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In Review

Adults With Autism Spectrum Disorders

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In the decades since autism was first formally described in the 1940s, there have been major advances in research relating to diagnosis, causation, and treatment approaches for children with this condition. However, research into prognosis, outcomes, or effective interventions for adults with autism spectrum disorders (ASDs) is much more limited.

In this paper, we review studies of outcome in adulthood. The findings indicate that, as adults, many people with ASD, including those of normal IQ, are significantly disadvantaged regarding employment, social relationships, physical and mental health, and quality of life. Support to facilitate integration within the wider society is frequently lacking, and there has been almost no research into ways of developing more effective intervention programs for adults. Moreover, most of the research on outcome has involved relatively young people in their 20s and 30s—much less is known about outcomes for people with ASD as they reach mid-late adulthood. Systematic follow-up studies from childhood through adulthood are needed if we are to gain a better understanding of trajectories of development over the lifespan, to identify the factors that influence prognosis, and to determine how these factors exert their effects and how they may be modified to ensure a better future.

Dans les décennies depuis que l'autisme a été officiellement décrit dans les années 1940, la recherche a fait de grands progrès relativement au diagnostic, aux causes, et aux approches de traitement pour les enfants souffrant de cette maladie. Toutefois, la recherche du pronostic, des résultats ou des interventions efficaces pour les adultes souffrant des troubles du spectre autistique (TSA) est beaucoup plus limitée.

Dans cet article, nous examinons les études à l'âge adulte. Les constatations indiquent qu'en tant qu'adultes, bien des gens souffrant de TSA, y compris ceux ayant un QI normal, sont significativement désavantagés en ce qui concerne l'emploi, les relations sociales, la santé physique et mentale, et la qualité de vie. Le soutien qui faciliterait l'intégration à l'ensemble de la société est souvent manquant, et il n'y a presque pas eu de recherche sur les façons d'élaborer des programmes d'interventions plus efficaces pour les adultes. En outre, la majeure partie de la recherche a porté sur des gens relativement jeunes, dans la vingtaine ou la trentaine — on en sait beaucoup moins sur les résultats des personnes souffrant de TSA qui atteignent le milieu ou la fin de l'âge adulte. Des études de suivi systématiques de l'enfance à l'âge adulte sont nécessaires si nous voulons mieux comprendre les trajectoires du développement de durée de vie, identifier les facteurs qui influencent le pronostic, et déterminer comment ces facteurs exercent leur influence et comment ils peuvent être modifiés pour un avenir meilleur de ces personnes.

Although Kanner's[1] initial descriptions of people with ASDs focused mainly on children, Asperger's account[2] included some examples of adults with this condition, and further descriptions of cohorts involving adults as well as children began to appear in the mid-1950s to the early 1960s.[3–5] These earliest accounts documented the wide variety of possible outcomes for people with ASD. Although many of the people described by Eisenberg,[4] for example, remained highly dependent on others for support, around one-third were said to have made at least a moderate social adjustment, despite the lack of any specialist provision or treatment available at that time. In the United Kingdom, Mildred Creak[3] described a hundred cases of "childhood psychosis," the term then often used for children with autism. A minority was rated as having made significant improvements but around one-half were permanently institutionalized. These largely descriptive accounts were followed, toward the latter part of the 1960s, by much more systematic studies of outcome that focused particularly on exploring childhood factors associated with prognosis in adult life.[6–8]

Epidemiology

As with much research on ASD, prevalence figures have been largely based on data from child cohorts. These have shown a steady rise in prevalence estimates, from 4 per 10 000 in studies conducted in the 1970s, to fairly consistent estimates of around 100 per 10 000 (that is, 1% of the child population) in studies from the mid-1990s onward.[9] Until very recently there had been no epidemiologic studies in adults; however, in 2011, Brugha et al[10] reported data on the presence of ASD in adults, based on the UK Adult Psychiatric Morbidity Survey. Their findings confirmed ASD prevalence rates of about 1%, but with prevalence higher in men (1.8 %) than women (0.2%). People with ASD were also more likely to be unmarried, poorly educated, and economically deprived than the general population.

Outcome Studies

A systematic search for follow-up studies on adults with ASD was conducted in PubMed, MEDLINE, and Ovid using the search terms follow-up, outcome, adult autism, ASD, and Asperger syndrome; studies listed in a previous review by Howlin[11] were also included. Criteria for inclusion in the present review were a sample size of 10 or more; a mean age of participants at follow-up of 16 years or older; and a mixed IQ range (that is, at least some participants with an IQ greater than 70). Cohorts in which all participants had ID were not included. The search identified 23 studies, within 26 references,[6–8,12–34] meeting inclusion criteria (Tables 1 and 2). Table 1 describes the sample characteristics and adult social outcomes for each study, and Table 2 provides specific data on independent living, employment, marital relationships, and friendships. Nine cohort studies were conducted between 1967 and 1999, and 14 between 2000 and 2011. If there were several papers published on the same cohort, these were included as a single study.

Although outcome data were reported in many different ways, many studies from 1970 onward adopted a modified form of the rating system used by Rutter and colleagues (see Lockyer and Rutter,[6] Rutter and Lockyer,[7] and Rutter et al[8]). This summarized adult functioning as poor to very poor; fair; or good to very good. In some studies, particularly those conducted pre-2000, these ratings are mainly subjective, but several later reports have attempted to derive a more objective rating based on composite scores for levels of independence, occupational status, and friendships or social relationships.

Abbreviations

ASD	autism spectrum disorder
CNV	copy number variant
ID	intellectual disability.
OCD	obsessive–compulsive disorder

Clinical Implications

- Specialist support services for adults with ASD are generally inadequate despite their being, as a group, at an increased risk of social deprivation and isolation and of physical and mental health problems.
- There is a need to develop much more accessible and specialist services to facilitate the transition from childhood to adulthood and to provide support throughout the lifespan.
- Funding for research into effective intervention programs for adults is essential.

Limitation

- Conclusions based on reviews of literature on outcome in adulthood are limited by relatively small samples that are not necessarily representative of the wider ASD population, few studies including adults of middle age or older, and variability in outcome measures across studies.

1960–1999

As is evident from the earliest follow-up studies, outcome in adulthood for people with ASD is extremely variable. Taking the average figures from studies conducted up to the end of the 20th century, and which provide adequate data, only a minority of people (23%) was rated as having a good outcome, with the range varying widely from 4% to 50%. Only in one Japanese study[17] were any people reported as having a very good outcome. However, the subjectivity of the ratings is illustrated by most of this Japanese cohort continuing to live with their families, and less than one-quarter being employed. In studies conducted pre-2000, the mean percentage living independently or semi-independently was 18% (range 1% to 44%); 57% (range 22% to 93%) were still living with parents; and 13% (range 0% to 48%) were in hospital care. On average, fewer than one-half (13% to 88%) were in any kind of employment, and information on other aspects of adult life, such as quality of friendships or marriage rates, was generally lacking.

2000–2011

In the last 2 to 3 decades, the prospects for young children with ASD have improved markedly. In developed countries, early recognition and intervention are becoming the norm, and many children are now diagnosed and have access to specialist education provision well before they are aged 5 years. Families, too, have better access to support and practical advice. Thus one might have expected that the rather disappointing findings from earlier follow-up studies would have improved in recent years. Nevertheless, even in studies conducted in the last decade, the mean percentage of people assessed as having a good–very good outcome, or as living independently or semi-independently, remains below 20%. However, fewer adults were continuing to live with their parents, and a much smaller number than in previous studies was in any form of hospital or institutionalized care. Although in some cohorts almost all adults were in some form of work (paid, sheltered, or voluntary) or educational

Table 1 Overall outcomes reported in follow-up studies of adults with ASD

Study	Diagnosis	*n*	Age, years Mean (range)	IQ Mean (range)	Outcome, %[a] Poor–very poor	Fair	Good–very good
			1960–2000				
Lockyer and Rutter,[6] Rutter and Lockyer,[7] Rutter et al[8]	Infantile autism	63	16	62[b]	61	25	14
Lotter[12]	Autism	29	ns (16–18)	71 (55–90)	62	24	14
Rumsey et al[13, c]	Infantile autism	14	28 (18–39)	9 had VIQ >80	29	35	35
Tantam[14]	Asperger syndrome	85	24 (ns)	ns	—	—	—
Gillberg and Steffenburg[15]	Infantile autism	23	20 (16–23)	mixed	48	48	4
Szatmari et al[16]	Autism, childhood schizophrenia–psychosis	16	26 (17–34)	92	25	25	50
Kobayashi et al[17]	Autism	197	22 (18–33)	mixed	46	27	27
Ballaban-Gil et al[18]	Autistic disorder	99	18 (12–30)	mixed	—		—
Larsen and Mouridsen[19]	Autism and Asperger syndrome	18	36[b] (ns)	mixed	45	28	28
			Post-2000				
Howlin et al[20]	Autism	19	24 (21–27)	ns (70–117)	74	11	16
Engström et al[21]	Asperger, high functioning autism	16	31	ns	12	75	12
Howlin et al[22]	Autism	67	29 (21–49)	PIQ 75 (51–137)	58	19	23
Billstedt et al[23,24]	Autistic disorder and atypical autism	108	ns (17–40)	ns	78	21	0
Cederlund et al[25]	Autism and Asperger syndrome	140	23 (16–36)	≥70	39	47	14
Eaves and Ho[26]	ASD	47	24 (ns)	mixed	47	32	21
Hutton et al[27]	Autism	135	35 (21–57)	>30	—	—	—
Mazefsky et al[28]	Autistic disorder	17	21 (18–32)	≥70 in 29% of sample	—	—	—
Farley et al[29]	Autism	41	33 (22–46)	89 (50–140)	17	34	48
Hofvander et al[30]	Autistic disorder, Asperger, PDD–NOS	122	ns (16–60)	ns (normal IQ)	—	—	—
Marriage et al[31]	ASD	33	21 (19–37)	≥70	ns	ns	15
Whitehouse et al[32]	ASD	11	22 (16–28)	ns	—	—	—
Gillespie-Lynch et al[33]	Autism	20 (from 70 at origin)	26.6	DQ 54 at first assessment	50	20	30
Taylor and Seltzer[34]	ASD	241	(20–35)	ns	—	—	—

[a] Summary ratings based on authors' own classification where provided; otherwise, they are categorized as poor (requires specialist residential accommodation or hospital provision [or parental home with close supervision most of the time]) to very poor, fair (some degree of independence or job; may require moderate levels of support and supervision but does not need specialist residential accommodation; no close friends but may have some acquaintances); or good (moderate to high levels of independence in job [or student] and [or] living, for example, at home with minimal supervision; some friends and acquaintances) to very good.

[b] IQ and (or) age based on a subsample because data were not available for all participants (for example, a participant may have died)

[c] Outcome scores based on employment and living status as only data available

— = no data; DQ = developmental quotient; ns = not specified (outcome category not used or outcome not specified or insufficient data); PDD-NOS = pervasive developmental disorder not otherwise specified; PIQ = performance IQ; VIQ = verbal IQ

Table 2 Specific achievements in adolescence and adulthood reported in follow-up studies

Study	Semi-independent, %	With parents, %	Residential placement, %	Hospital care, %	Employed (any type) or education, %	Long-term relationship or married, %	Some friends, %
Lockyer and Rutter,[6] Rutter and Lockyer,[7] Rutter et al[8]	ns	ns	ns	44	24	—	—
Lotter[12]	ns	ns	ns	48	21	—	—
Rumsey et al[13]	21	64	7	7	79	—	—
Tantam[14]	1	41	53	0	13	3	—
Gillberg and Steffenburg[15]	4	61	35	0	—	—	—
Szatmari et al[16]	31	63	6	0	88	25	—
Kobayashi et al[17]	5[a]	93[a]	2[a]	2	22	—	—
Ballaban-Gil et al[18, b]	—	—	24	—	27	—	—
Larsen and Mouridsen[19]	44	22	33	0	56	22	—
Howlin et al[20]	16	32	47	5	32	5	21
Engström et al[21]	56	6	31	6	31	38	—
Howlin et al[22]	10	38	38	12	34	4	27
Billstedt et al[23,24]	4	—	—	—	—	1	—
Cederlund et al[25]	16	—	—	—	6	11	—
Eaves and Ho[26]	8	56	35	0	56	33	10
Hutton et al[27]	10	27	60	3	16	—	—
Mazefsky et al[28]	0	41	47	12	94	—	—
Farley et al[29]	29	56	15	0	66	20	—
Hofvander et al[30, c]	50	—	—	—	43	16	—
Marriage et al[31]	—	—	—	—	—	—	—
Whitehouse et al[32]	—	—	—	—	91	0	36
Gillespie-Lynch et al[33]	15	50	35	—	65	—	25
Taylor and Seltzer[34]	—	70	30[d]	—	—	—	—

[a] Information based on employed participants (n = 43)

[b] Information based on adult subgroup only (n = 45)

[c] Information based on people aged 23 years or older (n = ns)

[d] Data unclear; number is approximate

— = no data; ns = not specified (information not provided, or insufficient data available to calculate scores)

programs, the average remained relatively low (49%, range 6% to 94%). In studies providing adequate data, an average of 14% of participants were rated as being married or having a long-term intimate relationship, and one-quarter had at least one friend.

There are no systematic data on the quality of these relationships, or patterns of family life, although clearly there can be major challenges in living with someone with ASD, and these can require considerable adaptations by both partners.[35–37] Systematic information about the children of parents with ASD is similarly limited. Although family genetic studies indicate that the risk to their children of having ASD is high,[38] fecundity among people with ASD also appears to be reduced,[39] and accurate data on prevalence rates among offspring are lacking. Personal accounts (and clinical experience) suggest that many people with ASD are able to parent well despite their own difficulties.[39] However, others can experience major problems, and adequate support for these families is rarely available.

Factors Affecting Outcome

Although, overall, there would appear to have been no major improvements in outcomes for adults with ASD in recent years, it is also evident that there is huge variation from study to study. This variation can be partly attributed to the different methods of data collection used, with some studies relying on telephone interview or parental accounts only and others using a combination of direct assessment and self- and informant reports. However, outcome is also clearly affected by the characteristics of the cohorts involved. Since the initial studies of Rutter and colleagues (see Lockyer and Rutter,[6] Rutter and Lockyer,[7] and Rutter et al[8]) it has been evident that intellectual ability is one of the main determining prognostic factors, with very few people with a childhood IQ below 75 living independently as adults.[11,15,22,26,29] Nevertheless, IQ alone is not the only determining factor, and many people with a high IQ in childhood still do poorly in adulthood. It seems that while only people with a childhood IQ of at least 70 to 75 do well

in adulthood, even among those with an IQ above this level, outcome can still be very poor.[22]

Early language development is another crucial factor, and it is well established that there is a strong link between early language abilities and subsequent outcome.[6–8;16,20,22,34,40,41] Thus most people who do well as adults have usually developed at least some useful speech by the age of 5 years. In contrast, (although there are individual exceptions) people who do not develop speech until after they are aged 5 years tend to have a much poorer outcome. In adulthood, people with good verbal comprehension, functional use of sentence speech, and a verbal IQ in the normal range are significantly more likely to be functioning well, socially, than those who are impaired in these areas.

There also appears to be an association between the severity of early autistic symptomatology and later outcome, although findings here are somewhat contradictory. Thus while some researchers have found that overall symptom severity is most predictive of later functioning,[7,8,42] others suggest that it is the severity of repetitive and stereotyped behaviours that is crucial[41]; still others indicate that the level of impairment in the social domain is the strongest prognostic indicator.[43] Gillespie-Lynch et al[33] also found that joint attention skills in the first 5 years of life were strong predictors of social functioning 20 or more years later. Unsurprisingly, the severity of autistic symptomatology in adulthood continues to affect social and economic independence, and several researchers have noted that inappropriate and (or) ritualistic and stereotyped behaviours are negatively correlated with employment status, the ability to develop close relationships, and general level of social functioning.[13,22]

The association between age and functional ability has still to be systematically explored. Although it is evident that overall severity of autism symptoms tends to reduce between early childhood and early adulthood,[44] there are no studies of the trajectories of change in older people. Thus we have almost no information on whether this decrease in symptom severity continues across the lifespan or whether there may be increases in difficulties at some later stage of life.

Mental health and medical problems (see below) also tend to have a negative impact on outcome, as does the presence of an additional comorbid condition, such as attention-deficit hyperactivity disorder. However, environmental factors may also be crucial, and there is some evidence that lack of appropriate support in adulthood can have a much greater impact on outcome and quality of life than factors such as the person's IQ.[41,45] The study by Farley et al[29] is particularly important in demonstrating how a high level of community support can influence outcome (most of the participants in that study were members of the Church of the Latter Day Saints in Utah). As such, compared with similar cohorts, adults in the Farley study were more likely to be employed and to have formed close relationships, and around one-half were rated as having good or very good outcomes. Farley et al[29] suggest that these findings are likely because the people grew up, and continue to live, in a very cohesive society, in which the inclusion of people with disabilities is a strong cultural value.

Access to appropriate educational programs also has an impact on later life. In the original follow-up studies of Rutter and colleagues (see Lockyer and Rutter,[6] Rutter and Lockyer,[7] and Rutter et al[8]) most children had never attended full-time school, and many spent their adult years in institutional care. However, by the 1980s, most children with autism in developed countries were in full-time education, and few would ever be placed in hospital care.[41] Nevertheless, the quality of education varies widely and, to date, little is known about the factors within educational programs that are likely to have the greatest impact on later progress.

Interventions for Adults

Despite the increasing number of high-quality intervention trials for children with ASD, the evidence base for effective interventions for adults remains very weak. There are few well-controlled studies of effective treatments or services for adults. Applied behavioural approaches, which have a relatively strong evidence base for children, have been evaluated much less for adults and, if used, focus mainly on training basic self-help skills or reducing challenging behaviours in people with more severe intellectual impairments. There is some evidence for the effectiveness of supported employment programs,[46,47] and these may have a long-lasting and positive impact.[48] A small number of other studies has investigated the effects of training in social and emotional awareness skills.[49,50] McClannahan et al[51] also describe the potential benefits of a broad-based behavioural intervention program for adults.

However, most adults with ASD have no access to specialist services and, unless they are supported by ID or mental health services, provision is both limited and inadequate,[34] often resulting in a reduction in progress after leaving school. Perhaps because of this lack of support, rates of medication use tend to be even higher in adults (including those of normal intelligence) than in children. For example, Esbensen et al[52] found that medication use increased steadily with age, with 88% of adults in their survey being on at least 1 medication and 40% taking 3 or more different types of medication. Moreover, once medication started, it was likely to continue over time. The most common medications reported were antipsychotics, antidepressants, (mainly selective serotonin reuptake inhibitors), and anticonvulsants.

Mental and Physical Health

Psychiatric Morbidity

Estimates of mental health difficulties in adults with ASD vary considerably, with some studies suggesting that up to 84% suffer from some form of diagnosable mental illness.[53,54] However, these data are often derived from

clinical samples of people referred to psychiatric services; cohorts selected from general epidemiologic or follow-up studies suggest rather lower rates (of around 25% to 30%[10,16,27,55]). Underwood et al[55] also found that adults with an ID and ASD were at no greater risk of psychiatric disorders than those without ASD. Although reported rates of specific mental health disorders differ from study to study, the most common diagnoses relate to anxiety, OCD, and depression (often in combination), with rates of schizophrenia and other psychoses generally no higher than in the general population.[16,53,56]

There have been many studies exploring factors that predispose people to mental health problems in ASD, again with rather variable results. Thus, although it has often been suggested that people with ASD and an IQ in the normal range are more likely than those with a low IQ to experience mental health problems,[57–59] Hutton et al[27] found that psychiatric disorders occurred equally in low- and high-IQ groups, a finding also supported by Simonoff et al[60] in their study of children. Data on other possible risk factors, such as severity of autistic symptomatology, age, or social deprivation are very limited, although environmental factors related to major life transitions, loss, inadequate support, or social isolation do seem to be related to onset in many cases.[27] It is also evident that emotional and psychiatric problems can have a very negative impact on general functioning.[53,54,61] Moreover, finding effective treatments can prove very difficult; response to medication can be unpredictable and paradoxical, and the benefits of cognitive-behavioural therapies for adults with ASD who also have significant mental health problems have yet to be demonstrated. As it is evident that mental health difficulties begin in childhood (almost 30% of children aged 10 to 14 years with ASD suffer from social anxiety disorders[60]), the development of early and effective treatments is clearly of major importance.

Mortality and Life Expectancy

There are no systematic data on life expectancy in autism, but there is some indication that death rates are higher than in the general population. Two studies conducted in the last decade in Denmark[62] and California[63] concluded that mortality rates were around twice as high as expected. Gillberg et al[64] reported even higher rates (5.6 times higher than expected) in their Swedish cohort of 120 adults with autism. Death rates appear to be particularly elevated among women,[62–64] in people with epilepsy,[65] and among those with severe or profound learning disabilities. In people with intellectual disabilities, deaths are often related to inadequate institutional care, poor medical supervision, or infection,[16–18] and Mouridsen et al[62] stress the need for care staff to be much better trained in dealing with the physical conditions associated with ASD. However, death rates are also elevated in people who do not have intellectual impairments, with drowning reported as a cause of death in several studies. In contrast, deaths due to smoking, alcohol, traffic, and work accidents are suggested as less common than in nonautistic peer groups.[66]

An increased risk of suicide by more able people with ASD has been reported in many adult studies.[14,67,68] However, these accounts are largely anecdotal and there are no systematic data on suicide rates in this group. Nevertheless, a better understanding of the difficulties that lead some young people to attempt suicide could help to avoid unnecessary loss of life.

Medical Morbidity

At least 10% of cases of ASD are associated with chromosomal or other genetically determined disorders (for example, fragile X syndrome and tuberous sclerosis complex). More recently, submicroscopic chromosomal deletions or duplications, known as CNVs, have been detected in around 5% of people with ASD.[69] These CNVs differ in different people and are also found among unaffected family members, thus their significance and causal role remains uncertain. Nevertheless, the Autism Consortium Clinical Genetics–DNA Diagnostics Collaboration[70] now recommends that chromosomal microarray analysis should become standard practice for genetic evaluation of people with unexplained developmental disorders, such as autism, not only for the purposes of studying heritability but also for identifying previously unknown causal factors.

In addition to the association with certain genetic disorders, there are many anecdotal accounts of increased rates of health problems in people with ASD (including gastric and digestive problems, muscular and sensory abnormalities, and increased susceptibility to infections) together with numerous claims for their treatment (diets, chelation therapy, hyperbaric oxygen, vitamin supplements, and many more). However, systematic reviews have failed to identify any clear association between ASD and susceptibility to viral infections or gastrointestinal or other disorders.[71–74] Nevertheless, it is clear that diagnosing physical problems in people who cannot adequately describe feelings of pain or distress presents many challenges, and there is evidence that undiagnosed or inappropriately treated physical symptoms may be the cause of aggressive, self-injurious, or other challenging behaviours.[75]

Epilepsy

Although lifetime prevalence estimates vary, between 11% and 39% of people with autism have been reported to develop epilepsy.[76–78] This is a significantly higher rate than in the general population,[79] and age of onset (in early teens) is also atypical. The presence of seizures is related to lower IQ, sex (risk higher in females), poorer language skills, greater behavioural disturbance, and higher mortality rates. In a recent study of 150 people diagnosed with autism in childhood, and followed up after they were aged 21 years, Bolton et al[80] found that epilepsy developed in 22% of the study participants, with generalized tonic–clonic seizures predominating (in 88% of all those with epilepsy). However, in more than one-half of participants with seizures, fits occurred weekly or less frequently, and

were well controlled with anticonvulsants. Although the presence of epilepsy was not associated with an increased risk of epilepsy in the relatives of participants, rates of epilepsy were associated with the presence of the broader autism phenotype in relatives (that is, having symptoms associated with, but not meeting full criteria for, autism)

Family Issues

It is well established that parents of children with ASD have a significant risk of increased rates of stress, psychological distress, depression, impaired quality of life, and increased levels of physical and mental health problems.[81] Moreover, the high heritability of autism means that many families have 2 or more affected children,[82,83] and some parents themselves have autistic traits (that is, show the broader autism phenotype.)[84,85] These factors further increase the burden on families regarding physical and emotional stress, social isolation, financial demands, and general quality of life.[86,87] Typically developing siblings are also affected and tend to show more social isolation, problems with peer relationships, behavioural disturbance, and greater concern about the future than other children.[88] However, most of the research on the impact of ASD has involved families of relatively young children, and there is little systematic research on parents or siblings of adults with ASD. In a recent symposium talk presented by Howlin et al[89] of 69 siblings (average age 40 years), all of whom had been ascertained as showing no autistic features when younger,[90,91] it was found that most were doing well, were living independently, and had jobs (often of a high level). However, some were still living with their parents and a few were experiencing difficulties with social relationships. Rates of mental health problems, mainly anxiety, depression, and OCD were higher than in the general population, especially among sisters.

Many siblings expressed considerable anxiety about what would happen when their parents died, leaving them as the main person responsible for their sibling with autism. Although only a minority of the adults with autism were still living at home, their parents, many of whom were now in their 70s or 80s, also expressed fears about the future and who would look after the welfare of their son or daughter when they were no longer alive. There were particular fears that, with forthcoming financial cuts to social services, people currently living in adequate residential placements may be relocated to cheaper, less appropriate settings if they had no one to advocate for them.

Summary and Future Research Needs

Although studies of the trajectories of development in ASD have shown that the severity of symptoms tends to reduce over time,[92] it is evident that outcome in adulthood is very mixed, including for people with a normal IQ. Even in the follow-up study with the most positive outcomes[29] fewer than one-half of the participants were rated as functioning totally independently. In those studies reporting on specific outcome measures, the average proportion of adults still living at home was 48%; the average proportion in employment (regular, supported, or sheltered) or full-time education was 46% and, for those in employment, jobs were often at a low level and poorly paid. Only 15% of people in the studies reviewed were reported to be (now or in the past) in a long-term sexual relationship, or to have married, although around one-quarter did have at least one friend.

Nevertheless, these findings are based on groups of people who were growing up at a time when specialist programs for children with autism were very limited, and when only more severely autistic children were likely to be given a diagnosis. In outcome studies conducted before 1980, almost no people had received full-time education; very few lived independently or had jobs; and, as adults, more than one-half were placed in long-stay hospitals or institutions for people with mental retardation. During the last 2 decades, access to early diagnosis, preschool intervention, specialist educational support in both school and college, and supported employment programs has greatly increased. It is also evident that early intervention programs, particularly focusing on behavioural approaches, positive parent–child interactions, joint attention, and play can lead to significant developmental and communication gains in at least some children.[93,94] However, whether these early improvements will be reflected in the adult lives of the current generation of children with ASD has yet to be demonstrated. Developing studies of the factors that can significantly improve outcome will be an essential focus of future research.

Perhaps the most significant gap in our current knowledge is what happens to people with autism as they approach old age. Almost all current adult outcome studies have focused on people in their 20s to 40s. Knowledge about the aging process in ASD is almost nonexistent, and systematic information about the physical and mental health needs of elderly people with ASD is lacking. For example, it is not known whether rates of dementia are likely to be higher or lower in this group than in the population as a whole. It is also evident that many people remain highly dependent on their families well into adulthood. How they will cope when parents are no longer able to support them is a further issue with major implications for society as a whole.

In summary, although research into children with ASD has made significant progress during recent years, leading to major advances in diagnosis and understanding of causes, research into adulthood still has a long way to go. Follow-up studies of people identified and fully assessed as children and followed up systematically from decade to decade is essential if we are to understand the factors that influence prognosis, how these factors exert their effects, and how they may be modified to ensure a better future.

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