all. One studied at a residential college for adult education.

Only the man with a regular job had a normal salary for his living. One person had a salary subsidy through his sheltered job, which he himself regarded as a salary. Thirteen had pensions from the state, seven with a temporary disability pension and six with a definitive disability pension. One person did not have a salary or a pension, but had to rely on social assistance for his living.

Support
The amount of support given to these people was assessed, in respect of both public and private support. Public support means interventions of various kinds for day-to-day needs from the municipality and/or from the health sector (psychiatry and/or habilitation). Private support means assistance from relatives and friends.

As can be seen in Table 1, four individuals lived with low public support and one with moderate public support, and 11 needed high support levels from the public sphere.

Concerning support from the family and friends, two had no contact at all, five a low level of private support, six a moderate private support level and three a high private support level.

Overall social adjustment
The overall social adjustment, according to the scale of Lotter, was rated good in only two cases (12 percent), fair in 12 (75 percent) and poor in two (12 percent). No individual was characterized as having a very poor outcome.

Discussion
This study describes psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. A comparison between our results and the previous studies reviewed by Howlin (2000) yields certain differences. We found fewer cases with an overall good outcome than in other studies, but we also found fewer cases with a poor outcome and no cases of very poor outcome. The majority was considered as having a fair psychosocial outcome.
ENGSTRÖM ET AL.: PSYCHOSOCIAL FUNCTIONING IN ADULTS

It is, however, difficult to compare the results across studies owing to known or unknown differences in the sampling of the cases. As far as we understand it, all other studies in this area are follow-up studies of clinical samples. Our study is based on cases that were found through an inventory made to all health facilities that regularly work with people with autistic disorders. Owing to the LSS legislation described earlier, it is highly unlikely that the inventory missed people known to have Asperger syndrome or high-functioning autism. The close similarity between our subsample and the whole sample in the inventory makes it probable that the subsample reflects cases of AS/HFA that are known in the health sector. The study is not, however, population-based, which certainly makes it difficult to generalize the results to the whole AS/HFA population in society.

The geographical distribution of cases in the county was quite uneven. Our interpretation of this finding is that the awareness of these diagnoses in adults is highly contingent on certain key persons, primarily psychiatrists or psychologists who are interested in this area. To be adequately diagnosed, one has to be lucky to come across a professional with such an interest.

Our sample had a high proportion of females, which is in accordance with the Danish study (Larsen and Mouridsen, 1997) but contrary to most other studies. In reviews of population studies of autism (Gillberg, 1995; Wing, 1993) the male:female ratio is believed to be closer to 2–3:1 rather than the often-quoted 4–5:1. Clinical studies of AS (Gillberg, 1989; Wing, 1981), have suggested a male:female ratio of 10–15:1, but a population study (Ehlers and Gillberg, 1993) suggests that it may be about 4:1 instead. The male:female ratio in this study was 4:3, which is even lower than in previous studies, but resembles the population data more than the clinical data. It is possible that the earlier knowledge of autistic disorders was based primarily on men and that the diagnostic threshold has therefore been lower for men with symptoms of this kind. The current knowledge of women with autistic syndromes is, however, rapidly increasing, which will probably lead to changes in the previously stated gender ratios.

The psychosocial functioning in our sample was better in some respects compared with other studies, but much worse in other aspects. In our sample, the majority had an independent living, which is in accordance with the Danish findings (Larsen and Mouridsen, 1997), but in contrast to the UK (Goode et al., 1999, Mawhood et al., 2000) and North American (Szatmari et al., 1989; Venter et al., 1992) findings. We do not view this parameter as a valid index on psychosocial functioning as such. There are reasons to believe rather that the differences found across different studies reflect various public strategies of handling living conditions for disabled people. In Scandinavia, there has been in recent decades a clear tendency...
towards promoting independent living for disabled people. There is certainly a need for scientific studies on the impact that support for independent living has on the quality of life in these people.

Quite a few in our group lived in group homes, most often consisting of four to six people who either share an apartment or have separate apartments in the same building. These group homes are staffed by the municipality during the daytime but are most often without staff during the night.

All people studied were unmarried. Five of them stated that they had a relationship with a partner, but four of these had very special arrangements for this contact. This leads to questions about whether these relationships are possible only on the condition that the partners do not cohabit. This means that they do not need to share all the common daily trivial details that often become problems for people with autism. This hypothesis should be investigated further.

Four of the six with partner relations were women. According to our clinical experience, women with AS often show a higher ability to enter into reciprocal interaction with others, even though this may be contingent on special prerequisites of different kinds.

Only one person in our sample had a regular job, and even this person had special circumstances concerning his employment, with a very understanding boss and a ‘supervisor’ who had very close contact with him to make things work out well. When comparing the previous studies, there are also large variations regarding employment. In the Scandinavian and British studies, the employment rate is very low, whereas in the North American studies, half of the cases are in a paid job. Considering the fact that the psychiatric morbidity was also much higher in the American studies, it seems that employment is a variable that probably depends more on social, political and commercial factors than on the disability itself. We believe that many more individuals with autistic spectrum disorders could have a paid job or a sheltered job if knowledge of these disabilities had been more widespread and if more creative solutions in finding ‘tailor-made’ employment were at hand.

The need for support is striking and prominent in most, if not all, individuals. One must remember, however, that our sample is collected through psychiatry and habilitation where people seek help. It is therefore self-evident that all our cases are in great need of support. In some cases, we found widespread needs in almost all practical and emotional aspects of life. In other cases, we found more specific needs, often of a very special nature, related to problems connected with AS/HFA. In these cases, the volume of needs may not be particularly large but they are nonetheless of utmost importance for the well-being of the individual. It is therefore very
important that professionals who work with people with AS/HFA are informed thoroughly about the general problems connected with the disability, but it is also extremely important to assess the specific individual needs of each person.

The families, most often the parents, regularly give much more support to their children than is usual at their age. The boundary between normal contact between parents and children and interference in the children's lives may often be narrow. We found that parents generally consider their sons or daughters to be in greater need of help than the children themselves. This discrepancy can also be found in many families without disabilities, but it is our impression that this finding is much more common and of greater severity in this group of people. What this means with relation to their quality of life has yet to be studied.

We found a relation between different sources of help. If public support is not available or adequate, the family often has to compensate for this shortage by providing much more help themselves. We found a clear need for closer cooperation between the relatives and the public sector to determine what needs there are to be met and who is best suited to offer the necessary help. In doing so, it is of utmost importance that the individuals with autism themselves are actively participating.

In summary, adult people with Asperger syndrome or high-functioning autism often have extensive need for help from their families and/or society. Very few are living in 'normal' psychosocial conditions. They most often live alone, seldom have partner relations and are often without employment of any kind.

We find this information of importance in trying further to develop adequate interventions that are in accordance with the individuals themselves. The relation between basic psychosocial conditions and the perceived quality of life has to be studied further.

References


Ability profiles in children with autism

Influence of age and IQ

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ABSTRACT To understand the effect of IQ and age on ability in children with autism, psychological data were analyzed for 164 3- to 15-year-olds with autism (IQs 14–143). As age increased, so did IQ, which probably reflects both an actual increase in IQ over time and the likelihood that brighter children are diagnosed later. Early in life, 67 percent had normal motor and delayed speech milestones. Verbal IQ continued to lag behind non-verbal IQ during the preschool years. By school age, the gap between verbal and non-verbal IQs had closed. Visual reasoning exceeded graphomotor scores for all children, and surpassed IQ for most. Graphomotor scores were significantly below IQ for both high-IQ groups. For school-age children with low IQs, math, spelling, and writing scores were consistent with IQ and reading was above IQ. School-age children with high IQs had average reading, math, and spelling scores and a weakness in writing.

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Previous research suggests that IQ may not be stable for children with autism. In an earlier study by the authors (Mayes and Calhoun, 1999), 33 percent of young children with autism who had serial IQ testing at least 1 year apart experienced a significant increase in IQ (≥15 points) over time. A longitudinal study by Freeman et al. (1985a) showed a gradual increase in verbal and non-verbal (or performance) IQs from age 4 to 7 for children with autism who had verbal and non-verbal IQs above 70. The mean verbal IQ increased from 82 to 96 and non-verbal IQ from 94 to 109. In contrast, IQ was stable for children in the low-IQ group. In another longitudinal study assessing only non-verbal IQ, Lord and Schopler (1989) reported a slight increase in non-verbal or performance IQ for young children from a mean of 57 at age 3 to 64 at follow-up at age 7. However, non-verbal IQ
was stable for older children (i.e. mean 58 at age 6, and 58 when re-evaluated at age 11). Significant IQ increases are also reported for young children with autism who receive intensive early intervention (Birnbrauer and Leach, 1993; Harris et al., 1991; Lovaas, 1987; McEachin et al., 1993; Ozonoff and Cathcart, 1998; Sheinkopf and Siegel, 1998; Smith et al., 2000).

Early studies using the WISC–R suggest that performance or non-verbal IQ is higher than verbal IQ in children with autism (Allen et al., 1991; Freeman et al., 1985b). However, an inclusion criterion in these two studies was a performance IQ of 70 or higher, without placing a similar constraint on verbal IQ. This created skewed samples with high performance and low verbal IQs. When the criterion for inclusion is based on full-scale IQ or when the same cutpoint is applied to verbal and performance IQs, findings are inconsistent. In a sample of children with a WISC–R full-scale IQ above 70, Asarnow et al. (1987) reported significantly higher performance than verbal IQs. In contrast, Ehlers et al. (1997) found a non-significant difference between WISC–R performance and verbal IQs in children with autism whose full-scale, verbal, or performance IQs were above 70. Both of these studies were of high-functioning children with autism. According to Szatmari et al. (1990), performance IQ exceeds verbal IQ in low-functioning children with autism, but not necessarily in high-functioning children. In a study of children with autism whose full-scale IQ was 80 or above, children were divided into two groups: those with and without an early history of speech delay (Mayes and Calhoun, 2001). By the time of evaluation for the study (mean age 6 years), children who had delayed speech milestones earned a mean verbal IQ in the average range, which was not significantly different from that earned by children without a speech delay. Therefore, early verbal IQ may be low relative to later verbal IQ in children with high-functioning autism.

Many authors note that children with autism have strong visual perceptual skills (Allen et al., 1991; Freeman et al., 1985b; Rumsey, 1992; Rumsey and Hamburger, 1990; Yirmiya and Sigman, 1991) and that high-functioning individuals with autism or Asperger's disorder have a weakness in motor coordination (Ghaziuddin et al., 1992; Gillberg and Ehlers, 1998; Rumsey, 1992; Szatmari et al., 1990; Volkmar and Klin, 1998; Wing, 1991). Previous studies of academic achievement in individuals with autism combined test scores for children and adults, without reporting analyses separately for the two age groups (Minshew et al., 1992; 1994; Szatmari et al., 1990). These studies involved individuals with relatively high IQs (mean 82–96) and showed low-average to average mean academic achievement test scores in reading, math, and spelling. Written expression has not been assessed in published studies.
In summary, prior research suggests that age and IQ may affect the stability of test scores over time and the pattern of abilities in children with autism. The purpose of our study is to identify and understand differences in ability test scores as a function of age and IQ and to generate implications for educational programming and intervention. In order to accomplish this, we used a sample that spanned a broad IQ range (14 to 143) and age range (3 to 15 years), unlike previous studies. The breadth of abilities assessed was also greater than in prior research and included motor and speech milestones; verbal, non-verbal, and full-scale IQs; visual reasoning; graphomotor skills; and academic achievement in reading, math, spelling, and written expression.

Method

Sample
The sample comprised 164 children with autism, 3 to 15 years of age (mean 5.9). Seventy-eight percent of the children were male, and 93 percent were white. Full-scale IQs ranged from 14 to 143, with a mean of 75.

Diagnosis
All children were evaluated in our child diagnostic clinic at a university-affiliated department of psychiatry and underwent an extensive psychological evaluation by a licensed doctoral level psychologist. Diagnoses were based on (1) questionnaires and behavior rating scales completed by the child's parents and teacher, (2) clinical observations of the child, (3) parent interview regarding the child's social, emotional, and behavioral functioning, autistic symptoms, and developmental history, and (4) review of prior evaluations and early intervention and school records. To insure diagnostic accuracy in our sample, a board-certified child psychiatrist independently reviewed all of the information in each child's chart and confirmed the diagnosis of autism based on DSM-IV criteria.

Ability instruments
Data for the study were collected by a licensed psychologist during the course of each child's diagnostic evaluation. At the time of the evaluation, parents completed a questionnaire which asked for age at onset of developmental milestones (including walking independently, speaking first words, and talking in two-word phrases). Three different intelligence tests were administered by the licensed psychologist to cover the mental age range of the children in our study. For children functioning at the 0 to 2 year level, the Bayley Mental Scale (I or II) was given \( n = 48 \). The Bayley version administered was the current version in use at the time the child was evaluated. The
Stanford–Binet Intelligence Scale–IV was used for children functioning at 2 to 5 years (n = 53), and the Wechsler Intelligence Scale for Children–III was given to children functioning at 6 years or above (n = 63). If the WISC–III was attempted but the child did not earn enough passes for basal levels on the verbal and non-verbal subtests, the Stanford–Binet–IV was substituted. If a child could not earn a basal level on the Stanford–Binet–IV verbal and non-verbal subtests, the Bayley was given. Verbal and non-verbal IQs for the WISC–III were based on the verbal and performance subscales. Stanford–Binet–IV verbal and non-verbal IQs were Sattler’s ‘verbal comprehension’ and ‘non-verbal reasoning/visualization’ factor scores (1988, p.260). For the Bayley, test scores were prorated for the verbal and non-verbal items separately to obtain verbal and non-verbal IQs. For example, if a child passed all of the Bayley language items through number 40, one-half from 41 through 50, and none beyond 50, the child’s prorated verbal raw score would be 45. Ratio IQs were calculated for the Bayley because scores in the manual do not extend below 50. The number of children at each age and IQ level who were administered each test are reported in Table 1.

Almost all of the children who were administered the Stanford–Binet–IV and WISC–III were given the Developmental Test of Visual-Motor Integration (VMI: Beery, 1997) to assess graphomotor skills (n = 99). The VMI requires children to copy geometric forms with a pencil. Most of the children were also tested on the Leiter International Performance Scale (Arthur, 1950) or the Test of Nonverbal Intelligence (TONI: Brown et al., 1997) in order to obtain a motor-free and language-free estimate of visual reasoning separate from the visual-motor and visual-verbal tasks on the Stanford–Binet–IV and WISC–III (which all involve fine motor or language components). On the TONI, the child selects pictures to complete visual patterns. On the Leiter, the child matches pictures on the basis of appearance (e.g. color and shape) and concepts (e.g. a pear with an apple and a

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<td>11</td>
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The TONI was administered to children who performed at or above the 6 year level (n = 44). Children below this level were given the Leiter (n = 21). Scores on the Leiter and TONI were collapsed to obtain a single visual reasoning score because there was a non-significant difference in scores between the two tests for children who were administered both the Leiter and the TONI (t = 0.4, p = 0.72). Academic achievement in reading (n = 97), math (n = 93), and spelling (n = 94) was assessed using the WIAT (for children tested on the WISC–III) and the Woodcock–Johnson Tests of Achievement–Revised (for children given the Stanford–Binet–IV). Children 8 years and older who were given the WIAT were also administered the WIAT written expression subtest, which measures compositional writing skills and cannot be administered to children under age 8 (n = 30).

Data analyses
Pearson correlation coefficients were calculated to assess the degree of linear relationship between IQ and ability test scores and age. Independent t-tests were used to determine the significance of differences in test scores between preschool (< 6 years) and school-age (≥ 6 years) children. Children with low (< 80) versus high (≥ 80) IQs were also compared. An IQ cutpoint of 80 was chosen because this is the cutpoint used in the WISC–III manual for differentiating between children with normal and those with below normal intelligence (Wechsler, 1991). To determine the degree of difference between ability test scores, dependent t-tests were calculated. Two-tailed tests and a significance level of 0.05 were used throughout the study.

In order to investigate the relationship between early developmental milestones and later IQ, children were categorized according to the presence or absence of delayed motor and speech milestones. A motor delay was defined as a delay of 25 percent or more compared to the norm for walking independently (i.e. walking at or after 16 months of age). A speech delay was defined as a delay of 25 percent or more (i.e. speaking first words at or after 16 months or talking in two-word phrases at or after 27 months) or a language regression (i.e. loss of speech between 1 and 2 years of age).

Results

Milestones and later IQ
The majority of children with both low (< 80) and high (≥ 80) IQs had a history of normal motor and delayed speech milestones (Table 2). Almost all (94 percent) of children with normal motor and speech milestones later
scored in the high-IQ group (Table 3). Interestingly, 71 percent of the children who had a speech delay with normal motor milestones also later scored in the high-IQ group.

## IQ and age

In the total sample, there was a significant positive relationship between age and full-scale IQ ($r = 0.33$, $p < 0.0001$). Mean IQ increased from 53 for children 3 years of age to 91 for children age 8 and older. Both verbal and non-verbal IQs increased significantly with age in the low-IQ group, but only verbal IQ increased significantly with age in the high-IQ group (Table 4).

## Non-verbal/verbal IQ discrepancy

As shown in Table 5, mean non-verbal and verbal IQs for the total group increased with the age of the children and stabilized by age 8. Because verbal IQ increased more than did non-verbal IQ, the non-verbal/verbal IQ discrepancy score decreased with age in the total group ($r = -0.44$, $p < 0.0001$), until age 7, when mean verbal IQ was actually somewhat higher than non-verbal IQ. The decreasing non-verbal/verbal discrepancy with increasing age was found for both the low-IQ group ($r = -0.35$, $p = 0.001$) and the high-IQ group ($r = -0.46$, $p < 0.0001$). However, the gap between

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**Table 2**  Percentage of children with autism in each IQ$^a$ group and corresponding history of early milestones

<table>
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<tr>
<th>Milestones</th>
<th>IQ &lt; 80</th>
<th>IQ ≥ 80</th>
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<tbody>
<tr>
<td>Motor normal, speech delay</td>
<td>65%</td>
<td>67%</td>
</tr>
<tr>
<td>Motor and speech delay</td>
<td>32%</td>
<td>11%</td>
</tr>
<tr>
<td>Motor and speech normal</td>
<td>3%</td>
<td>20%</td>
</tr>
<tr>
<td>Motor delay, speech normal</td>
<td>0%</td>
<td>3%</td>
</tr>
</tbody>
</table>

$^a$ Stanford–Binet–IV or WISC–III IQ.

**Table 3**  Percentage of children with autism in each milestones group who later earned normal or higher IQ$^a$

<table>
<thead>
<tr>
<th>Early milestones</th>
<th>Later IQ ≥ 80</th>
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</thead>
<tbody>
<tr>
<td>Motor and speech normal</td>
<td>94%</td>
</tr>
<tr>
<td>Motor normal, speech delay</td>
<td>71%</td>
</tr>
<tr>
<td>Motor delay (with or without speech delay)</td>
<td>50%</td>
</tr>
<tr>
<td>Motor and speech delay</td>
<td>44%</td>
</tr>
</tbody>
</table>

$^a$ Stanford–Binet–IV or WISC–III IQ.
non-verbal and verbal IQs closed at an earlier age (6 to 7 years) for children with high (versus low) IQs. For children in the low-IQ group, the non-verbal/verbal IQ discrepancy was maintained during the preschool years and did not begin decreasing until after age 5. The gap closed between ages 9 and 10, and by age 10, mean verbal IQ was higher than non-verbal IQ.

Visual and graphomotor skills

Visual reasoning ability (as measured by the TONI or Leiter) and graphomotor skills (VMI score) significantly decreased with age for children with high IQs ($r = -0.44$ and $-0.40$, $p < 0.01$). However, these scores did not change significantly with age in children with low IQs ($r = -0.01$ and $-0.18$, $p \geq 0.36$) (Table 6).
Ability profiles

Mean ability test standard scores for preschool and school-age children in the low- and high-IQ groups are shown in Figures 1 and 2. Thirteen significant differences were found between ability areas (Table 7). Additional data regarding individual variability in test scores and correlations with IQ are presented in Tables 8 and 9.

Discussion

The purpose of our study was to understand the effect of age and IQ on ability profiles in children with autism and the implications for developmental expectations and educational programming. These goals were accomplished by analyzing developmental milestones and ability test scores in a large sample (N = 164) of children with autism who spanned broad age (3–15 years) and IQ (14–143) ranges. Because no standardized ability test scores were available for children below age 3, parent report of age at acquisition of developmental milestones (walking, speaking single words,}

| Table 6 | Visual reasoning and graphomotor mean standard scores by age and IQ in children with autism |
|------------------|------------------|------------------|------------------|------------------|
|                  | IQ < 80          | IQ ≥ 80          |                  |                  |
|                  | < 6 years | ≥ 6 years | t    | p    | < 6 years | ≥ 6 years | t    | p    |
| Visual reasoning | 89       | 81       | 0.9  | 0.37 | 122      | 104      | 4.3  | < 0.001 |
| Graphomotor      | 71       | 73       | 0.4  | 0.73 | 93       | 86       | 2.5  | 0.02  |

| Table 7 | Significant differences between ability test scores in children with autism |
|------------------|------------------|------------------|------------------|------------------|
| Significant difference* | Preschool | School age | Preschool | School age |
|                  | IQ < 80 | IQ ≥ 80 | IQ < 80 | IQ ≥ 80 |
| Non-verbal IQ > verbal IQ | * | * | * | * |
| Visual reasoning > full-scale IQ | * | * | * | * |
| Visual reasoning > graphomotor | * | * | * | * |
| Full-scale IQ > graphomotor | * | * | * | * |
| Full-scale IQ > written expression | N/A | N/A | * | * |
| Reading > full-scale IQ | N/A | * | * | * |

* p < 0.05.
Note: all other ability test comparisons were non-significant.
and talking in phrases) was used to estimate early verbal and motor ability. These results must be interpreted with caution, given the potential unreliability of parent report. Parents in our study reported that the majority of
### Table 8  Individual variability in intelligence and ability test standard scores (N = 164)

<table>
<thead>
<tr>
<th></th>
<th>Preschool</th>
<th></th>
<th>School age</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>IQ &lt; 80</td>
<td>IQ ≥ 80</td>
<td>IQ &lt; 80</td>
<td>IQ ≥ 80</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Range</td>
<td>Mean (SD)</td>
<td>Range</td>
</tr>
<tr>
<td>Full-scale IQ</td>
<td>47 (17)</td>
<td>14–79</td>
<td>100 (13)</td>
<td>80–127</td>
</tr>
<tr>
<td>Verbal IQ</td>
<td>40 (18)</td>
<td>12–78</td>
<td>93 (13)</td>
<td>58–117</td>
</tr>
<tr>
<td>Non-verbal IQ</td>
<td>55 (22)</td>
<td>13–112</td>
<td>104 (15)</td>
<td>78–137</td>
</tr>
<tr>
<td>Visual reasoning</td>
<td>89 (18)</td>
<td>56–109</td>
<td>122 (16)</td>
<td>100–147</td>
</tr>
<tr>
<td>Graphomotor</td>
<td>71 (8)</td>
<td>63–84</td>
<td>93 (14)</td>
<td>61–125</td>
</tr>
<tr>
<td>Reading</td>
<td>N/A</td>
<td>N/A</td>
<td>107 (21)</td>
<td>74–150</td>
</tr>
<tr>
<td>Math</td>
<td>N/A</td>
<td>N/A</td>
<td>98 (14)</td>
<td>63–122</td>
</tr>
<tr>
<td>Spelling</td>
<td>N/A</td>
<td>N/A</td>
<td>92 (18)</td>
<td>56–123</td>
</tr>
<tr>
<td>Written expression</td>
<td>N/A</td>
<td>N/A</td>
<td>73 (9)</td>
<td>61–84</td>
</tr>
</tbody>
</table>
children with autism (66 percent) had normal motor and delayed speech milestones. This suggests that, as a group, language skills are impaired relative to motor ability early in life. However, this discrepancy does not persist over time. During the preschool years, standardized test scores showed that non-verbal IQ was still significantly higher than verbal IQ for children with both low (< 80) and high (≥ 80) IQs. However, by school age (6 years), the discrepancy between non-verbal and verbal IQ in both groups was non-significant. Therefore, early speech delay is not necessarily predictive of later verbal ability in children with autism.

Results of our study show a significant and positive relationship between increasing IQ and increasing age until age 8, when verbal and non-verbal IQs for the total group stabilized. The apparent increase in IQ during the preschool years is not likely attributable to intervention effects, because most children in the study were newly diagnosed with autism and had not yet received treatment. It could be argued that the apparent IQ increase is an artifact of using three different tests or that IQ is constant, but the three tests measure different aspects of intelligence. This is not a likely explanation, because research indicates that the Stanford–Binet–IV typically yields higher IQs than the WISC–III (Lukens and Hurrell, 1996; Prewett and Matavich, 1994), which is the opposite of our study findings. However, no studies have been conducted comparing Stanford–Binet–IV and WISC–III IQs in children with autism.

Because our study is cross-sectional and not longitudinal, the extent to which IQ scores for individual children actually increased with time is not known. One possible factor contributing to the increase in IQ with age is that brighter children with autism are likely to be identified later than lower-functioning children with autism (Gillberg et al., 1996). Therefore, children diagnosed at an older age tend to have higher IQs than those diagnosed at a

<table>
<thead>
<tr>
<th>Table 9</th>
<th>Correlations between ability test standard scores and full-scale IQ</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Preschool</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual reasoning</td>
<td>0.49</td>
</tr>
<tr>
<td>Graphomotor</td>
<td>0.65</td>
</tr>
<tr>
<td>Reading</td>
<td>N/A</td>
</tr>
<tr>
<td>Math</td>
<td>N/A</td>
</tr>
<tr>
<td>Spelling</td>
<td>N/A</td>
</tr>
<tr>
<td>Written expression</td>
<td>N/A</td>
</tr>
</tbody>
</table>
younger age. However, it is unlikely that this is the sole explanation for our findings, because longitudinal studies have also reported some increase in IQ with age during the preschool years (Freeman et al., 1985a; Lord and Schopler, 1989; Mayes and Calhoun, 1999). It has been noted that some children with autism make remarkable developmental progress during early childhood (Baird et al., in press; Mayes and Calhoun, 1999). Longitudinal research is needed to determine if the IQ increases reported for groups of children with autism reflect the significant gains of a few children or a trend for the majority to improve in IQ during the preschool years.

Ability profiles in children with autism may also be affected by age and IQ. Because verbal IQ increased more than non-verbal IQ during the preschool years, the discrepancy between non-verbal and verbal IQ decreased with age until reaching a point when verbal IQ was actually slightly higher than non-verbal IQ. For children in the high-IQ group, the non-verbal/ verbal IQ discrepancy decreased steadily during the preschool years, with the gap closing between ages 6 and 7. In the low-IQ group, a non-verbal/ verbal IQ discrepancy of approximately 15 points was maintained from ages 3 to 5, after which the discrepancy scores decreased until the non-verbal/ verbal gap closed between ages 9 and 10. Therefore, the change in the non-verbal/ verbal IQ discrepancy is related to both age and IQ. In both IQ groups, the discrepancy decreases with age, but this decrease begins at an earlier age in children with high (vs. low) IQs. These findings suggest that the intervention needs of young children with autism may differ from those of older children. During the preschool and early school-age years, emphasis should be placed on remediating the verbal weakness while teaching to the non-verbal strength. This approach would no longer apply after the gap between non-verbal and verbal abilities closes.

Our study also analyzed visual reasoning (i.e. scores on the TONI and Leiter) and graphomotor scores on the VMI. Visual reasoning test scores significantly exceeded graphomotor scores in all four of the IQ/age groups, and visual reasoning was superior to overall IQ in all groups except school-age children with high IQs. For preschool and school-age children in the high-IQ groups, IQ was significantly higher than graphomotor test scores. These findings are consistent with the reports of others that children with autism have a visual perceptual strength (Allen et al., 1991; Freeman et al., 1985b; Rumsey, 1992; Rumsey and Hamburger, 1990; Yirmiya and Sigman, 1991) and that high-functioning children with autism have a coordination weakness (Ghaziuddin et al., 1992; Gillberg and Ehlers, 1998; Rumsey, 1992; Szatmari et al., 1990; Volkmar and Klin, 1998; Wing, 1991). Academically, school-age children in the low-IQ group performed at or above expectancy based on IQ. Math, spelling, and written expression scores were not significantly different than IQ, and reading scores significantly
exceeded IQ. This is consistent with previous reports of hyperlexia in some children with autism (Mayes and Calhoun, 1999; Rumsey, 1992) and with the reported strength in rote memory for children with autism (Allen et al., 1991; Rumsey, 1992; Rumsey and Hamburger, 1990; Yirmiya and Sigman, 1991). For both of the high-IQ groups, mean IQ, reading, math, and spelling scores were in the average range. For school-age children with high IQs, though, written expression was significantly lower than IQ. The significant discrepancy between IQ and written expression is consistent with that reported for other neurobiological disorders, such as attention deficit hyperactivity disorder (Mayes et al., 2000).

Overall, these findings have implications for educational intervention. In all four groups, visual reasoning significantly exceeded graphomotor skills. Therefore, to maximize learning in school, educational programming for children with autism should focus on teaching to the students’ visual strength while bypassing and compensating for the writing weakness. This is especially important for school-age children with autism and normal intelligence whose written expression scores are significantly below IQ. The most obvious way to capitalize on the visual strength while circumventing the writing weakness is to teach keyboarding and word processing skills and allow the child to use a computer for written assignments. Previous studies demonstrate that children with writing disabilities benefit from the use of word processors (Glazer and Curry, 1988; Griffey, 1986; Keefe and Candler, 1989; Kerchner and Kistinger, 1984; MacArthur, 1996; 2000; McNaughton et al., 1997). Other accommodations shown to be beneficial include oral or dictated performance (Glazer and Curry, 1988; Lane and Lewandowski, 1994; MacArthur and Graham, 1987) and production prompts and additional time for written assignments (Graham, 1990). Another adaptation is to reduce the amount of written work by modifying tests and assignments (e.g. giving multiple choice, true–false, and fill-in-the-blank questions and not open-ended essay questions) and by providing class notes, outlines, and study guides so that the child does not need to rely solely on his or her own note taking.

In summary, the stability of verbal and non-verbal IQs and the ability profiles in children with autism are influenced by age and level of intelligence. These conclusions, though, are based on cross-sectional group data, and there is much individual variation. What is true for groups of children with autism is not necessarily true for individual children. However, awareness of these group findings should alert professionals to possible age- and IQ-related differences in children with autism, which then have implications regarding developmental and educational expectations and intervention.
References


The Parent Interview for Autism–Clinical Version (PIA–CV)

A measure of behavioral change for young children with autism

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ABSTRACT The Parent Interview for Autism–Clinical Version (PIA–CV) was developed to measure autism symptom severity across a wide range of behavioral domains. Two studies were conducted to examine the psychometric properties of the PIA–CV for a sample of children under 3 years old. Results of study 1 revealed adequate internal consistency for nine of the 11 PIA–CV dimensions, as well as significant group differences on social-communication domains between 2-year-old children with autism and a developmentally matched sample. Study 2 examined the association between changes in PIA–CV scores and changes in autism symptomatology from age 2 to age 4. Results revealed that changes on PIA–CV dimensions assessing social and communication skills were associated with clinically significant behavioral and diagnostic improvements. These findings support the utility of the PIA–CV for obtaining ecologically valid information from parents and for measuring behavioral change in young children with autism.

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Within the past several years has come increased recognition that children with autism can make substantial gains from participating in early intervention programs. Research conducted by a variety of investigators has
revealed significant improvements in cognitive and behavioral functioning for young children with autism who receive specialized intervention services (Harris et al., 1991; Lovaas, 1987; Rogers and Lewis, 1989; Strain et al., 1985). The success of these programs in facilitating substantial gains at young ages has generated increased interest in understanding the developmental features and natural history of autism in young children.

Until recently, there has been a relative paucity of information about behavioral characteristics of autism in children under age 3. The field of developmental psychopathology has been instrumental in calling attention to the developmental changes in symptom expression that occur in most childhood disorders (Garber, 1984; Lewis and Miller, 1990). Like other disorders, the behavioral manifestations of autism do not remain static throughout the life span. Differences in symptomatology occur as a function of age and development (Segel et al., 1990). For example, deficits in simple motor imitation and joint attention eye contact may be most apparent in young children (Mundy et al., 1994; Stone et al., 1997a), whereas stereotyped behaviors and a need for sameness may not emerge until later in development (Cox et al., 1999; Dahlgren and Gillberg, 1989; Lord, 1995; Stone et al., 1999).

Despite continued refinements in standard diagnostic criteria provided in the various updates of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association (APA), 1987; 1994; 2000), the diagnostic algorithm for autism provided in DSM-IV-TR (2000) makes no accommodations for variations in age or level of developmental functioning. Some of the DSM-IV-TR criteria for autism are not applicable to young children. For example, stereotyped language is often not present in very young children with autism, owing to the high prevalence of early language delays (Stone et al., 1994; 1999). Nevertheless, the same diagnostic algorithm is used for all individuals, regardless of age or developmental level. A significant contribution to the field was the development of the Autism Diagnostic Interview–Revised (Lord et al., 1994) and the Autism Diagnostic Observation Schedule–Generic (Lord et al., 2000), which serve to operationalize the DSM-IV-TR criteria in a manner that is sensitive to behavioral differences that may occur as a function of age and/ or language skills.

Unfortunately, the movement toward developmentally sensitive diagnostic measures has not yet been matched by comparable efforts to improve methods for identifying behavioral changes in young children with autism. Despite calls for more socially valid measures of treatment effects (Mundy and Crowson, 1997; Schreibman, 2000), many studies employ outcome measures that are non-specific (e.g., IQ scores), that have not been validated on autistic populations, or that were not designed to be sensitive to changes in symptomatology. The need for additional instruments for documenting
behavioral changes has been acknowledged by many prominent researchers (e.g., Bristol et al., 1996; Committee on Educational Interventions for Children with Autism, 2001; Lord and Risi, 1998). The ability to measure behavioral change accurately over time is important for understanding the differing developmental trajectories of children with autism spectrum disorders, for tracking developmental gains (or losses) in specific behavioral domains, and for assessing the efficacy of different treatments.

The primary purpose of the present study is to examine the utility of a parental report measure in detecting behavioral changes in young children with autism. Parents are in the unique position of being able to observe their children’s behavior across contexts and time (Glascoe, 2000). Information from parents can complement clinicians’ observations by describing behaviors that may not be observed readily or consistently in clinic settings, such as the child’s relationships with peers and/or the presence of stereotyped body movements (Stone et al., 1994). In addition, parental report measures can be an efficient method for monitoring changes in children’s behavior over time, as their administration does not necessarily require a lengthy clinic visit or an experienced clinician. For young children not yet enrolled in school or acclimatized to assessment situations, parents may be the only adults who have observed their child’s behavior in multiple contexts and who can judge what is typical of their child outside the clinic setting. For these reasons, the use of caregiver ratings of behavior is a common procedure in research involving children (Arnold et al., 2000).

There are numerous parental report measures of child behaviors that are currently used to document change over time or in response to treatment. However, they vary in their suitability for young children with autism, because of limitations either in the age and composition of their standardization samples, or in their ability to account for the common features of autism (e.g., developmental delay, language delay). For instance, the Child Behavior Checklist (Achenbach, 1991) has excellent psychometric properties and provides normative data for young children (Achenbach et al., 1987); however, it does not provide information in behavioral domains specific to autism (Luteijn et al., 2000). Other measures, such as the Aberrant Behavior Checklist (Aman et al., 1985; Marshburn and Aman, 1992), the Developmental Behavioral Checklist (Einfeld and Tonge, 1995; Hastings et al., 2001), and the Nisonger Child Behavior Rating Form (Aman et al., 1996), were designed for use with individuals with developmental disabilities, but are lacking in standardization data for children under 3 years old.

There are also several parental report questionnaires and interviews that have been developed specifically for individuals with autism. However, many were not designed for very young children, and thus have limitations
Examples of such measures are the Autism Behavior Checklist (Krug et al., 1980) and the Gilliam Autism Rating Scale (Gilliam, 1995). While both of these measures evaluate behavioral domains that are pertinent to autism, some items and subscales are inapplicable to very young children with this diagnosis, owing to the significant nature of their language delays.

The Parent Interview for Autism (PIA: Stone and Hogan, 1993) is a parental report measure that provides information about the presence and severity of autism symptomatology across a number of behavioral domains. Previous research involving a sample of children with autism under the age of 6 revealed that the PIA has strong psychometric properties and has utility in differentiating children with autism from developmentally matched children with other disabilities (Stone and Hogan, 1993). However, there are currently no data regarding its utility for children under age 3. The aims of this study were to: (1) examine the psychometric properties of an abbreviated form of the PIA with a very young sample of children; and (2) examine its utility in measuring change in symptomatology over time. Toward this end, two studies were conducted. Study 1 employed a sample of 2-year-old children with autism and a developmentally matched sample without autism to examine the internal consistency and validity of the behavioral domains comprising the revised PIA. Study 2 followed a group of children diagnosed with autism spectrum disorders from age 2 to age 4 to examine the relation between parent-reported change on the revised PIA and observational measures of behavioral and diagnostic change.

Study 1: internal consistency and validity

Participants
Participants were 30 children under the age of 3 years, 15 with diagnoses of autism and 15 with non-autistic developmental disorders. Twenty-eight participants were recruited from a regional diagnostic center, where they received multidisciplinary evaluations from teams that included a licensed psychologist, a speech-language pathologist, and a developmental pediatrician. The remaining two children were recruited from a regional speech and hearing center, and received a psychological evaluation from a licensed clinical psychologist. All children were evaluated between 1991 and 1995. Informed consent was obtained from parents prior to the administration of any research measures.

Inclusion criteria for all children were: (1) a diagnostic evaluation prior to age 3; (2) the availability of cognitive and language test scores; (3) the absence of identified metabolic or genetic disorders; and (4) the absence
of severe sensory and motor impairments. Additionally, none of the children had participated in the previous PIA study. The autistic group comprised children who received a clinical diagnosis of autism from a licensed psychologist. Diagnoses were based on criteria provided in either DSM-III-R (APA, 1987) or DSM-IV (APA, 1994), depending on the date of evaluation. In addition, only children who obtained scores within the autistic range on the Childhood Autism Rating Scale (CARS: Schopler et al., 1988) were included in this group (mean = 36.0, SD = 3.2). Children in the non-autistic group were individually matched to the children in the autistic group on mental age and expressive language age (within 4 months). Of the 15 children in this group, two had diagnoses of developmental delay, three had diagnoses of language impairment, and 10 had diagnoses of developmental delay and language impairment. Language diagnoses for children in this group were made by licensed speech-language pathologists. All children in this group had CARS scores within the non-autistic range (mean = 25.0, SD = 3.0).

T-tests revealed no significant group differences for mental age, expressive language age, or chronological age. Similarly, chi-square tests revealed no significant group differences for level of maternal education, gender or race (see Table 1). As expected, the two groups differed significantly on CARS scores (t(28) = 9.36, p < 0.001).

Table 1  Demographic characteristics for study 1

<table>
<thead>
<tr>
<th></th>
<th>Autistic (n = 15)</th>
<th>Non-autistic (n = 15)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronological age (months):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>32.2 (2.9)</td>
<td>30.7 (2.9)</td>
<td>t = -1.4 ns</td>
</tr>
<tr>
<td>Range</td>
<td>26–35</td>
<td>24–35</td>
<td></td>
</tr>
<tr>
<td>Mental age (months):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>17.2 (3.0)</td>
<td>18.5 (2.9)</td>
<td>t = -1.2 ns</td>
</tr>
<tr>
<td>Range</td>
<td>14–26</td>
<td>14–23</td>
<td></td>
</tr>
<tr>
<td>Expressive language age (months):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>12.5 (4.8)</td>
<td>15.2 (4.4)</td>
<td>t = -1.6 ns</td>
</tr>
<tr>
<td>Range</td>
<td>4–20</td>
<td>8–20</td>
<td></td>
</tr>
<tr>
<td>Maternal education:</td>
<td></td>
<td></td>
<td>x² = 0.45 ns</td>
</tr>
<tr>
<td>High school or beyond (%)</td>
<td>93</td>
<td>86</td>
<td></td>
</tr>
<tr>
<td>Less than high school (%)</td>
<td>7</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Race (%):</td>
<td></td>
<td></td>
<td>x² = 1.43 ns</td>
</tr>
<tr>
<td>Caucasian</td>
<td>80</td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>20</td>
<td>40</td>
<td></td>
</tr>
<tr>
<td>Male (%)</td>
<td>87</td>
<td>60</td>
<td>x² = 2.73 ns</td>
</tr>
</tbody>
</table>

13
Measures and procedures

Cognitive and language testing Cognitive and language tests were administered by licensed professionals on the child's diagnostic team. The Bayley Scales of Infant Development (BSID: Bayley, 1969; 1993) were used to assess children's cognitive/developmental level. Twenty-six children received the revised version, and four children received the original version. The BSID was administered either by a licensed psychologist or by a clinical psychology graduate student under the direct supervision of a licensed psychologist. Age equivalents derived from the BSID were used for matching the autistic and non-autistic samples.

Expressive language skills were measured using either the Sequenced Inventory of Communication Development–Revised (SCID–R: Hedrick et al., 1984) \( (n = 29) \) or the Preschool Language Scale–3 (PLS–3: Zimmerman et al., 1992) \( (n = 1) \). These measures were administered by a licensed speech-language pathologist. Scores on the SCID–R are derived from a combination of parental report and behavioral/observational items. Psychometric data include test-retest reliability ranging from 0.88 to 0.98 and interrater reliability ranging from 0.9 to 1.0 (Hedrick et al., 1975). Scores on the PLS–3 are based exclusively on the child's response to administered items. Psychometric properties of the PLS–3 include an interrater reliability of 0.98 and a test-retest reliability of 0.91 (Zimmerman et al., 1992). The expressive language age equivalents provided by these measures were used for matching the autistic and non-autistic samples.

Childhood Autism Rating Scale (CARS) The CARS (Schopler et al., 1988) is a 15-item behavioral rating scale used to evaluate the severity of symptoms of autism. It was completed by a licensed clinical psychologist on the basis of behaviors observed during the evaluation. CARS scores range from 15 to 60, with higher scores reflecting greater symptom severity. Scores of 30 and above are considered to reflect symptomatology consistent with autism.

Parent Interview for Autism–Clinical Version (PIA–CV) The PIA–CV was derived from the Parent Interview for Autism (PIA: Stone and Hogan, 1993). The PIA is a 118-item structured interview for parents developed to elicit information about autism symptomatology. It was designed for use in clinical and research settings. Items on the PIA are organized into 11 rationally derived dimensions: social relating, affective responses, imitation, peer interactions, object play, imaginative play, language understanding, non-verbal communication, motoric behaviors, sensory responses, and need for sameness (see Table 2 for sample items). Previous research with
the PIA has revealed strong psychometric properties (Stone and Hogan, 1993). For the total PIA score, test–retest reliability and alpha coefficients were 0.93 and 0.94, respectively. Alpha coefficients for nine of the 11 PIA dimensions (all except object play and motoric behaviors) were greater than 0.70. Significant correlations between the total PIA score and diagnostic/behavioral measures (i.e. total CARS score and number of DSM-IV criteria endorsed) were also obtained. Significant differences between children with autism and developmentally matched children with other disorders were obtained for the total PIA score as well as several dimension scores (Stone and Hogan, 1993).

The PIA–CV was used in the present study. This version was developed

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Sample items from each PIA–CV dimension</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dimension</td>
<td>Sample items</td>
</tr>
<tr>
<td>Social relating</td>
<td>Enjoys interacting with familiar adults</td>
</tr>
<tr>
<td>Affective responses</td>
<td>Seems to understand how others are feeling</td>
</tr>
<tr>
<td>Imitation</td>
<td>Imitates words or sounds when you want him/her to</td>
</tr>
<tr>
<td>Peer interactions</td>
<td>Joins in play with another child</td>
</tr>
<tr>
<td>Object play</td>
<td>Plays with lots of different toys</td>
</tr>
<tr>
<td>Imaginative play</td>
<td>Plays pretend games by him/herself, such as pretending to be an animal, a monster, or a superhero</td>
</tr>
<tr>
<td>Language understanding</td>
<td>Responds when you call his/her name</td>
</tr>
<tr>
<td>Non-verbal communication</td>
<td>Communicates to let you know he/she wants something, such as food or a toy</td>
</tr>
<tr>
<td>Motoric behaviors</td>
<td>Spins or whirls him/herself around for long periods of time</td>
</tr>
<tr>
<td>Sensory responses</td>
<td>Examines objects by sniffing or smelling them</td>
</tr>
<tr>
<td>Need for sameness</td>
<td>Insists on certain routines or rituals, such as wearing a certain jacket or making sure that all his/her toys are in the right place</td>
</tr>
<tr>
<td></td>
<td>Becomes upset if changes are made in his/her daily routine, such as having a different parent put him/her to bed or skipping his/her bath</td>
</tr>
</tbody>
</table>
for the primary purpose of reducing the interview length, to make it more
usable in clinical settings. Eliminating items that were judged to be repeti-
tive, ambiguous, or non-specific shortened the length of the PIA by 25
items. Eleven items were removed because they overlapped with other
items; seven items were removed because they were unclear to many
parents, and seven items were removed because they focused on behaviors
not specific to autism. The resulting measure consists of 93 items tapping
the original 11 dimensions, and takes about 30–35 minutes to administer.
Table 3 summarizes the changes made to the PIA.

Like the PIA, the PIA–CV is administered in an interview format. Parents
rate their child on each item based on the frequency of its occurrence using
a Likert-type scale that ranges from 1 (‘almost never’) to 5 (‘almost always’).
Negatively worded items are reverse coded, and item scores are then summed
to obtain scores for each of the 11 dimensions; higher scores reflect more
normative development. Because different dimensions contain different
numbers of items, the mean score for each dimension was used in the
present study to facilitate comparisons across dimensions. The total PIA–CV
score was calculated by summing the mean scores for each dimension.

The PIA–CV was administered on the day of the child’s diagnostic evalu-
atation. This interview was conducted by trained psychology students who

<table>
<thead>
<tr>
<th>Dimension</th>
<th>No. of items on original PIA</th>
<th>No. of items on PIA–CV</th>
<th>Reason items were dropped</th>
<th>PIA–CV alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social relating</td>
<td>19</td>
<td>17</td>
<td>1 U; 1 R</td>
<td>0.88</td>
</tr>
<tr>
<td>Affective responses</td>
<td>12</td>
<td>9</td>
<td>2 U; 1 N</td>
<td>0.78</td>
</tr>
<tr>
<td>Imitation</td>
<td>6</td>
<td>4</td>
<td>2 R</td>
<td>0.73</td>
</tr>
<tr>
<td>Peer interactions</td>
<td>8</td>
<td>5</td>
<td>2 U; 1 R</td>
<td>0.87</td>
</tr>
<tr>
<td>Object play</td>
<td>6</td>
<td>4</td>
<td>1 U; 1 N</td>
<td>0.10</td>
</tr>
<tr>
<td>Imaginative play</td>
<td>4</td>
<td>4</td>
<td>N/A</td>
<td>0.73</td>
</tr>
<tr>
<td>Language understanding</td>
<td>10</td>
<td>7</td>
<td>2 R; 1 N</td>
<td>0.87</td>
</tr>
<tr>
<td>Non-verbal communication</td>
<td>13</td>
<td>13</td>
<td>N/A</td>
<td>0.84</td>
</tr>
<tr>
<td>Motoric behaviors*a</td>
<td>6</td>
<td>4</td>
<td>1 R; 1 N</td>
<td>0.30</td>
</tr>
<tr>
<td>Sensory responses</td>
<td>21</td>
<td>16</td>
<td>4 R; 1 N</td>
<td>0.81</td>
</tr>
<tr>
<td>Need for sameness</td>
<td>13</td>
<td>10</td>
<td>1 U; 2 N</td>
<td>0.68</td>
</tr>
</tbody>
</table>
| Total PIA: 11 dimen-
| s                   | 118                          | 93                     | 7 U; 11 R; 7 N            | 0.95         |
| Total PIA: 9 dimen-
| s*b                 | N/A                          | 85                     | 6 U; 10 R; 5 N            | 0.95         |

U = unclear item; R = repetitive item; N = non-specific item.
*a These dimensions were included in the calculation of the total PIA on 11 dimensions, but were
omitted from all other subsequent analyses.
*b Omits scores from the object play and motoric behaviors dimensions.
were blind to the suspected diagnoses of the participants. PIA–CV interviews took place early in the evaluation schedule, before parents had received the results of their child’s diagnostic evaluation; thus parents were blind to their child’s diagnosis. Clinical diagnoses were made by the diagnostic team members, without knowledge of information obtained from the PIA–CV.

Results and discussion
Internal consistency for the 11 PIA–CV dimension scores is presented in Table 3. Alpha levels were equal to or above 0.70 for eight of the 11 dimension scores. The need for sameness dimension revealed a moderate level of internal consistency with an alpha of 0.68, and was retained for subsequent analyses. In contrast, the internal consistency for the object play and motoric behavior dimensions was weak, and these dimensions were eliminated from further analyses involving individual dimensions. Two total scores were calculated, one including all 11 dimensions and the other omitting the object play and motoric behavior dimensions. Both scores demonstrated adequate internal consistency.

A profile analysis was performed on the nine internally consistent dimensions of the PIA–CV to compare the patterns of performance of children in the autistic and non-autistic groups. MANOVA was used to examine whether there were group differences in the overall level of scores and whether the profiles for each group were parallel. A significant group difference was found for level of scores ($F(1, 28) = 15.06, p < 0.001$), with children in the autistic group obtaining lower (i.e. less normative) scores across the PIA dimensions. A significant interaction between group and PIA–CV dimension was also obtained ($F(8, 21) = 4.06, p < 0.01$), indicating that the profiles obtained by the two groups deviated significantly. This interaction suggests that there were group differences on some, but not all, PIA–CV dimensions. Profiles of the scores obtained by the two diagnostic groups on the PIA–CV dimension scores are illustrated in Figure 1.

To follow this omnibus test, univariate ANOVAs were conducted to determine the dimensions on which the autistic and non-autistic samples differed. Results revealed significant group differences for five PIA–CV dimension scores, with parents of children with autism reporting greater impairments than parents of non-autistic children for social relating, imitation, peer interactions, imaginative play, and language understanding. Significant group differences were also obtained for both total scores (see Table 4).

The results of this study suggest that the PIA–CV demonstrates strong psychometric properties for children under the age of 3. Adequate internal consistency was obtained for the total score as well as nine of the 11 dimension scores. The weak internal consistency of the object play and
Motoric behavior dimensions is consistent with findings from the previous version of the PIA (Stone and Hogan, 1993). Because it is unclear what these dimensions are measuring, consideration should be given to using

**Figure 1** PIA-CV dimension profiles for the autistic and non-autistic groups

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Autistic</th>
<th>Non-autistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social relating</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Affective responses</td>
<td>3.44</td>
<td>0.56</td>
</tr>
<tr>
<td>Imitation</td>
<td>2.72</td>
<td>0.75</td>
</tr>
<tr>
<td>Peer interactions</td>
<td>2.70</td>
<td>0.94</td>
</tr>
<tr>
<td>Imaginative play</td>
<td>1.10</td>
<td>0.16</td>
</tr>
<tr>
<td>Language understanding</td>
<td>2.24</td>
<td>0.65</td>
</tr>
<tr>
<td>Non-verbal communication</td>
<td>3.09</td>
<td>0.73</td>
</tr>
<tr>
<td>Sensory responses</td>
<td>3.81</td>
<td>0.64</td>
</tr>
<tr>
<td>Need for sameness</td>
<td>4.35</td>
<td>0.62</td>
</tr>
<tr>
<td>Total PIA: 11 dimensions</td>
<td>3.11</td>
<td>0.45</td>
</tr>
<tr>
<td>Total PIA: 9 dimensions</td>
<td>3.00</td>
<td>0.45</td>
</tr>
</tbody>
</table>

Scores range from 1 to 5, with higher scores reflecting more normative development.

* p < 0.05, ** p < 0.01, *** p < 0.001.
only the nine PIA dimensions with adequate internal consistency. This recommendation is further supported by our findings that internal consistency and diagnostic group differences were found for both the nine-dimensional and the 11-dimensional total scores. Consequently, eliminating these two dimensions is not likely to affect the utility or effectiveness of the total PIA-CV score.

Scores on the PIA-CV also differentiated between children with autism and developmentally matched peers, providing support for the validity of the behavioral domains. Although the PIA-CV is not intended as a diagnostic measure, it is important to demonstrate that its domains are tapping behaviors of clinical relevance to autism. The results obtained for children under 3 were similar to those obtained previously for preschool-age children (Stone and Hogan, 1993), in that group differences were obtained for the social relating, imitation, peer interactions, imaginative play, and language understanding dimensions, but not for the sensory or sameness domains. In contrast to previous findings, no group differences were found for the affective responses or non-verbal communication dimensions. These findings may reflect the younger ages of children in the present study. For example, it is possible that behavioral differences in these areas are not readily apparent to parents, because of the wide range of variability of infant behavior and/or the parents' natural tendency to scaffold social exchanges with their young children (Baranek, 1999).

Study 2: sensitivity to change

Participants
Participants were 37 children (29 male, eight female) who were involved in a longitudinal investigation of young children with autism spectrum disorders. Inclusion criteria for this study were: (1) a clinical diagnosis of either autism or pervasive developmental disorder not otherwise specified (PDD-NOS) at age 2 (time 1); and (2) participation in a follow-up diagnostic evaluation at age 4-5 (time 2). Nine of the participating children (24 percent) were also included in study 1. All children received their first diagnostic evaluation between 1993 and 1995. Diagnoses were made by a licensed psychologist with reference to criteria provided either in DSM-III-R (APA, 1987) or DSM-IV (APA, 1994), depending on the date of evaluation. Twenty-six children (70 percent) received an initial diagnosis of autism and 11 (30 percent) received an initial diagnosis of PDD-NOS. At time 1 the average chronological age, mental age, and language age of the sample were 31.4 months (SD = 3.4), 17.1 months (SD = 3.7), and 12.8 months (SD = 5.2), respectively. At time 2 the average chronological
age, mental age, and language age of the sample were 58.5 months (SD = 4.4), 47.3 months (SD = 15.9), and 25.9 months (SD = 10.8), respectively.

**Measures and procedures**

Measures and procedures were similar to those used in study 1. At time 1, children received multidisciplinary evaluations from teams that included a psychologist, a speech-language pathologist, and a developmental pediatrician. At time 2, children were evaluated by a psychologist and a speech-language pathologist. At both the time 1 and time 2 evaluations, diagnostic decisions were made independent of information obtained from the PIA–CV. Only items from the nine PIA–CV dimensions demonstrating adequate internal consistency were used for this study. Change scores on the PIA–CV were calculated for the dimension and total scores by subtracting the time 1 scores from the time 2 scores. Because higher PIA–CV scores indicate more adaptive behavior, higher PIA–CV change scores reflect greater degrees of improvement.

Change in PIA–CV scores was compared to two separate and independent measures of behavioral change. The first measure was the change in CARS scores from time 1 to time 2. Change scores were derived by subtracting the time 2 CARS score from the time 1 CARS score. Because higher CARS scores indicate higher levels of symptom severity, greater behavioral improvements are reflected in higher change scores. CARS change scores ranged from –7.0 to 16.5, with a mean of 3.1 (SD = 5.7).

The second measure of behavioral change was based on children's clinical diagnoses at time 1 and time 2. Children were classified into either an 'improved' group or an 'unimproved' group based upon a comparison of their clinical diagnosis at the two time points. Diagnostic improvement was defined a priori as meeting one of the following conditions for a change in diagnosis: from autism to PDD-NOS (n = 3); from autism to a non-spectrum diagnosis such as language impairment or developmental delay (n = 3); or from PDD-NOS to a non-spectrum diagnosis (n = 5). Lack of improvement was defined as receiving the same clinical diagnosis at time 1 and time 2. Based on these criteria, 11 children (eight male, three female) were classified as improved and 26 children (21 male, five female) were classified as unimproved.

For both time periods, there were no significant differences between the improved and unimproved groups for chronological age (t(35) = –0.27 for time 1 and t(35) = –0.21 for time 2, p > 0.80) or mental age (t(35) = –1.74 for time 1 and t(35) = –1.96 for time 2, p > 0.06). However, the two groups differed significantly on expressive language age at both time 1 (t(33) = –3.27, p < 0.01) and time 2 (t(35) = –5.67, p < 0.001), with the improved group obtaining higher scores. Demographic
Results and discussion
Paired sample t-tests were used to examine the extent to which PIA–CV scores changed over a 2 year period. Significant improvements over time were found for the PIA–CV total score and for all dimensions except need for sameness (see Table 6). Pearson correlations between change scores on the PIA–CV and change scores on the CARS were significant for the total PIA–CV score ($r = 0.53, p < 0.001$) and for five PIA–CV dimensions: social relating ($r = 0.38, p < 0.05$), affective responses ($r = 0.36, p < 0.05$), imaginative play ($r = 0.49, p < 0.01$), language understanding ($r = 0.44, p < 0.01$), and non-verbal communication ($r = 0.44, p < 0.01$). For these dimensions, improved symptomatology on the PIA–CV was associated with improved symptomatology assessed by the CARS.

Point biserial correlations were used to examine the relation between change in PIA–CV scores and change in diagnostic status (i.e. improved/unimproved). Results revealed significant positive correlations between diagnostic improvement and improvement for the total PIA–CV score ($r = 0.52, p < 0.001$), and four PIA–CV dimensions: affective responses ($r = 0.40, p < 0.05$), imaginative play ($r = 0.58, p < 0.001$), language understanding ($r = 0.36, p < 0.05$), and non-verbal communication ($r = 0.51, p < 0.001$). Given these results, it was also of interest to determine whether the improved and unimproved groups differed on any PIA–CV dimensions.
at time 1. T-tests revealed significant group differences for the imitation dimension only ($t(34) = -2.7, p < 0.05$), with children in the improved group exhibiting higher scores (i.e. more normative behaviors) at time 1.

These results suggest that, overall, parents reported improvements in their children’s behaviors between the ages of 2 and 4 for almost all areas measured by the PIA-CV. These findings are consistent with previous observations that social and communication impairments in autism, while representing core features, are in fact amenable to change (DiLalla and Rogers, 1994). The one PIA-CV dimension on which children did not exhibit improvement was need for sameness. Ceiling effects for this dimension may have constrained our ability to detect improvements over time. Moreover, the need for sameness and routines is an area of autism symptomatology that has been found to be more prominent in older children (Dahlgren and Gillberg, 1989; Lord, 1995), and thus would not necessarily be expected to improve between the ages of 2 and 4.

Improvement on five PIA-CV dimensions (social relating, affective responses, imaginative play, language understanding, and non-verbal communication) was associated with reduced symptomatology on the CARS and/or diagnostic improvement. The finding that changes in the PIA-CV dimensions assessing social and communication skills were related to clinically significant behavioral and diagnostic improvements supports the use of this instrument as a measure of change over time for young children.

**Table 6**  Study 2: PIA-CV scores at time 1 and time 2

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Time 1 (n = 37)</th>
<th>Time 2 (n = 37)</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Social relating</td>
<td>3.46</td>
<td>0.66</td>
<td>3.92</td>
</tr>
<tr>
<td>Affective responses</td>
<td>3.45</td>
<td>0.71</td>
<td>3.67</td>
</tr>
<tr>
<td>Imitation</td>
<td>2.78</td>
<td>0.95</td>
<td>3.52</td>
</tr>
<tr>
<td>Peer interactions</td>
<td>2.85</td>
<td>0.89</td>
<td>3.19</td>
</tr>
<tr>
<td>Imaginative play</td>
<td>1.21</td>
<td>0.38</td>
<td>2.11</td>
</tr>
<tr>
<td>Language understanding</td>
<td>2.34</td>
<td>0.70</td>
<td>3.23</td>
</tr>
<tr>
<td>Non-verbal communication</td>
<td>3.01</td>
<td>0.62</td>
<td>3.37</td>
</tr>
<tr>
<td>Sensory responses</td>
<td>3.72</td>
<td>0.60</td>
<td>4.00</td>
</tr>
<tr>
<td>Need for sameness</td>
<td>4.46</td>
<td>0.41</td>
<td>4.39</td>
</tr>
<tr>
<td>Total PIA: 9 dimensions</td>
<td>3.03</td>
<td>0.45</td>
<td>3.49</td>
</tr>
</tbody>
</table>

Scores range from 1 to 5, with higher scores reflecting more normative development.

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. 
General discussion

Psychometric properties of the PIA-CV
Results of the current study suggest that the PIA-CV is a reliable and valid instrument for measuring behavioral change in young children with autism. The PIA-CV demonstrated strong internal consistency for nine of 11 dimensions, as well as for the total score. The two dimensions in this study demonstrating the weakest internal consistency, object play and motoric behaviors, have demonstrated similar weakness in previous research with the PIA (Stone and Hogan, 1993). Omitting these dimensions from the total score did not affect its potency. Together, these findings suggest that use of the PIA-CV should be limited to the remaining nine dimensions.

The validity of the PIA-CV as a measure of symptom severity was assessed by comparing scores for samples of children with autism and children with other disabilities matched on chronological age, mental age, and expressive language. Consistent with previous research, group differences were found for the PIA-CV dimensions of social relating, imitation, peer interactions, imaginative play, and language understanding, and for the total score. Given that the present study featured the involvement of younger children, the use of more stringent matching criteria, and the inclusion of fewer PIA items, the robustness of these dimensions is notable.

In contrast to previous research with samples of older children, group differences were not found on the PIA-CV dimensions of affective responses and non-verbal communication. The failure to find group differences on the affective responses dimension is consistent with findings from other research involving young children. Lord (1995) found that significant differences in appropriateness and range of facial expressions between children with and without autism were reported at age 3, but not at age 2. It is possible that behavioral differences in this domain appear later in development.

Items on the non-verbal communication dimension require parents to interpret and make attributions about their child’s communicative intent, which may account for the failure to find group differences on this dimension. For example, several items on this dimension address the function of the child’s communication (e.g. to show off, to get a parent’s attention). It is possible that some parents may not recognize their child’s communicative deficits because they over-attribute meaning to non-communicative behaviors. Alternatively, parents may become sufficiently skilled at interpreting their child’s ambiguous or idiosyncratic attempts at communication that they do not recognize existing deficits. There is evidence that parents of children with autism tend to use compensatory strategies to engage their
children in social interaction, even before they first report concerns about their child’s development (Adrien et al., 1991; 1992; Baranek, 1999). Consequently, parents of young children with autism may be less cognizant of their child’s communicative deficits owing to their tendency to scaffold social-communicative exchanges with their child.

The sensory responses and need for sameness dimensions did not differentiate groups either in the present study with the PIA–CV or in previous research with the PIA. In fact, these scores were the highest of all dimension scores, indicating that parents reported the most normative development in these areas. Previous research using parent report methodology has also failed to obtain group differences for sensory and sameness behaviors in very young children (Cox et al., 1999). Moreover, results from other studies indicate that preference for routines and sameness is an area of autism symptomatology that emerges later in development and is more pronounced in older children (Dahlgren and Gillberg, 1989; Lord, 1995; Ohta et al., 1987; Stone et al., 1994). Behavioral differences in these behaviors may thus not be apparent at the age that children in this study were evaluated.

However, it is important to acknowledge that because the current study employed parent report methodology, it is not possible to draw definitive conclusions about why group differences were not found for the PIA–CV dimensions of affective responses, non-verbal communication, sensory responses and need for sameness. As discussed above, the failure to find group differences on these dimensions may reflect an absence of behavioral differences in some of these domains at young ages. However, the failure to find group differences may also reflect an inability on the part of parents to observe and report existing behavioral differences accurately. While it is possible that behavioral differences in these domains increase over time, it is also possible that parents simply become more astute observers and reporters of their child’s behavior. Future research combining parental report with corresponding observational measures in a longitudinal study is needed to address this issue.

The PIA–CV as a measure of change
The utility of the PIA–CV in measuring change in symptom severity was evaluated by comparing change in PIA–CV scores with change in total CARS scores and change in diagnostic status. These measures were considered to be stringent indicators of clinically significant behavioral and diagnostic change because they were: (1) completed independently from information obtained from the PIA–CV; and (2) derived on the basis of clinical observation rather than parental report. Changes for five dimensions – social relating, affective responses, imaginative play, language understanding, and
non-verbal communication – were associated with at least one of the independent measures of behavioral and diagnostic change employed.

Although social and communicative deficits represent core impairments in autism, in the current study children demonstrated significant improvements over time in these areas. Similarly, other research has revealed a significant reduction in social and communication impairments as measured by the CARS for children with autism who receive specialized intervention (DiLalla and Rogers, 1994). Together, these findings highlight the amenability of social communicative skills to change, and stress the importance of intervention addressing these areas. Furthermore, these results support the feasibility and utility of measuring changes in ecologically valid skills, as has been advocated by researchers in the field (Mundy and Crowson, 1997). Interventions should be evaluated with measures that are sensitive to change in the specific social and communicative behaviors that are central to autism, rather than with more global measures of development such as change in IQ scores (Committee on Educational Interventions for Children with Autism, 2001).

Results of this study also suggest the potential prognostic importance of expressive language and imitation skills. At age 2, the improved group demonstrated stronger skills in these areas relative to the unimproved group. It is possible that these early differences may have contributed to the behavioral gains observed in the improved group. Expressive language has long been considered prognostic of outcome in autism (Gillberg, 1991; Lotter, 1978). In addition, several studies have found a relation between expressive language and other social-communicative behaviors, such as social smiling and responsiveness (Lord and Pickles, 1996) and directing attention (Landry and Loveland, 1988; Mundy et al., 1987).

Similarly, the relation of early imitation skills to the development of social-communicative behaviors has been supported both theoretically (Rogers and Pennington, 1991) and empirically (Stone and Yoder, 2001; Stone et al., 1997b). Rogers and Pennington (1991) proposed a model of autism that describes imitation deficits in infancy as precursors to later problems in areas such as emotion sharing, pretend play, and language. The results from the current study are consistent with the prediction that children with autism who have less severe deficits in imitation develop more adaptive social and communicative skills than do children with more severe deficits in imitation. Perhaps the stronger early imitation skills exhibited by the improved group served as a protective factor against increasing autism symptom severity and fostered the social and communicative improvements demonstrated by this group on both the PIA–CV and the diagnostic and behavioral measures used.
Conclusions
Results of this study suggest that the PIA–CV is a useful instrument for measuring changes in symptomatology in young children with autism. The PIA–CV demonstrates adequate internal consistency and validity for children under the age of 3 years. Although the PIA–CV was originally constructed to provide scores across 11 dimensions of behavior, the results of the present research project suggest that use of the PIA–CV should be limited to nine dimensions and the total score derived from them.

Children with autism were described as having more symptoms than their non-autistic peers on the PIA–CV total score and the dimension scores for social relating, imaginative play, and language understanding. Changes in these three domains were also associated with change in diagnostic status and symptom severity over a 2 year period. It is interesting to note that these behavioral domains parallel the triad of impairments described by Wing (1981; Wing and Gould, 1979). Scores in these three dimensions may ultimately prove to be the most useful for research and/or clinical purposes. It is possible that scores for the three dimensions alone could be used to provide information about group differences and behavioral change over time. Doing so would reduce the number of interview items from 85 to 28 and would decrease the length of the interview to approximately 10 minutes. Future research could examine the diagnostic utility and psychometric properties of a brief version of the PIA–CV. In addition, developing a questionnaire format for a brief version of the PIA–CV may also add to its utility by increasing the ease with which it can be administered.

Finally, it is important to consider the limitations of the current study. First, the procedure of matching children with autism to those without autism can lead to somewhat skewed diagnostic samples. Developmental matching typically results in the exclusion of children with autism who are verbally and cognitively lower functioning, as well as children with non-autistic disorders who are functioning at higher levels of linguistic and cognitive ability. The characteristics of the resulting samples may or may not be representative of their respective populations. The relatively small sample sizes used in the present study are also likely to limit the generalizability of the findings. Replication of these results with larger samples will be necessary before firm conclusions can be drawn.

Second, the use of parent report methodology has some inherent limitations. Most pertinent to this study is the question of whether the failure to find group differences on some PIA–CV dimensions reflects an absence of behavioral differences in those domains, or an inability on the part of parents accurately to observe or report existing behavioral differences. Multimethod strategies employing observational measures that parallel parental report measures in content would help to clarify these results.
Third, it is important to emphasize that, to date, the PIA-CV has been used only to investigate differences between groups of children and to measure change in behavior over time. Although the PIA-CV can be used to elicit information about autistic symptomatology from parents, it was not designed to provide diagnoses for individual children. Its contribution is strongest as an instrument for obtaining ecologically valid information about very young children with autism, and for tracking developmental progress and changes in symptom severity over time. Such information is vital to the tasks of improving the accuracy of early detection, of increasing our understanding of early developmental trajectories, and of evaluating the efficacy of early intervention programs.

Acknowledgements
The authors would like to gratefully acknowledge the children and parents who participated in this research. This work could not have been completed without the significant contributions of Kerry Hogan, Opal Ousley, Susan Hepburn, Sue Lewis, Kimberly Dennis, Christia Brown, and Tanya Klepper to the assessment process. Special thanks are extended to Moria Smoski for her invaluable suggestions and comments regarding the manuscript.
This research was supported in part by grants from the John F. Kennedy Foundation; the University Research Council at Vanderbilt; NIMH grant MH50620; and NICHD grant T3207226.

Note
1 The sample originally comprised 38 children, with the intention of examining three groups of behavioral change: improvement, decline, and no change. However, only one child showed behavioral decline. As a result, it was possible to form only two groups, and this child was not included in the study.

References
AUTISM 7(1)


How well does early diagnosis of autism stand the test of time?

Follow-up study of children assessed for autism at age 2 and development of an early diagnostic service

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ABSTRACT Twenty children who presented with severe interactional and communication difficulties at age 2 underwent a comprehensive assessment for autism, and were reassessed at age 4–5. In common with other recent studies, diagnosis of autistic spectrum disorders at age 2 was found to be reliable and stable. The communication and social skills of the children showed little change overall by the second assessment. However, children whose scores deteriorated in the social domain tended to have presented initially with more significant behaviour problems. Few repetitive behaviours were observed at age 2, whereas these were more apparent by age 4–5. The finding that early diagnosis of autism is reliable and stable has led to the development of an early diagnostic service in Southampton, which is described. The importance of early diagnosis is that it opens the door to early intervention programmes, which in turn prevent many problems from occurring in later life.

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KEYWORDS assessment; autism; Autism Diagnostic Interview; early diagnosis; parent support

Introduction

Recent interest in the early identification and diagnosis of children with autism has been driven to a great extent by the reported success of specialized early intervention programmes (e.g. Hoyson et al., 1984; Lovaas, 1987; Ozonoff and Cathcart, 1998; Rogers and Lewis, 1989; Sheinkopf and Seigel,
1998; for reviews see Howlin, 1997; Jordan et al., 1999; Rogers, 1996; 1998). Because eligibility for participation in these programmes is often limited to children who have a formal diagnosis of autism, early identification and accurate assessment are crucially important. Furthermore, young children with undiagnosed autism may be assigned to inappropriate programmes which do not provide the necessary degree of continuity, staff expertise or adult/child ratio generally recommended for children with autism (Chung et al., 1995). The establishment of appropriate behaviour management strategies in the early years can also help to minimize or even avoid many subsequent behaviour problems occurring (Clements and Zarkowska, 2000; Howlin, 1998b; Howlin and Rutter, 1987). Other important opportunities offered by early identification include implementation of appropriate educational planning, access to professional support services, and genetic counselling (Cox et al., 1999). In addition, Howlin and Moore (1997) found that parents were much more satisfied with the diagnostic process if it occurred in the preschool years.

If diagnosis is to be attempted early, it needs to be established that signs of autism can be detected accurately in young children, and that early diagnosis can stand the test of time. Several recent studies have investigated the stability of early diagnosis by assessing children for possible autism around the age of 2 years, and reassessing the same children later when they were aged between 3 and 4 years (Cox et al., 1999; Lord, 1995; Stone et al., 1999). These studies have led to the general conclusion that autism can be reliably diagnosed at age 2 and that the diagnosis is stable. However, accurate diagnosis is dependent on comprehensive clinical assessment (including parental interview, child observation, and cognitive/developmental and language testing), and it is less reliable, particularly at age 2, if it focuses on one measure alone such as the Autism Diagnostic Interview (ADI: LeCouteur et al., 1989; Lord et al., 1994). The ADI relies on parental report of observed child behaviour, and the studies employing it suggest that this may be particularly prone to inaccuracies in the case of the subtle, qualitative behavioural features which are markers of autism in very young children (Cox et al., 1999; Lord, 1995). It also appears that clinicians themselves need to have considerable experience, both in the assessment of autism and in evaluating preschool children, for reliable early diagnosis to be made (Stone et al., 1999).

It is important therefore to consider what these subtle, early markers of autism are. The follow-up studies of Lord, Cox et al. and Stone et al. all reported more impairments in the social and communication domains than in the repetitive behaviour category; indeed repetitive behaviours were rarely observed in 2-year-olds, although they were found in most children with autism by the age of 3½; (Cox et al., 1999). Other studies have looked
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In spite of the considerable evidence of identifiable markers of autism in very young children, early diagnosis is not the norm (Chung et al., 1995; Howlin and Moore, 1997; Moore et al., 1999; O’Hare et al., 1998). For example, Howlin and Moore (1997) found in their survey of over 1000 parent members of UK autistic societies that, although the average age at which parents first had concerns about their child was 1.7 years, the average age of diagnosis was not until around the age of 6 years. Whilst there is evidence of a recent trend towards younger diagnosis, early identification and assessment is by no means common practice (Baird et al., 2001).

Mindful of this yawning gap between the early signs of autism and arriving at a diagnosis, but also aware of the need for diagnosis to be accurate and assessment to be comprehensive, we embarked on a follow-up study of children referred to our local child development centre for assessment of possible autism, with the eventual aim of setting up a comprehensive early diagnostic service in our local area.

**Method**

**Subjects**

Subjects were 20 children (16 boys and four girls) with severe communication and interactional problems referred to a nursery assessment group in the local child development centre (CDC). The average age at assessment was 2 years 10 months (range 2 years 5 months to 3 years 6 months). These same children were reassessed by the Autism Assessment Team based at Southampton General Hospital when they were aged between 4 and 5 years (average age at second assessment 4 years 5 months; range 4 years 0 months to 4 years 10 months).
One of the girls in the sample had been diagnosed at birth with Turner syndrome. There were no other children with known medical conditions or chromosomal abnormalities at the time of initial assessment.

**Procedure**

**Initial assessment**  Children showing significant communication and interactional problems were referred into the CDC by a community paediatrician for an assessment lasting typically 8 to 10 weeks. Assessment relied heavily on observations made during the child's attendance at a weekly nursery group for 1 1/2 hours. This afforded opportunities for ongoing assessment of language and communication skills carried out by a speech and language therapist and assessment of play, motor, cognitive and self-help skills carried out by trained nursery staff. In addition, each child was visited at home by a clinical psychologist in order to complete the ADI–R, carry out further observation of the child's behaviour and further cognitive/developmental testing (using the Griffiths Mental Developmental Scales: Griffiths, 1984) as appropriate.

The ADI–R was scored predominantly on the basis of parental report. However, if there was a clear discrepancy between this and observations in other settings, a consensus was reached in discussion involving all staff towards the end of the assessment. (For example, if a parent reported no pointing for interest, or no unusual sensory interests, but these had clearly been seen, the observation would be reflected in the child's score.) ICD-10 diagnosis was arrived at on the basis of the ADI–R scores, which did however incorporate the element of clinical judgement described. In practice, the differences between parental report and consensus were variable: in the majority of cases they were slight or non-existent, but in a small minority of cases they were more readily apparent.

**Follow-up assessment**  This was a 1 day assessment carried out by the Regional Autism Assessment Service based at Southampton General Hospital. This service has been described in detail elsewhere (Moore et al., 1998), and essentially comprised educational assessment carried out by a teacher; cognitive/developmental assessment and assessment of play, language and communication skills carried out by a speech and language therapist and clinical psychologist working together; and structured observation of the child during meal and break times carried out by a member of the nursing staff. Whereas in the initial assessment estimates of language levels had been based on detailed observations within the nursery setting, at the second assessment observation was combined with the use of formal tests where appropriate (see Moore et al., 1998). An ADI–R was
administered by a trained clinician (paediatrician or child psychiatrist) who was unaware of the ADI–R scores obtained by the clinical psychologist at the previous assessment. ICD-10 diagnosis was arrived at following team discussion at the end of the day. As above, the ADI–R scores incorporated an element of clinical judgement in that they were altered to reflect any clear discrepancies between parental report and observations made by trained staff during the course of the day.

All children in the study moved into supported educational placements following their attendance at the CDC for initial assessment. They therefore received comparable amounts of intervention between the two assessments.

Results

The diagnoses assigned to children on the basis of their early and second assessments are shown in Table 1.

Fourteen of the 16 children diagnosed with autism at their first assessment retained that diagnosis at their second assessment (87.5 percent). The remaining two children received diagnoses of ‘atypical autism’ at follow-up. (This diagnosis applied to children who met the ICD-10 diagnostic criteria for autism in one or two but not all three of the areas of abnormality specified.) Two children originally diagnosed with atypical autism received a diagnosis of autism at follow-up. The two remaining children (one with atypical autism and one with a language disorder) retained their original diagnoses. The girl with Turner syndrome met full ICD-10 criteria for autism on both occasions.

Since the children in the study had all been referred originally as a result of significant language and communication problems, they all had very delayed language development. The average levels of language development at the children’s initial assessment were 12.9 months for receptive language (range 9 to 22 months) and 15.2 months for expressive language (range

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Diagnoses based on early assessment (age 2) and second assessment (age 4)</th>
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<tr>
<td>Early assessment</td>
<td>Second assessment</td>
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<tr>
<td>Autism: 16</td>
<td>Autism: 14</td>
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<tr>
<td>Atypical autism: 3</td>
<td>Atypical autism: 2</td>
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<td>Language disorder: 1</td>
<td>Language disorder: 1</td>
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9 to 24 months). In the vast majority of cases there was no discrepancy between levels of expressive and receptive language. Where a discrepancy did exist (in three cases), expressive language was more advanced than comprehension. At the time of the children’s second assessment, the average level of expressive language was 20 months (range less than 12 months to 3 years 3 months) and the average level of receptive language was 21.1 months (range less than 12 months to 3 years 6 months). Only four children had sufficient speech to be scored on the verbal items of the ADI–R at their second assessment.

The children’s non-verbal skills spanned the ability range with an average non-verbal IQ of 71.4 (range 26–93). Two children had non-verbal IQs less than 50, six children had non-verbal IQs between 50 and 70, and the remaining 12 children had non-verbal IQs of 70 or above. These quotients were obtained using the Leiter International Performance Scale (Leiter, 1979) (three children), or from averaging quotients obtained on the two non-verbal scales (D and E) of the Griffiths Mental Development Scales (17 children). When scores for scales D and E were separated, it was noted that scores on scale E were significantly higher than scores on scale D (average D = 62.4; average E = 78.2; t = –8.52, d.f. = 16, p < 0.001).

The cut-off values for the three domains covered by the ADI–R are 10 for qualitative impairments in reciprocal social interaction, 7 (non-verbal) or 8 (verbal) for qualitative impairments in communication, and 3 for presence of repetitive and stereotyped patterns of behaviour. The scores children obtained in these three domains at their first and second assessments are shown in Figure 1.

![Figure 1](ADI-R domain scores at first and second assessments. Maximum possible scores for each domain are: social 30; communication 14; repetitive behaviour 10 (N = 19))
Whilst scores in the social and communication domains did not change for the group as a whole, there was a significant increase in scores for the repetitive behaviour category (Wilcoxon $Z = -3.23$, $p < 0.001$).

Within the social domain, whilst there was a tendency for scores to decrease (i.e. improve) by the time of the second assessment in components B1 (failure to use non-verbal behaviours to regulate social interaction), B3 (lack of shared enjoyment) and B4 (lack of socio-emotional reciprocity), there was a significant increase in scores on B2 (failure to develop peer relationships) (Wilcoxon $Z = -3.74$, $p < 0.001$).

Within the communication domain, there was a tendency for scores generally to decrease by the time of the second assessment, but none of these improvements were statistically significant. The four children who had developed sufficient speech to be scored on the verbal items of the ADI–R all showed autistic features in this area, particularly in component C2V (failure to initiate or sustain a conversational interchange).

In the repetitive behaviour category, parents were more likely to report the presence of body mannerisms, repetitive use of objects and unusual sensory interests than compulsions and rituals or unusual preoccupations at the age of 2. The data are shown in Figure 2.

Between the first and second assessments there were increases in circumscribed interests (which cannot be scored below the age of 4 years), unusual preoccupations, compulsions and rituals, hand and finger mannerisms and repetitive use of objects. However, none of these tendencies...

![Figure 2](image-url)  
**Figure 2** Scores for components of repetitive behaviours and stereotyped patterns domain at first and second assessments. Maximum possible score is 2 for each component ($N = 19$)
achieved statistical significance. There was a significant decrease in the reporting of complex mannerisms ($p < 0.004$, McNemar test).

Closer inspection of data for the social domain revealed that for 10 of the children diagnosed in the autistic spectrum at their second assessment, social scores had actually increased, whereas for the remaining nine children scores had decreased since the time of their first assessment. The children whose social scores were higher diverged from the rest of the group in particular on one component within the social domain, B2 (failure to develop peer relationships) ($Mann–Whitney Z = -3.05, p < 0.001$). The data are shown in Figure 3.

Although there was a tendency for children with increased social scores to obtain higher scores on other components within the social domain also (i.e. B1, B3 and B4), none of these differences were significant.

An increase in social score was not associated with the child's level of non-verbal functioning (using non-verbal IQ as a linear predictor of change in social score; $t = 0.66, p < 0.52$) or with the amount of language the child possessed (using language quotient, based on overall language level as a proportion of the child's chronological age, as a linear predictor of change in social score; $t = -0.76, p < 0.46$). However, inspection of the clinical notes of children whose social scores increased revealed that all children in this group had presented at their first assessment with behaviour problems which were sufficiently worrying to prompt referral to a

![Figure 3](adi-r-scores.png)

**Figure 3** ADI–R scores on components comprising social domain at second assessment. Number of questions (each with maximum possible score of 2) relating to each domain category are: B1 = 3, B2 = 4, B3 = 3, B4 = 5 ($N = 19$)
clinical psychologist. Indeed there was overwhelming evidence of an association between referral to clinical psychology and an increase in social score (Fisher's exact $p < 0.0001$). Problem behaviours were varied and included pica, temper tantrums, overactivity and insistence on sameness.

Although children in the group whose social scores decreased also showed behaviours which were difficult to manage, they were not of sufficient intensity to require input from a clinical psychologist, and this group tended generally to be more passive.

Discussion

The findings of the present study suggest that it is possible to make an informed clinical diagnosis of an autistic spectrum disorder in children aged 2–3 years with 100 percent accuracy. Specific diagnosis of autism was found to be somewhat less reliable, but was nonetheless made with 87.5 percent accuracy (14 of the 16 children diagnosed with autism at age 2 retained their original diagnosis at age 4). The two children who moved from a diagnosis of ‘autism’ to ‘atypical autism’ at their second assessment continued to show significant communication and social difficulties requiring considerable support. One of these children, a girl, was found following assessment to have a paternal duplication of chromosome 15 at the molecular level. Although she fell within the ‘atypical autism’ category, she presented with an unusual clinical picture of virtually non-existent expressive language, impaired social development and a large number of repetitive behaviours in the context of normal verbal comprehension and reasonably good non-verbal communication skills.

Our findings are consistent with those of other studies which have found that clinical diagnosis of autistic spectrum disorders at the age of 2 is reliable and stable (Lord, 1995), and that children who remain within the autistic spectrum continue to show significant impairments (Stone et al., 1999).

Other studies have also shown that whilst the ADI can effectively differentiate autism from learning disability and language impairments (Lord et al., 1993; 1997), below the age of 3 years its use needs to be supplemented by experienced clinical judgement based on information from a variety of sources (Baird et al., 2001; Cox et al., 1999; Lord, 1995) if reliable diagnosis is to be achieved. In the present study it was necessary to supplement parental report, which was sometimes inaccurate, with judgement and observations made by experienced clinicians. Parental inaccuracy in identifying the subtle early markers of autism has been noted before (e.g. Cox et al., 1999) and may occur for many reasons including failure to fully understand the question asked, poor observational skills, misinterpretation
of the child's behaviour, or an overriding wish for the child to be normal (Baird et al., 2001). These biases can be overcome to a large extent by careful observation of the child in situations contrived to elicit behaviours of interest to the clinician (Charman, 1998), for example through the use of the Autism Diagnostic Observation Schedule (ADOS-G: Lord et al., 1998). However, items in the ADI–R which depend on parental recall (those scored if they have 'ever' occurred) may still be particularly prone to inaccuracy in the assessment of older children, presumably because parents forget to report behaviours which are no longer so salient; for example the reporting of significantly fewer 'complex mannerisms' between first and second assessments by parents in the present study.

These observations underline the importance of ensuring that families have access to informed and objective professional judgement from the very earliest stages in the identification of autistic spectrum disorders. Since the literature suggests that there is wide variation in professionals' knowledge of and expertise in the area of identifying autism (Baird et al., 2000; Chung et al., 1995; O'Hare et al., 1998; Waite and Woods, 1999) this is a training issue which needs to be addressed.

The present study found little change overall in children's scores in the social and communication domains between their first and second assessments, and although there was a general improvement in level of language development, even those children whose speech increased most showed significantly impaired conversational skills. These findings attest to the pervasive nature of the communication and social problems which affect the lives of people who have autistic spectrum disorders (Howlin, 1998a; 1998b). Indeed the study group as a whole showed increasing difficulties in the area of peer relationships by the time of their second assessment. This finding is partly an artefact of the ADI–R's scoring system (some aspects of peer relationships cannot be scored below the age of 4) but the increasing difficulties in this area were shown predominantly by those children who presented initially with significant behaviour problems. It is not possible to determine whether these children showed more difficult behaviour because they were more socially impaired, or whether the fact that they presented with more difficult behaviour made it harder for them to develop social skills (possibly because adults and children they encountered reacted more negatively to them). In any event, Howlin's (1998b) recommendation that early behaviour management advice is crucial may be particularly important for this group, and our findings suggest that emphasis may need to be placed on helping young children with autism who present with a range of behaviour problems to develop their social interactions with other children. Indeed, one of the primary goals of early identification and assessment should be to facilitate referral to early intervention designed to develop skills as well as
manage behaviour, and this is now mandatory in the USA (Baird et al., 2001). In the UK, despite growing evidence that early intervention is beneficial (see the introduction), there remains wide variability in access to it (e.g. Moore et al., 1999).

The present study found, in common with others, that there was a general increase in the number of repetitive behaviours reported between the ages of 2 and 4 years (Cox et al., 1999; Stone et al., 1999). No one type of behaviour was reported to increase more than others, suggesting that the precise pattern is unpredictable and will vary from child to child. Unusual preoccupations and the presence of compulsions and rituals were particularly unlikely to be reported at the age of 2. Stone et al. (1999) also noted that routines and rituals were rarely observed in this young age group.

The children in our sample were less intellectually impaired than would be expected on the basis of population studies, which have shown that the majority of children with autism (70–75 percent) have an associated learning disability and half have an IQ of less than 50 (Howlin, 1998b). This may reflect a referral bias to the nursery group in question, which catered specifically for children with impaired language and communication skills, whereas other groups were available for children who presented with generalized developmental delay. However, some consideration also needs to be given to the types of tasks used to measure non-verbal functioning. The majority of children in the present study were assessed using scales D (eye and hand coordination) and E (performance) of the Griffiths Mental Development Scales, and it was found that they scored significantly better on the E scale (which contains a large number of puzzle items) than on the D scale (which contains a large number of drawing items). Superior performance on the E scale may attest to children with autism's known facility with puzzle-type items (Shah and Frith, 1993), and/or to a particular difficulty with early drawing. Preschool language-impaired children are known to find drawing tasks relatively difficult, suggesting that even in its earliest stages, drawing may contain symbolic elements which are difficult for them to grasp (Moore and Law, 1990). Care therefore needs to be exercised over the choice of non-verbal tasks used to assess intellectual functioning in children whose language and communication skills are delayed, including children with autism, as tasks with differing contents are likely to yield different results (see also Magiati and Howlin, 2001). Close scrutiny of these differences may in itself lead to better understanding of the cognitive deficits which are central to autism (cf. Frith, 1989; Happé, 1994).

One important consequence of undertaking this study has been the need to face parents with potentially devastating diagnostic information at a very early stage in their child's life. Many studies in the area of childhood disability have shown that the way in which such news is broken and the type
of support offered is crucially important. In general parents prefer to be told about their child’s disability as early as possible by empathic and informed clinicians, and they want immediate practical help with the management of their child, as well as ongoing emotional and practical support. Indeed several studies have stressed that breaking bad news is a process which may continue for many years rather than a ‘one-off’ event (Cottrell and Summers, 1990; Howlin and Moore, 1997; Leff and Walizer, 1992; Midence and O’Neill, 1999; Quine and Rutter, 1994). A diagnosis of autism, which is an ‘invisible’ condition evolving over time, may be particularly difficult to accept (Howlin and Moore, 1997; Midence and O’Neill, 1999). We have been struck by how traumatic this process can be for many families and also by how much variability exists in families’ reactions to their child undergoing an early autism assessment. In our view, it is of paramount importance for all health professionals involved in early assessment and diagnosis of autism to be sensitive to the differing needs of parents, and to offer ongoing support, both practical and emotional, to the families of children with autism.

The present study may be criticized on the grounds that although clinicians who undertook the second assessment did not have access to the ADI–R scores from the child’s earlier assessment, they did have access to information concerning the child’s tentative diagnosis. This was unfortunately unavoidable since data were collected as part of a clinical service in which information about previous assessments was required by the tertiary Autism Assessment Team before accepting referrals. It is also unfortunate that no comparison data were available from the follow-up of children who were not given a diagnosis within the autistic spectrum at their first assessment. Although this group of children existed, it was not considered appropriate to offer them further assessment by a team specifically concerned with diagnosis of autism (except in the one case of language disorder reported, when the parents requested a second assessment).

Development of Southampton early diagnostic service

On the basis of published work and the present study confirming the stability of diagnoses of autistic spectrum disorders made at age 2, we now offer a full early diagnostic service in the CDC for children referred between the ages of 2 and 3 years for consideration of possible autism. This has the advantage of enabling children to access suitable intervention and educational programmes at a much earlier stage than previously (e.g. the National Autistic Society’s EarlyBird programme: Shields, 2001). We no longer recommend further assessment at age 4–5 years except in a very small number of cases where diagnosis is difficult to determine and/or parents are unhappy with the diagnosis they receive.
Figure 4  Early diagnostic assessment process

Referral into CDC from community paediatrician

Medical investigations as necessary

Assessment of hearing

Assessment of vision

Nursery assessment over 8–10 weeks

Child
- Assessment of play and self-help skills (teacher)
- Assessment of motor skills (teacher, OT, physiotherapist as necessary)
- Assessment of language and communication skills (SALT)

Parent(s)
- Weekly parent support group (clinical psychologist and counselor)

ADOS assessment
(SALT and clinical psychologist)

Home-based assessment (clinical psychologist)
- Developmental assessment
- ADI-R

Full case discussion
CDC team + parents
- GP and health visitor invited

Feedback session (SALT and clinical psychologist)

Ongoing parent support group...

Child moves to educational placement/early intervention programme
The essential features of our early diagnostic service are described above (see 'Procedure'), but in the light of experience gained by carrying out the follow-up study it has been improved by the following additions:

- Routine use of ADOS-G (Lord et al., 1998). This is a structured play observation designed to elicit behaviours typically shown by children who have autistic spectrum disorders. It provides scorable observational data to complement the interview data derived from the ADI–R.
- Feedback session held between parents and a maximum of two professionals in which the child's diagnosis is discussed and ongoing support is offered.
- Weekly parent support group (facilitated by a clinical psychologist and trained counsellor) which takes place whilst the children are in the nursery group. This group has recently (at the parents' request) been extended beyond the point at which the children leave the CDC.

The main features of the early diagnostic service are shown in Figure 4. The service is labour-intensive, with each child and family receiving a great deal of professional input during the assessment period. The high levels of staff training needed to deliver the service may appear to be prohibitive, but it is worth remembering that inexperienced clinicians fare no better than chance in accurately diagnosing young children who have autistic spectrum disorders (Stone et al., 1999).

Acknowledgements
We would particularly like to thank all the children who took part in this study and their families. We are grateful to all members of the Wordsworth House Team and the Southampton Autism Assessment Service who contributed to the assessment process. We are indebted to Raj Mehta for statistical advice and to Jean Osman for typing the manuscript.

Notes
1 One girl deviated sharply from the rest of the group, showing receptive language within normal limits at her second assessment, whereas her expressive language remained below a 12 month level. Her data have been excluded (see 'Discussion').
2 ADI–R data are presented for the 19 children with diagnoses within the autistic spectrum. Data from the one child with a language disorder are omitted from this analysis.

References
MOORE & GOODSON: EARLY DIAGNOSIS OF AUTISM


AUTISM 7(1)


MOORE & GOODSON: EARLY DIAGNOSIS OF AUTISM


How well does early diagnosis of autism stand the test of time?

Follow-up study of children assessed for autism at age 2 and development of an early diagnostic service

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SALLY GOODSON
Tremona Road Children's Centre, Southampton, UK

ABSTRACT
Twenty children who presented with severe interactional and communication difficulties at age 2 underwent a comprehensive assessment for autism, and were reassessed at age 4–5. In common with other recent studies, diagnosis of autistic spectrum disorders at age 2 was found to be reliable and stable. The communication and social skills of the children showed little change overall by the second assessment. However, children whose scores deteriorated in the social domain tended to have presented initially with more significant behaviour problems. Few repetitive behaviours were observed at age 2, whereas these were more apparent by age 4–5. The finding that early diagnosis of autism is reliable and stable has led to the development of an early diagnostic service in Southampton, which is described. The importance of early diagnosis is that it opens the door to early intervention programmes, which in turn prevent many problems from occurring in later life.

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KEYWORDS
assessment; autism; Autism Diagnostic Interview; early diagnosis; parent support

Introduction
Recent interest in the early identification and diagnosis of children with autism has been driven to a great extent by the reported success of specialized early intervention programmes (e.g. Hoyson et al., 1984; Lovaas, 1987; Ozonoff and Cathcart, 1998; Rogers and Lewis, 1989; Sheinkopf and Seigel, 1998).
Because eligibility for participation in these programmes is often limited to children who have a formal diagnosis of autism, early identification and accurate assessment are crucially important. Furthermore, young children with undiagnosed autism may be assigned to inappropriate programmes which do not provide the necessary degree of continuity, staff expertise or adult/child ratio generally recommended for children with autism (Chung et al., 1995). The establishment of appropriate behaviour management strategies in the early years can also help to minimize or even avoid many subsequent behaviour problems occurring (Clements and Zarkowska, 2000; Howlin, 1998b; Howlin and Rutter, 1987). Other important opportunities offered by early identification include implementation of appropriate educational planning, access to professional support services, and genetic counselling (Cox et al., 1999). In addition, Howlin and Moore (1997) found that parents were much more satisfied with the diagnostic process if it occurred in the preschool years.

If diagnosis is to be attempted early, it needs to be established that signs of autism can be detected accurately in young children, and that early diagnosis can stand the test of time. Several recent studies have investigated the stability of early diagnosis by assessing children for possible autism around the age of 2 years, and reassessing the same children later when they were aged between 3 and 4 years (Cox et al., 1999; Lord, 1995; Stone et al., 1999). These studies have led to the general conclusion that autism can be reliably diagnosed at age 2 and that the diagnosis is stable. However, accurate diagnosis is dependent on comprehensive clinical assessment (including parental interview, child observation, and cognitive/developmental and language testing), and it is less reliable, particularly at age 2, if it focuses on one measure alone such as the Autism Diagnostic Interview (ADI: LeCouteur et al., 1989; Lord et al., 1994). The ADI relies on parental report of observed child behaviour, and the studies employing it suggest that this may be particularly prone to inaccuracies in the case of the subtle, qualitative behavioural features which are markers of autism in very young children (Cox et al., 1999; Lord, 1995). It also appears that clinicians themselves need to have considerable experience, both in the assessment of autism and in evaluating preschool children, for reliable early diagnosis to be made (Stone et al., 1999).

It is important therefore to consider what these subtle, early markers of autism are. The follow-up studies of Lord, Cox et al. and Stone et al. all reported more impairments in the social and communication domains than in the repetitive behaviour category; indeed repetitive behaviours were rarely observed in 2-year-olds, although they were found in most children with autism by the age of 3½; (Cox et al., 1999). Other studies have looked
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In spite of the considerable evidence of identifiable markers of autism in very young children, early diagnosis is not the norm (Chung et al., 1995; Howlin and Moore, 1997; Moore et al., 1999; O’Hare et al., 1998). For example, Howlin and Moore (1997) found in their survey of over 1000 parent members of UK autistic societies that, although the average age at which parents first had concerns about their child was 1.7 years, the average age of diagnosis was not until around the age of 6 years. Whilst there is evidence of a recent trend towards younger diagnosis, early identification and assessment is by no means common practice (Baird et al., 2001).

Mindful of this yawning gap between the early signs of autism and arriving at a diagnosis, but also aware of the need for diagnosis to be accurate and assessment to be comprehensive, we embarked on a follow-up study of children referred to our local child development centre for assessment of possible autism, with the eventual aim of setting up a comprehensive early diagnostic service in our local area.

**Method**

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**Procedure**

**Initial assessment**  Children showing significant communication and interactional problems were referred into the CDC by a community paediatrician for an assessment lasting typically 8 to 10 weeks. Assessment relied heavily on observations made during the child's attendance at a weekly nursery group for 1½ hours. This afforded opportunities for ongoing assessment of language and communication skills carried out by a speech and language therapist and assessment of play, motor, cognitive and self-help skills carried out by trained nursery staff. In addition, each child was visited at home by a clinical psychologist in order to complete the ADI–R, carry out further observation of the child's behaviour and further cognitive/developmental testing (using the Griffiths Mental Developmental Scales: Griffiths, 1984) as appropriate.

The ADI–R was scored predominantly on the basis of parental report. However, if there was a clear discrepancy between this and observations in other settings, a consensus was reached in discussion involving all staff towards the end of the assessment. (For example, if a parent reported no pointing for interest, or no unusual sensory interests, but these had clearly been seen, the observation would be reflected in the child's score.) ICD-10 diagnosis was arrived at on the basis of the ADI–R scores, which did however incorporate the element of clinical judgement described. In practice, the differences between parental report and consensus were variable: in the majority of cases they were slight or non-existent, but in a small minority of cases they were more readily apparent.

**Follow-up assessment**  This was a 1 day assessment carried out by the Regional Autism Assessment Service based at Southampton General Hospital. This service has been described in detail elsewhere (Moore et al., 1998), and essentially comprised educational assessment carried out by a teacher; cognitive/developmental assessment and assessment of play, language and communication skills carried out by a speech and language therapist and clinical psychologist working together; and structured observation of the child during meal and break times carried out by a member of the nursing staff. Whereas in the initial assessment estimates of language levels had been based on detailed observations within the nursery setting, at the second assessment observation was combined with the use of formal tests where appropriate (see Moore et al., 1998). An ADI–R was
administered by a trained clinician (paediatrician or child psychiatrist) who was unaware of the ADI–R scores obtained by the clinical psychologist at the previous assessment. ICD-10 diagnosis was arrived at following team discussion at the end of the day. As above, the ADI–R scores incorporated an element of clinical judgement in that they were altered to reflect any clear discrepancies between parental report and observations made by trained staff during the course of the day.

All children in the study moved into supported educational placements following their attendance at the CDC for initial assessment. They therefore received comparable amounts of intervention between the two assessments.

Results

The diagnoses assigned to children on the basis of their early and second assessments are shown in Table 1.

Fourteen of the 16 children diagnosed with autism at their first assessment retained that diagnosis at their second assessment (87.5 percent). The remaining two children received diagnoses of ‘atypical autism’ at follow-up. (This diagnosis applied to children who met the ICD-10 diagnostic criteria for autism in one or two but not all three of the areas of abnormality specified.) Two children originally diagnosed with atypical autism received a diagnosis of autism at follow-up. The two remaining children (one with atypical autism and one with a language disorder) retained their original diagnoses. The girl with Turner syndrome met full ICD-10 criteria for autism on both occasions.

Since the children in the study had all been referred originally as a result of significant language and communication problems, they all had very delayed language development. The average levels of language development at the children's initial assessment were 12.9 months for receptive language (range 9 to 22 months) and 15.2 months for expressive language (range

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9 to 24 months). In the vast majority of cases there was no discrepancy between levels of expressive and receptive language. Where a discrepancy did exist (in three cases), expressive language was more advanced than comprehension. At the time of the children's second assessment, the average level of expressive language was 20 months (range less than 12 months to 3 years 3 months) and the average level of receptive language was 21.1 months (range less than 12 months to 3 years 6 months). Only four children had sufficient speech to be scored on the verbal items of the ADI–R at their second assessment.

The children's non-verbal skills spanned the ability range with an average non-verbal IQ of 71.4 (range 26–93). Two children had non-verbal IQs less than 50, six children had non-verbal IQs between 50 and 70, and the remaining 12 children had non-verbal IQs of 70 or above. These quotients were obtained using the Leiter International Performance Scale (Leiter, 1979) (three children), or from averaging quotients obtained on the two non-verbal scales (D and E) of the Griffiths Mental Development Scales (17 children). When scores for scales D and E were separated, it was noted that scores on scale E were significantly higher than scores on scale D (average D = 62.4; average E = 78.2; \( t = -8.52, \) d.f. = 16, \( p < 0.001 \)).

The cut-off values for the three domains covered by the ADI–R are 10 for qualitative impairments in reciprocal social interaction, 7 (non-verbal) or 8 (verbal) for qualitative impairments in communication, and 3 for presence of repetitive and stereotyped patterns of behaviour. The scores children obtained in these three domains at their first and second assessments are shown in Figure 1.2

![Figure 1](ADI-R domain scores at first and second assessments. Maximum possible scores for each domain are: social 30; communication 14; repetitive behaviour 10 (\( N = 19 \))}
Whilst scores in the social and communication domains did not change for the group as a whole, there was a significant increase in scores for the repetitive behaviour category (Wilcoxon $Z = -3.23$, $p < 0.001$).

Within the social domain, whilst there was a tendency for scores to decrease (i.e. improve) by the time of the second assessment in components B1 (failure to use non-verbal behaviours to regulate social interaction), B3 (lack of shared enjoyment) and B4 (lack of socio-emotional reciprocity), there was a significant increase in scores on B2 (failure to develop peer relationships) (Wilcoxon $Z = -3.74$, $p < 0.001$).

Within the communication domain, there was a tendency for scores generally to decrease by the time of the second assessment, but none of these improvements were statistically significant. The four children who had developed sufficient speech to be scored on the verbal items of the ADI-R all showed autistic features in this area, particularly in component C2V (failure to initiate or sustain a conversational interchange).

In the repetitive behaviour category, parents were more likely to report the presence of body mannerisms, repetitive use of objects and unusual sensory interests than compulsions and rituals or unusual preoccupations at the age of 2. The data are shown in Figure 2.

Between the first and second assessments there were increases in circumscribed interests (which cannot be scored below the age of 4 years), unusual preoccupations, compulsions and rituals, hand and finger mannerisms and repetitive use of objects. However, none of these tendencies...
achieved statistical significance. There was a significant decrease in the reporting of complex mannerisms ($p < 0.004$, McNemar test).

Closer inspection of data for the social domain revealed that for 10 of the children diagnosed in the autistic spectrum at their second assessment, social scores had actually increased, whereas for the remaining nine children scores had decreased since the time of their first assessment. The children whose social scores were higher diverged from the rest of the group in particular on one component within the social domain, B2 (failure to develop peer relationships) ($\text{Mann–Whitney } Z = -3.05, p < 0.001$). The data are shown in Figure 3.

Although there was a tendency for children with increased social scores to obtain higher scores on other components within the social domain also (i.e. B1, B3 and B4), none of these differences were significant.

An increase in social score was not associated with the child's level of non-verbal functioning (using non-verbal IQ as a linear predictor of change in social score; $t = 0.66, p < 0.52$) or with the amount of language the child possessed (using language quotient, based on overall language level as a proportion of the child's chronological age, as a linear predictor of change in social score; $t = -0.76, p < 0.46$). However, inspection of the clinical notes of children whose social scores increased revealed that all children in this group had presented at their first assessment with behaviour problems which were sufficiently worrying to prompt referral to a

![Figure 3](image-url)  
*Figure 3*  ADI–R scores on components comprising social domain at second assessment. Number of questions (each with maximum possible score of 2) relating to each domain category are: B1 = 3, B2 = 4, B3 = 3, B4 = 5 ($N = 19$)
clinical psychologist. Indeed there was overwhelming evidence of an association between referral to clinical psychology and an increase in social score (Fisher’s exact \( p < 0.0001 \)). Problem behaviours were varied and included pica, temper tantrums, overactivity and insistence on sameness.

Although children in the group whose social scores decreased also showed behaviours which were difficult to manage, they were not of sufficient intensity to require input from a clinical psychologist, and this group tended generally to be more passive.

**Discussion**

The findings of the present study suggest that it is possible to make an informed clinical diagnosis of an autistic spectrum disorder in children aged 2–3 years with 100 percent accuracy. Specific diagnosis of autism was found to be somewhat less reliable, but was nonetheless made with 87.5 percent accuracy (14 of the 16 children diagnosed with autism at age 2 retained their original diagnosis at age 4). The two children who moved from a diagnosis of ‘autism’ to ‘atypical autism’ at their second assessment continued to show significant communication and social difficulties requiring considerable support. One of these children, a girl, was found following assessment to have a paternal duplication of chromosome 15 at the molecular level. Although she fell within the ‘atypical autism’ category, she presented with an unusual clinical picture of virtually non-existent expressive language, impaired social development and a large number of repetitive behaviours in the context of normal verbal comprehension and reasonably good non-verbal communication skills.

Our findings are consistent with those of other studies which have found that clinical diagnosis of autistic spectrum disorders at the age of 2 is reliable and stable (Lord, 1995), and that children who remain within the autistic spectrum continue to show significant impairments (Stone et al., 1999).

Other studies have also shown that whilst the ADI can effectively differentiate autism from learning disability and language impairments (Lord et al., 1993; 1997), below the age of 3 years its use needs to be supplemented by experienced clinical judgement based on information from a variety of sources (Baird et al., 2001; Cox et al., 1999; Lord, 1995) if reliable diagnosis is to be achieved. In the present study it was necessary to supplement parental report, which was sometimes inaccurate, with judgement and observations made by experienced clinicians. Parental inaccuracy in identifying the subtle early markers of autism has been noted before (e.g. Cox et al., 1999) and may occur for many reasons including failure to fully understand the question asked, poor observational skills, misinterpretation
of the child's behaviour, or an overriding wish for the child to be normal (Baird et al., 2001). These biases can be overcome to a large extent by careful observation of the child in situations contrived to elicit behaviours of interest to the clinician (Charman, 1998), for example through the use of the Autism Diagnostic Observation Schedule (ADOS-G: Lord et al., 1998). However, items in the ADI–R which depend on parental recall (those scored if they have ‘ever’ occurred) may still be particularly prone to inaccuracy in the assessment of older children, presumably because parents forget to report behaviours which are no longer so salient; for example the reporting of significantly fewer ‘complex mannerisms’ between first and second assessments by parents in the present study.

These observations underline the importance of ensuring that families have access to informed and objective professional judgement from the very earliest stages in the identification of autistic spectrum disorders. Since the literature suggests that there is wide variation in professionals’ knowledge of and expertise in the area of identifying autism (Baird et al., 2000; Chung et al., 1995; O’Hare et al., 1998; Waite and Woods, 1999) this is a training issue which needs to be addressed.

The present study found little change overall in children’s scores in the social and communication domains between their first and second assessments, and although there was a general improvement in level of language development, even those children whose speech increased most showed significantly impaired conversational skills. These findings attest to the pervasive nature of the communication and social problems which affect the lives of people who have autistic spectrum disorders (Howlin, 1998a; 1998b). Indeed the study group as a whole showed increasing difficulties in the area of peer relationships by the time of their second assessment. This finding is partly an artefact of the ADI–R’s scoring system (some aspects of peer relationships cannot be scored below the age of 4) but the increasing difficulties in this area were shown predominantly by those children who presented initially with significant behaviour problems. It is not possible to determine whether these children showed more difficult behaviour because they were more socially impaired, or whether the fact that they presented with more difficult behaviour made it harder for them to develop social skills (possibly because adults and children they encountered reacted more negatively to them). In any event, Howlin’s (1998b) recommendation that early behaviour management advice is crucial may be particularly important for this group, and our findings suggest that emphasis may need to be placed on helping young children with autism who present with a range of behaviour problems to develop their social interactions with other children. Indeed, one of the primary goals of early identification and assessment should be to facilitate referral to early intervention designed to develop skills as well as
manage behaviour, and this is now mandatory in the USA (Baird et al., 2001). In the UK, despite growing evidence that early intervention is beneficial (see the introduction), there remains wide variability in access to it (e.g. Moore et al., 1999).

The present study found, in common with others, that there was a general increase in the number of repetitive behaviours reported between the ages of 2 and 4 years (Cox et al., 1999; Stone et al., 1999). No one type of behaviour was reported to increase more than others, suggesting that the precise pattern is unpredictable and will vary from child to child. Unusual preoccupations and the presence of compulsions and rituals were particularly unlikely to be reported at the age of 2. Stone et al. (1999) also noted that routines and rituals were rarely observed in this young age group.

The children in our sample were less intellectually impaired than would be expected on the basis of population studies, which have shown that the majority of children with autism (70–75 percent) have an associated learning disability and half have an IQ of less than 50 (Howlin, 1998b). This may reflect a referral bias to the nursery group in question, which catered specifically for children with impaired language and communication skills, whereas other groups were available for children who presented with generalized developmental delay. However, some consideration also needs to be given to the types of tasks used to measure non-verbal functioning. The majority of children in the present study were assessed using scales D (eye and hand coordination) and E (performance) of the Griffiths Mental Development Scales, and it was found that they scored significantly better on the E scale (which contains a large number of puzzle items) than on the D scale (which contains a large number of drawing items). Superior performance on the E scale may attest to children with autism's known facility with puzzle-type items (Shah and Frith, 1993), and/or to a particular difficulty with early drawing. Preschool language-impaired children are known to find drawing tasks relatively difficult, suggesting that even in its earliest stages, drawing may contain symbolic elements which are difficult for them to grasp (Moore and Law, 1990). Care therefore needs to be exercised over the choice of non-verbal tasks used to assess intellectual functioning in children whose language and communication skills are delayed, including children with autism, as tasks with differing contents are likely to yield different results (see also Magiati and Howlin, 2001). Close scrutiny of these differences may in itself lead to better understanding of the cognitive deficits which are central to autism (cf. Frith, 1989; Happé, 1994).

One important consequence of undertaking this study has been the need to face parents with potentially devastating diagnostic information at a very early stage in their child's life. Many studies in the area of childhood disability have shown that the way in which such news is broken and the type
of support offered is crucially important. In general parents prefer to be told about their child’s disability as early as possible by empathic and informed clinicians, and they want immediate practical help with the management of their child, as well as ongoing emotional and practical support. Indeed several studies have stressed that breaking bad news is a process which may continue for many years rather than a ‘one-off’ event (Cottrell and Summers, 1990; Howlin and Moore, 1997; Leff and Walizer, 1992; Midence and O’Neill, 1999; Quine and Rutter, 1994). A diagnosis of autism, which is an ‘invisible’ condition evolving over time, may be particularly difficult to accept (Howlin and Moore, 1997; Midence and O’Neill, 1999). We have been struck by how traumatic this process can be for many families and also by how much variability exists in families’ reactions to their child undergoing an early autism assessment. In our view, it is of paramount importance for all health professionals involved in early assessment and diagnosis of autism to be sensitive to the differing needs of parents, and to offer ongoing support, both practical and emotional, to the families of children with autism.

The present study may be criticized on the grounds that although clinicians who undertook the second assessment did not have access to the ADI–R scores from the child’s earlier assessment, they did have access to information concerning the child’s tentative diagnosis. This was unfortunately unavoidable since data were collected as part of a clinical service in which information about previous assessments was required by the tertiary Autism Assessment Team before accepting referrals. It is also unfortunate that no comparison data were available from the follow-up of children who were not given a diagnosis within the autistic spectrum at their first assessment. Although this group of children existed, it was not considered appropriate to offer them further assessment by a team specifically concerned with diagnosis of autism (except in the one case of language disorder reported, when the parents requested a second assessment).

Development of Southampton early diagnostic service

On the basis of published work and the present study confirming the stability of diagnoses of autistic spectrum disorders made at age 2, we now offer a full early diagnostic service in the CDC for children referred between the ages of 2 and 3 years for consideration of possible autism. This has the advantage of enabling children to access suitable intervention and educational programmes at a much earlier stage than previously (e.g. the National Autistic Society’s EarlyBird programme: Shields, 2001). We no longer recommend further assessment at age 4–5 years except in a very small number of cases where diagnosis is difficult to determine and/or parents are unhappy with the diagnosis they receive.
Figure 4  Early diagnostic assessment process
The essential features of our early diagnostic service are described above (see 'Procedure'), but in the light of experience gained by carrying out the follow-up study it has been improved by the following additions:

- Routine use of ADOS-G (Lord et al., 1998). This is a structured play observation designed to elicit behaviours typically shown by children who have autistic spectrum disorders. It provides scorable observational data to complement the interview data derived from the ADI–R.
- Feedback session held between parents and a maximum of two professionals in which the child’s diagnosis is discussed and ongoing support is offered.
- Weekly parent support group (facilitated by a clinical psychologist and trained counsellor) which takes place whilst the children are in the nursery group. This group has recently (at the parents’ request) been extended beyond the point at which the children leave the CDC.

The main features of the early diagnostic service are shown in Figure 4.

The service is labour-intensive, with each child and family receiving a great deal of professional input during the assessment period. The high levels of staff training needed to deliver the service may appear to be prohibitive, but it is worth remembering that inexperienced clinicians fare no better than chance in accurately diagnosing young children who have autistic spectrum disorders (Stone et al., 1999).

Acknowledgements
We would particularly like to thank all the children who took part in this study and their families. We are grateful to all members of the Wordsworth House Team and the Southampton Autism Assessment Service who contributed to the assessment process. We are indebted to Raj Mehta for statistical advice and to Jean Osman for typing the manuscript.

Notes
1 One girl deviated sharply from the rest of the group, showing receptive language within normal limits at her second assessment, whereas her expressive language remained below a 12 month level. Her data have been excluded (see ‘Discussion’).
2 ADI–R data are presented for the 19 children with diagnoses within the autistic spectrum. Data from the one child with a language disorder are omitted from this analysis.

References


Book reviews


Researchers in the field of autistic cognition, particularly those interested in autistic savants, are familiar with the pioneering work of Hermelin and O’Connor. Dr Beate Hermelin has recently published this book, dedicated to Neil O’Connor, in which she discusses her personal experience in studying autistic savants.

The book contains 13 chapters. The first three chapters provide general descriptions of autism and methodological principles involved in the study of autism. Chapters 4 to 12 each present a particular domain of knowledge or expertise that can be seen in autistic savants. Some of these are frequent abilities found among autistic persons (for example, calendar calculation); others are much rarer and thus represent interesting challenges to current theories. For example, Chapter 4 presents a patient with Asperger syndrome who writes poetry to describe her internal world. This chapter illustrates the fact that autistic savants can have some degree of creativity and artistic ability, contrary to what is generally believed. An expression of their suffering and lack of understanding of the world in which they live can be realized through music, drawing, dance and poetry, as is exemplified here. The last chapter presents Hermelin’s theoretical account of autism and savant abilities. She proposes that their cognitive style of focusing on separate elements and features serves as the basic cognitive characteristic from which savant abilities can emerge.

Obviously, this book is addressed to a general audience. The first three chapters are very general, written for a non-professional audience. Very basic matters, such as statistical and methodological principles, are explained in simple terms that are accessible to the layperson. The subsequent chapters are very short and mostly descriptive, although they attempt to reach the explanatory level in a few cases. Each chapter presents a fine grain analysis of each ability and describes ingenious experimental manipulations conducted by the author’s group over the years to investigate the underlying mechanisms of autism. The majority of the chapters conclude that there is nothing especially atypical in the way that these individuals perform these abilities. Furthermore, it is unfortunate that no reference is provided so that
the interested reader can go back to the specifics of the numerous experiments. Given the subtitle of the book, 'A personal story of research with autistic savants', the reader does not expect a review of the most relevant and cogent literature on the topic. Indeed, this is far from the case: it is clear that the book is intended to be a personal account. Yet, given that theoretical propositions are clearly made, particularly at the end of the book, it may have been appropriate to discuss how scientific facts from other laboratories fit into the proposed scheme. A lot of interesting and new data and theories are overlooked here and might have contributed by supporting, enriching or even challenging the hypotheses proposed by the author.

In conclusion, the book will be of interest to two specific audiences. First, savant persons, clinicians, parents, undergraduates and any non-specialist with an interest in these fascinating aspects of autism will enjoy this book. At the other extreme, researchers with a specific interest in special abilities will also read this book with pleasure, as it provides valuable illustrations of a broad range of savant abilities.

SYLVIE BELLEVILLE
Université de Montréal, Canada


This readable book is intended specifically for teachers and parents of young people with autism, aiming to ‘offer a practical approach for staff and carers who want to develop the use of ICT (Information and Communications Technology) for children on the autistic spectrum’. It succeeds in this aim, as it provides a good background in deciding how to use ICT to address some of a child’s specific needs. It provides interesting first-hand examples of how the authors have previously gone about this, documenting case studies: describing the child, how difficulties were overcome and the various solutions that were decided upon. The authors are obviously enthusiastic about the use of ICT with children with autism, but they do not overstate the case, seeing computer work within the context of a broad range of educational activities.

The book starts with a full introduction to autism as clinically outlined, and also how those symptoms are presented in an educational context (Chapters 2 and 3). However, considering that this book is for teachers and parents of children with an autism spectrum disorder, it is not clear why such a comprehensive background is needed, as other books are available.
which can give a broader background to autism research and general teaching practice.

This book might have some practical tips for researchers using ICT with people with ASDs. However, those looking for a discussion of specific experimental studies demonstrating how use of ICT can positively influence children with autism will be disappointed. Some research is touched upon, but it is not a review of research into the interaction between technology and people with ASDs. For example, virtual reality is mentioned several times, yet no software and no research group is mentioned.

This book does have interesting ideas: the case studies are realistic and interesting, the photocopiable pages are useful and the enthusiasm for ICT is somewhat infectious. Yet there are aspects that needed greater consideration. It would have been useful for the book to highlight more obviously what age range and ability level different sections were intended for, as the chapters seem to leap about between ages and abilities. Readers who are not au fait with the English National Curriculum will be limited in their understanding at some points, owing to the frequent references and specialist terms used without explanation. Many technical terms are used that are not fully explained: a glossary would have been an obvious option to include in a book such as this. The figures used are frequently amateur and sometimes irrelevant to the text: more photographs illustrating the points made in the text would have been more appropriate. The figures are mostly not referred to in the text, and sometimes do not accompany the relevant piece of text. In the case study section, a triangular ‘ASD profile’ diagram was shown with each description of an individual child, which was not explained. At some points, the authors assume that the readers have too much prior information, and do not clearly explain the functions of software or hardware. The book is sometimes let down by inconsistent formatting and grammatical errors. The internet chapter could have been put to a more useful purpose by outlining how the internet is being used by some people with autism to make contact with others, for example through e-mail or chat-rooms like the IRC channel for people with Asperger syndrome.

This book makes a good starting point for any teachers or parents wanting to know more about how they can help a child with autism use ICT. However, there is still room for a more comprehensive guide for those requiring a more detailed approach.

ANNE LEONARD
University of Nottingham, UK

Written by a parent from the US, this book aims to aid teachers in helping children with non-verbal learning disabilities (NLD) ‘to achieve their full potential in the classroom’ (back cover). It is a follow-up to the author's previous title Nonverbal Learning Disabilities at Home.

In general I am a great supporter of parent-written texts. There are many families who find the education or health system fairly ineffective at either describing or supporting their children, and parental experience can be both comforting and empowering. However, I have a number of difficulties with this volume.

First, I feel the book presents mixed messages. This starts with the back cover introduction which describes the book as being for teachers, when in fact it is clearly for parents. In the ‘Afterword’, Pamela Tanguay stresses that 'we can become so involved in trying to “fix” the child’s problems that we forget to let her be a kid’ (p. 215), and yet the entire body of this volume is about how to ‘fix’ your child with NLD. It appears to be a book about parental experience, but in fact attempts a much wider presentation of both theory and practice.

Second, the book is imprecise and unclear about some aspects of NLD. For example, sections on mental flexibility, pragmatic language and social skills are confused, as is the issue of whether NLD is a description encompassing several other disorders listed (including Asperger syndrome, Williams syndrome, hydrocephalus, cerebral damage), or a syndrome, or a distinct disorder.

Third, there appear to be some strong claims that are given no real justification, have little information about their source, and rarely examine other possibilities. The usefulness of these claims is therefore less helpful to parents. One such claim is that ‘the disorder is caused by damage to white matter in the brain’, that there is a resulting ‘short circuit somewhere in the child’s brain’ and that there is more ‘white matter in the right hemisphere of the brain versus the left’ in individuals with NLD (pp. 24 and 25). Considering the wide range of syndromes included in NLD, this statement seems to me to at least require more examination by the author if it is to be addressed usefully. Other examples include a paragraph stating that concurrent anxiety is directly caused by the NLD, but no justification of this directional relationship is given (p. 26), and there is also a mention of ‘the physically adept ... AD/HD child’ (p. 46), which many parents and clinicians might question.
Finally, I am not convinced that the best way to empower parents is to provide a long list of ideals which they are unlikely to achieve. For example, in Chapter 3, parents are told that ‘During the early years [of school], the maximum class size should be between 6 and 8 children with fewer being ideal. There should be both a teacher and an aid’ (p. 50). As far as I am aware, this need for a 1:3 ratio is unlikely to be fulfilled even in the best-resourced special or private schools in the UK. Furthermore, the author states, a placement with children who have learning difficulties or emotional and behavioural difficulties would ‘seriously undermine her education’. The text continues with advice against pictures on walls, group activities, sitting next to a distracting child, desks in work groups rather than rows, desks too close to one another, and classroom aids that are not qualified teachers. At the same time, the reader is informed that ‘every step that is taken away from what the NLD child needs compromises her ability to succeed’ (p. 53).

There are some good sections – mainly those which describe what life with a child who has NLD can be like (e.g. p. 34). Many parents will recognize their children in these well written passages which contain subtle observations often missed by professionals. The text is very accessible and the chapters are relevant to the readers it aims to reach. There are some useful suggestions for teachers (e.g. p. 143), a comprehensive glossary, a bibliography and a list of (mainly US based) contact organizations. However, in my experience of families with difficulties, parents sometimes feel weighed down by guilt that they are somehow failing to do the best for their child. Unclear, unsubstantiated and unrealistic advice does little, in my opinion, to alleviate these feelings. There is nothing wrong with ideals, as long as parents are given real information about how systems work so that they can strive to change them effectively.

NICOLA BOTTING
University of Manchester, UK


The topic of this book is an idea whose time has come. Sexuality has been around since the beginning of time and people on the autism spectrum are sexual beings like anyone else. People with autism spectrum differences just have not been thought of as sexual beings until recently.
I do remember growing up hearing all of the myths and misconceptions about autism. Since I am now almost 34 and was diagnosed at age 3½, I have heard them all. Some myths were that people with autism did not want friends, did not date, and most certainly did not marry. Of course, these are all false. Now, the last two may not apply for all persons on the autism spectrum, but the first most certainly does. All three of these areas are important to me. I have seen enough people on the spectrum doing all three of these things to see that the statements that I heard were myths and not facts.

I can relate to many of the statements made in Jerry and Mary's book. In school, I was a shy and awkward guy who could not get a date. I was not seen as ‘dating material’. The girls would all consider me to be ‘sweet’ and a friend, but were not attracted to me. This was the same in college as well. I made a lot of the mistakes that Jerry stated in his book while trying to get women to go out with me. My lack of confidence, my desperation, and other things of that nature did not make me attractive. I did not like myself for who I am and it showed. Since the age of 25, with years of counselling, things have been going a lot better for me.

Once I cared about myself, women tended to be more attracted to me. Dates and relationships started happening. I did not do as many of the desperate things that I had done in the past. I let myself go and do things and saw where things would go. Then, relationships would happen. Currently, I am in a relationship with engagement and marriage potential. I can now look back at the things that Jerry mentioned and say, yes, I did these things, but I do not do them anymore.

I could still use a lot of the information that the book gives. As a person on the autism spectrum, some things do come with the territory. Figuring out non-spectrum people is definitely something that I could use help with. My girlfriend is very understanding of me and my differences. We did have to play the social games at first, but we don’t anymore. For example, there are expected ways that people are supposed to act when attracting the opposite gender: instead of being direct, blunt, and honest, we have to be superficial, fake, and indirect. That is what is expected of us and some of us on the spectrum can do that. Unlike non-spectrum people, we know that what we are doing is not the way we are. At least at first, we have to be that way. As we get to know the other person, then we can be who we are. Jerry and Mary describe the things that guys and gals have to do to get to the point where people do not have to play games, but to be themselves. Some challenges are: not taking chances, not moving too fast, not being taken advantage of etc.

Autism/Asperger's and Sexuality: Puberty and Beyond is a book that everyone on the autism spectrum and everyone interested in the autism spectrum should
have. It could be a basic text in the field. For many people, the thought of their children being sexual is a hard thought, but being a fully sexual being is part and parcel of being a human being, and we are human beings! I wish this book had been out when I was in high school. It would have been a big help to me. I had to learn by trial and error and made lots of errors, like most other people. Plus, being on the spectrum definitely made the errors more common and the good luck less likely. Having a romantic/intimate relationship is not a natural thing for people on the spectrum to try to do with non-spectrum people. It is definitely possible that people on the autism spectrum will date non-spectrum people, but it takes more work for us to understand and be understood than for a non-spectrum person. The book goes through the childhood years of socialization, puberty, and adult sexuality. The descriptions are from the viewpoint of a couple, both of whom are people on the autism spectrum. This book is a must read!

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