Outcomes in adults with autism spectrum disorders: a historical perspective
Natalie A. Henninger and Julie Lounds Taylor
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What is This?
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 (ASDs) 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. Although nearly all of these studies have agreed that the majority of adults with ASD 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

Outcomes in adults with autism spectrum disorders: a historical perspective

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 (Kanner, 1943). 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 (ASDs) 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 et al. (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 et al., 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 and Moss, in press; Taylor, 2009) (see Table 1 for a summary of included studies). 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 before the introduction of criteria for ASDs 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. Although some researchers had written descriptive accounts of adults with autism, Rutter et al. (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
Table 1. Selected outcome studies of adults with autism

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Criteria for overall outcome</th>
<th>Overall outcome results</th>
<th>Other results</th>
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<tbody>
<tr>
<td>Rutter et al., 1967</td>
<td>63 individuals with an average age of 16: infantile psychosis</td>
<td>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</td>
<td>Good: 14%; Fair: 25%; Poor: 13%; Very poor: 48%</td>
<td>Employed: 5%; Institution: 53% (for those 16 years and older)</td>
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<tr>
<td>Gillberg and Steffenburg, 1987</td>
<td>46 individuals aged 16–23 in Goteborg, Sweden: infantile autism and other childhood psychoses</td>
<td>Rutter et al.'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</td>
<td>Good: 4%; Fair: 13%; Restricted but acceptable: 22%; Poor: 44%; Very poor: 15%</td>
<td>Institution: 44%</td>
</tr>
<tr>
<td>Larsen and Mouridsen, 1997</td>
<td>18 adults in Denmark, average age 36 years: Asperger's syndrome and childhood autism</td>
<td>Rutter et al.'s criteria</td>
<td>Good: 28%; Fair: 28%; Poor: 16%; Very poor: 28%</td>
<td>Employed: 22%; Institution: 33%</td>
</tr>
<tr>
<td>Engstrom et al., 2003</td>
<td>16 adults over the age of 18 with an IQ &gt; 70 in the Orebro county of Sweden: high functioning autism and Asperger’s syndrome</td>
<td>Rutter et al.'s criteria</td>
<td>Good: 12%; Fair: 75%; Poor: 12%; Very poor: none</td>
<td>Independent employment: 6%; Living independently: 6%; Living in own home with support: 56%</td>
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<tr>
<th>Study</th>
<th>Sample</th>
<th>Criteria for overall outcome</th>
<th>Overall outcome results</th>
<th>Other results</th>
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<tr>
<td>Billstedt et al., 2005</td>
<td>120 individuals aged 17–40 in Goteborg Sweden: autistic disorder and atypical autism</td>
<td>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</td>
<td>Good: none</td>
<td>Living independently: 3%</td>
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<tr>
<td>Cederlund et al., 2008</td>
<td>70 males in Goteborg, Sweden aged 16–36: autistic disorder</td>
<td>Billstedt et al., 2005 criteria</td>
<td>Good: none</td>
<td>Ordinary job: 1%</td>
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<tr>
<td>Kobayashi et al., 1992</td>
<td>201 individuals aged 18–33 in Japan: autism</td>
<td>(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 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</td>
<td>(1) Language Development – Very good: 16% Good: 31% Fair: 32% Poor: 9% Very poor: 12%; (2) Adaptive Functioning – Very good: 11% Good: 16%; Fair: 27%; Poor: 23%; Very poor: 23%</td>
<td>Employed: 21%; Lives in a special care unit: 38%; Hospital: 2%</td>
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<td>Study</td>
<td>Sample</td>
<td>Criteria for overall outcome</td>
<td>Overall outcome results</td>
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<td>Howlin et al., 2000</td>
<td>19 adult males age 21–26: autism</td>
<td>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 dialog 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 difficulty = 5–8</td>
<td>Near normal functioning: 16% Moderate difficulties: 10% Considerable levels of difficulty: 74%</td>
<td>Never competitively employed: 74%; Living independently: 16%; No friends with shared interests: 47%</td>
</tr>
<tr>
<td>Howlin et al., 2004</td>
<td>68 adults aged 21–48 with an IQ &gt; 50 in London: Autism</td>
<td>Overall Outcome Rating: Work (employed to unemployed) = 0–3 points; Friendship (&gt;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</td>
<td>Very good: 12%; Good: 11%; Fair: 19%; Poor: 46%; Very poor: 12%</td>
<td>Employed: 34%; Independently employed: 13%; Living independently: 5%; Long stay hospital: 13%</td>
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<tr>
<td>Eaves and Ho, 2008</td>
<td>48 individuals born 1974–1984: autism</td>
<td>Overall Outcome Rating (Howlin et al., 2004)</td>
<td>Very good: 4% Good: 17% Fair: 32% Poor: 46% Very poor: none</td>
<td>Independently employed: 4%; Living independently: 8%; Close friendship(s): 33%</td>
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<tr>
<td>Gillespie-Lynch et al., 2011</td>
<td>20 individuals diagnosed from late 1970s to early 1980s: autism</td>
<td>Modification of Overall Outcome Rating (Eaves and 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</td>
<td>Very good: 20% Good: 10% Fair: 20% Poor: 50% Very poor: none</td>
<td>Living independently: 15%; Full-time employment: 20%</td>
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<tr>
<td>Study</td>
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<td>Criteria for overall outcome</td>
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<td>Esbensen et al., 2010</td>
<td>70 adults with comorbid intellectual disability, aged 22 years and older: autism spectrum disorder</td>
<td>Modification of Overall Outcome Rating (Eaves and 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. Composite score: 0–2 = very low independence; 3–5 = low independence; 6–8 = moderate independence; 9–11 = high independence; 12 = very high independence</td>
<td>Very high: 2%</td>
<td>High: 9%</td>
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<td>Moderate: 28%</td>
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<td>Low: 45%</td>
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<td>Very low: 16%</td>
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<td>Farley et al., 2009</td>
<td>41 individuals in Utah within near-average or average range of cognitive functioning: autistic disorder</td>
<td>Modification of Overall Outcome Rating (Eaves and 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</td>
<td>Very good: 24%</td>
<td>Good: 24%</td>
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<td>Fair: 34%</td>
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<td>Poor: 17%</td>
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<td>Very poor: none</td>
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<td>Living independently: 12%</td>
<td>Have a driver's license: 27%</td>
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<td>Full-time employment: 27%</td>
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<td>Billstedt et al., 2011</td>
<td>108 of 120 individuals from the 2005 sample: autistic disorder and atypical autism</td>
<td>(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. (2) Parent/carer rating of individual's well-being in the residential setting (scale of 1–5, very good to very poor)</td>
<td>(1) Mean category percentages –</td>
<td>Very good: 20%</td>
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<td></td>
<td>Good: 51%</td>
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<td>Fair: 13%</td>
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<td>Poor: 14%</td>
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<td>Very poor: 1%</td>
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<td>(2) Very good: 61%</td>
<td>Good: 30%</td>
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<td>Fair: 5%</td>
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<td>Very poor: 2%</td>
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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 et al.’s phrases ‘normal or near-normal social life’ and ‘potential for social progress’ require a great deal of investigator interpretation. However, Rutter et al.’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 nine 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 aged 16 to 18 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 Steffenburg (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 et al.’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 et al.’s (1974) and Rutter et al.’s (1967) findings, Gillberg and Steffenburg (1987) found 59% to have a poor or very poor outcome and 43% living in an institution.

Two studies using Rutter et al.’s criteria found slightly more optimistic results in overall social functioning (Engstrom et al., 2003; Larsen and Mouridsen, 1997). Larsen and 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. Seventy-eight percent had average or near average IQ. The authors note that these results should be interpreted with caution owing to the small sample size, unreliable diagnostic procedures, and high IQ levels. When focusing only on the nine 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 and Mouridsen (1997), the cognitive functioning of this group is not representative of all of those diagnosed with ASD.

Billstedt et al. (2005) defined five overall outcome categories based on Rutter et al.’s criteria. Qualifications for each category included various employment and residential situations and the presence/absence of comorbid psychiatric disorders. 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.
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 used their own criteria for overall outcomes, with varying results. In a Japanese follow-up study (Kobayashi et al., 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, as in Billstedt et al. (2005), were more specific than Rutter et al.’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). Although 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., 1992).

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 Steffenburg (1987) added a fifth category to Rutter et al.’s original four; Billstedt et al. (2005) added specific qualifications to Rutter et al.’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,
whereas 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 et al. (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 OOR scale (Eaves and Ho, 2008; Howlin et al., 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 (achieving a high level of independence, having some friends and a job); score of 3–4 = good (generally in work but requiring some degree of support in daily living; some friends/acquaintances); score of 5–7 = fair (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 (requiring special residential provision/high level of support; no friends outside of residence); and score of 11 = very poor (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 ASDs 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 some kind of volunteer or sheltered work experience. Note that although the authors used the term ASD, their sample is comparable to those in previous studies in that they were mostly diagnosed with infantile autism before the widening of the diagnostic criteria.

A few studies have applied a slightly modified version of the OOR scale (Eaves and 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 et al. (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, 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 and Dalrymple, 1996). When transition to adulthood became a US 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 with social expectations, the person-environment relationship tells a more dynamic and complete story of outcomes in adulthood.

Along these lines, Billstedt et al. (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 from 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 et al., 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 although 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 ASD 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 vary 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 participants in 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 such as high functioning autism and Asperger’s syndrome. Although a few of these studies did use 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 probably leave many individuals in lower socioeconomic groups underrepresented (Shattuck et al., in press). Although two of the reviewed studies are considered to be reasonably representative of all children with autism in the Goteborg region of Sweden (Gillberg and Steffenburg, 1987; Billstedt et al., 2005), the vast majority are samples of convenience. As individuals with ASD from lower-income families are likely to have less access to services (Shattuck et al., 2011), including these groups would potentially result in poorer outcomes than what is typically reported (Shattuck et al., in press; Taylor and Seltzer, 2010).
Reasons to expect that outcomes may improve in the future

Although 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 et al., 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 and Furstenberg, 2005). These tasks include milestones such as 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 et al., 2005). Although 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.

Although 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 and Steffenburg, 1987; Lotter, 1974). Although these variables confound objective independence criteria, they are probably 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 probably 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 have an impact on independence outcomes for adults with ASD, are relatively resistant to intervention (Ruble and Dalrymple, 1996). Ruble and 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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