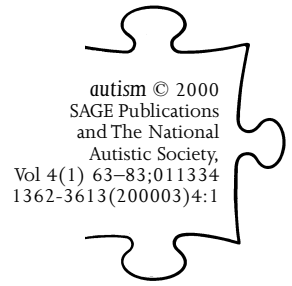


Outcome in adult life for more able individuals with autism or Asperger syndrome



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ABSTRACT The paper reviews what is known about outcome in adult life for more able individuals within the autistic spectrum. Because of the problems associated with differential diagnosis, the results of studies involving high-functioning people with autism and Asperger syndrome are combined. The review focuses predominantly on long-term follow-up research and covers outcome in terms of cognitive, linguistic, academic and adaptive functioning; educational and employment history; independence and social relationships; and behavioural and psychiatric problems. The stability of IQ and other measures over time, and variables related to outcome, are also investigated.

KEYWORDS
Asperger
syndrome;
autism;
follow-up
studies;
outcomes

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Introduction

Information on outcome in adult life for more able individuals within the autistic spectrum derives from a variety of sources, including an increasing number of fascinating autobiographical accounts (e.g. Jolliffe et al., 1992; Williams, 1992; 1994; Grandin, 1995; Gerland, 1996; Lawson, 1998; O'Neill, 1999). The most valuable data, however, come from long-term follow-ups from childhood to adulthood and it is these that will be the focus of the paper. Additional information will be drawn from relevant clinical case reports and small group studies. It has not been possible to distinguish specifically between high-functioning individuals with autism and those with Asperger syndrome for a number of reasons:

- 1 Individuals currently being studied as adults will usually have been diagnosed as autistic when children. Prior to 1980 (when Wing, 1981 and subsequently Frith, 1991 revived interest in Asperger's writings) few clinicians were aware of Asperger syndrome.

- 2 The hierarchical system employed by DSM-IV (American Psychiatric Association, 1994) (so that a diagnosis of autism rules out a diagnosis of Asperger syndrome and vice versa) gives rise to particular problems for clinicians. Thus, diagnostic criteria for Asperger syndrome are frequently used inconsistently (see Ghaziuddin et al., 1992; Klin et al., 1995; Schopler and Mesibov, 1992; Szatmari, 1998). The label of Asperger syndrome may be used for all cases who are of high IQ and have good communication skills (regardless of early language development) or the more general label of 'high-functioning autism' may be used instead.
- 3 Research studies frequently fail to distinguish between autism and Asperger syndrome in a consistent way. Some make the distinction on the basis of current linguistic functioning (Ozonoff et al., 1991). Others differentiate between subgroups on the basis of IQ (e.g. Rumsey et al., 1985).

Because of the problems related to differential diagnosis, this paper will aim to summarize what is known about outcome for individuals who clearly fall within the autistic spectrum and who have relatively well developed cognitive and communication skills. Unless studies differentiate clearly between the two conditions, data on 'high-functioning individuals with autism' and those with Asperger syndrome will be combined.

Research in adulthood

Anecdotal accounts

In 1973, Kanner reported on 96 individuals in their 20s and 30s whom he had first seen as children (see also Kanner and Eisenberg, 1956). The majority remained highly dependent, with many in institutional care. Nevertheless, 11 individuals had jobs (ranging from an accountant, a lab technician and a meteorologist to a dish washer and a shelf stacker) and one was at college. Seven of the group had their own homes and one individual (a successful music composer) was married with a child. The remainder lived with their parents. Although many belonged to social groups or clubs (involving singing, hiking, sport, transport, bridge or church) few had any close or intimate relationships.

Asperger (1944) also commented on the very variable outcome amongst his patients. In those more able individuals who had made good progress (not all were of normal IQ) it was often their special skills or interests that 'eventually led to social integration'. Asperger quotes examples of many individuals who had done remarkably well in later life, including a professor of astronomy, mathematicians, technologists,

chemists, high-ranking civil servants and an expert in heraldry. Indeed he suggests that perhaps:

only such people are capable of certain achievements. Their unswerving determination . . . their narrowness and single mindedness . . . can be immensely valuable and lead to outstanding achievements in their chosen areas. (translation by Frith, 1991)

Group studies

Tantam (1991) described outcome in 46 adults (mean age 24 years) with a diagnosis of Asperger syndrome. However, all had been diagnosed as having autism as children and although the average IQ was in the normal range (VIQ 92; PIQ 87), five individuals had IQs below 70. Over 90 percent showed continuing problems in communication (either verbal or non-verbal) and a similar proportion had circumscribed or unusual interests (e.g. electricity pylons or carrots). Only two individuals had had any education after school and only four were in jobs. Two had married and one other had experienced a heterosexual relationship. Just under half still lived with their parents and 53 percent were in residential care. Neurological problems (epilepsy, EEG or CT scan abnormalities) were present in over 40 percent and around a third met criteria for psychiatric illness, mostly with depressive disorders or anxiety. Approximately 3 percent had a diagnosis of schizophrenia. Outcome was more positive and problems were less pervasive in individuals of higher IQ.

A somewhat similar group of 93 young adults (average age 23 years) was described by Newson et al. (1982), although formal diagnostic and IQ data are lacking. Rather more individuals in this study had received further education (11 percent) and 22 percent were in jobs. One individual was married and 15 percent were reported to have had heterosexual relationships. Seven percent lived independently but over 70 percent still lived with their parents and 16 percent were in residential care.

Follow-up studies from childhood to adulthood

Studies that have systematically monitored outcome from childhood to adulthood are of particular clinical and research value. These make it possible to trace the course of the disorder over time and to identify early characteristics that may be related to later prognosis. However, much of this research has involved individuals across the IQ range, including those with severe intellectual impairments (e.g. Rutter and Lockyer, 1967; Rutter et al., 1967; Lockyer and Rutter, 1969; 1970; Lotter, 1974a; 1974b; Gillberg and Steffenberg, 1987; Kobayashi et al., 1992). Only investigations with a specific focus on individuals of 'normal' intellectual ability (generally IQ 70+) are reviewed below (see Table 1). The main outcome

Table 1 Summary of follow-up studies of high-functioning individuals with autism

	Rumsey et al. (1985)	Szatmari et al. (1989)	Venter et al. (1992), Lord and Venter (1992)	Larsen and Mouridsen (1997) ^d	Mawhood et al. (1999)	Goode et al. (1999)
N	9	16	22	14	19	43
Mean age	27	26	18+	37.7	23.8	31.4
Gender (M:F)	All male	12:4	(35:23) ^c	8:6	All male	39:4
FSIQ ^a	103	92	(79) ^c	71-85+	78	85
VIQ	103		(80) ^c		73	83
PIQ	104		(83) ^c		83	89
College/university education	22%	50%	5%	7%	32%	7%
Living semi/independently	33%	31%	36%	50%	16%	16%
Number married	0	1	0	2	0	1
In paid work	44%	44%	55%	21%	5%	19%
Psychiatric diagnoses	89%	69%		50%	11%	9%
Number with:						
Depression/anxiety	8	4		2	1	4
Schizophrenia	0	1		1		
Hallucinations/delusions/paranoid thoughts	0	2				
Other		3 OCD 1 schizoid		2 schizoid/ schizotypal 2 catatonia	1 catatonic-type withdrawal	
Outcome rating:						
Good	44% ^b	25% ^b		28%	16%	26%
Fair	56%	50%		36%	10%	37%
Poor/very poor	0	25%		36%	74%	37%

^aAverage of PIQ and VIQ if full scale figure not reported.
^bOutcome ratings in these studies based on information on independent living, jobs etc.
^cThese scores based on whole sample aged 10-37 years.
^dData on all individuals with IQ >70 combined.

measures are grouped as follows, although not every study covers each of these.

- 1 IQ, academic skills and adaptive behaviours
- 2 language ability
- 3 behavioural problems
- 4 education and employment history
- 5 independence and social relationships
- 6 psychiatric history (if available)
- 7 stability of IQ over time, and variables related to outcome.

Rumsey and her colleagues (1985) followed up 14 young men aged between 18 and 39 years, all of whom fulfilled DSM-III criteria for autism. Several had initially been diagnosed by Kanner himself. Data on cognitive functioning in childhood are not provided, but as adults nine individuals had a full scale IQ of above 80. Although reading, spelling and arithmetic skills were commensurate with age and IQ, Vineland scores (Doll, 1965) were often 'strikingly' low. Over half of this more able group exhibited unusual use of language, such as stereotyped and repetitive speech. Five individuals had completed high school and two had attended junior college. Four had jobs (as janitor, cab driver, library assistant and keypunch operator) but only two had found these independently; three were in special training or college courses, one was in a sheltered workshop and one was unemployed. Six individuals still lived with their parents and two were in supervised apartments; only one lived entirely alone. Socially, all continued to have marked difficulties: five were described as aloof; only one had friends (mostly through his church); none was married. One-third showed socially inappropriate behaviours. Seven people exhibited stereotyped movements and four had obsessional ideation. No individual showed any first-rank symptoms of schizophrenia, although six showed symptoms of generalized anxiety and two of depression.

Szatmari et al. (1989) in Toronto studied a group of 26 young adults of normal IQ. Length of follow-up ranged from 11 to 27 years. Educationally, half the group had received special schooling but the other half had attended college or university, with 44 percent obtaining a degree. On the Vineland Adaptive Behaviour Scale (Sparrow et al., 1984) 75 percent achieved a score of 70 or above and six had a score of over 100. On the Rating Scale for Social Impairment (Bartolucci et al., 1987) two-thirds showed limited gesture and facial expressiveness; one-third had limited eye contact and lacked affective responsiveness. Social initiations were described as 'clumsy' in 40 percent; one-third had problems in conversation and two-thirds had overly formal speech. On the whole impairments were greater on non-verbal than verbal items.

Fifty-six percent of the group had never experienced a close sexual relationship, but a quarter had dated regularly or had long-term relationships and one man was married. Two people were unemployed and four were in sheltered workshop schemes; three were still studying; one worked in the family business; and six were in regular, full time employment (two in libraries, a physics tutor, two salesmen with semi-managerial positions, and one in a factory). Only one person was in a group home. Five individuals lived independently and, although 10 were still at home, three of these were said by their parents to be completely independent, five required some minimal supervision, one required moderate care and one was felt to need constant supervision. Psychiatrically, four individuals exhibited symptoms of anxiety; three had an obsessive-compulsive disorder; two showed signs of paranoid thoughts and/or auditory hallucinations; and one was being treated for chronic schizophrenia.

IQ had remained stable over time (from 89 initially to 92 at follow-up) but in contrast with some earlier studies (presumably because the ability range was relatively restricted) little or no relationship was found between early measures of language or social behaviour and later functioning. However, there was a high and significant correlation between current IQ and social functioning as measured by the Vineland Adaptive Behaviour Scale.

The authors are open about the problems related to the study, including the small sample size and high refusal rate (only 20 out of the 45 cases identified agreed to take part). Nevertheless they conclude: 'A small percentage of non-retarded autistic children . . . can be expected to recover to a substantial degree. It may take years to occur, and the recovery may not always be complete, but substantial improvement does occur.'

A further sample of 58 high-functioning children (35 males and 23 females; mean full scale IQ 79) from Canada and North Carolina is described by Venter et al. (1992) and Lord and Venter (1992). Twenty-two cases were aged 18 or over when followed up, on average 8 years after initial evaluation. Although 81 percent of those with an IQ of 70+ had a reading age above 8 years, academically the group had done less well than the individuals studied by Szatmari and his colleagues (1989) and only three individuals had a Vineland score above 70. Only one individual had completed a degree course; another had attended university but had left without a degree. Eight young adults were living at least semi-independently (two on their own and six with minimal supervision). Fourteen individuals had found employment, but two had also lost jobs. Jobs were relatively low level, mostly in service industries, and all but one individual had required special assistance in finding employment. All those in

competitive employment were male, and two out of the three individuals with no day-time programme were female.

There was little change in IQ scores over time. Mean performance IQ was 80 at initial testing and 83 at follow-up and correlations between initial and follow-up scores were high (from 0.63 to 0.70). Although childhood IQ correlated significantly with adult scores on the Vineland and attainment tests, early language scores on the Peabody Picture Vocabulary Test were the most powerful predictor of later outcome. There was no relationship between outcome and presence of epilepsy, but very few in this group had developed seizures. The relationship with early symptomatology was more complex in that there was no association with total number of symptoms, as rated on the ADI, but there was a relationship between early patterns of restricted behaviour and language deviance and later adaptive scores. Although those in work were of higher verbal IQ than the group as a whole, there was little association between employment and non-verbal IQ or Vineland scores in adulthood.

In a Swedish study, Larsen and Mouridsen (1997) compared nine individuals diagnosed as autistic with nine with a diagnosis of Asperger syndrome (based on ICD-10 criteria: World Health Organization, 1993) who had been followed up over 30 years. Average age was 39.1 years in the Asperger group and 36.5 years in the autism group. All the Asperger group had an IQ above 70; in the autism group four individuals had an IQ below 70. No details of academic functioning are reported. In the Asperger group, five individuals had their own homes and lived independently or with minimal help; two lived with their parents; and one was in a psychiatric institution. In the autism group, three people had their own homes and one lived with his parents; two were in psychiatric institutions and two were in institutions for the mentally retarded (one of these had an IQ of 70+). Four individuals in the Asperger group were or had been married, with six children in total; one was living with a partner. None of the autism group had married although one was living with a partner and one had had a long-term relationship. Eight in the Asperger group but none of the autism group had attended mainstream school and only two people in each group had received any post-school training. Only one individual in the Asperger group was in paid employment (as an insulator) although one other had worked for several years as a driver before claiming disability pension. Four others had had temporary or sheltered employment but were currently living on disability benefits; two were in sheltered workshops. In the autism group two people (both with IQs above 70) had jobs, one as a porcelain painter, the other as a kindergarten teacher. Overall, seven of the Asperger group were rated as having a good or fair outcome and two as having a poor outcome; in the autism group three had a good

or fair outcome, six poor or very poor. Differences in outcome, however, could be due to IQ rather than diagnostic differences. If outcome for all those with an IQ over 70 ($n = 14$) is combined, four had a good outcome, five fair, three poor and two very poor.

Conclusions from this study must remain tentative because of the very unusual composition of the sample. First, in the autism group, females outnumbered males by three to one! Second, two-thirds of the Asperger group and all but one of the autism group had been admitted to adult psychiatric departments, many with 'massive psychiatric illness', including schizotypal disorder and schizophrenia. To complicate matters further, two individuals from the autism group were currently diagnosed as having Asperger syndrome and three of the Asperger group were currently diagnosed as having schizoid personality disorder or schizotypal disorder. The authors themselves note the unrepresentative nature of their sample and admit that the early differential diagnosis between Asperger syndrome and autism may well have been unreliable.

In a London based study (Howlin et al., 2000; Mawhood et al., 2000) the outcome for 19 high-functioning young men with autism was studied as part of a comparative follow-up study of individuals with autism and developmental language disorders. Individuals had initially been seen at a mean age of 7.0 years when their average performance IQ was 93 and their verbal IQ 67. At follow-up, full scale IQ scores remained within the average range but on tests of academic ability over half scored below a 10-year level for reading accuracy and reading comprehension and just under half for spelling. As found by Venter et al. (1992), although there were significant correlations between Vineland and Wechsler IQ scores (from 0.56 to 0.81 for the different scales), Vineland scores were consistently lower than IQ, with a mean standard score of 51 for communication, 46 for socialization and 65 for daily living.

Similarly, although correlations between verbal IQ and receptive and expressive language were above 0.85, 68 percent of the group scored below a 10-year level on the British Picture Vocabulary Scale, and 53 percent were below this level on the One Word Expressive Language Test. Over half had immature or very limited speech, and on both observational and parent report measures (Autism Diagnostic Interview (ADI), Lord et al., 1994; Autism Diagnostic Observation Schedule (ADOS), Lord et al., 1989) over 80 percent were rated as having continuing problems in maintaining or initiating conversations. Approximately half the group still showed echolalic and stereotyped speech and abnormal prosody was noted in around 75 percent. Almost half had been educated primarily in specialist autistic provision and only three had attended mainstream school. Nevertheless, five individuals obtained some formal qualification and six

had attended college or university. Only one person, a laboratory technician, was in independent employment; three worked in sheltered or voluntary jobs and two were in full time education. Data from the ADI and ADOS indicated a high frequency of social abnormalities and only three individuals were rated as having any close friendships. No individual had married or had a close sexual relationship and eight still lived with their parents; nine were in residential accommodation and three lived independently, one of these in sheltered accommodation. One person was in a long stay hospital for the mentally retarded. Ritualistic and stereotyped behaviours were common, with 68 percent showing moderate to severe problems related to unusual preoccupations and/or rituals and half remaining resistant to change. One individual had required inpatient psychiatric treatment at the age of 15 when he became very unresponsive, lethargic and withdrawn. He recovered rapidly and there was no recurrence. Another had become very disturbed and disruptive, possibly associated with a depressive disorder, and had been treated as an outpatient. A composite rating of outcome, based on communication skills, friendships, levels of independence and behavioural difficulties, indicated that overall only three subjects were considered to have a good outcome; two remained moderately impaired and 14 (74 percent) continued to show substantial impairments.

There were significant correlations between initial and adult IQ scores (from 0.43 to 0.49) but whereas non-verbal IQ scores had dropped by around 12 to 14 points, verbal IQ had risen over time. There were modest correlations between initial IQ and adult Vineland scores (between 0.41 and 0.52) but, as in the Venter et al. (1992) study, regression analysis indicated that the most powerful predictor of linguistic and social functioning in adulthood was the childhood PPVT score. Neither initial performance IQ nor ratings of friendship in childhood were significantly associated with adult outcome.

In a further study based at the same centre (Goode et al., 1999) outcome was examined for 75 individuals of 21 years or older who had initially been assessed prior to the age of 16. Of this group, 43 had an IQ of 70+ on at least one cognitive test at follow-up. Again, despite their IQ scores being in the normal range, only 63 percent scored above a 10-year level for spelling, 51 percent for reading accuracy and 26 percent for reading comprehension.

A third of this group had attended a specialist autistic school at some stage but 19 percent had spent most of their time in mainstream schools. Fourteen had obtained some formal qualifications, six of these at an A-level equivalent or above. One individual had attended university; two others had obtained college diplomas. Employment levels, however, were

generally disappointing. Only seven individuals were in regular, paid employment and one was self-employed; two others worked in a voluntary capacity. A quarter were in some form of sheltered employment but almost half attended day or residential centres, where there was little scope for the development of competitive work skills. Three individuals lived independently and another four were in semi-sheltered accommodation. Over half lived with their parents and 26 percent were in residential provision, mostly for people with autism. Two individuals were in long-term hospital care, and one of the people living at home was there because he had been excluded from all other provision. One individual was married, although he later divorced, and another has married more recently. Forty-two percent were said to have made friendships that involved some sharing but almost half had no friends. Four individuals had been diagnosed as having a psychiatric illness: two with anxiety disorders and two with a combination of depression and anxiety disorder.

A composite rating of outcome, based on social interactions, level of independence and occupational status, indicated that just over a quarter could be described as having a 'good' or 'very good' outcome. Most of these had some friends and either had a job or were undergoing training. Even if they still lived at home they had a relatively high level of independence, being largely responsible for their own finances, buying their own clothes or taking independent holidays. Thirty-seven percent continued to be moderately dependent on their families or other carers for support, and few in this group had any close friendships. The remainder were highly dependent, with 33 percent living in special residential units and two individuals in long-term hospital care. Overall outcome for the few women in the group was poorer than for the men and no women fell within the 'good' or 'fair' outcome group. However (probably because of the very small number of females), there were no significant gender differences in IQ or attainment scores, or any of the other measures of adult functioning.

Performance IQ scores remained relatively stable over time (mean 86 initially; 89 at follow-up) but the correlations between initial and later IQ measures were not particularly high. Moreover, neither early language nor cognitive functioning appeared to be predictive of later outcome. Surprisingly, too, there were no differences on adult outcome measures between individuals with an IQ of 100+ and those with an IQ between 70 and 99.

Table 1 attempts to summarize the findings from these six studies. Despite the groups being apparently relatively homogeneous the results are extremely variable. Thus, the proportion in work ranges from 5 to 44 percent; the proportion living independently from 16 to 50 percent; assessments of 'good' outcome from 16 to 44 percent; and rates of psychiatric

disturbance from 11 to 67 percent. Differences in the assessment measures used and in the selection of subjects may explain some of these inconsistencies, but as Lord and Venter (1992) point out, there is also considerable variability across geographical areas. Within this more able group, employment levels and residential placement may be more dependent on where individuals live, and what support services are available, than on any other factors.

Problems related to adulthood

Deterioration

Generally, the risk of deterioration in adolescence or early adulthood seems to be highest in individuals who are of low IQ and/or develop epilepsy (Nordin and Gillberg, 1998). In the higher-functioning group adolescence may actually bring about an improvement in functioning. For example Kanner (1973) noted that in a number of individuals who had done particularly well, in the majority of these 'a remarkable change took place' around their mid teens. Piven et al. (1996), in a retrospective study of 38 high-functioning individuals, compared functioning at age 5 (as reported on the ADI) with current functioning when aged between 13 and 28 years. Composite ADI scores for communication and social functioning had improved in 82 percent of cases and 55 percent showed improvement in ritualistic/stereotyped behaviours. The differences were significant for the communication and social domains, but not for ritualistic behaviours. There was no significant difference in the pattern or extent of change shown by males and females

Epilepsy

The onset of epilepsy in autism often occurs in adolescence or early adulthood. Gillberg (1992) suggests that the most common form of seizure disorder is complex-partial (psychomotor) epilepsy, with the rates being highest in those with severe to profound learning difficulties. If this subgroup is excluded, the incidence is around 18 to 20 percent (Tantam, 1991; Goode et al., 1994), with little difference between those of normal IQ and those with moderate learning disabilities. Some adolescents or young adults may have one or two isolated fits, but no more, and because of the disadvantages of giving unnecessary medication, this is usually not prescribed unless there are more frequent attacks. There is no evidence to suggest that successful control is particularly difficult to achieve for people with autism, although, because individuals are unlikely to report unwanted side effects themselves, careful monitoring of their response to treatment is essential.

Mortality

Gillberg (1991) has suggested that mortality rates in people with autism below the age of 30 years may be substantially increased (from 0.6 percent in the general population to almost 2 percent in autism), although this increase could be due to an association with severe mental retardation and/or medical complications such as epilepsy (Goode et al., 1994). In a recent review Isager et al. (1999) concluded that mortality rates from childhood to early/middle adulthood in autism were not significantly higher than in the population as a whole. However, in a 25-year study of 324 patients with autism and related disorders (mean age 31 years) the same authors reported a crude mortality rate of 3.4 percent, considerably higher than the figure for non-autistic males of the same age. Death rates were higher in those of low IQ, and were often associated with epilepsy. Death in the three 'normal IQ' individuals in the study was due to suicide in one case, accidental drug overdose in another and pneumonia (associated with Hodgkin's disease) in a third. Deaths reported in other studies of mixed-ability groups have resulted from a range of different causes including head injury due to severe self-injury, encephalopathy, nephrotic syndrome and asthma (Kobayashi et al., 1992). Accidental death (e.g. traffic accidents) seems to be commoner in more able individuals (Kanner, 1973; Larsen and Mouridsen, 1997).

Psychiatric illness

There are no epidemiological studies of psychiatric morbidity in individuals with autism or Asperger syndrome and any estimates must be treated with caution because of problems of sampling and referral bias. In a recent paper Clarke et al. (1999) reviewed the findings from 20 case reports of psychiatric illness in individuals with autism and Asperger syndrome. Table 2 combines Clarke's data on high-functioning cases with psychiatric information reported in the six follow-up studies reviewed above and on the 83 cases described by Tantam (1991) in his study of outcome in Asperger syndrome. This information does not of course provide an estimate of the incidence of psychiatric disorder in individuals with autism or Asperger syndrome and any generalization is problematic because of the variety of diagnostic criteria used in the different reports. However, it serves to give some indication of the pattern of psychiatric disturbance that is likely to be found. By far the most common psychiatric diagnosis was depression, often associated with severe anxiety, with this representing over a third of the reported psychiatric diagnoses in the studies reviewed. Tantam (1991) reported that 12 percent of adults with Asperger syndrome referred for behavioural or psychiatric problems had an affective psychosis and a further 8 percent suffered from problems related to depression or anxiety. He

Table 2 Patterns of psychiatric disorder reported in cases of autism and higher-functioning autism and Asperger syndrome

<i>Psychiatric diagnoses reported^a</i>	<i>% in cases of Asperger and high-functioning autism (n = 74)</i>
Depression (including severe social withdrawal)	41
Bipolar disorder	9
Schizophrenia (undifferentiated)	9
Hallucinations	6
Mania	5
Psychotic disorder (NOS)	3
Catatonic disorder	4
Delusional disorder	1
Paranoid schizophrenia	1
Anxiety	8
Attempted suicide	7
Schizoid	3
OCD	1

^aBased on review of 20 case studies by Clarke et al. (1999), plus cases reported by Larsen and Mouridsen (1997), Mawhood et al. (1999), Rumsey et al. (1985), Szatmari et al. (1989), Tantam (1991), Goode et al. (1999). Also includes the 'schizoid' group described by Wolff and Chick (1980).

also noted that in several cases the illness incorporated a delusional content, often linked with the individual's autistic preoccupations. Wing (1981; data included in Table 2) found that 23 percent of a group of 18 individuals with Asperger syndrome showed signs of an affective disorder. Two had attempted suicide and one other had talked about doing so, although their attempts had not been successful. Wolff and McGuire (1995) noted that death from suicide was greater in their sample of 'schizoid' men and women (several of whom were probably suffering from Asperger syndrome) than in the general population (10 out of 17 women and 17 out of 32 men had attempted suicide).

Bipolar disorders and mania appeared to be the next most common type of disorder, representing about 21 percent of diagnoses in the higher-functioning samples reviewed here. Schizophrenic-type illnesses were far less frequent, representing around one-tenth of all psychiatric diagnoses. Overall, there seems little to support claims of 'an excess of schizophrenia in later life' as suggested by Wolff and McGuire (1995). However, although the presence of first-rank schizophrenic symptoms is relatively unusual, a number of follow-up studies, as well as clinical case reports, suggest that there is often evidence of some psychotic symptomatology, including auditory hallucinations, paranoid ideas or delusional thoughts. For example, one young man described by Wing (1981) could not be deterred from his conviction that some day Batman was going to come and take him away as

his assistant. Szatmari et al. (1989) and Rumsey et al. (1985) also describe a number of cases with obsessional or compulsive symptomatology, although they caution: 'We found it very difficult ... to distinguish between obsessive ideation and the bizarre preoccupations so commonly seen in autistic individuals.' There are also inherent problems in making an accurate diagnosis of psychosis in people with autism because of their impoverished language (Howlin, 1997), literal interpretation of questions (Wing, 1986), concrete thinking (Dykens et al., 1991) and obsessionality (Volkmar and Cohen, 1991). Nevertheless, Volkmar and Cohen (1991) conclude that the frequency of schizophrenia in individuals with autism is around 0.6 percent (roughly comparable to that in the general population). A preliminary study by Abramson and colleagues (1992) suggests that the overall risk of affective disorders may be as high as 33 percent. This is similar to Tantam's combined estimate of the rates for mania (9 percent), depression (15 percent) and clinically significant anxiety disorders (7 percent). Thus, despite the lack of epidemiological data, it is evident that high-functioning adults with autism or Asperger syndrome are at considerable risk of developing depressive and anxiety related disorders.

More research into psychiatric conditions in adulthood is badly needed, not only to identify the true level of risk, but also to improve knowledge amongst clinicians about how psychiatric disorders in this group are manifest. Better understanding of appropriate intervention strategies, both pharmacological and psychological, is also required. Clinical experience suggests that delays in diagnosing and treating psychiatric disorders in this group are particularly undesirable as behaviour patterns that are established during the course of the illness (e.g. disturbed waking and sleeping patterns) can then be very difficult to alter, even when the patient's condition generally has improved.

Forensic issues

There is little evidence of any excess of crimes amongst more able people with autism, despite occasional and sometimes lurid media publicity suggesting otherwise. However, isolated incidents of offending, often related to obsessional tendencies or impaired social understanding, have been reported. These include injuries to others resulting from an obsession with experimentation (Wing, 1981; Tantam, 1991); and attacks on infants and young women apparently associated with a 44-year-old man's preoccupation with finding a girlfriend, his dislike of certain styles of dress and the noise of crying (Mawson et al., 1985). 'Sexual offending' in the young man with Asperger syndrome described by Chesterman and Rutter (1994) related mainly to his obsession with washing machines and women's night-dresses. A number of cases of arson have also been reported (Everall

and Le Couteur, 1990; Tantam, 1991). Tantam (1991) noted that in the group whom he studied, violence, in a fight, in an explosion of rage or in sexual excitement, was rare. Sexual offending, too, was unusual, although some got into trouble for indecent exposure, and property offences were uncommon except as the 'side-effects of the pursuit of a special interest'.

Because offending by high-functioning individuals with autism often seems to be associated with lack of social understanding, rigidity of behaviour or obsessional interests (Howlin, 1997) the crimes committed may well be of an unusual or bizarre nature. For example, there is Baron-Cohen's (1988) account of a 21-year-old man who had, over a period of several years, violently assaulted his 71-year-old 'girlfriend'. Wing (1986) also describes one individual's attempts to drive away an unattended railway engine because of an obsession with trains; another caused explosions and fires because of a preoccupation with chemical reactions. Occasionally, crimes are unwittingly or unwillingly committed at the instigation of others, such as the young man who was deliberately prompted by a local gang to lay concrete blocks across a railway line (Howlin, 1997).

The only relatively large-scale study of offending by people with Asperger syndrome or autism was conducted by Scragg and Shah (1994), who assessed the entire male population of Broadmoor Special Hospital in the UK. By means of cases notes, personal interviews and the Handicaps, Behaviour and Skills Schedule of Wing and Gould (1978), they identified three cases with autism and six with Asperger syndrome (defined according to Gillberg and Gillberg's 1989 criteria). Out of a total of 392 patients this represented a prevalence rate for autism and Asperger syndrome of just over 2 percent. The offences committed included violence or threats of violence, unlawful killing (including one case of matricide) and fire setting. Six individuals had a fascination with poisons, weapons, murder books or combat. Because the number of Asperger/autism patients was higher than predicted on the basis of population data, the authors suggest that there is an association between Asperger syndrome and violent offences. A similar conclusion was reached by Mawson et al. (1985) on the basis of their case study.

However, it is clearly invalid to base estimates of pathology on either single cases or studies of highly selected individuals. Ghaziuddin et al. (1991) noted that the incidence of violence or other offences by people with autism or Asperger syndrome is actually very small. In a review of 132 reports of people with Asperger syndrome, they found that only the three described by Wing (1981), Baron-Cohen (1988) and Mawson et al. (1985) had a clear history of violent behaviour. This figure compares favourably with a rate of 7 percent for violent crimes in the 20–24 year age group in the United States (US Bureau of Justice Statistics, 1987). As Scragg

and Shah (1994) suggest, there may well be more people with autism in prisons or secure accommodation than is realized, and it is clearly important that such individuals are correctly identified and treated. Nevertheless, in the absence of epidemiological research, there is no reason to suppose that people with Asperger syndrome are more prone to committing offences than anyone else. Indeed, because of the very rigid way in which many tend to keep to rules and regulations, they may well be more law-abiding than the population generally.

Similarly, although no data on alcohol or drug abuse in autism exist, many high-functioning individuals with autism seem to make strenuous attempts to avoid drugs of any kind (including those prescribed for a medical condition). Instead, they may get themselves into trouble for interfering with people who are smoking or drinking, and one patient of the author's placed himself in a highly vulnerable position by openly lecturing members of a drug gang in his neighbourhood. However, given the rigidity of behaviour patterns in autism, it also seems that if drug or alcohol habits become established, these can then be extremely difficult to modify.

Is it possible to improve outcome in adulthood?

Noting that 11 to 12 percent of his original sample had done well in the absence of any specialist intervention or support, Kanner (1973) speculated that the outcome for people with autism might well improve in future years as recognition of the disorder spread, and knowledge about effective educational and therapeutic facilities progressed. Despite often extravagant claims for the effectiveness of various therapies there is no evidence to suggest that *long-term outcome* can be dramatically improved following the implementation of any particular intervention programme (Howlin, 1998). Nevertheless, early intervention and support for parents can help to minimize secondary behavioural problems, and to ensure that children develop their existing skills to the full. Moreover, since Kanner's time, there have also been significant improvements in educational provision for children with autism and steady increases in academic attainments (Rutter and Bartak, 1973; Venter et al., 1992).

Comparisons of outcome in mixed-ability groups of adults with autism have indicated marked improvements over the decades between 1960 and 2000, with a steep decline in institutional care and some increases in employment opportunities (Howlin and Goode, 1998). However, because of the relative paucity of studies with a specific focus on higher-functioning individuals, it has not been possible to assess whether there have been improvements for this particular group over time. Although it is evident that at least a minority is able to live independently,

find jobs, make relationships and even get married, outcome is extremely variable. To some extent, prognosis is related to innate cognitive and linguistic abilities, but the adequacy of local provision may also have a significant impact on outcome (Lord and Venter, 1992). For example, appropriately structured educational programmes may influence later academic and occupational attainments (Kunze and Mesibov, 1998). Mawhood and Howlin (1999) also demonstrated that access to specialist supported employment schemes could significantly improve the chances of individuals finding and maintaining suitable employment. Specialist social skills groups, too, may help to improve social competence and to develop peer relationships (Mesibov, 1992; Howlin and Yates, 1999).

It is also clear that diagnostic provision needs to improve considerably if more able individuals are to be given the help they need. In a recent survey of over 1000 families, Howlin and Moore (1997) found that the average age of diagnosis for children with Asperger syndrome was over 11 years (compared to 5 years for those with autism) and many were not diagnosed until their late teens or even adulthood. This failure to recognize their problems, or to provide them with necessary support from early school age onwards, can lead to a downward spiral of rejection and low self-esteem, possibly resulting in severe emotional and psychiatric problems in later life.

Conclusions

Although high-functioning people with autism or Asperger syndrome may succeed well as adults, such achievements rarely come easily. Few specialist support systems exist and most individuals have to rely heavily on the support of their families in finding jobs or accommodation. Social contacts often centre around special interests and skills, rather than involving close, spontaneous friendships. Above all, there may be constant pressure to 'fit in' with the demands of a society that fails to understand their needs or difficulties. Inability to meet these demands may lead to stress and anxiety and even psychiatric breakdown. Since Kanner's (1943; 1949) studies, provision for individuals with autism has improved beyond recognition thanks to dedicated schooling and residential accommodation. If those who are high functioning are to be given the opportunity to make the most of the skills that they undoubtedly possess, much more is required in terms of appropriate educational facilities, help with supported living and accommodation and the development of wider social support networks. In many areas, too, clinical expertise needs to be enhanced, not only to ensure early diagnosis but to improve recognition and treatment of emotional or psychiatric disturbance in adulthood.

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