Where are they now? Long-term outcome of children with autism who received early intervention during their preschool years. A pilot study of 15 young adults.

Birta Brynjarsdóttir[1], Sigríður Lóa Jónsdóttir[2], Evald Sæmundsen[2,3] and

Jón Friðrik Sigurðsson[1, 3]

[1]Reykjavík University, [2]The State Diagnostic and Counselling Centre, [3]University of Iceland

Prologue

The prevalence of autism in adults is constantly increasing, but little is known about their transition from childhood into adulthood. In the years 1995 to 2000 a small group of children with autism participated in the Iceland Young Autism Project (IYAP), affiliated to the UCLA Multi-site Young Autism Project. The objective of the IYAP was to investigate the outcome of an intensive early behavioural intervention. Participants were followed from when they received a diagnosis of childhood autism (ICD-10/F84.0) before 42 months of age to the age of 6 years. Sigríður Lóa Jónsdóttir, psychologist, was the project leader of the IYAP and worked closely with the children in that study. It had been an ambition of hers to follow-up on them again and now was as good a time as any. We therefore set out to assess the participants' outcome and status today when they are in their early twenties. Because of the small and fixed sample size we wanted to do a comprehensive assessment and measure as many factors as possible. We contemplated the process of the study for some time, how best to procure the information we wanted, what measurements to use, what to ask about and so forth. To begin with we set out ambiguously and had interest in assessing intellectual ability and diagnostic stability, but as it turned out we did not have the funds to do that. However, at the completion of the study, it is my sincere opinion that we did a good job at gaining insight into many factors in the lives of young adults with autism. The study is the first in Iceland which has been conducted on the outcome and status of adults with autism and will hopefully encourage more to come.

The present study is a final thesis in the MSc programme in Clinical Psychology at the Reykjavík University. The thesis gives 30 credits (ETCS) and was carried out over three semesters. At the first semester the study was formulated, literature was explored and an outline of the introduction was written, in addition we applied for the permission from both the Scientific Ethical Committee at the State and Counselling Centre and the National

Bioethics Committee of Iceland. The permissions were granted at the beginning of the second semester and the data collection was carried out, the methods chapter was also drafted at that time. On the third and final semester the data analysis was conducted and the final draft of the thesis was written and edited until complete. The interviews with participants took place at the State Diagnostic and Counselling Centre, at the participants' home or over the phone, whatever suited them or their parents best.

The present study was conducted under the supervision of Sigríður Lóa Jónsdóttir and Evald Sæmundsen, psychologists at the State and Diagnostic and Counselling Centre in Iceland, and Jón Friðrik Sigurðsson, psychologist and Professor at Reykjvík University. I want to give my outmost gratitude to my advisors for their guidance, support, expertise and supervision. My family, friends and classmates also deserve a big thank you for being awe-inspiring in every way. Finally, I'm especially grateful for the participants and their families who gave their valuable time to participate in the study, a huge thanks goes out to them.

Abstract

Objectives: The prevalence of autism in adults is constantly increasing, but little is known about their transition from childhood into adulthood. This encourages studies on how children diagnosed with autism at an early age fare later in life. The aim of this study was to examine long-term outcome of children with autism who received different forms of early intervention. *Methods*: Participants were 15 individuals who participated in the Iceland Young Autism Project (IYAP), affiliated to the UCLA Multi-site Young Autism Project, during the period from 1995 to 2000. Five of the participants received behavioural intervention, but the remaining 10 formed a control group and received intervention as usual. Participants were followed from their first autism diagnosis before 42 months of age (time 1) to the age of 6 years (time 2). The participants are now in their twenties (time 3). Information was gathered from parents on autism symptoms, co-occurring disorders, adaptive behaviour, functioning and participation, service use and quality of life. *Results*: About half of the participants have received diagnosis of a co-occurring condition and more than half take psychotropic medication. Their adaptive behaviour and quality of life is poorer than that of the general population. Hardly any differences were found between the original experimental and comparison groups. *Conclusions*: This study is the first to examine outcome and status of young adults with autism in Iceland. The results showed great individual variation in most variables that were measured, which suggests that although all of the participants received the same diagnosis at an early age, the outcome for them in adulthood is diverse. The difference between those who received behavioural intervention and those who did not seems to have neutralised over the years.

Keywords: long-term outcome, early behavioural intervention, young adults with autism, quality of life, adaptive behaviour, co-occurring disorders

Autism was early on presumed to be a rare disorder, but its prevalence has increased massively. In a recent study in Iceland the estimated prevalence in children was 1.2% (Sæmundsen, Magnússon, Georgsdóttir, Egilsson, & Rafnsson, 2013). Recent epidemiological research has confirmed that the prevalence of autism in adults is parallel to that in children, where it is constantly increasing as well (Howlin, 2014). Despite this, research on interventions for adults with autism are scarce, as apparent in a recent examination of almost 150 studies on interventions, with only 1.7% of the participants 20 years or older (Edwards, Watkins, Lotfizadeh, & Poling, 2012).

Early behavioural intervention

In 1987, Lovaas' study on early behavioural intervention was published showing preeminent results. Intellectual ability and academic performance of children who received intensive behavioural intervention improved significantly (Lovaas, 1987). Results in Iceland have also demonstrated the success of such intervention. The preliminary results of the Iceland Young Autism Project (IYAP), affiliated to the UCLA Multi-site Young Autism Project, indicated that children who received early behavioural intervention showed considerably better progress than children in the comparison group (Jónsdóttir & Eikeseth, 2000). Today, early behavioural intervention has repeatedly demonstrated success for children with autism (Eldevik et al., 2009; Myer, & Johnson, 2007; Warren et al., 2011). However, information on long-term effects is unfortunately limited, but promising (McEachin, Smith, & Lovaas, 1993).

Outcome in adulthood

Long-term studies utilize the concept of outcome to assess the general state of adult individuals with autism (Jónsdóttir, 2014). At the end of the last century, long-term research on adults with autism suggested poor outcome overall (Billstedt, Gillberg, & Gillberg, 2005). Through the years outcome has improved and recent research indicates

better prognosis for many individuals. The reasons for this may be diverse, e.g. young people with autism may have more opportunities now than before and in most instances they have received earlier diagnosis, special education, speech therapy and/or behavioural intervention. Furthermore, more individuals with a good intellectual ability are nowadays diagnosed with autism (Eaves & Ho, 2008; Edwards et al., 2012; Howlin, Goode, Hutton, & Rutter, 2004; Rutter, 2005). Thus, increasing prevalence and more variable group of individuals with autism further encourage research on adults.

In order to evaluate overall outcome among adults with autism, researchers have developed standardised outcome criteria (Henninger & Taylor, 2013; Howlin, 2005; Howlin et al., 2004). Using these criteria, Howlin (2014) performed a systematic examination on 23 long-term studies on adults with autism. The results were variable because of the diversity of the samples, but only a minority of the participants fulfilled the criteria for good outcome and the majority fulfilled criteria for poor outcome.

Quality of life and adaptive behaviour

Certainly, more things matter than employment or residence and interest in quality of life as a part of an outcome measure in autism has increased substantially. Quality of life is a wide concept which unites physical health, mental state, independence, social participation, personal opinion, rights and relationship with the environment. When quality of life is assessed, subjective factors are taken into consideration, such as how the individual himself, and those who are close to him, perceive his quality of life. A recent meta-analysis showed a large difference in quality of life between adults with and without autism (Billstedt, Gillberg, & Gillberg, 2010; Schalock, 2004; Van Heijst & Geurts, 2014).

In addition, adaptive skills play an important role in the prognosis of children with autism and have been shown to be highly associated with outcome. Adaptive behaviour is

defined by the extent to which an individual is adept of being self-sufficient in everyday life (Billstedt et al., 2005; Farley et al., 2009; Freeman, Del'Homme, Guthrie, & Zhang, 1999; Howlin et al., 2004).

Co-occurring disorders

Co-occurring disorders can play a great part in the outcome of individuals with autism, influence wellbeing, behaviour and development. Co-occurring disorders can be a further cause of impairment and reflect additional disability for the individual in question (Billstedt, 2000; Gjevik, Eldevik, Fjæran-Granum, & Sponheim, 2011; Simonoff, et al., 2008). As many as three of every four individuals with autism meet diagnostic criteria for another disorder. Therefore co-occurrence of other disorders is the rule rather than the exception when it comes to autism (Billstedt, 2000; Eaves & Ho, 2008; Simonoff, et al., 2008).

The aim of this study was to examine long-term outcome of children with autism who received different forms of early intervention during their preschool years by answering these two main research questions: 1) Does the difference that existed between the experimental and comparison groups after the behavioural intervention they received when they were in preschool still exist? 2) How do these young individuals with autism fare fifteen years later?

Methods

Participants

In the years 1995 to 2000 a small group of children with autism participated in the Iceland Young Autism Project (IYAP), affiliated to the UCLA Multi-site Young Autism Project. The objective of the IYPT was to investigate the outcome of intensive early behavioural intervention. Participants were followed from when they received a diagnosis of childhood autism (ICD-10/F84.0) before 42 months of age (time 1) to the age of 6 years

(time 2). Six of the participants received behavioural intervention based on the UCLA young autism project (Shull, 2013), but the remaining 14 formed a control group and received intervention as usual (Jónsdóttir et al., 2007). The participants are now in their early twenties (time 3), and the present study gathered data on this point in time. Of these 20 individuals and their parents, who were contacted, 15 agreed to participate, five from the original experimental group and 10 from the comparison group.

The average age of the participants was 21.9 years (range 19 to 24 years) and the group comprised of 13 males and two females.

Measures

Information regarding outcome and status

To gather information about outcome and status of the participants an open interview was conducted. The interview consisted of 17 open ended questions regarding present residence, occupation/education, services, friendship, hobbies, wellbeing/mental disorders and medication. The questions were designed especially for the purpose of this research.

Adaptive Behaviour

To assess current adaptive behaviour, the Vineland Adaptive Behavior Scales, Second Edition (VABS-II; Sparrow, Cicchetti, & Balla, 2005), a semi-structured interview was administered to a parent or caregiver of the relevant individual. VABS-II assesses an individual's day-to-day adaptive functioning in a reliable and validated way. For the age groups involved, the interview measures three domains of adaptive behaviour: communication; daily living skill; and socialization. Items are scored on a scale from 0-2 and these are converted into standard scores with the average of 100 and a standard deviation 15 (Gillham, Carter, Volkmar, & Sparrow, 2000; Sparrow, Cicchetti & Balla, 1989; Sparrow et al., 2005).

Symptoms of autism

Present symptoms of autism were assessed using the Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003). SCQ is a short screening instrument that was developed on the basis of the Autism Diagnostic Interview-Revised (ADI-R). SCQ consists of 40 items that parents or caregivers answer yes or no. The cut-off score of 15 has been recommended. SCQ is available in lifetime and current behaviour versions. The lifetime version emphasizes the whole developmental history of the individual in question but the current behaviour version, which was used in this study, emphasizes current status (Berument, Rutter, Lord, Pickles, & Bailey, 1999; Rutter et al., 2003; Witwer & Lecavalier, 1999).

Attention deficit hyperactivity disorder (ADHD)

ADHD Rating Scale screens for symptoms of hyperactivity/impulsiveness and attention deficits (Magnússon et al., 2006). The statements are based on the DSM-IV diagnostic criteria of ADHD. Four versions of the questionnaire exist; self-report of symptoms in childhood (5-12 years), 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 present, and attention deficits in childhood and present. Scores are then converted into standard scores with the average of 50 and a standard deviation 10, the cut-off score of 65 (1.5 *SD* from the mean) is recommended (Magnússon et al., 2006; Zhang, Faries, Vowles, & Michelson, 2005).

Quality of life

The Quality of life Scale (QOLS; Burckhardt & Anderson, 2003) was used to assess the participants' quality of life. The scale is intended to measure general satisfaction with life and is based upon many different factors. QOLS contains 16 items that assess; material and physical wellbeing, relationships with other people, social, community and civic

activities, personal development and fulfilment, and recreation. Scores range from 16 to 112, larger values indicating better quality of life (Burckhardt & Anderson, 2003; Dantas & Ciol, 2014).

Functioning and participation

The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0; Üstün, Kostanjsek, Chatterji & Rehm, 2010) is a questionnaire that assesses daily functioning and participation of individuals with some sort of disability in six areas; understanding and communication skills, activity in life, participation in society, how an individual takes care of himself/herself, how he or she 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 less functioning and participation (Chi et al., 2014; Üstün et al., 2010).

Progress

The Parent Satisfaction Questionnaire (PSQ; Smith, Buch, & Gamby, 2000) was used to measure progress on a few skills as perceived by parents. The PSQ was constructed for the Multi-site Young Autism Project. The first part assesses the attitudes of parents towards progress on a few skills and behaviours, i.e. communication, socialisation, leisure activities or play, aggression or temper tantrums, repetetive behaviour, and self-help, and the second part assesses their attitudes towards the intervention that was provided. Only the first part of the PSQ was used at time 3, where the parents were asked to evaluate whether the participant had made progress from childhood on a seven point scale, 1) considerably worse, 2) much worse, 3) somewhat worse, 4) no change has occurred, 5) some progress has been made, 6) much progress has been made, or 7) no longer a problem.

Overall outcome

The standardised outcome criteria that was used to classify overall outcome was based on

those employed by Howlin et al. (2004) and Magiati et al. (2014), where the overall outcome is the sum of scores from three domains, i.e., work, friendship, and independent living. The ratings are then combined into outcome categories.

Procedure

The research project was carried out at the State Diagnostic and Counselling Centre (SDCC) in Iceland. An invitation of participation, with an introduction letter and informed consent, was sent out to the participants and their parents. In the letter, the participants and/or parents were asked to contact one of the researchers (SLJ), who was the project leader of the IYAP, in order to give their consent for participation. If the participant/parent had not answered within a couple of weeks, the researcher (SLJ) phoned them. The main researcher (BB) then contacted the participants and set a date for an interview, which took place at the SDCC, at the participants' home or over the phone. The interview with the participants residing in the countryside took place over the phone and the questionnaires were sent to their home. 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 six questionnaires, i.e. about quality of life (QOLS), ADHD symptoms, both present and in childhood (ADHD-RS), functioning and participation (WHODAS 2.0), present autism symptoms (SCQ), and progress (PSQ). The participants were asked to fill out two of the questionnaires, the QOLS and the WHODAS 2.0. If the participant did not have the ability to answer for him/herself the assessment was solely based on information from parents. Permission from both the Scientific Ethical Committee at the State and Counselling Centre and the National Bioethics Committee of Iceland were granted for this study.

Results

Residence, occupation and education. 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 caregivers were satisfied with the current living arrangements. Thirteen participants had graduated from high school and one had gone on to receive a university diploma. Information regarding how much support they received in educational settings was not gathered, but most likely the majority received substantial support. Six of the participants spent a part of the day at a rehabilitation centre where they received individualised training, most often without salaries. Four participants were employed with support, one had a full-time job and the remaining four were unemployed.

Service. Most of the participants received good service in childhood but it decreased as they got older. In childhood, the majority of the participants had personal support, support families or short-term placements in institutions, as well as travel assistance and special education. Seven of the participants were not receiving any service when the interview took place, four of them because they didn't need any. The majority of the parents were pleased and grateful for the service their child had received and were especially pleased with the service that was provided in pre-, elementary- and high school. However, the parents were displeased with the fact that much of the service their children received terminated after they graduated from secondary school. Many of them said that their child needed more activity today, 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 service they could receive, shortage of appropriate residence arrangements, and support for individuals living alone.

Leisure activities, interests and friendship. The majority of 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, not uncommon for young people. Eight of the participants had no friends other than family members. 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.

Co-occurring disorders. Of the 15 participants, seven had received a comorbid diagnosis. Five had been diagnosed with some kind of anxiety disorder and of those, two with major depressive disorder. The remaining two had been diagnosed with ADHD. Some of the others were suspected of having a co-occurring disorder, although not formally diagnosed. Five parents suspected that their child had ADHD, four anxiety disorder and two obsessive compulsive disorder (OCD). The majority (73%) of the parents were concerned about the participants' mental health, most commonly about anxiety and depression. Of the 15 participants, nine were on some kind of psychotropic medication, most commonly anxiety medication.

Overall outcome

Five participants were rated as having good outcome, i.e., they had friends and acquaintances, worked with or without support and lived independently or had a relatively good independence, albeit they required minor degree of support in daily living. Five participants were rated as having fair outcome, i.e., worked with support, were generally living with their parents, needed some degree of support and had some or no friends. The remaining five participants were rated as having poor outcome, i.e., 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. Two of the authors rated the outcome independently of each other. The observed agreement between the two raters on the overall outcome was 86.6%. One of them rated a case as having a good outcome, while the other one rated it as having a fair outcome, and the reverse applied to another case. This was primarily

due to the fact that one of the raters, who had taken the interviews, had more information than the other one.

Adaptive behaviour

Table 1 shows descriptive statistics for the VABS-II and the three domains. The mean composite score on the VABS-II was more than two standard deviations from the general age norms, mean 58.5 (*SD* = 26.16). Paired t-test comparing domain scores for the participants revealed that scores on the communication domain were significantly lower than on the daily living skills domain; $t(14) = -2.74$, $p = 0.016$. The difference between the socialisation and the communication domains were not significant; $t(14) = -2.01$, $p = 0.065$, and the difference between scores on the socialisation and daily living skills domains were non-significant as well; $t(14) = 0.02$, $p = 0.983$.

Table 1, about here

Functioning and participation, present autism and ADHD symptoms and quality of life

Nine participants had considerable symptoms of autism and scored over the cut-off score on the SCQ. 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. Table 2 shows descriptive statistics for the WHODAS 2.0, the SCQ, the OQLS and the ADHD-RS.

Table 2, about here

Table 3 describes correlations between four measurements in the study, the VABS-II, the SCQ, the QOLS and the WHODAS 2.0. Correlation between functioning and participation, as measured by the WHODAS 2.0, was positively correlated with symptoms of autism and negatively correlated with adaptive behaviour and quality of life. This suggests that as functioning and participation increases, so does quality of life and adaptive behaviour, while

symptoms of autism increase, functioning and participation decreases. The correlation between adaptive behaviour and symptoms of autism turned out to be moderate but non-significant.

Table 3, about here

Six of the participants were able to report on their own quality of life as well as functioning and participation. The assessment of those six and the corresponding parents regarding quality of life (QOLS) was nearly identical and the difference was non-significant, i.e., 83.0 (*SD* = 19.6) and 81.3 (*SD* = 19.0), respectively. Their mean score regarding functioning and participation (WHODAS 2.0) was 23.6 (*SD* = 16.4) and 20.0 (*SD* = 14.6), respectively with the corresponding parents, a non-significant difference.

Assessment of progress from childhood

Ten of the parents estimated that considerable progress had occurred in communication skills from childhood, or that communication was no longer a problem for their child. Only four of the participants had made limited or even no progress as evaluated by their parents. Ten of the parents claimed that their child had made limited or no progress regarding socialization and only four of them reported progress. Ten parents claimed that self-help skills were no longer a problem for their child and the remaining four that some or considerable progress had been made. Six of the parents said that their child had made considerable progress regarding leisure activities or play or that it was no longer a problem for them, but eight of the parents said that limited or no progress had been made. Repetitive behaviour was no longer a problem in six instances, in seven, considerable or some progress had been made, and in one instance no change had occurred. Finally, 11 of the parents said that aggression or temper tantrums were no longer a problem for their child, but two claimed that it had gotten worse.

Comparison between groups

Table 4 shows the mean scores, standard deviations and range for the experimental and comparison groups on the VABS-II, the QOLS, the SCQ and the WHODAS 2.0. The difference between the groups turned out to be inconsiderable.

Table 4, about here

The difference between the experimental and comparison groups was non-significant on all measures, i.e., adaptive behaviour ($t(13) = -0{,}274$, $p = 0{,}786$), quality of life ($t(12) = -0{,}241$, $p = 0{,}813$), functioning and participation ($t(11) = -0{,}864$, $p = 0{,}406$) and present autism symptoms ($t(12) = -0{,}283$, $p = 0{,}782$).

Figure 1 shows the means and standard deviations on the VABS-II on time 2 and 3. As can clearly be seen, the variance is larger at time 3 than at time 2, especially for the comparison group.

Figure 1, about here

Figure 2 shows the participants' total scores on the VABS-II. A paired sample t-test was performed to see whether there was a difference in adaptive behaviour between time 2 and time 3. The difference was non-significant $t(14) = 0.605$, $p = 0.555$. Individual comparison on the VABS-II total scores at time 2 and time 3 revealed that 10 participants had higher scores now than when they were 6 years old (see Figure 2).

Figure 2, about here

Discussion

The present study is the first that has been conducted on the status and outcome of young adults with autism in Iceland. The assessment covered many different factors, from residence, occupation, and friendship, to adaptive behaviour, co-occurring disorders, and quality of life. The results show great individual variation on most variables that were measured, which suggests that although all of the participants received the same diagnosis at an early age, the outcome for them in adulthood is diverse. Some live independently, have

received good education and are employed, while others live in a group home and need constant support. In terms of the standardised criterion of overall outcome (Howlin et al., 2004; Magiati et al., 2014), just over 30% of the participants in the present study were considered showing good outcome and just over 30% poor outcome. This is a better outcome than was found in a recent systematic analysis by Howlin (2014) and Magiati et al. (2014). In their review, the majority (50% or more) of the participants were considered to have poor outcome, i.e., the participants remained largely or completely dependent on caregivers.

Adaptive behaviour was generally poor among the participants in the present study, but the group mean was more than two standard deviations from general age norms, which suggests that the majority of the participants need support when it comes to daily activities. As in other studies (Magiati et al., 2014), there was a large individual difference in adaptive behaviour, with some individuals needing support regarding almost every adaptive behaviour skill, while others needing little or no support with daily living. Research has shown that adaptive functioning among individuals with autism tends to improve with age (Freeman et al., 1999; Magiati et al., 2014) and that was true for ten of the participants in the present study, although in most instances the improvement was small and overall non-significant. Adult adaptive functioning was reported to be better in daily living skills and socialisation than communication, which is different from other studies where socialisation appeared to be the poorest domain (Farley et al., 2009; Magiati et al., 2014).

Generally, results on long-term outcome among individuals with autism have shown diagnostic stability over time, but also imply a decrease in autism symptoms (Howlin, Moss, Savage, & Rutter, 2013; Magiati et al., 2014). In the present study, one can assume the same in some instances, where reported symptoms of autism had decreased or at least caused decreased impairment according to their parents' evaluation on both the SCQ and the PSQ. Six of the participants had total scores which were beneath the recommended cut-off score on

the SCQ, and again the individual difference was substantial. The same can be said regarding symptoms of attention deficit, where half of the participants who screened above the cut-off score regarding attention deficit symptoms in childhood, screened above the cut-off on present symptoms. This was not the case regarding symptoms of hyperactivity/impulsivity, where the same three participants screened above cut-off, regarding both childhood and current symptoms. Other studies have reported rates of 30% of ADHD in young adults with autism (Billstedt et al., 2005; Lugnegård et al., 2011).

Importantly, the participants reported better quality of life than people receiving transdiagnostic cognitive behavioural group therapy (TCBGT) in primary care for depression and/or anxiety, but poorer than university students in Iceland (Hrafnsson & Guðmundsson, 2007). Billstedt et al. (2010) 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 equally high or higher than almost 12% of the general populations (Üstün, 2010). In a recent large study (Chi et al., 2014), the WHODAS 2.0 was used to measure disability and compare it in a wide group of people with e.g., schizophrenia, hearing impairment, stroke, dementia, bipolar, depression, mental retardation, autism, and spinal cord injury. The mean score for people with autism was very close to the mean score in our sample, i.e., 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. In the same study they also classified people with mild to complete impairment. Using those criteria in the present sample, five participants would be considered to have mild impairment, six moderate and three severe.

Assessment of participants and corresponding parents regarding quality of life

(QOLS) and functioning and participation (WHODAS 2.0), was in most cases similar and the difference non-significant. 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 (Egilson, Ólafsdóttir, Leósdóttir, & Sæmundsen, 2016; Van Heijst & Geurts, 2014). Only six participants could answer for themselves, but this little difference suggests that parents are reliable informants regarding their grown-up children's state of mind.

As it turned out, most of the parents were concerned about their child's mental health, and co-occurring disorders were common in the group. Nearly half of the participants had received comorbid diagnoses, which is in fact a lower rate of comorbidity than has commonly been found among adults with autism (Eaves & Ho, 2008), and which can place more weight on the parents' concerns. Anxiety disorders were most common, with five participants having received a diagnosis of anxiety disorder and four suspected of having one. Other studies have shown that about half of adults with autism have comorbid anxiety disorders (Eaves & Ho, 2008; Lugnegård et al., 2001). For some individuals, comorbid 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. Comorbid disorders can therefore greatly influence outcome when they are present and information about these disorders is important when it comes to service and interventions for young people with autism. It would serve people around an individual with autism well to remember that comorbidity is the rule rather than the exception (Billstedt, 2000; Eaves & Ho, 2008).

There turned out to be no considerable difference between the original experimental and comparison group on adaptive behaviour, functioning and participation, quality of life and present autism symptoms. Pre-intervention (time 1) intellectual ability, as assessed with standardized tests, and symptoms of autism, as assessed with the ADI-R, and the Childhood Autism Rating Scale (CARS) (Schopler, Reichler, DeVellis, & Daly, 1980), were comparable

between the groups, but post intervention (time 2) the participants who had received early behavioural intervention progressed considerably more than those in the control group (Jónsdóttir & Eikeseth, 2000). Today (time 3) it looks as though the difference that existed between the groups at time 2 has neutralised over the years. It is hard to speculate as to why, since the confounding variables can be infinite. A long time has passed between follow-up measures. Most individuals have received varied levels of service since then, received different kinds of education, lived in different enviroments, and now work at different places. The question also arises that if the early behavioural intervention had been ongoing for a longer period of time, whether the experimental group had maintained their superior progress over the comparison group? Assessment in the present study was almost entirely based on parents´ reports, and one can wonder whether parents in the experimental group made more thorough demands regarding their child´s behaviour than did parents in the comparison group. The parents in the experimental group went through extensive training in applied behaviour analysis which includes critical thinking regarding behaviour and how to make specific and sublime goals. Comorbid disorders can also play a part in outcome.

The study had a few limitations, the first being the small sample size. Any results need to be interpreted with caution considering such a small sample. In addition, there was a small variance considering age in the present sample and only two participants were female. Additional limitation concerns comparison of long-term effects, but the instruments that were used in the first study could not be used in the present one because of lack of funds, with the exception of the VABS-II. In IYAP, autism symptoms were assessed with the ADI-R and/or the CARS but in the present study the screening instrument SCQ was used. It would have been preferable to add a direct observation of behavior with the Autism Diagnostic Observation Schedule (Lord et al., 1989). In addition, intellectual ability was not assessed in the present study (time 3) and therefore could not be compared with the first two

measurements (time 1 and 2). As a result an important comparison between the groups could not be made. The strength of the study was the comprehensive measurements of outcome and status of young adults with autism, were many different factors were taken into account in the assessment.

The present study demonstrates the value and the feasibility of outcome research on adults with autism. The results will hopefully encourage more studies in this field in order to help parents, clinicians, and carers to gain insight into the diversities, impairments and quality of life of young people with autism.

References

Berument, S. K., Rutter, M., Lord, C., Pickles, A., & Bailey, A. (1999). Autism screening questionnaire: diagnostic validity. *The British Journal of Psychiatry*, *175*(5), 444–451. doi:10.1192/bjp.175.5.444

Billstedt, E. (2000). Autism and Asperger syndrome: coexistence with other clinical disorders. *Acta Psychiatrica Scandinavica*, *102*(5), 321–330. doi:10.1034/j.1600-0447.2000.102005321.x

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2005). Autism after adolescence: population-based 13-to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, *35*(3), 351–360. doi: 10.1007/s10803-005-3302-5

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2010). Aspects of quality of life in adults diagnosed with autism in childhood: a population-based study. *Autism*, 15, 7–20. doi: 10.1177/1362361309346066

Burckhardt, C. S., & Anderson, K. L. (2003). The Quality of Life Scale (QOLS): reliability, validity, and utilization. *Health and Quality of Life Outcomes*, *1*(1), 60. doi: 10.1186/1477-7525-1-60

Chi, W. C., Chang, K. H., Escorpizo, R., Yen, C. F., Liao, H. F., Chang, F. H., ... & Liou, T. H. (2014). Measuring disability and its predicting factors in a large database in Taiwan using the world health organization disability assessment schedule 2.0. *International Journal of Environmental Research and Public Health*, *11*(12), 12148–12161. doi:10.3390/ij erph1121248

Dantas, R. A. S., & Ciol, M. A. (2014). Flanagan Quality of Life Scale. *Encyclopedia of Quality of Life and Well-Being Research* (pp. 2284–2288). Springer Netherlands. doi: 10.1007/978-94-007-0753-5_1057

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *38*(4), 739–747. doi:10.1007/s10803-007-0441-x

Edwards, T. L., Watkins, E. E., Lotfizadeh, A. D., & Poling, A. (2012). Intervention research to benefit people with autism: how old are the participants? *Research in Autism Spectrum Disorders*, *6*(3), 996–999. doi:10.1016/j.rasd.2011.11.002

Egilson, S. T., Ólafsdóttir, L. B., Leósdóttir, T., & Saemundsen, E. (2016). Quality of life of high-functioning children and youth with autism spectrum disorder and typically developing peers: Self-and proxy-reports. *Autism*. doi: 10.1177/1362361316630881

Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2009). Meta-analysis of early intensive behavioral intervention for children with autism. *Journal of Clinical Child & Adolescent Psychology*, *38*(3), 439–450. doi:10.1080/15374410902851739

Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., & Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, *2*(2), 109–118. doi:10.1002/aur.69

Freeman, B. J., Del'Homme, M., Guthrie, D., & Zhang, F. (1999). Vineland Adaptive Behavior Scale scores as a function of age and initial IQ in 210 autistic children. *Journal of Autism and Developmental Disorders*, *29*(5), 379–384.

Gillham, J. E., Carter, A. S., Volkmar, F. R., & Sparrow, S. S. (2000). Toward a developmental operational definition of autism. *Journal of Autism and Developmental Disorders*, *30*(4), 269–278.

Gjevik, E., Eldevik, S., Fjæran-Granum, T., & Sponheim, E. (2011). Kiddie-SADS reveals high rates of DSM-IV disorders in children and adolescents with autism spectrum

disorders. *Journal of Autism and Developmental Disorders*, *41*(6), 761–769. doi: 10.1007/s10803-010-1095-7

Henninger, N. A., & Taylor, J. L. (2013). Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism*, *17*(1), 103–116. doi: 10.1177/1362361312441266

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, *45*(2), 212–229. doi: 10.1111/j.1469-7610.2004.00215.x

Howlin, P. (2005) Outcomes in autism spectrum disorders. In: Volkmar F, Paul R, Klin A, Cohen D, editors. *Handbook of autism and pervasive developmental disorders*. 3rd edition., volume 1. (201–220). New Jersey: John Wiley & Sons.

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid-to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry*, *52*(6), 572–581. doi:10.1016/j.jaac.2013.02.017

Howlin, P. (2014) Outcomes in adults with autism spectrum disorders. In: Volkmar F., Rogers S., Paul R., & Pelphrey K, editors . *Handbook of autism and pervasive developmental disorders*. 4th edition., volume 1. (97–115). New Jersey: John Wiley & Sons.

Hrafnsson, Ó., & Guðmundsson, M. (2007) *Próffræðilegir eiginleikar Lífsgæðakvarðans (QOLS)*. [Psychometric properties of the quality of life scale (QOLS)]. Unpublished BA. thesis, Univeristy of Iceland, Social science department.

Jónsdóttir, S. L., & Eikeseth, S. *Intensive behavioural intervention of children with autism in a pre-school setting in Iceland and Norway*. Poster presentation. IX Autism-Europe International Congress, Glasgow May 19. - 21. 2000.

Jónsdóttir, S. L., Sæmundsen, E., Ásmundsdóttir, G., Hjartardóttir, S., Ásgeirsdóttir, B. B., Smáradóttir, H. H., ... & Smári, J. (2007). Follow-up of children diagnosed with

pervasive developmental disorders: stability and change during the preschool years. *Journal of Autism and Developmental Disorders*, *37*(7), 1361–1374. doi: 10.1007/s10803-006-0282-z

Jónsdóttir, S.L., (2014). Frá bernsku til fullorðinsára [From childhood to adulthood]. In: Sigríður Lóa Jónsdóttir og Evald Sæmundsen, editors. *Litróf einhverfunnar* [The Autism Spectrum] (193–202). Reykjavík: University press.

Lord, C., Rutter, M., Goode, S., Heemsbergen, J., Jordan, H., Mawhood, L., & Schopler, E. (1989). Autism Diagnostic Observation Schedule: A standardized observation of communicative and social behavior. *Journal of Autism and Developmental Disorders*, 19, 185–212.

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, *55*(1), 3.

Lugnegård, T., Hallerbäck, M. U., & Gillberg, C. (2011). Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. *Research in Developmental Disabilities*, *32*(5), 1910–1917. doi:10.1016/j.ridd.2011.03.025

Magnússon, P., Smári, J., Sigurðardóttir, D., Baldursson, G., Sigmundsson, J., Kristjánsson, K., et al. (2006). Validity of self-report and informant rating scales of adult ADHD symptoms in comparison with a semistructured diagnostic interview. *Journal of Attention Disorders, 9*, 494–503. doi: 10.1177/1087054705283650

Magiati, I., Tay, X. W., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: a systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*, *34*(1), 73–86. doi:10.1016/j.cpr.2013.11.002

McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *Mental Retardation, 97,* 359–372.

Myers, S. M. & Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Pediatrics*, *120*(5), 1162–1182.

Rutter, M., Bailey, A., & Lord, C. (2003). *The social communication questionnaire: Manual*. Western Psychological Services.

Rutter, M.(2005). Incidence of autism spectrum disorders: Changes over time and their meaning. *Acta Paediatrica*, *94*(1), 2–15. doi: 10.1080/08035250410023124

Schalock, R. L. (2004). The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research*, *48*(3), 203–216. doi: 10.1111/j.1365-2788.2003.00558.x

Schopler, E., Reichler, R. J., DeVellis, R. F., & Daly, K. (1980). Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *Journal of Autism and Developmental Disorders*, *10*(1), 91–103

Shull, L. (2013). UCLA Young Autism Project. *Encyclopedia of Autism Spectrum Disorders*, 3199–3202. doi: 10.1007/978-1-4419-1698-3_1312

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, *47*(8), 921–929. doi:10.1097/CHI.0b013e318179964f

Smith, T., Buch, G. A., & Gamby, T. E. (2000). Parent-directed, intensive early intervention for children with pervasive developmental disorder. *Research in developmental disabilities*, *21*(4), 297-309.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (1989). The Vineland Adaptive Behavior Scales. *Major Psychological Assessment Instruments*, *2*, 199-231.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). Vineland Adaptive Behavior Scales (2nd ed.). Circle Pines, MN: American Guidance Service.

Sæmundsen, E., Magnússon, P., Georgsdóttir, I., Egilsson, E., & Rafnsson, V. (2013). Prevalence of autism spectrum disorders in an Icelandic birth cohort. *BMJ Open*, *3*: e002748. doi:10.1136/bmjopen-2013-002748

Van Heijst, B. F., & Geurts, H. M. (2014). Quality of life in autism across the lifespan: A meta-analysis. *Autism*, doi:10.1177/1362361313517053

Warren, Z., McPheeters, M. L., Sathe, N., Foss-Feig, J. H., Glasser, A., & Veenstra-VanderWeele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics*, *127*(5), e1303–e1311. doi: 10.1542/peds.2011-0426

Witwer, A. N., & Lecavalier, L. (2007). Autism screening tools: an evaluation of the social communication questionnaire and the developmental behaviour checklist–autism screening algorithm. *Journal of Intellectual and Developmental Disability*, *32*(3), 179–187. doi: 10.1080/13668250701604776

Zhang, S., Faries, D. E., Vowles, M., & Michelson, D. (2005). ADHD Rating Scale IV: psychometric properties from a multinational study as a clinician-administered instrument. *International Journal of Methods in Psychiatric Research*, *14*(4), 186. doi: 10.1002/mpr.7

Üstün, T.B., Kostanjsek, N., Chatterji, S., & Rehm, J. *Measuring health and disability: manual for WHO Disability Assessment Schedule (WHODAS 2.0).* World Health Organization; 2010.

Table 1.

Descriptive Statistics for Adaptive Behaviour (VABS-II)

	n	Range	Mean	SD
Adaptive Behaviour Total composite score	15	20 - 108	58.5	26.16
Communication	15	21- 104	56.13	26.47
Socialization	15	20 -103	63.40	27.62
Daily living skills	15	25 -112	63.33	24.90

Note. Total score on the VABS-II is the Adaptive Behaviour Total composite score (*M*=100, *SD*=15). Communication, Socialization, Daily living skills are domains of adaptive behaviour that are assessed in the VABS-II.

Table 2.

Descriptive Statistics for Functioning and Participation (WHODAS 2.0), Present Symptoms of Autism (SCQ), Quality of Life (QOLS) and ADHD Symptoms (ADHD-RS)

	n	Range	Mean	SD
Functioning and participation (WHODAS 2.0)	14	7.64 - 68.06	32.44	19.46
Autism symptoms (SCQ)	14	7 - 26	15.79	5.56
Quality of life (QOLS)	13	57 - 110	78.38	13.65
Attention deficit in childhood (ADHD-RS)	14	50 - 94	71.14	14.54
Attention deficit present (ADHD-RS)	14	40 - 84	58.86	16.83
Hyperactivity/impulsivity in childhood (ADHD-RS)	14	43 - 80	57.71	12.83
Hyperactivity/impulsivity present (ADHD-RS)	14	39 - 85	51.50	15.28

Table 3.

Correlations (Spearmans) between Adaptive Behaviour (VABS-II), Present Symptoms of Autism (SCQ), Quality of Life (QOLS) and Functioning and Participation (WHODAS 2.0)

	Adaptive behaviour (VABS-II)	Autism symptoms (SCQ)	Quality of life (QOLS)	Functioning and participation (WHODAS 2.0)
Adaptive behaviour (VABS-II)	1	-.471	.111	-.606*
Autism symptoms (SCQ)		1	-.293	.652**
Quality of life (QOLS)			1	-.716**
Functioning and participation (WHODAS 2.0)				1

*p< 0.05 (2-tailed).

**p< 0.01 (2-tailed).

Table 4.

Comparison of Range, Mean and Standard Deviation on Adaptive Behaviour (VABS-II), Quality of Life (QOLS), Functioning and Participation (WHODAS 2.0), and Present Symptoms of Autism (SCQ) between groups (the original Experimental and Comparison group)

	n	Range	Mean	SD
Experimental Group				
Adaptive Behaviour (VABS-II)	5	23 - 73	55.8	19.42
Quality of Life (QOLS)	5	57 - 95	74	15.12
Functioning and participation (WHODAS-II)	5	6,63 - 47.92	30.49	17,05
Autism symptoms (SCQ)	5	10 - 19	15.2	3.83
Comparison Group				
Adaptive Behaviour (VABS-II)	10	20 - 108	59.9	29.85
Quality of Life (QOLS)	8	69 - 110	81	12.98
Functioning and participation (WHODAS-II)	9	5,21 - 58.40	30,77	20,56
Autism symptoms (SCQ)	9	7 - 26	16.1	6.52

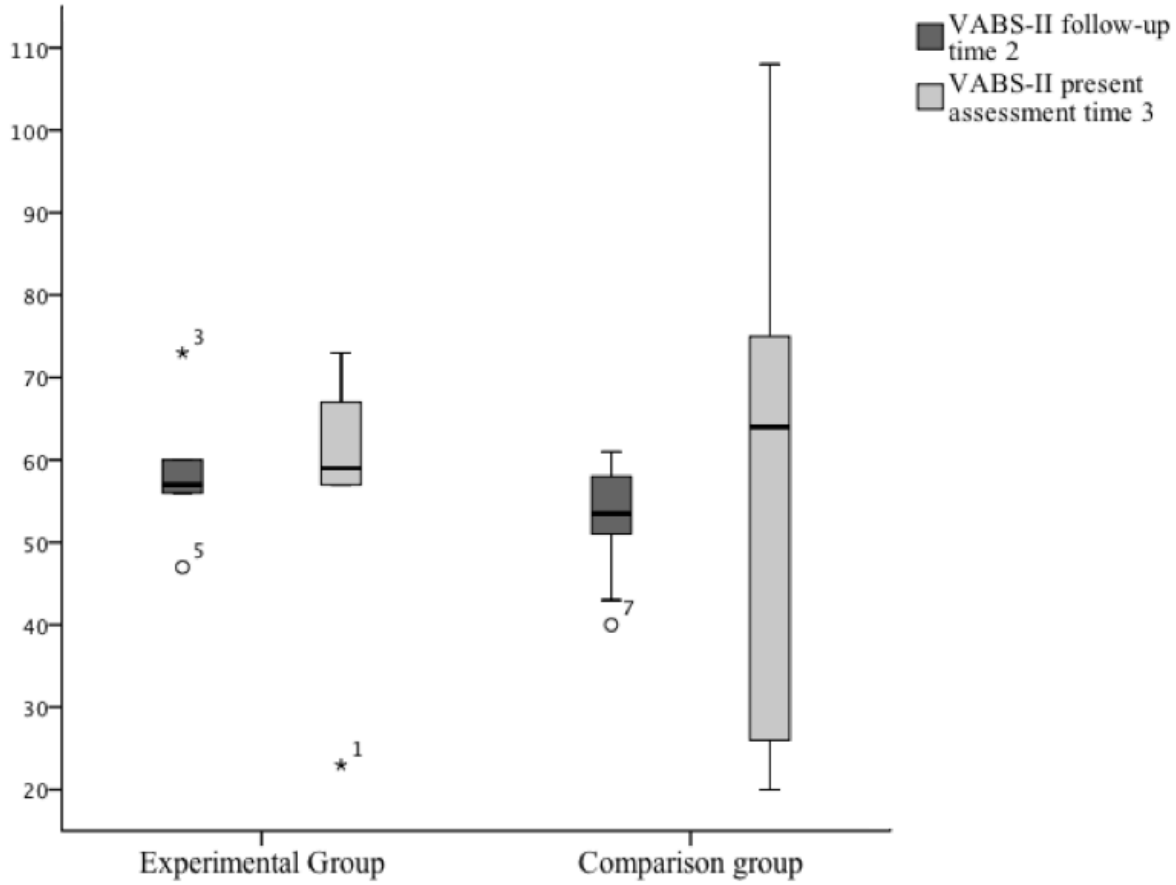

Figure 1. Box plots of VABS-II scores in the experimental and comparison group at time 2 and 3.

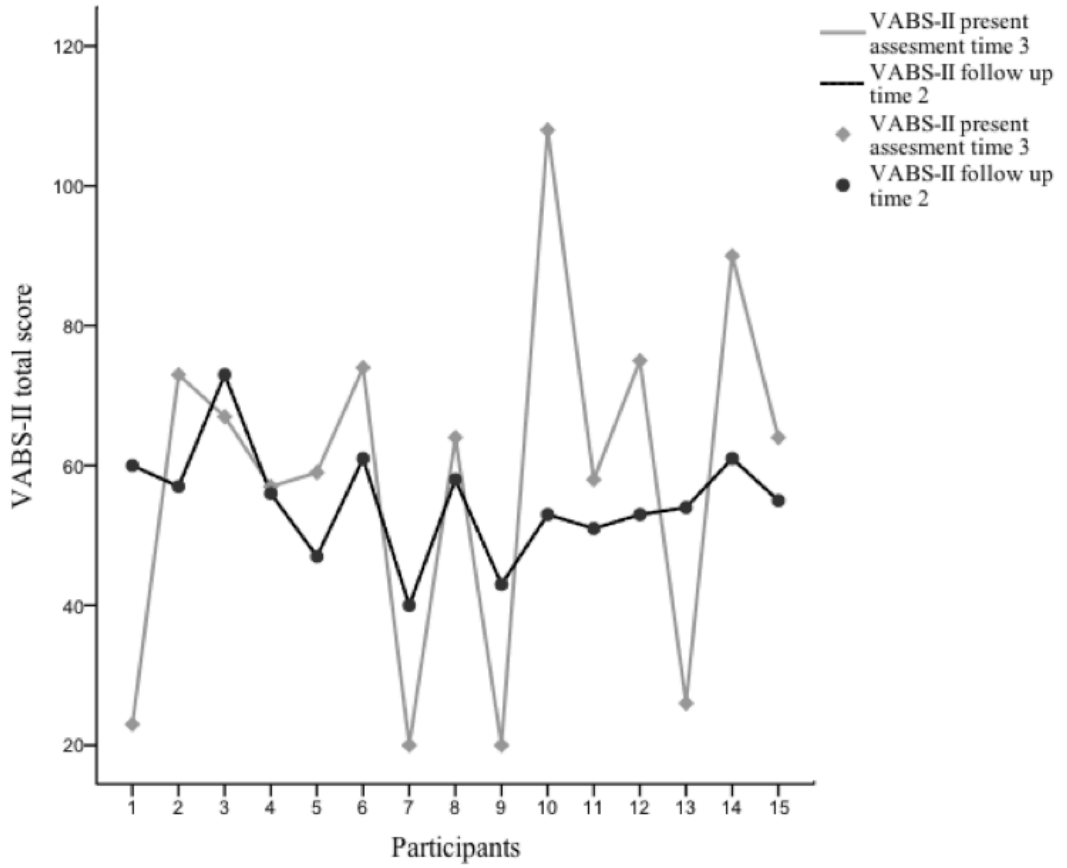

Figure 2. Individual comparison on VABS-II total scores at time 2 and time 3.