Long-Term Outcome for People With Severe Intellectual Disabilities: Impact of Social Impairment

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Abstract
Results from a 25-year follow-up study of the Camberwell Cohort (L. Wing & Gould, 1978, 1979) were presented. Ninety-one people, ranging in age from 27 to 41 years, were traced, and an outcome measure was developed incorporating independent functioning, residential placement, employment, and quality of life. Outcome was rated as either poor (53%) or fair (43%), with only 3% having a good outcome. Using logistic regression methods, we found that the best predictor of outcome was social impairment, with those who were socially impaired, particularly those in the aloof category, having a poorer outcome. Higher IQ at Time 1 and lower challenging behavior were also predictive of better outcome. An in-depth look at social impairment revealed that social impairment remained stable over time.

Historically, there have been remarkably few investigations of the ways in which and the degree to which children and adults with intellectual disabilities could gain skills over time, so that opinions about poor outcomes for people with intellectual disabilities were based on little more than prejudice. Some studies did appear in the 1960s, in which researchers examined the effect of deinstitutionalization (Edgerton, 1967) or monitored the outcome in one specific group of people, such as those with Down syndrome (Carr, 1995) or autism (Gillberg & Steffenburg, 1987; Lotter, 1978). Most of these investigators recorded either changes in intelligence or adaptive behaviors, with only a few examining more specific aspects of functioning, such as social or language skills (e.g., Shah, 1986). Moreover, there was a tendency to concentrate on people who were still quite young at follow-up (usually 21 to 23 years of age), although some of the investigators examining deinstitutionalization did follow people for longer or monitor changes in older people.

With regard to the deinstitutionalization studies (Conroy & Bradley, 1985; Edgerton, 1967, 1988; Edgerton & Bercovic, 1976; Edgerton, Bolinger, & Herr, 1984; Kleinberg & Galligan, 1983; Lowe, de Paiva, & Felce, 1993), most researchers have found that individuals’ skills improve initially with deinstitutionalization, but that they quickly reach a plateau after the initial effects of the move from institution to community.

Where investigators have concentrated on skill development in people with Down syndrome living in the community, it appeared that there was usually a consistent improvement in skills in the early years, followed by a slowing of development and subsequent decline later on, probably with the onset of Alzheimer-like changes (Carr, 1975, 1995; Cornwall & Birch, 1969; Rasmussen & Sobsey, 1994; Silverstein et al., 1988; B. Smith & Phillips, 1992).

Findings from studies of people with autism have suggested that, in general, the adaptive skills of children with autism are initially higher but
improve less than those of children without autism. This was especially true for those with a higher IQ (Jacobson & Ackerman, 1990; Loveland & Kelly, 1988; Schatz & Hamdan-Allen, 1995). The greatest difference between children with and without autism has tended to be on socialization items. There have also been a number of studies in which researchers have looked at the outcome for people with autism in more general terms than adaptive skills and have found that general outcome is poorer for those with autism, especially for those with an IQ below 50 (Gillberg & Steffenburg, 1987; Lotter, 1978; Rutter, 1970; Rutter, Greenfeld, & Lockyer, 1967; Rutter & Lord, 1994).

However, in general, these outcome studies have been conducted with reasonably small samples of people with less severe intellectual disabilities and/or people who were younger at follow-up. For example, Gillberg and Steffenburg’s (1987) sample of 46 people (23 with autism, 23 with other childhood psychoses) were 16 to 23 years of age, and only 23% of those with autism had an IQ less than 50. Rutter et al.’s (1967) sample of 63 children who were 15 to 16 years old and had “infantile psychosis” (57 of whom had autism) had a mean IQ of 62.5, with 51% having an IQ below 50 and 34% having an IQ above 70.

In a recent study, Mawhood, Howlin, and Rutter (2000) compared 19 people with autism and 20 with developmental receptive language disorders at age 23 to 24 years. They found that both verbal IQ and receptive language increased over time for the autism group; for the language disorder group, only verbal IQ increased. The increases in verbal IQ were higher for the autism group as were increases in receptive language scores. The language disorder group was less severely impaired in their social use of language, but many of them did show abnormalities in this area. Early language ability was predictive of outcome for the autism group but not for the language group. Howlin et al. (2000) examined the social, behavioral, and psychiatric outcome of a subset matched for nonverbal IQ (mean 92 to 93) and expressive language and found that those with autism who were 23 to 24 years old showed more impairments in all three areas: more stereotyped behavior patterns, fewer social relationships, fewer jobs, and generally lower levels of independence. However, there was greater overlap between the two groups than there had been in childhood, and early language ability was predictive of outcome for the autism group but not the language group.

Despite the fact that social impairment is one of the core impairments in autism and forms part of the “triad of impairments” (L. Wing & Gould, 1979), there have been few studies of how social impairment changes over time. Although prevalence rates for autism have varied across studies, time, and country, researchers in Great Britain have recently found prevalence rates for classic autism as diagnosed in the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV) to be 16.8 children in every 10,000 live births (Chakrabarti & Fombonne, 2001). When the wider definition of autistic spectrum disorders is used, the prevalence has been reported to be as high as 57 children per 10,000 (Scott, Baron-Cohen, Botton, & Brayne, 2002). These studies included children without intellectual disabilities. For those with an IQ less than 70, impairments in social interaction have been reported to occur in 21.2 of every 10,000 children under 15 (L. Wing & Gould, 1979). Among those who were impaired, Wing and Gould identified three distinct categories of social impairment: aloof, passive, and active but odd. In the original sample, Wing and Gould reported that 50% of their sample were aloof and 50%, either passive or active but odd. Gillberg and Steffenburg (1987) found that 2 out of 5 of their sample of “psychotic” adolescents were aloof, about 25% were passive, and one third were active but odd. Very few researchers conducting outcome studies have examined social impairment; however, Rutter et al. (1967), Rutter (1970), Lotter (1978), and Gillberg and Steffenburg (1987) all pointed to poorer general outcomes for those who had autism and found little change in social skills/impairments over time.

Apart from these more general studies on changes in skills and outcome, there is little other literature on this topic, except for the Camberwell Cohort study by L. Wing and colleagues in the early 1970s (J. Wing & Hailey, 1972; L. Wing, 1971; L. Wing & Gould, 1979). The original study (Time 1) was followed-up in the early 1980s (Time 2) by L. Wing and colleagues (Shah, 1986). Initial data analyses (for the first 75 people seen) indicated that in terms of social impairment, 92% of the participants remained in the same category (impaired vs. sociable). However, 51% changed the way in which they manifested social impairment: 68% of this subsample became more socially impaired over time (e.g., moving from passive to aloof). There was a significant relationship.
between the presence of social impairment and admission to a special unit that had been established to offer an intense program of behavior modification to children with severe mental retardation (13 children had attended this unit at Time 1). Shah reported that there was no significant relationship between IQ group (severe, moderate, or mild mental retardation) and the presence of behavior problems. However, there was a significant association between the presence of social impairment and the presence of behavior problems. On the self-care scale, independence was significantly related to IQ and to social impairment, with those individuals with lower IQs and more social impairment having less advanced self-care skills. The relationship between either IQ or social impairment and independence in going out alone was not significant. However, those children considered to be socially impaired were less able to occupy themselves in constructive activities and, instead, engaged in no spontaneous activity or only repetitive activity. A fuller analysis of all the Time 2 follow-up data by Beadle-Brown et al. (2002) showed that social impairment in general did not change between childhood and adolescence/young adulthood; if socially impaired as children, then people tended to be socially impaired when young adults. However, level of impairment (i.e., aloof, passive, or active but odd) tended to deteriorate over time, perhaps because of the increasing social demands of people as they become adults.

In the present study, a further follow-up of the Camberwell Cohort (Time 3), we investigated the long-term outcome for people with severe intellectual disabilities and/or at least one of the triad of impairments. Shah (1986) had suggested that those who were socially impaired would have a poorer outcome than those who were not socially impaired. Findings by Gillberg and Steffenburg (1987) and Gillberg (1991) illustrated that those who had autism or a psychosis had a poorer outcome (in their early 20s) than did those who did not. There is little research on the effect of institutionalization on long-term outcome as compared to those who were never institutionalized. However, in the Darenth Park Study, L. Wing (1989) showed that those who stayed in institutional care had a poorer outcome in terms of skills than those moved into the community. In terms of the effect of challenging behavior on outcome, Emerson (1995) illustrated some comparative work showing that challenging behavior is associated with greater risk of abuse, exclusion from community services, and more barren experience inside institutions. Finally, Gillberg and Steffenburg (1987) found that outcome was lower for those with an IQ below 50. In the present study we focused on the factors that predict outcome for this cohort of people who are, in general, older and have more severe intellectual disabilities than any other group for whom outcome has been studied to date. We used a series of logistic regression analyses to investigate whether social impairment, autism, institutionalization, challenging behavior, and/or IQ were predictive of outcome. The term outcome is used here to refer to the level of independence and quality of life at Time 3. So, whereas the term predictive is used here in its technical sense, we acknowledge that we chose some of the analyses in this study in order to determine whether status, including current status at Time 3 (e.g., whether the person is socially impaired or not, has challenging behavior or not), predicts overall outcome at Time 3. Therefore, it is not strictly speaking “predictive” in the everyday usage of the word.

Method

Participants

In the early 1970s, L. Wing (1971), J. Wing and Hailey (1972), L. Wing and Gould (1978, 1979) undertook an epidemiological study of all children with severe intellectual disabilities and/or autism under 15 years of age, who had a parental home in the Camberwell District of South London (total population of 155,000). There were 34,900 children under 15, and 914 of these were identified for screening. The MRC Social Psychiatry Unit’s Camberwell Register (L. Wing, Bramley, Hailey, and Wing, 1968) was used as was the list of those attending special schools/classes for children with intellectual disabilities. Using the two screening criterion shown below, L. Wing et al. identified 173 children who met at least one of the criteria.

The first criterion was presence of at least one of the following: (a) absence or impairment of social interactions, especially with peers; (b) absence of impairment of development of verbal or non-verbal language; and (c) repetitive stereotyped activities of any sort. The second criterion was presence of severely impaired functioning on formal tests or in educational achievement, regardless of the pattern of behavior and social impairment.

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Of the 173 people identified, 6 died and 1 moved away before they were visited, leaving a sample of 166 children in the original sample. Twelve years later, 145 adolescents or young adults were traced. Twenty-five years later, for this follow-up, 104 people (72%) were traced, but we completed the Schedule of Handicaps Behaviors and Skills (L. Wing & Gould, 1979) for only 91 (88%) of them; 13 people refused participate.

Measures

The Schedule of Handicaps Behaviors and Skills is a structured interview used with a main caregiver to assess each individual’s basic/self-care, communication, educational, practical/independent living, and social skills. It is also used to assess inappropriate and problem behavior. The reliability of this measure is presented and discussed elsewhere (Beadle-Brown et al., 2000, 2002; L. Wing & Gould, 1978); in general, this interview shows good interrater and interinformant reliability. The main question from the Schedule of Handicaps Behaviors and Skills that was used to assess social impairment is provided below in addition to how it was coded for various purposes. The other items that made up this category were amount of eye contact, social use of eye contact, spontaneous show of affection, response to peers, friendships, level of social play/activity, and willingness to join in social activities. The coding of social impairment with the quality of social interaction question from the Schedule of Handicaps Behavior was as follows:

1. **Aloof:** 0 = indifferent, 1 = interacts only to obtain needs, 2 = engages in physical contact only, such as chasing games, tumble play, tickling. 3 = responds but does not initiate social contact (not just physical); takes the passive role, such as patient or baby, in social/imaginative play. 5 = shy but interacts appropriately with those he or she knows well, including peers.

2. **Active but odd:** 4 = approaches actively but interaction is naïve, bizarre, or one-sided; no attempt is made to take account of the needs or responses of the other person.

3. **Sociable:** 5 = shy, but has interactions appropriate for mental age with both adults and peers; the dichotomous social impairment measure for this group is sociable. 6 = interacts appropriately for mental age with both adults and peers.

Those with a rating of 0, 1, 2, 3, and 4 were all categorized as socially impaired.

The Leiter International Performance Scales (Leiter, 1980) was used as a measure of nonverbal intellectual functioning and the Reynell Language Development Scales (Reynell, 1977), as a measure of comprehensive and expressive language ability. These were also the measures used in the 1980 follow-up of the cohort.

The Adaptive Behavior Scales: Residential and Community Part 2—ABS (Nihira et al., 1993) was administered in questionnaire format. We used a brief specifically designed questionnaire on personal details to collect information on, for example, medical problems, diagnosis, placement history, day activity, contact with family. A quality of life questionnaire was administered to as many participants and their caregivers as possible. This questionnaire consisted of the Lifestyle Satisfaction Scale (Harner & Heal, 1993; Heal, Harper, Novak Amado, & Chadsey-Rusch, 1992), some of the questions from the Quality of Life Questionnaire (Schalock & Keith, 1993), and some additional questions that allowed expansion of the responses given to questions in the Lifestyle Satisfaction Scale.

Procedure

Each participant who could be traced was approached for consent to participate in the research. When possible, the persons themselves were asked for consent. When this was not possible, parents or appropriate others were asked for consent. Special attention was given to the mostly nonverbal signs of nonconsent from the participants at the time of testing (if people refused or appeared not to be consenting, they were not included).

The main caregiver (usually a parent or key worker in a residential home) was interviewed using the Schedule of Handicaps Behaviors and Skills, which normally takes 1 to 2 hours. In 22% of cases the interview was completed by the mother; in 54%, by a key worker or member of staff who knew the person well; in 24%, someone else completed the questionnaire (in almost all of these cases it was a home manager who had known the person longer than most of the care staff).

The questionnaire on personal details and the ABS were left with a reply envelope to be returned to the researchers as soon as they were complete. Each participant who could be assessed was then tested on the measures of intellectual functioning and language skills.

In general, the information was collected over two visits separated by no more than 2 to 3 weeks. However, for those that involved a longer distance, all information was collected in one visit.

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The first author conducted all the Time 3 interviews and was blind to the Time 1 and Time 2 status and scores of each participant.

Calculation of outcome variable. For each participant at Time 3, the mean score for each of the subcategories (basic, communication, educational, independent living, and social skills) from the Schedule of Handicaps Behaviors and Skills was calculated and recoded into an outcome score that ranged from 1 to 4, on the basis that lower scores in each of these areas represented more independent functioning, but acknowledging that these areas are also obviously related to overall level of ability (further information on the recoding of variables used in the outcome measure can be obtained from the first author). Mean scores for all of these subcategories were highly correlated, \( p < .001 \), with Spearman’s \( r \) values ranging from .42 to .80 across the different pairs of subcategories.

In addition, outcome scores of 1 to 4 were derived from the person’s work situation and residential placement on the basis of what is generally accepted to offer more independence and empowerment. Lower scores equate to more independent living and working arrangements. For example, a score of 1 on the work situation represented an independent paid job, with benefits, etc.; a score of 2 represented work experience (unpaid) in integrated workplace or paid employment in sheltered workshop; 3 signified accessing day services at least one day per week; and 4 represented accesses no day services at all. For residential placement, a score of 1 represented independent living; and 4 signified living in a large residential facility for more than 20 people or a hospital ward. We acknowledge that it would be possible and indeed should be possible to argue that living in a residential group home offered more independence than living in a parental home. However, in our experience people living in group homes in the community do not necessarily have more choice, autonomy, social networks, or other aspects of independent living than those in parental homes. As such, we decided to treat these two situations the same, and both were recoded as a score of 2.

Finally, the measure of quality of life for each participant was completed by their main caregiver (this was a combination of the Lifestyle Satisfaction Questionnaire and some of the questions from the Quality of Life Questionnaire). The scores on the quality of life measure varied from 1 up to a maximum of 121. Quartiles were used to recode the scores on a scale of 1 to 4, with a score of 66.75 or above = 1; 41.5 to 66.74 = 2; 24 to 41.49 = 3, and less than 24 = 4, on the basis that the lower the score the better the quality of life.

The mean of these outcome scores (on skills, work, residential placement, and quality of life) was calculated to produce an overall outcome category of good (mean score of 0 to 1.49), fair (1.5 to 2.49), poor (2.5 to 3.49), or very poor (3.5 to 4). If one of the eight items used to calculate the mean was missing but the mean over seven variables was no different than the mean over eight variables, that person was included in the outcome analysis. However, if the two means were different or more than two variables were missing, that person was eliminated from the analysis. An outcome measure was calculated for 76 people.

Through a series of logistic regression analyses (using SPSS Version 11), we examined the predictive value of (a) social impairment (socially able = 1, socially impaired = 0) at Times 1, 2, and 3; (b) social impairment on group classification (aloof, passive, active but odd, and sociable) at Times 1, 2 and 3; (c) a diagnosis of either childhood autism or atypical autism (autism = 1, no autism = 0) at Time 1; (d) IQ and language ability at Times 1, 2, and 3; (e) length of time spent in institutional settings (1 = extended periods, 2 = occasional admissions, 3 = residential/boarding school attended, 4 = none. This was recoded into 1 = 3 years or more in institutional care and 0 = less than 3 years. Also included was abnormal behavior and behavior problems at Times 1, 2, and 3 as assessed using the Schedule of Handicaps Behaviors and Skills and challenging behavior on the ABS Part 2 (Nihira et al., 1993).

Due to the relatively small sample, no more than 4 variables were entered into any single regression analysis and due to the multicolinearity of many of the variables, we found it necessary to carry out some univariate analyses. Only results where the Omnibus Test of Model Coefficients (chi-square) was significant at the .01 level are reported because of the number of analyses necessary.

Results

Sample Characteristics at Time 3

A summary of the age, IQ, and language ability of the cohort at each time point can be found in Table 1.

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Table 1. Means and SDs of Participant Characteristics by Time

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Time 1</th>
<th></th>
<th>Time 2</th>
<th></th>
<th>Time 3 (N = 38)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
<td>n</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Agea</td>
<td>36</td>
<td>8;11</td>
<td>3.89</td>
<td>35</td>
<td>20;11</td>
<td>4.15</td>
</tr>
<tr>
<td>Performance IQ</td>
<td>33</td>
<td>51.64</td>
<td>16.55</td>
<td>30</td>
<td>46.13</td>
<td>17.09</td>
</tr>
<tr>
<td>Comprehensive language</td>
<td>33</td>
<td>37.09</td>
<td>25.53</td>
<td>34</td>
<td>39.65</td>
<td>24.12</td>
</tr>
<tr>
<td>Expressive language</td>
<td>32</td>
<td>34.03</td>
<td>25.16</td>
<td>29</td>
<td>49.79</td>
<td>23.06</td>
</tr>
</tbody>
</table>

Note: *Mean chronological age in years; months.

Cognitive ability. At Time 3, only 33% of the sample able to be tested on the Leiter (n = 36) had an IQ above 50. Of those, we were unable to test (n = 55) on all measures, 3 refused to be tested in terms of granting consent, 42 people were either too challenging to test or their level of ability was too low (i.e., they did not respond to any attempts to test or they performed below floor level of test and we were not able to calculate an IQ).

Living situation. Twenty-eight percent of the sample was living within the family home; 48%, in group homes in the community; 19%, in a hostel or large residential unit in the community; and 4%, in a hospital ward. One person lived independently.

Diagnosis. A measure of diagnosis was recorded using historical records and a personal details questionnaire completed at Time 3. From this assessment, 21% of the sample had a diagnosis of autism. Fourteen percent had intellectual disabilities with characteristics of autism; this group contained people whose primary diagnosis was intellectual disabilities but for whom autistic features were noted—either in the records, on the questionnaire, or during the visits—or for whom caregivers said that they thought the person had autism but no formal diagnosis had been made. Of the remaining individuals, 20% had Down syndrome; 9%, cerebral palsy; 21%, intellectual and/or physical disability with other known cause. There was no known cause of diagnosis for 15% of our sample.

Social impairment. Seventy-two percent of the sample was socially impaired at Time 3 (36% of the sample, aloof; 13.5%, passive; and 22.5%, active but odd).

Interventions. The interventions and services received by the total sample between Times 1 and 2 are described in Beadle-Brown et al. (2002). Records were not available for interventions between Times 2 and 3. Many of the sample members moved out of larger institutions at that time; it is, therefore, conceivable that they had some special programs to help them adjust to life in the community, but this is unlikely to have been more than daily living skills for most people. A small minority of the sample (those with severe challenging behavior) had attended the MIETS Programme (Murphy, Holland, Fowler, & Reep, 1991).

Changes in Social Impairment Over Time

Table 2 presents a summary of the descriptive statistics for social impairment and social skills for the three time points. In terms of membership of the dichotomous social groups, there was no change over time on a Cochran Q test of difference for nominal data. On the four-group measure, there was also no change over time on a Friedman repeated measures ANOVA.

There was no significant change in social skills overall. However, for (a) eye contact (ranging from no eye contact at all through some eye contact but mostly inappropriate, that is, very brief or staring at or through people) through appropriate eye contact; (b) level of engagement in social activities (ranging from no engagement at all through simple games of chasing or simple group games) through playing simple table/board games with others and cooperative play in a group (e.g., organized football, drama); and (c) overall quality of social interaction, discussed earlier (see p. 4), there were significant changes over time. For eye contact, scores were lower at both Times 2 and 3 than they were at Time 1, Friedman $\chi^2(2, N = 77) = 35.29, p < .001$. For level of engagement in social activities, Time 3 scores were higher than Time 1 scores, Friedman $\chi^2(2, N = 80) = 15.54, p < .001$. In contrast, overall quality of social in-
Table 2. Descriptive Statistics (in Percentages) for Social Skills by Time

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socially impaired</td>
<td>65</td>
<td>66</td>
<td>72</td>
</tr>
<tr>
<td>Aloof</td>
<td>30</td>
<td>39</td>
<td>36</td>
</tr>
<tr>
<td>Passive</td>
<td>23</td>
<td>11</td>
<td>13.5</td>
</tr>
<tr>
<td>Active but odd</td>
<td>12</td>
<td>16</td>
<td>22.5</td>
</tr>
<tr>
<td>Socially able</td>
<td>35</td>
<td>34</td>
<td>28</td>
</tr>
<tr>
<td>Overall social skills</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>2.3</td>
<td>2.13</td>
<td>2.13</td>
</tr>
<tr>
<td>Median</td>
<td>2.5</td>
<td>2</td>
<td>2.43</td>
</tr>
<tr>
<td>IntQ range</td>
<td>1.5–3</td>
<td>1.3–3</td>
<td>1.25–3</td>
</tr>
<tr>
<td>Eye contactb</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.75</td>
<td>2.96</td>
<td>2.98</td>
</tr>
<tr>
<td>Median</td>
<td>3</td>
<td>4</td>
<td>3.5</td>
</tr>
<tr>
<td>IntQ range</td>
<td>2–4</td>
<td>4–4</td>
<td>2.25–4</td>
</tr>
<tr>
<td>Level of social participationc</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.07</td>
<td>3.47</td>
<td>3.73</td>
</tr>
<tr>
<td>Median</td>
<td>4</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>IntQ range</td>
<td>1–5</td>
<td>1–4</td>
<td>0–6</td>
</tr>
<tr>
<td>Overall quality of social interactiond</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>4.39</td>
<td>3.77</td>
<td>3.09</td>
</tr>
<tr>
<td>Median</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>IntQ range</td>
<td>2–6</td>
<td>2–6</td>
<td>1–5</td>
</tr>
</tbody>
</table>

Note. The mean and median scores and interquartile (IntQ) ranges are reported for the three variables for which there was a significant change over time on the Friedman-related measures analysis of variance.

*Interquartile. bN = 80. cN = 83. dN = 89.

Impact of social impairment

Overall Outcome and the Impact of Social Impairment

The percentage of participants in each outcome group was as follows: 1% had a very poor outcome (mean score of between 3.5 and 4 over all outcome variables); 53% had a poor outcome (2.5 to 3.49); 43%, a fair outcome (1.5 to 2.49); and 3%, a good outcome (0 to 1.49). This was recoded for further analyses into those who had a fair or good outcome (46%) and those who had a poor or very poor outcome (54%).

Results from regression analysis. In all of the results reported below, the model entered correctly predicted over 60% of the observed values and the significance of the Hosmer and Lemeshow test was greater than 0.6, illustrating that the models used in each circumstance fitted the data well.

Social impairment. Social impairment at Time 3 as expressed by the dichotomous (0 = not impaired, 1 = impaired) variable was highly predictive of outcome; the model correctly predicted 72% of observed values, with those who were socially impaired more likely to show a poor or very poor outcome, Wald statistic = 11.09, p < .001, coefficient: −2.40, odds ratio: 0.09. To examine the effect of social impairment at all three time points more closely, we ran the analysis again, using the ratings derived from the Quality of Social Interaction question on the Schedule of Handicaps Behaviors and Skills at each time point. Again, this model was highly significant and predicted almost 77% of the observed values. Those who were aloof at Time 3, Wald statistic = 11.03, p < .001, coefficient: −3.98, odds ratio: 0.02, were likely to show a poor or very poor outcome. However, multicollinearity was very much a feature in this model because ratings of social interaction at each time-point were highly correlated, r values over 0.50 on Spearman’s rank order correlation. Therefore, we conducted univariate analyses for social group at Times 1 and 3, producing significant regression coefficients in both cases. For social impairment at Time 3, it was those who were aloof (Wald statistic = 17.61, p < .001, coefficient: −4.07, odds ratio: 0.02) and those who were active but odd (Wald statistic = 4.05, p < .05, coefficient: −1.57, odds ratio: 0.21, who were more likely to have a poor or very poor outcome. Those who were aloof at Time 1 also tended to have a poorer outcome, Wald statistic = 11.74, p < .001, coefficient: −2.44, odds ratio: 0.09, as did those who were rated as passive at Time 1, Wald
statistic = 8.35, \( p < .01 \), coefficient: -1.90, odds ratio: 0.15.

**Cognitive functioning.** Due to the small numbers of those tested at Time 3 (\( n = 36 \)) and the multicollinearity among most of the measures of cognitive functioning, we initially conducted five univariate analyses. Using the Leiter International Performance Scales at Time 3, we found that IQ was significantly associated with outcome on Kappa, 0.433, \( p < .001 \), but in the regression analyses, IQ at neither Times 1 nor 3 were predictive of outcome. However, IQ group at Time 1 (see Table 3) was predictive of outcome, with higher scores predictive of better outcome, Wald statistic = 15.36, \( p < .001 \), coefficient: 0.74, odds ratio: 2.09. For language comprehension age equivalent at Time 3 (as assessed using the Reynell Language Development Scale), there was no effect. In contrast, language comprehension (expressed as an age equivalent) as estimated at Time 1 was significantly predictive of outcome: the higher the language comprehension at Time 1 predicted a better outcome at Time 3, Wald statistic = 8.65, \( p < .01 \), coefficient: 0.04, odds ratio: 1.04.

**Presence of challenging behavior.** Again due to the high correlations, Spearman \( r > 0.5 \), between total score on the ABS Part 2 and the total score for abnormal behavior and behavior problems as rated by Schedule of Handicaps Behaviors and Skills at Time 2 and Time 3, only the scores on the latter measure at Time 1 and the total standard score on the ABS at Time 3 were entered into this analysis. Only the ABS total score was predictive of outcome, with a higher score (lower challenging behavior) predictive of a better outcome, Wald statistic = 7.75, \( p < .01 \), coefficient: 0.06, odds ratio: 6.89. However, the coefficient for the Schedule of Handicaps Behaviors and Skills (difficult behavior) approached significance at the .08 level, Wald statistic 3.05, \( p = .08 \), coefficient: 1.93, odds ratio: 1.06. When the two variables were examined separately, we found that both models were significant, total score on ABS:RC Part 2, Wald statistic = 9.17, \( p < .01 \), coefficient: 0.06, odds ratio: 1.06; mean score on behavior problems and abnormal behavior at Time 1 as measured by the Schedule of Handicaps Behaviors and Skills, Wald statistic = 7.20, \( p < .01 \), coefficient: 2.72, odds ratio: 15.23. However, the model using total score on the Schedule of Handicaps Behaviors and Skills (difficult behaviors) at Time 1 predicted more of the observed values (65.8%) than did the model using total score on ABS at Time 3 (58.5%).

**Diagnosis.** Diagnosis in general was not significantly predictive of outcome for this sample. However, when the effect of a diagnosis of autism was examined, we found that those who did not have autism (on ICD-10 criteria) at Time 1 had a better outcome, with this model correctly predicting 74% of the observed values, Wald = 14.82, \( p < .001 \), coefficient: 2.66, odds ratio: 14.25.

**Other variables investigated.** In addition to the effect of a diagnosis of autism, a dichotomous measure of challenging behavior at Time 3 and the number of residential placements plus the effect of time spent in institutional care were all examined. None of these variables were correlated at Spearman’s \( r \) over .5 or associated with Kappa over .45. Not having a diagnosis of autism was predictive of a better outcome, Wald = 7.79, \( p < .01 \), coefficient 3.13, odds ratio: 22.93, and having spent any time in institutional care was predictive of a poorer outcome, extended periods—Wald = 4.95, \( p < .05 \), coefficient: -2.66, odds ratio: 0.07; occasional periods—Wald = 5.51, \( p < .05 \), coefficient: 3.36, odds ratio: 0.04. This model predicted 73% of the observed values. If the diagnosis of autism was removed from the equation, then only extended periods (i.e., more than 3 years) in institutional care was significant, but with the model still correctly predicting 73% of observed values, Wald = 3.90, \( p < .05 \), coefficient 1.72, odds ratio: 0.18.

**Final modeling of outcome predictors.** Those variables for which significant results had been reported in the above analyses (i.e., social group at Time 3, autism at Time 1, total score on ABS at Time 3, total score on the Schedule of Handicaps Behaviors and Skills at Time 1 (abnormal respons-

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**Table 3. Cross Tabulation for IQ Group at Time 1 and Social Impairment at Time 3**

<table>
<thead>
<tr>
<th>IQ group at Time 1</th>
<th>Social group at Time 3</th>
<th>Aloof</th>
<th>Passive</th>
<th>Active but odd</th>
<th>Sociable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Untestable</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>6</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>25–39</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>40–54</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>55–69</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>70–84</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>85 +</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Impact of social impairment

(abstract continues)

es and behavior problems), institutionalization, and IQ group at Time 1) were re-entered into a new analyses. Social group at Time 1 (which was highly correlated with social group at Time 3 but less strongly predictive) and the dichotomous coding of social impairment at Time 3 were not entered. The initial model predicted 87% of the observed values and showed social group at Time 3 (in particular, aloof: Wald = 7.83, \( p < .01 \), coefficient = \(-4.17 \), odds ratio = 0.02, and IQ group at Time 1 to be significantly predictive of outcome, Wald = 6.69, \( p < .05 \), coefficient = 0.82, odds ratio = 0.03. The final model after stepwise elimination of the least significant variable included only social group at Time 3, ABS total score at Time 3, and IQ group at Time 1, and this model still predicted 81% of observed values. Having a lower IQ, Wald = 7.99, \( p < .01 \), coefficient = 0.79, odds ratio = 2.19, more challenging behavior, Wald = 5.63, \( p < .05 \), coefficient = 0.78, odds ratio = 1.08, and being aloof, Wald = 10.31 \( p < .001 \), coefficient = \(-4.37 \), odds ratio = 0.01, was predictive of a poor or very poor outcome.

Table 3 presents the cross-tabulation for IQ group at Time 1 and social group at Time 3. Treating these as limited ordinal scales, we found that a Spearman correlation coefficient was significant at the .01 level, but with an \( r \) of only 0.298. The direction of significance was in favor of a positive relationship between social impairment and IQ, with the higher the IQ the higher the score on social impairment (i.e., less social impairment). There was no significant relationship between either of these variables and challenging behavior as measured by Part 2 of the ABS at Time 3, Spearman’s \( rs \) were .22 and .07, respectively.

Conclusions

Overall, there was little change in social impairment (as measured by the Schedule of Handicaps Behaviors and Skills) over time: Those who were socially impaired as children tended to be socially impaired as adolescents and as adults. A few people who were socially able at Time 1 became socially impaired as they became older, and for a few people, social impairment became more severe (e.g., a child coded as passive might have been classified as aloof as an adult). However, for the whole sample, these differences were rarely significant and when they were, it was difficult to decipher the effect of time from the effect of different informants. It is important to emphasize that this sample did not comprise only those who had autism: Social impairment appears to be chronic for many individuals with intellectual disabilities.

As well as being chronic, social impairment also is influential in predicting outcome for people with intellectual disabilities; in general, those who are socially impaired tend to have a poorer outcome. This result is not simply explained by the relationship of social impairment to other factors, such as autism, challenging behavior, and/or time spent in institutional care. Although there are some associations between each of these variables, these are not particularly strong, and in all analyses in which social impairment was included, it emerged as the most predictive factor. In particular, those who were aloof at Time 3 (\( n = 29 \)) had the poorest outcome. Although there was a relationship between IQ group at Time 1 and outcome, it is difficult to use IQ to explain the social impairment findings because quite large numbers of the aloof group were untestable. Also, because the sample members generally had severe disabilities, the majority of those who could be tested still had an IQ below 50. There was not a strong relationship between IQ at either Time 1 or Time 3 and social impairment. The fact that IQ itself did not predict behavior whereas IQ group at Time 1 did is probably explained by the fact that it was possible at Time 1 to test more children given a variety of different measures and to estimate intellectual functioning on the basis of this testing. The IQ group variable also allowed the people who were untestable at Time 1 to be included, thus increasing the size of the sample and the range of ability that was included.

It seems, therefore, that both social impairment, especially being aloof, and having a low IQ are predictive of a poorer outcome. In addition, challenging behavior as measured by the total score on the ABS Part 2 at Time 3 was also predictive of outcome. There were no significant relationships between social impairment group, IQ group, and challenging behavior as measured by the ABS Part 2, which might indicate that the finding on social impairment or IQ is an artifact of challenging behavior. The findings on diagnosis are somewhat difficult to interpret because the diagnostic criteria used were not formalized. We acknowledge that if access to a formal diagnosis had been made at Time 1, these findings would have strengthened our results in this respect.
The practical/clinical implications of a chronic impairment in social interaction are important. People who are socially impaired in childhood are likely to continue to have difficulty making friends and interacting with others. As partly illustrated by the poorer outcome for those who are socially impaired, this will likely affect their ability to gain meaningful employment that reflects their level of ability in terms of IQ and other skills, their social networks, and possibly their mental health. If people with social impairments are to have a chance at a better quality of life, it is necessary that services are focused on this issue, in particular in early intervention and educational services.

The possibility of producing lasting improvements in outcome for children with autism has been examined in a number of studies. Rogers (1996) reviewed early intervention programs and found that, in general, researchers reported significant acceleration of developmental gains, significant language gains, improved social behavior, and decreased symptoms of autism. However, there is little independent evaluative work available on many of the interventions that are offered to parents. In the current study we found that the two most important factors in long-term outcome are IQ and social impairment. From evaluation of early intervention work, such as that by McEachin, Smith, and Lovaas (1993), T. Smith, Groen, and Wynn (2000), Eikeseth, Smith, Jahr, and Eldevik (2002), it appears that such early interventions (based on applied behavior analysis) improve the former but not the latter. Lovaas’ 1987 definition of normal functioning was in terms of intellectual and adaptive behavior, and evaluative research conducted by Lovaas and his colleagues does not deal in detail with how the children’s social skills improved.

Given the latter finding, however, it is essential to also establish how social impairment is affected by early intervention. For children with autism, improving social skills might be the major objective in any early intervention study. This is the aim of the Son-Rise Options program, but there is no formal evaluation of this program (although pilot work is presently underway). The burning question remains, can social impairment or at least the effect it has, be lessened with training in the right environment and at the right time? This should be the focus of future researchers, in particular those looking at early intervention in autism.

References


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