

Young Adult Outcome of Autism Spectrum Disorders

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Abstract To learn about the lives of young adults with ASD, families with children born 1974–1984, diagnosed as preschoolers and followed into adolescence were contacted by mail. Of 76 eligible, 48 (63%) participated in a telephone interview. Global outcome scores were assigned based on work, friendships and independence. At mean age 24, half had good to fair outcome and 46% poor. Comorbid conditions, obesity and medication use were common. Families noted unmet needs particularly in social areas. Multilinear regression indicated a combination of IQ and CARS score at age 11 predicted outcome. Earlier studies reported more adults with ASD who had poor to very poor outcomes, however current young people had more opportunities, and thus better results were expected.

Keywords Autism outcomes · Young adults with autism

Children with autism spectrum disorders (ASD) grow up and develop needs beyond home and school, yet most of the focus in autism literature is on the identification, assessment and treatment of children. Few studies examine the outcome into adulthood, and most of these were done years ago or focused only on higher functioning individuals. Thus planning and prognoses within the wider autism spectrum are limited. Little is known about transition to the adult world, but it is thought to be a “confusing maze of

misinformation, limited opportunities, insufficient resources and inappropriate or time-limited services” (Gerhardt and Holmes 1997). Since there is so little information, families fear that growing up will bring new difficulties and there can be great anxiety about how their child will cope when they can no longer care for them.

Previous studies were often anecdotal, varied in sample size and in heterogeneity of subjects, with a wide range of age or age at diagnosis, making interpretation difficult. Intervention and treatment have changed, presumably contributing to outcome. The early research suggested that 60–75% of people with autism had poor or very poor adjustment in adulthood. Lotter (1978) reviewed outcome studies and found that 50–75% lived in large institutions and very few were receiving appropriate residential and vocational services. Only 5–15% had a near-normal or normal social life and acceptable functioning in school or work. There had been some improvement in educational opportunities, with far more having attended school than expected. This contrasted with the outcome of children diagnosed in the 50s and early 60s, where only half had as much as 2 years of schooling (Lotter 1978; Rutter and Lockyer 1967; Rutter et al. 1967). Kanner, who first described autism in 1943, reported that most “did not fare well in adulthood” (Kanner 1971; Nordin and Gillberg 1998).

There is some evidence that higher functioning individuals (those with IQ > 70 or with Asperger syndrome, a variant of autism spectrum disorder) have a better outcome (Szatmari et al. 1989) although this is not consistently reported (Howlin et al. 2004). Howlin included only those with IQ > 50 and found that 58% had poor or very poor outcome and only 22% good or very good. However, even for those with average IQs, the majority had no close friends, were dependent on their families, and employment

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status was low (Howlin 2000). In a sample of 42 high functioning individuals, Engstrom et al. (2003) found that most had been diagnosed after childhood. At mean age 30.8 outcome was good for only 12%. Only one was employed, few had close relationships and there was an “extensive need for support.”

Gillberg and Steffenberg (1987), reporting on 23, found one person was independent and almost half were functioning fairly well. Speech before age 6 and an IQ above 50 at diagnosis were predictors of better outcome. They also found that up to 30% experience cognitive deterioration during adolescence, which for many is temporary. Behavioral deterioration including self-destructiveness and aggression occurred in up to 20%, although the negative behavior may not have been a change. It is more likely that it was ongoing but was now in adults whose large size made such behavior appear dangerous (Gillberg and Coleman 1992). Other concerns are a decrease in physical activity with young adults becoming lethargic and up to 40% developing epilepsy before age 30. Seizures were most likely to occur in lower functioning individuals but incidence was still around 18–20% when those with severe to profound mental handicap were excluded (Goode et al. 1994; Tantam 1991). Not surprisingly, lower functioning individuals did not do well (Stein et al. 2001).

Even in the early studies there was a suggestion of risk for anxiety and depression (Rutter 1970). Up to 25% showed signs of affective disorder, however studies were not based on representative samples so results must be treated with caution. It is of course difficult to make such diagnoses in persons who are literal and concrete, with impoverished language and obsessiveness, all traits of autism (Howlin and Goode 1998).

Kobayashi et al. (1992) reported on a large Japanese sample of 201 using a mail-back survey. Over a quarter were described as having a good or very good outcome which meant working and living close to independently. Consistent with other studies, 20% had developed seizures and outcome was correlated with early language skills and intellectual functioning for males. Four (2%) had died.

Goode et al. (1994) re-examined 75 young adults in London and found 20% had a good or very good outcome with independence, some friends and a job. More recently they reported on 68 individuals with autism and childhood IQ > 50. The majority, 46%, had poor or very poor (12%) outcome. Those with childhood IQ > 70 did better. Most remained highly dependent on others (Howlin et al. 2004).

Another English study used mail-back questionnaires sent to 1,200 families of adults with autism with a 38% response rate. Almost half had Asperger syndrome and/or late diagnosis, which made the sample somewhat unique. However outcome was negative for most, with only 14% in full time paid employment, 11% living mostly

independently, while 65% had difficulty making friends. They noted that these adults with ASD fell through the gap between mental health and learning disability (mental retardation) services and they strongly recommended more government support (Barnard et al. 2001).

More recently Billstedt et al. (2005) reported on a large sample followed prospectively. Almost half had childhood IQs < 50. Outcome was very poor for 57%, poor for 21%, fair for 8% and none had a good outcome. Only one lived independently, and three were independent but isolated. More had poor or very poor outcome than expected and there was more epilepsy. Women and those with atypical autism did no worse than men or those with autistic disorder. Half had medical conditions needing regular medical attention, and self-injury and violent behavior were common. They cautioned that in view of the current practice of diagnosis being given to a wider “spectrum” and to higher functioning individuals, these results may not apply to children now being diagnosed.

Similar results were found by telephone in a Canadian sample of 15 families (mean age 22). Most were living at home, 63% had 1–2 friends and 41% were employed part time. It was reported that they had found speech therapy, medication and behavior therapy that was “skill building” as helpful (Ellison et al. 2005).

There was general research consensus about three factors related to later outcome. First was early language development, with those having useful speech by about age 5 doing better. Degree of mental handicap was also a factor: those with IQ < 55 usually remained highly dependent in adulthood. Third was the amount of education, however, this would be confounded by language and IQ so may not be a good predictor alone (Howlin and Goode 1998).

Studies have reported improved outcome over the years with fewer living in institutions and more working and living independently (Howlin and Goode 1998). However, there is a need for more research with typical autism samples in view of the changes that have occurred in the field. Today’s young adults had many more opportunities than their predecessors. In most cases they were identified early, received special education, speech language therapy and behavioral training for their families. In many jurisdictions they were fully included in neighborhood schools with individual support and post secondary training was available. Also, in many places institutions have closed, so that is not an option for their living arrangements. There is a need to identify in what ways, if any, their outcome is different than in the past.

There are also many more children diagnosed with ASD (Charman 2002; Gurney et al. 2003). Most of the increase is believed to be due to heightened awareness of the condition and to changes in and broadening of the definition

with more higher and lower functioning individuals now included (Fombonne 2003). What it means for the future is that there will be many more young people needing adult services. Thus it is important to know just what is happening with current young adults to enable planning.

The goal of the present study was to learn about the health, physical activity, educational attainment, social adjustment and quality of life of young adults with ASD and to identify factors in their early life related to better or worse outcome. Since current young people had more opportunities than in the past, better outcomes would be expected.

Specifically, we asked, how did the outcome, in terms of work, friendships and independence, compare with earlier reports? Did additional diagnoses or health concerns occur, what was the use of medications, and were they physically active? Was childhood degree of mental handicap or autism related to outcome?

Further goals were to identify the quality of life and community support for these young people, to learn what families saw as unmet needs and what they had found to be helpful or unhelpful when raising their children. Results should be helpful to government and support agencies in preparing budgets and service plans for the increasing number of children with ASD entering adulthood every year.

Methods

The young adults were born from 1974 to 1984 and diagnosed with ASD at Sunny Hill Health Centre for Children in Vancouver, British Columbia as preschoolers. Seventy-six participated in a follow-up assessment when they were mean age 11½ years (range 8–17; Eaves et al. 1994; Eaves and Ho 1996). For the present follow-up, 15 (19%) could not be located. Sixty-one were contacted by mail and invited to take part in a telephone interview. Thirteen (20% of those located) declined to participate. One died recently but the foster family agreed to be interviewed. Thus, 48 (63% of those eligible) participated in the interview conducted by a research assistant, taking up to 2 h. Respondents included 38 (79%) mothers, two fathers, three both father and mother, four foster mothers and one group home manager.

There were three sets of data: childhood (Time 1), early adolescence (Time 2), and the young adult information (Time 3). The items of interest from Times 1 and 2 were verbal and performance IQ (VIQ and PIQ) and an autism rating score. This was a composite score of autistic features at Time 1 and the Childhood Autism Rating Scale (CARS) at Time 2.

The interview consisted of quantifiable questions concerning current health, physical activity, education, public supports, work, and friendships. Some were rated on a 1–5 scale; some were counts, for example, of medical conditions, levels of schooling, types of service received, extent and type of work and levels of activity.

There were also two open-ended questions to permit the family to expand on their views and concerns and express themselves in more depth. They were asked if they saw any unmet needs of their young person and what things had been both helpful and unhelpful in raising their child.

Outcome Rating

Each young adult was given a global rating (Overall Outcome Rating, OOR) of very good to very poor outcome based on occupation, friendships and independent living. This was similar to what has been used in previous autism research (Lotter 1974, 1978; Howlin and Goode 1998; Howlin et al. 2004; Billstedt et al. 2005). Although somewhat subjective, such a rating permits comparisons across various samples over the years. Lower scores reflect better outcomes.

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

Friendship ratings were the number of friends/acquaintances and the quality according to the degree of sharing and mutual participation of the relationship involved. Scores ranged from 0 (close friendship involving sharing and exchange of confidences and a range of different activities together), to 3 (no friends; no joint activities).

Independence ratings were 0 = living independently; 1 = in semi-sheltered accommodation or still at home but with high degree of autonomy; 2 = living with parents, some limited autonomy; 3 = in residential accommodation with some limited autonomy; 4 = residential accommodation with little or no autonomy; 5 = hospital or institution.

OOR score was the total of all three areas: 0–2 = *Very good* outcome: achieving a high level of independence, some friends and a job. 3–4 = *Good* outcome: generally in work but requiring some support in daily living; some friends/acquaintances. 5–7 = *Fair* outcome: some degree of independence, and although requires support and supervision does not need specialist residential provision; no close friends but some acquaintances. 8–10 = *Poor* outcome: Requiring special residential provision/high level of support; no friends outside of residence. 11 = *Very poor*: needing high level care, no friends, no autonomy.

Characteristics of Participants in Childhood and Adolescence

Age

Mean childhood age at Time 1 was 6.8 years, (range 3–12). At Time 2, adolescence, mean age was 11.4 (range 8–17).

Diagnoses

Systems for classification of autism have changed over the years, however the criteria currently used in DSM-IV is very similar to what was defined by Rutter (1978) or earlier versions of DSM (AMA 1980, 1987) which were used at Time 1 to assist with diagnosis and to obtain an Autism Score. Twenty-six (57%) were diagnosed with autism (infantile autism) and the remainder had lesser variants of what is now called the autism spectrum. This included atypical PDD or autism, or language disorder or mental handicap with autistic features. Mean CARS score was 34.4 (*SD* 5.1, range 25–46).

Diagnoses remained similar at Time 2 with 61% (27) autistic and the remainder lesser variants on the spectrum. Five high functioning individuals were described as schizoid personality disorder, which might now be called Asperger disorder (Wing 1996; Wolff, chap. 10 in Klin, Volkmar & Sparrow, 2000). Mean CARS score was 31.0 (*SD* 5.9, range 21–47.5). DSM3R was 10.7 (*SD* 1.6, range 7–15).

IQ

IQ scores were from the test most suitable to their age and developmental level. This included the Wechsler Preschool and Primary Scale of Intelligence (1967), the Wechsler Intelligence Scale for Children (1974), Bayley Scale of Mental Development (1969) or Leiter International Performance Scale (1952).

At time 1, half scored >50 in verbal IQ (VIQ). Eight were >70 (17.4%); 15 (33%) mild (50–69), 16 (35%) moderate and 7 (15%) severe to profound intellectual disability. For non-verbal IQ (PIQ) 61% were >50. Eleven (24%) had mild intellectual disability, 12 (26%) moderate and 15 (33%) severe to profound.

At Time 2, the pattern was similar however there were slightly fewer scoring >50, 47% for VIQ and 57% for PIQ.

Results

The Participants in Young Adulthood

At Time 3, mean age 24 years, there were 48 (11 females) subjects. The mean OOR was 6.79, range 2–10, *SD* = 2.16.

Good or very good outcome was found for 21%. None had a very poor rating (Table 1).

Health and Mental Health

The most common emotional or psychiatric problem was general “emotional difficulty” for 30 (62.5%). Half (24) were thought to have OCD, and half (24) anxiety. Ten were depressed (21%), and three were bipolar. Five had Tourette syndrome, and 18 (38%) had conduct disorder.

Regarding other conditions, obesity, vision problems and epilepsy were relatively common but only one or two had asthma, orthopedic problems or diabetes. Two were underweight and nine had sleep disturbance. Three had Fragile X syndrome and one Tuberous Sclerosis.

Twenty-eight (58%) were taking medication, nine for seizures, four for thyroid problems, two for sleep disturbance and several for allergies. Nineteen (39.5%) were on prescription drugs for behavior, most commonly respiradol. Six were on more than three drugs.

The individual who died at age 23 was lower functioning, and was on medication for both seizure disorder and depression. Cause of death was complications of a massive infection.

Education and Employment

These young people all went to regular elementary schools with special educational support. Three attended a

Table 1 Characteristics of 48 young people with ASD at mean age 24 (range 19–31)

Outcome variable	Number (%)
Died	1 (2%)
Outcome	
Very poor	0
Poor	22 (46%)
Fair	15 (32%)
Good	8 (17%)
Very Good	2 (4%)
Additional psychiatric problems/diagnoses	37 (77%)
Genetic syndromes	4 (8%)
Epilepsy	9 (19%)
Aggressiveness	12 (25%)
Self-injury	15 (31%)
Overweight	20 (42%)
Regression/change	
Steady improvement or no change	17 (35%)
Clear improvement at one point	10 (21%)
Worse at ages 10–17	18 (37.5)
Worse at ages 2–6	3 (6%)

residential program for ASD for 2 years as adolescents. They finished school, academic or not, at a mean age of almost 18 years (range 13–21). In high school, 33 (69%) were in special classes and 37 (77%) had aides. Twenty-one percent were seeing a speech language pathologist and 40% a school counselor. Estimates of academic achievement indicated 33% could not read, but 23% read at grade a grade 9–13 level. For writing, 35% had no skills and 13% were at a high school level and for math, 42% could not do any, while 20% were at or above Grade 9. Almost 30% (14) attended post-secondary, only one at a university. None had yet received a certificate of completion or degree.

Only 27 (56%) had ever been employed, most in volunteer, sheltered or part time work, averaging 5 h a week. Jobs included delivering papers, Meals on Wheels or sorting recycle with another person. Only two worked independently and one supported himself.

Residence

Twenty-seven (56%) lived with parents and 17 (35%) were in supported arrangements such as group homes, foster care or a home managed by the individual’s microboard (2). Four lived more or less independently. Most (38, 79%) received the government disability pension and had a social worker. A variety of other services were used, the most common being 56% getting some form of respite care and 40% attending a day center.

Relationships

In terms of friendships and relationships, 16 (33%) were reported to have at least one friendship that involved selectivity, closeness and enjoyment of each other’s company. Eighty-five percent had a hobby and 31% spent time with people around their hobby or special interest. Almost 30% attended a social, church or club regularly. Ten percent were reported to have had a romantic relationship, none current and none married or cohabiting.

Relationships with family were good to excellent for 71%. Half were reported to be calm and positive in outlook and half showed some anxiety or depression. For 69%, activities were not limited due to emotional or behavioral difficulties.

Activity

Only 46% did moderate or vigorous physical activity at least once a week, but 85% walked at least 10 min 2+ times

a week. Mean time spent sitting was 13 h a day. A variety of reasons were given for preventing the person from being more active. Most common were lack of energy, disability or cost (30–35%), lack of leaders or partner (42%) or lack of athletic ability (63%)

Quality of Life and Satisfaction with Services

Parents rated quality of life at 5.2 on a 1–10 scale. Most (79%) were reported to have good to excellent health and none had limited activities due to health. In terms of self-care 42% had difficulty maintaining personal hygiene but 58% were independent at bathing, 69% in dressing, 75% in toileting and 91% in eating. They were less successful at household tasks with only 35–45% able to shop, prepare meals, do housework or laundry independently. Over half (54%) had difficulty managing day to day life; 43% could take public transport.

Parents were asked to rate their satisfaction with various areas of the young person’s life. Eighty-one percent were satisfied to very satisfied with health care, 65% with community support, 51% with government support and working life and only 42% with education.

Prediction of Outcome

From both childhood and adolescence the best predictor of outcome was verbal IQ. When VIQ and the autism score were combined to predict OOR, the partial *F* ratio for the autism score after VIQ was statistically non-significant. In other words, autism score contributes little after VIQ. From childhood, none of the other candidate predictors significantly improved the straight-line function of VIQ as a model for mean OOR.

Table 2 shows the correlations between IQ and autism scores in childhood and adolescence and outcome. All were significant with the exception of the autism rating in

Table 2 Correlations between Overall Outcome Rating and variables in childhood and adolescence

	Correlations with OOR	
	Childhood Correlation	Adolescence Correlation
Autism Score	.08 (n.s.)	.40*
PIQ	-.53*	-.56*
VIQ	-.54*	-.58**
CARS	.50*	.64*

**p* < .003

**With an outlier, who had high IQ but poor outcome. Without him, *r* = -.70, sig. 00002

childhood (based on Rutter 1978 and early versions of the DSM).

Multilinear regression indicated that a combination of IQ and CARS score predicted outcome moderately well, whether from childhood or adolescence. Using the childhood scores, $R^2 = 0.61$; while the adolescence scores resulted in, $R^2 = 0.46$.

Responses to Open-ended Questions

A content analysis was conducted on the open-ended questions, and the parents' responses were grouped into common themes. The number of times each theme was mentioned was counted.

Do you See any Unmet Needs?

Twenty percent reported that there were no unmet needs and their young person was generally contented and living a satisfactory life. Some remarked that they were very pleased with how their child had turned out given their experience and expectations in the early years.

Many more however had concerns. Close to 30% saw a great need for social outlets. They sought programs for young adults with disabilities or more social skills training, and 10% mentioned the need for a "buddy" or support worker to take them to activities. Twenty-five percent said that their young adult needed friends or a "loving relationship." A further 8% suggested that the person was lonely, possibly depressed and didn't have enough to do. Altogether, 75% pointed to a social need of some kind.

Twenty-nine percent indicated the need for a job or more hours of work, and 15% sought more education. There were also some health concerns ranging from wanting doctors and dentists who knew autism to improved drugs or better understanding of the young person's health. Two mentioned that more financial support was needed (Table 3).

What was Helpful?

When respondents were asked, "What three things have been the most important, helpful or made the most difference in raising your child over the years?" the answers were remarkably consistent (Table 4).

The top two responses were family members (52%), often their husband or grandparents, and specific individuals such as a teacher or classroom aide in the school system (50%). Many named themselves (17%) or the schools in general (14.5%) as being very helpful. Agencies

Table 3 Unmet needs reported by families of young adults with ASD

Identified unmet need	Percent reporting (n)
None	20% (9)
Social programs/social outlets	31% (15)
Friends	25% (12)
Work	29% (14)
Education	15% (7)
Support worker for activities/buddy	10% (5)
Improved living situation	6% (3)
Respite for family	4% (2)
Medical attention	8% (4)
More to do	8% (4)
More money/income	4% (2)

Table 4 Supports and services found to be helpful or unhelpful

Source	Helpful (n)	Unhelpful
Self	17% (8)	–
Family members	52% (25)	–
Family friends	15% (7)	–
Individuals (teacher, social worker)	50% (24)	29% (14)
Association or agency	25% (12)	
School	15% (7)	29% (14)
Autism agencies	17% (8)	2% (1)
Government ministry	10% (5)	27% (13)
Other professionals (psychiatrists, doctors, psychologists)	8% (4)	12% (6)
Lack of services/work	–	29% (14)
Ignorance/attitudes	–	27% (13)
Nature of autism	–	15% (7)

serving people with disabilities (25%) or offering specifically behavior support for those with autism (16%) were also singled out.

Only one named a specific treatment method but three mentioned services their young adult received before age 5 (a preschool or speech language therapy). None mentioned behavioral therapy as a positive influence although 16% did name one of the three agencies in the province that offered such intervention when their children were young.

What was Unhelpful?

When asked, "What three things have been unhelpful, frustrating or even harmful for you and your child?" they identified the school system (29%) and the government ministry responsible for children, families and the disabled (29%). Parents often noted that it was difficult to know

what was available and how to access it. The bureaucratic maze was annoying and stressful. Some found the government attitude to be negative in that the focus was on problems or needs, and higher functioning individuals had to “prove” that they required services. A lack of supports, work, or an awkward transition to adult funding was cited as a problem by 29%. They lamented that adult services were not as good as those for children.

Over a quarter (27%) found the attitudes and ignorance of autism by others was unhelpful and 15% identified the nature of autism itself with the repetitive, rigid behavior or a concrete view of the world as frustrating.

Almost 30% recalled a specific individual such as a teacher, social worker or other support person who had been a negative influence or even harmful to their young person, and they identified the individual as the problem, rather than the agency.

Discussion

The results from parents or caregivers about young adults with ASD indicated limited independence, low economic status and, for many, persisting behavioral concerns. The sample represented a narrower age range than most studies on adult outcome and they were born in the 70s and 80s after many more opportunities became available for persons with autism. They represented the full IQ range although it is known that individuals with low IQs will have challenges living independently or holding a job regardless of autism.

We found about half having a fair to good outcome and half poor (but none very poor) which was better than earlier studies that indicated 60–75% with poor outcome or more recently Billstedt et al. (2005) where none had good outcome and 52% very poor. In our sample, 60% lived at home with a disability pension and several were in group homes, but none in institutions. Many had jobs but only a few hours a week, menial and often supervised or sheltered. Only four lived semi-independently and most were living with their families and receiving government disability pension.

It is possible that some of our young people in group homes were close to the “very poor” outcome which was defined as no friends, no autonomy and needing high level care. They may have failed to receive this lowest rating due to currently held higher expectations by their caregivers and a wider variety of activities available to them. Many worked with their group home staff delivering papers or sorting recycle and went on outings. We do not know what level of autonomy they had in these circumstances. Institutional care is no longer available in British Columbia but

the level of care offered by some group homes may be comparable.

Although overall outcome was only fair for most, there were fewer of the negative symptoms reported by Billstedt et al. (2005). In the Swedish sample there were high numbers of self-injury and aggression (almost half) and in our sample it was only 25–31%. Nineteen percent of our sample had epilepsy and they found 40%. On the other hand, 16–17% of their sample reported pubertal regression while we had twice as many. In our group up to half had co-morbid conditions and 58% were on medication.

Obesity was common (42%) and they were not very active. Rates are rising in North America, however our sample had close to double the rate of 23% obesity in adults (Ho et al. 1997; Statistics Canada 2005).

Schooling was in regular schools with special educational support. Over a third had no academic skills, less than a quarter were at a high school level and a third attended post secondary schooling. Full inclusion in neighborhood schools may be important for social reasons but cognitive ability probably determines academic achievement.

Childhood level of functioning, particularly verbal IQ was related to outcome. From adolescence, both IQ and autism ratings predicted outcome. Similar to previous reports, worse outcome was correlated with lower IQ and more severe autism (higher CARS score) and better outcome with higher IQ (Rumsey et al. 1985; Gillberg and Steffenberg 1987; Howlin et al. 2004).

There may have been some biases in our sample which could limit the ability to generalize from it. We had a high percentage of participation of eligible families (63%), however it may have been ones with more positive outcomes who chose to do so. Many of the young people still lived at home suggesting that they were not difficult to live with. A few of those who declined did so because their young person was living in a group home which could imply more dependence and or challenging behavior.

The somewhat better results than in previous studies, with none having a very poor outcome, could also be partly related to the younger age of the sample, all born since 1974 when many changes in the identification and treatment of children with autism occurred in North America. They were diagnosed as preschoolers, received a range of interventions, which for most included some speech language therapy and as well as behavioral intervention. Agencies worked with families to help them learn behavioral techniques. They attended local schools with individualized educational plans and teachers were increasingly knowledgeable about techniques for pupils with autism. The small improvements over other studies could be due to sampling bias or interpretation of the data

but may also be the result of early identification, full inclusion in schools and better educational practices.

Another potential limitation to the study was the use of a telephone survey rather than face to face interviews. We used this method for cost and time efficiency and because it ensured a higher response rate than mail but was less intrusive to families than personal interviews. Telephone surveys have a long and respected history but the method may be a potential source of imprecision and bias that could contribute to sampling error. To minimize some of the difficulties we worded the questions carefully, did not order them in any way that could distort and provided clear response choices. The interviewer was able to ensure answer completeness and minimize item non-response by probing or clarifying. Lavrakas (1993) identifies the challenges for telephone surveys and solutions to make them accurate for their purposes.

Ideally when studying outcome, the young adults would be re-examined and given standardized measures, rather than relying on parent report. This was not done for reasons of time and budget constraints. Moreover, it was not the purpose of the study to examine the evolution of autistic features or the reliability of earlier diagnoses. We had extensive standardized data on the participants from childhood and adolescence documenting their disabilities, and a large part of the adult data was relatively objective, such as facts about health, education or and medical conditions. For the open-ended questions, we were actually interested in the subjective experiences of the families.

Not surprisingly, when families recalled what was helpful or not in raising their children, it was people, not a treatment method or program. Family members or individuals working closely with them were what they remembered as making a difference to them. Several described a teacher, classroom aide or support worker. Although no specific beneficial interventions were commonly identified, family attitudes were positive in most cases.

There were needs identified in social areas with many lacking social activities or friends. Almost a third indicated a need for work, and among the higher functioning individuals this was most evident. Twenty percent did not identify any unmet needs but this may have reflected a realistic acceptance of the young person's capabilities, in other words, they weren't seeking friends or work.

This study provides a picture of young people with autism who were diagnosed at a time when the definition was somewhat narrower than at present. They also represented the full IQ range, and it was shown again here that both the intensity of autistic symptoms and low IQ have a negative impact on long-term functioning. Although in some ways this sample was doing better than earlier ones,

we echo the lament of Howlin et al. (2004) that, “the great increase in educational opportunities for children with autism over the past 30 years has not necessarily resulted in significant improvement in outcome in adulthood” (p. 14). Moreover, it appears that services for adults do not appear to have kept pace with the increases in services to children leading to frustrations in many families.

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