Journal of Autism and Developmental Disorders, Vol. 35, No. 3, June 2005 (© 2005)
DOI: 10.1007/s10803-005-3302-5

Autism after Adolescence: Population-based 13- to 22-year Follow-up Study of 120 Individuals with Autism Diagnosed in Childhood

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Background: Prospective population-based follow-up study of 120 individuals with autism followed from childhood to adulthood. *Methods*: Individuals with autism, diagnosed in childhood, were followed prospectively for a period of 13–22 years and re-evaluated at ages 17–40 years. The instruments used at follow-up were the DISCO, WAIS-R, WISC-III, Vineland Adaptive Behavior Scales, psychiatric-medical examination and GAF-scale. A set of criteria was used for the classification of outcomes, taking into consideration employment, higher education/vocational training, independent living and peer relations. *Results*: Six of the 120 (5%) had died at the time of follow-up, and six declined participation. Overall outcome was poor in 78% of cases. Only four individuals were independent albeit leading fairly isolated lives. Childhood IQ-level was positively correlated with better adult outcome, as was the existence of some communicative phrase speech at age six years. *Conclusions*: Children with autism as diagnosed in the 1960s, 1970s, and 1980s may have an even worse psychosocial outcome than previously believed.

KEY WORDS: Autism; epidemiology; outcome; epilepsy; adolescence.

INTRODUCTION

Follow-up studies of autism performed in the 1970s and 1980s indicated that the intermediate-term outcome is variable but, on average, psychosocially poor (Gillberg, 1991; Lotter, 1978; Nordin & Gillberg, 1998). According to these studies, about two thirds of people with autism had no indication of independence (work, education, independent living) in early adult life. There was a high rate of epilepsy in early childhood and adolescence (Olsson, Gillberg, & Steffenburg, 1988; Volkmar & Nelson 1990), and possibly a higher rate of poor outcome in the epilepsy subgroup (Kobayashi & Murata, 1998). Females with autism appeared to do worse than males. Symptom aggravation and deterioration were frequent complications, particularly in those with epilepsy (Gillberg & Steffenburg 1987). A tendency towards poorer outcome in the group with "classic" autism than in those with autistic-like conditions was noted by some authors (Nordin & Gillberg, 1998).

Recent studies of the short-term outcome have suggested a substantially better prognosis in many cases. This may have been due to earlier and more effective interventions, to the inclusion of proportionately more high-functioning individuals include in the studies, or to other factors (Howlin, 1998; Lovaas, 1987; Schopler & Mesibov, 1983; Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989).

Little is known about the long-term natural outcome of autism. Only a very limited number of studies have been published, and they have usually

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referred to small or selected, clinical case samples (Howlin, Mawhood, & Rutter, 2000; Isager, Mouridsen, & Rich, 1999Kanner, 1971; Larsen & Mouridsen, 1997; Mawhood, Howlin, & Rutter, 2000; Rumsey & Hamburger, 1988). Some population-based studies have followed children prospectively from childhood through adolescence into early adulthood (Beadle-Brown *et al*, 2002; Gillberg & Steffenburg, 1987; Lotter, 1974), but there has, to our knowledge, been no report on a reasonably large population-based case series followed from childhood into adulthood.

The present study is the first ever to present this kind of long-term epidemiological perspective on the longitudinal natural outcome of autism. It includes a fairly large group with DSM-III-R autistic disorder (American Psychiatric Association, 1987), and a comparison group of autistic-like cases, both of which were recruited from the general population of children in Göteborg, Sweden, and followed prospectively for 13–22 years until age 17–40 years.

Our hypotheses—based on the aforementioned published studies and reviews of autism outcome—were that (i) autism would have a psychosocially poor outcome with about two thirds of individuals showing no independence in early adult life, (ii) would be associated with a history of/current epilepsy in about one third of the group, and that the subgroup with epilepsy would have a particularly high rate of pubertal aggravation, and a higher rate of very poor outcome compared to the subgroup without epilepsy, (iii) would be associated with poorer outcomes in females than in males, and (iv) would have a significantly worse outcome in the core condition (autistic disorder) than in the atypical variant (autistic-like condition).

PARTICIPANTS AND METHODS

Outline of Population Samples

One hundred and twenty individuals (84 males, 36 females,) with autistic disorder/infantile autism (61 males, 17 females) or autistic-like conditions/atypical autism (23 males, 19 females) were included in the study (see below for definitions). They had all been recruited in population-based studies of autism performed in Gothenburg, Sweden in the 1980s (Gillberg, 1984; Gillberg, Steffenburg, & Schaumann, 1991; Steffenburg & Gillberg, 1986). All had been diagnosed after in-depth examination in childhood and were followed prospectively for a period of 13–22 years and re-evaluated at ages 17–40 years (mean age 25.5 years). The ratio of autistic disorder to atypical autism was 2.4:1. The 120 cases included comprised *all* cases included in three *population-based* studies. These studies had all screened for autism in all clinics, hospitals, university departments, and schools in one geographical region with the aim of identifying all children with the condition born in a specific period of time and living in the region on a specific census day. The first study included 51 children, 26 of whom met the 1978 criteria by Rutter (1978) and the DSM-III-criteria (American Psychiatric Association, 1980) for infantile autism—later shown to meet also the DSM-III-R-criteria for autistic disorder. The majority of this group has been followed-up once before (in the 1980s) at ages 16–23 years (Gillberg & Steffenburg, 1987). The second study included 52 children, 35 of whom met criteria for DSM-III-R autistic disorder. Six children in the second study were also included in the first study, meaning that the total number remaining after pooling the two cohorts was 97. The third study included 75 children, 55 of whom met criteria for DSM-III-R autistic disorder. All 52 cases included in the second study were also included in the third study. Thus, when pooling the cohorts of all three studies, we were left with 120 individuals.

These 120 individuals (78 with DSM-III-R autistic disorder and 42 with autistic-like conditions) are reasonably representative of all children with autistic disorder/autistic-like conditions (as conceptualised in the 1980s) born in 1962–1984 and living in the Gothenburg region at the time of the original diagnostic studies. Nevertheless, there are some caveats. The Gothenburg region was slightly differently delineated at the three census dates. Also, differently from those born in 1975–1984, the population of children born in 1962–1974 was not re-screened in 1988. Finally, it was discovered in a later epidemiological study of severe mental retardation and epilepsy, that a small, but significant number of autistic disorder cases had been missed by the original screening procedures (Steffenburg, Gillberg, & Steffenburg, 1996).

Current Study Groups

Autistic Disorder

The 78 individuals with autistic disorder had all met the criteria of the DSM-III-R at the time of first being diagnosed in the original population screening studies. They had all been tested before

age 10 years—with an age—and ability—appropriate neuropsychological, developmental, or social developmental test—and found to have severe mental retardation (SMR = IQ < 50) in 36 cases (46%), mild mental retardation (MMR = IQ 50–70) in 26 cases (33%), near average IQ (NA = 71–85) in 12 cases (15%) or average IQ (A = IQ > 85) in 4 cases (5%). Twenty-nine (37%) individuals in this autistic disorder group had no phrase speech at all at 6 years of age.

Atypical Autism/Autistic-like Conditions

The 42 individuals with atypical autism/autistic-like conditions had all met 6 or more of the 18—but not full—DSM-III-R-criteria for autistic disorder. Like the autistic disorder group, they too had been tested before age 10 years, and had been found to have SMR in 20 cases (48%), MMR in 16 cases (38%), NA in 5 cases (12%), and A in 1 case (2%). Two of the individuals in the atypical autism group had been diagnosed as "disintegrative psychosis" in the first diagnostic study. Twelve (29%) individuals in this atypical autism group had no phrase speech at all at 6 years of age.

Original Diagnostic Assessment

Both study groups had been assessed in childhood with the autism instruments that were state-of-the-art at the time of the diagnostic studies (e.g. in-depth clinical interview, the Handicaps, Behaviours, and Skills Schedule (Wing, 1980), the Childhood Autism Rating Scale (Schopler, Reichler, DeVellis, & Daly, 1980), and the Autistic Behavior Checklist (Krug, Arick, & Almond, 1980)). All 120 children had been examined by either Christopher Gillberg or Suzanne Steffenburg, experts in the field of autism. Autism diagnostic instruments, such as the Autism Diagnostic Interview (ADI) (LeCouteur *et al.*, 1989) or the DIagnosis of Social and COmmunication Disorder schedule (DISCO) (Wing, Leekam, Libby, Gould, & Larcombe, 2002) were not available at the time when the cohorts were recruited. Almost all cases had also received a full medical assessment including a karyotype, EEG, neuroimaging, auditory brainstem response examination, assessment of hearing and vision, and a number of urine, blood and cerebrospinal fluid examinations (Steffenburg, 1990).

Instruments Used at 2001 Follow-up

Six individuals in the original cohort of 120 individuals (5%) had died at the time of follow-up (see below). The vast majority ($n = 108$, 95%) of the remaining 114 individuals were followed-up with in-depth examinations. These were performed in 2000–2001 (85%) or in late 1999/ early 2002 (15%). The following instruments were used:

(i) The DISCO: This 2–4 hour investigator-based interview intended for use with a person (often a parent) who knew the individual with a suspected autism spectrum disorder from early childhood, was completed for 105 individuals. It has excellent inter-rater and test–retest reliability, and is highly valid for assigning diagnoses (including common comorbidity diagnoses) in the autism spectrum (Wing *et al.*, 2002). The DISCO was chosen rather than the ADI, (LeCouteur *et al.*, 1989) because the latter is designed for use in the diagnosis of core autism, whereas the DISCO includes a range of items intended to detect milder forms of autism spectrum disorders. In addition, the DISCO has a developmental perspective and is specifically intended for use throughout the person's lifespan (Wing *et al.*, 2002).

(ii) The Wechsler Intelligence Scales for adults (WAIS-R) (Wechsler, 1981) and for children (WISC-III) (Wechsler, 1992a). These well-established IQ-tests, including full-scale IQ (FSIQ), and subtests for verbal IQ (VIQ) and performance IQ (PIQ), were given to 25 individuals (WAIS-R $n = 17$, WISC-III $n = 8$) (by the first author). They were corrected according to Swedish normative data (Wechsler, 1992b, 1999).

(iii) The Vineland adaptive behaviour scale (Sparrow, Balla, & Cicchetti, 1984). All individuals participating in the study, including those taking the WAIS-R or the WISC-III, where given the Vineland adaptive behaviour scales (by the first author).

(iv) Psychiatric-medical examination. The psychiatric-medical assessments, which were all performed by the second author, comprised observation, a semi-structured interview with verbal subjects, medical history and a brief psychiatric/ physical examination. In addition, a structured interview with a parent (or other person close to the individual with autism) was performed. This interview covered among other problem behaviours, hyperactivity, violent and self-injurious behaviours.

(v) GAF-score. The DSM-III-R Global Assessment of Functioning scale (GAF) (American Psychiatric Association, 1987) was used independently by the first and second author in all cases. This measure yields scores from 0 to 100, 70 and above indicating good functioning or only mildly abnormal psychosocial situation.

Autism Spectrum Disorder Diagnosis at Follow-up

A clinical diagnosis of autism spectrum disorder at follow-up was made–conjointly by the two first authors on the basis of all available information excluding the DISCO—to be present in individuals who were functionally moderately severely impaired and who had handicapping symptoms from at least two of the three domains of the triad of social, communication and imagination/behavioural impairments (Wing *et al*., 2002). Cases were subdivided into those with autistic disorder/childhood autism meeting criteria for this diagnosis according to the DSM-IV (American Psychiatric Association, 1994)/ICD-10 (World Health Organisation, 1993), and atypical autism according to the ICD-10 in individuals showing 4 or more of the 12, but not full DSM-IV/ICD-10 diagnostic criteria for autistic disorder/childhood autism. In addition "other autism spectrum disorder" was in those not meeting criteria for autistic disorder or atypical autism but fulfilling the criteria for a clinical diagnosis of autism spectrum disorder. The diagnostic criteria for Asperger syndrome by Gillberg and Gillberg (1989) were also checked. The third author who had been involved in the original diagnostic studies did not contribute to the diagnostic process in the follow-up study.

Research diagnoses of autism spectrum disorders were also made according to the algorithm of the DISCO. These were generated by computer on the basis of the results obtained at the DISCO-interview. There was good-excellent correspondence across clinical and DISCO-diagnosis, but the match was not perfect (see Results).

Criteria for Poor and Good Outcome

A set of criteria were used for the classification of outcomes, similar to those employed in the study at 16–23 years by Gillberg and Steffenburg (1987) of the first of the three population cohorts included in the present study. This classification, in turn, was based on the outcome criteria published by Lotter (1978). Reliability studies—to our knowledge—have not been performed. The classifications were made by the first and second author conjointly and were based on all available information (including from the DISCO) at the time of examination. The outcome criteria were:

Good outcome: (a) being employed or in higher education/vocational training, *and*, (b) if over the age of 23 years, living independently, if 22 years or younger, having two or more friends/a steady relationship;

Fair outcome: either (a) or (b) under very good outcome;

Restricted but acceptable outcome : neither (a) *nor* (b) under good outcome, *and* not meeting criteria for a major psychiatric disorder other than autistic disorder or another autism spectrum disorder. This category refers to a group of people with the characteristics of poor outcome but who have been accepted by a group of peers or personnel to such an extent that their handicaps are not so readily obvious.

Poor outcome: Obvious severe handicap, no independent social progress, some clear verbal or non-verbal communicative skills.

Very poor outcome: Obvious very severe handicap, unable to lead any kind of independent existence, no clear verbal or non-verbal communication.

Statistical Methods Used

Group differences were examined using the chi-square test with Yates's correction whenever appropriate. Means were compared using Fisher non-parametric permutation tests.

Ethics

The study was approved by the Medical Ethical Committee of Gothenburg University.

RESULTS

Attrition

Of the 114 families with children still alive at the time of the follow-up study, 6 declined participation, leaving 108 for examination (Table I). Slightly more individuals from the atypical autism group dropped out from the follow-up study.

Mortality

Six of the 120 (5%) had died at the time of the follow-up. They were 7, 10, 15, 18 and 19 years at the time of their death. In one case, the timing and cause of death could not be determined because the records did not show the last four ID-digits essential for identifying individuals in Sweden. The causes of death were in the other five cases (1) status epilepticus (a girl with idiopathic autistic disorder), (2) unknown

Table I. Outcome in 120 Individuals with Autistic Disorder or Atypical Autism

Outcome variable	Autistic disorder N = 78	Atypical autism N = 42
Attrition	2 (3%)	4(10%)
Dead at follow-up	3 (4%)	3 (7%)
Very poor outcome	38/73 (52%)	24/35 (69%)
Poor outcome	17/73 (23%)	6/35 (17%)
Restricted but acceptable outcome	12/73 (16%)	2/35 (6%)
Fair outcome	6/73 (8%)	3/35 (9%)
Good outcome	0	0
Independence	3/73 (4%)	1/35 (3%)
Mean GAF-score (SD)	22.2 (16.8)	18.5 (15.2)
GAF-score 50 or more	10/73 (14%)	3/35 (9%)
GAF-score 20 or less	45/73 (62%)	25/35 (71%)
Clinical diagnosis of autistic disorder at follow-up	62/73 (85%)	30/35 (86%)
DISCO algorithm diagnosis of autistic disorder at follow-up	59/71 (83%)	27/34 (79%)
Not meeting criteria for an autism spectrum disorder at follow-up	1/73 (1%)	0
"Psychosis" diagnosed by adult psychiatrist	5/73 (7%)	3/35 (9%)
Epilepsy reported by collateral informant	30/73 (41%)	16/35 (46%)
Severe self-injury	34/73 (47%)	20/35 (57%)
Severe violence	39/73 (53%)	17/35 (49%)
Hyperactivity	27/73 (37%)	13/35 (37%)
Pubertal regression	12/73 (16%)	6/35 (17%)
Catatonia	8/73 (11%)	5/35 (14%)

All differences non-significant.

but occurring during sleep and suspected of being associated with status epilepticus (a girl with autism diagnosed in early childhood much later shown to be suffering from Rett syndrome), (3) accidental major fire in one case (a boy with autistic disorder/fragile X syndrome), (4) complications after major heart surgery in one case (a boy with trisomy 13 and a major heart malformation) and (5) brain tumour in one case (a girl with atypical autism).

Diagnosis within the Autism Spectrum at Follow-up and Diagnostic Stability Over Time

The majority of individuals with autistic disorder in the original studies still met clinical diagnostic criteria for that condition at follow-up (62 out of 73 examined = 85%). Many of those with atypical autism now met criteria for autistic disorder (30 out of 35 examined = 86%), and only 5 in this group were now given a diagnosis of atypical autism. Significantly more of those with an early diagnosis of autistic disorder remained within their diagnostic category at follow-up than of those with an early diagnosis of atypical autism ($p < .0001$, $\chi^2 = 47.2$, df 1). One hundred and three (of the 108) individuals with an original diagnosis of autistic disorder or atypical autism were still clinically classified as having either of these two diagnosis at follow-up. Four individuals were classified as having another autism spectrum disorder. Only one individual (a man with autistic disorder and normal IQ in the diagnostic study) no longer met criteria for an autism spectrum disorder.

Five of those with autistic disorder in the original study fitted the Gillberg & Gillberg criteria for Asperger syndrome at follow-up. Four of these also met criteria for autistic disorder and one met criteria for atypical autism at follow-up. There was one male with MMR in this subgroup. The remaining three males and one woman in this Asperger syndrome subgroup were all of average IQ, both at original study and at follow-up.

The DISCO-interview classified the vast majority of cases in the same diagnostic category as the clinicians (Table I).

Overall Outcome

Fifty-seven per cent had a very poor outcome with no statistically significant differences across the subgroups (autistic disorder vs. atypical autism), 21% had poor outcome, 13% had restricted but acceptable outcome, 8% had fair outcome, and none had good outcome.

Independency

One man was independent and living in a long-term relationship with a woman. Three further individuals (two men, one woman) were independent but leading fairly isolated lives.

GAF-scores

The inter-rater reliability for GAF-scores across the two examiners (ICG and EB) was Pearson $r = .98$, ($p < .001$, $n = 108$). The difference across raters was 5 points or less in 87% of the cases, and in no case was there a discrepancy of more than 12 points. After the completion of the inter-rater-reliability study, the two raters discussed each case and agreed on a conjoint rating.

The mean GAF-score for the whole rated group ($n = 108$) was 21.1 (SD 16.4, range 4–67). Thirteen

individuals (12%) of the 108 examined at follow-up had GAF-scores of 50–69 indicating moderate, or mild psychiatric problems or functional impairments. However, none had a score of 70 or above. Of these, 7 had had an IQ of 70 or above in the original diagnostic study, whereas the remaining 6 had tested in the MMR range. All but one of the 13 still tested in the same range as follow-up (one individual with near average IQ in the original study tested in the MMR range at follow-up). Nine of the 13 had had autistic disorder in the original study, and 4 had atypical autism. The ratio of autistic disorder to atypical autism (2.3:1) was almost identical to that in the group with GAF-score under 50 (2.4:1).

The mean GAF-score for those 32 individuals (30% of those examined) who had no speech (not even non-communicative echolalia) at age 6 years was 8.8 (SD 3.3, range 5–20). The corresponding mean GAF-score for those who had some speech at age 6 years was 26.3 (SD 16.8, range 4–67) (Fisher non-parametric permutation test, $p < .001$).

Psychiatric Disorders

Psychosis

Eight individuals (5 males, 3 females) had been diagnosed by independent (adult) psychiatrists as suffering from psychosis. Only in one individual (male) had the psychotic condition been labelled schizophrenia, In another male, a formal diagnosis of bipolar disorder had been made but there were histories suggestive of this diagnosis in four further of those receiving a diagnosis of psychosis. All of these received lithium medication. Only one of the 8 with psychosis had intermediate outcome, while the remaining 7 were in the very poor outcome category (6 of whom had GAF-scores of 15 or under).

Non-psychotic Depression

One young man (belonging in the small group with restricted but acceptable outcome) had recurrent unipolar depressive episodes.

Tic Disorders

One woman (with neurofibromatosis and autistic disorder) had a severe case of Tourette syndrome. Twenty-five further individuals (23%) were reported to have periods of substantial tics without fulfilling the criteria for Tourette syndrome.

Psychiatric Medication

At the time of the study, 35 individuals (32% of those examined) were prescribed neuroleptic medication by independent psychiatrists. Eight further individuals received medication with lithium (see above). All of these had major behavioural problems, commonly dominated by episodes of violent outbursts and self-injury, sometimes also by hyperactivity.

Self-injurious Behaviours

Fifty-four individuals (50%) had engaged in moderate or severe degrees of self-injurious behaviours at some point in time during development.

Hyperactive Behaviours

Thirty-six individuals (33%) were perceived as being very hyperactive. Twenty-three of these were also engaging in self-injurious acts.

Violent Behaviours

Twenty individuals (19%) were reported to often show extremes of violent behaviours, and another 25 (23%) were violent often enough or severely enough to cause considerable concern.

Epilepsy

Forty-three per cent of the 108 individuals examined had had epileptic seizures in the past or continued to have epilepsy at the time of the follow-up study. At least two of the remaining 12 had had epilepsy in the past and one of these had died from status epilepticus. Thus, at least 40% of the total cohort of 120 had/had had epilepsy. No individual had developed epilepsy after age 20 years. Detailed data on epilepsy will be reported elsewhere.

Anti-epileptic medication for epilepsy was still used by 31% of the whole group of 108. Another 14% were given anti-epileptic medication for major behaviour problems.

Other Medical Disorders

Medical Syndromes

Twenty-seven individuals in the original diagnostic studies (23%) had already been shown at the time of those studies to suffer from a ''syndromal'' medical disorder, such as tuberous sclerosis ($n = 1$),

neurofibromatosis (4), fragile X syndrome (9), Moebius syndrome (3), Rett syndrome (3), Williams syndrome (1), operated hydrocephalus (1), or another named/known syndrome (5). However, all of them—except the boy with hydrocephalus and the boy with trisomy 13—had originally been diagnosed as suffering from autism and the associated medical disorder had only been uncovered in the course of the autism diagnostic assessments. Those with the fragile X syndrome constituted a relatively large subgroup. This subgroup tended to do a little better at follow-up than the others who had an associated medical disorder. In the subgroup of 9 individuals with fragile X syndrome, there was one death, but the mean GAF-score in those 8 living at the time of follow-up was 33.2 (SD 19.3, range 12–62) to be compared with 11.7 (SD 6.2, range 3–26) in the remainder with a medical disorder (Fisher's non-parametric permutation test, $p < .001$).

Other Medical Problems

Medical problems not specifically or necessarily a part of any of the mentioned syndromes were quite common. Two women and one man suffered severe attacks of "migraine". Two men had chronic nocturnal enuresis. Two men had severe atopic dermatitis. One young man had a stricture of the oesophagus after eating dish-washing powder. Another man had recently suffered severe anaemia and had to be transfused after regurgitation and chronic oesophageal bleeding. One of the young women with psychosis had developed diabetes mellitus. Several individuals had been operated on because of epilepsy (2), heart conditions (2, of whom 1 had a chromosomal disorder), scoliosis (3, of whom 1 had Rett syndrome), or shortening of the Achilles tendon (5, of whom 2 had Rett syndrome). Except for one woman with chronic eye-infections due to faecal smearing, and one man with chronic skin infections due to auto-mutilation, severe infections were not reported in any of the 108 individuals examined.

Altogether 49% of the 108 individuals examined had a major medical problem (whether related to an underlying medical disorder or not) needing regular medical attention.

Catatonia

Thirteen individuals (12%) had clinically diagnosed catatonia with severe motor initiation problems. Another 4 would be classified as having possible catatonia according to the criteria by Wing (2000) on the basis of results obtained at DISCO-interview. In the majority of the latter group, the motor problems were mild or moderate, and, seemingly, not interfering in a major fashion with daily life activities. Most of the individuals affected were perceived as having very awkward gait movements.

Intellectual Functioning at Follow-up

Only a handful of all individuals included were able to take a complete IQ-test. However, 108 were assessed using Vineland interview allowing us to make reasonable clinical assessment regarding whether or not an individual should be diagnosed as belonging in the SMR category. Our previous follow-up study has used the broad categories of SMR, MMR, near average intelligence (NA) and average intelligence (A). Because of this, and because of the unreliable nature of any *very* precise IQ score in individuals belonging in this notoriously difficult to-test population we have used the same broad measures here. SMR was found in 68% in the autistic disorder group and in 77% in the atypical autism group (n.s.). Correspondingly, MMR was found in 25% and 20% of the groups (n.s.), NA in 3% and 0% of the groups (n.s.), and A in 4% and 3% of the groups (n.s.). The rate of SMR in the atypical autism group was significantly higher at follow-up than at the original diagnostic study ($< .02 = 5.1$, df 1).

Of those with SMR in the original diagnostic study, all were still in that category at follow-up. Of those with NA in the original study, many were now diagnosed as having MMR or even, in one case, SMR.

Overall, collapsing the autistic disorder and atypical autism groups, there was a downward shift of IQ-level from the diagnostic study to the follow-up evaluation. Fifty-six of the original 120 children had been diagnosed as having SMR in the first study. At follow-up, 77 of 108 (71%) were diagnosed in this category ($p < .001$, $\chi^2 = .2$, df 1).

Puberty

Of those surviving into adult age, 38% had had a remarkably problem-free adolescent period. However, 31% had shown major problems and more than half of these had deteriorated significantly in puberty. Thus, altogether 17% of the 108 examined were reported to have had a clear set-back in puberty and half of these never really recovered. Data on pubertal

onset was available in 98 cases (parents report). In 22 cases (20%) onset was "late" ($n = 8$) or reported to have occurred at or after age 16 years ($n = 14$). In 3 cases onset of puberty was reported to have occurred at or under 10 years of age.

Male–Female Differences

The females in the study were relatively few. Nevertheless, there was no statistically significant association between female gender and overall outcome, GAF-scores, rate of epilepsy or deterioration in adolescence. If anything, there was a (non-significant) tendency for the females in the study to do better than the males at follow-up, the male:female ratio in the higher GAF-score group (50–69) being 1.6:1 compared to 2.5:1 in the group with lower GAF-scores (n.s.).

DISCUSSIONS

This is the longest and largest prospective follow-up study ever published of a community sample of individuals with autism followed from childhood through adolescence into adulthood. Because the sample of cases included are representative of autism as diagnosed in the 1970s and 1980s, the results must be considered to be of particular interest, given that most of the previously published studies have related to much smaller, and/or possibly highly selected samples. Another strength is the use in the follow-up study of diagnosticians who were not involved in the original diagnostic process in the childhood.

None of the hypotheses were clearly supported by the data. Thus, poor and very poor outcome affected more individuals than predicted, epilepsy was even more common than expected, and it did not predict deterioration or poor outcome to any considerable degree (except insofar as it may have contributed to increased mortality), female gender was not associated with worse outcomes, and the outcome of atypical autism was as restricted as that of "classic" autistic disorder.

As in previous studies (Nordin & Gillberg, 1998) IQ at original diagnostic study (under age 10 years) was a strong predictor of outcome. It could be argued that the present findings reflect the outcome of individuals with low IQ rather than of autism *per se*. Nonetheless, the outcome was relatively poor even for those—admittedly few—individuals with autism with relatively higher levels of IQ. None of all the 120 individuals from the population-based groups of individuals included had a good outcome, in spite of the fact that almost 10% had normal (or low-normal) IQ in the original study. Those with fair or restricted but acceptable outcomes and those with (relatively) higher GAF-scores had considerably better verbal IQ, and it is possible that better verbal skills rather than performance peaks are associated with less poor outcomes in adult age. The presence of some communicative phrase speech at age 6 years was also correlated with a relatively somewhat better outcome. This too is in line with results of early studies in the field (Rutter, 1970).

Mortality was increased in the present sample, and this appeared to be especially the case if there was an associated medical disorder. All six deaths in the sample occurred prior to age 20 years, and three of these were clearly associated with severe complications typical of an underlying medical disorder. One girl died of status epilepticus without a known associated medical disorder. In one case—the boy with fragile X syndrome who died in an accident—there was no indication that the primary medical disorder was specifically linked with the cause of death, and in yet another case, the real cause of death could not be determined with certainty.

New cases of epilepsy appeared in the post-adolescent period, but it would seem that after the age of 20 years, new epilepsy cases are not likely to develop in autism. Previous studies have suggested a discrete peak of new epilepsy cases in adolescence (Rutter, 1970), but the present study does not support a single peak time period for onset of epilepsy in autism.

Slightly under one in five of all typical/atypical autism cases deteriorated in adolescence, a deterioration that appeared to be permanent in 50% of the cases. However, many individuals in the autism spectrum appeared to have a fairly uneventful, "easy" adolescent period, at least according to parents recollection.

Catatonia was quite a common phenomenon at or after adolescence. It affected 12% of the whole group examined, a finding which is similar to that reported by Wing (2000) in more able people in the autism spectrum.

Self-injury and extremely violent behaviours were very common and cause for much concern and attempts at treatment interventions. These two problems together with epilepsy were possibly the major reasons why people with autism or atypical autism were

considered for/given medication trials. It is well known that self-injury and violent behaviours are very common in autism (Wing, 1980), but it is equally clear that these are among the most difficult-to-handle problems among the larger group of individuals with autism spectrum disorder.

About half of all those with autism or autistic-like conditions had a medical problem needing regular medical attention. Major medical problems were very common even in those who did not have an identified underlying medical disorder (such as tuberous sclerosis or the fragile X syndrome). This flies in the face of the generally held notion that people with autism have few physical health problems and underscores the need for (autism expert) regular medical check-ups in this severely communication handicapped population.

The present study relates to individuals considered typical or (slightly) atypical of autism 15–30 years ago. The sample included is not necessarily representative of all individuals currently diagnosed as having childhood autism/autistic disorder or of atypical autism (Gillberg & Wing, 1989; Wing, 1996). The outcome seen in the present study is probably not typical of high-functioning autism and autism spectrum disorders. Therefore, the results of the present study cannot be generalized to apply to individuals within the upper ranges of the autism spectrum, and should not be used for parental guidance when discussing outcome in young children with Asperger syndrome or other variants of high-functioning autism spectrum disorders.

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