Adult outcome for children with autism

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Background: Information on long-term prognosis in autism is limited. Outcome is known to be poor for those with an IQ below 50, but there have been few systematic studies of individuals with an IQ above this. **Method:** Sixty-eight individuals meeting criteria for autism and with a performance IQ of 50 or above in childhood were followed up as adults. Their mean age when first seen was 7 years (range 3–15 years); at follow-up the average age was 29 years (range 21–48 years). Outcome measures included standardised cognitive, language and attainment tests. Information on social, communication and behavioural problems was obtained from the Autism Diagnostic Interview (ADI). **Results:** Although a minority of adults had achieved relatively high levels of independence, most remained very dependent on their families or other support services. Few lived alone, had close friends, or permanent employment. Communication generally was impaired, and reading and spelling abilities were poor. Stereotyped behaviours or interests frequently persisted into adulthood. Ten individuals had developed epilepsy. Overall, only 12% were rated as having a 'Very Good' outcome; 10% were rated as 'Good' and 19% as 'Fair'. The majority was rated as having a 'Poor' (46%) or 'Very Poor' (12%) outcome. Individuals with a childhood performance IQ of at least 70 had a significantly better outcome than those with an IQ below this. However, within the normal IQ range outcome was very variable and, on an individual level, neither verbal nor performance IQ proved to be consistent prognostic indicators. **Conclusions:** Although outcome for adults with autism has improved over recent years, many remain highly dependent on others for support. This study provides some information on prognostic indicators, but more fine-grained research is needed into the childhood variables that are associated with good or poor outcome. **Keywords:** Autistic disorder, prognosis, adulthood, follow-up studies. **Abbreviation:** ADI: Autism Diagnostic Interview.

Studies of autism in adult life

For the parents of any child with a developmental disorder, accurate information about future progress can be crucial in helping them come to terms with the diagnosis and in assisting them to develop effective ways of coping. Predicting outcome in autism, however, presents particular problems because of the very wide spectrum of cognitive, linguistic, social and behavioural functioning associated with the condition. Moreover, despite a number of follow-up studies of older adolescents or adults with autism, information about prognosis remains inconclusive because of the heterogeneity of subjects, the variability of outcome measures used, and other fundamental problems of research design (see Howlin & Goode, 1998).

The earliest follow-up studies were largely anecdotal and involved people of very different ages, so that it was difficult to determine the outcome for adults specifically (e.g., Creak, 1963; Eisenberg, 1956). However, in 1973 Kanner reported on 96 individuals, mostly in their twenties and thirties. The majority was highly dependent, living with parents, in sheltered communities, in state institutions for people with learning disabilities or in psychiatric hospitals. Outcome was more positive for those with better-developed communication skills and amongst this group just over half was functioning relatively well. Eleven individuals had jobs and one was still at college. Seven had their own homes and one man (a successful music composer) was married with a child.

The first systematic outcome studies were conducted by Rutter and his colleagues (Lockyer & Rutter, 1969, 1970; Rutter, Greenfeld, & Lockyer, 1967; Rutter & Lockyer, 1967). Thirty-eight individuals were aged 16 years or older, having initially been diagnosed in the 1950s and early 1960s. At follow-up over half were in long-stay hospitals; 7 lived with their parents, with no outside occupation, 4 others attended day centres and 3 were living in residential communities; only 3 had paid jobs. Overall, 14% were said to have made a 'Good' social adjustment; 25% were rated as 'Fair' and 61% as 'Poor'.

Lotter (1974a, b) followed up 29 individuals, aged 16 to 18 years, who had been diagnosed as autistic when younger. Amongst the 22 who had left school, only one had a job and almost half were in long-stay hospital provision. Two individuals were living at home and 5 were attending day training centres. Fourteen per cent were rated as having a 'Good' outcome; 23% as 'Fair', and 63% as 'Poor' or 'Very Poor'.

In 1987, Gillberg and Steffenburg reported on a group of 23 individuals aged 16 or over, living in Sweden. Only one person was found to be fully self-supporting; of the remainder, 48% were rated as having a 'Fair' outcome and the same proportion as 'Poor'/'Very Poor'.

Kobayashi, Murata, and Yashinaga and colleagues (1992) used a postal survey to follow up 201 people, aged 18 to 33 years, in Japan. The average follow-up period was fifteen years. Four individuals, all male, had died; 5% were still attending school or college; 20% were employed, mostly in food and service industries. All but 3 of those with jobs still lived with their parents; one was in a group home and 2 had their own apartments; none was married. Twenty-seven per cent of the group was rated as having a 'Good' or 'Very Good' outcome, on the basis of their adaptive skills. The same proportion was rated as 'Fair', whilst 46% were rated as 'Poor' or 'Very Poor'.

A telephone survey by Ballaban-Gil, Rapin, Tuchman, and Shinnar (1996) found that amongst 45 adults, initially diagnosed as children, over half (53%) were in residential placements and only one was living independently. Three people had died. Eleven per cent were in regular employment (all in menial jobs) and a further 16% were in sheltered placements. Rates of behavioural difficulties were high and only 3 adults were rated as having no social deficits. Estimates of changes in IQ levels from child to adulthood indicated that cognitive functioning remained very stable and only 18% showed a marked change in IQ. When change did occur, this usually indicated an improvement rather than decline in intellectual ability.

Comparisons between studies need to be treated with caution because of differences in sample selection and in the measures used. Most investigations have involved relatively small groups of subjects, diagnostic criteria are sometimes imprecise and/or the quality of data on early intellectual functioning is poor. Overall judgements of whether outcome is 'Good', 'Fair' or 'Poor' also tend to be based on variable criteria. Nevertheless, the one consistent conclusion from these reports is that a positive prognosis in adulthood is highly dependent on IQ – very few individuals with an IQ below 50 achieve good functioning in adulthood (Gillberg & Steffenburg, 1987; Lockyer & Rutter, 1969; Lord & Bailey, 2002; Lotter, 1974b). Outcome is also poor for those who fail to acquire some useful language by the age of 6 years or so. However, even amongst individuals of higher IQ outcome is very variable.

Rumsey, Rapoport, and Sceery (1985) followed up 14 men aged between 18 and 39 years of age, all of whom fulfilled DSM-III criteria for autism. Verbal and/or Performance IQ scores were 60 or above. Socially, all the group continued to have marked difficulties. Only one individual had friends and four people were in independent employment. Most (71%) remained very dependent on their parents or others for support and one was in a state hospital. Similarly low levels of employment and social functioning were reported by Tantam (1991) in his cross-sectional study of 46 individuals (mean age 24 years) with Asperger syndrome.

Venter, Lord, and Schopler (1992) described outcome for 22 individuals aged 18 years or over who had a pre-school IQ of 60+. Around a third were competitively employed, but again jobs were generally at a very low level and the majority was in sheltered employment or special training programmes; 3 had no occupation. Only 4 individuals (18%) lived more or less independently. However, Szatmari and his colleagues (Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989) reported rather more positive findings for their group of 12 males and 4 females (all 17 years or over; mean IQ >90). Half had attended college or university, and over a third were in regular, fulltime employment. Half were described as being completely independent, although some of these still lived at home. Although over half the group had never formed close relationships, a quarter had dated regularly or had long-term relationships and one was married.

More recently, Mawhood and colleagues (Howlin, Mawhood, & Rutter, 2000; Mawhood, Howlin, & Rutter, 2000) followed up 19 men with autism (mean WAIS PIQ 83) who had initially been diagnosed between 4 and 9 years of age. Although the majority had improved over time, all showed continuing problems in communication, social relationships and independence. Almost half remained socially isolated, only 3 lived independently and over two-thirds had significant difficulties associated with obsessional or ritualistic tendencies. Only 3 individuals (16%) were considered to have a good outcome; 2 (10%) remained moderately impaired and 14 (74%) continued to show substantial impairments.

Background to the present study

Previous follow-up studies have generally involved only small numbers of individuals above the age of 21; ratings of adult functioning have frequently been somewhat unsystematic, and the IQ range has either been very extensive (ranging from severe retardation to average) or restricted to high functioning participants only. Studies involving mixed IQ groups have generally found that outcome is poorest in individuals with an IQ below 50 (see Lord & Bailey, 2002). However, few people with this degree of cognitive impairment, whether or not they are autistic, achieve high levels of independence as adults. An investigation of factors influencing long-term outcome in individuals with autism with an IQ above 50 is, therefore, of considerable practical importance.

In the present study, cases were only included if they had a non-verbal IQ in childhood of 50 or above. Follow-up data included detailed psychometric testing, and social functioning in many different areas was assessed using standardised measures. The longitudinal design also made it possible to explore the relationship between IQ in childhood and adult outcome variables.

The paper focuses on 3 main questions:

- What is the long-term outcome, in terms of social, cognitive, linguistic and behavioural functioning for individuals with autism who, as children, had a performance IQ of at least 50?
- How stable are childhood measures of IQ?
- How does early cognitive ability relate to prognosis in adulthood and what other factors are predictive of outcome?

Methods

Participants

The participants were referred to the Children's Department at the Maudsley Hospital, London, because of concerns about their development. All were diagnosed as having an autistic disorder. Diagnosis was based on the criteria applicable at the time the children first attended. Although classification systems have been modified over the years, the 4 core criteria currently used in DSM-IV-TR and ICD-10 remain closely similar to those defined by Rutter (1966, 1972, 1978), which were used for cases seen in the earlier years, viz:

- Onset prior to 30/36 months
- Impaired social development which has a number of special characteristics and is out of keeping with the child's intellectual level
- Delayed and deviant language development, which also has certain defined features and which, again, is out of keeping with the child's intellectual level
- 'Insistence on sameness' as shown by stereotyped play patterns, abnormal preoccupations or resistance to change.

At the start of the follow-up all case notes were checked again by MR to ensure that they met criteria for autism. Cases were excluded if they clearly failed to meet these criteria. A number of other exclusion criteria were also employed (see Appendix 1 for details). Individuals were then included in the adult follow-up study if:

a) they had been seen as children (i.e., prior to 16 years) primarily for a *diagnostic* assessment (those initially referred for deterioration or psychiatric disorders other than autism were not included but the presence of comorbid disorders was **not** a reason for exclusion if individuals were referred for a diagnosis of possible autism) *and*
b) they had a non-verbal IQ in childhood of 50 or above *and*
c) they had reached the age of 21 at the time of follow-up.

Seventy-nine individuals meeting these criteria were identified. Families were traced by means of previous addresses, NHS registers and personal contacts and were then approached in writing to request their cooperation. One individual had died of status epilepticus; 2 families refused to take part; 6 cases could not be traced or did not respond (after repeated attempts to contact them); 2 families were not contacted due to an administrative error. The current age and initial IQ of the 10 individuals who refused or were not contacted did not differ significantly from the study sample (mean age at time of follow-up 33.5 years; sd 10.3 years; initial PIQ 82.3; sd 11.44).

The final sample comprised 68 individuals, but only partial follow-up data were available for one of these and some ADI information was missing on another. The average age of the group at follow-up was 29.33 years (sd 7.97 years; range 21.16 to 48.58 years). Nineteen individuals had been first seen between 1950 and 1959; 28 between 1960 and 1969 and the remainder between 1970 and 1979. Over this period, and particularly during the 1950s and 1960s, few children with autism were seen at local clinics and hence the sample was much less selective than would be the case today. Moreover, findings from the Maudsley Hospital samples have been consistently similar to those from comparable epidemiological studies over the same period. The key feature of all samples (clinical and epidemiological) seen many years ago is that the prevailing diagnostic concept of autism then was more restricted to seriously handicapping disorders than would be the case today.

Characteristics of the group in childhood. The group comprised 61 males and 7 females. This ratio is higher than the male:female ratio of around 4:1 typically reported in the literature, probably because individuals with an IQ below 50 were excluded from the sample and there tend to be more females within this lower functioning group (Lord & Schopler, 1985). The average age when children were initially seen was 7.24 years (sd 3.10 years; range 3.1 to 15.66 years).

Initial IQ estimates were based mainly on the Performance Scale of the Wechsler Intelligence Test for Children (WISC-R; Wechsler, 1974) or the Wechsler Pre-School and Primary Scale of Intelligence (WPPSI; Wechsler, 1990) ($n = 30$), or scores on the Merrill Palmer (Stutsman, 1948) ($n = 34$). Two children were assessed on the Leiter (Levine, 1982), one on the Stanford–Binet (Terman & Merrill, 1961) and one on the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984). The mean Performance IQ score derived from the most detailed testing was 80.21 (sd 19.28, range 51–137).

On verbal tests 22 children obtained a verbal IQ score on either the WISC or WPPSI, 10 scored on the Peabody Picture Vocabulary Test (PPVT; Dunn, 1965) or British Picture Vocabulary Scale (BPVS; Dunn, Dunn, Whetton, & Pintillie, 1982), 4 on the Reynell Language Scales (Reynell, 1977), 2 on the Mecham Scale (Mecham, 1958) and one on the Stanford–Binet vocabulary test (Terman & Merrill, 1961). The average verbal IQ estimate (based on scaled scores where appropriate; LA/CA × 100 if not) was 61.49 (sd 21.26, range 21–106). For children scoring on both performance and verbal tests there was a low but significant correlation between performance IQ scores and verbal IQ estimates at this age ($n = 39$, $r = .34$, $p = .04$) but performance scores were significantly higher ($t = 4.99$, df 38, $p < .001$).

Measures

Assessment measures in adulthood. Follow-up interviews and assessments were conducted between 1985 and 1991, in almost all cases by SG, but with a few assessments undertaken by PH and MR.

Diagnostic and behavioural assessment. Diagnosis in adulthood was re-confirmed for all subjects using the

Autism Diagnostic Interview (ADI; Le Couteur et al., 1989), generally with parents as informants. In one case parents had died and information was collected from a sibling. The ADI was also used to obtain ratings of current language functioning (both appropriate and inappropriate use) and to assess the severity of stereotyped behaviours/interests (see below).

Social functioning. Current levels of social competence were assessed using the ADI and information was also obtained from parents on educational background, employment and independence. Because the range of language skills in the group was too wide for comparability of self-reports, the outcome measures used were based on a combination of detailed, standardised interview schedules of demonstrated reliability and validity, and psychometric assessments. Whenever relevant, assessments were supplemented by reports from employers, or other professionals, and medical records. From the parental questionnaire, a composite outcome rating score was derived by summing individual scores for Occupation, Friendships and Independent Living (see Appendix 2). A rating of 0 indicated a 'Very Good' outcome (i.e., subjects achieving a high level of independence); 1 = 'Good' outcome (generally in work but requiring some degree of support in daily living); 2 'Fair' (has some degree of independence, and although requires support and supervision does not need specialist residential provision); 3 = 'Poor' (requiring special residential provision/high level of support) and 4 = 'Very Poor' (needing high-level hospital care).

Autistic-type behaviours in adulthood. The severity of stereotyped and ritualistic behaviours was assessed using a composite rating on the ADI (Le Couteur et al., 1989), which included scores for verbal and behavioural rituals, unusual preoccupations and object attachments, and motor mannerisms (see Appendix 2 for details).

Cognitive and linguistic abilities. At follow-up, the participants completed a battery of cognitive assessments appropriate to their developmental level. Ideally, a Performance IQ score was obtained from the Wechsler Adult Intelligence Scale-Revised (WAIS-R; Wechsler, 1981). Individuals unable to obtain a performance score on the WAIS-R were assessed (in order of preference) on the Raven's Progressive Matrices (Raven, 1976), the Leiter (Levine, 1982) or Merrill Palmer Scales (Stutsman, 1948). Full-scale and Verbal IQ scores were also calculated for those individuals able to complete the WAIS-R. The British Picture Vocabulary Scale (Dunn et al., 1982) was used to assess language comprehension. Other aspects of language usage in adulthood were assessed using the ADI which provided ratings of overall language competence and extent of abnormal language usage in adulthood, age of first words and phrases, and level of language development by the age of 5 years (see Appendix 2 for details of all language measures). Attainments in reading and spelling were assessed by means of the Neale Test of Reading Ability (Neale, 1977) and the Schonell Spelling test (Schonell & Schonell, 1960).

Statistical analysis

Parametric analyses were used for comparison where the data permitted. When sub-group sizes were small and/or variances significantly unequal, non-parametric tests, with the appropriate corrections for ties or sample size, were used. Non-parametric analyses were also used when comparing overall ratings of abnormality/competence (as on ADI data). However, in the tables means rather than medians are reported as these illustrate more clearly the differences between sub-groups.

Because of the relatively large number of comparisons conducted, the analysis focuses on the *consistency* of the pattern of findings, rather than on the statistical significance of individual variables. Single results are not reported as significant unless they reach a p value of at least .01; probability tests are two-tailed.

Results

Educational attainments

Only 10 individuals had been educated predominantly in mainstream schools. Twenty-nine (43% of the total group) had spent most of their school years in specialist autistic provision; 9 (13%) had attended schools for children with more general learning disabilities and 16 (24%) had spent the majority of their time in a variety of other educational settings such as hospital schools, schools for emotional and behavioural problems, language units, home tuition etc. Data on schooling were not available for 4 individuals. Forty-two people (62%) had spent at least some time in boarding school. For most, school placements were relatively stable with fewer than 3 changes of school during either primary or senior school.

Academic attainments generally were not particularly high, with over one-third of the group failing to score on any of the attainment tests. Mean age equivalent scores (and sd's) on the Neale test of Reading Accuracy and Comprehension, and on the Schonell spelling test, were 10.54 years (2.13); 8.70 years (2.32) and 11.68 years (2.83) respectively. Twenty-nine individuals scored at or below the basal of 5–6 years on Accuracy, 32 were below basal for Comprehension and 26 below basal for Spelling.

The majority (53; 78%) left school without any formal qualifications. Of the 13 who did obtain academic qualifications, 6 had obtained at least one GCSE or equivalent and 2 had passed A levels; 2 had successfully completed diplomas (one in accounting, one in design), 3 had obtained degrees (in science or computing) and 2 of these had postgraduate qualifications.

Jobs

At the time of the follow-up (which, according to government statistics, was a period of steadily increasing employment in the UK), almost one-third of the group (23 individuals) was in some form of

employment. Eight were working independently and one man was a self-employed fabric printer, although this did not provide him with a living wage. Fourteen individuals worked on a supported/sheltered or voluntary basis (2 worked for the family business and one in a shop run by his residential centre). One other man, previously employed in a factory, had been unemployed for some years. Because employment status was subject to change, information on jobs was updated by Hutton (1998) as part of a separate study. This showed no increase in the numbers in independent work (see Table 1), although 2 individuals who had experienced difficulties in keeping jobs were now in supported job schemes, but still on full salary. Of those initially in sheltered schemes, one had moved into a supported employment scheme for individuals capable of more independent work; one had resigned his job and was now unemployed; and another, who had been working as a decorator for his father, no longer did so. One man who was previously unemployed, and another, initially working in a sheltered job scheme as a grave digger, were now in specialist schemes run

by their day or residential centres. Ten further individuals who had previously had no jobs were involved in off-site schemes organised by their day or residential centres. Five other individuals carried out some routine work (weaving, gardening, bakery, etc.) within the residential centre. The remaining 27 were described as being in general work/leisure programmes within their day or residential units. As is evident from Table 1, most of the jobs were low level and several had been found via parental contacts, rather than through the open job market; pay was generally poor. The majority was in sheltered schemes or occupational programmes provided by their residential or day centres. However, only one person had no daytime occupation and this was due to the breakdown of his previous residential placement. (Information was missing for 2 cases.)

Friendships

Friendships were rated on the basis of parental information from the ADI. 'Frequency' of friendships was rated according to the numbers of

Table 1 Employment levels in adulthood (→ indicates changes when cases reviewed in subsequent follow-up – Hutton, 1998)

Type of job	Employment status
Scientific officer, oil company	Independent
Electrical work	Independent
Cartographer	Independent
Postal assistant	Independent
Factory work	Independent
Factory work	Independent
Computing	Independent (→ *supported)
Accounts	Independent (→ *supported)
Fabric design	Self employed
Washing up	Voluntary/low pay scheme
Grave digger	Sheltered (→ scheme run by residential centre)
Office/accounts assistant	Sheltered (→ *supported)
Factory work	Sheltered (→ resigned, now unemployed)
Charcoal burning/gardening	Sheltered
Factory work	Sheltered
Administrative assistant	Sheltered
Data input	Sheltered
Assembly work	Sheltered
Supermarket trolleys	Sheltered
Electronic work	Sheltered
Special shop	Sheltered (→ factory assembly; scheme run by residential centre)
Decorating with dad	Family based (→ no job)
Office (with parents)	Family based
Not initially in work (n = 10)	**→ Scheme organised by residential/day centre**
	Part time office assistant
	Wood/metal work × 2
	Carpentry
	Gardening × 2
	Factory assembly work × 2
	General work × 2
Not initially in jobs (n = 5)	**→ Scheme within residential/day centre**
	Assembly work, gardening, weaving, bakery etc.
In day/residential unit but no specific work (n = 27)	
No occupation (n = 1)	
Not known (n = 2)	

*Supported schemes are those that offer assistance within the *regular* workplace. Job coaches fade out their support with time. The level of support is much less than in sheltered schemes, and job levels are generally higher.

friends/acquaintances the individual had, and 'Quality' according to the degree of sharing and mutual participation the relationship involved. Information on friendships was missing for 2 individuals. Eighteen individuals (26%) were rated as having a relationship with at least one other person in their age group that involved participation in a range of interests or activities, although in 2 cases these interests were quite stereotyped. Ten (15%) had some acquaintances with whom they might talk or share activities but these were generally within arranged social groups. The majority (38; 56%) was rated as having no friends or acquaintances.

Thirteen individuals (19%) were considered by their parents to have one or more relationships that involved some degree of selectivity and sharing (of enjoyment, activities or confidences) and self-initiative in seeking contacts. Four more were described as sharing activities with others but as showing little pleasure in this; over half (35; 51%) were said to have no friends with whom they shared activities, and in 16 cases (23%) the quality of friendships was unknown. Very few individuals had had a close sexual relationship. At the time of the follow-up one man had married, although he later divorced. Two men have married subsequently.

Independent living

Three individuals lived by themselves, with only limited parental support, and 4 others were in semi-sheltered hostel-type accommodation, offering some ongoing support. Twenty-six individuals, over a third of the group, still lived at home (in 3 cases this was because alternative placements could not be found or had broken down). However, a few of those living at home still had considerable independence; one, for example, lived in a separate apartment at the end of his parents' garden and 8 others spent much of their time away from home in independent social activities. Half of the group was in some form of residential accommodation – 14 in specialist autistic provision with little independence; 12 in residential settings with some degree of independence; and 8 in long-stay hospital provision. In the hospital group, 4 individuals had extreme behavioural difficulties that necessitated a very high level of supervisory care. The others were all in the older age group (35+) and had generally been placed in hospital accommodation because no alternatives had been available at the time when they were seeking a placement. Data were missing for one individual.

Overall social outcome

An overall estimate of social competence was derived by summing the rating scores for 'Friendships', 'Work placements' and 'Independent living'. Information

was missing on one case but of the remainder, 8 individuals (12% of the sample) were rated as having a 'Very Good' outcome, in that they were in paid employment, had some friends and a high level of independence. A further 7 individuals were considered to have a 'Good' outcome, i.e., they were working (albeit with some support), could travel independently and organise their own activities, and had some friends. Thirteen (19%) had a 'Fair' outcome; they were generally living at home and required considerable support in daily living but they did have some degree of autonomy. Thirty-one individuals (46%) were rated as 'Poor' – almost all of these were in residential accommodation with very limited autonomy or were living at home because nowhere else would accept them. A further 8 were in long-stay hospitals and were rated as having a 'Very Poor' outcome.

Autism-related problems

Autistic-type symptoms, including rituals and stereotyped behaviours, resistance to change, unusual object attachments and unusual/intense preoccupations, were assessed using the 'Current' section of the ADI (Le Couteur et al., 1989). From this a composite score for abnormalities related to ritualistic and stereotyped behaviours was calculated (see Appendix 2). Information was missing on 2 cases. Of the remainder, 8 individuals (12%) were rated as showing few/no problems of this kind as adults, 28 (42%) showed mild problems, 23 (35%) moderate problems and 7 (11%) severe problems.

Epilepsy

Ten individuals (15% of the total group) were reported as having epilepsy (defined as at least one fit after the age of 5 years). In 3 cases there had been just one epileptic attack (although it was clear that this was a major attack), 6 were on regular anticonvulsant medication and one was undergoing further testing to establish the most appropriate drug to use. In all cases, the epilepsy was confirmed by detailed interviewing on the nature and context of the attacks.

Cognitive and language abilities

As adults, 44 individuals were able to obtain a Full Scale IQ score on the WAIS-R; 2 others completed the Performance scale only and one the Verbal scale only. Of those unable to complete either of the Wechsler scales, 15 were assessed on the Raven's, 5 on the Leiter and one on the Merrill Palmer. Taking scores from the highest-level IQ test completed (see Appendix 2 for details), the overall mean performance IQ score was 75.00 (sd 21.52). The mean performance IQ score of those tested on the WAIS-R was 84.48 (sd 16.06); for those tested on the Raven's it was 61.53 (sd 17.94) and for those who could

complete only the Merrill Palmer or Leiter it was 39.67 (sd 4.59).

Forty-five adults were testable on the WAIS-R Verbal Scale. The mean verbal IQ of these individuals was 79.78 (sd 18.86). The difference between WAIS Performance and Verbal IQ scores for those completing both scales was not significant ($t = 1.97$; df 43, $p = .055$). Sub-test profiles on the WAIS are illustrated in Figure 1. Highest scores were for Block Design, Object Assembly and Digit Span; the lowest were for Comprehension, Picture Arrangement and Picture Completion.

All adults were administered the British Picture Vocabulary Scale but 4 individuals scored below baseline (raw score ≤10) and for many of the remainder it was not possible to assign a standard score because their age was above the upper limit for the test. Instead age equivalent scores were calculated. The average language age equivalent was 8.26 years (sd 6.21 years) but problems in calculating age scores (see Appendix 2 for details) mean that this estimate must be treated with considerable caution. Nevertheless, the generally poor level of linguistic functioning within the group is apparent from the fact that 33 (48%) had a language age below 6 years; 24 (35%) scored within the 6 to 15 year range, and only 11 (16%) scored above a 15-year level.

ADI ratings (Le Couteur et al., 1989) were used to derive an overall composite score of language usage. Seven individuals (10% of the group) were rated as having good language; 21 (31%) as having mild impairments; 6 (9%) as moderately impaired; 27 (40%) as severely impaired; and 6 (9%) had no language. Abnormal use of language was also rated using the ADI. Fourteen individuals had no or insufficient speech to be coded on this variable and information was missing for one case. Twenty-three (43% of the remainder) were rated as showing no or very few

abnormalities; 21 (40%) as showing occasional/mild problems; and 9 (17%) as having moderate/severe problems. (See Appendix 2 for full details of codings.)

I. *Associations among adult outcome measures*

Correlations among almost all outcome measures were highly significant and substantial (see Table 2). Thus individuals with the highest social outcome ratings had higher scores on cognitive, language and reading and spelling tests; they showed greater use of social language and abnormal language features and ritualistic behaviours were less frequent. Generally, correlations among social outcome measures were higher with verbal IQ than with performance IQ, although the differences were not significant.

The sample was also split into 3 sub-groups according to overall outcome: Very/Good; Fair; Very/Poor. One Way Analysis of Variance indicated significant between group differences on all the principal adult measures, although post-hoc (Scheffé) analysis indicated that for many variables there was relatively little difference between the Very/Good and Fair Outcome groups (see Table 3).

II. *The associations between childhood measures and outcome in adulthood*

A. Stability of IQ from childhood to adulthood
Performance IQ. Scores on tests of performance IQ remained relatively stable over time. Although the average time gap between initial and follow-up assessments was 22.1 years (range 6.8 to 41.3 years), there was a significant correlation between individuals' child and adult performance IQ ($n = 68$, $r = .54$, $p < .001$; scores based on the most detailed measure on each occasion). Thirty-one individuals remained within their initial IQ band (i.e., ≥100; 70–99; 50–69) over time and 11 moved up one band. Twenty-five individuals moved down by one band and one showed a decrease of 2 bands (see Figure 2). Stability tended to be greater amongst individuals with an initial performance IQ of at least 70. Among the 45 children scoring 70 to 100+ initially, 35 (78%) remained in this range. In the lower IQ band there
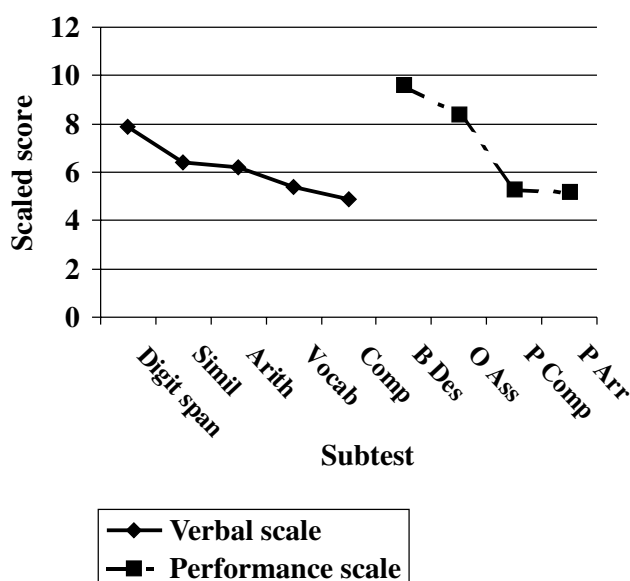

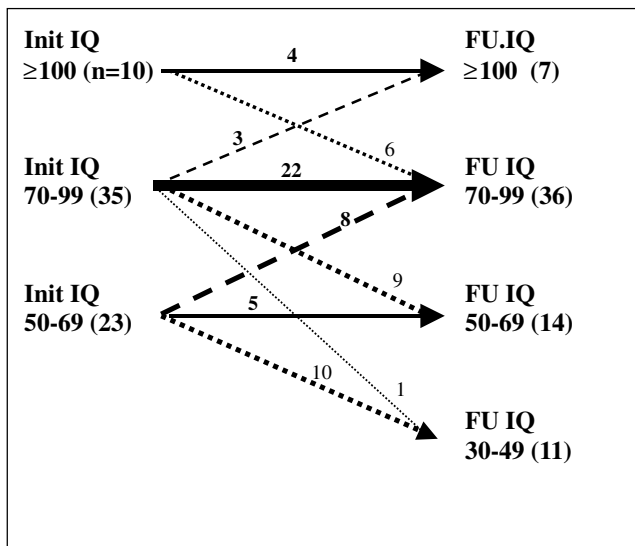**Figure 1** Profile of subtest scores on WAIS

Table 2 Correlations between social outcome and other variables in adulthood

	Social outcome score
PIQ	.66 ($n = 67$)
VIQ (or VIQ estimate)	.81 ($n = 67$)
BPVS age equivalent	.80 ($n = 67$)
Reading comprehension	.64 ($n = 35$)
Reading accuracy	.58 ($n = 38$)
Spelling	.51 ($n = 41$)
Social use of language	.67 ($n = 67$)
Abnormal use of language	−.45 ($n = 53$)
Ritualistic and stereotyped behaviours	−.34 ($n = 66$)

All correlations significant at $p ≤ .01$.

Table 3 Cognitive and other adult scores according to overall outcome rating

Outcome Group[1] → Adult variable ↓	1. Very/Good (n = 15) Mean (sd)	2. Fair (n = 13) Mean (sd)	3. Very/Poor (n = 39) Mean (sd)	F	p	Post–hoc (Scheffé)
PIQ	94.8 (12.2)	85.4 (14.3)	64.5 (19.5)	19.54	<.001	1 = 2 > 3
VIQ	98.7 (16.9)	76.6 (11.9)	37.8 (26.9)	43.39	<.001	1 > 2 > 3
BPVS age equivalent (yrs)	16.3 (4.5)	10.5 (5.0)	4.5 (3.3)	51.69	<.001	1 = 2 > 3
Reading comprehension (yrs)	10.5 (2.2)	8.5 (2.3)	7.0 (0.5)	10.37	<.001	1 = 2 > 3
Reading accuracy (yrs)	12.2 (1.1)	11.5 (1.7)	8.9 (1.9)	13.76	<.001	1 = 2 > 3
Spelling (yrs)	13.1 (2.4)	12.5 (1.9)	9.7 (3.0)	7.55	.002	1 = 2 > 3
Social outcome score[2]	2.4 (1.4)	6.2 (0.8)	9.4 (1.0)	237.07	<.001	1 < 2 < 3
Social use of language[2]	3.6 (3.3)	7.4 (3.6)	14.7 (6.9)	23.10	<.001	1 = 2 < 3
Abnormal use of language[2]	1.3 (1.4)	2.6 (2.9)	4.1 (2.7)	6.46	<.001	1 = 2 < 3
Ritualistic and stereotyped behaviours[2]	3.3 (2.1)	5.2 (3.6)	7.3 (4.9)	5.47	<.001	1 = 2 < 3

[1]Outcome data missing on one case.
[2]The higher the score the more abnormal the behaviour.

Figure 2 Stability of PIQ from child to adulthood

was somewhat more movement, although there was no significant relationship between stability and initial performance IQ (df 3,64; $F = 1.99$, $p = .125$).

Mean performance IQ scores from child to adult testing fell slightly over time (initial PIQ 80.21, sd 19.28; adult PIQ 75.00, sd 21.52; df 67, $t = 2.19$, $p = .03$). However, amongst those testable on Wechsler tests on both occasions there was a small increase in Performance IQ (from 81.84, sd 15.89, to 86.80, sd 16.68; $t = 1.48$, df 24, $p = .15$). Test–retest correlations on the Wechsler tests were moderate (child–adult WAIS-R PIQ $r = .47$, $n = 25$, $p = .02$). Of the 10 individuals whose performance IQ declined from the average range initially (i.e., ≥70) to below 70 at follow-up, only 2 had initially been testable on the WISC. In addition, all but 2 of the 10 were rated as having very poor/no language when first tested and their language abilities in adulthood remained severely impaired. The one individual who showed the largest decline (from 95 initially to only 34 at follow-up) was testable only on the Leiter scales on both occasions.

Verbal IQ. Just over half the sample ($n = 39$) had obtained a score on a verbal test in childhood and within this group the correlation between child verbal IQ (or estimates based on PPVT/BPVS) and adult verbal IQ scores was significant ($r = .67$; $p < .001$). However, as is apparent from Figure 3, there was considerable movement in verbal IQ levels over time. There was a slight overall rise in verbal IQ scores (initial VIQ/VIQ estimate 61.49, sd 21.26; adult VIQ 69.64, sd 27.16; df 38, $t = 2.49$, $p = .017$). The increase was greater for those scoring on Wechsler tests on both occasions, from 70.64 (sd 15.26) in childhood to 82.41 (sd 17.28) in adulthood (df 21, $t = 4.0$, $p = .001$; child–adult VIQ $r = .65$, $n = 22$, $p = .001$). Stability was greatest in the 14 individuals who had initially achieved a verbal IQ (or IQ equivalent) of ≥70 and all but 2 in this sub-group had maintained the same level. Of the 23 initially scoring between 30 and 69, 16 (69%) had moved upwards; only 4 remained the same and 3 had moved downwards. Moreover, amongst the 31 individuals who had either been untestable, or scored
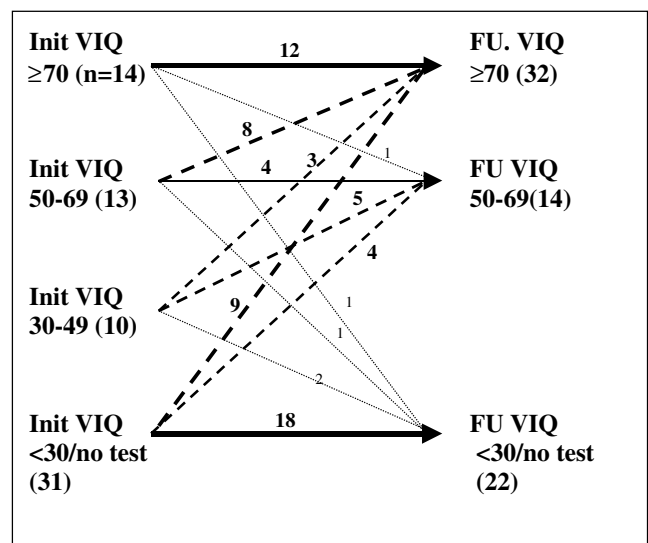

Figure 3 Stability of VIQ from child to adulthood

Table 4a Initial cognitive level and outcome rating measures: differences between individuals with a childhood IQ ≥ 70 and IQ 50–69

Childhood IQ	Mean (sd)			
	≥70 (n = 45[a])	50–69 (n = 23)		
Parental rating[c]			*Mann Whitney Z*[b]	*p*
Residential status	2.68 (1.52)	4.13 (1.79)	3.20	.001
Quality of friendships	1.75 (1.37)	2.69 (.70)	2.75	.006
Educational level	3.16 (1.43)	4.00 (0)	2.89	.004
Level of work	2.14 (1.17)	2.69 (.76)	2.13	.033
Total social outcome rating	6.38 (3.21)	8.83 (2.08)	3.12	.002

[a]Parental data missing on 1 case in this group.
[b]Means, rather than medians, are presented for ease of reference. However, because data were not normally distributed, non-parametric statistics were used for group comparisons.
[c]The higher the score the greater the abnormality, see Appendix 2.

Table 4b Initial cognitive level and outcome rating measures: differences between individuals with a childhood IQ ≥ 70 and IQ 50–69

Childhood IQ	≥70 (n = 45[a])	50–69 (n = 23)		
Parental rating[c]	*Mean (sd)*	*Mean (sd)*	*Mann Whitney Z*[b]	*p*
Social use of language	8.73 (5.89)	14.78 (8.52)	2.83	.005
Abnormal use of language	2.67 (2.82)	3.77 (2.20)	1.75	.080
Ritualistic behaviours	5.16 (3.33)	7.68 (5.78)	1.71	.087
Standard test scores	*Mean in years (sd)*	*Mean in years (sd)*	*t*	
BPVS age equivalent	10.31 (6.54)	4.24 (2.58)	5.54[d]	<.001
Neale accuracy age	10.81 (2.13)	9.56 (1.91)	1.59	.118
Neale comprehension age	9.13 (2.44)	7.20 (.93)	3.41[d]	.002
Spelling age	12.14 (2.75)	9.69 (2.43)	2.31	.026

[a]Parental data missing on 1 case in each group.
[b]Means for rating scores, rather than medians, are presented for ease of reference. However, because of the nature of these data, non-parametric statistics were used for group comparisons.
[c]The higher the score the greater the abnormality, see Appendix 2.
[d]Equal variances not assumed.

<30 when first seen, over a third (13) were scoring at a considerably higher level as adults – 9 above 70 and 4 between 50 and 69.

B. Childhood indicators of adult outcome

Performance IQ. When first assessed, all the children had completed some form of non-verbal IQ test. Thus it was possible to examine the impact of this variable on later functioning in every case. Participants were split into 2 main IQ bands: those with a childhood performance IQ in the normal range (i.e., 70+, n = 45; of whom 10 had an IQ ≥ 100) and those with a performance IQ in the mildly intellectually impaired range (i.e., 50–69; n = 23).

There were significant differences between the 70+ and 50–69 groups on a number of social outcome variables (see Table 4a). Of those with a performance IQ initially below 70, only one was described as having friends and only one was living semi-independently; the remainder was rated as highly dependent. The 3 individuals who were living at home because no other placement could be found for them, and 4 out of the 8 people in long-stay hospital care all had non-verbal childhood IQs below 70 (no one with a childhood IQ above 100 was in hospital care).

Although relatively few individuals had obtained any formal qualifications, there was a significant difference between the IQ bands. No one with an initial performance IQ of below 70 had obtained any formal qualifications and the childhood IQ scores of the 5 individuals who went on to college or university were all 70 or above (119, 97, 80, 76 and 70). Mean ratings for levels of employment were similar but almost all those currently in some form of employment (paid, voluntary or sheltered) had an initial performance IQ of 70+; only one of the 9 people in independent employment had an initial IQ below 70 (Fisher exact test for *n* in work in ≥70 and 50+ groups, *p* = .005. See also Table 4a).

Group differences on the total social outcome score (based on summed ratings for 'Friendships', 'Work' and 'Independent living') also indicated a significant difference between the two IQ groups (see Table 4a). Of the 23 individuals with a non-verbal childhood IQ below 70, only one achieved a 'Very Good' outcome rating in adulthood; 3 others were rated as 'Fair'; the remainder as 'Poor' or 'Very Poor'. In the ≥70 group, 7 individuals were rated as 'Very Good', 7 as 'Good', 10 as 'Fair', and 20 as 'Poor'/'Very Poor'. Further examination of the data showed that

there was no difference in outcome between those with an initial performance IQ of over 100 and those with an initial IQ of 70–99 (Mann–Whitney $Z = 1.37$, $p = .17$). Indeed, somewhat surprisingly, none of those in the 'Very Good' outcome group as adults had a childhood IQ of 100 or above.

Comparisons of ADI ratings of language competence also indicated significant differences between the ≥70 and <70 bands (see Table 4b). All the individuals with a childhood IQ below 70 were rated as having at least mild language problems as adults and 15 out of the 23 had severe problems or no speech. Nevertheless, over half (19) of the 70–99 IQ group were rated as having moderate or severe problems and although none of the 100+ IQ group had failed to develop language, 3 out of the 10 were still described as having severe problems.

There was no significant association between childhood IQ and abnormal use of language in adulthood. None of the individuals with an IQ of 100+ in childhood showed markedly abnormal use of language in adulthood, and the majority (25/34) of those in the 70–99 range also had only mild or insignificant problems. However, although generally the frequency of severe problems area was relatively low in each of the groups, the distribution of language abnormalities was variable (see Table 4b).

The average number of ritualistic behaviours reported by parents was somewhat higher in the lower IQ band (falling in the 'moderate range') compared to a rating in the 'mild' range for the individuals with an IQ ≥ 70, but there was no significant group difference (see Table 4b) and again, no difference between individuals with an IQ ≥ 100 and those with an IQ of 70–99.

The relationship between early IQ and scores on standardised tests was less consistent (see Table 4b). Adult BPVS age equivalent scores were significantly higher in the group with a childhood IQ ≥ 70 but again, further examination of the data indicated that there was no difference between those with an IQ of 70–99 and those with an IQ ≥ 100 ($t = .54$, $p = .59$). There was a significant difference between sub-groups on Reading Comprehension, a marginal difference for Spelling and no difference for Reading Accuracy. However,

whereas the majority (28 out of 45) in the ≥70 IQ group scored above basal on all 3 attainment tests, in the lower IQ band only 8 (35%) were able to score above the basal of 5–6 years.

Overall, it appeared that performance IQ in childhood was related to adult outcome in several areas, especially those associated with social functioning. The crucial cut-off point appeared to be around 70, with very few individuals scoring below this level as children achieving any real degree of independence as adults. Nevertheless, even above this cut-off, the picture proved to be very mixed. Of the 45 individuals with an initial IQ of 70 or above, only 7 could be considered to have a 'Very Good' outcome, in terms of living reasonably independently, holding down a job, and having some outside friendships. Another 7 were considered to have a 'Good' outcome in that, although still living with their families or in sheltered provision, they all had some form of occupation and some outside friendships. Ten were rated as 'Fair'. These individuals were not able to live independently but they had either sheltered employment or some form of friendships and had some freedom to travel outside their home or place of residence. The remainder was significantly impaired, mostly living with their families, in specialist autistic provision, or in institutional care. Individuals with a childhood IQ of over 100 did not tend to have a better outcome than those with an IQ between 70 and 99 and, in fact, several individuals with an initial IQ of 70–99 had made better progress (in terms of academic attainments, jobs and general level of functioning) than those with an IQ above 100.

Table 5 illustrates the very variable picture, according to overall social outcome, amongst individuals with an initial IQ of ≥70. Having an IQ well within the normal range (i.e., 100+) as a child did not seem to be related to adult outcome within this sub-group. However, whereas all the individuals with a 'Very Good' outcome, and the majority of those rated 'Good' or 'Fair', had some speech at 5, this was true for only 13 out of 20 in the poorest outcome group. Within the 'Very/Poor' outcome group the majority continued to show significant language impairments, and as adults they had higher levels of ritualistic behaviours. In addition, half of this group had

Table 5 Child and adult characteristics of individuals with an initial IQ above 70 (full data missing on one individual)

Outcome (n)	Child (n)			Adult (n)					
	IQ >100	Some speech at 5	PIQ >100	Cognitive decline (>1sd)	Formal qualifications	In work*	Signif. language problems	Some abnormal use of lang	Mod-severe rituals
Very good (7)	None	All	3	None	6	All	None	None	None
Good (7)	4	6	2	2	5	All	1	4	2
Fair (10)	4	8	2	2	2	3	3	5	4
Very/poor (20)	2	13	1	10	1	None (1 in past)	18	16	12

*Includes all individuals in independent, sheltered, voluntary or self-employed work. Employment status not known in one case.

shown a decline in IQ from child to adulthood of at least 1 standard deviation (15 points or more).

Verbal ability. When first seen, over 40% of the group (29 children) failed to score at all on any verbal test and 2 others had scores below 30. Moreover, when the group was divided into those with a childhood verbal IQ/IQ estimate of ≥70 ($n = 14$) and those with a verbal IQ estimate of 30–69 ($n = 23$), no significant differences were found on any of the social outcome variables (overall social competence, job, friendships, educational level or residential status). There were no group differences in adulthood on frequency of ritualistic behaviours or abnormal language usage, and only a weak effect for use of language in adulthood (Mann–Whitney $Z = 2.19$, $p = .028$). There were, however, a number of significant differences between the 31 individuals who were not able to score on a language test to begin with and those who were (see Tables 6a & b).

Similar comparisons were conducted taking language level at age 5 as the independent variable. Forty-two individuals were rated as having some useful speech at 5 years (i.e., ADI scores 0–2) and 17 had little or no useful speech (ADI scores 3/No speech). Early language data were not available for the remaining cases. Compared with those who had no speech at 5 years, those with speech had significantly higher median scores for overall social rating (7.0:8.5; $Z = 2.74$, $p = .006$) and residential status (2.0:3.0; $Z = 3.17$, $p = .002$) but there were no significant differences for educational level, friendship rating, social or abnormal use of language or ritualistic behaviour and only a marginal difference for work level ($Z = 2.45$, $p = .014$). There were no differences on reading or spelling tests. There was a marginal difference on language comprehension scores, as measured by the BPVS. The average language age in adulthood of individuals with some speech at age 5 was 9.7 years (sd 6.3) compared to 5.4 years (sd 4.9) for those without useful speech at 5 ($t = 2.5$, $p = .014$).

Can we predict who will have the best outcomes?

Correlations between overall social rating scores and childhood IQ measures, although significant, were moderate. There was no significant difference in the correlations between social outcome rating and child verbal IQ or Performance IQ (r. social outcome/VIQ = .52; r. social outcome/PIQ = .31; $p \geq 14$) but the failure of many children to obtain a verbal IQ score in the early years limits the value of this vari-

Table 6a Childhood verbal scores and social outcome measures: differences between individuals scoring above 30 IQ on verbal test as children and those below this level, or unable to score

	Mean (sd)			
Child language test	VIQ ≥ 30 ($n = 37$)	VIQ <30/not testable ($n = 31$)		
Parental rating[b]			*Mann Whitney Z*[a]	*p*
Residential status	2.69 (1.43)	3.74 (1.93)	2.65	.008
Quality of friendships	1.89 (1.35)	2.29 (1.13)	1.18	.236
Educational level	3.38 (1.19)	3.50 (1.30)	1.10	.271
Level of work	2.03 (1.18)	2.68 (.83)	2.79	.005
Total social outcome rating	6.44 (2.95)	8.13 (3.04)	2.68	.007

[a]Means, rather than medians, are presented for ease of reference. However, because of the nature of the data, non-parametric statistics were used for group comparisons.
[b]The higher the score the greater the abnormality, see Appendix 2.

Table 6b Childhood verbal scores and adult outcome measures: Differences between individuals scoring above 30 IQ on verbal test as children and those below this level, or unable to score

	Mean (sd)			
Child language test	VIQ ≥ 30 ($n = 37$)	VIQ <30/not testable ($n = 31$)		
Parental rating[b]			*Mann Whitney Z*[a]	*p*
Social use of language	8.03 (6.44)	14.03 (7.29)	3.74	.001
Abnormal use of language	2.79 (2.94)	3.20 (2.31)	0.95	.343
Ritualistic behaviours	5.22 (4.11)	6.93 (4.67)	1.82	.069
Standard test scores	*Mean in years (sd)*	*Mean in years (sd)*	*t*	
BPVS age equivalent	10.6 (5.9)	5.5 (5.4)	3.69	<.001
Neale accuracy age (yrs)	11.1 (1.7)	9.4 (2.4)	2.64	.012
Neale comprehension age (yrs)	8.7 (2.4)	8.8 (2.4)	0.16	.875
Spelling age (yrs)	11.8 (2.5)	11.2 (3.9)	0.66	.512

[a]Means for rating scores, rather than medians, are presented for ease of reference. However, because of the nature of the data, non-parametric statistics were used for group comparisons.
[b]The higher the score the greater the abnormality, see Appendix 2.

able in predicting outcome. Moreover, as is evident from Figure 4, having a higher verbal IQ in childhood did not necessarily predict a positive outcome in adulthood. Only 6 individuals out of the 14 with an initial VIQ ≥ 70 had a 'Good'/'Very Good' outcome and 4 were rated as 'Poor'. Of the 26 individuals who obtained a verbal IQ ≥ 50 as children, 9 achieved a 'Good'/'Very Good' outcome; 9 others were rated as 'Fair' and 8 as 'Poor/Very Poor'. The proportion rated as 'Good'/'Fair'/'Poor' was also similar for individuals with an initial verbal IQ *below* 50. And, as previously noted, even amongst those who obtained a performance IQ score ≥ 70 as children, less than one-third (14/44) was rated as having a 'Good' outcome in adulthood (see Figure 4).

Whilst neither Performance nor Verbal IQ alone in childhood proved a particularly good predictor of later outcome, the combination of these measures did provide a more reliable indicator. All those with a verbal IQ 70 *and* a Performance IQ ≥ 100 had a 'Good' or 'Fair' outcome, but as only 3 cases fell within this grouping this is likely to be of little gen-

eral predictive value. More individuals (*n* = 11) fell within the PIQ ≥ 70 *plus* VIQ ≥ 70 range, and of these 5 had a 'Good'/'Very Good' outcome; only 2 were rated 'Poor'. Within the group PIQ ≥ 70/ VIQ ≥ 50 (*n* = 20), 8 had a 'Good'/'Very Good' outcome; 7 were rated as 'Fair' and 5 as 'Poor'. (See Figure 4.)

In some ways it proved easier to identify correlates of 'Poor' outcome than the variables predictive of good prognosis. No one with a childhood performance IQ below 70 *and* a verbal IQ below 30 achieved even a 'Fair' rating in adulthood (see Figure 5) and only one individual with PIQ <70 + VIQ < 50 did so. Most individuals with an initial performance IQ below 70 (*n* = 23) were highly dependent as adults; only one had a 'Very Good' outcome and 3 others were rated as 'Fair'. Having a low verbal IQ initially was also associated with poorer outcome, but because VIQ increased substantially in some individuals over time the relationship was less consistent. Thus, although among those with a childhood VIQ <70 (*n* = 54) 35 had a
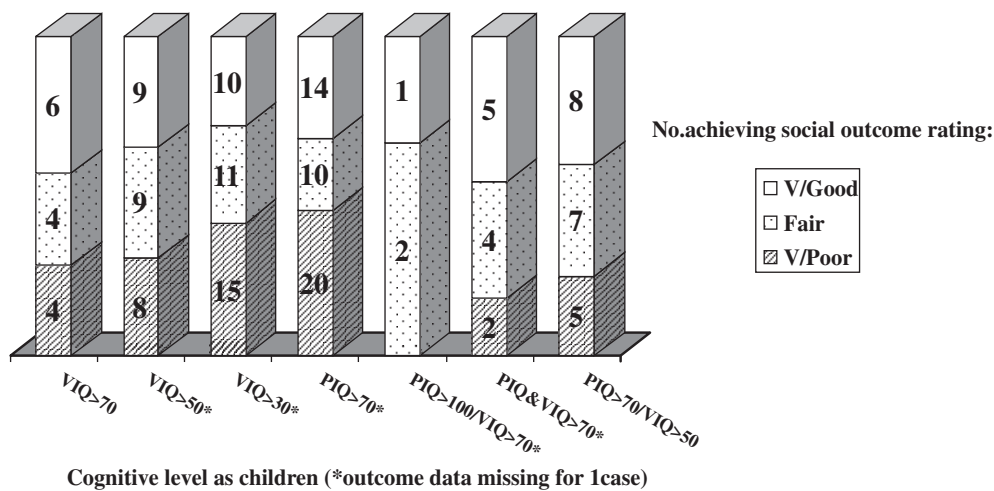

No.achieving social outcome rating:
□ V/Good
□ Fair
☒ V/Poor

Cognitive level as children (*outcome data missing for 1case)

Figure 4 Variables associated with good adult outcome

No. achieving social rating:
□ V/Poor
□ Fair
☒ V/Good

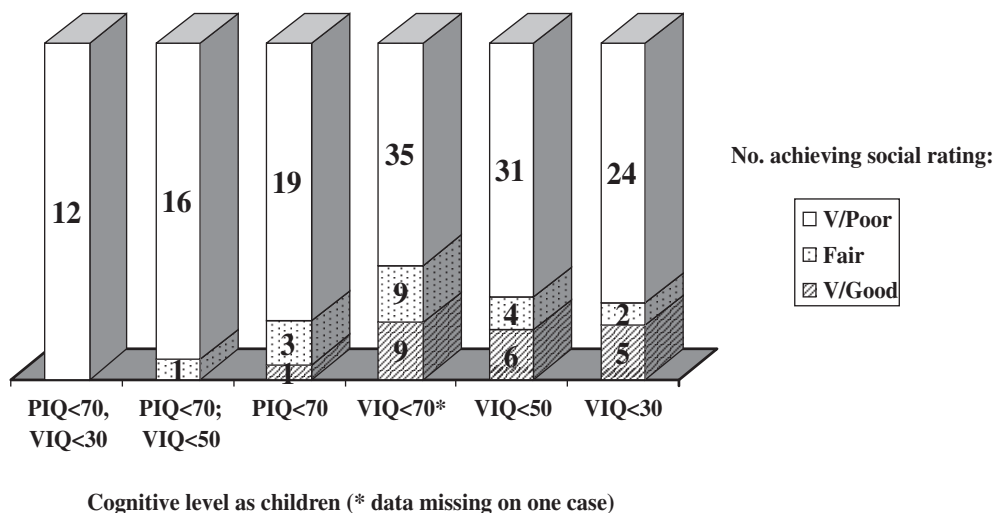**Cognitive level as children (* data missing on one case)**

Figure 5 Variables associated with poor adult outcome

'Poor'/'Very Poor' outcome, 4 individuals were rated as 'Very Good', 5 as 'Good' and 9 as 'Fair' as adults (data missing on one case). Of the 41 with a verbal IQ <50 in childhood, the majority (31) had 'Very'/'Poor' outcomes but 2 were rated as 'Very Good', 4 as 'Good' and 4 as 'Fair'. Even amongst those who, as children, were untestable or had a verbal IQ <30 ($n = 31$), 2 individuals were rated as 'Very Good', 3 as 'Good' and 2 as 'Fair' in adulthood. Thus despite a relatively strong statistical correlation between early verbal IQ scores, the clinical value of this variable in predicting *individual* outcomes was limited.

Gender differences in outcome

As there were only 7 women in the sample, any conclusions about possible gender differences can only be tentative. Males and females were a similar age when first assessed (M:7.1 yrs; F:7.6 yrs) and their non-verbal IQ scores were comparable (M:80.2 yrs; F:79.6 yrs). At follow-up women were slightly older (M:28.8 yrs; F:34.0 yrs) but the difference was not significant. Scores for verbal and non-verbal IQ, and on language, reading and spelling tests did not differ. As in the total sample, Performance IQ scores remained very stable over time and only one woman showed a major change (from an initial IQ of 137 to a follow-up IQ of 74); the remainder all remained within the same band as when first assessed. Verbal IQ scores were somewhat more variable. Two women who were initially untestable on a verbal IQ test scored above 70 at follow-up; 3 moved upwards (from VIQ ≤ 49 to VIQ 50–69); one individual who had scored above 70 as a child could no longer score on a verbal IQ test in adulthood and one remained untestable. There were no differences between men and women on measures of language level, abnormal use of language or repetitive and stereotyped behaviours, or on overall social outcome ratings (Mann–Whitney U test Z values all $p \geq .05$). However, no female was rated as having a 'Good' outcome in adulthood and five were within the 'Poor' or 'Very Poor' groups. None had ever attended normal school or obtained any formal qualifications. Only one had a job of any sort (helping out in the family firm); the remainder was all in special day or residential centres. None was reported to have friends or to be living independently; 3 were in some form of residential unit, one lived with her parents and 3 were in long-stay hospitals.

Discussion

General functioning in adulthood

This report on 68 individuals with autism and a non-verbal IQ of at least 50 represents one of the largest systematic follow-up studies of this condition in adult life. Other relatively large follow-up studies (Lockyer & Rutter, 1969, 1970; Rutter & Lockyer, 1967; Rutter et al., 1967; Kobayashi et al., 1992) have included both adults and children/adolescents and have combined data on those who are severely intellectually impaired (and for whom prognosis is almost certain to be poor) with those of higher IQ. The outcome measures used in the present study also cover many different domains, and were based on information from standardised tests and structured interviews of established reliability and validity. Detailed and systematic IQ data, rather than estimates of cognitive functioning, are also available from child to adulthood.

In terms of general outcome, the results suggested that many people had continued to make progress since they were seen in childhood. One-fifth had managed to obtain some academic qualifications at school and 5 of these individuals had gone on to college or university, with 2 studying at postgraduate level. Almost a third was in employment, and around a quarter of the group was described by parents as having some friendships involving shared interests or activities. Nevertheless, only 8 individuals could be rated as having achieved a high level of independence. Six of these were in paid employment and all showed a fair degree of independence, although only 2 (both of whose mothers had died) survived with little regular support (financial, social and/or emotional) from their families.

The majority, however, remained highly dependent on their families or required some form of residential provision. Even amongst those in employment, jobs tended to be poorly paid and did not provide individuals with adequate financial support to live independently. One young man, for example, who had become a skilled charcoal burner, remained in a MENCAP hostel. Although he would have preferred to live independently, he could not afford to do so. Another man, working in a graveyard, wanted to move to Social Services accommodation, rather than living at home. As his wages could in no way cover the costs of this, he was given the choice of keeping his job and remaining at home, or leaving home and giving up his job.

Overall, few individuals could be considered to be fully self-supporting and the proportion (57%) of those rated as having a 'Poor' or 'Very Poor' outcome remains similar to that reported in original follow-up study of Rutter and his colleagues (1967) over 30 years ago. Follow-up studies in Sweden (Gillberg & Steffenburg et al., 1987), Japan (Kobayashi et al., 1992) and North America (Ballaban-Gil et al., 1996; Szatmari et al., 1989; Venter et al., 1992) indicate similarly high levels of dependence, low economic status, and persisting language and/or behavioural difficulties. There are, of course, some positive findings. The percentage in open or sheltered employment, although relatively low (34%), is much higher

than the figures of below 10% reported in studies conducted in the 1970s and 80s. And, whereas almost half of the individuals in the Rutter and Lockyer studies were living in long-stay hospitals as adults, this was the case for only a minority in the present study. The proportion of individuals able to live semi/dependently, whilst small (around 10%), is also higher than the very low rates reported in some earlier studies (Ballaban-Gil et al., 1996; Gillberg et al., 1987; Rutter et al., 1967; Kobayashi et al., 1992; Lotter, 1974).

However, despite the group's relatively high IQ, attainments in many areas were disappointingly low. Not only had very few obtained any formal qualifications at school, even basic skills were very poor and almost half the group was unable to score above basal level (of 5 and 6 years respectively) on either the spelling or reading tests. Similarly, their mean age equivalent on the British Picture Vocabulary Scale was only eight years.

On the whole, it would appear that the huge increase in educational facilities for children with autism over the past 3 decades has not necessarily resulted in significant improvements in outcome for *adults*. What then, if anything, is predictive of outcome? All previous major follow-up studies of autism have indicated that outcome is almost invariably poor for individuals with a childhood IQ of below 50 (cf. Nordin & Gillberg, 1998; Lord & Bailey, 2002). However, as noted earlier, few people of this cognitive level, whatever the cause of their difficulties, achieve independence as adults. The present study therefore focused on prognosis in individuals with an IQ above 50.

The first issue investigated concerned the consistency of IQ over time. It has often been suggested that the results of early testing with children with autism are likely to be unreliable because of the children's poor understanding or social withdrawal. However, if the appropriate tests are chosen, it should not prove difficult to obtain good cooperation and reliable results (Clark & Rutter, 1979, 1981; Lord & Bailey, 2002). In the present study it was apparent that IQ remained remarkably stable over time. Correlations between adult and childhood IQs were highly significant; in many cases actual IQ scores showed little change and there were few significant differences in overall measures of either performance or verbal IQ over time. Over three-quarters (35/45) of those with an initial IQ of 70 or above remained within this range. There was also a significant relationship between adult IQ and other outcome measures.

Other follow-up studies have also noted the relative stability of IQ in autism, although generally over shorter time periods (cf. Ballaban-Gil et al., 1996; Lockyer & Rutter, 1970; Venter et al., 1992). The majority (51/68) in the present sample was beyond the age of 5 when first seen, and the consistency in IQ here may be a function of the age at which they were initially assessed. Thus the children tested before 5 years showed greater change in performance IQ than those assessed after 5 (a mean decrease of 13 points compared to a mean drop of 2.5 points in the older group; $t = 1.96$, df 66, $p = .054$). However, this is in marked contrast to the significant *improvements* in IQ (of 30 points or more) reported for children aged between 2 and 4 years who have been enrolled in early intensive, behaviourally based preschool programmes (Lovaas, 1987, 1993; McEachin, Smith, & Lovaas, 1993). All that can be concluded is that, if children are tested in the early school years, and if appropriate tests are used, then, in the absence of *intensive*, specialised intervention, marked changes in IQ from child to adulthood are infrequent. Intensive therapy might have well have resulted in greater changes, although it is also important to note that serious concerns have been raised about the way in which IQ changes have been calculated in these early intervention studies (Magiati & Howlin, 2001).

Given that early IQ testing does produce stable findings, the next issue concerns the relationship of childhood IQ to later outcome. Lord and Bailey (2002) suggested that variations in non-verbal IQ between 50 and 70 have a somewhat similar effect to those below 50 (although the effects are less), but that variations in non-verbal IQ within the normal range are of little predictive value. Our results are broadly in keeping with their conclusion. As compared to individuals with an initial IQ over 70, those with an initial performance IQ in the range of 50–69 appeared to have a much poorer prognosis in adulthood. The majority in the latter group remained highly dependent, and few had jobs or friends of any kind. Language skills were also generally very impaired. Outcome for those in the 70+ IQ range was significantly better in almost every domain assessed. These findings are important, for whilst previous studies had indicated that an IQ cut-off of around 50 is critical in determining which individuals do and do not do well, here it appears that only individuals with an IQ in the normal range (70+) have a real chance of living independently as they reach adulthood. Below this level outcome is likely to be much poorer.

Nevertheless, the findings also showed that, although having an IQ of at least 70 is a crucial prognostic factor, above this level outcome can still be very variable. There was little difference in adulthood between those with a childhood IQ of 100 or more, compared with those with an IQ between 70 and 99, and even those in the highest IQ group experienced many problems as adults. One individual, for example, with a childhood IQ of 119, and high ratings on many of the adult outcome measures, was frequently in trouble, at work and elsewhere, for inappropriately following or touching females, and he appeared to have little or no understanding of the potential impact of these behaviours. Another individual (initial IQ 80) had obtained a degree and

various computing qualifications in adulthood. He had also married (although he later divorced). However, he had no ability to perceive others' social intentions and was constantly being defrauded of large sums of money because of this. A third individual (initial IQ 97) was in danger of losing his job on several occasions because of his inability to understand social rules. Despite working in a culturally mixed office he often gave unwitting offence by referring disparagingly to people's race or colour or to the fact that they were 'foreigners'.

There were also certain aspects of adult functioning, mainly related to autistic-type behaviours (routines, rituals, stereotypies etc.), that did not appear to be strongly related to early IQ. Although the more able group was less likely to show very severe difficulties in these areas, the distribution of such symptoms was generally fairly evenly spread and within each IQ band, the majority of individuals continued to have at least mild to moderate problems associated with repetitive and stereotyped behaviours. Thus, although having a childhood IQ within the normal range is clearly a crucial factor in determining outcome, within this sub-group the presence of ritualistic and/or stereotyped behaviours may still prevent individuals from attaining an optimal level of functioning. In the case of one man (initial IQ 80), for example, ritualistic checking behaviours seriously compromised his ability to work independently, despite his having obtained various postgraduate qualifications. In another (initial IQ 114), the level of anxiety engendered by his need for predictability meant that he could only cope within highly supportive, specialist autism provision as an adult. The very fixed routines and preoccupations of another (initial IQ 107) also resulted in his needing specialist support in adulthood, both in work and accommodation.

It is clear that childhood performance on non-verbal tests of intelligence, whilst being a *relatively* good predictor of outcome, is by no means perfect and Lord and Bailey (2002) have proposed that childhood verbal IQ is a far more reliable indicator of later functioning. However, as is apparent from the present study, many children who failed to score above the basal level (or even to score at all) on verbal IQ tests when young went on to show significant improvements in this area over time. In the case of other children, who *were* able to obtain a verbal IQ score when first assessed, the relationship with adult outcome was very variable. Thus, from a clinical perspective, verbal IQ in early childhood appears to have only limited predictive value.

Lord and Bailey (2002) also suggested that the presence of useful speech by age 5 is highly predictive of later outcome. Certainly, for many young children it is much easier to obtain information of this kind than to obtain a verbal IQ score, although there may be some problems of recall if interviewing parents of older individuals. However, in the present study this variable, too, was only weakly associated with adult outcome. Over 40% of children who had little or no language when first assessed had developed useful language as adults, and the higher their linguistic levels as adults, the more likely they were to do well on a range of other outcome measures. Other research has pointed to the impact that improvements in language may have on the developmental trajectory of children with autism (Szatmari, 2000) but as yet we have little information on what is associated with such improvement. In an ongoing study we are examining in more detail patterns of early cognitive functioning that may be associated with increases, or decline, in levels of functioning, and the ways in which these may contribute to the picture in adult life.

Summary

There is no doubt that therapeutic and educational provision for individuals with autism has improved over the past 3 decades, and, as this and other studies show, a substantial minority of adults, although continuing to be affected by their autism, can find work, may live independently, and develop meaningful social relationships with others. Nevertheless, the majority remains very dependent on parents or others for support.

One of the most significant factors determining outcome appears to be level of intellectual functioning in childhood, and IQ scores, at least on non-verbal tests, tend to remain relatively stable over time. However, whereas earlier studies had suggested that an IQ level of above 50 was associated with a more positive outcome, the findings here indicate that only individuals with an IQ of over 70 are likely to do well. Nevertheless, even within this higher functioning group, outcome tends to be very variable and it seems that the fundamental deficits associated with autism, in particular the degree of ritualistic and stereotyped behaviours, may at times 'swamp' the effects of a relatively high IQ (see also Howlin et al., 2000; Mawhood et al., 2000). In addition, despite the relatively small changes in IQ overall, in a minority of cases there were considerable changes in IQ levels (both upwards and downwards) over time. Factors influencing change from child to adulthood, and the trajectories that different individuals may follow, are clearly important issues for future research.

Finally, the ability to function adequately in adulthood life may depend as much on the degree of support offered (by families, employment and social services) as on basic intelligence (Lord & Venter, 1992; Mawhood & Howlin, 1999). Although admissions to hospital care have fallen, and expectations about the future for people with disabilities generally have risen over the years, dedicated services for adults with autism would not seem to have kept pace

with the growth in specialist educational provision for children. A focus on access to more extensive and appropriate supported living and employment schemes could help to ensure much greater progress in the future.

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Appendix 1

Selection of subjects for adult follow-up study

Inclusion criteria

These were the same as for the genetic family study of Bolton et al. (1994), i.e.:

Singleton (not twin)
- Caucasian
- No evidence of specific medical disorders possibly related to autism (tuberous sclerosis, phenylketonuria, infant spasms, neurofibromatosis)
- No evidence of major physical or sensory impairment
- No prolonged period in institutional care.

(See Bolton et al., 1994, for further details.) *However, in contrast to the Bolton et al. (1994) sample:*

- Adoptees were included, as were individuals later found to have chromosomal abnormalities.

Additional criteria for inclusion in the present study:

- First *diagnostic* assessment prior to the age of 16 years (individuals initially referred before this age because of primary concerns about mental health problems/deterioration were not included)
- Minimum gap of 3 years between initial and follow-up assessments
- Initial performance IQ $\geqslant 50$.

Appendix 2

Details of assessments

Ratings of adult functioning

These were based principally on parental information from the Autism Diagnostic Interview (ADI; Le Couteur et al., 1989). This is the earlier version of the revised ADI (ADI-R; Lord, Rutter, & Le Couteur, 1994). For further details of scoring criteria see Le Couteur et al., 1989.

Social functioning and independence

Work ratings were 0: employed or self-employed; 1: voluntary work/job training or low-pay scheme; 2: supported/sheltered employment; 3: in special centre/no occupation

Friendship. 'Frequency' of friendships was rated according to the numbers of friends/acquaintances

the individual had, and 'Quality' according to the degree of sharing and mutual participation the relationship involved. Scores ranged from 0 (>1 close friendships involving sharing and exchange of confidences and range of different activities together) to 3 (no friends; no joint activities).

Independence ratings were 0: living independently; 1: in semi-sheltered accommodation (or still at home) but with high degree of autonomy; 2: living with parents, some limited autonomy; 3: in residential accommodation with some limited autonomy; 4: specialist autistic or other residential accommodation with little or no autonomy, 5: in hospital care or at home because nowhere else would accept the individual.

A composite measure of overall social functioning was based on the sum of scores in the areas noted above. Ratings were as follows:

0 = 'Very Good' outcome – i.e., achieving a high level of independence, having some friends and a job (total for all 3 areas above 0–2)
1 = 'Good' outcome – generally in work but requiring some degree of support in daily living; some friends/acquaintances (total 3–4)
2 = 'Fair' – has some degree of independence, and although requires support and supervision does not need specialist residential provision; no close friends but some acquaintances (total 5–7)
3 = 'Poor' – requiring special residential provision/ high level of support; no friends outside of residence (total 8–10)
4 = 'Very Poor' – needing high-level hospital care, no friends; no autonomy (total 11).

Composite ratings were checked both by PH & SG and agreement for all cases was 100%.

Current language usage was assessed using a composite score obtained from the ADI. The composite was based on the sum of ratings for utterance length, spontaneous communication, conversational ability, reporting of events, amount of social communication, and intonation and vocal expressiveness. Scores for each variable were as follows: 0 = little or no abnormality; 1 = mild problems (not interfering with intelligibility of speech, etc.); 2 = difficulties that occurring frequently or sufficient to interfere with intelligibility; 3 = problems both frequent and severe. Subjects with no intelligible speech were assigned a score of 8. (See Le Couteur et al., 1989, for further details.)

A composite score of 0 indicated normal or near-normal linguistic functioning (total 0–2); a score of 1 mild to moderate impairments (total 3 to 7); a score of 2 moderate impairment (8 to 10); a score of 3 severe impairment (11+), and a score of 4 no language.

Abnormal use of language was based on the total ADI ratings for *current* immediate echolalia, stereotyped utterances, pronoun reversal, neologisms, idiosyncratic language and inappropriate speech. For each variable a score of 0 indicated little or no abnormality; 1 = mild/occasional problems; 2 = frequent occurrence but with some appropriate use of speech; 3 = almost all speech abnormal. Subjects with no intelligible speech were not rated on these variables.

A *composite* score of 0 indicated little or no abnormal usage (total 0–1); a score of 1 occasional or mild abnormalities (total 2 to 5); a score of 2 definite and frequent abnormalities (total 6+). The maximum obtained by any individual on this measure was 10. Subjects with little or no useful language were not rated on this measure.

Autistic-type problems in adulthood

Ratings were based on the ADI scores for presence of verbal rituals, unusual preoccupations, rituals and compulsions, resistance to change, unusual attachment to objects, unusual sensory interests, and complex hand/body mannerisms. For each variable a score of 0 indicated little or no abnormality; 1 = mild/occasional problems; 2 = frequent problems; 3 = frequent problems with considerable disruption to family life.

A *composite* score of 0 indicated few or no problems (total 0–1); a score of 1 occasional or mild problems (total 2 to 5); a score of 2 definite and frequent problems in several areas (total 6 to 10) and a score of 3 severe problems in multiple areas (total score 11+).

Cognitive testing

A 'best estimate' adult IQ was assigned to each subject for the purpose of banding into IQ groups. The IQ score was assigned in a hierarchical manner, taking either the WAIS Full Scale or Performance IQ score (whichever was higher) if available ($n = 46$). One individual scored only on the WAIS Verbal Scale and his 'best estimate IQ' was based on this. If subjects could not score on the WAIS, the Raven's IQ score was used ($n = 15$); if not then the Leiter ($n = 5$), then the Merrill Palmer ($n = 1$).

Language – BPVS scores

In the majority of cases, raw scores were below basal for the individual's age ($n = 40$) or chronological ages were above ceiling ($n = 7$) and it hence was not possible to calculate a standard language score; instead language age equivalents were used. The 7 individuals with raw scores above the level for which an age score could be calculated from the test norms were randomly assigned scores between 19 years 6 months and 21 years (i.e., between the maximum test age and the upper confidence limit for this). The 4 who scored below the minimum age level of 1 year 8 months were randomly assigned scores between zero and 1 year 8 months (see Mawhood et al., 2000).