

# Autism Spectrum Disorder Grown Up: A Chart Review of Adult Functioning

Samantha Marriage BSc<sup>1</sup>; Annie Wolverton BA, MEd<sup>2</sup>; Keith Marriage MBBS, FRCPC<sup>2</sup>

## Abstract

**Objective:** To survey the adult functioning of patients with Autism Spectrum Disorder (ASD), and to compare the outcomes for those diagnosed in childhood with those diagnosed as adults. **Methods:** Using a chart review, we evaluated the adult outcomes for 45 individuals diagnosed with ASD prior to age 18, and compared this with the functioning of 35 patients whose ASD was identified after 18 years. Concurrent mental illnesses were noted for both groups. **Results:** Adult outcome was poorest for those with the combination of ASD and Intellectual Disability (ID). The sub-group of individuals with Autism identified in adulthood whose functioning was assessed after 25 years of age had achieved more in the areas of education and independent living. All three groups had a high frequency of psychiatric co-morbidity. **Conclusion:** While co-morbid ID and ASD generally imply a poor outcome, for children and youth with ASD and normal range IQ, adult functioning is more variable and difficult to predict. Because of delays in ongoing social development, some of these individuals may attain educational, independent living and relationship goals, but reach them a decade or more later than typical for the general population.

**Key words:** Autism Spectrum Disorder, adults with Autism, Asperger's Disorder, Intellectual Disability

## Résumé

**Objectif:** Étudier le fonctionnement de patients adultes souffrant de troubles envahissants du développement (TED). Comparer les résultats des patients diagnostiqués dans l'enfance à ceux diagnostiqués à l'âge adulte. **Méthodologie:** Le dossier de 45 sujets adultes qui ont reçu un diagnostic de TED avant l'âge de 18 ans a été étudié; ces données ont été comparées à celles de 35 patients diagnostiqués après l'âge de 18 ans. Les deux groupes souffraient de comorbidités psychiatriques. **Résultats:** Les adultes souffrant de TED et de déficience intellectuelle (DI) affichaient les plus mauvais résultats. Les sujets évalués après l'âge de 25 ans affichaient de meilleurs résultats en matière d'éducation et d'autonomie. Les comorbidités psychiatriques étaient fréquentes dans les trois groupes. **Conclusion:** Bien que les sujets TED avec DI affichaient généralement de mauvais résultats, les enfants et adolescents souffrant d'un TED, mais qui avaient un QI normal, devenaient des adultes dont le fonctionnement était variable et difficile à prédire. Malgré leur retard de développement au niveau social, ces enfants et adolescents atteignaient certains objectifs en matière d'éducation, d'autonomie et de relations interpersonnelles, mais avec un retard de dix ans sur la population générale.

**Mots clés:** trouble envahissant du développement, adultes autistes, syndrome d'Asperger, déficience intellectuelle

<sup>1</sup>University of Melbourne Medical School, Melbourne, Australia

<sup>2</sup>BC Children's Hospital, Vancouver, British Columbia

Corresponding email: kmarriage@cw.bc.ca

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## Introduction

"Autism" refers to a group of developmental disorders characterized by deficits in social interaction and communication, and a markedly restricted repertoire of activities and interests (American Psychiatric Association, 2000). While 6-10% of patients with Autism also present with associated neuro-developmental syndromes (e.g. Down Syndrome, Fragile X Syndrome, Tuberous Sclerosis, phenylketonuria), for the majority the cause is unknown. It is likely that a number of different etiological pathways result in this symptom complex. Recent genetic studies have suggested a number of candidate chromosomal sites as influencing the phenotype, but proven associations account for only a small percentage of cases (Muhle et al., 2004; Wassink et al., 2004).

In the past two decades there has been a shift in our perception of Autism, and the diagnosis has expanded to encompass the "Autism Spectrum Disorders" (ASD). This includes cases defined by DSM-IV as Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. It should be noted that, because of the continuing controversy over validity of the diagnosis of Asperger's Disorder (AD) versus Higher Functioning Autism (HFA), we will not distinguish between the two, but refer to them both as being on the Autistic

Spectrum (ASD), together with PDD-NOS (Howlin, 2000).

The frequency of ASD diagnoses has roughly tripled since the 1980's, which may not, however, reflect an increase in population prevalence. Two standardized assessment instruments, the Autism Diagnostic Observation Schedule (ADOS, Lord et al., 1989), for the patient, and the Autism Diagnostic Interview – Revised (ADI-R, Lord et al., 1994) for the parent, originally designed for research, have also, in the last 10 years, become the "gold standard" for clinical practice. This has improved reliability of diagnosis, but has also broadened the criteria for inclusion in the spectrum. Changes between DSM III and DSM IV and ICD 10 may have further widened the spectrum (Fombonne, 2005). Increased public and professional awareness resulting in more case finding, and the evolution of diagnosis specific funding for families of ASD children, may have both contributed to the "epidemic of Autism" sometimes cited by the popular press. Thus, the prevalence of Autism was held to be 4/10,000 in the 70's and 80's, but current estimates for ASD prevalence is 60/10,000, with 13/10,000 meeting criteria for Autism (Fombonne, 2005).

Since broader diagnostic criteria identify a larger and more heterogeneous patient population, expectations for prognosis must be re-examined. For example, about 80%

of patients diagnosed with Autism in the 1970's and 1980's were also intellectually disabled. In contrast, more individuals classified within the Spectrum today will have IQs in the normal range. This latter group might be expected to have a better long term outcome.

For those diagnosed with ASD in childhood, most will become adults with a significant degree of disability (Cederlund et al., 2008; Howlin et al., 2004; Seltzer et al., 2004; Howlin, 2000). As summarized by Seltzer et al, there is evidence of persisting social and communication deficits, together with psychiatric and behavioral co-morbidity. They concluded that, despite considerable heterogeneity in social outcomes, "few adults with autism live independently, marry, go to college, work in competitive jobs or develop a large network of friends". However, the trend within individuals is for some functional improvement over time, as well as a decrease in autistic symptoms (Howlin et al., 2004; Seltzer et al., 2004). Some authors suggest that a sub-group of 15-30% of adults with autism will show more positive outcomes (Cederlund et al., 2008; Seltzer et al., 2004).

Patients with co-morbid ASD and Intellectual Disability (ID) had significantly worse outcomes than those with normal IQ's, suggesting that IQ may be a prognostic factor (Cederlund et al., 2008; Howlin et al., 2004). That said, previous studies have shown that even for those in the HFA/AD group with IQ's greater than 70, many had poor social outcomes, and lower levels of independence and vocational achievement in adult life. It was also noted that co-morbid psychiatric disorders and development of epilepsy, as well as high dependence on families and institutions, were prevalent in this group (Cederlund et al., 2008; Engstrom et al., 2003; Howlin, 2000).

Because ASD comprises cognitive, social and behavioral deficiencies, it can be difficult to characterize individual outcomes as "positive" or "negative", especially with regards to interpersonal relationships. Howlin et al. (2004), and Cederlund et al. (2008) assigned global ratings of social functioning based on achieving independence, friendships / a steady relationship, and education and/or a job. These two papers described respectively 22% and 27% of groups of higher functioning (IQ above 70) ASD adults as attaining "Very Good" or "Good" outcomes.

Literature on the efficacy of childhood interventions and support programs in relation to later functional outcomes is still limited. The consensus is that formal programs such as social skills training, vocational programs, and supported accommodation may be at least as important as individual prognostic factors, such as IQ, early language development or severity of autistic symptoms, in influencing adult outcomes. Family dynamic factors and emotional, practical, and financial support may all have an important positive influence on eventual social functioning (Engstrom et al., 2003; Renty & Roegers, 2006; Nordin & Gilberg, 1998; Venter et al., 1991).

In addition to those previously discussed, there is a

new group of patients who should be considered – those who are being diagnosed with ASD after they have become adults. These individuals are, of course, not equivalent to ASD children followed into maturity, but still have something to teach us about the range of outcomes in the Autistic Spectrum.

This paper briefly reviews our own clinical experience following children with ASD into adulthood. We then report on the functioning of patients whom we have diagnosed as adults. We expected to find that IQ significantly influenced outcome, and, from our clinical impressions from working with this population, that establishing intimate relationships would prove challenging for most individuals. We see the establishment of Gender identity and the negotiation of a reciprocal sexual interaction as two of the more complex tasks facing any young person as they mature.

## Methods

### *Participants and diagnostic process:*

Our first group comprised 45 individuals referred as children or youth to our clinic over the past 11 years (1998-2008) for diagnosis and/or management of ASD. All had been followed up until after their 19<sup>th</sup> birthday. The initial ASD assessment was made by the third author, KM, or had been made at another center, according to the prevailing standard at that time, DSM III-R or DSM IV. Since 2003, the ADI-R and ADOS instruments had been part our evaluation. 12 of these patients had been found to have Intellectual Disability, i.e. FSIQ <70, WISC 111 or WISC IV (Wechsler, 1992 & 2003).

The second group of 51 patients had been referred as adults for evaluation of possible ASD. These diagnoses were all made by KM, a psychiatrist with 22 years experience in the field of Autism, who has performed more than one thousand assessments. The diagnostic process for this adult group included:

1. A developmental history, with co-lateral information about childhood functioning from parents and siblings when possible, assisted by standardized questionnaires; The Child Symptom Inventory (Gadow et al., 2002), the Australian Scale for Asperger's Disorder (Garnet et al., 1997), and after 2003, the ADI-R if parents were available for direct interview (completed for 21/51 patients).
2. Evaluation of current (adult) symptoms, assisted by Baron-Cohen's Autism Quotient questionnaire (Baron-Cohen et al., 2001) completed by the patient, and family members, including spouse, when available.
3. A vocational and social history (focusing on the adult years)
4. A mental status exam was performed. From 2003, the ADOS was added to the assessment instruments (used for 38/51 patients).

**Table 1. Characteristics of Subject Groups**

Subjects	Diagnosed ASD Before 18 Normal Range IQ	Diagnosed ASD Before 18, with Intellectual Disability	Diagnosed ASD After 18 Normal Range IQ
	n= 33, M:F = 29:4	n=12, M:F = 8:4	n=34*, M:F =25:9
Mean Age of Diagnosis (SD) Range	12.4 (3.4) 5-17	11 (5.0) 3-17	31.2 (10.4) 19-55
Mean Age at functional assessment (SD) Range	21.3 (4.0) 19-37	21.5 (5.0) 19-30	Function assessed at time of diagnosis

\*One adult diagnosed ASD at 32 of age years had been previously diagnosed with Intellectual Disability.

From this second group, 35 were diagnosed with ASD, and many were found to have a history of concurrent psychiatric disorders, including one patient with Intellectual Disability. The 16 adults found not to be on the Autistic Spectrum all had other Axis I or Axis 2 psychiatric diagnoses.

#### *Evaluation of Adult Adaptive Functioning*

We reviewed the charts of our subjects, using all interview, questionnaire and co-lateral information, and, following the approaches of Cederlund et al., Engstrom et al., and especially Howlin et al., we assigned scores in 5 areas of Adult functioning: Education, Vocation, Independence, Friendships and Intimate relationships. A score of 1 equalled poor functioning, and a score of 5 equalled age appropriate attainment (see Appendix 1). For example, on the Vocation Scale, 1 equalled living on disability pension, and 5 denoted employment at full potential. The group diagnosed prior to age 18 were assessed on the most recent follow-up, while those diagnosed as adults were assessed at the time of initial presentation (see Table 1).

Since a lesser degree of self sufficiency is expected of young adults, particularly those in post secondary education, we adjusted the vocational, educational and independence scales for those subjects 19-to-25 years of age (Appendix 1). We also recorded any history, present or past, of co-morbid psychiatric disorders.

#### **Analysis**

We used Students T Test to compare the outcome

variables between those diagnosed with ASD before 18 years, comparing patients with and without Intellectual Disability. For adults without Intellectual Disability, the group whose ASD had been diagnosed after nineteen were on average 10 years older at time of assessment. In an effort to compare individuals who had similar time to achieve developmentally, we sub-grouped those diagnosed before and after 18 (without ID), comparing subjects whose functioning was assessed before, or after 25, years of age.

#### **Results**

##### *Adaptive Functioning*

##### *Group diagnosed in Childhood*

Comparison of adult outcome within the group of subjects diagnosed with ASD prior to 18 years of age showed significantly poorer functioning for those with co-morbid Intellectual Disability, except in the domain of establishing intimate relationships. Even in the normal IQ group, the mean total score, i.e. the sum of the 5 domains, was relatively low at 12.1 out of a possible 25.

##### *Those with functional assessment performed before age 25 years.*

We next examined results for those with normal range IQ whose adult functional assessment was performed before age twenty-five. This division was in an effort to compare like with like, participants who were more nearly at the same phase of their lives. We compared subjects with ASD diagnosed before (n= 29), or after (n=21),

**Table 2. Adult Functioning for patients diagnosed with ASD as Children & Youth**

Subjects	Normal Range IQ n=33	Intellectual Disability n=12	P value
Adult Functioning (SD)			
Education	2.87 (1.25)	1.33 (0.47)	0.002
Vocation	2.78 (1.53)	1.18 (0.27)	0.008
Independence	3.00 (1.07)	1.58 (0.64)	0.003
Social	2.09 (1.26)	1.08 (0.27)	0.009
Intimate Relationships	1.36 (1.00)	1.08 (0.28)	0.34
Mean Total Score	12.12	6.16	

Adult Functioning 1=Poor 5=Good

**Table 3. Adult Attainment of Higher Functioning Individuals diagnosed with ASD: Those assessed at over 25 years of age**

Mean age at assessment (SD)	Diagnosed before 18 years N= 4	Diagnosed after 18 years N= 21	P value
Adult Functioning	29.5 (4.71)	39.1 (8.65)	
Education	2.25 (1.64)	4.33 (0.89)	0.001
Vocation	1.75 (1.29)	2.95 (1.46)	0.143
Independence	3.00 (1.22)	4.47 (0.66)	0.002
Social Relationships	2.00 (1.73)	2.47 (1.8)	0.469
Intimate Relationships	2.00 (1.73)	2.90 (1.57)	0.308
Total of Means	11.00	17.33	

**Table 4. Co-Morbid Psychiatric Illnesses, Current or Past**

Group	Dx <18, ASD and Intellectual Disability N=12	Dx <18, ASD N=33	Dx >18, ASD N=34
Anxiety Disorders	4 (25%)	9 (27%)	8 (23%)
OCD	1 (8%)	5 (15%)	
Depression	4 (25%)	8 (24%)	15 (44%)
Psychosis (ever)	–	2 (6%)	2 (5%)
Substance Abuse	–	4 (12%)	4 (11%)
Other psychiatric disorders	Tourette's –1 (8%)	ADHD – 8 (24%)	
Tourettes – 2 (6%)	–		
Those without co-morbid psychiatric illness*	5 (40%)	7 (21%)	7 (20%)

\*There was no significant difference in mean adaptive functioning between those patients with or without past or present co-morbid psychiatric illness.

18 years of age. We found that the mean age at functional evaluation was the same (20.1 years) for both groups, and that there were no significant differences in attainment in any of the five domains.

*Those with functional assessment performed after age 25 years.*

Despite dividing the higher functioning subjects according to age of adaptive assessment, in the older group there remained a 10 year difference in age of evaluation between those diagnosed before 18, (n=4, mean age of assessment 29.5yrs) and those diagnosed as adults (n=13, mean age of assessment 39.1yrs.). Those diagnosed as adults had achieved significantly more in the domains of education and independence (see table 3).

Some authors have described a subgroup of 15-27% of adult ASD patients who attained more positive outcomes (Cederlund et al., 2008; Howlin et al., 2004). Defining an arbitrary adaptive score of 20/25 as "Good" for our normal IQ patients, 8 of thirty four (25%) of those diagnosed as adults achieved this level. Only 5 of the thirty three (15%) diagnosed in childhood made the cut-off. (The cut off was consistent with a well, but not superlatively, functioning member of society. It was not normed against a clinical non-ASD sample). None of the Intellectually Disabled ASD subjects scored above 10.

#### *Co-Morbid Mental Illness*

All three groups had a high rate of co-morbid psychiatric illnesses. Depression was particularly frequent in those diagnosed as adults, consistent with other reports (e.g. Howlin, 2000). Anxiety disorders were also prevalent in the higher functioning participants, 25-27%.

#### **Discussion**

It was expected that Intellectual Disability would be associated with poorer outcomes. Additionally, we anticipated that the formation of intimate bonds with a partner would be the most complex challenge that ASD patients face. All three groups of participants had poor mean scores in this domain, although some had in fact found long term relationships.

Anecdotally, about one third of the patients, male and female, had no interest in establishing a sexual relationship, and seemed asexual in their orientation. Some, mostly males, had tried but failed, usually because their self presentation was poor and their approach clumsy. Two males had in late adolescence developed a belief that they were transgender and sought gender reassignment treatment.

With respect to the differences in adult achievement within the group of higher functioning individuals, it should be emphasized that for the sub-group diagnosed

as children or youth assessed before twenty-five, there were no differences from the adult diagnosed group assessed in the same age range. For those evaluated after twenty-five, the superior attainments in employment and independence of those diagnosed as adults might well be due to their having an average of ten years to develop further. It is our observation that many ASD individuals in their 20's are still dealing with the early teenage issues of separation and individuation, establishing academic competence and being secure in their sexual orientation.

For the higher functioning ASD group there were a very wide range of outcomes, from poor to very good, e.g. from an isolated individual living on a disability pension to a married university professor. Very few of the subjects diagnosed as children and none of these assessed as adults had received autism specific interventions such as Applied Behavioral Analysis. Rather, anecdotally, it would appear that the support of dedicated family members, generic learning and behavioral assistance in school, and finding a tolerant workplace and partner variously contributed to a better adjustment in adulthood.

Most of the higher functioning ASD individuals, whether diagnosed before or after 18 years of age, were functioning well below the potential implied by their normal range intellect. Clinically, there seemed to be three principal reasons for this:

Firstly, a combination of social difficulties and sensory sensitivities made negotiating educational, vocational and community settings difficult. Many described feeling overwhelmed and unable to think clearly around other people, and some felt they had been victimized by classmates or co-workers. Some had found a situation that minimized these challenges – e.g. studying online, or a job that was semi-solitary. Others were able to attend a college or university, full or part-time, but were doing better academically than socially.

Secondly, most patients showed significant difficulties in executive functioning, i.e. the motivation, planning and implementation to successfully reach the goals they and their families had for them (Kenworthy et al., 2009). Those who were able to endure within the relatively structured setting of high school often floundered in post secondary education, even with assistance from the Students with Disabilities services.

The third factor, noted for some individuals followed up after being diagnosed with ASD as children, was the protectiveness of their families. When these children began to struggle socially and academically, often after making the transition of high school, their parents withdrew them and tried home schooling. This arrangement usually decreased the structure in their lives and left the initiative for completion of the work more with the student. Given the often poor executive functioning of this group, education often stalled at this point. In addition, their exposure to social situations usually decreased,

making the youth more comfortable, but more isolated. A number of these patients entered their twenties living at home, unemployed and out of school, in contact with the outside world only through their "online" existence. Their parents then began to worry about the fate of the youth when they would no longer be able to care for him or her.

The above possible explanations for most participants performing below their theoretical potentials might warrant a future more systematic study, if information of reasonable reliability was available from the participants and co-lateral sources.

Some parents complained that, at the time of the initial diagnosis, they had received a negative forecast of their child's future functioning that was quite demoralizing. Several parents had set out to prove the "experts" wrong by aggressively interceding for added resources. A few joined organizations that championed the cause of autism as a different, but equally valued, lifestyle in comparison with that of "neurotypical" mainstream populations. Other parents, however, had become pessimistic and protective.

In our clinic, when making the diagnosis of ASD, we answer the usual questions "will my child finish high school, find a job, find a partner?" with a clear "we don't know – some of these children have the potential to achieve those things, but we can't predict any child's future."

## Conclusions

Our findings were generally in agreement with other recent publications in the field, particularly those focusing on outcome for higher functioning individuals (Cederlund et al., 2008; Renty et al., 2006; Engstrom et al., 2003; Howlin, 2000). For the more able subjects, there was a wide range of adult attainment, with a subgroup of 15-25 % living independently, participating full time in post secondary education and/or employed in the general workforce. Those patients with co-morbid ASD and Intellectual Disability conformed to the stereo-typed outcome previously expected all Autistic persons, that of continued low functioning and dependence into adult life.

As in other fields of psychiatry, evolving diagnostic concepts and management approaches give rise to the situation in which the new patients we assess for ASD today will be evaluated differently, understood differently, and treated differently to those seen one or two decades ago, whose outcomes we are now observing. This "moving target" of diagnosis and therapy, together with the very wide range of potentials displayed by our patients, and the shifting societal response to individuals identified as "on the Spectrum", means that we are unable to predict the future experiences and functioning of those we are assessing today. Further evaluation of adult outcomes for children and youth now being diagnosed, especially with respect to the interventions now being funded and applied, will be important in understanding the efficacy of our current efforts.

### Limitations

Our measure of adaptive functioning was elaborated from those used by several other groups of authors. The psychometric properties of these instruments have not been evaluated, and the resulting characterization of patient's outcomes should be considered more Qualitative than Quantitative.

### Acknowledgements/Conflict of Interest

The authors have no financial relationships or conflicts to disclose.

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## Appendix One

### Criteria for Functional Rating of Subjects

#### Education

- Did not graduate from high school
- Graduated from an adapted program in high school
- Graduated from regular high school
- Attended college/university
  - If < 25 years, in college = 5
  - If > 25 years, attending college = 4
- Graduated from college/university

#### Employment

- Disability pension, never employed, not in educational program
- Employed briefly, unemployed now
- Series of jobs, briefly in or out of work now, or in school part-time, no job
- Stable employment or in school full-time, if > 25 years
- Employed at potential or, if < 25 and in school full-time

#### Living Arrangements/Independence

- Lives with parents, needs support in activities of daily living and routine
- Lives with parents, needs some support to manage in community
- Lives with parents, self sufficient managing life otherwise, if > 25 years
- Lives independently, needs some support to manage finances ,etc
- Living independently, manages affairs alone, or, < 25, lives with parents, manages affairs alone

#### Social Relationships (outside the family)

- Isolated, lives in own world, no friends
- Somewhat isolated, has some acquaintances – not necessarily any shared interests
- Some acquaintances around shared interests
- Has one or more friendships – only short term
- Has one or more close and enduring friendships

#### Intimate Relationships

- No partner – ever, no interest
- Some attempt at finding partner, brief relationships, unsatisfactory to subject
- Relationships of a few months or more
- One or more long term (> 6/12) relationships, or divorced
- Married / living common-law, satisfactory to both partners