
Brief Reports

Brief Report: Stability and Change in Cognitive and Behavioral Characteristics of Autism Through Childhood¹

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Longitudinal studies are difficult to conduct, and in the field of autism, are complicated by understandardized definitions which have undergone constant refinement (American Psychiatric Association [APA], 1980, 1987, 1994; Volkmar, Bregman, Cohen, & Cicchetti, 1988). Much of what we know about how children with autism grow and develop came from a few studies done years ago when such children did not have the benefits of early identification, education, and integration with typically developing peers, and up to half still lived in institutions (Bartak & Rutter, 1973; DeMyer et al., 1973; Lockyer & Rutter, 1969; Lotter, 1974; Rutter, Greenfeld, & Lockyer, 1967).

Thus, the evolution of autistic characteristics, and the relationship of outcome to initial diagnosis or changes in diagnoses, have not been extensively studied. Some children who were clearly autistic at age 5 changed so much as to be considered only "odd" later (Gillberg & Coleman, 1992) or not autistic in adulthood (Rutter, 1970). Often, in very young children, a tentative diagnosis such as Autistic Features (AF) or Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) may be given rather than the firmer and probably more devastating Autistic Disorder (AD). In these cases a change in diagnosis might appear to have occurred.

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Stability of IQ during childhood has been reported and it is as predictive for children with autism as for the typical and those with mental handicaps. (Freeman, Ritvo, Needleman, & Yokata, 1985; Lockyer & Rutter, 1970; Lord & Schopler, 1989; Lotter, 1978; Rutter, 1983; Venter, Lord, & Schopler, 1991). Two studies reported declining skills in puberty (Gillberg & Schauman, 1981; Waterhouse & Fein, 1984) whereas DeMyer et al. (1974) found children with IQs above 50 improved more than those below 50. Scores declined on average 2 to 6 points, possibly due to more demanding tests given at later ages (Lord & Venter, 1992).

Earlier studies were consistent in demonstrating that initial IQ, early language use, milder degree of autism and educational functioning in childhood were related to a better outcome (Bartak & Rutter, 1976; DeMyer et al., 1973; Lockyer & Rutter, 1970; Lotter, 1974; Rutter, 1983; Rutter et al., 1967) and to each other (Gillberg & Coleman, 1992). The majority (61–73%) had a poor or very poor outcome with limited independence and only 5–17% had what could be considered a good outcome, with normal or near normal social functioning.

In adolescence, 10–30% deteriorated behaviorally (Gillberg & Schumann, 1981; Rutter, 1970). Gillberg & Steffenberg (1987) noted that this may not represent true deterioration but rather persistent autistic behavior in children who had grown bigger.

Somewhat more encouraging results were found recently, particularly for higher functioning individuals. Results ranged from no deterioration (Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989) to very little (Venter et al., 1991) to none in those with IQs over 50 (Gillberg & Steffenberg, 1987). Kobayashi, Murata, and Yoshinaga (1992) followed a group to age 21 and found over half had a good to fair outcome with 43% improving in adolescence. They attributed this to the availability of special education. They referred to the earlier literature as describing “autism in the first generation.” Their study, along with others (Venter et al., 1991) would represent “autism in the second generation,” with children born in the 1960s and early 1970s who as a result of more opportunities had a more positive outcome.

The present study of children born after 1974 could be seen as “autism in the third generation,” or those who had many more opportunities than their predecessors. In the past 20 years not only have notions of etiology, definitions, and treatment changed but community involvement and deinstitutionalization have had an impact. The purpose of this study was, in view of the changes, to examine autistic and behavioral characteristics and cognitive abilities through childhood. The subjects did not receive any specific treatment but were exposed to what has come to be considered standard practice, that is, early identification, special education, speech/language therapy, and behavioral training support for families.

Specific hypotheses were that stability would be seen in cognitive ability, as measured by Verbal and Performance IQ and in the number and severity of autistic characteristics, as reflected in diagnostic categories and on DSM-III-R. Improvement in language and social skills was expected as the result of early intervention and inclusion with typical peers in school. These children should be doing better than those studied years ago if the general treatment model of using behavioral and communication techniques with community integration and support were effective.

METHOD

Subjects

Seventy-six children (57 boys, 19 girls, male:female ratio 3.3:1) born between 1974 and 1984, were selected at random from a larger sample (Eaves, Ho, & Eaves, 1994) referred to a multidisciplinary developmental diagnostic clinic at Sunny Hill Health Centre for Children in Vancouver, B.C., Canada. The data for the present study came from two assessments: Time 1, which was the child's most complete and reliable assessment (mean age = 7 years, 6 months), and Time 2, (mean age = 11 years, 6 months). Those seen at Time 2 were compared with those in the larger sample who were not ($n = 90$), on variables collected at Time 1. They did not differ in any significant way in Verbal IQ (VIQ), Performance (PIQ), father's and/or mother's education, race, sex, and location within the Province ($p \leq .26-.66$).

Diagnoses at both Time 1 and 2 were based on several things including the clinical consensus of the experienced team, Rutter (1978), the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1986), and DSM-III and DSM-III-R (APA, 1980, 1987). Diagnoses were adjusted to reflect current terminology and for some children, who did not have a CARS or DSM-III-R rating at Time 1 because the scales were not in use at the time, the scores were calculated retrospectively from the detailed information available on their charts. The diagnoses, number in each category, and DSM-III-R score at Time 2 were as follows: AD, $n = 46$, 10.2; PDDNOS, $n = 12$, 8.75; Mentally Retarded or Language Disordered with Autistic Features (MR or LD with AF), $n = 10$, 5.7. Children who had high-functioning autism or were schizoid on the first occasion were reclassified as Asperger syndrome if warranted (AS, $n = 8$, 8.12). The clinical diagnosis was made by the experienced clinicians regardless of DSM-III-R or CARS score and the sample was representative of the known spectrum of autistic disorders with no children excluded for medical or neurological conditions.

Psychological Assessment

In addition to an observation and interview to rate autistic characteristics, the assessment included a standardized test of cognitive ability yielding VIQ and nonverbal or PIQ scores. Given the range in age and level of cognitive functioning in children with autism a variety of tests was used. If the child was unable to score in a valid and reliable fashion on the Wechsler Intelligence Scale for Children-Revised (WISC-R; Wechsler, 1974) then tests that relied less on verbal skills or measured skills at a lower level were given. The number, percentage of the sample, and mean IQ for each test was as follows: WISC-R, $n = 52$, 68%, IQ = 75; Stanford Binet Intelligence Scale (4th ed.), $n = 5$, 6.5%, IQ = 39 (Thorndike, Hagen, & Sattler, 1986); Leiter International Performance Scale ($n = 5$, 6.5%, IQ = 41 (Leiter, 1949); Bayley Scales of Infant Development, Mental Scale ($n = 14$, 18%, IQ = 16 (Bayley, 1969). For children who received the Bayley, derivation IQs were calculated separately for verbal and non-verbal items. For children who had only a Leiter, the receptive vocabulary standard score from the Peabody Picture Vocabulary-Revised, Form L was used for a "verbal IQ" (Dunn & Dunn, 1981).

RESULTS

General Comparisons Time 1 and Time 2

General characteristics at Time 1 and Time 2 are shown in Table I. Slightly lower scores were obtained on the CARS and DSM-III-R on follow-up. Group mean IQs were virtually unchanged, and highly correlated (for VIQ, $r = .91$; for PIQ, $r = .88$).

Table I. Descriptive Characteristics of 76 Children with Autistic Spectrum Disorders^a

	Time 1		Time 2	
	Mean	Range	Mean	Range
Age (years)	7.1	3.1-12.7	11.6	8-17
CARS	34	24-49	31	21-47.5
DSM-III-R	10.6	7-15	9	3-12
Verbal IQ	58	6-135	58	5-135
Perf. IQ	63	6-126	62	5-114

^a57 boys (75%); 19 girls; male:female ratio = 3.3:1.

Significant correlations were found between IQ (VIQ and PIQ) and degree of autism as measured by CARS and DSM-III-R, stronger with the CARS ($r = -.63$ and $-.64$) than with DSM-III-R ($r = -.20$ and $-.28$). Lower IQ is usually associated with more severe expression of autism (higher CARS or DSM-III-R scores) hence the inverse relationship.

The mean IQs were in the mildly mentally handicapped range (50–69), however, this sample had a wider range than is usually reported, with more children in the average to borderline range (IQ > 70) at Time 2 (Table II).

For VIQ but not PIQ there were 10% more children at Time 2 in the IQ > 70 range. For both VIQ and PIQ the mild category (IQ = 50–70) was smaller at Time 2 (by 10–11%) and severe/profound (IQ < 30) increased by about 4%. These changes may simply reflect the steady improvement in verbal skills for most children with autism and the increasing accuracy of testing with age, especially for low-functioning young people.

Use of Verbal Language

Twenty percent ($n = 15$) at Time I and 14.5% ($n = 11$) at Time 2 were nonverbal. The low number may be partly due to the definition of nonverbal, which was using five or fewer words to communicate, at home according to parents, or during the assessment. In all but one case, the low verbal skills were associated with overall low intellectual functioning. The four who improved were still quite limited in language use.

Positive and Negative Changes

Children were defined as not having done as well as expected (deterioration) if they (a) received a diagnosis reflecting more severe autistic

Table II. Percentage of Children with Autistic Spectrum Disorders in Each IQ Category at Time 1 (Early Childhood) and Time 2 (Early Adolescence)^a

IQ category	Verbal IQ		Performance IQ	
	Time 1	Time 2	Time 1	Time 2
Average (>80)	19	22	24	33
Borderline (70–80)	9	16	21	15
Mildly handicapped (50–69)	25	15	21	10
Mod. handicapped (30–49)	29	25	20	24
Severely handicapped (20–29)	11	7	11	7
Profoundly handicapped (<20)	7	15	4	12

^a $N = 76$.

symptoms (14, 18%), (b) obtained a VIQ or PIQ 10 or more points lower on the second occasion and/or moved into a lower IQ category (20, 26%), or (c) showed social/emotional deterioration in the form of increased aggressiveness, destructiveness, or hyperactivity (5, 6.5%). Thirty nine (51%) deteriorated.

Improvement was measured in two ways: (a) a diagnosis reflecting milder autism or fewer autistic symptoms (10, 13%), or (b) increased cognitive skill (10 or more points in VIQ or PIQ) and/or moving into a higher IQ category (19, 25%). Twenty eight (37%) improved.

There was no relationship between change in diagnosis and changes in IQ. Also, there was no relationship between the cognitive and diagnostic changes and behavioral deterioration or differences in mean PIQ or VIQ of the 25% who improved in IQ compared with those who did not. Age was related to improvement in IQ score with younger children showing the most improvement.

Changes in Verbal IQ. Thirteen children (17%) changed into a higher category, and 10 into a lower one (13%). Only 7 children (9%) showed changes that had an impact on their functioning. Five increased more than 15 points in VIQ score with 3 moving from Mildly Handicapped to Average. Two moved down more than 20 points.

Changes in Performance IQ. Eight children (10%) improved at least one category and 16 children (21%) went down. Four children (5%) showed meaningful changes with 3 going from Mildly Handicapped to Average, and 1 from the Moderately Handicapped to Profound.

Changes in Diagnoses. All children had autistic spectrum disorder diagnoses on both occasions. At Time 2, 10 had only AF; 1 of these was very mild and 5 of these were low functioning (mean IQ = 26). Autistic features in low-functioning individuals are very common and it is often difficult to distinguish AD in such cases. Overall moderate stability was seen with 47 (62%) receiving the same diagnosis on both occasions. The ratio of the percentage staying the same versus changing was estimated to be 1.62 with upper and lower 95% confidence limits at 1.02 and 2.57, respectively. In other words, a child was about 1.62 times more likely to keep the same diagnosis as to change. (Table III). Ten children (13%) received a diagnosis that reflected milder autism on the second occasion and 11 (15%) seemed more clearly autistic and were called AD. This group was described as having AF, mental handicap or language disorder with AF, or PDDNOS on the first occasion. There is not an obvious explanation as to why their autistic features became more pronounced. Only 4 were very young when they were first seen, which might have caused the diagnostic team to offer a more tentative diagnosis.

Table III. Diagnostic Categories for Children with Autistic Spectrum Disorders Compared at Time 1 (Early Childhood) and Time 2 (Early Adolescence)

Time 1 diagnosis	Diagnostic category at Time 2				Total (N = 76)
	AD	AF	PDDNOS	AS	
Autistic disorder	35	2	2	4	43
AF ^a	9	4	2	1	16
PDDNOS ^b	2	4	6	1	13
Asperger syndrome	0	0	2	2	4

^aMental retardation and/or language disorder with autistic features.

^bPervasive Developmental Disorder-Not Otherwise Specified.

Table IV. Most to Least Stable DSM-III-R Characteristics of Autism Compared at Time 1 (Childhood), and Time 2 (Early Adolescence)^a

Characteristic	% Same both times	Rank order (% improved)	% with trait	
			Time 1	Time 2
Nonverbal	96	1 (3)	16	15
No friends	92	4 (7)	98	93
Abnormal pragmatics	91	5 (7)	81	77
Abnormal nonverbal	88	6 (11)	96	86
No pretend play	80	2 (5)	69	78
Abnormal play	80	8 (17)	97	83
Abnormal form/content speech	76	10 (23)	82	61
Stereotypic body movements	74	11 (24)	95	72
No imitation	74	9 (18)	42	32
Abnormal production speech	66	7 (11)	61	73
Aloof	63	14 (34)	75	44
Narrow interests	64	15 (33)	71	37
Resists change	62	12 (28)	34	15
No comfort seeking	58	3 (6)	15	46
Rigid	54	13 (33)	45	25
Sensory/object disturbance	50	16 (43)	82	46

^aMost stable = 74–96% staying the same; least stable = 50–66% staying the same. N = 70–76.

Changes in DSM-III-R Autistic Characteristics. Because, as seen above, changes in diagnostic category do not clearly suggest how features of autism change, the autistic characteristics outlined in DSM-III-R (APA, 1987) were compared at Time 1 and Time 2. These include 16 items: 5 social impairments, 6 language impairments, and 5 in the area of stereotyped, restricted, or repetitive behavior.

Despite the improvement in some children on some traits, in general, the traits were highly stable. On individual items 50–96% (average = 73%)

of the children received the same rating on both occasions. Table IV shows the most to least stable traits with the rank order for the percentage of children improving (1 = least improvement or most stable trait, with 3% of the children changing, and 16 = most improvement or least stable trait with 43% of the children changing) along with the percentage with each trait.

DISCUSSION

This study reports behavioral and cognitive stability and change in 76 children with autistic spectrum disorders followed an average of 4 years to early adolescence. All were identified early (before age 5), attended preschool, were in school with special educational support, and most had speech/language therapy in varying intensity and duration. Many had home and school behavioral support. On follow-up only 13% were considered to be less autistic but a number improved in cognitive skills giving "improvement" for just over one third. Twenty (26%) declined in IQ score or range, 14 (18%) received a more autistic diagnosis, and 5 (6.5%) showed negative behavioral changes resulting in "deterioration" for half.

IQ was stable with only 4 and 7 (5 and 9% for VIQ and PIQ, respectively) children changing more than 15 points up or down, which might have an impact on their education or functioning. This is consistent with the recent literature that shows early cognitive tests in children with autism are quite predictive of later ones (Lord & Schopler, 1989). The high-functioning children (IQ > 70) in the present study were even more stable than Lord and Schopler found with 88–95% staying in the same IQ range and similar in stability to the severe to profound group (IQ < 30) where 88–91% stayed in that range. Less stable were the mildly handicapped (IQ = 50–69), where less than 40% stayed in that range.

The language and social characteristics changed little apart from general trends with age. More improvement was seen in the areas of reduction of fixed interests, increased flexibility, and in less sensory disturbance. Many children became less aloof but also sought comfort less. Even children who were not aloof, or who were socially interactive with adults and had some interest in other children, did not have normal peer friendships. Parents reported that 7% had developed friendships. In the past there was debate as to whether the social deficit was primary or secondary to the language deficit. These data suggest that social relatedness or the lack of it is a distinct part of the triad of autism, not secondary to language, and quite stable over time. Relatively good language or cognitive skills did not guarantee social success.

Community support and early identification have been shown to be related to family well-being (Bagenholm & Gillberg, 1991). Despite the stability in most autistic characteristics, with the children very similar to their younger selves, the impression for the majority was of general improvement, resourceful families and, in most cases, community support. Almost half of the families had child care workers after school and 38% used respite care. Over half reported that they belonged to the provincial organization for autism, and almost 60% of the families received support from one of the provincial agencies that provided behavioral support, consultation to schools, and case management for children with autism. Although the neurodevelopmental handicap that is autism may be resistant of change, society and environmental supports have definitely changed.

Educational treatment has also changed, largely due to philosophical shifts, not empirical evidence about the best treatment methods. Class placement or institutionalization used to be an outcome variable that reflected the degree of successful adaptation by the person with autism. Now, in many communities, institutions and separate schools have closed and most children with autism attend their neighborhood school in either regular or special classes, regardless of how well or poorly they function. None of the subjects in the present study were in institutions or segregated schools, although 14% had gone into foster care or a residential treatment program. Just over half were in regular classes, most with the support of a classroom aide.

CARS and DSM-III-R scores were lower on follow-up indicating the general amelioration of autistic features with age (Paul, 1987). Mesibov (1988) reported an average drop of 2 points on the CARS after age 13, close to what it was here. It is well known that more severe autism is related to lower IQ (Schopler et al., 1986). There was a weaker association between DSM-III-R and IQ compared with the strong association between CARS and IQ. The DSM-III-R rating of autistic features has been criticized for being insufficiently sensitive to developmental levels (Siegel, 1991). Low-functioning children must obtain a higher percentage of items to be considered autistic because they cannot be rated on ones that apply only to more capable children (e.g., absence of peer friends in a child with a mental age below 2 years; pragmatic language difficulties in a nonverbal child). Thus, some severely autistic children with low IQs may have low DSM-III-R scores contributing to the low correlations observed here. Their CARS scores would have been higher due to the weighting of items on that scale.

It was reported in the past and is often quoted today that up to half of children with autism are nonverbal (Bartak & Rutter, 1974; Rutter, 1978; Wing & Attwood, 1987). Our findings with only 14.5% are similar to recent studies. Freeman (1993) found only 17%, and Szatmari et al. (1993) 23%.

Lord and Schopler (1989) had 28% with “no language” at age 10 as measured by a receptive language task. Our definition of nonverbal was quite strict, and many of the “verbal” subjects with more than five words were very poor communicators. Fewer nonverbal children in recent samples may be a result of the emphasis on language training and the early intervention in speech and language that most children with autism receive.

It has been estimated that 70–85% of children with autism are mentally retarded (APA, 1987; Ritvo & Freeman, 1977; Volkmar & Cohen, 1989). We found only 53% with PIQ and 62% with VIQ below 70. The percentage of IQs below 50 (43–49%) was about the same as in other studies, but there were fewer in the 50–70 range (10–15% vs. 28%) and more above 70 (38–48% vs. 24–28%) (Kobayashi et al., 1992; Lockyer & Rutter, 1970). Fewer mentally handicapped young people in this sample might be attributable to the effects of early identification and special education in the community, with such efforts having more impact on the more capable children.

Another reason for finding more young people with IQs above 70 could be because children with Asperger syndrome or high-functioning autism were included. They may not have been referred to clinics specializing in autism years ago. Volkmar, Szatmari, and Sparrow (1993) suggested that clinics tend to see lower functioning children and thus report lower IQs and more nonverbal children. Since this clinic serves an entire province at no charge to parents it may see a wider spectrum of autism.

Most of the low-functioning individuals had a relatively poor outcome. They remained low functioning, nonverbal, and quite handicapped, similar to the results of Gillberg and Steffenberg (1987).

Among those who improved were some who later appeared to have primarily neurological dysfunction. Further investigation is needed to sort out these children from the “classically autistic” as a young age so as to offer families hope for better prognosis. Very young children with very delayed development, language disorders, motor planning, and/or sensory integration difficulties or the so-called nonverbal learning disability pattern (VIQ > PIQ) often appear to be autistic until language, cognitive skill, or motor functioning improves. Although early identification is important and laudable, the younger the age at which a child is identified, the more likely he or she could be a false positive.

Five boys (6.5%) did not really deteriorate but did not do as well as expected. They had relatively normal early development but showed increasing cognitive problems as they grew so that they functioned in the moderately handicapped range on follow-up. This may be a variation of the Childhood Disintegrative Disorder (CDD; APA, 1994; Volkmar, 1992). In the present study it was about as common as the 6% Volkmar and Co-

hen (1989) reported in a group of children with AD or the 8% Lord and Schopler (1989) found whose nonverbal IQ scores declined over time.

Five young people deteriorated behaviorally. A higher number deteriorating in adolescence has been reported (Rutter, 1970) and chiefly among the lower functioning (Gillberg & Steffenberg, 1987). A larger number was not expected in the present sample since the mean age was 11.5 and only half were adolescents. However, the increased aggressiveness and difficult behavior were not confined to the low functioning.

This study of children in the "third generation of autism" reinforced the notion that such children form a heterogeneous group and that change occurred in both positive and negative directions. IQ and more severe expression of autistic symptoms were once again shown to be very stable. The present treatment for children with autism, which includes early identification and intervention, special education, communication training, and inclusion in the community, may have contributed to fewer nonverbal and more nonretarded young people in this sample, but there were no great differences between the children here and those studied in the past.

Although not specifically measured in this study, the positive attitudes of the families and the supports available to them were an impressive outcome, and the result of changes in society and education for children with autism in the past 20 years.

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