

## Long-term outcome of children with autism who received different forms of early intervention during their preschool years: a pilot study of 15 young adults

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### Abstract

**Background:** Studies on early intervention have reported significant gains for many children with autism. Knowledge on how these children fare in adulthood is limited.

**Objective:** To examine long-term outcome of children with autism who received different forms of early intervention.

**Method:** Participants were 15 young people who had all been diagnosed with ICD-10 childhood autism during the preschool years. Five received intervention based on the UCLA model for early intensive behavioral intervention, and 10 received eclectic treatment. Participants were followed from their first autism diagnosis during the preschool years (time 1) to the age of six years (time 2). The participants are now in their twenties (time 3), and at this point in time, information on autism symptoms, co-occurring disorders, quality of life, functioning, participation, adaptive behavior, and overall outcome was gathered from parents. Six of the participants answered questionnaires on quality of life, functioning, and participation.

**Results:** The groups were comparable on all measures at time 1. Reassessment at time 2 showed that the early intensive behavioral intervention group had made significant gains in IQ, and that autism symptoms had decreased significantly, whereas such changes were not found for the eclectic treatment group. At time 3, most participants had considerable autism symptoms. Approximately half of them had received diagnosis of a co-occurring condition. Their quality of life and adaptive behavior was less favorable than that of the general population, but only a third had “poor” overall outcome. However, at time 3, hardly any differences were found between the groups.

**Conclusions:** To maintain gains made during the preschool years, appropriate intervention and services may need to be extended into adulthood. These services should take into account the perceived needs of the individual, as expressed by himself/herself and his/her family.

**Keywords:** adulthood; autism; early intervention; long-term outcome

### Introduction

There is a long tradition in follow-up studies on adults with autism spectrum disorder (hereafter, autism) of using the concept of “overall outcome” to summarize how they are faring. Outcome ratings are generally based on independence and social competence regarding employment, friendship, and living arrangements and are categorized accordingly

as ranging from “very poor” to “very good” (1, 2). Reviews of follow-up studies of adults with autism show that overall outcome was variable, where the diversity of the samples is an important contributing factor. However, only around 20% of participants fulfilled the criteria for “very good/good” outcome, and around 50% had “very poor/poor” outcome (3, 4).

Many long-term studies have also evaluated outcomes in specific areas, such as autism diagnosis, IQ, adaptive behavior and co-occurring disorders. A systematic review of follow-up studies in adulthood showed that the diagnostic status of autism remained stable, although most studies reported some overall improvements in autism symptoms. There was great individual variability in terms of stability and/or change in IQ over time, but the general trend was stability or some decrease. Although variability was also observed in adaptive behavior scores, they were relatively low over time, with some improvements (5).

Co-occurring disorders can affect the outcome of individuals with autism, influencing well-being, behavior and development. They can be a further cause of impairment and reflect additional disability (6, 7), but at least three of every four individuals with autism meet diagnostic criteria for another disorder (6, 8).

Quality of life has received increased attention as an important part of outcome measures, including assessments of both objective and subjective perceptions (by the individual and by persons close to the individual) of his or her well-being, and also how well the environment meets the individual's needs (1). A recent meta-analysis (9) showed that adults with autism had significantly lower quality of life than adults without autism. However, studies on quality of life in adults with autism have reported more positive results, compared with those based on the objective overall outcome measures (10, 11). Thus, to get a more complete picture of overall outcome, both objective and subjective criteria need to be taken into account.

Over the years, studies have indicated some improvements in outcome for people with autism. The reasons may be diverse, for example, young people with autism may have more opportunities now than before and, in most instances, they have received earlier diagnosis and specialized intervention. Furthermore, more individuals with good intellectual ability are nowadays diagnosed with autism (2, 5, 8, 12).

Lovaas' pioneer study (13) on early intensive behavioral intervention (EIBI) showed outstanding results, where intellectual ability and academic performance improved significantly. EIBI has repeatedly demonstrated success for children with autism, where they have outperformed children in control groups in cognitive functioning, language, and adaptive behavior (14-16). However, information on long-term effects into adolescence is limited, but promising (17).

The aim of this pilot study was to examine the long-term outcome of children with autism who received different forms of early intervention during

their preschool years, enquiring two research questions: 1) How do these individuals with autism fare in early adulthood? 2) To what extent do the different gains achieved during preschool years by different interventions persist into adult life?

## Method

### *Participants*

In the years between 1995 and 2000, a small group of children participated in the Iceland Young Autism Project (IYAP) and received intervention based on the UCLA model for EIBI (Supplement 1). Inclusion criteria were (i) a diagnosis of childhood autism according to ICD-10/F84.0 (18); (ii) chronological age between 24 and 42 months at intake; (iii) a ratio IQ/DQ score above 35 on the Bayley Scales of Infant Development-Second Edition (19); and (iv) residence in one of the three local communities in the capital area that had agreed to implement the program within their preschools. Exclusion criteria were (i) a presence of severe medical conditions that would prevent full participation in the treatment and (ii) parents not able or willing to adhere to their part in the treatment protocol (see Supplement 1).

Autism diagnosis took place at the State Diagnostic and Counselling Centre (SDCC) and was based on interdisciplinary evaluation. The procedures included the Autism Diagnostic Interview, Revised (ADI-R; 20), direct observation of behavior with the Childhood Autism Rating Scale (CARS; 21), developmental tests, neurological evaluation, and clinical observations from team members (22).

Parents of newly diagnosed children, who met the inclusion criteria during the recruitment period (1995 to 1997) for the study, were informed about the IYAP and invited to enroll their child. As a result, six children received EIBI, and 14 eclectic treatment (ET; 23). The children in the ET group were diagnosed at the SDCC during the same time period as the EIBI group and met all the inclusion criteria except for residence.

Participants were followed from intake (time 1) to the age of six years (time 2). The groups were comparable on age and all standardized measures at time 1. Reassessment at time 2 showed that the EIBI group had made significant gains in IQ, and that autism symptoms had decreased significantly, whereas such changes were not found for the ET group. Although statistical differences were not detected between the groups at time 2, effect sizes were large on all variables (Supplement 2). The participants are now in their early twenties (time 3), and the present study gathered data on them at this point in time. Of the original 20 individuals and their parents, 15 agreed to participate, five from the EIBI group and 10 from the ET group. The average age of the participants was 21.9 years (range, 19 to 24 years),

and the group comprised 13 male and two female participants.

## Measures

### *Symptoms of autism*

The Social Communication Questionnaire (SCQ; 24) is a screening instrument that was used to evaluate present symptoms of autism. The SCQ was developed on the basis of the ADI-R and consists of 40 items to which parents or caregivers answer yes or no. Cut-off score of 15 was used, as has been recommended. SCQ is available in lifetime and current behavior versions, and the latter was used in this study.

### *Attention-deficit hyperactivity disorder*

The Attention-deficit Hyperactivity Disorder-Rating Scale (ADHD-RS; 25) screens for symptoms of hyperactivity/impulsiveness and attention deficits. The items are based on the DSM-IV diagnostic criteria of ADHD. Four versions of the questionnaire exist: self-report of symptoms in childhood, self-report of current symptoms in adulthood, informant report of symptoms in childhood and informant report of current symptoms in adulthood. The latter two, or the informant-based versions, were employed in the present study. Items are scored on four parts: hyperactivity/impulsiveness in childhood and at present, and attention deficits in childhood and at present. Scores are then converted into standard scores with the average of 50 and a standard deviation of 10; the cut-off score of 65 is recommended (25, 26).

### *Adaptive behavior*

The Vineland Adaptive Behavior Scales, Second Edition (VABS-II; 27), a semi-structured interview administered to a parent or caregiver, was used to assess current adaptive behavior. For the age groups involved, the VABS measures three domains of adaptive behavior: communication, daily living skills, and socialization. Items are scored on a scale from 0 to 2, and these are converted into standard scores with the average of 100 and a standard deviation of 15.

### *Quality of life*

The Quality of Life Scale (QOLS; 28) was used to assess the participants' quality of life. The scale is intended to measure general satisfaction with life and contains 16 items that assess the following: material and physical well-being; relationships with other people; social, community and civic activities; personal development and fulfilment; and recreation. Scores range from 16 to 112, where larger values indicate better quality of life.

### *Functioning and participation*

The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0; 29) is a questionnaire that assesses daily functioning and participation of individuals with disability in six areas: understanding and communication skills, activity in life, participation in society, how an individual takes care of himself/herself, how the individual gets around, and how he or she gets along with other people. Scores range from 0 to 100; the higher the score, the higher level of disability and the lower the level of functioning and participation.

### *Status and overall outcome*

An interview with parents was designed for the purpose of the study to obtain information about the status and overall outcome of the participants. The interview consists of 17 open-ended questions regarding present residence, occupation/education, services, friendship, hobbies, well-being/mental disorders, and medication. This information was used to rate overall outcome in social functioning and independence as proposed by Howlin et al. (2), where the sum of scores from three domains, that is, employment, friendship, and independent living, are combined into outcome categories ("very good," "good," "fair," "poor," and "very poor").

## Procedure

An invitation to participate, with an introduction letter, was sent to the participants and their parents. When informed consent had been given, a date was set for an interview, which took place either at the SDCC, at the participant's home, or over the phone. Interviews with participants residing outside the capital area took place over the phone, and the questionnaires were sent to their homes. The researcher started with the open interview, and then moved on to the semi-structured interview (VABS-II), and finally asked the participants and/or parents to fill out the questionnaires, that is, QOLS, ADHD-RS, WHODAS 2.0, and SCQ. The participants were asked to fill out two of the questionnaires, the QOLS and the WHODAS 2.0. Nine participants did not have the ability to answer for themselves, and in those cases, the assessment was solely based on information from parents.

Permissions from the Scientific Committee at the SDCC and the National Bioethics Committee of Iceland (VSMb2015090020/03.01) were granted for this study.

## Data analysis

Data were analyzed for the whole group and comparisons were also made between the original EIBI and ET groups. Statistical analysis was

performed using SPSS-20. Descriptive statistics were explored, and correlations between variables were computed. Because of the small sample size, statistical significance was not reported. The findings should be treated as preliminary and need to be tested further in future studies.

## Results

### *Present symptoms of autism and co-occurring disorders*

Fourteen parents answered the SCQ, with the mean score of 15.79 (standard deviation = 5.56, range: 7 to 26). Nine participants had considerable symptoms of autism and scored above the cutoff score (15 points) on the SCQ. Of the 15 participants, seven had received a co-occurring diagnosis: five with different kinds of anxiety disorders, and of these, two with major depressive disorder. The remaining two participants were diagnosed with ADHD. Some of the others were suspected of having a co-occurring disorder, but without formal diagnosis. Parents of five participants suspected that their child had ADHD, parents of four suspected anxiety disorder and parents of two suspected obsessive-compulsive disorder. The majority (73%) of parents were concerned about the participants' mental health, most commonly anxiety and depression.

On the ADHD Rating Scale, four participants screened positive for attention-deficit disorder, and three for hyperactivity/impulsivity (T-score over 65). Regarding symptoms in childhood, eight participants screened positive for attention-deficit disorder and three for hyperactivity/impulsivity disorder.

Of the 15 participants, nine were on psychotropic medication, most commonly targeting anxiety.

### *Adaptive behavior, quality of life, functioning, and participation*

The VABS-II interview was administered to parents of all 15 participants. The mean of the adaptive behavior composite score was 58.53 (standard deviation = 26.16, range: 20 to 108). The mean score on the Communication domain was 56.13 (standard deviation = 26.47, range: 21 to 104), the Socialization domain 63.40 (standard deviation = 27.62, range: 20 to 103), and the Daily Living Skills domain 63.33 (standard deviation = 24.90, range: 25 to 112).

Parents of 13 participants answered the QOLS, with a mean score of 78.38 (standard deviation = 13.65, range: 57 to 110), and parents of 14 participants answered the WHODAS 2.0, with a mean score of 32.44 (standard deviation = 19.46, range: 7.64 to 68.06). Six of the participants were able to report on their own quality of life as well as functioning and participation. Their mean score on the QOLS was 83.00 (standard deviation = 19.55, range: 54 to 112), and on the WHODAS 2.0, 23.62

(standard deviation = 16.41, range: 3.47 to 42.92). The mean score of those 6 and the corresponding parents on the QOLS was nearly identical, that is, 83.00 and 81.30, respectively.

The mean scores of participants and their parents on the WHODAS 2.0 were 23.62 and 20.02, respectively.

### *Status and overall outcome: interview with parents*

#### *Service*

In childhood, the majority (n = 14) of participants had personal support, travel assistance, and special education, and their families received respite care. Seven of the participants were not receiving any service when the interview took place, four of them because the parents claimed they did not need any. The majority (n = 14) of the parents were pleased and grateful for the service their children had received. However, they were displeased with the fact that much of the service terminated after graduation from secondary school at 16 years of age. Many of them said that their child needed more activity, especially social and leisure activities, and challenging enough employment. Lastly, some of the parents and the participants mentioned that there was not enough information available regarding what services they were eligible for, a lack of appropriate residential arrangements, and insufficient support for individuals living alone.

#### *Residence, education, and occupation*

Of the 15 participants, seven lived with their parents, four in a home for people with disabilities, and four resided independently. A great majority of both participants and parents were satisfied with the current living arrangements. Thirteen participants had graduated from high school and one had received a university diploma, but the majority received substantial support. Six of the participants spent a part of the day at a rehabilitation center where they received individualized training, most often without salaries. Four participants were employed with support, one had a full-time job, and the remaining four were unemployed.

#### *Leisure activities, interests, and friendship*

All the participants had few but intense interests and could spend a lot of their time fulfilling those interests. Movies, cinema, music, sports, cooking, and computers were dominating interests. Eight of the participants had no friends other than family members, and the remaining seven said they had at least one friend they spent some time with. One should bear in mind that some of the participants were not interested in having friends.

*Overall social outcome*

Five participants were rated as having a “good” outcome, that is, they had friends and acquaintances, worked with or without support, and lived independently, albeit they required a minor degree of support in daily living. Five participants were rated as having a “fair” outcome, that is, worked with

support, were mostly living with their parents, needed some degree of support, and had some or no friends. The remaining five participants were rated as having a “poor” outcome, that is, they lived with their parents or in a home for people with disabilities, required considerable or almost complete support in daily living, and had no friends.

**TABLE 1.** Descriptive statistics for the early intensive behavioural intervention (EIBI) group and the eclectic treatment (ET) group on standardized measures at time 3

	Mean (SD; Range)	
	EIBI Group (n=5)	ET Group (n=10)
Autism symptoms*	15.20 (3.83; 10-19)	16.11 (6.53; 7-26)
Attention deficit present <sup>†</sup>	54.40 (16.35; 40-81)	61.33 (16.64; 45-84)
Hyperactivity/impulsivity present <sup>†</sup>	48.00 (11.02; 39-67)	53.44 (17.51; 39-85)
Adaptive behavior <sup>‡</sup>	55.80 (19.42; 23-73)	59.90 (29.85; 20-108)
Communication	57.20 (21.59; 21-77)	55.60 (29.69; 21-104)
Socialization	59.20 (24.43; 20-82)	65.50 (30.12; 20-103)
Daily living skills	58.60 (10.95; 42-68)	65.70 (29.88; 25-112)
Quality of life <sup>§</sup>	74.20 (15.12; 57-95)	81.00 (12.98; 69-110)
Functioning and participation <sup>  </sup>	30.69 (16.62; 7-48)	33.41 (21.68; 5-58)
Overall social outcome <sup>¶</sup>	6.60 (2.88; 4-11)	5.70 (3.37; 0-10)

Note. \*SCQ, Social Communication Questionnaire

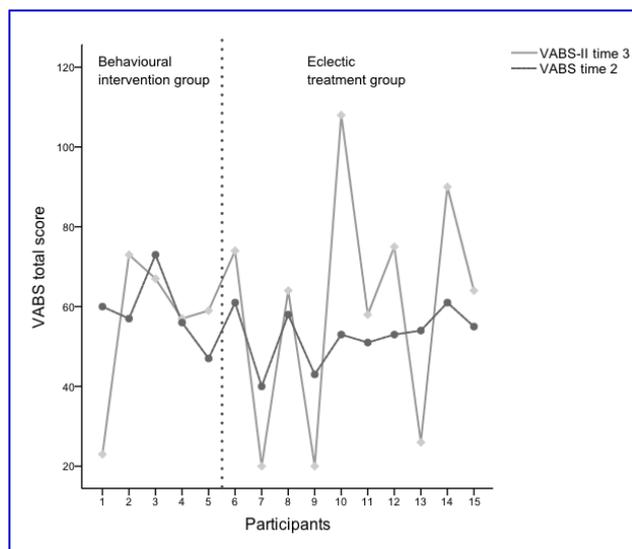
<sup>†</sup>ADHD-RS, ADHD Rating Scale

<sup>‡</sup>VABS-II, Vineland Adaptive Behavior Scales, Second Edition

<sup>§</sup>QOLS, Quality of life Scale

<sup>||</sup>WHODAS-2, WHO Disability Assessment Schedule 2.0

<sup>¶</sup>See Howlin et al. (2004) for outcome rating



**FIGURE 1.** Individual comparison on VABS at time 2 and VABS-II at time 3. VABS indicates Vineland Adaptive Behavior Scales.

### ***Comparison between groups in adulthood***

Table 1 shows the mean scores, standard deviations, and ranges for the original EIBI and ET groups at time 3, on the SCQ, the ADHD-RS, the VABS-II, the QOLS, the WHODAS 2.0, and overall social outcome. The differences between the groups were negligible on all measures, but there were considerable variations in scores between individuals on all of them.

Figure 1 describes the participants' total scores on adaptive behavior at time 2 (VABS) and 3 (VABS-II), which also show great individual variation, and show 10 participants having higher scores now (time 3) than when they were six years old.

### ***Relationship between childhood measures and adult outcomes***

#### *Childhood cognitive ability*

The correlation of IQ at time 2 and overall outcome at time 3 was high ( $r_s = -0.76$ ). Thus, three of the four individuals with  $IQ \geq 70$  at time 2, had "good" overall outcome at time 3, and one of them had "fair" outcome. Three of the four individuals who had  $IQ \leq 50$  at time 2 had a "poor" outcome at time 3, and one of them a "fair" outcome. IQ at time 2 was also related to VABS-II at time 3 ( $r_s = 0.79$ ).

#### *Childhood autism symptom severity*

CARS scores at time 2 were correlated to both overall outcome at time 3, ( $r_s = 0.56$ ) and VABS-II at time 3 ( $r_s = -0.54$ ).

Other relationships between time 2 and time 3 variables were moderate or low.

## **Discussion**

The present study examined the outcome of young adults who were diagnosed with childhood autism at an early age and received different forms of early intervention during the preschool years. The results show a great individual variation in symptoms of autism and co-occurring disorders, and in the form of residence, occupation, friendship, adaptive behavior, and quality of life.

Generally, the long-term outcome of individuals with autism shows diagnostic stability over time, although autism symptoms may decrease (5). In some instances, in the present study, one can assume the same, where reported symptoms of autism had decreased. Six of the participants had lower total scores than the recommended cutoff on the SCQ, but individual differences were substantial.

Most of the parents were concerned about their child's mental health, and co-occurring disorders

were common. Nearly half of the participants had received co-occurring diagnoses, which is a lower rate of comorbidity than has commonly been found among adults with autism (8, 30). Anxiety disorders were most common, with five participants having received a diagnosis of anxiety disorder, and four suspected of having one. In one study, approximately half of the adults with autism had anxiety disorders (8), and in other studies, the range was from 22% to 39% (30). Half of the participants who screened above the cutoff score of symptoms for attention deficit in childhood screened above the cutoff on present symptoms. Regarding hyperactivity/impulsivity, the same three participants screened above the cutoff in both childhood and adulthood. Previous studies have reported rates of ADHD in young adults with autism as high as 28% (30). For some individuals, co-occurring conditions were so pronounced that they caused considerable difficulty, affected independence, and some of the participants were unable to seek employment due to anxiety and/or depression. Co-occurring disorders can greatly influence outcome, and information about these disorders is important when it comes to services and interventions for young people with autism.

A high proportion of the participants in the present study were on psychotropic medication, which is consistent with other studies on adolescents and adults with autism (31, 32). Moreover, it has been shown that these individuals are likely to continue on medication over time, and the proportion of those who are on medication tends to increase with age (31). We did not collect information on what type of medication the participants were on, but such information may be useful to understand the use and the effectiveness of this medically prescribed treatment.

Adaptive behavior was generally poor among the participants in the present study, and individual variability great. The group mean was more than two standard deviations from general age norms, which suggests that the majority of the participants need support with daily activities. Other studies have also shown individual differences in adaptive behavior, and thus the degree of support needed with daily living. Moreover, they have shown that adaptive functioning among individuals with autism tends to improve with age (5, 33). This was true for 10 of the participants in the present study, although in most instances, the improvement was small. Adult adaptive functioning was reported better in daily living skills and socialization than communication, which differs from other studies where socialization appeared to be the poorest domain (5, 34).

Importantly, the participants reported better

quality of life than Icelandic people receiving trans-diagnostic cognitive behavioral group therapy in primary care for depression and/or anxiety, but poorer than university students (35). Billstedt et al. (10) reported similar results, where the quality of life of adult individuals with autism was better than could be expected despite impairments and low level of independence.

The mean score on the WHODAS 2.0 was as high as or higher than almost 12% of the general population (29). In a recent large study (36), the WHODAS 2.0 was used to measure disability among a diverse group of people. The mean score for people with autism was very close to the mean score in our sample (32.44 vs. 33.10), that is, significantly higher than that of people without disability, similar to that of people with schizophrenia and mental retardation, and considerably lower than that of people with dementia and stroke.

Assessment by participants and their corresponding parents regarding quality of life (QOLS) and functioning and participation (WHODAS 2.0) was in most cases similar. This has not been the case in other studies, where parents rate the quality of life of their children lower than the children themselves do, whether or not based on proxy methods (9, 37).

The results show great individual differences regarding the participants' status, with some of them living independently, having received good education and being employed, whereas others lived in a group home and needed constant support. About a quarter (26.7%) of the participants lived by themselves. This is a higher proportion compared with other studies based on similar autism populations, which have shown that a minority of adults with autism achieve independent living, or only up to 13% (2, 8, 10).

All the participants had attended mainstream schools where they received support and one had graduated from a university. Generally, there is a great variability in findings on school attendance among individuals with autism, where most of them have either been in special schools or provisions (8, 10), or in regular schools with support (2, 38). Only a few individuals, in comparable longitudinal studies, have attended or graduated from a university (2, 8, 10, 38).

Almost three-quarters (73.7%) of the participants had some kind of work, which was most often in a rehabilitation center. One had supported employment, and one had a full-time job. The employment level of adults with autism varies between studies. Some show results similar to ours (10, 38, 39), whereas others report higher (13.2%) employment participation without support, where the most able individuals were working independently or self-employed (2). Still higher

(21.8%) employment rate was reported in a Japanese study, which at that time reflected prosperous economic conditions with high demand for labor (40). Reviews on adults with autism have shown that employment levels are generally disappointing, even for those who are high functioning (30, 41).

Developing friendship is a challenge for many individuals with autism. However, almost half (46.7%) of the participants had at least one friend. In other comparable studies, the rate is somewhat lower, or ranging from 12% to 33% (2, 8, 10), and in one study, friendships were rarely reported (38).

In terms of overall outcome, just over 30% of the participants in the present study were considered as having a "good" outcome, and just over 30% a "poor" outcome. This is a more favorable outcome than that reported in recent reviews (5, 30), where approximately half of the participants were considered to have a "poor/very poor" outcome, and even more favorable compared with the rate (61.9%) reported for samples containing only participants with childhood autism (4).

Both IQ and CARS scores at time 2 were related to overall outcome at time 3. Autism severity, IQ, and verbal functioning in childhood are among the strongest prognostic factors in autism. However, even among individuals with favorable measures in childhood, variations in adulthood have been observed (5, 30). Thus, the individual in our study with the highest IQ (> 100), and the lowest level of autism symptoms, was rated as having a "fair" outcome. In this case, co-occurring disorders, such as depression and anxiety, affected independence and well-being.

The small sample size means that comparisons between the groups should be interpreted with caution. Pre-intervention (time 1), IQ, and symptoms of autism were comparable between the groups, but at post-intervention period (time 2), the participants who had received EIBI showed, on average, more gains than those in the ET group (Supplement 2). Today (time 3), it looks as though the different effects of the early intervention methods have faded out over the years. It is hard to speculate why, as confounding variables are many and 15 years have passed between follow-up measures. The participants have received varied levels of service, different kinds of education, lived in different environments, and now work at different places. Comorbid disorders can play an important part in their outcome, and the question arises as to whether the EIBI group would have maintained their superior progress over the ET group if their specific intervention had been ongoing for a longer period of time.

This pilot study has some important limitations. The sample size was small and only two participants

were female. An additional limitation concerns comparison of long-term effects. The instruments used in the first study could not be used in the present one because of lack of funds, with the exception of the VABS. In IYAP, autism symptoms were assessed with the ADI-R and the CARS, but in the present study, the SCQ was used. It would have been preferable to add a direct observation of behavior with a standardized autism spectrum disorder diagnostic instrument. In addition, IQ was not assessed in the present study (time 3), and therefore could not be compared with IQ at times 1 and 2. As a result, an important comparison between the groups could not be made. Finally, the investigator, who collected the data at time 3, was not blind to the group assignment.

However, the study has some strengths. First, the inclusion criteria were precise, where all participants received the same diagnostic procedures, and the same classification (ICD-10/F84.0). Second, outcome measures were comprehensive. Third, there was repeated follow-up of the same individuals.

This is one of the few studies investigating the long-term effect of EIBI. Longitudinal studies on adults who received EIBI and other interventions in childhood are necessary on a larger scale, and with a more rigorous methodology, before definite conclusions can be drawn regarding their long-term effectiveness.

### **Clinical significance**

The overall social outcome in this study seems more favorable than reported in most long-term studies on adults with autism (4, 5, 30). However, most of the young people participating in the study experienced many difficulties in their daily life. This even applied to those where early intervention resulted in large gains. To maintain these gains, appropriate intervention and support may need to be extended beyond the preschool years.

Although IQ and autism severity in childhood (time 2) were statistically correlated with overall outcome in early adulthood (time 3) for the group as a whole, the clinical value of this relationship is not straightforward on an individual level. Thus, an individual with an IQ score > 100, and autism symptoms below cutoff on the CARS at time 2, was rated as having a “fair” outcome at time 3, and the same applied to an individual with IQ < 50, and severe autism symptoms on the CARS. This suggests that outcome in adulthood may depend heavily on the continuation and the appropriateness of the services.

Knowledge and understanding of both short- and long-term needs and challenges should be included in intervention programs. Changing service needs over the lifespan call for an on-going individual

assessment and monitoring of these needs. It would be worthwhile to include therein periodical screening for co-occurring disorders. For example, anxiety and depression emerge during adolescence in a high proportion of individuals with autism, and ADHD is also common (8, 30). There was an indication that these disorders were underdiagnosed in our sample. Preventive actions and appropriate treatment should aim at ameliorating the effect that co-occurring disorders may have on their well-being, functioning, and participation in daily life.

Although all the participants in our study were diagnosed with childhood autism, they are quite a heterogeneous group. This calls for individualized and flexible services in terms of support provided. Parents were generally satisfied with the services provided through secondary school, but at present, they expressed concerns regarding leisure activities, work, and living arrangements. This is consistent with the major parental concerns reported in a recent study in a somewhat different culture in southern Europe (38). This supports the notion that provision of services for adults with autism has not kept up with the development and growth of services available for the younger age groups and needs to be given greater attention. This also relates to adult intervention research, which is way behind research focusing on children, in both quantity and quality (3, 42).

Overall social outcome and quality of life do not only depend on individual characteristics and service provisions but also on how well the individual and his/her family perceive that his/her needs are met. Thus, it is important to give them the opportunity to express themselves about these issues and to take their opinion into account when services are organized and provided.

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### **Conflicts of interest**

The authors declare no conflict of interest.

### **References**

1. Henninger NA, Taylor JL. Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism* 2013;17:103-16.
2. Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *J Child Psychol Psychiatry* 2004;45:212-29.
3. Howlin P. Outcomes in adults with autism spectrum disorders. In: Volkmar F, Rogers S, Paul R, Pelphrey K (eds). *Handbook of*

- Autism and pervasive developmental disorders 4th ed. vol. 1. Hoboken, NJ: John Wiley & Sons; 2014. p. 97-116.
4. Steinhausen HC, Mohr Jensen C, Lauritsen MB. A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood. *Acta Psychiatr Scand* 2016;133:445-52.
  5. Magiati I, Tay XW, Howlin P. Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clin Psychol Rev* 2014;34:73-86.
  6. Billstedt E. Autism and Asperger syndrome: coexistence with other clinical disorders. *Acta Psychiatr Scand* 2000;102(5):321-30.
  7. Gjevik E, Eldevik S, Fjæran-Granum T, Sponheim E. Kiddie-SADS reveals high rates of DSM-IV disorders in children and adolescents with autism spectrum disorders. *J Autism Dev Disord* 2011;41:761-9.
  8. Eaves LC, Ho HH. Young adult outcome of autism spectrum disorders. *J Autism Dev Disord* 2008;38:739-47.
  9. Van Heijst BF, Geurts HM. Quality of life in autism across the lifespan: a meta-analysis. *Autism* 2015;19:158-67.
  10. Billstedt E, Gillberg IC, Gillberg C. Aspects of quality of life in adults diagnosed with autism in childhood: a population-based study. *Autism* 2011;15:7-20.
  11. Moss P, Mandy W, Howlin P. Child and adult factors related to quality of life in adults with autism. *J Autism Dev Disord* 2017;47:1830-7.
  12. Rutter M. Incidence of autism spectrum disorders: changes over time and their meaning. *Acta Paediatr* 2005;94:2-15.
  13. Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *J Consult Clin Psychol* 1987;55:3-9.
  14. Eldevik S, Hastings RP, Hughes JC, Jahr E, Eikeseth S, Cross S. Meta-analysis of early intensive behavioral intervention for children with autism. *J Clin Child Adolesc Psychol* 2009;38:439-50.
  15. Makrygianni MK, Reed P. A meta-analytic review of the effectiveness of behavioural early intervention programs for children with autistic spectrum disorders. *Res Autism Spectr Disord* 2010;4:577-93.
  16. Peters-Scheffer N, Didden R, Korzilius H, Sturmey P. A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with autism spectrum disorders. *Res Autism Spectr Disord* 2011;5:60-9.
  17. McEachin JJ, Smith T, Lovaas OI. Long-term outcome for children with autism who received early intensive behavioral treatment. *Am J Ment Retard* 1993;97:359-372.
  18. World Health Organization. The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines. Geneva: World Health Organization; 1992.
  19. Bayley N. Manual for the Bayley Scales of Infant Development. 2nd ed. New York: Psychological Corporation; 1993.
  20. Rutter M, Le Couteur A, Lord C. Autism Diagnostic Interview–Revised. Los Angeles CA: Western Psychological Services; 2003.
  21. Schopler E, Reichler RJ, Renner BR. The Childhood Autism Rating Scale (CARS): Manual. Los Angeles, CA: Western Psychological Services; 1988.
  22. Jónsdóttir SL, Saemundsen E, Antonsdóttir IS, Sigurdardóttir S, Ólason D. Children diagnosed with autism spectrum disorder before or after the age of 6 years. *Res Autism Spectr Disord* 2011;5:175-84.
  23. Jónsdóttir SL, Saemundsen E, Ásmundsdóttir G, Hjartardóttir S, Ásgeirsdóttir BB, Smáradóttir HH, et al. Follow-up of children diagnosed with pervasive developmental disorders: stability and change during the preschool years. *J Autism Dev Disord* 2007;37:1361-74.
  24. Rutter M, Bailey A, Lord C. The Social Communication Questionnaire: Manual. Los Angeles, CA: Western Psychological Services; 2003.
  25. DuPaul GJ, Power TJ, Anastopoulos AD, Reid R. ADHD Rating Scale-IV: Checklists, Norms, and Clinical Interpretation. New York, NY: Guilford; 1998.
  26. Magnússon P, Smári J, Sigurðardóttir D, Baldursson G, Sigmundsson J, Kristjánsson K, et al. Validity of self-report and informant rating scales of adult ADHD symptoms in comparison with a semistructured diagnostic interview. *J Att Disord* 2006;9:494-503.
  27. Sparrow SS, Cicchetti DV, Balla DA. Vineland Adaptive Behavior Scales. 2nd ed. Circle Pines, MN: American Guidance Service; 2005.
  28. Burckhardt CS, Anderson KL. The Quality of Life Scale (QOLS): reliability, validity, and utilization. *Health Qual Life Outcomes* 2003;1:60.
  29. Üstün TB, Kostanjsek N, Chatterji S, Rehm, J (Eds). Measuring health and disability: Manual for WHO Disability Assessment Schedule WHODAS 2.0. Geneva: World Health Organization; 2010.
  30. Howlin P, Magiati I. Autism spectrum disorder: outcomes in adulthood. *Curr Opin Psychiatry* 2017;30(2):69-76.
  31. Esbensen AJ, Greenberg JS, Seltzer MM, Aman MG. A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. *J Autism Dev Disord* 2009;39:1339-49.
  32. Buck TR, Viskochil J, Farley M, Coon H, McMahon WM, Morgan J, Bilder DA. Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *J Autism Dev Disord* 2014;44:3063-71.
  33. Freeman BJ, Del'Homme M, Guthrie D, Zhang F. Vineland Adaptive Behavior Scale scores as a function of age and initial IQ in 210 autistic children. *J Autism Dev Disord* 1999;29:379-8.
  34. Farley MA, McMahon WM, Fombonne E, Jenson WR, Miller J, Gardner M, et al. Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Res* 2009;2:109-18.
  35. Hrafnsson Ó, Guðmundsson M. Próffræðilegir eiginleikar Lífsgæðakvarðans (QOLS). [Psychometric properties of the Quality of Life Scale (QOLS)]. BA [thesis]. Reykjavík: University of Iceland; 2007.
  36. Chi WC, Chang KH, Escorpizo R, Yen CF, Liao HF, Chang FH, et al. Measuring disability and its predicting factors in a large database in Taiwan using the World Health Organization Disability Assessment Schedule 2.0. *Int J Environ Res Public Health* 2014;11:148-61.
  37. Egilson ST, Ólafsdóttir LB, Leósdóttir T, Saemundsen E. Quality of life of high-functioning children and youth with autism spectrum disorder and typically developing peers: self-and proxy-reports. *Autism* 2017;21:133-41.
  38. Operto, FF, Martino F, Rinaldi A, Cerracchio A, Salvati G, Orza M, et al. Long-term outcome of autism spectrum disorder: a retrospective case study in a southern Italian region. *Ital J Pediatr* 2017;43:83.
  39. Saldaña D, Álvarez RM, Lobatón S, Lopez AM, Moreno M, Rojano M. Objective and subjective quality of life in adults with autism spectrum disorders in Southern Spain. *Autism* 2009;13:303-16.

40. Kobayashi R, Murata T, Yoshinga K. A follow-up study of 201 children with autism in Kyushu and Yamaguchi areas in Japan. *J Autism Dev Disord* 1992;22:395-410.
41. Levy A, & Perry A. Outcome in adolescents and adults with autism: a review of the literature. *Res Autism Spectr Disord* 2011;5:1271-82.
42. Edwards TL, Watkins EE, Lotfizadeh AD, Poling A. Intervention research to benefit people with autism: how old are the participants? *Res Autism Spectr Disord* 2012;6:996-99.

## Supplement 1

### Intervention for children receiving early intensive behavioural intervention

The intervention was based on the UCLA model for early intensive behavioural intervention (EIBI), an applied behaviour analytic (ABA) intervention model. The teaching methods consisted of discrete trial teaching, incidental teaching, and natural environment teaching. A curriculum was developed for each child, and it was continually revised based on day-to-day data recordings, and regular skill assessments. The teaching programme was comprehensive, in that it addressed skills in all areas of development. Desired behaviour, related for example to language, social skills, play skills, self-help skills, and academics, was increased with positive reinforcement. Undesirable behaviour, such as self-stimulatory and self-injurious behaviour, temper tantrums, and aggression towards others, were not reinforced, and thus decreased (1-3).

The intervention was mainly carried out in normal pre-schools close to the children's homes, since Icelandic legislation provides children with developmental disabilities the right to services at that level. The preschool provided each child with a tutor, or a special educator, who received training in the teaching methods based on ABA.

To begin with, the intervention was one-to-one in a separate room. When working on basic social skills, one or more of the typically developing peers were invited and prepared to interact with the autistic child. When the child was ready to participate in a normal group setting, or when working on generalization and maintenance, he or she entered that setting in the preschool with the tutor, who then provided whatever support was needed. The preschool provided the child with at least 30 hours per week of special education based on ABA. In addition, parents were responsible for providing intervention for five to ten hours per week, at home and in other environments that are a part of a normal child's everyday environment, where the emphasis was on generalization and maintenance of newly learned skills.

An intervention team was established for each child, consisting of two to three tutors who worked directly with the child, the parents, the head of the child's department in the preschool, a consultant from the local community, the project leader, and a clinic supervisor. The project leader had completed a 12-month internship with Dr. Lovaas at UCLA, as well as courses on teaching methods based on ABA. Clinic supervisors, who visited the teams in Iceland regularly, came from other sites affiliated with the UCLA Multi-Site Young Autism Project, and had passed the relevant UCLA criteria. This was before the *Behavior Analyst Certification Board*<sup>®</sup> was established in 1998.

At the start of the intervention, a two- to three-day workshop was provided for the parents and tutors, and all others who would be involved with the intervention, such as support families. Thereafter, weekly meetings were held with the treatment team, where the purpose was to provide further training and feed-back on the use of teaching methods, to coordinate the work of everyone involved, to review programmes, and to introduce new ones. One-day workshops were held three to four times a year with a clinic supervisor from abroad. Video supervision was also provided when needed, and the treatment team was in regular contact with the clinic supervisor through e-mail.

Treatment fidelity for the site director and the clinic supervisors was established through the UCLA standards, which included supervised work with children of various developmental levels, written exams, and passing the UCLA criteria for level II therapists. Every six months, the trainers each provided a 15-minute videotape, where they demonstrated teaching certain basic programmes. The clinic supervisors and the site director scored the videotapes, and a sample of them was sent to the director of the UCLA Multi-Site Young Autism Project for scoring and approval.

## References

1. Lovaas OI. Teaching individuals with developmental delays: Basic intervention techniques. Austin, TX: Pro-Ed; 1993.
2. Shull L. UCLA Young Autism Project. In: Volkmar FR. Encyclopedia of Autism Spectrum Disorders. New York, Springer; 2013;3199-3202. doi: 10.1007/978-1-4419-1698-3\_1312.
3. Smith T, Lovaas OI. Intensive and early behavioral intervention with autism: the UCLA Young Autism Project. *Infants Young Child* 1998;10:67-78.

## Supplement 2

Pre-intervention and follow-up of the early intensive behavioural intervention group (EIBI) ( $n=6$ ) and the eclectic treatment group (ET) ( $n=14$ ) for chronological age, IQ/DQ, adaptive behaviour, and autism symptoms

	Time 1. Pre-intervention		Time 2. Follow-up	
	EIBI Group <i>M (SD)</i>	ET Group <i>M (SD)</i>	EIBI Group <i>M (SD)</i>	ET Group <i>M (SD)</i>
CA (months)	34.50 (5.08)	38.79 (7.82)	66.50 (5.35)	70.07 (4.21)
IQ /DQ	49.17 (7.68) <sup>a)</sup>	52.50 (10.29) <sup>b)</sup>	66.67 (24.04) <sup>c)</sup> *	49.93 (19.54) <sup>d)</sup>
VABS	54.83 (4.35)	55.00 (1.00) <sup>e)</sup>	57.00 (9.27)	49.93 (7.87)
CARS	43.50 (5.84)	40.68 (5.80)	33.83 (4.20) *	39.00 (7.38)
ADI-R				
Soc	17.33 (3.20)	14.27 (3.04)		
Com	13.33 (3.33)	10.36 (4.67)		
RRB	3.67 (1.97)	2.82 (1.54)		

*IQ/DQ*, Intelligence Quotient/Developmental Quotient; *n*, number of participants; *SD*, standard deviation; *CA*, Chronological Age; *VABS*, Vineland Adaptive Behavior Scales; *CARS*, Childhood Autism Rating Scale; *ADI-R*, Autism Diagnostic Interview, Revised; *Soc*, Social Interaction; *Com*, Communication; *RRB*, Restricted Repetitive Behavior; *BSID-II*, Bayley Scales of Infant Development, Second Edition; *WPPSI-R*, Wechsler Preschool and Primary Scale of Intelligence, Revised.

<sup>a)</sup> Measured with *BSID-II* ( $n = 6$ ); <sup>b)</sup> Measured with *BSID-II* ( $n=13$ ), and with *WPPSI-R* ( $n = 1$ ); <sup>c)</sup> Measured with *BSID-II* ( $n = 1$ ), and with *WPPSI-R* ( $n = 5$ ); <sup>d)</sup> Measured with *BSID-II* ( $n = 7$ ), and with *WPPSI-R* ( $n = 7$ ); <sup>e)</sup> only available for three participants. \*  $p < .05$

The groups did not differ on chronological age, IQ, VABS, CARS, and ADI-R at time 1. For the EIBI group, IQ increased significantly from time 1 ( $Mdn = 45.00$ ) to time 2 ( $Mdn = 57.50$ ),  $U = 21$ ,  $\zeta = 2.20$ ,  $p = .028$ ,  $r = .90$ , and autism symptoms, as measured with the CARS, decreased significantly from time 1 ( $Mdn = 43.00$ ) to time 2 ( $Mdn = 34.75$ ),  $U = .000$ ,  $\zeta = -2.214$ ,  $p = .027$ ,  $r = .90$ . VABS scores did not change significantly between time 1 ( $Mdn = 53.50$ ), and time 2 ( $Mdn = 56.50$ ),  $U = 15$ ,  $\zeta = .943$ ,  $p = .345$ ,  $r = .38$ .

The ET group did not show significant gains in IQ over time, (time 1  $Mdn = 53.00$ ; time 2  $Mdn = 52.00$ ),  $U = 37$ ,  $\zeta = -.944$ ,  $p = .365$ ,  $r = .25$ , nor did they show decreases in autism symptoms, (time 1  $Mdn = 40.50$ ; time 2  $Mdn = 39.00$ ),  $U = 18$ ,  $\zeta = -1.651$ ,  $p = .099$ ,  $r = .44$ . Since VABS was missing for most of the participants in this group, it was not included in the analysis.

The differences between the groups at time 2 on IQ, CARS and VABS were not significant, however they did represent large-sized effects. More detailed results on this are as follows: IQ for the EIBI group ( $Mdn = 57.50$ ), and the ET group ( $Mdn = 52.00$ ),  $U = 27$ ,  $\zeta = -1.240$ ,  $p = .115$ ,  $d = .85$ . CARS scores for the EIBI group ( $Mdn = 34.70$ ), and the ET group ( $Mdn = 39.00$ ),  $U = 26$ ,  $\zeta = -.939$ ,  $p = .192$ ,  $d = .83$ . VABS scores for the EIBI group ( $Mdn = 56.50$ ), and the ET group ( $Mdn = 52.00$ ),  $U = 24.50$ ,  $\zeta = -1.445$ ,  $p = .153$ ,  $d = .90$ .