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Outcomes in Adults with Autism Spectrum Disorders: A Historical Perspective

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Abstract

In this review, we examine the ways in which researchers have defined successful adult outcomes for individuals with autism spectrum disorders, from the first systematic follow-up reports to the present day. The earliest outcome studies used vague and unreliable outcome criteria, and institutionalization was a common marker of poor outcomes. In the past decade, researchers have begun to standardize the measurement of adult outcomes with specific criteria based on friendships, employment, and living arrangements. While nearly all of these studies have agreed that the majority of adults with autism have poor outcomes, evolving concepts of what it means to be an adult could have an impact on outcomes measured. For example, some researchers have suggested that taking into account the person-environment fit could reveal a more optimistic picture of outcomes for these adults. Suggestions for future research are discussed.

Keywords

autism spectrum disorders; follow-up; outcome; adulthood

In 1943, Leo Kanner described a unique condition he called “inborn autistic disturbances of affective contact” in 11 children, all under the age of 12. Twenty-eight years later, Kanner (1971) gave a follow-up account of each of those 11 individuals. He deemed only two cases “success stories,” and one as having reached a “state of limited but positive usefulness” (p. 143). In those cases, the adults were able to live with family members and had communication skills sufficient for engaging in work, social, and community activities. The remaining four that could be reached he called the “worst” cases (67% of the available sample). All of those adults had been institutionalized. After admission to the state hospital, Kanner reported that they seemed to have “lost their luster” (p. 143), becoming unresponsive to psychological testing and having markedly diminished language skills.

Research on outcomes for adults with autism spectrum disorders (ASD) has been conducted using widely varying sample sizes, time of follow-up, populations, and criteria; but nearly all have produced similar results to Kanner's (1971) report. The consensus among most outcome reports is that the majority of individuals with ASD have poor outcomes. “Poor” and “good” outcomes, however, have had a variety of definitions over time, and what it means to be successful in adulthood for individuals with ASD has not always been clear.

The way that researchers have defined and measured adult outcomes for individuals with ASD can be divided into three major eras. From the first systematic follow-up studies in the 1960s and early 1970s into the early 2000s, most of the literature classified adults into outcome categories ranging from *good* to *very poor* based on non-specific criteria developed by Rutter, Greenfeld, & Lockyer (1967). These criteria for success in adulthood were vague, and there were few attempts at establishing reliability within category definitions or between studies. In the next era, Howlin and colleagues operationalized outcome categories based on specific concrete goals of independence with the Overall Outcome Rating (OOR) scales (Howlin, Goode, Hutton, & Rutter, 2004). The use of ordinal scoring scales focused on independent living, friendship, and occupational domains facilitated reliability within and between studies. Finally, some of the most recent outcome studies have integrated a consideration of the fit between individuals and their environment. Through this approach, they take into account the adult's subjective experience relative to objective criteria such as those measured in the OOR scales. This approach has the potential to add dimension and validity to our characterization of outcomes for adults with ASD.

In this review, we summarize key outcome studies that represent each of these three eras. We used a two-prong search process: (1) we searched literature databases (e.g., Psycinfo) to identify studies on adult outcomes for individuals with ASD; and (2) we conducted backwards citation searches of recent reviews focused on outcomes of adults with ASD (Gillespie-Lynch et al., 2011; Howlin, 2005; Howlin & Moss, in press; Taylor, 2009). Studies were included if they (1) systematically followed children through adolescence and adulthood; and (2) attempted to integrate outcomes into an overall summary or index (as opposed to describing specific psychiatric, social, or autistic symptom outcomes only). Note that because many of the samples described in these studies were diagnosed prior to the introduction of criteria for Autism Spectrum Disorders in the DSM-IV (American Psychiatric Association, 1994), we accordingly refer to the samples as they were diagnosed.

Vague and Unreliable Criteria: Mid 1900s to early 2000s

The earliest criteria for outcomes in adults with autism were vague and potentially unreliable. Because autism (then used interchangeably with “infantile autism” and “infantile psychosis”) was a relatively newly defined disorder, researchers were just beginning to explore the overall picture of outcomes in the autism population, and they lacked a reliable standard. While some researchers had written descriptive accounts of adults with autism, Rutter, Greenfeld, and Lockyer (1967) were the first to explicitly define criteria for adult outcomes, using the labels *good*, *fair*, *poor*, and *very poor*. According to Rutter et al. (1967), one with a *good* outcome “was leading a normal or near-normal social life and was functioning satisfactorily at school or at work;” one with a *fair* outcome “was making social and educational progress in spite of significant, even marked, abnormalities in behavior or interpersonal relationships;” someone with a *poor* outcome “was severely handicapped and unable to lead an independent life, but there was still some measure of social adjustment and it was felt some potential for social progress remained;” and someone with a *very poor* outcome “was unable to lead any kind of independent existence.”

These category definitions are inherently vague, and only one study to our knowledge has reported on the reliability of this index (Lotter, 1974). Rutter's phrases “normal or near-normal social life” and “potential for social progress” require a great deal of investigator interpretation. However, Rutter's criteria did aid in more meaningful comparisons by providing an element of standardization to outcome studies that was lacking previously (Lotter, 1978).

Applying these criteria to adults with autism revealed that their outcomes were generally poor. In a clinical sample of 63 individuals with infantile psychosis, Rutter and his colleagues (1967) found that only 9 had a *good* outcome (14%). Over half (61%) had *poor* or *very poor* outcomes, and of those 16 and older, 53% were in a long-stay hospital placement. Subsequent follow-ups using Rutter et al.'s criteria confirmed their pessimistic results. Lotter (1974) conducted an outcome study on a sample of 32 individuals, ages 16 to 18 years in Middlesex, UK. He found that 62% of the sample fell into the *poor* or *very poor* categories. 48% were living in an institution, and only 4% were employed. Gillberg and Steffenberg (1987) reported on the outcomes of 46 individuals over the age of 16 and diagnosed with infantile autism or autistic-like conditions in Goteborg, Sweden. Adding to Rutter's criteria, they created an intermediate category between *fair* and *poor* that they called *restricted but acceptable* outcome. They defined individuals in this category as having "characteristics of the poor group but who have nevertheless been accepted by a group of peers or personnel to such an extent that their handicaps are not so readily obvious" (p. 279). Similar to Lotter's (1974) and Rutter et al.'s (1967) findings, Gillberg and Steffenberg (1987) found 59% to have a *poor* or *very poor* outcome, 43% living in an institution, and 4% employed.

Two studies using Rutter's criteria found slightly more optimistic results in overall social functioning (Engstrom, Ekstrom, & Emilsson, 2003; Larsen & Mouridsen, 1997). Larsen & Mouridsen (1997) found that just under half (44%) of their sample had *poor* or *very poor* outcomes, and 22% were employed. The sample consisted of 18 individuals originally diagnosed as "psychotic" in childhood. Diagnoses of Asperger's Syndrome (n=9) and childhood autism (n=9) were made based on the individuals' psychiatric records. 78% had average or near average IQ. The authors note that these results should be interpreted with caution due to the small sample size, unreliable diagnostic procedures, and high IQ levels. When focusing only on the 9 individuals with diagnoses of childhood autism, a much larger proportion had *poor* or *very poor* outcomes (67%), resembling previous findings. Engstrom et al. (2003) also described outcomes in a small sample (N=16) of adults diagnosed with Asperger's Syndrome and high functioning autism. All of these individuals had an IQ of 70 or greater. The majority of these adults (75%) had *fair* outcomes, and none had a *very poor* outcome. As in Larsen & Mouridsen (1997), the cognitive functioning of this group is not representative of all of those diagnosed with ASD.

Billstedt, Gillberg, & Gillberg (2005) defined five overall outcome categories based on Rutter's criteria. Qualifications for each category included various employment and residential situations, as well as the presence/absence of comorbid psychiatric disorders in the category definitions. While moving towards specificity, the investigators note that these criteria still lack studies of reliability. In the largest longitudinal outcome study up to that time with a sample of 120 individuals with autistic disorder and autistic-like conditions in Goteborg, Sweden, they found that 78% of their sample had a *poor* or *very poor* outcome, and none had a *good* outcome. This investigative team conducted a later follow-up study of 82 males with autism in Sweden, using the same definitions, and found nearly identical results (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008). The results of these studies, which were based on larger and older samples and more specific criteria than previous studies, indicated an even greater portion of adults with poor outcomes than expected.

Some studies employed their own criteria for overall outcomes, with varying results. In a Japanese follow-up study (Kobayashi, Murata, & Yoshinaga, 1992), outcome criteria included a measure of language development from *very good* to *very poor* and a measure of overall adaptive functioning from *very good* to *very poor*. These two scales, like in Billstedt, Gillberg, & Gillberg (2005), were more specific than Rutter's criteria, but still required

some subjective interpretation. For example, on the Present Language Developmental Level (PLDL) scale they defined *very good* as being able to “communicate freely with a rich vocabulary” and on the Present Adaptive Level (PAL) scale as someone who is “employed (or goes to school) and adapts satisfactorily, his/her ability to work is highly estimated” (Kobayashi et al., 1992, p. 400). While the PLDL scale had a much lower percentage in the *poor* or *very poor* groups (21%) than in previous studies (with the most frequent category being 32%, *fair*), the proportion of *poor* or *very poor* outcomes on the PAL was closer to previous findings at 46%. Also similar to previous findings, 40% of the individuals were living in a “special unit” or psychiatric hospital. However, in contrast to most previous studies, 21% were employed. The authors attributed their high employment percentages to a high demand for labor in Japan’s thriving economy, rather than study differences such as a broader definition of employment (Kobayashi et al., 1996).

Despite general agreements in outcome findings, these early studies lacked a reliable and specific definition of success in adulthood for individuals with ASD. Although they began to adopt a more standardized approach, appraisals of overall functioning in these studies still require considerable interpretation. For example, what exactly does Rutter et al. (1967) mean by a “normal or near-normal” social life? The answer may differ significantly among researchers, and their methods rarely describe attempts at inter-rater reliability. In addition, criteria varied from study to study. Gillberg and Steffenberg (1987) added a fifth category to Rutter’s original four; Billstedt et al. (2005) added specific qualifications to Rutter’s definitions; and Kobayashi and colleagues (1992) used completely different scales based on language and adaptive functioning. According to Howlin (2005), these evaluative classifications are “based on variable criteria, and these are often poorly defined and rarely backed up by assessments of reliability or validity” (p. 203).

Move Toward Specificity and Reliability: Early 2000s to Present Day

Follow-up studies published in the past decade have moved toward implementing more rigorous and quantifiable outcome criteria. These criteria are made up of empirical definitions of optimal social functioning such as having meaningful friendships, being competitively employed, and living independently. This focus on practical independence in adult life almost certainly reflects the deinstitutionalization movement for adults with autism and other intellectual disabilities. Kanner’s (1971) cases of profound social deterioration following admission to an institutional setting were once the norm. However, with institutions across North America closing their doors and more adults with ASD living in the community, researchers sought to describe whether they were thriving in the community. Success in adulthood no longer means avoiding institutionalization, but achieving practical independence in relationships, employment, and living arrangements.

In addition to identifying specific goals of independent functioning in the community, another shift has been an increased emphasis on reliability among outcome measurements. All of the studies in this era used nominal scales of independence in various domains that combine to a composite outcome score. This method facilitates reliability evaluations within follow-ups as well as replicability between studies. This era’s emphasis on reliability is demonstrated in two ways. First, while only 14% of the studies described in the previous section reported any type of reliability, over half of the following studies attempted some kind of inter-rater reliability to ensure that different members of the study teams coded outcome categories in the same way. Also, the wider use of specific, standardized definitions of outcome categories (*very good* to *very poor*) increased the reliability of comparisons made between outcome studies.

Perhaps the first study to delineate and apply a numerical index of overall functioning was conducted by Howlin, Mawhood, and Rutter (2000). The four criteria they used to describe overall outcomes in adults with autism were autistic behaviors, language, friendship, and independence. Autistic behaviors were rated on a scale of 0 to 6, and language, friendship, and independence were each rated on a scale of 0 to 2 with specific criteria for each score. A composite score of 0–1 describes an outcome of normal / near normal social functioning in adulthood. Across domains, scores of 0 (normal / near normal) describe an adult who has minimal or no problems with stereotyped/repetitive behaviors, competence in communication and relationships, and independence in daily functioning. Their results indicated that 74% of the adults with autism had a *poor* or *very poor* outcome according to this scale.

The rest of the studies in this category assessed overall outcomes with variations of the Overall Outcome Rating (OOR) scale (Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004). This global rating, first proposed by Howlin and colleagues (2004), is the sum of scores from three domains – work, friendship, and independent living – with 0 denoting the best outcomes. Work ratings range from 0 to 3 (employed to unemployed); friendship ratings also range from 0 to 3 (close friendship to no friends); and independence ratings range from 0 to 5 (living independently to institutionalization). These ratings are combined into 5 overall categories: score of 0–2 = *very good* (i.e., achieving a high level of independence, having some friends and a job); score of 3–4 = *good* (i.e. generally in work but requiring some degree of support in daily living; some friends / acquaintances); score of 5–7 = *fair* (i.e. has some degree of independence, and although requires support and supervision does not need specialist residential provision; no close friends but some acquaintances); score of 8–10 = *poor* (i.e. requiring special residential provision/ high level of support; no friends outside of residence); and score of 11 = *very poor* (i.e. needing high-level hospital care, no friends; no autonomy).

Using these more rigorous scoring scales, studies were still generally in agreement with each other as well as with earlier studies. Howlin and colleagues (2004) collected outcome data on a sample of 68 adults with an IQ of at least 50, diagnosed with autistic disorder between 1959 and 1979. At the time of follow-up, they found that only 4% of adults lived independently, 13% were independently employed, and just under one-half had significant friendships. Overall, the results were similar to findings in previous literature, with 57% of adults demonstrating a *poor* to *very poor* outcome. Eaves and Ho (2008) assigned outcome categories to a sample of 48 young adults with autism spectrum disorders (ASD) in British Columbia. Their data indicated slightly more optimistic results than previous studies, with just less than one-half having *poor* outcomes and none having a *very poor* outcome. Over 50% were still residing with their parents, and 35% were in some kind of supported living arrangement such as a group home or foster care. Only two young adults were independently employed, but about one-half had had some kind of volunteer or sheltered work experience. Note that while the authors used the term ASD, their sample is comparable to those in previous studies in that they were diagnosed mostly with infantile autism prior to the widening of the diagnostic criteria.

A few studies have applied a slightly modified version of the OOR scale (Eaves & Ho, 2008; Howlin et al., 2004) to their samples. Gillespie-Lynch et al. (2011) found results similar to Eaves and Ho (2008), with 50% of their sample having a *poor* outcome, but none having a *very poor* outcome. Esbensen, Bishop, Seltzer, Greenberg, & Taylor (2010) examined a sample of 70 adults with ASD and comorbid intellectual disability, finding that 61% fell into the two lowest independence categories (comparable to the *poor* and *very poor* OOR categories). Farley et al. (2009) conducted a follow-up with 41 adults with autism who had an IQ of 70 or greater to see if outcomes would be better for individuals with average or

near-average cognitive abilities. Over one-half of the participants were found to be independently employed, a much higher number than in any previous study. A majority of the adults were also involved in social activities, ranging from church activities to martial arts classes. However, 56% of the sample was still living at home with parents. Overall, these adults – who had higher cognitive functioning than most previous samples – had more optimistic outcomes. About one-half had *good* or *very good* outcomes, 34% had *fair* outcomes, 17% had *poor* outcomes, and none had a *very poor* outcome. Farley et al. attributed these results in part to their sample’s cultural context. Nearly all of the participants were members of the Church of Jesus Christ of Latter Day Saints (LDS Church), which places a strong emphasis on inclusion and community. As a result, adults in this sample may have been more likely to benefit from the support of religious and community activities throughout their lives than adults in cultural contexts that lack this emphasis on inclusion.

Integrating Person and Environment

Despite the positive shift from vague and unreliable criteria to more specific, observable goals of independence, a few researchers have called for further reevaluation of outcome measures for adults with ASD. One such suggestion is for the addition of a broader and more dynamic framework in measuring outcome success, which takes into account the fit between the person and his or her environment (Ruble & Dalrymple, 1996). When transition to adulthood became a federal initiative in the mid -1980s (Will, 1984), many criticized the narrowness of its goal of employment for adults with disabilities. Although these goals were later expanded to include a variety of positive post-school activities, Halpern (1993) advocated adding more dimension by considering four dichotomies: (1) subjective versus objective perspectives, (2) personal choice versus universal entitlements, (3) personal needs versus social expectations, and (4) personal intervention versus social policy development.

At the basis of these four dichotomies is the relationship between the specific criteria outlined in the OOR scales and the individual’s subjective experience in his or her environment. With objective (3), for example, Halpern (1993) suggested that it is important not only to meet societal norms and expectations of adulthood, but also for the individual and his or her family to feel that personal needs and goals have been achieved. To illustrate this point, consider one individual who has achieved OOR scale criteria such as independent living and competitive employment, but does not have adequate support in his or her living arrangement and dislikes his or her job. Classifying this as a *very good* outcome may not reveal a complete picture. Likewise, if a particular individual resides in a group home and has reached optimal levels of objective independence with the support of that setting, that individual and his or her family may disagree with the classification of only a *fair* outcome. By comparing personal needs to social expectations, the person-environment relationship tells a more dynamic and complete story of outcomes in adulthood.

Along these lines, Billstedt, Gillberg, and Gillberg (2011) reevaluated the sample from their 2005 study, adding measures of the relationship between the person and his/her environment. For their first measure, called “Autism-Friendly Environment”, they created a global assessment scale from (1) *very good* to (5) *very poor*. The item quality categories were: (a) staff and caregivers have specific “autism knowledge;” (b) applied structured education implemented; (c) individual specific treatment/training plan for the person with autism implemented; (d) occupation or everyday life activity corresponding to his/her level of capacity; and (e) overall quality of life level. A second measure, “Parent/Carer-Rating of Individual’s Well-Being”, simply asked the parent or caregiver to rate the individual’s well-being in his or her residential setting on a 1 to 5 scale, *very good* to *very poor*.

Results from these person-environment measures revealed dramatically different results compared with the 2005 results that were based on friendships, education, work, and living

arrangements only. Whereas 78% of the sample fell into the *poor* or *very poor* category with the 2005 criteria (Billstedt, Gillberg, & Gillberg, 2005), 62% were in the *good* or *very good* category for “Autism-Friendly Environment.” Moreover, 91% of parents/caregivers rated the residential well-being of their child in the *good* or *very good* categories. Residential statuses included living in the parents’ home (38%) or community-based group homes (49%), with a few in apartments with or without support. Few were competitively employed, and while many parents/caregivers expressed continued concern over meaningful occupation for their son or daughter, over half still rated “occupation at level of capacity” as *good* or *very good*. Considering this research group’s 2005 study had the highest percentage of individuals with *poor* or *very poor* outcomes, these high person-environment ratings were especially surprising. Furthermore, they reveal the need to balance criteria based on objective societal norms with criteria that reveal the individual’s subjective perspective of his or her success. Taking both of these into account will reveal a more complete and multi-dimensional picture of adult outcomes for individuals with ASD.

Summary and Directions for Future Research

Follow-up literature focused on individuals with autism has attempted to define what it means to have a successful outcome in adulthood. However, changing criteria make comparisons of prognosis through the years a difficult task. The earliest studies used vague and unreliable scales of outcome, based on criteria first defined by Rutter et al. in 1967 for individuals with infantile psychosis. Studies conducted in the past decade mark a focus on more rigorous and empirical measures based on independence in residential placement, employment, and relationships. However, criteria still varies slightly from study to study. More subjective person-environment fit perspectives have been largely absent in the literature until very recently, even though suggestions for using this framework when evaluating outcomes for adults with ASD were made as far back as the early 1990s and may reveal a more dynamic picture of outcomes.

Representativeness of the samples in the extant literature

It is important to note that the extant outcome literature may not be representative of the population diagnosed with ASD today. One reason is the recent expansion of autism diagnostic criteria to include individuals with broader ranges of functioning. All of the samples described in this review were diagnosed prior to the DSM-IV (American Psychiatric Association, 1994) criteria that widened the autism diagnosis beyond autistic disorder to include higher functioning forms like High Functioning Autism and Asperger’s Syndrome. While a few of these studies did employ a minimum IQ (Farley et al., 2009; Howlin et al., 2004), most described samples with classic autistic disorder, not ASD. A study representing a population on the full spectrum may find more positive outcomes.

On the other hand, sampling biases in studies of adults with ASD likely leave many individuals in lower socioeconomic groups underrepresented (Shattuck et al., in press). While two of the reviewed studies are considered to be reasonably representative of all children with autism in the Goteborg region of Sweden (Gillberg & Steffenberg, 1987; Billstedt et al., 2005), the vast majority are samples of convenience. As lower SES adults with ASD are likely to have less access to services (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011), including these groups would potentially result in poorer outcomes than what is typically reported (Shattuck et al., in press; Taylor & Seltzer, 2010).

Reasons to expect that outcomes may improve in the future

While it is discouraging that the percentage of adults with ASD with poor outcomes has essentially stayed the same over time, there is hope for more optimistic findings in the

future. For example, advancements in early intervention therapies may result in more positive outcomes in adulthood (Ballaban-Gil, Rapin, Tuchman, & Shinnar, 1996). Children receiving the benefits of intensive early intervention are just now entering adulthood, and the long-term effects of these interventions have yet to be determined.

Another reason we may expect more positive outcomes in the future is the changing concept of adulthood. Criteria like the OOR scales reflect a focus in the sociological literature on the achievement of certain “developmental tasks” as criteria for success in adulthood (Fussell & Furstenberg, 2005). These tasks include milestones like leaving home, finishing school, finding a job, getting married, and starting a family. However, with changing economic and social conditions, these achievements are no longer the norm in the general population of young adults (Furstenberg, Raumbaut, & Settersten, 2005). While adults with ASD have generally poor outcomes based on this definition of success in adulthood, alternative perspectives may allow more positive outcomes to be measured.

A more recent theory of adulthood focuses less on these specific criteria and more on the individual’s concept of adulthood. The Emerging Adulthood Theory (Arnett, 2000) posits that the transition period between adolescence and adulthood is characterized by identity exploration and individualism. In contrast to the traditional developmental tasks perspective, “emerging adults” were more likely to say that being responsible for oneself, establishing a personal value system, relating to parents as adults, and becoming financially independent were markers of becoming an adult (Arnett, 2001). The National Longitudinal Transition Study-2 (NLTS2) found that adults with ASD are less likely than the general population to have their own checking account or credit card, indicating that they may also have less financial independence (Newman, et al., 2011). Other than this example, the Emerging Adulthood perspective has not yet been considered when measuring outcomes for the ASD population, so further research is needed to determine its effect on outcome results.

While Emerging Adulthood outcomes for individuals with ASD are largely undocumented, a few researchers have looked at outcomes through the person-environment fit perspective. This conception of adulthood could allow populations with more severe limitations to attain more positive outcomes. Many studies have shown that low IQ and early language deficits are the two strongest predictors of poor outcomes (e.g., Gillberg & Steffenburg, 1987; Lotter, 1974). While these variables confound objective independence criteria, they are likely less related to achieving a good fit between the person and his or her environment. Thus, an individual who enjoys living in a group home and contributing to the community through volunteer work would likely attain a more positive outcome through the incorporation of subjective measures than by objective indices of independence alone. Outcome criteria based on both independence and the way in which the individual experiences a particular level of independence would take into account whether the outcome is congruent with his or her desires and functional abilities (Taylor, 2009).

Potential implications for intervention and services

Furthermore, studies examining predictors of positive outcomes among adults with ASD should incorporate factors that are amenable to intervention. Language and IQ, which impact independence outcomes for adults with autism, are more or less unaffected by intervention (Ruble & Dalrymple, 1996). Ruble & Dalrymple (1996) suggest that focusing on feasible adjustments to the environment rather than intervention directed at the level of the individual has significant potential to improve outcomes. From this perspective, the extant research may suggest promising environmental variables for future study. For example, Billstedt et al. (2011) found that the only variable correlated with their person-environment measures was daytime recreational activities. In addition, Farley et al. (2009) suggested that the support of religious congregations through community inclusion

contributed to their sample having more positive independence outcomes than in previous research. In both of these studies, the authors highlighted a possible target for intervention in the community (increasing daytime recreational activities or community inclusion). Studies that examine malleable predictors of both subjective and objective outcomes for adults with ASD have the greatest potential to impact services that will improve these outcomes in the future.

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References

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4. 1994.
- Arnett J. Emerging adulthood: A theory of development from the late teens through the early twenties. *American Psychologist*. 2000; 55:469–480. [PubMed: 10842426]
- Arnett J. Conceptions of the transition to adulthood: Perspectives from adolescence through midlife. *Journal of Adult Development*. 2001; 8:133–143.
- Ballaban-Gil K, Rapin I, Tuchman R, Shinnar S. Longitudinal examination of the behavioral, language, and social changes in a population of adolescents and young adults with autistic disorder. *Pediatric Neurology*. 1996; 15(3):217–223. [PubMed: 8916159]
- Billstedt E, Gillberg C, Gillberg C. Autism after adolescence: Population-based 13-to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*. 2005; 35(3):351–360. [PubMed: 16119476]
- Billstedt E, Gillberg IC, Gillberg C. Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism*. 2011; 15(1):7–20. [PubMed: 20923888]
- Cederlund M, Hagberg B, Billstedt E, Gillberg IC, Gillberg C. Asperger syndrome and autism: A comparative longitudinal follow-up study more than 5 years after original diagnosis. *Journal of Autism and Developmental Disorders*. 2008; 38:72–85. [PubMed: 17340200]
- Eaves LC, Ho HH. Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2008; 38(4):739–747. [PubMed: 17764027]
- Engstrom I, Ekstrom L, Emilsson B. Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. *Autism*. 2003; 7:99–110. [PubMed: 12638767]
- Esbensen AJ, Bishop S, Seltzer MM, Greenberg JS, Taylor JL. Comparisons between individuals with autism spectrum disorders and individuals with down syndrome in adulthood. *American Journal on Intellectual and Developmental Disabilities*. 2010; 115(4):277–290.
- Farley MA, McMahon WM, Fombonne E, Jenson WR, Miller J, Gardner M, Coon H. Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*. 2009; 2(2):109–118. [PubMed: 19455645]
- Furstenberg, FF.; Raumbaut, RG.; Settersten, RA. On the frontier of adulthood: Emerging themes and new directions. In: Settersten, RA.; Furstenberg, FF.; Rumbaut, RG., editors. *On the frontier of adulthood: Theory, research, and public policy*. Chicago: University of Chicago Press; 2005. p. 3-29.
- Fussell, E.; Furstenberg, FF. The transition to adulthood during the twentieth century. In: Settersten, RA.; Fursteberg, FF.; Rumbaut, RG., editors. *On the frontier of adulthood: Theory, research and public policy*. Chicago: University of Chicago Press; 2005. p. 29-75.
- Gillberg C, Steffenburg S. Outcome and prognostic factors in infantile autism and similar conditions: A population-based study of 46 cases followed through puberty. *Journal of Autism and Developmental Disorders*. 1987; 17(2):273–287. [PubMed: 3610999]
- Gillespie-Lynch K, Sepeta L, Wang Y, Marshall S, Gomez L, Sigman M, Hutman T. Early childhood predictors of the social competence of adults with autism. *Journal of Autism and Developmental Disorders*. 2011.1007/s10803-011-1222-0

- Halpern AS. Quality of life as a conceptual framework for evaluating transition outcomes. *Exceptional Children*. 1993; 59(6):486–498.
- Howlin, P. Outcomes in autism spectrum disorders. In: Volkmar, FR.; Paul, R.; Klin, A.; Cohen, D., editors. *Handbook of autism and pervasive developmental disorders*. 3. Vol. 1. Hoboken, NJ: Wiley and Sons; 2005. p. 201-220.
- Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*. 2004; 45(2):212–229. [PubMed: 14982237]
- Howlin P, Mawhood L, Rutter M. Autism and developmental receptive language disorder – A follow-up comparison in early adult life. II: Social, behavioural, and psychiatric outcomes. *Journal of Child Psychology and Psychiatry*. 2000; 41:561–578. [PubMed: 10946749]
- Howlin P, Moss P. Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*. in press.
- Kanner L. Autistic disturbances of affective contact. *Nervous Child*. 1943; 2:217–250.
- Kanner L. Follow-up study of eleven autistic children originally reported in 1943. *Journal of Autism and Childhood Schizophrenia*. 1971; 1(2):119–145. [PubMed: 5172388]
- Kobayashi R, Murata T, Yoshinaga K. A follow-up study of 201 children with autism in Kyushu and Yamaguchi areas, Japan. *Journal of Autism and Developmental Disorders*. 1992; 22(3):395–411. [PubMed: 1383189]
- Larsen FW, Mouridsen SE. The outcome in children with childhood autism and Asperger syndrome originally diagnosed as psychotic. A 30-year follow-up study of subjects hospitalized as children. *European Child and Adolescent Psychiatry*. 1997; 6:181–190. [PubMed: 9442996]
- Lotter V. Social adjustment and placement of autistic children in Middlesex: A follow-up study. *Journal of Autism and Childhood Schizophrenia*. 1974; 4:11–32. [PubMed: 4406453]
- Lotter, V. Follow-up studies. In: Rutter, M.; Schopler, E., editors. *Autism: A reappraisal of concepts and treatment*. New York: Plenum Press; 1978. p. 475-495.
- Newman, L.; Wagner, M.; Knokey, A.; Marder, C.; Nagle, K.; Shaver, D.; Wei, X.; Cameto, R.; Contreras, E.; Ferguson, K.; Greene, S.; Schwarting, M. The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2011–3005). Menlo Park, CA: SRI International; 2011.
- Ruble L, Dalrymple N. An alternative view of outcome in autism. *Focus on Autism and Other Developmental Disabilities*. 1996; 11:3–14.
- Rutter M, Greenfield D, Lockyer L. A five to fifteen year follow-up study of infantile psychosis: II. Social and behavioural outcome. *The British Journal of Psychiatry*. 1967; 113:1183–1199. [PubMed: 6075452]
- Shattuck P, Roux A, Hudson L, Taylor JL, Maenner M, Trani J. Services for adults with an Autism Spectrum Disorder. *Canadian Journal of Psychiatry*. in press.
- Shattuck PT, Wagner M, Narendorf S, Sterzing P, Hensley M. Post-high school service use among young adults with an autism spectrum disorder. *Archives of Pediatric and Adolescent Medicine*. 2011; 165:141–146.
- Taylor JL. The transition out of high school and into adulthood for individuals with autism and for their families. *International Review of Research in Mental Retardation*. 2009; 38:1–32.
- Taylor JL, Seltzer MM. Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders*. 2010; 40:1431–1446. [PubMed: 20361245]
- Will, M. OSERS programming for the transition of youth with disabilities: Bridges from school to working life. Washington, DC: Office of Special Education and Rehabilitative Services; 1984.

Table 1

Selected Outcome Studies of Adults with Autism

Study	Sample	Criteria for Overall Outcome	Overall Outcome Results	Other results
Rutter, Greenfield, & Lockyer, 1967	63 individuals with an average age of 16 Infantile psychosis	Good = normal or near-normal social life and functioning satisfactorily at school or work; Fair = making social and educational progress despite social abnormalities; Poor = severely handicapped, but some potential for social progress; Very poor = unable to lead any kind of independent existence	Good: 14% Fair: 25% Poor: 13% Very poor: 48%	Employed: 5% Institution: 53% (for those 16 years and older)
Lotter, 1974	32 individuals ages 16–18 at follow up in Middlesex, UK Autism	Rutter's criteria	Good: 14%; Fair: 24%; Poor: 14%; Very poor: 48%	Employed: 4%; Institution: 48%
Gillberg & Steffenburg, 1987	46 individuals ages 16–23 in Goteborg, Sweden Infantile autism and other childhood psychoses	Rutter's criteria, plus Restricted but Acceptable category = characteristics of poor group but who have nevertheless been accepted by a group of peers or personnel to such an extent that their handicaps are not so readily obvious	Good: 4%; Fair: 13%; Restricted but acceptable: 22%; Poor: 44%; Very poor: 15%	Employed: 4% Institution: 44%
Larsen & Mouridsen, 1997	18 adults in Denmark, average age 36 years Asperger's Syndrome and childhood autism	Rutter's criteria	Good: 28% Fair: 28% Poor: 16% Very poor: 28%	Employed: 22% Institution: 56%
Engstrom, Ekstrom, & Emilsson, 2003	16 adults over the age of 18 with an IQ > 70 in the Orebro county of Sweden High functioning autism and Asperger's Syndrome	Rutter's criteria	Good: 12% Fair: 75% Poor: 12% Very poor: none	Independent employment: 6% Living independently: 6% Living in own home with support: 50%
Billstedt, Gillberg, & Gillberg, 2005	120 individuals ages 17–40 in Goteborg Sweden Autistic disorder and atypical autism	Good = (a) being employed or in higher education and (b) if over the age of 23 years, living independently, if 22 years or younger, having 2 or more friends/a steady relationship; Fair = either (a) or (b) under Good outcome; Restricted but acceptable = neither (a) nor (b) under Good outcome, and not meeting criteria for a major psychiatric disorder other than autistic disorder or another autism spectrum disorder; Poor = obvious severe handicap, no independent social progress, some clear verbal or non-verbal communicative skills; Very poor = obvious severe handicap, unable to lead any kind of independent existence, no clear verbal or non-verbal communication	Good: none Fair: 8% Restricted but acceptable: 13% Poor: 21% Very poor: 57%	Living independently: 3%;
Cedertund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008	70 males in Goteborg, Sweden ages 16–36 Autistic disorder	Billstedt, Gillberg, & Gillberg, 2005 criteria	Good: none Fair: 7% Restricted: 12% Poor: 20% Very poor: 56%	Ordinary job: 1% Living independently: 8% (for those 23 years and older)
Kobayashi, Murata, & Yoshinaga, 1992	201 individuals ages 18–33 in Japan Autism	(1) Language Development: Very good = can communicate freely with a rich vocabulary; Good = can communicate, but unnaturally and sometimes inappropriately; Fair = can understand others in daily life, but	(1) Language Development – Very good: 16% Good: 31%	Employed: 21% Lives in a special care unit: 38% Hospital: 2%

Study	Sample	Criteria for Overall Outcome	Overall Outcome Results	Other results
Howlin, Mawhood, & Rutter, 2000	19 adult males age 21 to 26 years Autism	cannot communicate verbally; Poor = vocalizes echolalic speech mostly in single words; Very poor = vocalizes "words" of no meaning, or does not talk; (2) Adaptive Functioning: Very good = employed (or goes to school) and adapts satisfactorily; Good = employed (or goes to school), lives a normal life almost independently; Fair = behaves a little inappropriately but lives a daily life at home, or not employed but lives a daily life with a little aid; Poor = has poor social skills, cannot adapt socially, always needs much aid	Fair: 32% Poor: 9% Very poor: 12%; (2) Adaptive Functioning – Very good: 11% Good: 16%; Fair: 27%; Poor: 23%; Very poor: 23%	Never competitively employed: 74% Living independently: 16% No friends with shared interests: 47%
Howlin, Goode, Hutton, & Rutter, 2004	68 adults ages 21–48 with an IQ > 50 in London Autism	Composite Rating: Autistic type, stereotyped and repetitive behaviors (none/minimal problems to severe problems) = 0–6; Language (sentences with mature grammar, understands 2–3 step instructions, conversation flows with others, and able to build on other person's dialogue to none of those = 0–2; Friendship (normal friendships with people own age and sharing activities to no friends) = 0–2; Independence (fully independent in self-care activities to little or no independence) = 0–2 Composite score: Near normal functioning = 0–1; Moderate difficulties = 2–4; Considerable levels of difficulties = 5–8 Overall Outcome Rating: Work (employed to unemployed) = 0–3 points; Friendship (>1 close friend to no friends) = 0–3 points; Independence (living independently to in hospital) = 0–5 points Composite Score - Very good = 0–2 points; through Very poor = 11 points Very good = high level of independence; Good = generally in work but requiring some degree of support in daily living; Fair = some degree of independence, and although requires support and supervision does not need specialist residential provision; Poor = requiring special residential provision / high level of support; Very poor = needing high-level hospital care	Very good: 12%; Good: 11%; Fair: 19%; Poor: 46%; Very poor: 12%	Employed: 34%; Independently employed: 13%; Living independently: 5%; Long stay hospital: 13%;
Eaves & Ho, 2008	48 individuals born from 1974–1984 Autism	Overall Outcome Rating (Howlin et al., 2004)	Very good: 4% Good: 17% Fair: 32% Poor: 46% Very poor: none	Independently employed: 4% Living independently: 8% Close friendship(s): 33%
Gillespie-Lynch et al., 2011	20 individuals diagnosed from late 1970s to early 1980s Autism	Modification of Overall Outcome Rating (Eaves & Ho, 2008; Howlin et al., 2004) Very good = residential and employment independence as well as some friendships; Good = either paid or voluntary employment with some degree of support in daily living and some friendships or acquaintances; Fair = some supported independence and acquaintances but no close friendships; Poor = requires a high level of support and has few social contacts; Very poor = living in a hospital	Very good: 20% Good: 10% Fair: 20% Poor: 50% Very poor: none	Living independently: 15% Full-time employment: 20%
Esbensen, Bishop, Seltzer, Greenberg, & Taylor, 2010	70 adults with comorbid ID, ages 22 years and older Autism spectrum disorder	Modification of Overall Outcome Rating (Eaves & Ho, 2008; Howlin et al., 2004) Residential independence (hospital/institution to living independently) = 0–4; Social contact with friends (never visiting with friends or seeing them less than yearly to seeing friends more than once per week) = 0–4; Vocational independence (volunteer work or no formal day activity to competitive employment) = 0–4	Very high: 2% High: 9% Moderate: 28% Low: 45% Very low: 16%	

Study	Sample	Criteria for Overall Outcome	Overall Outcome Results	Other results
Farley, et al., 2009	41 individuals in Utah within near-average or average range of cognitive functioning Autistic disorder	<p>Composite score: 0-2 = very low independence; 3-5 = low independence; 6-8 = moderate independence; 9-11 = high independence; 12 = very high independence</p> <p>Modification of Overall Outcome Rating (Eaves & Ho, 2008; Howlin et al., 2004) Very good = paid employment without any extra supports to perform duties, existence of important social relationships, and a high level of independence in daily life; Good = generally high level of independence in work and home life with some extra support, at least one friendship or some acquaintances; Fair = need for regular support in work or home life but no need for a special residential facility; Poor = need for very high level of support, such as that provided through a special residential facility and day programming for people with developmental disabilities; Very poor = need for a high level of care in a hospital setting with no autonomy, no friendships</p>	Very good: 24% Good: 24% Fair: 34% Poor: 17% Very poor: none	Living independently: 12% Have a driver's license: 27% Full-time employment: 27%
Billstedt, Gillberg, & Gillberg, 2011	108 of 120 individuals from the 2005 sample Autistic disorder and atypical autism	<p>(1) Autism-Friendly Environment (scale of 1-5, very good to very poor, for each category): (a) staff and caregivers have specific autism knowledge, (b) applied structured education implemented, (c) individual specific treatment/training plan for the person with autism implemented, (d) occupation or everyday life activity corresponding to his/her level of capacity, (e) overall quality of life</p> <p>(2) Parent/Carer Rating of Individual's Well-Being in the residential setting (scale of 1-5, very good to very poor)</p>	(1) Mean category percentages – Very good: 20% Good: 51% Fair: 13% Poor: 14% Very poor: 1% (2) Very good: 61% Good: 30% Fair: 5% Poor: 2% Very poor: 2%	Living independently: 4% ; No daytime occupation: 18%