

Twenty-Year Outcome for Individuals With Autism and Average or Near-Average Cognitive Abilities

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Previous studies found substantial variability in adult outcome for people with autism whose cognitive functioning was within the near-average and average ranges. This study examined adult outcome for 41 such individuals (38 men and 3 women) originally identified through an epidemiological survey of autism in Utah. Mean age at the time of their previous cognitive assessment was 7.2 years ($SD = 4.1$, range = 3.1–25.9 years) and at follow-up was 32.5 years ($SD = 5.7$ years, range = 22.3–46.4 years). Outcome measures included standardized assessments of diagnostic status, cognitive ability, and adaptive behavior. Additional information collected concerned demographic variables, indicators of independence, social relationships, medical and psychiatric conditions, and social service use. Outcomes for this sample were better than outcomes described in previous work on individuals with similar cognitive functioning. For example, half of the participants were rated as “Very Good” or “Good” on a global outcome measure. As in previous studies, there was considerable variability in measured cognitive ability over time. Over half of the sample had large gains or losses of cognitive ability of greater than 1 standard deviation. Cognitive gain was associated with better outcome, as was better adaptive functioning. While all participants had baseline IQs in the nonimpaired range, there was limited evidence to support the use of other early childhood variables to predict adult outcome.

Keywords: autism; adult; outcome; longitudinal

Introduction

Although much research has been conducted on autistic disorder (AD) in the past 60 years, few studies address AD in adults. Even fewer studies describe outcomes for adults with AD and no cognitive impairment, a population associated with greater variability in individual outcome [Engstrom, Ekstrom, & Emilsson, 2003; Gillberg & Steffenburg, 1987; Howlin, 2003; Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Mawhood, & Rutter, 2000; Kanner, 1971; Lotter, 1974; Piven, Harper, Palmer, & Arndt, 1996; Rumsey, Rapoport, & Sceery, 1985; Szatmari, Bartolucci, Brenner, Bond, & Rich, 1989]. Communicative phrase speech before age 6 and a relatively high childhood IQ appear to be critical factors for a “good” outcome [Billstedt, Gillberg, & Gillberg, 2005; Kobayashi, Murata, & Yoshinaga, 1992]. Cross-sectional studies and case reports describe adults with AD who have achieved significant independence in multiple domains, but longitudinal studies of those diagnosed in the 1970s and

earlier have shown that few adults with AD live outside of their childhood residences or institutional settings. Competitive and sheltered employment occupy less than 40% of adults with AD studied longitudinally [Howlin, 2003; Howlin et al., 2004]. Few adults with AD in these studies marry or develop reciprocal friendships, in spite of increased interest in developing social relationships as individuals with AD age [Nordin & Gillberg, 1998; Rumsey et al., 1985]. Some core characteristics of AD abate moderately in many adults, and functional abilities often improve [Piven et al., 1996; Rumsey et al., 1985; Seltzer et al., 2003]. Low IQ, adolescent onset of epilepsy, and comorbid psychiatric disorders frequently complicate the course of AD [Howlin, 2002]. These co-occurring disorders may be major contributors to the higher mortality rate for individuals with AD [Gillberg, 1991].

We now report our study of adult outcome in a sample of individuals from a population-based group ascertained 20 years ago that comprised participants who, when first

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assessed, were diagnosed with AD and had an $IQ \geq 70$. Our aims were to (1) define current function and service needs; (2) explore the feasibility of studying a larger statewide sample; and (3) examine relations among historical and current variables not reported in other recent outcome studies.

Methods

Participants

Participants were identified originally through a statewide epidemiological survey of autism that occurred between 1984 and 1988 [Ritvo et al., 1989]. The aim of the survey was to identify all cases of autism born between 1960 and 1984 living in Utah at the time of the survey. A team of clinician–investigators used parent interviews, direct observations, and records reviews to determine diagnostic status for each case [cf. Ritvo et al., 1989 for details]. A total of 489 people were screened for autism. Of these, 241 were diagnosed with DSM-III autism, 138 were determined not to have autism, and 110 were excluded from the study because they were out of the study age range, uncooperative, or lost to follow-up.

Inclusion criteria for this follow-up study were a diagnosis of AD by the epidemiological survey team and a nonverbal or full scale IQ score of 70 or more. The exclusion criterion was the presence of a medical condition that precluded completion of follow-up assessments or which might have significantly affected independent living. Seventy-five participants were eligible for this follow-up study.

Contact information for eligible individuals and their parents was obtained using public records databases, published telephone directories, and original contact information from the 1980s epidemiological survey. Letters of invitation to participate were mailed to potential participants and their parents. Two weeks after the letters were mailed, we attempted telephone contact with those who had not yet scheduled an appointment. One month after the first mailing, we mailed a second invitation letter and again attempted telephone contact 2 weeks later.

We collected data for 41 participants (53%). Four people (5%) declined to participate. We were unable to locate 9 individuals (12%), and 14 others (19%) did not respond to our contact attempts. Seven individuals (9%) agreed to participate but did not complete the evaluation. The follow-up sample included 38 men and 3 women (male to female ratio: 12.7:1.0). Mean age at the time of the adult assessments was 32.5 years ($SD = 5.7$ years, range = 22.3–46.4 years). Time elapsed between historical and current testing was 24.42 years ($SD = 3.75$ years, range = 15.25–34.17 years). Only one participant was over age 14 when first assessed. There were two sets of siblings among those participating in the follow-up.

Outcome measures between siblings were markedly different.

Ethics Approval

Approval for this study was obtained from the Institutional Review Boards of the University of Utah and Utah's State Department of Human Services.

Measures

Most assessment procedures were conducted in participants' homes, with the remainder performed in our research offices.

Diagnostic assessments. The Autism Diagnostic Interview—Revised [ADI; Lord, Rutter & LeCouteur, 1994] and Autism Diagnostic Observation Schedule—Generic [ADOS; Lord et al., 2000] were used to obtain lifetime and current information for autistic symptoms and current diagnostic status. All assessment procedures were performed by the first author and a research staff person who had achieved research reliability standards in ADOS and ADI administration. Two participants refused to be assessed directly but allowed their parents to be interviewed. Parents who were also legal guardians for 2 other participants refused to allow research staff to interact with their children, citing previous negative experiences with mental health workers. Thus, ADOS scores were collected for 37 of 41 participants.

In all cases, a parent participated in completing the ADI and other caregiver interviews. Some parents were aided by their adult child's social services case manager, spouse, or adult sibling. Three parents reported substantial difficulty recalling details of their child's early development, so valid lifetime ADI results could not be obtained for these 3 participants.

Adaptive behavior and independent living. Adaptive behavior in adulthood was assessed using the Vineland Adaptive Behavior Scales—Survey Edition [VABS; Sparrow, Balla, & Cichetti, 1984]. Another interview concerning a variety of outcome characteristics was developed for this study and administered to parents and other significant adults. Questions addressed chronic medical and comorbid psychiatric conditions affecting daily functioning; transportation, employment, and residential histories; experiences with law enforcement agents; and use of social services. We also asked questions about the level of assistance participants required from caregivers and from social services, using definitions for levels of help devised by Engstrom et al. [2003]. Detailed information concerning education histories was obtained through the ADI.

Social functioning. In the interview developed for this study, we asked parents a number of questions about participants' social relationships and involvement in social organizations. Questions about friendships and romantic relationships addressed historical and current

relationships as well as the reporters' impressions of the participants' level of interest in developing additional relationships.

Overall functioning. A composite rating on a 5-point scale of overall social and independent living functioning was based on work status, residential situation, and number and quality of friendships [Howlin et al., 2004]. Criteria for a "Very Good" rating were paid employment without any extra supports to perform duties, existence of important social relationships, and a high level of independence in daily life. A "Good" outcome was defined as a generally high level of independence in work and home life, requiring some extra support. A "Good" outcome also meant the person had a friendship or some acquaintances. A "Fair" outcome reflected the need for regular support in work or home life but no need for a special residential facility. A person with this rating was reported to have acquaintances through regularly scheduled activities but no particular friends. A "Poor" rating indicated the person needed a very high level of support, such as that provided through a special residential facility and day programming for people with developmental disabilities. A person obtaining this rating would have no friendships outside of the residential setting. A "Very Poor" rating meant the person required a high level of care in a hospital setting with no autonomy. A person with this rating would have no friendships. Ratings were assigned independently by the first author and a graduate research assistant. The intraclass correlation coefficient for the composite ratings was 0.97. Rating discrepancies were reviewed, and consensus was reached through a case conference.

Adult cognitive abilities. Cognitive abilities in adulthood were measured using the Wechsler Adult Intelligence Scale—Third Edition [WAIS-III; Wechsler, 1997]. Four participants declined to complete the WAIS-III, and the parents/legal guardians of two other participants refused to allow staff to assess their adult children. Two participants attempted but were unable to complete the tasks on the WAIS-III due to cognitive impairments. Two participants obtained PIQ scores but lacked sufficient language ability to complete verbal subtests. One participant was unable to complete two verbal subtests due to interference in his home testing environment; therefore, only his PIQ is reported. In summary, 30 participants obtained an FSIQ score, and only the PIQ was obtained for 3 participants.

Historical cognitive abilities. Direct assessments of participants' cognitive and language abilities were not made as part of the epidemiological survey, yet all but one participant had been evaluated by service providers who obtained IQ scores prior to the epidemiological survey. The previously untested man was given an IQ test through that study. Data from a variety of assessment instruments and age ranges were used to estimate historical cognitive abilities in this sample; thus, interpretations of results from the historical to current

assessments must be treated cautiously. The global measure of cognitive ability nearest age 8 was the first test selected for use; Wechsler tests were most preferred, followed by the Stanford–Binet. For two children, the Denver Developmental Screening Measure was the only estimate of cognitive ability available. Since developmental age was the metric reported from this measure, the formula $DA/CA \times 100$ was used to calculate an estimate of cognitive ability. When a global measure was unavailable, a measure of nonverbal ability was used as the best estimate of cognitive ability. Again, the score obtained closest to age 8 was used. For many participants, multiple measures were available for global, nonverbal, and verbal abilities. Data were analyzed using the best measures available in each domain.

Data on the ages of single word use and phrase speech, in months, were extracted from the historical records. Parents were also asked for this information through the ADI. If parental responses to the ADI differed from historical information, details concerning the nature of the participant's language development were discussed in order to isolate the best-estimated ages. Seven participants did not have these data in the records, nor were their parents able to confidently recall the ages at which their children acquired language milestones.

Statistical Analyses

Data were entered twice to ensure accuracy and analyzed using SPSS Version 16.0. For comparisons of interval-level variables, two-tailed *t*-tests and ANOVA were used. Spearman's ρ tests were used in nonparametric analyses.

Results

Representativeness of the Sample

To estimate potential sample bias, we compared cases in the follow-up study to those not included. Comparisons were made using the historical records and the Utah Population Database (UPDB), a repository for genealogical, medical, and demographic information concerning families in Utah. The groups were compared for significant differences on 14 variables including historical IQ scores, age at testing, gender, ages of single word acquisition and phrase speech, availability of adult data in the UPDB, marriage, driver's license, birth of offspring, and seizure disorder in childhood. A significant difference between groups emerged only for the age at which they acquired single words. Participants were significantly older ($n = 32$, $M = 46.1$ months, $SD = 34.9$) than nonparticipants ($n = 29$, $M = 28.0$ months, $SD = 26.0$; $t(56.9) = 2.31$, $P = 0.024$). This result could suggest that the group participating in this study had greater communicative impairments; however, there were no significant differences between groups on measured global cognitive or verbal ability measures.

Diagnostic Stability

Thirty-six of the 38 participants for whom a valid ADI was collected obtained a lifetime ADI diagnosis of autism. Two participants fell short of the cutoff of 3 on the Restricted Interests and Repetitive Behaviors Domain, each obtaining a score of 2. Their scores exceeded the cutoffs in the Social and Communication Domains. Therefore, they amply met the DSM-IV [APA, 1994] diagnostic criteria for AD. The ADOS was administered to 37 participants. Due to impaired expressive language abilities, two participants were administered Module 1, and three participants completed Module 2. Although both individuals who were administered a Module 1 were described as using phrase speech regularly, their language production appeared suppressed during the assessments. The 5 individuals who were administered ADOS Modules 1 and 2 met ADOS criteria for autism. Twenty-two of the 32 participants who completed the ADOS Module 4 obtained an ADOS diagnosis of autism. Four scored in the autism spectrum disorder range but did not meet ADOS criteria for autism. Six participants did not score within the autism or autism spectrum disorders ranges on the ADOS. However, only one of these adults was described by himself and others as no longer having any significant autistic-type symptoms. Remaining participants who did not meet full ADOS criteria for an autism spectrum disorder reportedly retained difficulties interpreting subtle social behaviors and participating with others in a fully reciprocal manner.

Educational Attainments

Twenty-three participants (56%) attended public school in special education programs until the maximum age of 21 years, 11 months. The remaining 18 (44%) completed high school at grade 12 with a diploma, and 16 (39%) went on to receive postsecondary education. Four of these earned an associate's degree or technical training certificate, and 7 others earned one or more bachelor's degrees. Five participants were in full-time postsecondary training or education at the time of the study, and 3 were in school on a part-time basis. Of these 8 participants, 5 also worked full-time jobs, and 2 worked part-time.

Employment

Half of the participants were employed in either full-time ($N = 11$, 27%) or part-time ($N = 11$, 27%) independent, paid jobs. Three participants (7%) worked in supported employment positions, 2 (5%) were part-time volunteers, 10 (24%) participated in day programs, and 4 (10%) were unemployed.

Thirty-eight participants (93%) were members of the Church of Jesus Christ of Latter Day Saints (LDS Church). Many young men and some young women in the LDS

Church perform a 2-year mission in young adulthood. Some members serve a service mission, working in local church institutions, while others serve proselytizing missions in the US or other countries. Proselytizing missions are highly social endeavors in which the missionary is with one or more assigned "companions" at all times, except during tasks associated with personal hygiene. They make frequent social overtures to strangers. Missions typically last for 2 years. Three participants served international missions for which they learned a new language. Five served missions in US cities away from their homes, and 2 served service missions while residing at their family home.

Friendships and Social Life

Three participants (7%) were married at the time of the interviews, and all 3 had children, for a total of 7 offspring. Grandparents of only one of these children expressed concerns regarding their grandchild's autistic-like characteristics. Two other participants (5%) were divorced. One previously married participant was newly engaged. Three other participants (7%) were in long-term relationships. Eighteen individuals (44%) had never dated. Thirteen (32%) had dated in both group and single couples interactions. Nine (22%) had dated only in group settings, and one had dated only in a single couple arrangement. When asked whether they felt their adult child wished to have a romantic partner, parents of 15 (44%) participants not already in a relationship said they believed their son or daughter would like to be in a relationship. Parents of 17 participants (41%) said their son or daughter did not want a romantic partner. Some of these reported their child's concern about passing autism on to children or about being too difficult, themselves, for another person to manage. Others were described as having no desire for a close interpersonal relationship beyond pre-existing family relationships. Only 2 parents (5%) felt uncertain as to whether their son or daughter wished to be involved in a romantic relationship.

Parents were also asked about their adult child's involvement in organized groups. Thirty-five participants (85%) regularly attended church activities, and 7 (17%) participated routinely in Special Olympics. Twelve participants were also involved in other organized activities (e.g., martial arts classes). Four participants (10%) were uninvolved in any regularly occurring meetings with other people.

Transportation

Eleven participants had a driver's license and drove regularly (27%). Eleven others took public transit on a regular basis. Four participants (10%) used a special public transit service for people with disabilities or rode regular public transit with support from others. Eight

participants (20%) relied on family or social services staff to transport them.

Independent Living

Three participants (7%) lived in their own homes that they had purchased themselves, and 2 (5%) lived independently in their own apartments. One individual lived in an apartment with a sibling, receiving limited assistance from the sibling with daily living tasks. Another participant lived in his own apartment but was checked on several times a week by a parent. Parents of 2 participants established a separate apartment with an independent entrance in their own home for their adult children. Twenty-three participants (56%) lived with their parents. In 6 cases, continued residence with parents was due to a son or daughter being in school and unable to afford their own independent home. Parents of 3 of these participants expected their son or daughter would move out in the near future. Three participants lived alone in an apartment with support from social services agencies, and 4 lived in group homes. Two participants lived in a state facility for adults with developmental disabilities.

We used questions written by Engstrom et al. [2003] to ask parents how much help their son or daughter needed from caregiving others. No participant had a rating of "None," signifying "no contact with family." Eleven participants (27%) required a "Low" level of help, meaning "normal or near-normal contact with parents, siblings, and other relatives; support and practical assistance from time to time." Another 11 participants required a "Moderate" level of help, meaning that they required "regular practical assistance at home; daily contact by phone or physically; help with local authorities." Nineteen individuals (46%) required a "High" level of assistance, meaning they needed "extensive help with social contacts and employment sites; total control of economic affairs; lives with relatives from time to time" [Engstrom et al., 2003, p 103].

Overall Social Outcome

We applied Howlin et al.'s [2004] method for estimating overall social outcome to our sample. The number and percent of participants by category was as follows: "Very Good," 10 (24%); "Good," 10 (24%); "Fair," 14 (34%); "Poor," 7 (17%); and "Very Poor," 0 (0%).

Comorbid Psychiatric Problems

Twenty-four participants (59%) had at least one diagnosed or suspected comorbid psychiatric condition, and 11 (27%) had two or more comorbid diagnoses. Fifteen participants (37%) were described as taking prescription medication aimed at regulating behavioral difficulties. The most common psychiatric comorbidity was depres-

sion, which was diagnosed for 13 participants (32%) and strongly suspected in 4 other cases (10%) who refused to seek treatment. Nine participants (22%) were described as having an anxiety disorder other than obsessive-compulsive disorder (OCD); three (7%) had a diagnosis of OCD. Six participants (15%) had a childhood diagnosis of an attention-deficit disorder and were treated with medications, but 2 were no longer medicated as adults. Two had Tourette's Disorder. One had a diagnosis of schizophrenia, and another individual had been diagnosed with bipolar disorder. One person had a history of pica and had been diagnosed with antisocial personality disorder, intermittent explosive disorder, and had a history of severe self-inflicted violence. When asked whether participants had destroyed property in anger over the past year, 6 reporters (15%) assented that this behavior occurred, and 2 (7%) stated that it occurred very rarely.

Chronic Medical Conditions

Seven individuals (17%) were reported to have a seizure disorder at some time in their lives. Five were treated for seizures at the time of the study; one had febrile seizures only in early childhood, and another man's seizures ended in his early 20s without recurrence.

Seven participants (17%) had confirmed sleep problems. Only 2 (5%) of the individuals affected with sleeping difficulties were being treated. Reporters for 8 participants (20%) noted abnormalities in sleep behavior, such as the apparent need for little sleep or unusual times of sleeping and waking, but none reported that the participant seemed excessively tired or adversely affected by their sleep behavior.

The health history was good, with 26 participants denying any chronic medical disorders. Medical conditions reported by the others included food and/or seasonal allergies in 7 participants (17%); 2 each (5%) with chronic back pain or hemorrhoids; and one each with a thyroid disorder, anemia, gout, flat feet, and high blood pressure.

Social Services

Parents reported on their adult son's or daughter's social services support, including Vocational Rehabilitation, the Division of Services for People with Disabilities (DSPD), Social Supplemental Income (SSI), and Medicaid. At the time of the study, 16 individuals (39%) were DSPD clients, and 3 (7%) were on a waiting list. Twenty-two (54%) had never applied for DSPD funding. Of the 25 individuals not receiving funding for services through DSPD, 13 (52%) had accessed Vocational Rehabilitation services in the past. Twenty-three participants (56%) received SSI and Medicaid benefits.

We used Engstrom et al.'s ratings of the level of social services needed. Twelve individuals (29%) required no support from social service agencies in adulthood. Eight participants (20%) required a "Low" level of support, meaning that they required "advice and support from habilitation; regular home help service." "Moderate" support was required by another 8 adults (20%), suggesting they needed "continuous home support; sheltered job; job assistant; regular support from psychiatry and/or habilitation." Thirteen participants (32%) required a "High" level of social services support indicating a need for "supported living; group home or institution; day center; personal assistant" [Engstrom et al., 2003, p 103].

Forensic Issues

Parents reported their adult child's history with law enforcement, either due to actual infractions or misinterpretations of their child's behavior. Fourteen participants (34%) had previous interactions with law enforcement officers, although in 2 cases these occurred only in early childhood when their son or daughter escaped caregivers' attention. The other 12 participants experienced some problem in late adolescence or adulthood. Behaviors resulting in intervention by law enforcement officers included performing maintenance tasks in restricted areas without any formal relationship to the business; observing children in public from a short distance; engaging in dangerous driving behavior under instructions from peers; sexual behavior aimed at a peer with developmental disabilities; stalking peers in pursuit of friendships; running from a police officer in a reportedly suspicious manner; and failing to pay parking tickets.

Cognitive Abilities

WAIS-III [Wechsler, 1997] full scale scores were available for 30 participants and only PIQ scores were available for 3 others (Table I). A paired *t*-test of the VIQ and PIQ scores for the 30 individuals who completed the entire

WAIS-III yielded no significant difference between these scores ($t(29) = 0.68, P = 0.505$).

Adaptive Behavior

VABS scores were obtained for all participants. The mean Adaptive Behavior Composite score for the sample was 65.0 (SD = 32.8, range = 20–116). The mean Communication domain score was 63.7 (SD = 33.9, range = 20–109), and the mean Daily Living Skills domain score was 76.2 (SD = 34.9, range = 20–119). The group mean Socialization domain score was 62.0 (SD = 31.8, range = 20–125). Paired *t*-tests comparing domain scores demonstrated that the Daily Living Skills domain was significantly higher than either the Communication ($t(40) = -4.21, P = 0.000$) or Socialization domains ($t(40) = -4.40, P = 0.000$). The difference between the Communication and Socialization domains was not significant ($t(40) = 0.56, P = n.s.$).

Associations Among Adult Outcome Measures

Correlations between the social functioning composite and other adult outcome measures were all large and significant (ranging from 0.50 to 0.83). The strongest correlations were between the social functioning composite and VABS scores ($r = 0.78$ – 0.81 ; Fig. 1). WAIS-III PIQ scores shared the weakest association with the social functioning composite, but the relationships were still moderate to strong ($r = 0.55$). High levels of support from caregivers and social service agencies were negatively correlated with the social functioning composite ($r = -0.76$ and -0.73 , respectively).

Associations Between Historical Measures and Outcome Measures

Correlations between historical and current cognitive indices were moderate to high. The correlation between historical global IQ and the WAIS-III FSIQ for the 30 individuals completing both measures was 0.51. Historical verbal IQ was correlated with current VIQ at $r = 0.58$,

Table I. IQ Test Results

	Childhood assessment			Adulthood assessment ^a	
	Age in years		Score	Score	
	<i>n</i>	Mean (SD) [range]	Mean (SD) [range]	<i>n</i>	Mean (SD) [range]
Nonverbal IQ	31	6.96 (2.82) [3.50–13.42]	87.68 (13.17) [65–115]	33	89.09 (23.36) [57–144]
Verbal IQ	25	7.28 (2.69) [3.75–13.42]	78.72 (17.34) [51–114]	30	89.10 (25.24) [51–139]
Full scale IQ	38	7.35 (4.12) [3.08–25.92]	83.68 (17.56) [36–137]	30	88.93 (25.73) [50–140]
Best IQ estimate ^b	41	7.17 (4.11) [3.08–25.92]	86.66 (15.44) [69–137]	–	–

^aMean age at the time of the adult assessments was 32.48 years (SD = 5.67 years, range = 22.33–46.42 years).

^bThe IQ score is the best available estimate of global cognitive ability as close to age 8 as possible. Seventy-five percent (31) were FSIQ, 17% (7) were PIQ, and IQ test type for 7% (3) was unknown.

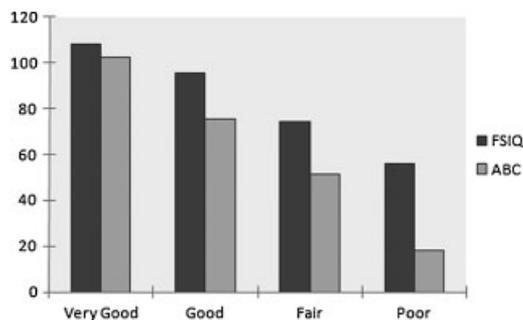


Figure 1. Trends in adult outcome variables by social functioning composite.

and historical nonverbal ability was moderately correlated to current PIQ ($r = 0.41$).

Historical full scale or global IQ was a moderately useful metric for prediction of outcome level ($df\ 3,37$; $F = 3.94$, $P = 0.016$), but historical verbal and nonverbal scores were not. Early global IQ was available for 38 of the 41 people assessed. When controlling for age of assessment, this score accounted for approximately 23% of the variance in predicting outcome category, close to current VIQ, which accounted for 27% of the variance. Current PIQ accounted for only 14% of the variance.

All participants were reported to have had communicative phrase speech or better language by age 6. Neither the age of single word use nor the use of phrase speech as a continuous variable was a useful factor in discriminating between outcome groups overall. However, of the 7 participants in the “Very Good” outcome group, 6 had acquired phrase speech by age 4. Of the 7 participants in the “Poor” outcome category with this data, 5 were reported to have acquired phrase speech after age 4, but before age 6.

Change in IQ Scores

Despite the moderate to high correlations between historical and current IQ scores, there was substantial change in individual scores. Global cognitive ability/FSIQ changed by 1 standard deviation or more in 17 of the 30 people assessed on both occasions (10 increased and 7 declined). Almost half of those ($n = 9$ of 20) completing measures of verbal ability on both occasions demonstrated a change of at least 1 standard deviation (7 increased and 2 declined), and 11 of the 24 participants who completed nonverbal measures on both occasions obtained a difference in scores of at least 1 standard deviation (6 increased and 5 declined). As a group, those with “Very Good/Good” outcomes showed improved cognitive ability and those with “Fair/Poor” outcomes showed declines in measured cognitive ability ($t(29) = 4.47$, $P = 0.000$); a large increase in IQ was

associated with better social outcome. Change in measured verbal ($t(19) = 3.36$, $P = 0.004$) and nonverbal ($t(23) = 2.25$, $P = 0.036$) abilities also yielded significant differences between “Very Good/Good” and “Fair/Poor” categories.

Discussion

Diagnostic Stability

In spite of historical and ADI information strongly supporting a lifetime diagnosis of AD, 6 participants presented improved autistic symptoms to the point where they obtained subclinical scores on the ADOS. In cross-sectional samples, diagnostic procedures that assess current symptoms may miss adults with childhood AD who have made significant gains over time. Our results suggest that the ADOS, when used alone, may lack adequate sensitivity for correctly diagnosing some adults with past diagnoses of AD and ongoing, related difficulties. Furthermore, parent/caretaker recall of childhood symptoms and temporal events appears diminished over two decades. Our study highlights the importance of treating AD as a *lifetime* diagnosis, corroborated by childhood records.

Cognitive Functioning and Adaptive Behaviors

A change in global cognitive ability of one standard deviation or more was evident in 17 out of 30 participants. Variability in individual cognitive ability has also been noted in other samples [Howlin et al., 2004; Mawhood, Howlin, & Rutter, 2000; Rumsey, 1992]. A decrease in IQ may be a marker for important biological changes in a subset of individuals with AD.

The finding that adaptive behavior measures were the variables most closely correlated with outcome may have implications for training/intervention programs to foster independence in adulthood, particularly since the Daily Living Skills domain was the most closely related to better outcome. There were cases of individuals who obtained high IQ scores but lacked the practical living skills assessed on the VABS. It was clear that several of these people felt frustrated by these practical limitations. In contrast, 3 participants with relatively low IQ scores were able to care for themselves with little assistance. These individuals obtained “Good” or “Very Good” outcome ratings in spite of borderline cognitive abilities.

Outcome Adjustment Status

Overall, this sample obtained comparable or better outcomes in adulthood than other samples of similar early cognitive ability. Several factors could account for the relative success of this sample. We recruited only half of the eligible individuals, so we may have undersampled

lower functioning cases. However, our analyses of the representativeness of the follow-up sample do not support this notion. Some participants in this study were in early adolescence at the time of the initial assessment, and their cognitive ability level and other abilities may have stabilized by the time of their assessment. Participants in some previous studies were identified through clinical referrals for developmental concerns, whereas participants in this study were identified through research aimed at identifying all cases of autism in Utah using previously identified cases, reviews of clinical records, referrals from education and other service agencies, and self-referrals in response to media campaigns. Thus, some participants from purely clinical samples may have had more severe developmental concerns than some participants in this study.

Another possible factor is the support of the LDS communities in which many participants grew up and continue to live. The church building that members attend is determined by their address; thus, children go to school, attend church activities, and reside in a neighborhood as a cohort. Inclusion of individuals with disabilities is a strong LDS cultural value. Parents attend services and activities with their neighbors, sharing joys and concerns about their families. Families are often large, and in many cases a sibling's social circle extended to include the participant. Some participants had assistance finding work through these networks.

Comorbid Psychiatric Conditions

Rates of comorbid psychiatric difficulties were lower in this sample than in other samples, possibly due to limitations in our methodology [Eaves & Ho, 2008; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Howlin, 2003; Rumsey et al., 1985; Szatmari et al., 1989]. In some cases, comorbid conditions were so pronounced that they seemed to be the participants' primary difficulty. In spite of high IQ scores and adequate practical skills, a handful of participants were unable to seek employment and independence due to difficulties with anxiety.

Limitations of the Study

This study is limited by a number of factors. Our recruitment rate was just over half of those eligible. While the epidemiological survey records are a rich data source, standardized data collected from that time is limited. Much information was derived from records of service providers who used a wide range of assessment instruments. There was substantial variation in the ages at which participants were evaluated by these service providers and by the epidemiological survey team. There was also variation among participants in the time elapsed

between initial assessments and follow-up. Given that this sample comes from the extreme end of the range of cognitive functioning, it is likely that measurement error and regression to the mean are at play, and the true score for a participant with a historical IQ score of 70 could actually be much lower. Therefore, conclusions drawn from the early cognitive data must be treated cautiously.

Another limitation related to measurement was that the follow-up assessment protocol did not include alternative measures of cognitive ability for the 5 individuals who were unable to complete the WAIS-III. While results on alternative measures for those who appeared to lack the cognitive ability to complete the WAIS-III would likely have been low, this information may have increased the predictive power of other measures.

Other limitations are related to the nature of the sample. The calculated prevalence rate in the epidemiological survey sample was lower than in other studies during the same period [Fombonne, 2005], and it is likely that cases were missed. Participants in this study were diagnosed using DSM-III criteria [APA, 1980] and may have had more severe symptoms in childhood than would children diagnosed using the broader DSM-IV criteria [APA, 1994].

The sample was drawn from a unique geographic and cultural group with a significant religious influence, offering advantages and disadvantages to this project. The advantages were many, including a general willingness to help others and a strong focus on family relationships that may benefit individuals with AD. A disadvantage for this project could be that this sample may be less representative of the experience of other adults with autism and average-range cognitive abilities than would be the case with a sample from a more heterogeneous population.

Future Research

This study demonstrates both the feasibility and value of longitudinal autism research. While progress is being made by cross-sectional research in understanding autism spectrum disorders, longitudinal work is required to uncover childhood variables associated with level of functioning in adults with AD. While some individuals in our DSM-III defined sample were quite successful as adults, others were not. Identifying environmental supports associated with better outcome may guide decisions made by parents, policy makers, and clinicians.

This study encourages further research with the larger sample that was part of the epidemiological survey 20 years ago. Results from the current sample of individuals with DSM-III diagnosed AD and $IQ \geq 70$ should be complemented by the full sample of 241 DSM-III positive

and 138 children who did not meet DSM-III criteria. This unique source of longitudinal data is a valuable resource that is highly likely to yield important new information on the natural history of autism. Challenges lay in recruitment, retention, and the time remaining for meaningful participation by the subject's aging parents. Nevertheless, the potential gains from such future studies are visible on the horizon and call for renewed efforts.

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