MASTER THESIS

Learning in Complex Systems

2014

Outcome in Adulthood for Children with Autism Spectrum Disorder who have received Early Intensive Behavioral Intervention

Astrid Kristin Holm

Faculty of Health Sciences

Department of Behavioral Science

OSLO AND AKERSHUS
UNIVERSITY COLLEGE
OF APPLIED SCIENCES

Acknowledgements

The data collection conducted in the research article was founded by Regional kompetansetjeneste for autisme, ADHD, Tourettes syndrom og narkolepsi, Helse Sør-Øst. Staff of Glenne regionale senter for autisme, Regionale kompetansetjenester i Helse Sør-Øst conducted one part of the data collection in the research article. The other part of the data collection was conducted by an independent clinical special educator. My college-supervisor on this project has been Professor Svein Eikeseth, Ph. D. I wish to thank them all, and say good luck with the work on collecting the remaining data, and completing this project. It has been a pleasure working with you, and an honor to start this highly necessary and valuable research project. Sadly, I am not able to see it through at the time being. Last, but not least, I wish to thank my family, for their support and patience.

July-2014, Astrid Kristin

Article content

Article I:

Article II:

Appendix (in Norwegian)

List of tables and figures in Article II

Tables:

Figures:

Combined abstract

The following master thesis contains two articles. The first gives a theoretical outlining of Early Intensive Behavior Intervention (EIBI) and the research regarding the short-term effectiveness of this intervention. Then followed by an account for autism adult outcome research. The article reveals that there is currently no evidence available regarding the adult outcome for persons with autism who received EIBI in their childhood. Further, the paper emphasizes the need for longitudinal outcome studies for persons with autism, investigating whether EIBI may result in better adult outcome.

The second article is an empirical research article, which presents adult outcome data on eight persons who were diagnosed with Childhood Autism and received intensive educational intervention in early childhood. This is an 18-year follow-up of the studies of Eikeseth, Smith, Jahr and Eldevik (2002, 2007), which compared a group of children receiving EIBI (N = 13) to a group of children receiving intensive eclectic treatment (N = 12). They found that the EIBI group made extensively larger progress than the eclectic group. In this current study, the data has been analyzed individually, as one group and as two groups. The small sample size (N = 8) extensively compromises the validity of the results. However, the data show that, as a group there is progress on both IQ and adaptive function from childhood to adulthood, but no significant change. The group with persons who received EIBI, show significant change for IQ. Further, no significance was found for adaptive behavior, but a larger change was found for the EIBI group than for the persons who received the eclectic treatment. These preliminary findings indicate that EIBI may be effective in long-long term and contribute in producing better adult outcome for persons with Autism Spectrum Disorder (ASD).

MASTER THESIS

Learning in Complex Systems

2014

Early Intensive Behavioral Intervention
and
Adult Outcome for Persons with Autism Spectrum Disorder

Astrid Kristin Holm

Faculty of Health Sciences

Department of Behavioral Science

OSLO AND AKERSHUS
UNIVERSITY COLLEGE
OF APPLIED SCIENCES

Abstract

The purpose of this article is to argue for the need of investigation on the long-term effect of Early Intensive Behavior Intervention (EIBI) for children with Autism Spectrum Disorder (ASD). The paper outlines the concept of EIBI, and reviews research from both the EIBI research tradition and the adult outcome research tradition for persons with ASD. Thus, the paper reviews research that has contributed in the establishing of the short-term-effectiveness of EIBI, focusing on meta-analytic studies and follow-up research. The meta-analytic studies show evidence for statistically valid EIBI effectiveness in the short-term. However, the EIBI-research methodology suffers from limitations in the scientific accuracy of the results due to non-randomization, as well as operating with small sample sizes. Reviewing the follow-up studies in the EIBI-research show that there is some evidence for long-term effects of EIBI into the children’s late childhood. Currently, there are no published studies evaluating outcome in adulthood for children that received EIBI during their childhood. However, a number of studies have evaluated outcome in adulthood for children not receiving EIBI, and the majority of these studies show that adult outcome is “poor” or “very poor”. In summary, there are substantial evidence supporting EIBI, but not in the long term. The EIBI researchers need to follow up their referrals in adolescence and adulthood, and thus contribute to the longitudinal research regarding persons with ASD to see whether EIBI may contribute to a better adult outcome.

Keywords: EIBI, meta-analyses, follow-up, autism adult outcome.

Early Intensive Behavioral Intervention and Adult Outcome for Persons with Autism Spectrum Disorder

Early Intensive Behavioral Intervention (EIBI) is an empirically supported comprehensive educational program for children diagnosed with Autism Spectrum Disorder (ASD) (Eikeseth, 2009; Eldevik, Hastings, Hughes, Jahr, Eikeseth, & Cross, 2009; Rogers & Vismara, 2008). ASD is a Pervasive Developmental Disorder (PDD) and the main deficits are within areas of communication and social interaction, as well as excessive display of repetitive and stereotyped behavior patterns (American Psychiatric Association, 2013). The children may show difficulty learning both language comprehension as well as speaking. Some children do not utter sounds at all, while others have fluent language that appears to be normal. The latter children struggle with misinterpretation of both vocal and non-vocal communication, and thus respond inadequately in social interactions. Further, the children show limited social motivation, which contributes to the lack of learning social behaviors when spending time with adults and peers. A child with ASD may also display repetitive behavior such as hand flapping or spinning toys around. They show lack of appropriate play behavior and are often in need of strict routines and predictability in everyday life.

EIBI is based on the principles of Applied Behavioral Analysis (ABA) and behavior analytic procedures are applied to teach children with ASD communication, social skills, individual- and social play, adaptive- and self-help skills, as well as academic skills (Leaf & McEachin, 1999; Lovaas, 2003). A number of peer-reviewed outcome studies have over the years, since Lovaas' pioneer study in the 1970s (Lovaas, Koegle, Simmons & Long, 1973), contributed to the large scope of evidence supporting this treatment. These studies show that intensive one-to-one treatment is effective in the short term after one year, and after two years or more (Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Ben-Itzchak & Zachor, 2007; Bibby, Eikeseth, Martin, Mudford, & Reeves, 2001; Birnbrauer & Leach, 1993; Cohen, Amarine-Dickens, & Smith, 2006; Dawson et al., 2010; Eikeseth, Klintwall, Jahr, & Karlsson, 2012; Eikeseth, Smith, Jahr, & Eldevik, 2002, 2007; Eldevik, Eikeseth, Jahr, & Smith, 2006; Eldevik, Hastings, Jahr, & Hughes, 2011; Handleman, Harris, Celbiberti, Lilleheht, & Tomchek, 1991; Harris, Handleman, Gordon, Kristoff,& Fuentes, 1991; Harris Handleman, Kristoff, Bass, & Gordon, 1990; Hayward, Eikeseth, Gale, & Morgan, 2009; Howard, Sparkman, Cohen, Green, & Stainslaw, 2005; Hoyson, Jamieson, & Strain, 1984; Lovaas, 1987; Lovaas, 1993; Magiati, Charman, & Howlin, 2007; McEachin, Smith, & Lovaas, 1993; Mudford, Martin, Eikeseth, & Bibby, 2001; Remington et al., 2007; Perry et al., 2009; Sallows & Graupner, 2005; Sheinkopf & Siegel, 1998; Smith, Groen, & Wynn, 2000). Questions about the scientific accuracy of the studies conducted have recently been raised. A lack of randomized controlled trials (RCT), together with a reliance on non-randomized controlled trials such as clinical controlled trials (CCT), indicates that evidence supporting EIBI is limited (Reichow, Barton, Boyd, & Hume, 2012). Nevertheless, EIBI is by far the best-researched and best-documented intervention for children with ASD (Eikeseth, 2009; Eldevik et al., 2009; Rogers & Vismara, 2008).

An important dimension of EIBI that still needs investigation is the long-term effect and the adult outcome of this intervention. Only one study, McEachin, Smith, and Lovaas (1993), has assessed outcome in adolescence after receiving EIBI in childhood. Recent research articles emphasizes the importance of long term follow-up studies, and give suggestions for this type of research in the future (Eikeseth, 2011; Henninger & Taylor, 2012; Klintwall & Eikeseth, 2012; Levy & Perry, 2011; Magiati, Moss, Charman & Howlin, 2011; Matson & Konst, 2013; Nordin & Gillberg, 1998; O’Connor & Healy, 2010).

The following review contains three main sections. The first outlines a theoretical description of EIBI with practical examples. The second gives an overview of research establishing the short-term effectiveness of EIBI including meta-analytic- and follow-up studies, and focus on predictors of outcome of EIBI. Finally, the third section gives a brief overview of a selection of adult outcome studies. The evolvement of adult outcome research methodology and the importance of future research regarding outcome in adulthood for persons with ASD, are briefly discussed.

Description of EIBI

EIBI has been defined by Green, Brennan, and Fein (2002) as having 10 important characteristics, which all must be present for the term EIBI to be accurately used and for achieving full clinical gains from an EIBI program. The 10 characteristics are (a) comprehensive and individualized treatment that addresses all skill domains; (b) a number of behavior analytic procedures is used to teach new skills and to reduce interfering behavior (e.g., differential reinforcement, prompting, discrete-trial teaching, natural environment teaching, incidental teaching, activity-embedded trials, task analysis, and others); (c) the intervention is directed and supervised by one or more professionals with advanced training in EIBI with young children with autism and applied behavior analysis; (d) the selection of intervention goals and short-term objectives is guided by normal developmental sequences; (e) parents serve as active co-therapists for their children; (f) initially intervention is delivered one-to-one, with gradual transitions to small-group and large-group formats when warranted; (g) intervention typically begins in the home and is carried over into other environments (e.g., community settings), with gradual, systematic transitions to preschool, kindergarten, and elementary school classrooms when children develop the skills required to learn in those settings; (h) intensive, year-round teaching, including 20 to 30 hours of structured sessions per week plus informal instruction and practice throughout most of the children’s other waking hours; (i) usually the duration of intervention is two or more years; and (j) most children start intervention at three-to-four-years of age.

Behavioral Principles Used in EIBI

Reinforcement is the key element for behavior change and the most important principle of behavior analysis (Cooper, Heron & Heward, 2007; Eikeseth, 2001; Eikeseth, 2011). When a behavior is immediately followed by the presentation of a stimulus and as a result, the behavior occurs more often in the future, positive reinforcement has occurred. When a behavior is immediately followed by the termination of a stimulus and, as a result, the behavior occurs more often in the future, negative reinforcement has occurred. The key issue with reinforcement is that it strengthens the behavior it follows.

Stimulus control occurs when a behavior is being reinforced in the presence of a stimulus and not in the presence of other stimuli (Cooper et al., 2007). The antecedent stimulus is then a discriminative stimulus, which controls future occurrences of the behavior that has been reinforced in its presence (Cooper et al., 2007). In teaching children with autism, it is important to reinforce behavior specifically in the presence of antecedent stimuli to teach the child to make discriminations about what is the correct behavior in this particular situation. However, this does not always happen without some assistance, or prompt. There are two kinds of prompt; response prompt and stimulus prompt (Cooper et al., 2007). The three main types of response prompts are physical guidance, verbal instructions or modeling. Examples of stimulus prompts are pointing to the right answer or placing the right item closer to the child. It is important to plan for both the implementation of the most effective prompt for the child to achieve the task, and for the most efficient way to transfer the control over to the natural occurring stimulus, to fade the prompt gradually. One example of techniques to do so is the most-to-least prompts (Cooper et al., 2007). Within this technique the teacher initially uses a great amount of prompt, for example physically guides the child through the entire response sequence. In further rehearsals of the same response, the teacher uses less and less physical guidance and the child is soon able to perform the response independently under natural stimulus control.

The antecedent stimulus, the response and the consequence together constitute the three-term contingency. B. F. Skinner first described the three-term contingency or the contingency of reinforcement, in 1969 (Cooper et al., 2007). This is according to Glenn, Ellis and Greenspoon (1992), "considered the basic unit of analysis in the analysis of operant behavior" (sited from Cooper et al., 2007). In the practical implementation of EIBI, the three-term contingency underlies and regulates the way teaching is being planned, carried out, and evaluated.

Conditional discrimination is another technical term used in EIBI that derives from ABA. The three-term contingency becomes a four-term contingency when it comes under control of another antecedent stimulus, hence the conditional stimulus (Eikeseth, Smith & Klintwall, 2014). In EIBI, this is a teaching strategy within discrimination learning, which is an important feature of language acquisition. The child with autism needs to learn how to tell things apart and that all things have different names. When two objects are present in front of the child, the right object to choose depends on the teacher's instruction. Thus, which object to be the discriminative stimulus for the child's response is arbitrary until the conditional antecedent stimulus is vocally presented by the teacher.

Motivating operations (MO) are described by Jack Michael in Cooper et al. (2007) as being an environmental variable with two defining effects. The first effect is the value-altering effect, which is either an establishing operation when there is an increase in the reinforcing effectiveness of some stimuli, or an abolishing operation when there is a decrease in the reinforcing effectiveness of some stimuli. The second effect is the behavior-altering effect. There is either an evocative effect that involves an increase in the frequency of a behavior that has been reinforced by some stimuli, or an abative effect that involves a decrease in the current frequency of behavior that has been reinforced by some stimuli. In other words, when hungry (MO) food has reinforcement value and behavior that leads to food occurs with increased frequency. It is important to consider the child’s MO when making decisions for the teaching process. If the child appears to be tired it would probably be a bad idea to practice playing with peers. If the child shows interest in the toys in the classroom, there may be a good time for one-to-one sessions with access to toys contingent upon right answers and cooperation.

Another term from ABA often used in EIBI is stimulus generalization. This means that similar stimuli to the one who has stimulus control also may evoke the same response (Cooper et al., 2007). In child development, this happens more or less without any effort. However, when the child has ASD, this learning ability is somehow defected and the child will need to learn how to generalize. The same tendency occurs with response generalization, where one discriminative stimulus can evoke several topographically different responses.

Teaching Procedures

Discrete trial teaching (DTT). DTT is an evidence-based teaching approach derived from ABA (Smith, 2001). The procedure is a one – to – one teacher directed strategy which purpose is to teach the child with ASD new skills by dividing the skill into smaller and measureable units by applying task analysis (Eikeseth, 2011). These units are either needed for further learning (prerequisites) or are part of a bigger response unit (chaining) (Eikeseth, 2011). The teaching sessions are carefully planned with individualized learning targets and the child’s progress is being continuously measured and analyzed to ensure constantly optimal learning opportunities. According to Smith (2001), each trial consists of five parts: (a) the antecedent stimulus; (b) the prompt; (c) the response; (d) the consequence and finally (e) the inter-trial interval. The antecedent stimulus or cue can mean that the teacher gives an instruction, shows a picture, or displays a model for imitation. For example, the teacher says, “Do this” and puts her hands in the air. The prompt is provided if needed, immediately after the cue to prevent the child from making a mistake. This is called errorless learning (Eikeseth et al., 2014). The prompt procedure and how to fade the prompt, is carefully planned and may vary amongst programs (Eikeseth, 2011), i.e. the prompt properties are physical in motor imitation programs and by model in programs containing instruction following. Further, the child emits either a correct or an incorrect response. Whether the response is considered correct or not, depends on the current mastery criteria set for this individual child. For example, if the teacher shows a picture of a spoon and asks the child “What’s this?” and the child answers “poon” may this be considered correct if the child has not yet mastered the sp – combination of sound in verbal imitation. The consequence or reinforcement is provided immediately after a correct response. Within DTT, the consequence does not need to correspond directly with the response. For example, the child can receive his favorite piece of candy for saying “teddy bear”, he does not need to receive an actual teddy bear. Gradually to teach the child the value of social feedback, the artificial reinforcer is always combined with praise. When the child does not make a perfect response, but makes a good approximation, only praise is delivered. If the child makes an error, the teacher does not respond to that, but simply starts a new trial with an immediate prompt to inhibit the chance of another error (Klintwall & Eikeseth, 2014,. For the child to learn from this situation it is important to present the task once more without the prompt, so that an independent response can be reinforced. Prompted responses are not reinforced unless the child is not yet able to perform the response independently, for example in the beginning of a new program. An important reinforcement procedure that is being applied is differential reinforcement. When a new task is introduced, the mastery criterion changes gradually for the child’s response to approximate closer and closer the target response (Cooper et al., 2007). The final part is the inter-trial interval. After the consequence has been delivered, the teacher waits for one to five seconds before presenting the next antecedent stimulus.

Natural environment training (NET). Equally important to discrete trial teaching is NET. During NET, acquired skills are rehearsed and new skills are taught under natural occurring conditions (Eikeseth, 2011). NET also promotes child spontaneity by waiting for the child’s initiative, then reinforcing every occurrence. Sundberg and Partington (1998) emphasize the utilizing of the child’s current interests to teach language in natural environment, and point out that the stimulus presented must directly correlate with the reinforcement available. For example, if the child shows interest in a ball, it will be a good teaching opportunity to make the child say “ball” or an approximation to the word “ball” and maybe make eye contact with the teacher, before giving the child access to the ball.

Incidental teaching. Incidental teaching is a well-documented teaching strategy for training in the natural environment, and was first described by Hart and Risley in 1975. Fenske, Krantz and McClannahan (2001) have modified this procedure to fit the teaching of children with autism. Incidental Teaching is a child directed approach to teach spontaneous communication. By facilitating the child’s environment, naturally occurring motivational operations within the child may produce some kind of initiative from the child. At first, the initiative itself is being reinforced with the naturally occurring reinforcement, which is the object or event that the child wants. Then, when the child learns that he can manipulate his own environment by initiating, the teacher provides some kind of prompt after the occurring initiative slightly to improve the child’s ability to communicate with language, and eventually more elaborated language. The prompt then, needs to be provided for some time while it is being gradually faded, but then it is important to wait for the taught response to replace the initial initiative. For example, the child enjoys physical play and makes an initiative that he wants to be lifted up by approaching an adult and raising his hands. The first time this happens, the teacher may say, “Oh, you want to get UP”, with emphasis on the word that later will be the expected response from the child, and lift the child up and play physically with him for a short while. The adult then sets the child down and maybe he wants more. When the child again approaches and gives the initiative, the adult may try to make slight eye contact with him before giving the verbal and physical consequence. The next time this happens the adult may try to have the child imitate the word “up” before lifting him up. The child may not respond perfectly for the reinforcement to be delivered, the main issue is that the child makes a verbal approximation.

Curriculum

The EIBI curriculum is described in detail in a variety of treatment manuals (Leaf & McEachin, 1999; Lovaas, 1977, 2003; Lovaas et al., 1981; Maurice, Green & Luce, 1996). In combination with behavioral principles, the curriculum is comprehensive, which means that all areas of the child’s deficits are addressed, however individualized tailoring is required (Eikeseth, 2011). In the manuals, the curriculum is commonly divided into these following categories: (a) beginning curriculum, (b) intermediate curriculum, and (c) advanced curriculum. There is often a section dealing with school integration as well.

Research establishing the short-term effectiveness of EIBI

Meta-analyses.

The Cochrane Collaboration describes meta-analyses as “the statistical combination of results from two or more separate studies” (Higgins & Green, 2011). The advantages of meta-analysis is the potential of increasing the power and improve the precision, as well as answering different questions than in the individual studies, in addition to offer a suggestion for settlement to disagreeing claims. On the other hand, meta-analysis has been criticized for combining apples and oranges (Higgins & Green, 2011; Matson & Jang, 2013; and Reichow, 2012). This means that the primary studies differ clinically, for example within the way that comparisons are carried out. What to combine is a subjective decision based on discussion and clinical evaluation, and agreement can be difficult to achieve (Higgins & Green, 2011).

Searches in literary databases, Science Direct, ERIC and Psych Info, gave all together nine hits with search words “EIBI” and “meta-analysis” (Eldevik et al., 2009; Kuppens & Onghena, 2011; Makrygianni & Reed, 2010; Peters-Scheffer, Didden, Korzilius & Sturmey, 2010; Reichow, 2012; Reichow & Wolery, 2009; Spreckley & Boyd, 2009; Strauss, Mancini, the SPC Group & Fava, 2013; Virués-Ortega, 2009). Reichow (2012) presents an overview of meta-analysis on EIBI for young children with ASD. Strauss el al. (2013) gives a synthesis of meta-analysis on EIBI, and in addition takes parent inclusion in treatment into consideration. Kuppens and Onghena (2011) present an introduction to Sequential meta-analysis (SMA). SMA is not well known in the research fields of mental health and disabilities. The strategy gives a statistical framework that determines whether the cumulative knowledge in meta-analysis is sufficient, and might be helpful when statistical conclusions are to be drawn.

The remaining six meta-analytic studies present data on several outcome studies of EIBI on children with difficulties within the spectrum of autism or pervasive developmental disorders (PDD). Five show evidence for EIBI effectiveness (Eldevik et al., 2009; Makrygianni & Reed, 2010; Peters-Scheffer et al., 2010; Reichow & Wolery, 2009; Virués-Ortega, 2009). The sixth meta-analysis (Spreckley & Boyd, 2009) found no scientific evidence for EIBI being superior the control groups. Reichow (2012) points out that this might be a result of the differences in inclusion criteria amongst the five meta-analyses (the sixth meta-analysis, Peters-Scheffer et al. (2010), was not included in this paper). Spreckley and Boyd (2009) made a different interpretation of one of the included studies (Sallows & Graupner, 2005) than the other authors of the meta-analyses. In the study of Sallows and Graupner (2005), an EIBI experimental group was compared to a parent directed EIBI group and the results for the two groups were similar. Spreckley and Boyd (2009) treated the parent directed EIBI group as a control group, which the other authors did not. Reichow (2012) arguments, that this probably is the reason for the weak effect size difference in the meta-analysis of Spreckley and Boyd (2009), and an example of the “apples and oranges” problem (Smith, Eikeseth, Sallows & Graupner, 2009).

In the following, the meta-analyses will be reviewed and to some extent compared. The first published meta-analysis will be more thoroughly described than the others.

The Reichow and Wolery (2009) meta-analysis.

The first published meta-analysis of EIBI for children with autism was the one of Reichow and Wolery (2009, published online in 2008). They executed a three part comprehensive synthesis consisting of a descriptive analysis, an effect size analysis, and a meta-analysis. The seven inclusion criteria were that the studies incorporated EIBI with direct reference to the pioneer work of Lovaas and colleges in the UCLA young autism project. The participants were diagnosed with ASD, PDD or PDD-NOS (Not Otherwise Specified) and had a mean age of less than 84 months at treatment start. Further, the mean duration of EIBI was larger or equal to one year. At least one child outcome measure needed to be reported as well as the usage of an experimental research design (i.e. pre- / post-test multiple group design) or quasi-experimental research design (i.e. nonequivalent control group design). Finally, the results needed to be published in English in a peer-reviewed journal (Reichow & Wolery, 2009). Their literary search found 14 results based on the seven inclusion criteria. Two modifications were made. One study was a replication of another, and therefor treated as one (Lovaas, 1987 and McEachin et.al., 1993). In another study, both experiments were based on EIBI and therefor treated as two (Sallows and Graupner, 2005). They ended up analyzing 14 samples from 13 studies (Anderson et al., 1987; Bibby et al., 2001; Birnbrauer & Leach, 1993; Boyd & Corley, 2001; Cohen et al., 2006; Eikeseth et al., 2007; Eldevik et al., 2006; Lovaas, 1987; Magiati et al., 2007; Sallows & Graupner, 2005; Sheinkopf & Siegel, 1998; Smith, Eikeseth, Klevstrand & Lovaas, 1997, and Smith et al., 2000).

The descriptive analysis showed that the methodological quality or rigor of the studies varied between strong (23 %), middle or adequate (38 %) and weak (38 %), which was acceptable. Limitations were found within four methodological variables: experimental design, assignment to groups, procedural fidelity, and measures. The use of RCT, random assignment to groups, was only found in two studies, the one of Sallows and Graupner (2005) and by Smith et al. (2000). The others were quasi-experimental designs. None of the studies ensured treatment fidelity satisfactory. All but one of the studies included indirect measures on adherence and competence, in addition to a use of treatment manual. The one study directly measured adherence and competence (Anderson et al., 1987). Some of the studies reported indirect measures on differentiation and a few reported direct measures. Reichow and Wolery (2009) strongly advice that future studies include direct measure of procedural fidelity across therapists, participants and conditions to strengthen the research conclusion. Outcome data were in most of the studies reported pre- and post-intervention on IQ, adaptive behavior, expressive and receptive language, academic placement (post only), psychopathology and diagnostic recovery (post only).

The descriptive analysis of participant characteristics showed differences between the studies. The mean IQ at intake differed from 28 to 83. The homogeneity of the participant groups were compromised by the general heterogeneity of children with autism and the small sample sizes, as well as usage of different editions of the diagnostic manual. However, the impairment of language and adaptive behavior on average was present at pre-intervention. Intervention characteristics was divided into density, duration, total hours, training model, service coordination model, parent role, qualification of therapists, location of therapy and usage of physical aversives. A variation between the studies was detected, with one exception. Therapy partly took place in the participant’s home in all the studies.

Descriptive outcome analysis carried out on placement, psychopathology, and diagnostic reclassification show support on EIBI effectiveness for many children with autism. The results for psychopathology imply that on average, the children display fewer or less severe symptoms of autism after intervention. Some children will also perform adequately in typical educational settings, according to the results from academic placement and diagnostic reclassification (Reichow & Wolery, 2009).

In the effect size analysis of Reichow and Wolery (2009), the analysis by sample included calculation of mean change effect sizes for IQ, adaptive behavior and expressive – and receptive language. Not all studies reported on all of these categories. With only a few exceptions, the results show large change in effect size. The category with most variation and the least obvious change was adaptive behavior.

The between groups analysis of comparative studies was analyzed and organized according to type of comparison. Most studies compared their EIBI treatment group to other treatments (e.g., eclectic treatment). Two studies made comparison to minimal-treatment, and two studies compared clinic based EIBI to parent based EIBI. The standardized mean difference effect size was calculated and the findings suggested that EIBI groups gained more than the other treatment groups, with exception of the clinic/parent comparison study. Although the evidence for EIBI being superior to other treatments were strong, limitations due to the nonrandom assignment to groups and the lack of adequate comparison groups were present.

In their meta-analysis, Reichow and Wolery (2009) excluded the comparison group data because of the lack of similarity across studies. IQ was the only category in which the treatment samples reported enough data to conduct a standardized mean change effect size. The mean effect size was statistical significant and supported the claim that EIBI is an effective intervention for increased IQ for children with autism. Calculation of publication bias showed that there was a chance for this being present. The calculation of homogeneity of the data indicated a need for moderator analysis, which showed that the only variable with statistically significance to the relation of IQ change was supervisor-training model. The other moderators were density, duration, total hours of treatment, pre-treatment chronological age, and pre-treatment IQ.

The synthesis of Reichow and Wolery (2009) presents evidence for the effectiveness of EIBI, especially in relation to IQ scores, but it also revealed many knowledge gaps, which makes the findings somewhat unreliable.

The Eldevik et al. (2009) meta-analysis.

The second meta-analysis on EIBI for children with autism was published by Eldevik and colleges in 2009. This was a replication and extension of the Reichow and Wolery (2009) meta-analysis. Six methodological improvements were made. A precise definition of EIBI and the control/comparison groups, and only studies with a control or comparison group were selected. A requirement of more uniform outcome measurement that only included full-scale measures of IQ was made. A meta-analysis of changes in adaptive behavior was added. Other studies were included because of the later time of literary search and the slightly different definition of EIBI. Inter rater reliability was conducted for the literary search and the initial selection of studies. Finally, the analysis was based on individual raw data provided by the authors, instead of group average data.

Nine studies met the inclusion criteria and were further analyzed (Birnbrauer & Leach, 1993; Cohen et al., 2006; Eikeseth et al., 2002; Eldevik et al., 2006; Howard et al., 2005; Lovaas, 1987; Remington et al., 2007; Smith et al., 1997; Smith et al., 2000). Seven of these were also included in the meta-analysis of Reichow and Wolery (2009). The studies of Howard et al. (2005) and Remington et al. (2007) were only included in Eldevik et al. (2009). Further, some of the included studies from Reichow and Wolery (2009) did not meet the inclusion criteria of Eldevik et al. (2009) (Anderson et al., 1987; Bibby et al., 2001; Boyd & Corley, 2001; Magiati et al., 2007; Sheinkopf & Siegel, 1998; and Sallows & Graupner, 2005).

The results of the meta-analysis of Eldevik et al., (2009), showed homogeneity among the studies despite the small sample sizes, and a common effect size for all the studies combined could be calculated as well. For IQ and adaptive behavior composite (ABC) scores, the standardized mean difference effect size was calculated, which means that the effect size was measured in relation to the effect size of the comparison or control groups. The results were in favor of EIBI for both IQ and ABC, and there were no publication bias found seen in light of the technical limitations due to the small sample sizes.

The Spreckley and Boyd (2009) meta-analysis.

The third published meta-analysis is the one by Spreckley and Boyd (2009). This stands out as the one who found no evidence supporting EIBI and a possible reason for this is outlined below. After further inspection, this meta-analysis contains four studies only, and two of these are parent directed home-based EIBI (Sallows & Graupner, 2005; and Smith et al., 2000). The authors of the four articles wrote a letter to the editor of the Journal of Pediatrics where the Spreckley and Boyd (2009) meta-analysis was published (Smith, Eikeseth, Sallows & Graupner, 2009), where they point out what they see as problems with Spreckley and Boyd’s (2009) meta-analysis. In brief, the problems were the handling of the study of Sallows and Graupner (2005) as a comparison of EIBI versus standard care when both groups received EIBI (center based EIBI versus parent managed EIBI), and hence, is incorrect to classify parent managed EIBI as standard care (i.e., control). The authors argue that the result of the meta-analysis would have turned out differently if the two groups had been classified as EIBI groups instead. The four studies showed strong positive gains for the EIBI groups.

The Makrygianni and Reed (2010)-, the Virués-Ortega (2010)-, and the Peters-Scheffer et al. (2011) meta-analyses.

These meta-analyses found support for EIBI being an effective intervention for young children with autism. Makrygianni and Reed (2010) evaluated 14 studies. Seven of these were also in the Eldevik et al. (2009) study (Cohen et al., 2006; Eldevik et al., 2006; Howard et al., 2005; Lovaas, 1987; Remington et al., 2007; Smith et al., 1997; and Smith et al., (2000), and eight of the Reichow and Wolery (2009) study (Anderson et al., 1987; Cohen et al., 2006; Eldevik et al., 2006; Lovaas, 1987; Magiati et al., 2007; Sallows & Graupner, 2005; Smith et al., 1997; and Smith et al., 2000) . In addition, they analyzed Ben-Itzchak and Zachor (2007); Reed, Osborne, & Corness (2007a); Reed, Osborne, & Corness (2007b); and Weiss (1999).

The Virués-Ortega (2010) study included 22 studies, in which 16 were also included in other meta-analyses. They found EIBI to be more effective on IQ, receptive and expressive language, and communication, than on non-verbal IQ, social functioning and daily living skills. Nevertheless, the results show positive effects on all areas.

The meta-analysis of Peters-Sceffer et al, (2010) contained 11 studies, all of them included in former mentioned meta-analyses. They found clinically significant large effect size between the groups in areas of IQ, non-verbal IQ, receptive and expressive language. They found smaller difference between the groups in terms of adaptive behavior.

These three meta-analyses agree with both the Reichow and Wolery (2009) and the Eldevik et al. (2009) meta-analyses that EIBI is effective on IQ, language skills, communication and social skills, and moderate to high effect on adaptive behavior for children with ASD. Further, those who made comparison assessments agree that EIBI is more effective than other treatments (Makrygianni & Reed, 2010; Peters-Scheffer et al., 2010).

Follow-up studies

According to Matson and Konst (2013), a “true” follow-up assesses the effect of a treatment after the intervention is terminated to see if the results maintain. Matson and Konst (2013) further point out that there seem to be variation in use of the term follow-up amongst the EIBI effectiveness researchers, and that treatment might be ongoing during follow-up- or post-test assessment. A search in the literary database Science Direct gave 74 hits with search words EIBI and follow up. However, a search in the database ERIC with the same term only gave four hits, strangely enough. Reading the titles and abstracts limited the overall results from both searches down to 15 articles (Bibby et al., 2001; Eikeseth et al., 2012; Fernell et al., 2011; Fava et al., 2011; Klintwall & Eikeseth, 2012; Kovshoff, Hastings & Remington, 2011; Magiati et al., 2011; Magiati et al., 2007; Mazurek, Kanne & Miles, 2012; O’Connor & Healy, 2011; Peters-Scheffer, Didden, Mulders & Korzilius, 2010; Stock, Mirenda & Smith, 2013; Strauss et al., 2012; and Zachor & Ben-Itzchak, 2010). Several of these are included in the Matson & Konst (2013) review. This paper contained 22 studies which allocated as follows: 10 studies conducted post-tests six to twelve months after treatment start (Ben-Itzchak, Lahat, Burgin & Zachor, 2008; Ben-Itzchak & Zachor, 2007; Eikeseth et al., 2012; Fava et al., 2011; Karanth, Shaista & Srikanth, 2010; Smith et al., 2010; Stahmer, Akshoomoff & Cunningham, 2011; Strauss et al., 2012; Wallece & Rogers, 2010; and Zachor & Ben-Itzchak, 2010). Five studies conducted post-tests up to two years after treatment initiation (Fernell et al., 2011; Howard et al., 2005; Magiati et al., 2007; Strain & Bovey, 2011; and Weiss, 1999). One study reported three-year post-test data (Eikeseth et al., 2007), and one study reported post-test data after four years (Sallows & Graupner, 2005). In two studies, the post-test varied from child to child based on treatment responding (O’Connor & Healy, 2010; Valenti, Cerbo, Masedu, De Caris & Sorge, 2010). Finally, three studies presented true follow-up measures (Akshoomoff, Sthamer, Corsello & Maher, 2010; Kovshoff et al., 2011; Richards, Walstab, Wright-Rossi, Simpson & Reddihough, 2009).

To begin with the “true” follow-up studies, Akshoomhoff et al. (2010) studied 29 children with ASD who originally took part in the study of Stahmer and Ingersoll (2004). The children received pivotal response treatment, incidental teaching, and small group discrete trial instruction. The training duration was one year in an inclusive toddler program. The follow-up assessment took place at least one year after treatment termination. The results showed, across time from entry to follow-up, a significant increase in the verbal IQ, communication and daily living skills. The diagnosis placement was stable and child-related parent stress remained high.

The Richards et al. (2009) study is a RCT and examined whether a 12 months home based program gave improvements in cognition and adaptive skills. Change was also assessed with respect to what they label “behavior”, which include behavioral difficulties as well as developmental trajectories within motoric behavior and social behavior. The intervention was early but did not base on behavioral principles for neither the intervention group nor the control group. Details of the individualized intervention are not thoroughly described in the paper, but emphasizes building the child’s self-esteem. Both groups received 5-hour center-based intervention per week for 12 months. The intervention group received in addition a home-based program with parent-inclusion, in which the intensity was a mean of 35, 5 hours per week with a one and a half hour teacher-visit per week in 40 weeks. Daily living skills, and understanding and dealing with challenging behavior, were focused upon. One year after treatment termination, they found significant change between the groups on IQ at follow-up. Basically, the intervention group made larger progress than the control group. However, the authors suggest a more intensive program who emphasizes improvement on communication and language skills, such as early intensive behavioral interventions, in order to make changes that are more distinguishable.

A common feature for these two follow-up studies is that the duration of the intervention is too short to match the definition of EIBI by Green et al. (2002). The third follow-up study mentioned by Matson and Konst (2013) is the Kovshoff et al. (2011) study. This is a follow-up of the Remington et al. (2007) study, which is considered an important outcome study for children with autism receiving EIBI. Although not an RCT, this study holds high scientific merit (Klintwall & Eikeseth, 2014). The study is included in some of the meta-analytic studies mentioned above. The Remington et al. (2007) and the follow-up (Kovshoff et al. 2011) aimed at measuring any benefits of a fixed amount of EIBI, i.e. two years. The follow-up assessment was conducted two years after treatment termination. The treatment group consisted of two subgroups, in which the first was university-supervised and the second was parent-commissioned. The control group received treatment as usual (TAU). In the study of Remington et al. (2007), the results of the two subgroups were quite similar and were treated as one group. The follow-up (Kovshoff et al. 2011) revealed a different result and the two subgroups needed to be treated separately. It turned out that the parent-commissioned group sustained the gains obtained during the two years of intervention much better than the university-supervised group. The TAU-group did not change significantly during the two years of intervention, and showed no change at follow-up. The IQ level of the university-supervised group fell from the same level as the parent-commissioned group to the level of the TAU-group during the two-year period without treatment. Looking more closely, the baseline level of IQ differed between all the three groups, and the university-supervised group had the lowest average baseline IQ level. This group made slightly higher percentage progress than the parent-commissioned group during treatment. However, the gap between them stayed approximately the same. Whilst the parent-commissioned group maintained their IQ level of slightly above 80, the university-supervised group lost more than they gained, and ended up at an average of slightly above 50. All children, independent of group, met criteria of autism-diagnosis at the time of follow-up. The authors of this study are clear about the weaknesses the initial group differences provide, and that this limits their opportunity to draw any conclusion about the effect of time-limited EIBI.

All but two of the post-test outcome studies that appeared in the literary search as mentioned earlier, as well as the ones from Matson and Konst (2013), show support for EIBI. The studies of Fernell et al. (2011), and Zachor and Ben-Itzchak (2010) showed no significant difference in support for EIBI. The study of O’Connor and Healy (2010) is based upon children that did show significant gains from EIBI treatment and evaluates whether these changes maintained in a fulltime regular classroom setting with typically developing peers. The results were mixed, but overall the gains did not maintain.

The follow-up of the study of Lovaas (1987) by McEachin, Smith and Lovaas (1993) did not appear in either of the searches, nor in the review of Matson and Konst (2013). This study is recognized as the only one to date that has evaluated the long-term effect of EIBI. The study found evidence for long-lasting gains from behavioral treatment by reexamining the participants at the mean age of 13 years in the experimental group and 10 years in the control group. The examination took place after termination of treatment, although there was a variation of treatment duration amongst the participants. Eight of the nine participants who achieved best outcome in the 1987 study, did not receive any treatment after the two years of EIBI and they maintained their gains and were categorized as normal functioning. The rest of the participants in the experimental group had also maintained their level of function. The level of function in the control group had changed minimally from onset of treatment to the time of follow-up (McEachin et al. 1993).

It should be noted that the study of Magiati et al. (2007) was followed up by Magiati et al. (2011). They report outcome measures seven years after treatment initiation at a mean age of 10, 3 years (n = 36). All children had received EIBI in early childhood, so this was not a comparison-controlled study. Nevertheless, the investigation found evidence for long-term effect of EIBI, but not equally large as reported in other outcome studies (Magiati et al. 2011).

Thirteen of the above-mentioned pre-post-test or follow-up studies describe possible predictors of positive outcome. Repeatedly, IQ level at intake and language skills are mentioned, but also elements such as treatment fidelity and parental stress are noted. One study aims at the children’s initial reinforcement conditions as predictors of outcome (Klintwall & Eikeseth, 2012). This study suggests that children who initially show some degree of social motivation, and is learning from socially mediated reinforcers, make greater progress in EIBI treatment than children who display self-stimulatory behavior maintained by automatic reinforcement (Klintwall & Eikeseth, 2012). Perry et al. (2011) and Perry, Blacklock and Geier (2013) conducted research specifically on predictors of outcome in children enrolled in EIBI programs in Ontario, Canada. Perry et al. (2013) found evidence for age at intake being a strong predictor for large IQ gain. The young group (N = 60 and two – five years of age) gained an average of 17 IQ points whilst the older group (N = 60 and six – 13 years of age) gained an average of two IQ points. Perry et al. (2011) investigated whether age at entry, initial cognitive level, initial adaptive level, and diagnostic severity serves as predictors of outcome. They found that all of these were predictors of outcome, but initial cognitive level was the strongest. At the same time, they did not find sure predictors for poor outcome. A pattern of low IQ at intake was the only one, and they give suggestions for further investigation on this matter in the future. To investigate predictors of poor outcome will benefit the group of children with autism that make little progress despite early onset of EIBI, and may give some answers to the questions of what these children might need instead (Klintwall & Eikeseth, 2012; McEachin, et al. 1993).

The current review of follow-up studies revealed that there are only a small number of “true” follow-up studies regarding EIBI. Hence, there is a need for more research on the effects of EIBI after the intervention has ended.

Adult outcome studies

A literature search in Science Direct gave 232 hits with the search phrase “autism AND adult outcome”. A search in PubMed using the same phrase gave 408 hits, and searching in ERIC gave 29 hits. By reading the newest systematic reviews and noticing to whom they refer, the selection of articles became more refined.

The most recent systematic review is by Magiati, Tay and Howlin (2014). This will together with Henninger and Taylor (2012), pose as basis for the following overview of adult outcome studies. The overview will only comprise a selected sample of adult outcome studies with main emphasize on the studies published after 2010. Initially, however, a historical view will be provided by looking at the pioneer work of Leo Kanner (1943, 1971) regarding people with autism.

Leo Kanner was the first to describe children, all younger than 11 years of age, and with characteristic behavior patterns, and began labeling them as autistic. In his first paper, published in 1943, Kanner describes 11 children (eight boys and three girls) in a lively manner that makes the features recognizable to those of us familiar with this diagnosis, many years later. After approximately 30 years, Kanner made a follow-up study of these children, published in 1971. One of the persons had died suddenly at age of 29, other than that they were in their thirties. Two of the persons were not reached for follow-up, and the study therefor consisted of nine cases. Four of the children had very poor outcome as they after institutionalization withdrew themselves and stopped completely responding to social contact. Two of the children were, on the other hand, described as success stories as they both were employed in regular work at the time of the follow-up. At this time, autism was not yet accepted as a diagnosis, and not included in diagnostic material such as the DSM II. Children with autism got the diagnosis “Schizophrenia, childhood type”. This was also the time were therapy of both children and parents were at the very beginning, and the parents role had just altered from distant spectator to an active contributing co-therapist. Kanner suggested that future 20 – 30 year follow-up studies of other groups of children with autism will reveal knowledge and material for a more hopeful outcome prognosis.

Still, in 2014, knowledge of adult outcome for persons with autism is limited (Magiati et al. (2014). Several authors agree that the amount of research of this topic is small, yet the knowledge and amount of research on effective treatment and short-term outcome in early to middle childhood is well established (Eaves & Ho, 2008; Howlin, 1997; Levy & Perry, 2011; Magiati et al., 2014; McDonald & Machalicek, 2013; Palmen, Didden & Lang, 2012).

A number of longitudinal adult outcome studies for people with autism have been published over the years. The studies may assess outcome across multiple domains or examine the topics specifically, i.e. cognitive- and adaptive skills, autism severity and comorbid conditions using standardized assessment methods (Magiati et al. 2014). Commonly, the earliest studies do not include details of any early intervention or other early therapy the subjects may have undergone in their childhood. However, some researchers began to highlight the importance of education in early years in children with autism already then. Especially the research of Michael Rutter and colleagues was concerned with this (i.e. Lockyer & Rutter, 1969). Anyway, there were a variety of different measurements and designs with vague and unreliable criteria characterizing the adult outcome studies published pre the 2000s (Henninger & Taylor, 2012). Labels as “Good”, “Fair”, “Poor” and “Very poor” were used to categorize outcomes. Rutter, Greenfield and Lockyer (1967) made a definitional index of each category: “Good” outcome was referring to that the person lead a normal or close to normal life, and had a satisfactory level of function at school or at work. “Fair” outcome meant that in spite of abnormalities in behavior and / or relations to other people the person made social and educational progress. “Poor” outcome implied sever handicap with little ability of independent living, but some measure of social adjustment and potential for social progress remained. “Very poor” was described in terms of that the person was unable to lead independent existence of any kind.

This scale has been refined over the years and come to include an additional measure of “restricted but acceptable” placed between “fair” and “poor” (Gillberg & Steffenburg, 1987) and measures of language and adaptive development ranged from “very good” to “very poor” with more detailed descriptions attached (Kobayashi, Murata & Yoshinaga, 1992).

Studies published post 2000 show increasing rigor and more quantification of outcome and thus increasing specificity and reliability (Henninger & Taylor, 2012). Howlin, Goode, Hutton and Rutter (2004) applied another variety of the scale, the Overall Outcome Rating (OOR), to rate the scores from assessment of three domains: work, friendship, and independent living. Each category gave a composite score based on different descriptions and the rating zero indicated good outcome. The ratings constitute five overall categories: (a) “very good”, (b) “good”, (c) “fair”, (d) “poor”, and (e) “very poor”. The composite scores were compared and seen in relation with each other, thus used to derive possible variables associated with “good” and “poor” outcome. No sure predictors of “good” outcome were found, but a performance IQ of < 70 and a verbal IQ of < 30 as children, indicate a “poor” and “very poor” outcome. Overall results of this study show that 57 % (n = 68) was rated as “poor” and “very poor” outcome. According to Howlin et al. (2004), this result matches the results of previous follow-up studies as well. However, they found tendencies for more positive outcome with respect to decreased hospitalization and increased sheltered employment.

The OOR is frequently used during the 2000s and in some of the latest adult outcome studies as well, measuring social outcome in adults with ASD (e.g. Billstedt, Gillberg & Gillberg, 2005; Eaves & Ho, 2008; Gillespie-Lynch et al., 2012; Howlin, Moss, Savage, Rutter, 2013). An extension of the outcome scale might be the quantification of measuring the impact ASD has on quality of life (QoL). One example is the study of Barneveld, Swaab, Fagel, van Engeland and de Sonneville (2014). They compared a group of young high functioning adults with ASD to groups containing persons with other child psychiatric diagnosis such as Attention Deficit Hyperactivity Disorder (ADHD) and types of affective disorders. They found that in the ASD group the QoL was more compromised than in the other groups even in the ones with high education, independent work and living, and with friends ("very good" outcome). Findings from a systematic review by Tobin, Drager, and Richardson (2014) suggest that informal social support from social networks facilitates social participation- and functioning, and the QoL for adults with ASD. Billstedt, Gillberg and Gillberg (2011), reexamined their sample from 2005 (Billstedt, Gillberg & Gillberg, 2005) measuring the relationship between the person and his environment. They developed a global assessment scale ranging from "very good" to "very poor" based on a measure called "Autism-Friendly Environment". By looking at the results from their 2005 study differently, the results changed from having a 78 % share of "poor" or "very poor" outcome, to a 62 % share of "good" or "very good". They give suggestions for further conceptualization of what "Autism-Friendly Environment" might imply, as well as develop tools to better assess QoL for people with ASD. A quantitative measure of QoL might be an interesting aim in adult outcome research. Regardless of level of functioning, what does high QoL imply for an adult person with autism? Perhaps one might consider including an analysis of the participant's reinforcement conditions in longitudinal outcome studies, as well as including type of early intervention, if any. Furthermore, there might be expedient to evaluate more specific whether the participant have received any types of evidence based intervention later in childhood, adolescence and / or adulthood.

Research on intervention for adolescents and young adults with autism are summarized in McDonald and Machalicek (2013) and Palmen, Didden and Lang (2012). They found that there is a growing amount of research in the categories of (a) social skills, (b) communication skills, (c) challenging behavior, (d) academic skills, (e) vocational skills, (f) independence and self-help skills, (g) physical development, and (h) domestic skills. In some of these studies the intervention is based on ABA and the study is designed as an N = 1, and controlled by e.g. multiple baseline. Whether the subjects underwent EIBI as children are not accounted for. Nevertheless, the amount of knowledge regarding facilitation and teaching strategies that might be effective for an increase in competence in people with ASD, is growing.

Based on the reviews by Henninger and Taylor (2013) and Magiati et al. (2014), most of the longitudinal studies report on “poor” or “very poor” outcome for the majority of referrals in their studies. IQ level seem to decrease over time with exception of those with initial high IQ. Some studies found a positive correlation between early language ability and / or responsiveness to joint attention, and later social outcome. In terms of adaptive functioning, only a few studies reported on this. There seem to be a slight improvement in overall composite scores into adulthood, as well as for the domain score of daily living skills. ASD core symptoms in adulthood appear to be relatively stable over time.

Both Henninger and Taylor (2013) and Magiati et al. (2014) recommend EIBI researchers to follow up their participants over time into adulthood in order to evaluate the long-term effect of this treatment, as well as continuing to reveal effective intervention factors. They also expect that the effects of successful intervention in childhood will start to show in imminent adult outcome studies. Magiati et al. (2014) also encourage researchers to explore ageing in autism, a relatively uncharted territory.

Conclusion

This article outlines the concept of EIBI for children with autism. With an emphasis on the research that has contributed in the establishing of the short-term-effectiveness of this treatment, the need for studies providing more evidence for the long-term-effectiveness, has been illuminated. There is currently no studies available examining outcome in adulthood for children receiving EIBI during childhood, but a number of studies examine outcome in adulthood for nonspecific treatments. The majority of these studies report “poor” or “very poor” outcome. In conclusion, the amount of evidence supporting EIBI is large, but not in the long term. The time has come for EIBI researchers to follow up their referrals in adolescence and adulthood, and contribute to the body of knowledge in a lifetime perspective regarding persons with ASD.

References:

Akshoomoff, N., Stahmer, A. C., Corsello, C., & Mahrer, N. E. (2010). What happens next? Follow-up from the children's toddler school program. *Journal of Positive Behavioral Interventions, 12,* 245–253.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (4th ed.)*. Washington, DC: American Psychiatric Association.

Anderson, S. R., Avery, D. L., DiPietro, E., & Edwards, G. L. (1987). Intensive home-based early intervention with autistic children. *Education and Treatment of Children*, *1,* 352–366.

Barneveld, P. S., Swaab, H., Fagel, S., van Engeland, H., & de Sonneville, L. M. J. (2014). Quality of life: a case-controlled long-term follow-up, comparing young high-functioning adults with autism spectrum disorders with adults with other psychiatric disorders diagnosed in childhood. *Comprehensive Psychiatry, 55,* 302 – 310.

Ben-Itzchak, E., Lahat, E., Burgin, R., & Zachor, A. (2008). Cognitive, behavior and intervention outcome in young children with autism. *Research in Developmental Disabilities, 29* (5), 447–458.

Ben-Itzchak, E., & Zachor, D. A. (2007). The effects of intellectual functioning and autism severity on outcome of early behavioral intervention for children with autism. *Research in developmental disabilities*, *28* (3), 287–303

Bibby, P., Eikeseth, S., Martin, N. T., Mudford, O. C., & Reeves, D. (2001). Progress and outcomes for children with autism receiving parent-managed intensive interventions. *Research in Developmental Disabilities, 22,* 425 – 447.

Billstedt, E., Gillberg, 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.

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults with diagnosed with autism in childhood: a population-based study. *Autism, 15* (1), 7 – 20.

Birnbrauer, J. S., & Leach, D. J. (1993). The Murdoch Early Intervention Program after 2 years. *Behaviour Change*, *10* (2), 63–74.

Boyd, R. D., & Corley, M. J. (2001). Outcome survey of early intensive behavioral intervention for young children with autism in a community setting. *Autism, 5,* 430 – 441.

Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: replication of the UCLA model in a community setting. *Journal of developmental & behavioral pediatrics*, *27* (2), 145–155.

Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied Behavior Analysis (second edition)*. New Jersey, Prentice Hall.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A., & Varley, J. (2010). Randomized, Controlled Trial of an Intervention for Toddlers with Autism: The Early Start Denver Model. *Pediatrics*, *125* (1), 17–23.

Eaves, L. C. & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *38* (4), 739–747.

Eikeseth, S. (2001). Recent critiques of the UCLA young autism project. *Behavioral Interventions*, *16,* 249–264.

Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in developmental disabilities*, *30* (1), 158–178.

Eikeseth, S. (2011). Intensive Early Intervention. In J. L. Matson & P. Sturmey (Eds.), *International Handbook of Autism and Pervasive Developmental Disorders* (pp. 321 – 338). New York: Springer.

Eikeseth, S., Klintwall, L., Jahr, E., & Karlsson, P. (2012). Outcome for children with autism receiving early and intensive behavioral intervention in mainstream preschool and kindergarten settings. *Research in Autism Spectrum Disorders*, *6*, 829–835.

Eikeseth, S., Smith, D. P., & Klintwall, L. (2014). Discrete trial teaching and discrimination training. In J. Tarbox, D. R. Dixon, P. Sturmey, & J. L. Matson (Eds.), *Handbook of Early Intervention for Autism Spectrum Disorders. Research, Policy and Practice* (pp. 293-324). New York: Springer.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism. *Behavior modification*, *26* (1), 49 – 68.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007). Outcome for Children With Autism Who Began Intensive Behavioral Treatment Between Ages 4 and 7. *Behavior modification*, *31*(3), 264 – 278.

Eldevik, S., Eikeseth, S., Jahr, E., & Smith, T. (2006). Effects of low-intensity behavioral treatment for children with autism and mental retardation. *Journal of Autism and Developmental Disorders*, *36* (2), 211–224.

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 and adolescent psychology*, *38* (3), 439–450.

Eldevik, S., Hastings, R. P., Jahr, E., & Hughes, C. J. (2011). Outcomes of Behavioral Intervention for Children with Autism in Mainstream Pre-School Settings. *Journal of Autism and Developmental Disorders*. DOI 10.1007/s10803-011-1234-9.

Fava, L., Strauss, K., Valeri, G., D'Elia, L., Arima, S., & Vicari, S. (2011). The effectiveness of a cross-setting complementary staff- and parent-mediated early intensive behavioral intervention for young children with ASD. *Research in Autism Spectrum Disorders, 5,* 1479–1492.

Fenske, E. C., Krantz, P. J., & McClannahan, L. E. (2001). Incidental teaching: A Not-discrete-trial teaching procedure. In C. Maurice, G. Green, and R. M. Foxx, (Eds.), *Making a Difference: Behavioral Intervention for Autism*, (pp. 75–82). Austin TX: Pro-Ed.

Fernell, E., Hedvall, Å., Westerlund, J., Høglund Carlsson, L., Eriksson, M., & Gillberg, C. (2011). Early intervention in 208 Swedish preschoolers with autism spectrum disorder. A prospective naturalistic study. *Research in Developmental Disabilities, 32* (6), 2092–2101.

Gillberg, C. & Steffenburg, S. (1987). Outcome and prognostic factors in infantile autism and similar conditions: A population-based study of 46 cases followed through puberty. *Journal of Autism and Developmental Disorders*, *17* (2), 273–287.

Green, G., Brennan, L. C., & Fein, D. (2002). Intensive behavioral treatment for a toddler at high risk for autism. *Behavior Modification, 26*, 69-102.

Handleman, J. S., Harris, S. L., Celiberti, D., Lilleheht, E., & Tomchek, L. (1991). Developmental changes of preschool children with autism and normally developing peers. *Infant-Toddler Intervention*, *1* (2), 137–143.

Harris, S. L., Handleman, J. S., Gordon, R., Kristoff, B., & Fuentes, F. (1991). Changes in cognitive and language functioning of preschool children with autism. *Journal of Autism and Developmental Disorders*, *21* (3), 281–290.

Harris, S. L., Handleman, J. S., Kristoff, B., Bass, L., & Gordon, R. (1990). Changes in language development among autistic and peer children in segregated and integrated preschool settings. *Journal of Autism and Developmental Disorders*, *20* (1), 23–31.

Hart, B., & Risley, T. R. (1975). Incidental teaching of language in the preschool. *Journal of Applied Behavior Analysis*, *8,* 411-420.

Hayward, D., Eikeseth, S., Gale, C., & Morgan, S. (2009). Assessing progress during treatment for young children with autism receiving intensive behavioural interventions. *Autism*, *13* (6), 613 –633.

Henninger, N. A., & Taylor, J. L. (2012). Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism*, *17* (1), 103 – 116.

Higgins, J. P. T., Green, S. (eds). (2011) *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0 [updated March 2011]. The Cochrane Collaboration. Available from www.cochrane-handbook.org.

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.

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. *American Academy of Child & Adolescent Psychiatry*, *52* (6), 572 – 581.

Howard, J. S., Sparkman, C. R., Cohen, H. G., Green, G., & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, *26* (4), 359–383.

Hoyson, M., Jamieson, B., & Strain, P. S. (1984). Individualized group instruction of normally developing and autistic-like children: The LEAP curriculum model. *Journal of Early Intervention*, *8* (2), 157–172.

Kanner, L. (1943) Autistic disturbances of affective contact. *Nervous Child, 2,* 217–250.

Kanner, L. (1971) Follow-up study of eleven autistic children originally reported in 1943. *Journal of Autism and Childhood Schizophrenia*, *1* (2), 119–145.

Karanth, P., Shaista, S., & Srikanth, N. (2010). Efficacy of communication DEALL: An indigenous early intervention program for children with autism spectrum disorders. *Indiana Journal of Pediatrics, 77*, 957–962.

Klintwall, L., & Eikeseth, S. (2012). Number and controllability of reinforcers as predictors of outcome for children with autism receiving early and intensive behavioral intervention: a preliminary study. *Research in Autism Spectrum Disorders, 6* (1), 493 – 499.

Klintwall, L., & Eikeseth, S. (2014). Early and intensive behavioral intervention (EIBI) in autism. In V. B. Patel, V. R. Preedy, & C. R. Martin (Eds.), *Comprehensive Guide to Autism* (pp. 117 – 137). New York: Springer Science + Business Media

Kobayashi, R., Murata, T., & Yoshinaga, K. A. (1992) Follow-up study of 201 children with autism in Kyushu and Yamaguchi areas, Japan. *Journal of Autism and Developmental Disorders, 22* (3), 395–411.

Kovshoff, H., Hastings, R. P., & Remington, B. (2011). Two-year outcomes for children with autism after the cessation of early intensive behavior intervention. *Behavior Modification, 35,* 427–450.

Kuppens, S., & Onghena, P. (2012). Sequental meta-analysis to determine the sufficiency of cumulative knowledge: the case of early intensive behavioral intervention for children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6,* 168 – 176.

Leaf, R. & McEachin, J. (1999). *A work in progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism.* New York: DRL Books, L. L. C.

Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: a review of the literature. *Research in Autism Spectrum Disorders, 5,* 1271 – 1282.

Lockyer, L., & Rutter, M. (1969). A five to fifteen year follow-up study of infantile psychosis: III. Psychological aspects. *The British Journal of Psychiatry, 115,* 865 – 882.

Lovaas, O.I. (1977). *The autistic child: Language development through behavior modification*. New York: Irvington Publishers.

Lovaas, O. I. (1987). Behavioral Treatment and Normal Educational and Intellectual Functioning in Autistic Children. *Journal of consulting and clinical psychology*, *55* (1), 3–9.

Lovaas, O. I. (1993). The development of a treatment-research project for developmentally disabled and autistic children. *Journal of Applied Behavior Analysis, 26* (4), 617.

Lovaas, O. I. (2003). *Teaching Individuals with Developmental Delays: Basic Intervention Techniques*. Texas: PRO-ED.

Lovaas, O. I., Ackerman, A., Alexander, D., Firestone, P., Perkins, M., & Young, D. B. (1981). *Teaching developmentally disabled children: The ME Book.* Austin, TX: Pro-Ed.

Lovaas, O.I., Koegel, R.L., Simmons, J.W., & Long, J.S. (1973). Some generalization and follow-up measures on autistic children in behavior therapy. *Journal of Applied Behavior Analysis*, *6*, 131–161.

Magiati, I., Charman, T., & Howlin, P. (2007). A two-year prospective follow-up study of community-based early intensive behavioural intervention and specialist nursery provision for children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, *48* (8), 803–812.

Magiati, I., Moss, J., Charman, T., & Howlin, P. (2011). Patterns of change in children with autism spectrum disorders who received community based comprehensive interventions in their pre-school years: a seven year follow-up study. *Research in Autism Spectrum Disorders, 5* (3), 1016 – 1027.

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,* 73 – 86.

Makrygianni, M. K., & Reed, P. (2010). A meta-analytic review of the effectiveness of behavioural early intervention programs for children with autistic spectrum disorders. *Research in Autism Spectrum Disorders, 4,* 577–593.

Matson, J. L., & Jang, J. (2013). Autism spectrum disorders: methodological considerations for early intensive behavioral interventions. *Research in Autism Spectrum Disorders, 7,* 809 – 814.

Matson, J. L., & Konst, M. J. (2013). What is the evidence for long term effects of early autism interventions? *Research in Autism Spectrum Disorders, 7,* 475 – 479.

Maurice, C. (Ed.), Green, G., & Luce, S. (Co-Eds.). (1996). *Behavioral intervention for young children with autism: A manual for parents and professionals.* Austin, TX: PRO-ED.

McDonald, T. A., & Machalicek, W. (2013). Systematic review of intervention research with adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 7,* 1439 – 1460.

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* (4), 359–372.

Michael, J. (2007) Motivating operations. In J. Cooper, T. Heron, & B. Heward, *Applied Behavior Analysis.* New Jersey, Pearson Education.

Mudford O. C., Martin, N., Eikeseth, S., & Bibby, P. (2001). Parent-managed behavioral treatment for pre-school children with autism: Some Characteristics of UK Programs. *Research in Developmental Disabilities, 22,* 173-182.

Nordin, V., & Gillberg, C. (1998). The long-term course of autistic disorders: update on follow-up studies. *Acta Psychiatrica Scandinavica, 97* (2), 99 – 108.

O'Connor, A. B., & Healy, O. (2010). Long-term post-intensive behavioral intervention outcomes for five children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 4* (4), 594–604.

Palmen, A., Didden, R., & Lang, R. (2012). A systematic review of behavioral intervention research on adaptive skill building in high-functioning young adults with autism spectrum disorder. *Research in Autism Spectrum Disorders, 6,* 602–617.

Perry, A., Blacklock, K., & Geier, J. D. (2013). The relative importance of age and IQ as predictors of outcomes in intensive behavioral intervention. *Research in Autism Spectrum Disorders, 7,* 1142 – 1150.

Perry, A., Cummings, A., Geier, J. D., Freeman, N. L. Hughes, S., LaRose, L., Managhan, T., Reitzel. J., & Williams, J. (2009). Effectiveness of Intensive Behavioral Intervention in a large, community-based program, *Research in Autism Spectrum Disorders 2,* 621-642.

Perry, A., Cummings, A., Geier, J. D., Freeman, N. L., Hughes, S., Managhan, T., Reitzel, J-A., & Williams, J. (2011). Predictors of outcome for children receiving intensive behavioral intervention in a large, community-based program. *Research in Autism Spectrum Disorders, 5,* 592 – 603.

Peters-Scheffer, N., Didden, R., Korzilius, H., & Sturmey, P. (2010). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders 2,* 621 – 642.

Reed, P., Osborne, L. A., & Corness, M. (2007a). Brief Report: Relative effectiveness of different home-based behavioural approaches to early teaching intervention. *Journal of Autism and Developmental Disorders, 37,* 1815–1821.

Reed, P., Osborne, L. A., & Corness, M. (2007b). The real-world effectiveness of early teaching interventions for children with autistic spectrum disorders. *Exceptional Children, 73,* 413–417.

Reichow, B. (2012) Overview of meta-analyses on early intensive behavioral intervention for young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42,* 512 – 520.

Reichow, B., Barton, E. E., Boyd, B. A., & Hume, K. (2012). Early intensive behavioral Intervention (EIBI) for young children with autism spectrum disorder (ASD). *Cochrane Database of Systematic Reviews* 2012, Issue 10. Art. No.: CD009260. DOI: 10.1002/14651858.CD009260.pub2.

Reichow, B., & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA young autism project model. *Journal of Autism and Developmental Disorders, 39*, 23-41.

Remington, B., Hastings, R. P., Kovshoff, H., Espinosa, F., Jahr, E., Brown, T., et.al. (2007). Early intensive behavioral intervention: Outcomes for children with autism and their parents after two years. *American Journal on Mental Retardation, 112,* 418-438.

Richards, A. L., Walstab, J. E., Wright-Rossi, R. A., Simpson, J., & Reddihough, D. S. (2009). One-year follow-up of the outcome or a randomized controlled trial of a home-based intervention program for children with autism and developmental delay and their families. *Child: Care, Health and Development, 35,* 593–602.

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child & Adolescent Psychology*, *37* (1), 8–38.

Rutter, M., Greenfeld, D., & Lockyer, L. (1967). A five to fifteen year follow-up study of infantile psychosis: II. Social and behavioural outcome. *The British Journal of Psychiatry, 113,* 1183–1199.

Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation*, *110* (6), 417–438.

Sheinkopf, S. J., & Siegel, B. (1998). Home-based behavioral treatment of young children with autism. *Journal of autism and developmental disorders*, *28* (1), 15–23.

Smith, I. M., Koegel, R. L., Koegel, L. K., Openden, D. A., Fossum, K. L., & Bryson, S. E. (2010). Effectiveness of a novel community-based early intervention model for children with autistic spectrum disorders. *American Association of Intellectual and Developmental Disabilities, 115,* 504–523.

Smith, T. (2001). Discrete trial training in the treatment of autism. *Focus on Autism and Other Developmental Disabilities*, *16* (2), 86–92.

Smith, T., Eikeseth, S., Klevstrand, M., & Lovaas, O. I. (1997). Intensive behavioral treatment for preschoolers with severe mental retardation and pervasive developmental disorder. *American Journal of Mental Retardation*, *102* (3), 238 – 249.

Smith, T., Eikeseth, S., Sallows, G. O., & Graupner, T. D. (2009). Efficacy of applied behavior analysis in autism. *The Journal of Pediatrics, 155,* 151–152.

Smith, T., Groen, A. D., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, *105* (4), 269–285.

Spreckley, M., & Boyd, R. (2009). Efficacy of applied behavioral intervention in preschool children with autism for improving cognitive, language, and adaptive behavior: A systematic review and meta-analysis. *The Journal of Pediatrics, 154*, 338-344.

Stahmer, A. C., Akshoomoff, N., & Cunningham, A. B. (2011). Inclusion for toddlers with autism spectrum disorders. *Autism, 15,* 625–641.

Strain, P. S., & Bovey, E. H. (2011). Randomized, controlled trial of the LEAP model of early intervention for young children with autism spectrum disorders. *Topics in Early Childhood Special Education, 31,* 133–154.

Strauss, K., Mancini, F., the SPC Group, & Fava, L. (2013). Parent inclusion in early intensive behavioral interventions for young children with ASD: a synthesis of meta-analyses from 2009 to 2011. *Research in Developmental Disabilities, 34* (9), 2967 – 2985.

Strauss, K., Vicari, S., Valeri, G., D'Elia, L., Arima, S., & Fava, L. (2012). Parent inclusion in early intensive behavioral intervention: The influence of parental stress, parent treatment fidelity and parent-mediated generalization of behavior targets on child outcomes. *Research in Developmental Disabilities, 33,* 688–703.

Sundberg, M. L., & Partington, J. W. (1998). *Teaching Language to Children with Autism and Other Developmental Disabilities.* Pleasant Hill, CA: Behavior Analysts, Inc.

Tobin, M. C., Drager, K. D. R., Richardson, L. F. (2014). A systematic review of social participation for adults with autism spectrum disorders: support, social functioning, and quality of life. *Research in Autism Spectrum Disorders, 8,* 214 – 229.

Valenti, M., Cerbo, R., Masedu, F., De Caris, M., & Sorge, G. (2010). Intensive intervention for children and adolescents with autism in a community setting in Italy: A single-group longitudinal study. *Child and Adolescent Psychiatry and Mental Health, 4,* 1–6.

Virués-Ortega, J. (2010). Applied behavior analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose-response meta-analysis of multiple outcomes. *Clinical Psychology Review, 30*, 387–399.

Wallace, K. S., & Rogers, S. J. (2010). Intervening in infancy: Implications for autism spectrum disorders. *Journal of Child Psychology and Allied Disciplines, 51,* 1300 - 1320.

Weiss, M. (1999). Differential rates of skill acquisition and outcomes of early intensive behavioral intervention for autism. *Behavioral Interventions, 14* (1), 3–22.

Zachor, D. A., & Ben-Itzchak, E. (2010). Treatment approach, autism severity and intervention outcomes in young children. *Research in Autism Spectrum Disorders, 4,* 425–432.

MASTER THESIS

Learning in Complex Systems

2014

Outcome in Adulthood for Eight Children with Autism who received Intensive Educational Intervention during Preschool and Kindergarten Age: An 18-Year Follow-Up Study

Astrid Kristin Holm

Faculty of Health Sciences

Department of Behavioral Science

OSLO AND AKERSHUS
UNIVERSITY COLLEGE
OF APPLIED SCIENCES

Abstract

To date, no evidence is available on the effects of Early Intensive Behavioral Intervention (EIBI) into adulthood for people with Autism Spectrum Disorder (ASD). This study is unique in terms of being the very first to present results on adult outcome for persons who were diagnosed with Childhood Autism and received intensive educational intervention in their childhood. This is an 18-year follow-up of the studies of Eikeseth, Smith, Jahr and Eldevik (2002, 2007) in which eight of the participants from the original sample were reassessed for changes in IQ, adaptive function and autism psychopathology. In addition, by filling out a questionnaire, knowledge about their way of life is available as well. The data is analyzed individually, as one group and as two groups. However, because of the small sample size the results are to be treated as preliminary and as part of a bigger study (in preparation). The findings show that the majority has made progress in terms of IQ and adaptive function into adulthood, although not significant change. When looking at the persons who received EIBI (n = 4) and the persons who received eclectic treatment (N = 4) separately, the EIBI group has made better progress and maintained their progress at a larger extent than the eclectic group. In terms of autism severity, one participant seems to have no problems within the autism spectrum, and two have achieved milder symptoms. The questionnaire revealed that the majority have no friends, even when the results are good. Only one lives independently, and most have some kind of occupation during the day. The EIBI-research designation of “best outcome” versus the adult outcome-research allocation of “very good” to “very poor” outcome are discussed, as well as the threats to the internal validity of the results. The results suggest that EIBI may be leading to better outcome in adulthood for persons with autism. Of course, verification by studies with stronger scientific power is needed.

Keywords: autism spectrum disorder, EIBI, long-term follow-up, adult outcome.

Outcome in Adulthood for Eight Children with Autism who received Intensive Educational Intervention during Preschool and Kindergarten Age: An 18-Year Follow-Up Study

Autism Spectrum Disorder (ASD) is a Pervasive Developmental Disorder (PDD) in which core symptoms manifest within areas of communication and reciprocal social interaction, and engagement in stereotyped and repetitive behavior patterns (American Psychiatric Association, 2013). Children with ASD may have problems in learning language comprehension and speaking. Their social motivation is usually limited, in which affect social learning. Children with ASD may also display repetitive behavior such as shrugging their body or staring manically at a moving light or a spinning washing machine. Often children with ASD do not play appropriately, not alone nor with peers, and they may demand strict routines and predictability in everyday life.

Leo Kanner was the first to describe children with these types of behavioral patterns in 1943. He followed up with descriptions of the same persons after approximately 30 years in 1971. From the mid 1960-ies, others have contributed in adult outcome research. However, this may not stand out as a well-documented field of inquiry. According to the review of Henninger and Taylor (2013), there was a variety of measurement procedures with vague operationalization, which made replication of studies difficult and somewhat unreliable. Nevertheless, the studies published in the time span of 1960 – 2000, despite the heterogeneity of procedure, agreed that the overall adult outcome for persons with autism was “poor” or “very poor” (Henninger & Taylor, 2013). A common feature in the pre-2000 adult outcome studies is the use of global criteria for outcome distributed from “very poor” to “very good” (Rutter, Greenfield & Lockyer, 1967), which was based on wide and imprecise definitions of outcome that needed interpretation by the investigator. Research conducted post 2000 for the most use the Overall Outcome Scale (OOR) introduced by Howlin, Goode, Hutton and Rutter (2004), however maybe slightly modified (e.g. Billstedt, Gillberg & Gillberg, 2005; Eaves &

Ho, 2008; Gillespie-Lynch et al., 2012; Howlin, Moss, Savage & Rutter, 2013). The scale incorporates a numerical index of measuring the sum of scores across work, friendship and independent living. In the reviews of Henninger and Taylor (2013) and Magiati, Tay and Howlin (2014) it is shown that the post 2000 adult outcome studies also find a majority of “poor” outcome.

Some of the post 2000 adult outcome studies also account for intelligence and adaptive function, language and diagnostic stability (Magiati et al., 2014). For the studies that were able to report reliable changes in IQ from childhood to adulthood, the results showed that the IQ remained stable. In terms of change in adaptive function, there was some improvement over time, although not many studies accounted for this. Outcome in language showed some improvement across the studies, but very few achieved normal speech-fluency. Of the reviewed studies in Magiati et al. (2014), the majority have reported on diagnostic stability, in addition to overall social outcome. For those who report on changes from childhood to adulthood, there is an overall improvement, although no full recovery. Lately, some researchers have changed the scope of which outcome for adults with autism are perceived. For example, Billstedt, Gillberg and Gillberg (2011) made a refined evaluation of their 2005- sample. They measured outcome based on an “autism-friendly environment”, which involved caregivers with knowledge of autism, structured education, individualized plan for treatment, facilitated everyday occupation, as well as a measure of quality of life. The results changed from a 78 % “poor” outcome to a 62 % “good” outcome.

None of the adult outcome studies from the reviews of Henninger & Taylor (2013) and Magiati et al. (2014) accounts for any kind of intervention early- nor later in the life course of their referrals. Both papers strongly inquire follow-up studies of persons who received Early Intensive Behavioral Intervention (EIBI) in childhood years. Henninger and Taylor (2013) further estimates that because of EIBI, adult outcome for persons with autism will improve in the future. Many children who received EIBI as children are now entering adulthood, thus there are opportunities to gather data for adult outcome after intervention.

EIBI was developed by Lovaas and his associates during the late 1960s and early 1970s (Lovaas, Koegel, Simmons & Long, 1973). In a later study of Lovaas (1987), nine children of 19 in the intervention group achieved normal function and thus were labeled “best outcome”.

The principles of EIBI derives from Applied Behavior Analysis (ABA), and utilizes techniques in which involves reinforcement (natural as well as contrived), stimulus control, conditional discrimination, prompting, shaping and generalization (Eikeseth, Smith & Klintwall, 2014). The main procedure in EIBI is Discrete Trial Teaching (DTT). This is a highly structured one-to-one teacher-governed setting in which consists of five basic elements (Smith, 2001). These elements derive from the three-term contingency of antecedent – response – reinforcement (Cooper, Heron & Heward, 2007). The teaching is carefully planned and carried out in terms of exact description of the teacher instruction or question for the child (antecedent), and what kind of prompt-procedure to use. Then the mastery criteria for the child’s response are set. There is a need for a recent motivational assessment to provide the child with highly preferred goods as consequence (reinforcement) for emitting correct response. Finally, there is an inter-trial interval of one to five seconds (Eikeseth, et al., 2014; Smith, 2001).

EIBI takes place in the natural environment as well, in which the skills taught in DTT format are generalized and maintained under natural occurring conditions (Eikeseth, 2011). New skills may be taught by utilizing the child’s current motivation in terms of for example, having the child ask for what he wants in a gradually more elaborated manner (Fenske, Krantz & McClannhan, 2001; Sundberg & Partington, 1998).

A number of treatment manuals containing EIBI curriculum are developed, in which the curriculum usually is divided into beginning, intermediate and advanced (Leaf & McEachin, 1999; Lovaas, 1977, 2003; Lovaas et al., 1981; Maurice, Green & Luce, 1996). The curriculum is comprehensive, which means it addresses the core deficits of autism (communication, socialization and stereotypic or problematic behavior), as well as when specifically tailored, addresses each individual child's difficulties (Eikeseth, 2011).

According to Green, Brennan and Fein (2002), EIBI consists of 10 characteristics.: (a) comprehensive and individualized treatment; (b) behavior analytic procedures is used; (c) the intervention is directed and supervised by EIBI professionals; (d) the selection of intervention goals is guided by normal developmental sequences; (e) parents are co-therapists; (f) initially one-to-one with gradual transitions to increasingly larger groups; (g) intervention begins in the home with gradual transitions to kindergarten and school classrooms; (h) year-round teaching with 20 – 30 hours of structured sessions per week and informal instruction throughout most of the children's awake hours; (i) duration of intervention is two or more years; and (j) intervention start at three-to-four-years of age.

Many researchers have contributed to the vast body of research that makes EIBI an empirically supported comprehensive educational program for children with ASD (e.g. Eikeseth, 2009; Eikeseth, Smith, Jahr, & Eldevik, 2002; Eldevik, Hastings, Hughes, Jahr, Eikeseth, & Cross, 2009; Magiati, Charman, & Howlin, 2007; Remington et al., 2007; Rogers & Vismara, 2008; Sallows & Graupner, 2005; Smith, Groen, & Wynn, 2000). However, resent reviewers criticizes EIBI-researchers for concluding effectiveness based on insufficient scientific accuracy (Reichow, Barton, Boyd, & Hume, 2012), and randomized controlled trials to improve this is needed. Nevertheless, meta-analyses conducted agree that despite the lack of randomization in the majority of published papers as well as an almost consistent negligible sample size, there are statistical evidence for high effect of EIBI in terms of IQ, language skills, communication and social skills, and moderate to high effect on adaptive behavior for children with ASD (Eldevik et al., 2009; Makrygianni & Reed, 2010; Reichow & Wolery, 2009; Peters-Scheffer, Didden, Korzilius & Sturmey, 2010; Virués-Ortega, 2010). Meta-analytic comparison assessments demonstrate that EIBI is more effective than other treatments e.g. eclectic treatment (Makrygianni & Reed, 2010; Peters-Scheffer et al., 2010).

The short-term effect is well-established, and a number of these studies have been followed up in the children's later childhood. These studies aimed at investigating the effect of EIBI in a longer term, and the majority have found that the children receiving EIBI maintained their gains at a larger extent than did children receiving the comparison control condition (e.g. Eikeseth, Smith, Jahr & Eldevik, 2007; Kasari, Gulsrud, Freeman, Paparella & Hellemann, 2012; Kovshoff, Hastings & Remington, 2011; Magiati, Moss, Charman & Howlin, 2011; McEachin, Smith, & Lovaas, 1993; O'Connor & Healy, 2010). However, no studies have to date, examined outcome in adulthood for children receiving EIBI in their childhood. Equivalent to the autism adult outcome researchers, several authors within EIBI research have emphasized the need for long-term follow-up in adulthood for persons with autism (Eikeseth, 2011; Klintwall & Eikeseth, 2012; Magiati et al., 2011; Matson & Konst, 2013). It is important to investigate whether there are progress and / or maintenance into adulthood, and if that is the case, whether this is due to the person receiving EIBI as a child.

This present study is the first of its kind to investigate adult outcome after receiving intensive educational intervention in childhood. In this paper, results are presented for eight adults who were diagnosed with Childhood Autism as children and received EIBI or eclectic treatment in their kindergarten and early school years. This 18-year follow-up of the studies of Eikeseth et al. (2002, 2007), has measured outcomes on IQ, adaptive skills and autism severity. Data on the referrals life history and current way of living was collected by questionnaire. The data has been analyzed individually and as one group, as well as two groups, and may provide an indication on the extent to which the effects of EIBI are present in adulthood. The results are preliminary and part of a larger subsequent study.

Method

Background

In this present study, the participants are from the same sample as of the original study of Eikeseth et al. (2002, 2007).

Eikeseth et al. (2002). In the initial study of Eikeseth et al. (2002) the children were assessed at intake and after one year of treatment. The children had to meet four intake criteria: (a) diagnosis of Childhood Autism (ICD-10) (World Health Organization, 1993) from both Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter, & LeCouteur, 1994) and an independent child clinical psychologist, (b) chronological age between 4 and 7 year at intake, (c) deviation IQ of 50 or above on the Whechsler Preschool and Primary Scale of Intelligence-Revised (WIPPSI-R) (Wechsler, 1989) or ratio IQ of 50 or above on the Bayley Scales of Infant Development-Revised, and (d) absence of major medical conditions other than autism. The ADI-R was conducted by an independent child clinical psychologist who had received training from one of the developers of the instrument. The diagnoses were established at least 6 months before entering the study. All children were from Norway and the counties of Akershus and Vestfold, and they were all clients of either Akershus or Vestfold habilitation teams, which are state-founded agencies. All children would have received the same treatment independent of the implementation of this study. The children's parents or other caretakers, agreed to the children's participation in the study.

The director of the habilitation team, who was independent of the study, assigned the children to groups. The assignment was based on the habilitations team's current availability of supervisors qualified of behavioral treatment. The children was either assigned to a behavioral treatment group (hereinafter denoted EIBI group) (n = 13; 8 boys), or an eclectic treatment group (n = 12; 11 boys). The treatment, both behavioral and eclectic, took place in public kindergartens and elementary schools for typically developing children. The treatment was conducted by a team consisting of one special educator and at least one aid. All children received training in separate rooms and were shadowed in mainstreamed classroom settings to promote generalization.

The behavioral treatment that the children in the EIBI-group received was based on the Lovaas et al. manual of 1981, and associated videotapes made by Lovaas and Leaf in 1981 (Eikeseth et al. 2002), without the use of aversive consequences. The behavioral treatment initially entailed highly structured one – to – one sessions in a discrete trial format, consisting of relatively simple tasks. As the child made progress, the tasks became more complex and the training took place in other settings to emphasize generalization and maintenance, as well as adjustment to peers and classroom routines. The teachers and aids were in advance of this study not familiar with behavioral intervention for young children with autism, and they received 10 hours supervision pr. week in an apprenticeship format. This format entailed a supervisor-demonstrated arrangement and execution of treatment programs. Subsequently, the teacher and aid provided the treatment and received hands-on guidance from the supervisor. The children's parents did also participate in the treatment and this is considered important to the treatment. The first three months the parents carried out the treatment alongside the teacher and received supervision. After three months, the parents focused on training in the home and community settings. The children's programs were adjusted at the weekly two-hour meeting for each child, where the child, the teacher, parents and supervisor attended.

As for the eclectic treatment group, the treatment consisted of a variety of different interventions, for example the TEACCH project (Schopler, Lansing, & Waters, 1983), sensory-motor therapies (Ayres, 1972), and applied behavior analysis (Lovaas et al., 1981), and in addition, methods derived from personal experience. A multidisciplinary team of school personnel gave recommendation on the individualized selection of intervention each child should receive. The training took place in a separate room and in a one – to – one format. The teachers received weekly two-hour consultation from the supervisors that oversaw behavioral treatment in this study. Both intervention groups received approximately the same amount of treatment hours, M = 28, 52 hours per week.

The assessment at intake and after one year consisted of a measure for IQ, language and adaptive behavior. The IQ measure was conducted with either the WPPSI-R (Wechsler, 1989) or the WISC-R (Wechsler, 1974). In cases where these were not applicable, the Bayley Scales of Infant Development – Revised (Bayley, 1993) was administered. For assessment of visual – spatial skills the Merrill- Palmer Scale of Mental Tests (Stutsman, 1948) was given at intake and at follow-up for those children aged below six years and six months. The Reynell Developmental Language Scales (Reynell, 1990) assessed the language level at intake for all the children and at follow-up for those younger than seven years old. Level of adaptive functioning was assessed with the Vineland Adaptive Behavior Scales, VABS (Sparrow, Balla, & Cicchetti, 1984). Therapy measures conducted evaluated hours per week of one-to-one treatment, as well as treatment goals and the teacher and aids level of education.

The study found significantly larger gains in the EIBI group than in the eclectic group, as well as contributing to the clarification of intensity of treatment not being a possible explanation for outcome.

Eikeseth et al. (2007). In their second publication, Eikeseth et al. (2007) reassessed the participants. The children were now at a mean age of 8,2 years and had entered elementary school. The follow-up assessed child measures of IQ, adaptive function and behavioral problems. For evaluating IQ the WPPSI-R (Wechsler, 1989), or WISC-R (Wechsler, 1974) or the Bayley Scales of Infant Development (Bayley, 1993) was used. Adaptive function, also including the maladaptive subdomain, was conducted with the WABS

(Sparrow et al., 1984). The school teachers completed the Achenbach Child Behavior Checklist – Teacher Report Form, TRF (Achenbach, 1991) to evaluate the extent of behavioral problems. Therapy measures were also conducted in terms of hours per week of one-to-one treatment in separate room, and hours per week in in mainstream classroom setting with shadow teacher. Treatment goals, intervention methods, as well as the teacher and aids level of education were measured. The results showed that the EIBI group gained both with respect to IQ and adaptive function. The gains in IQ were most prominent within the first year of treatment. The gains of adaptive function on the other hand, were significant in the year 1 – follow-up interval. For the eclectic group the results of the follow-up were somewhat different. The IQ scores remained stable, but the adaptive function declined in terms of both the composite score as well as for the subdomain scores. In terms of behavioral problems, the groups did not differ significantly. However, the EIBI group had less behavioral problems than the eclectic group, and this was especially evident in the subdomain of maladaptive behavior in the VABS. Age at intake was not proven to be an important predictor of positive outcome in this study, nor did high IQ at intake correlate with large IQ gains. However, in the eclectic group, the VABS scores served as predictors for outcome. For the eclectic group the intake scores were more often connected with outcome and changes in scores, than for the EIBI group.

Participants

For this current project, a letter requesting participation initially was sent to 25 persons who were diagnosed with Childhood Autism in early childhood and received systematic training in kindergarten and / or early elementary school. They all took part in the previous studies of Eikeseth et al. (2002, 2007). An identical request was also sent to the parents.

To date, only eight persons and their parents have given their consent to participate in this study. The sample for this study consists of seven male and one female participants, aged within the range of 21 – 25 years old. Four of the participants originally were in the EIBI group and four were in the comparison group, which received eclectic treatment.

Counting this current assessment, the eight participants have been assessed four times. At intake and before onset of treatment (T1), they were at a mean chronological age of 5,2 years old. After one year of treatment (T2), they were 6,2 years old. At second follow-up (T3), there are no individual data on age, but the original sample of 25 had a mean age of 8,2 years, which may serve as an estimate of mean age for the eight at T3. At 18-year follow-up (T4), the mean age for the group of eight is 23 years old.

Setting

The data collection was carried out in the participant's home. The reason for this was to prevent the unpleasantness of needing to travel to contribute in this study, and thus make it easier for both the participants and the parents.

Measures

In this study, four measures were used to evaluate the participant's progress and development since childhood. Assessments were carried out on IQ, adaptive behavior, autism symptoms, and the way of living. Standardized psychological assessments were used to measure IQ, adaptive behavior and symptoms of autism. The tests were WAIS IV (Wechsler Adult Intelligence Scale) (Wechsler, 2008) and Wechsler Nonverbal Scale of Ability (WNV) (Wechsler & Naglieri, 2006), ADOS (Autism Diagnostic Observation Schedule) (Lord, Rutter, FRS, DiLavore, & Risi, 1989), and VABS (Vineland Adaptive Behavior Scales, Second Edition) (Sparrow, Cicchetti & Balla, 2005). A questionnaire developed particularly for this project by the project-coordinating master's student, was used to measure the person's current way of living and some historical aspects of their life course.

The WAIS IV. To conduct a new assessment of the participant's cognitive function, WAIS IV was used. WAIS IV is a test developed to measure the level of intelligence within adults and young adults. The test scores verbal IQ, performance IQ and full scale IQ (FSIQ). The test's structure is applicable in the age span of 16 – 90 years of age and consists of four scales: (a) Verbal comprehension scale which include three core subtests (similarities, vocabulary, and information), and one supplemental subtest (comprehension), (b) Perceptual reasoning scale which include three core subtests (block design, matrix reasoning, and visual puzzles), and two supplemental subtests (picture completion and figure weights (16 – 69 only)), (c) Working memory scale that includes two core subtests (digit span and arithmetic), and one supplemental subtest (letter – number sequencing (16 – 69 only)), and finally (d) Processing speed scale, including two core subtests (symbol search and coding), and one supplemental subtest (cancellation (16 – 69 only)) (http://images.pearsonclinical.com/images/assets/WAIS-IV/WAISIV2_6_08.pdf, downloaded May 8th, 2014).

WAIS IV was not applicable for two of the participants due to severe impairment in their overall function and limited verbal skills. Instead, Wechsler Nonverbal Scale of Ability (WNV) was used. This test is developed to serve individuals who, for different reasons do not benefit from ordinary intelligence- or ability tests, where language is an important feature. The WNV is suitable for persons from diverse linguistic groups, people with limited language skills, people who are deaf or hearing disabled, persons with language disorders, and gifted children from linguistically and culturally diverse populations. The test has an age range of 4 – 21 years of age, and gives a measure of ability equivalent to ordinary IQ-tests, M = 100, SD 15 (Wechsler & Naglieri, 2006).

For this project, an independent and blinded specialist in clinical neuro-psychology conducted the WAIS IV with three of the participants and the WNV for two participants. Another psychologist, also independent and blinded, conducted WAIS IV on two participants.

The parents of one person, only agreed to conduct the VABS and fill out the questionnaire, and no new data on IQ is available for this participant.

The ADOS. The autism symptomatic level was measured with the ADOS. The protocol consists of a variety of structured- and semi-structured tasks involving social interaction between the examiner and the subject. The examiner observes and identifies the subject's behavior and allocates this into predetermined categories of observation. Examples of tasks are reciprocal communication, display of empathic behavior, and making comments on other people's emotions. Subsequently, the categorized observations are combined and produce quantitative scores for analysis. A potential diagnosis of autism or other autism spectrum disorders are identified by research-determined cut-off scores. Administration time is 30 – 60 minutes. The ADOS consists of four modules, and the determination of which module that is most suitable, is based on the subject's developmental- and language level. ADOS does not serve adults who are nonverbal.

For this project, an independent and blinded clinical special education therapist conducted the ADOS. She is certified for conducting ADOS for research purposes. ADOS Module 4 was applied for six of the participants, whereas ADOS module 2 was applied for one participant. The parents of one person, only agreed to conduct the VABS and fill out the questionnaire, and no new information on autism symptoms is available for this person.

The VABS. To examine the participant's current level of adaptive function, the VABS was applied. The VABS is administered as a semi-structured interview, with either the referral or parents / caregivers, or others that is well familiar with the referral. This is a recognized test, which is widely used in the diagnostic process of mental retardation, autism, Asperger's syndrome, and other disorders. The administration time is 20 – 60 minutes, and the test is applicable in all age ranges (Birth – 90 years old). The three domain structures are communication, daily living, and socialization. The content and scales are organized within these domains. In addition, there are a motor-skill domain and a maladaptive behavior index, in which the latter is optional. Within the domains, there are several subdomains. Within the domain of communication, the subdomains are receptive, expressive and written. As for daily living skills, the subdomains are personal, domestic, and community. Within the domain of socialization, the subdomains are interpersonal relationship, play and leisure time, and coping skills. The subdomains of the domain of motor skills are gross and fine. The subdomains gives v-Scale scores (M = 15, SD = 3) with indication on adaptive level and age-equivalence. The domains give Domain and Adaptive Behavior Composite (ABC) – Standard Score (M = 100, SD = 15) and set percentile range, adaptive level and age-equivalence (Sparrow, Cicchetti, & Balla, 2005).

The same psychologists that conducted WAIS IV conducted the VABS with six of the participant’s parents. For one of these participants, a government employed caregiver served as referral together with the participant’s mother. A special educator and a social educator, who both have clinical practice within assessment and diagnosing autism, conducted VABS with two of the participant’s parents.

Questionnaire. To get a picture of the person’s way of living and a historical perspective on their lives, a questionnaire was made. The participants were asked to fill this out, either by themselves or together with- or by a significant other. The questionnaire contained questions about living conditions, any help from public service, marital status, whether or not they have any kids, social circle, schooling, education, occupation, any social security benefits, other diagnoses, and if they have a driver’s license. All eight referrals have answered the questionnaire.

Data Analysis

The study is a group comparison study following up eight subjects 18 years after treatment initiation. The data have been examined individually and as one group where intake scores were compared to follow-up scores to examine the extent to which scores have changed significantly. Between-group comparisons were conducted as well. For these purposes, a paired t-test and a Wilcoxon signed rank test were used. Because of the small sample sizes, the study lack experimental control, and thus the results are to be treated preliminary and as part of a larger study.

Ethical considerations

The study is approved by the Norwegian Ethical comities for medical and health care research (REK).

Results

Participant 1

Participant 1 is currently 24 years old and started receiving EIBI at age 3,8 years old. From the time of T1 to T4, he has had an increase from 70 to 100 on IQ, and an increase from 67 to 84 on ABC.

As displayed in Figure 1, he made intellectual progress in his childhood. At intake, T1, he scored FSIQ of 70. After one year of EIBI, T2, he scored 97 points, which means he gained 27 points. Further, at the second follow-up, T3, he obtained a FSIQ of 112, and gained a total of 42 points. At T4, he scored 100 points and thus lost 12 points.

Results from the VABS assessment for participant 1 are shown in Figure 1. At T1 he scored 67, on T2 he scored 71, and at T3 he scored 77. Then at T4, he scored 84, which means a slight improvement. Separately, the domain scores for communication, social skills and daily living skills show a similar trend. As shown in Figure 9, on the communication domain he scored 69 (T1), 87 (T2), 94 (T3), and 95 (T4). On the daily living domain he scored 57 (T1), 61 (T2), 67 (T3), and 85 (T4), see Figure 10. Regarding the social skill domain, he scored 68 (T1), 80 (T2), 78 (T3), and 79 (T4), see Figure 11.

Participant 1 has improved and maintained on all the domain and composite scores on the ABC. He has also improved on IQ, but he did not maintain full improvement.

The results from the ADOS assessment show that he is below cut-off for both autism and autism spectrum in the combined communication-and-reciprocal social interaction column, although he scores borderline cut-off of autism spectrum at these categories separately. This result may imply a reduced psychopathological severity of the autism spectrum disorder, as shown in Table 1.

The questionnaire was filled out by himself. He lives in a sheltered municipal housing with personnel. However, he does not specify the amount of assistance, although he has only checked for financial support in the column of “public assistance”. His marital status is single and he has no children. He has two or more friends. He has finished schooling at high school level, and attended a one-year folk school (Norwegian: Folkehøgskole). He is currently working, but is receiving work assessment allowance and financial housing support. He denotes himself as a “handyman” and is working in a sheltered company during time of occupational definition. He has the diagnosis of Infantile Autism, with no comorbidity. He does not have a driver license.

Participant 2

Participant 2 is 22 years old and started receiving EIBI at the age 4,6 years old. From the time of T1 to T4, he has had an increase from 52 points to 89 points on IQ, and a decrease from 51 to 48 on the ABC.

As displayed in Figure 2, his FSIQ at intake, T1, was 52 points. During the first year of EIBI, T2, he gained 32 points and obtained 84 points. This was maintained at the next assessment, T3, where he also got a score of 84 points. At T4, he was assessed with the WNV and obtained a WNV full-scale score of 89.

The ABC scores of the VABS are for Participant 2, shown in Figure 2. The results show an increase of 21 points from 51 at T1 to 72 at T2. Then there was a decrease of 15 points from T2 (72 points) to T3, which showed 57 points. The alleviation continued, and at T4 the score was 48. For communication, there was a stable increase of 28 points from T1 to T3, (57, 73 and 85 points). Then there was a decrease of 13 points at T4, 72 points, see Figure 9. The daily living domain, as shown in Figure 10, looks different. There was an increase from 54 at T1 to 66 at T2, and then a decrease from to 45 at T3. Again, an increase is shown in the T3 – T4 period as he scored 61points. The social skill domain show, see Figure 11, that he scored 56 at T1, 68 at T2, 56 at T3, and 36 on T4.

Participant 2 has not improved nor maintained neither on the ABC nor on the domains. On the other hand, he has improved and sustained the improvement on IQ.

The ADOS suggests that the diagnosis of Infantile Autism sustain, as he scored within the range of autism cut-off, see Table 1.

The questionnaire is filled out by the team leader at the private health care company that provides therapeutic assistance for Participant 2. He receives around the clock service with two – to – one staffing during day- and evening-time, and one person awake during nighttime. He also receives sheltered employment. He is not married, nor has any children. He has no friends, but he has some acquaintances who he meets in social settings two times per month. He has completed schooling at high school level with a large degree of special educational assistance the entire time. He is currently working two days per week, and receives full financial social support, as the employment is sheltered. He does janitor tasks and produces firewood. This employment is organized and run by the private health care company. He has the diagnosis of Infantile Autism, but no comorbid conditions. He has not a driver license.

Participant 3

Participant 3 is 23 years old and started receiving EIBI at 4,9 years of age. The parents of Participant 3 only agreed to conduct the VABS and questionnaire for the 18-year follow-up. Thus, there are only a T1 – T3 measure of IQ available. The difference from T1 to T4 on ABC shows a decrease from 49 to 42.

At intake, T1, he scored FSIQ of 50. Then it decreased at T2 (44 points) and kept a stable position of 45 points at T3.

The ABC scores of the VABS show, as visualized in Figure 3, that Participant 3 has been relatively stable over the years. There was an increase from T1 (49 points) to T2 (53 points), with a subsequent continuous decrease. At T3 he scored 49 points and at T4 he scored 42, which is lower than the intake measure of 49. The domain scores of communication are displayed in Figure 9, and show a relatively stable trend throughout the childhood measures. He obtained 54 points at T1, 60 at T2, and 55 at T3. Then the score dropped to 39 at T4. The domain of daily living skills, shown in Figure 10, shows a continuous decrease from T1, 52 points – T3, 35 points. However, by the time of T4, it was back at intake level, 54 points. As for the domain of social skills, see Figure 11, the trend was somewhat different. There is stability at around 55 – 56 for T1, T2 and T4, with the exception of T3 where he scored 70 points.

The result profile of Participant 3 is variable. On the ABC, he does not show neither progress nor maintenance, nor on the domains other than social skills, which is stable.

The questionnaire is filled out by his mother. He lives partly at home and partly in a sheltered municipal housing with personnel. He receives therapeutic assistance at daily basis and he has personal assistance. He is not married or have any children. He has two or more friends, although no close friends. He has finished schooling at high school level with large amount of special educational assistance the entire time. He is working in a rehabilitation company and produces parts used in bathrooms and plumbing. This is sheltered employment, and he receives financial social support labeled “Young disabled” and other financial benefits. He has the diagnoses of Infantile Autism and moderate Intellectual Disability. He does not hold a driver license.

Participant 4

Participant 4 is 25 years old and started receiving EIBI at age 6,4 years old. From T1 to T4 he has made progress from 56 to 117 on IQ, and 45 to 111 on ABC.

As Figure 4 shows, he has made continuous intellectual progress. At intake, T1, he scored FSIQ of 56 points. By the first year of EIBI, T2, he gained 30 points and obtained 86 points. At the second follow-up, T3, he obtained FSIQ of 106 points, which is an additional gain of 20 points. At T4, he scored FSIQ of 117 points, which gives him an overall IQ gain of 60 points.

The ABC scores, also displayed in Figure 4, show a similar result as for the IQ. He makes continuous progress on the ABC as well as on the domain scores. By the time of T4 he is within the range of “normal functioning”, above 100 points, on all the domains and the composite scores. Initially however, he scored relatively low on each. At T1, he scored a composite score of 45. It increased to 68 at T2 and continued to 81 at T3. At T4, the composite score is 111. The trend for domain score of communication, shown in Figure 9, show 51 points at T1, 85 at T2, 90 at T3, and 108 on T4. As for daily living skills, shown in Figure 10, he scored 39 at T1, 66 at T2, 78 at T3 and 108 at T4, which is a staggering 69-point increase. On social skills, he scored 55 points at T1, 69 points at T2, 90 points at T3, and 109 points at T4, see Figure 11.

Participant 4 has made progress on IQ and adaptive skills, on all measures throughout childhood and continued to make progress into adulthood.

On the ADOS he scored below the threshold of cut-off for both autism and autism spectrum, and this may indicate that he no longer has an Autism Spectrum Disorder, see Table 1.

The questionnaire is filled out by himself. He lives in a sheltered municipal housing, but he clarifies that the amount of therapeutic assistance from the personnel is minimal. However, he receives financial guidance and debt counselling, other types of guidance, as well as receiving assistance from psychologist / psychiatrist. He does not specify this any further. He is not married nor in a relationship, nor having any children. Furthermore, he does not have any friends. He completed elementary school with a large amount of special educational assistance, but completed secondary school with only a small degree of special education. At high school, however, he completed with a large degree of special educational help. Then, he attended a one-year folk school (Norwgian: Folkehøgskole), and has attended adult education, this with no special education involved. He mentions that he has achieved general university admissions certification this spring. He currently does not work and receives financial social support labeled “Young disabled”. He has the diagnosis of Infantile Autism, but no comorbid conditions. He does not have a driver license.

Participant 5

Participant 5 is today 24 years old and started receiving eclectic treatment at the age of 5,4 years old. From the time of T1 to T4, he regressed from 50 to 47 on IQ, but made an increase from 52 to 64 on ABC.

As shown in Figure 5, the FSIQ level has decreased over the years. At intake, T1, he had a score of 50 points. After one year of treatment, T2, he gained three points. By the time of the second follow-up, T3, he had lost eight points and scored only 45 points. At T4, he scored 47 points.

The VABS scores show a stable path with an increase at T4. As shown in Figure 5, the ABC was 52 at T1, 56 at T2, 45 at T3, and 64 at T4. The scores of communication domain are stable over time, as shown in Figure 9. At T1 he scored 44, at T2 he scored 47, at T3 he scored 45, and at T4 he scored 46. On the contrary, on the daily living skills he scored 55 (T1), 64 (T2), 46 (T3) and 82 (T4), which means a strong increase at the end (see Figure 10). As for the domain of social skills, presented in Figure 11, this stands out on behalf of Participant 5, as being his strongest, yet equally stable, feature. He starts out at 72 (T1), 71 (T2), 64 (T3) and ends up at 75 (T4).

Participant 5 has made little progress during childhood, but maintained stable when entering adulthood.

In an e-mail, his mother informed that the diagnosis of autism was reversed some years ago. The result of the ADOS is in accordance with this as the scores are not within the range of autism nor autism spectrum. For display, see Table 1.

The questionnaire is filled out by his mother. He still lives with his parents and receives no public assistance other than assisted sheltered employment. He is not married nor has any children. He has two or more friends. He has completed schooling at high school level of education although with large degree of special educational assistance. He has achieved a vocational certification of industrial engineer, and he has attended a one-year folk-school (Norwegian: Folkehøgskole). He is currently working, but as this is sheltered employment, he also receives financial social support labeled “Young disabled”. He is not working as an industrial engineer. Within the sheltered employment, he does janitor assignments, some assembling tasks, and making and delivery of fruit baskets to local firms (Norwegian: “Jobbfrukt”). His current diagnosis is Intellectual Disability. He does not have a driver license.

Participant 6

As a boy, participant 6 started receiving eclectic treatment at age 3,9 years old. Today he is 22 years old. From the time of T1 to T4, he has regressed from 52 to 49 points on IQ, and from 37 to 24 on the ABC.

Assessment at intake,T1, showed an IQ of 52. The IQ decreased throughout the first year of treatment to 48 points, T2. The IQ continued to decrease and by the next assessment, T3, he had 39 points. At T4 he obtained 49 points, which is a 10-point increase (see Figure 6).

The ABC scores, also shown in Figure 6, were at T1 at 37 points. At T2 he scored 45, and at T3, 39 points. By the time of T4, the score had decreased to 24. Looking more closely, the domain score of communication is by far his weakest feature, see Figure 9. He started out with a 38-point score at T1. Then he gained 11 points during his first year of treatment to 49 points. By the time of T3, he had almost lost what he gained and scored 41. At T4, he scored only 24 points. The daily living domain, presented in Figure 10, show a different trend. There is an increase form T1 (36 points) to T2 (46 points). Then it drops to 40 by T3, and ends up at 45 points at T4. As for the social skills domain, see Figure 11, there are similarities to the communication domain. He gained points in between T1 (46 points) and T2 (50 points), but lost the gain by T3 (47 points). Then at T4, he has a 15-point loss and ends up at 32 points.

Participant 6 regresses throughout his childhood on the ABC. The IQ is stabilizing in adulthood, but was on a downward path in his childhood. The domain scores show stability, except for the regression in the communication domain.

As for the ADOS assessment, the module 2 was applied which is primarily used with children. The result showed a cut-off for autism-spectrum on communication, and cut-off of autism on the reciprocal social interaction part, and at the combined communication and reciprocal social interaction. He also had a high score on the evaluation of fantasy and creativity, as well as display of stereotypic behavior and restricted interests. This stipulates that the diagnosis of Childhood Autism sustain, as shown in Table 1.

The questionnaire is filled out by the head of the department at his sheltered housing. This showed that he receives two – to – one therapeutic assistance twenty-four-seven, and that he is living in a sheltered detached municipal housing, who him being the only resident. He is not married nor having any children, and he has no friends other than colleagues at an especially adjusted day care center organized by the staff of his housing. He has completed schooling at high school level with large degree of special educational assistance the entire time. High school was conducted in a homeschool format. He does not work, and receives financial social support labeled “Young disabled”. His current diagnosis is Childhood Autism and moderate Intellectual Disability. He does not have driver license.

Participant 7

Participant 7 is 23 year old and started receiving eclectic treatment at age 6,2 years old. Between the time of T1 and T4 there is an increase from 101 to 112 on IQ, and an increase from 58 to 69 on the ABC.

His IQ level has been stable over the years, as shown in Figure 7. At intake, T1, he obtained FSIQ of 101 points. After one year of treatment, T2, he scored 109, and at T3 he scored 106 points. At T4, he obtained 110 points.

The ABC scores of the VABS are displayed in Figure 7. At T1 he scored 58, at T2 he scored 65, then it dropped to 38 at T3, however returns to 69 at T4. For the domain score of communication, as shown in Figure 9, the results show 68 (T1), 64 (T2), 49 (T3) and 63 (T4). The domain of daily living skills is the only one of which there is progress from T1 (60 points) and T2 (72) to T4 (96 points), despite a tremendous drop at T3 (24), see Figure 10. As for the domain of social skills he scored 62 (T1), 76 (T2), 51 (T3), and 56 (T4), see Figure 11.

Participant 7 was intellectually high functioning already as a child. Even so, the IQ remained stable throughout the years. The trend of the ABC is also stable, but not nearly as high as the IQ. He has practically made no progress, except for daily living skills in adolescence. Whatever happened at the time of T3 that resulted in the poor results remains unanswered.

At the ADOS he scored within the range of autism spectrum cut-off, which may indicate a reduced psychopathological severity, see Table 1.

The questionnaire is filled out by himself. He lives on his own in a freehold apartment, and he receives support in terms of personal support together with three others. He is not married nor in a relationship, nor has he any children. He has no friends. He has completed high school and he has a formal education in the field of woodwork. He does not specify the extent of special educational assistance during his schooling. He is currently working in a sheltered company doing computer work. He receives assistance from NAV (Norwegian social security agency) regarding occupational definition, during which he receives financial social support in terms of work assessment allowance. He has the diagnosis of Childhood Autism. He has a driver license.

Participant 8

Participant 8 is the only female in the sample of this study. She is today 21 years old and started receiving eclectic treatment at an age of 6,2 years old. Between T1 and T4 she made progress from 68 to 80 on IQ, but regressed from 71 to 48 on the ABC.

As shown in Figure 8, she scored 68 points at onset of treatment, T1. During her time of treatment, T2, she gained four points and got a score of 72, but those were lost at T3, and she scored 68. At T4, she scored 80 points.

As for the VABS, the data from T3 assessment for participant 8 is missing. As showed in Figure 8, the composite score of the VABS are as follows: 71 (T1), 67 (T2), N/A (T3), and 48 (T4). There has been a 23-point decrease over the years. For the domain of communication, shown in Figure 9, there is also a decreasing trend 73 (T1) – 65 (T2) – N/A (T3) – 48 (T4). Not equally unfortunate as far as daily living skills goes, she scored 60 (T1), 68 (T2), N/A (T3), and 61 (T4), see Figure 10. On the domain of social skills, shown in Figure 11, she scored 66 (T1), 72 (T2), N/A (T3), and 55 (T4). Again, a decrease has occurred.

Participant 8 made no progress during childhood, but seem to have increased intellectually within the last twelve years. As for the ABC, there is a descending trend, which also is evident in the domain scores, thus a regression into adulthood.

With the ADOS, she scored within the range of autism cut-off, which indicates that the diagnosis of Infantile Autism still stands, see Table 1.

The questionnaire is filled out by her mother. She is living at home with her mother and has completed schooling at high school level, although with a large extent of special educational assistance. She receives around the clock care by her mother, and receives no public assistance beyond that. She is not married and is without children, and she has one friend. She is currently not working, and receives financial social support labeled “Young disabled”. She has the diagnosis of Infantile Autism, but no additional diagnoses. She has not a driver license.

Group results

The data has also been examined on a group level. A comparison has been made between the intake- and the 18-year follow-up measures on IQ and ABC, to see if there has been significant change from T1 (intake measure) to T4 (18-year follow-up). A paired two-tailed t-test was conducted and found no significant change neither for IQ nor ABC, see Table 2. Because of the small N, a Wilcoxon signed rank test was conducted as well. The result was in accordance with the paired two-tailed t-test. There should be noted that the result for change in IQ show borderline significance on both the paired t-test and the Wilcoxon signed rank test. The *t*-test gave a *p*-value of 0,0572 and the Wilcoxon signed rank test gave a W-value of 3 in which significance is 2 and below. Additionally, when separately analyzing the participants who received EIBI and the participants who received eclectic treatment using paired t-test, the IQ change for the EIBI group is significant, but the IQ change for the eclectic group is non-significant (see Table 3).

The difference in mean outcome for the two groups is displayed in Figure 12 for IQ and Figure 13 for ABC. By visual inspection, it is evident that the persons who received EIBI as children has made larger progress and maintained their progress at greater extent than the persons who received the eclectic treatment. Additionally, it is also evident that all participants had a relatively equivalent starting point.

Discussion

This study examined the outcome for eight persons who were diagnosed with childhood autism as children and received intensive educational intervention during early childhood years. Four of the participants received EIBI and four received eclectic treatment. The follow-up assessment was conducted, at average, 18 years after their pretreatment assessment. The data has been analyzed individually, as one group, and as two separate intervention groups.

The results for IQ change show that most of the participants have made progress and maintained their achievement into adulthood. As a group, there is borderline significant change. The persons who received EIBI have, on average, gained and maintained their gains to a larger extent than the persons who received eclectic treatment. The IQ-change for the EIBI group is significant. Because of the small sample size, the results are to be treated as preliminary and no firm conclusion can be drawn. However, in this study the persons who received EIBI as children have made far better progress and maintained this progress into adulthood to a larger extent than the persons who received eclectic treatment as children. This may serve as an indication of the long lasting effect of EIBI in terms of changes in IQ. Of course, larger studies with strong statistical power have to investigate and possibly verify these results.

Regarding adaptive function, one-half made progress and one-half regressed in the period from childhood to adulthood. As a whole group, the gain was 7,5 points. On average, the persons who received EIBI made a 14,5-point gain, whereas the persons who received eclectic treatment had a 3,25-point regression. Again, the small sample size makes concluding impossible and the results are to be treated with caution. This is because the study is designed as a group study and not as a single case study. Nevertheless, the persons who received EIBI as children in this study have made progress and maintained this progress into adulthood. The persons who received eclectic treatment as children have on the contrary not made progress and they have regressed over time. Although maybe incidental, this may also serve as an indication of the long lasting effect of EIBI in terms of changes in ABC. Naturally, larger studies with strong statistical power have to investigate and possibly verify these findings.

All of the eight participants were diagnosed with Childhood Autism as children. The questionnaire reveals that, for all but one participant the formal diagnostic status still is Childhood Autism. One participant lost the Childhood Autism diagnosis some years ago according to e-mail correspondence with the mother. He currently has the diagnosis of Intellectual Disability. This is something the result of the testing at this point may support, with the IQ around 50, the social skill domain being one of his strongest features, as well as scoring outside cut-off range for autism spectrum on the ADOS. The ADOS further indicates that one of the participants no longer has Childhood Autism or ASD, and that two of the participants seem to have less severe symptoms within the range of autism spectrum. A common feature amongst these three participants is progress on adaptive function from childhood to adulthood. Two of these scores within normal range on both IQ and ABC, one of which no longer shows ASD symptoms. They both received EIBI as children. One of these three is intellectually high functioning, but he has not achieved normal function on ABC. The last three participants remain within the cut-off range for autism. One of the participants who did not show any progress has comorbid intellectual disabilities. The other two participants show regression on adaptive function from childhood to adulthood.

Literature searches gave no result in finding published studies comparable with this one. As it turns out, there are no published studies on post-intervention adult outcome for persons with autism, neither when searching for single subject research designs nor group comparison designs. Intervention comparison studies who claims to be long-term or longitudinal, measures only into later childhood (Kasari et al., 2012; Magiati et al., 2011; McEachin et al., 1993). Adult outcome studies have a long-term perspective, but do not take any intervention in childhood into account (e.g. Ballaban-Gil, Rapin, Tuchman & Shinnar, 1996; Eaves & Ho, 2008; Gillberg & Steffenburg, 1987; Howlin et al., 2004; Howlin et al., 2013; Howlin, Savage, Moss, Tempier & Rutter, 2013; Kobayashi, Murata & Yoshinaga, 1992; Rutter et al., 1967).

The study of O’Connor and Healy (2010) is comparable to this study in terms of small sample size and an individualized data analysis. They present a post-intensive follow-up of five children with autism after termination of EIBI. The children made progress during EIBI and were integrated in mainstream classes. The study aims at measuring maintenance of progress in a mainstream setting. The children were at a mean age of eleven at the time of the follow-up and had attended mainstream classes for nearly two years. The study is not directly comparable when it comes to measurement procedures as different tests were applied, with exception of the VABS, as well as having no comparison group. Nevertheless, there are results for IQ, ABC and autism severity. Four of five participants had decreased in IQ and adaptive behavior, and all sustained their diagnosis of autism. Comparing that to the sample of four who received EIBI in this present study, all of which made progress and sustained their progress on IQ, and two made and sustained progress on ABC, they achieved an overall better outcome. All the participants in this present study received EIBI or eclectic treatment beyond two years, and all continued to receive treatment during the T3 assessment. The participants in the O’Connor and Healy (2010) study received a mean amount of three years of EIBI. The authors note that their study supports the need for further treatment in school and home even when the benefit from EIBI in pre-school was large.

The results of the questionnaire are interesting, and may be analyzed in the same way as of other adult outcome studies, although the sample size is too small to make any statistical interpretations. Nevertheless, it is possible to grade the participants individually in terms of “good” vs. “poor” outcome based on the OOR scale of Howlin, et al. (2004). This scale is based on scores on work, friendship and independent living, and are widely used in adult outcome studies to display social outcome for persons with autism (Henninger & Taylor, 2013). It is also interesting to see the extent to which the category placement of “good” vs. “poor” is in accordance with the label “best outcome”, which refers to children with autism obtaining normal function after receiving EIBI (Lovaas, 1987; McEachin, Smith & Lovaas, 1993).

Participant 4 stands out with his remarkable progress on IQ and ABC, and which the ADOS suggests he ought to have his autism diagnosis revised. This is a case of “best outcome” based on the measures of the standardized tests applied in the former studies of Eikeseth et al. (2002, 2007). According to the questionnaire, he lives independently, although in a sheltered municipal housing. However, he has no friends and no work, but currently he is a full time student. Thus, he will probably not obtain “very good” or even “good” outcome based on the OOR scale, but possibly “fair”. When taken the fact that he is a full time student into account, however, the outcome might be “good”. Participant 1 on the other hand, will in terms of the OOR, most likely obtain “good” or “very good” outcome. He lives independently, although in sheltered municipal housing, holds a job (sheltered) and he has two or more friends. In addition, he made intellectual and adaptive progress in childhood, which has maintained into adulthood. This makes him one of the “best outcome” children of the sample of Eikeseth et al. (2002, 2007). Participant 7 is a possible “good” outcome. He has his own apartment, has a formal education, and holds a full time job, however currently sheltered. What makes this case a not “very good” outcome, is that he has no friends. However, it should be mentioned him being the one with the driver license. On the other hand, he is not a “best outcome” case, as the adaptive level has remained relatively low throughout the years. His intellectual level has always been within the normal range. Participant 5 also seem to have a “good” outcome according to the OOR as he has a formal education, holds a sheltered job and has two or more friends. He is currently living with his parents, which probably does not qualify as independent. He does not categorize as “best outcome” as both IQ and adaptive levels remain below normal range. Participants 2, 3, and 6 most likely fall into the “poor” or “very poor” category, as they all receive twenty-four seven supervision, their work is highly facilitated and they have no close friends. Their adaptive level supports this, as well as the downward trend in adaptive behavior from childhood into adulthood. Participant 2 did make intellectual progress during the first year of EIBI, and this gain has sustained within normal range. Even so, he does not come out as a “best outcome” because of small gain on the ABC and a descending trend into adulthood. Participant 8 categorizes as “poor” as well, as she lives at home being supervised around the clock by her mother. She does not work, but she has one friend. She is not a case of “best outcome” as the IQ and adaptive level remain too low.

As it turns out, this study reveals an adult outcome of three (40 %) “very good” and “good”, one (10 %) “fair”, and four (50 %) “poor” or “very poor”. Having a 50 % “poor” outcome is actually in accordance with other longitudinal studies of adult outcome for persons with autism (Henninger & Taylor, 2013; Magiati, Tay & Howlin, 2014). It also reveals that there necessarily does not need to be correspondence between “good” or “very good” outcome and “best outcome”. No study has previously examined this relationship in particular, and it might be an issue to consider highlighting in future adult outcome research, especially post EIBI follow-up research.

This present study has several limitations. Firstly, the original sample of Eikeseth et al. (2002) was small. However, that study had a statistical power of 97 % on IQ and 96 % on ABC and thus was able to derive a valid statistical conclusion (Shadish, Cook & Campbell, 2002). An even smaller sample in this present study extensively limits the value of the results, and the research design holds no statistical power and has little experimental control.

Secondly, there are in this study threats to the validity of the results. In terms of internal validity, i.e. establishing cause and effect, the threats are related to heterogeneity of the sample, history, maturation, and the loss of referrals (Shadish et al., 2002). The eight persons, who constitute the sample of this study, have three common features only. They are aged between 21 and 25, and got the diagnosis of Childhood Autism as children, and they received systematic intensive intervention in early childhood years. Other than that, they are completely heterogeneous, and there might be additional factors that contributed to the progression or regression, other than the childhood intervention.

This study does not account for any historical events that may influence on the results. One example is the ABC results for Participant 7, which drops unexplainably at the T3 measure, but recovers at T4. Maybe the questionnaire could have been developed to identify in more detail, the historical aspects of the participant’s lives.

Maturation is another problem that threats the internal validity of the results. Adult outcome studies that does not account for any intervention in childhood, show that some persons with autism, especially those with IQ above 70, to some degree show recovery with increasing age (Levy & Perry, 2011). In terms of autism severity, there are limitations of knowing whether the outcome would turn out differently for these persons if they did not receive the intervention, EIBI or eclectic.

This study suffers from loss of referrals, which is the largest threat to the internal validity of the results. If all the 25 participants of the original study of Eikeseth et al. (2002, 2007) had given their consent to participate, the results would be far more precise in estimating whether EIBI is the cause of changes and the maintenance of changes into adulthood or not.

The strengths of this present study are the usage of standardized tests for measurement conducted by specially trained, independent and blind assessors. This makes the preliminary results presented in this study reliable and useful if the adult outcome of the remaining persons with autism from the original sample of Eikeseth et al. (2002, 2007) will be obtained later. Another strength of this study is the availability of comparison data for all eight participants. Four data points in the period of early childhood to beginning adulthood is valuable knowledge for these participants individually, as well as for the contribution to the autism body of research.

Conclusion

In the original study of Eikeseth et al. (2002, 2007) the evidence showed EIBI being effective in the short term and that the progress had maintained after three years. 18 years later, four of the participants from the Eikeseth et al. (2002, 2007) study who received EIBI have maintained their gain, and some have even progressed into adulthood. The four participants who received eclectic treatment did not gain nearly as much, and some have regressed into adulthood. Despite the small sample size, this study may contribute with longitudinal data on the adult outcome for children with autism who received intensive educational intervention in their childhood, and show some support for the long lasting effect of EIBI for four persons with ASD.

References:

Achenbach, T. M. (1991). *Manual for the Teacher's Report Form and 1991 profile.* Burlington: University of Vermont, Department of Psychiatry.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (4th ed.)*. Washington, DC: American Psychiatric Association.

Ayres, A. J. (1972). *Sensory integration and learning disorders.* Los Angeles: Western Psychological Services.

Ballaban-Gil, K., Rapin, I., Tuchman, R., & Shinnar, S. (1996). Longitudinal examination of the behavioral, language, and social changes in a population of adolescents and young adults with autistic disorder. *Pediatric Neurology, 15* (3), 217 – 223.

Bayley, N. (1993). *Bayley scales of infant development* (2nd ed.). San Antonio, TX: The Psychological Corporation.

Billstedt, E., Gillberg, 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.

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults with diagnosed with autism in childhood: a population-based study. *Autism, 15* (1), 7 – 20.

Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied Behavior Analysis (second edition)*. New Jersey, Prentice Hall.

Eaves, L. C. & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38* (4), 739–747.

Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in developmental disabilities, 30* (1), 158–178.

Eikeseth, S. (2011). Intensive Early Intervention. In J. L. Matson & P. Sturmey (Eds.), *International Handbook of Autism and Pervasive Developmental Disorders*, (pp. 321 – 338). New York: Springer.

Eikeseth, S., Smith, D. P., & Klintwall, L. (2014). Discrete trial teaching and discrimination training. In J. Tarbox, D. R. Dixon, P. Sturmey, & J. L. Matson (Eds.), *Handbook of Early Intervention for Autism Spectrum Disorders. Research, Policy and Practice* (pp. 293-324). New York: Springer.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism. *Behavior Modification, 26* (1), 49 – 68.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7. *Behavior Modification, 31* (3), 264 – 278.

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 and adolescent psychology, 38* (3), 439–450.

Fenske, E. C., Krantz, P. J., & McClannahan, L. E. (2001). Incidental teaching: A Not-discrete-trial teaching procedure. In C. Maurice, G. Green, and R. M. Foxx, (Eds.), *Making a Difference: Behavioral Intervention for Autism*, (pp. 75–82). Austin TX: Pro-Ed.

Gillberg, C. & Steffenburg, S. (1987). Outcome and prognostic factors in infantile autism and similar conditions: A population-based study of 46 cases followed through puberty. *Journal of Autism and Developmental Disorders, 17* (2), 273–287.

Gillespie-Lynch, K., Septa, L., Wang, Y., Marshall, S., Gomez, L., Sigman, M., Hutman, T. (2012). Early childhood predictors of the social competence of adults with autism. *Journal of Autism Developmental Disorder, 42*, 161 – 174.

Green, G., Brennan, L. C., & Fein, D. (2002). Intensive behavioral treatment for a toddler at high risk for autism. *Behavior Modification, 26*, 69-102.

Henninger, N. A., & Taylor, J. L. (2012). Outcomes in adults with autism spectrum disorders: a historical perspective. *Autism, 17* (1), 103 – 116.

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.

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. *American Academy of Child & Adolescent Psychiatry, 52* (6), 572 – 581.

Howlin, P., Savage, S., Moss, P., Tempier, A., Rutter, M. (2013). Cognitive and language skills in adults with autism: a 40-year follow-up. *Journal of Child Psychology and Psychiatry, 55*, 49 – 58.

Kanner, L. (1943) Autistic disturbances of affective contact. *Nervous Child*, *2,* 217–250.

Kanner, L. (1971) Follow-up study of eleven autistic children originally reported in 1943. *Journal of Autism and Childhood Schizophrenia*, *1* (2), 119–145.

Kasari, C., Gulsrud, A., Freeman, S., Paparella, T., & Helleman, G. (2012). Longitudinal follow-up of children with autism receiving targeted interventions on joint attention and play. *American Academy of Child and Adolescent Psychiatry, 51* (5), 481 – 495.

Klintwall, L., & Eikeseth, S. (2012). Number and controllability of reinforcers as predictors of outcome for children with autism receiving early and intensive behavioral intervention: a preliminary study. *Research in Autism Spectrum Disorders, 6* (1), 493 – 499.

Kobayashi, R., Murata, T., & Yoshinaga, K. A. (1992) Follow-up study of 201 children with autism in Kyushu and Yamaguchi areas, Japan. *Journal of Autism and Developmental Disorders, 22* (3), 395–411.

Kovshoff, H., Hastings, R. P., & Remington, B. (2011). Two-year outcomes for children with autism after the cessation of early intensive behavior intervention. *Behavior Modification*, *35,* 427–450.

Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: a review of the literature. *Research in Autism Spectrum Disorders*, *5,* 1271 – 1282.

Leaf, R. & McEachin, J. (1999). *A work in progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism.* New York: DRL Books, L. L. C.

Lord, C., Rutter, M., FRS, DiLavore, P. C., & Risi, S. (1989). *Autism Diagnostic Observation Schedule.* Los Angeles: Western Psychological Services.

Lord, C., Rutter, M., & LeCouteur, A. (1994). Autism Diagnostic Interview – Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorder. *Journal of Autism and Developmental Disorders, 24,* 659 – 685.

Lovaas, O.I. (1977). *The autistic child: Language development through behavior modification*. New York: Irvington Publishers.

Lovaas, O. I. (1987). Behavioral Treatment and Normal Educational and Intellectual Functioning in Autistic Children. *Journal of consulting and clinical psychology, 55* (1), 3–9.

Lovaas, O. I. (2003). *Teaching Individuals with Developmental Delays: Basic Intervention Techniques*. Texas: PRO-ED.

Lovaas, O. I., Ackerman, A., Alexander, D., Firestone, P., Perkins, M., & Young, D. B. (1981). *Teaching developmentally disabled children: The ME Book.* Austin, TX: Pro-Ed.

Lovaas, O.I., Koegel, R.L., Simmons, J.W., & Long, J.S. (1973). Some generalization and follow-up measures on autistic children in behavior therapy. *Journal of Applied Behavior Analysis*, *6*, 131–161.

Magiati, I., Charman, T., & Howlin, P. (2007). A two-year prospective follow-up study of community-based early intensive behavioural intervention and specialist nursery provision for children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, *48* (8), 803–812.

Magiati, I., Moss, J., Charman, T., & Howlin, P. (2011). Patterns of change in children with autism spectrum disorders who received community based comprehensive interventions in their pre-school years: A seven year follow-up study.

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,* 73 – 86.

Makrygianni, M. K., & Reed, P. (2010). A meta-analytic review of the effectiveness of behavioural early intervention programs for children with autistic spectrum disorders. *Research in Autism Spectrum Disorders, 4,* 577–593.

Maurice, C. (Ed.), Green, G., & Luce, S. (Co-Eds.). (1996). *Behavioral intervention for young children with autism: A manual for parents and professionals.* Austin, TX: PRO-ED.

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* (4), 359–372.

O'Connor, A. B., & Healy, O. (2010). Long-term post-intensive behavioral intervention outcomes for five children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 4* (4), 594–604.

Pearson Education inc. Introducing the WAIS® IV. Retrieved from: (http://images.pearsonclinical.com/images/assets/WAIS-IV/WAISIV2_6_08.pdf, down loaded May 8th, 2014)

Peters-Scheffer, N., Didden, R., Korzilius, H., & Sturmey, P. (2010). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders, 2,* 621 – 642.

Reichow, B., Barton, E. E., Boyd, B. A., & Hume, K. (2012). Early intensive behavioral Intervention (EIBI) for young children with autism spectrum disorder (ASD). *Cochrane Database of Systematic Reviews, 10*. Art. No.: CD009260. DOI: 10.1002/14651858.CD009260.pub2.

Reichow, B., & Wolery, M. (2009). Comprehensive synthesis of early intensive behavioral interventions for young children with autism based on the UCLA young autism project model. *Journal of Autism and Developmental Disorders, 39*, 23-41.

Remington, B., Hastings, R. P., Kovshoff, H., Espinosa, F., Jahr, E., Brown, T., et.al. (2007). Early intensive behavioral intervention: Outcomes for children with autism and their parents after two years. *American Journal on Mental Retardation, 112,* 418-438.

Reynell, J. K. (1990). *Reynell Developmental Language Scales.* Windsor, UK: Nfer-Nelson.

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child & Adolescent Psychology*, *37* (1), 8–38.

Rutter, M., Greenfeld, D., & Lockyer, L. (1967). A five to fifteen year follow-up study of infantile psychosis: II. Social and behavioural outcome. *The British Journal of Psychiatry, 113*, 1183–1199.

Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation, 110* (6), 417–438.

Schopler, E., Lansing, M., & Waters, L. (1983). *Individualized assessment and treatment for autistic and developmentally disabled children: Vol. 3. Teaching activities for autistic children.* Austin, TX: Pro-Ed.

Shadish, W. R., Cook, T. D., & Campbell, D. T. (2002). *Experimental and quasi-experimental designs for generalized causal inference.* Boston: Houghton Mifflin Company.

Smith, T. (2001). Discrete trial training in the treatment of autism. *Focus on Autism and Other Developmental Disabilities*, *16* (2), 86–92.

Smith, T., Groen, A. D., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, *105* (4), 269–285.

Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland Adaptive Behavior Scales.* Circle Pines, MN: American Guidance Service.

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

Stutsman, R. (1948). *Guide for administering the Merrill-Palmer Scale of Mental Tests.* New York: Harcourt, Brace & World.

Sundberg, M. L., & Partington, J. W. (1998). *Teaching Language to Children with Autism and Other Developmental Disabilities.* Pleasant Hill, CA: Behavior Analysts, Inc.

Virués-Ortega, J. (2010). Applied behavior analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose-response meta-analysis of multiple outcomes. *Clinical Psychology Review, 30*, 387–399.

Wechsler, D. (1974). *The Wechsler Intelligence Test for Children – Revised.* San Antonio, TX: Psychological Corporation.

Wechsler, D. (1989). *Wechsler Preschool and Primary Scale of Intelligence – Revised.* San Antonio, TX: Psychological Corporation.

Wechsler, D. (2008). *Wechsler Adult Intelligence Scale (4th ed.).* USA: Pearson.

Wechsler, D., & Naglieri, J. A. (2006). *Wechsler Nonverbal Scale of Ability*. San Antonio, TX: Harcourt Assessment.

World Health Organization. (1993). *International Classification of Diseases (ICD-10).* Geneva: Author.

Tables and figures

Tables:

Table 1: Results of the ADOS for each participant.

	Diagnosis at intake	**Current diagnosis (questionnaire)**	**ADOS result**
Participant 1	Childhood Autism	Childhood Autism	Autism Spectrum
Participant 2	Childhood Autism	Childhood Autism	Childhood Autism
Participant 3	Childhood Autism	Childhood Autism & Intellectual Disability	N/A
Participant 4	Childhood Autism	Childhood Autism	Not ASD
Participant 5	Childhood Autism	Intellectual Disability	Not ASD
Participant 6	Childhood Autism	Childhood Autism & Intellectual Disability	Childhood Autism
Participant 7	Childhood Autism	Childhood Autism	Autism Spectrum
Participant 8	Childhood Autism	Childhood Autism	Childhood Autism

Table 2: Significance test IQ and ABC, group as a whole.

	T1				**T4**				
					Change				
IQ	N	Mean	SD	SEM	N	Mean	SD	SEM	p-value
	7	64,14	18,11	6,85	7	84,86	28,16	10.64	0,0572
ABC	N	Mean	SD	SEM	N	Mean	SD	SEM	p-value
	8	53,75	11,22	3,97	8	61,25	27,18	09,61	0,4625

Table 3: Significance test EIBI vs. eclectic group.

	T1				**T4**				
					Change				
IQ EIBI	N	Mean	SD	SEM	N	Mean	SD	SEM	p-value
	3	59,33	9,45	14,11	3	102,00	14,11	08,14	0,0451*
IQ Eclectic	N	Mean	SD	SEM	N	Mean	SD	SEM	p-value
	4	67,75	23,58	11,79	4	72,00	30,65	15,32	0,38524
ABC EIBI	N	Mean	SD	SEM	N	Mean	SD	SEM	p-value
	4	53.00	9,66	4,38	4	71,25	32,35	16,17	0,3558
ABC Eclectic	N	Mean	SD	SEM	N	Mean	SD	SEM	p-value
	4	54,50	14,11	7,05	4	51, 25	20,25	10,13	0,7353

*The p-value is significant.

Figures:

Figure 1.

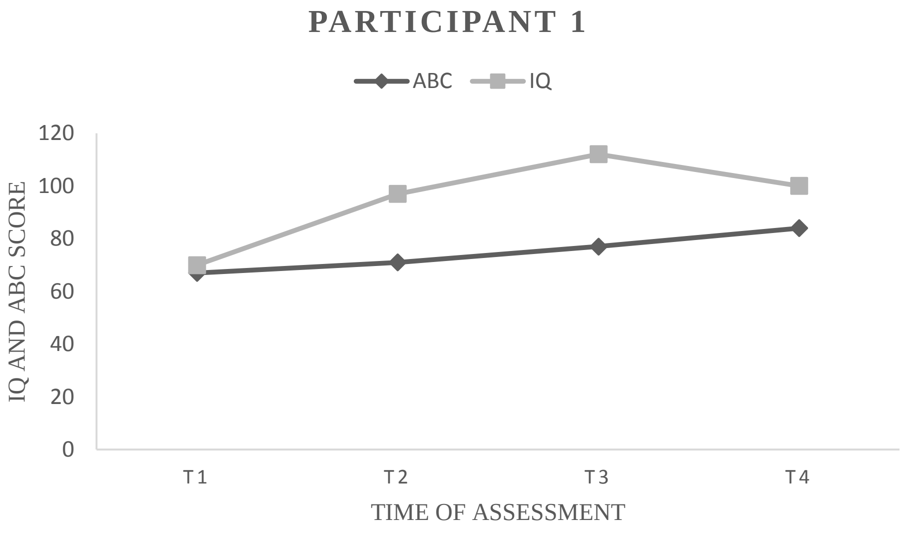


Figure 2.

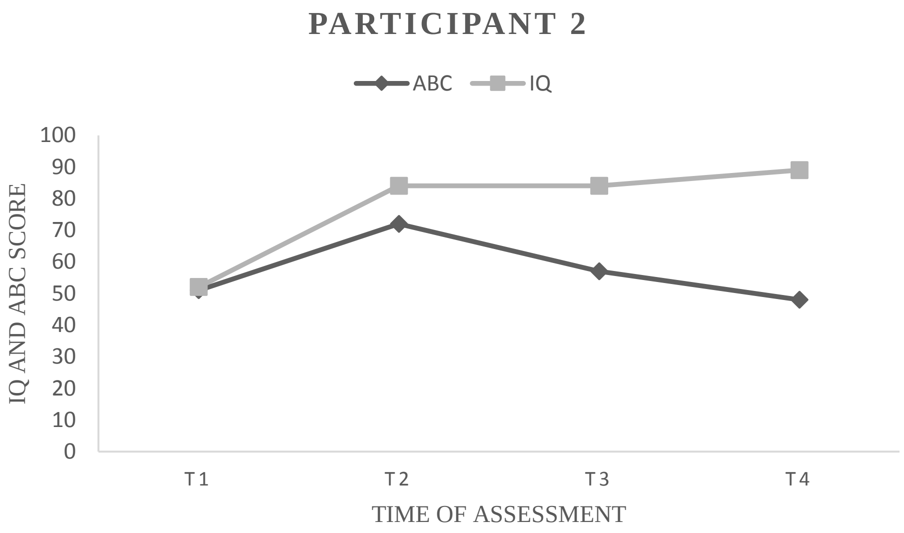


Figure 3.

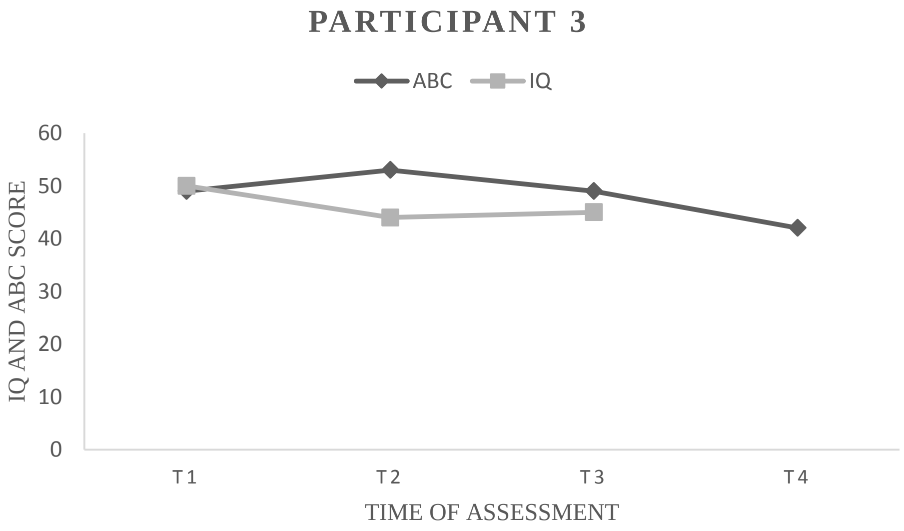


Figure 4.

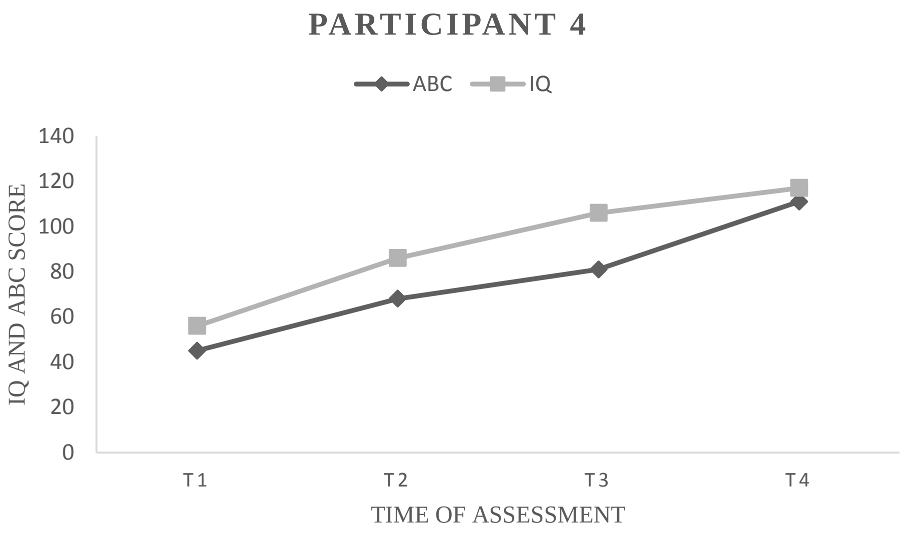


Figure 5.

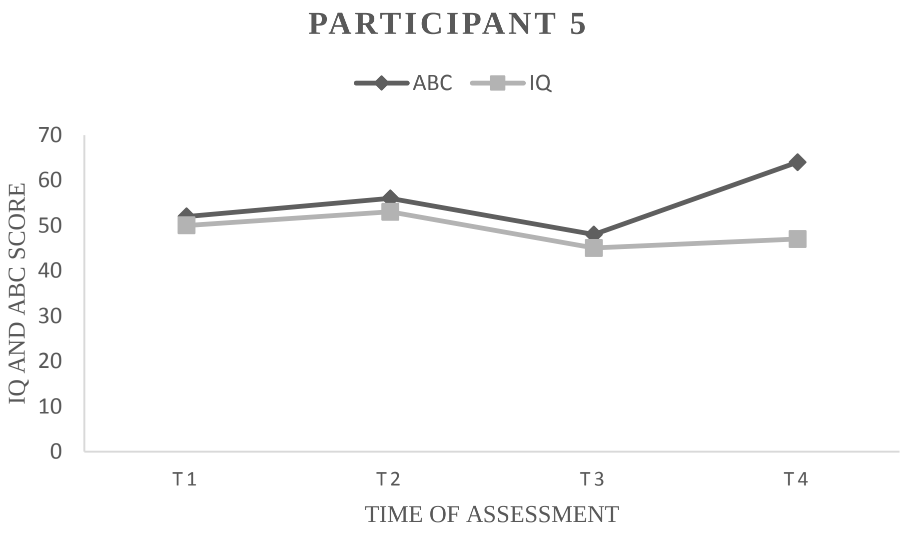


Figure 6.

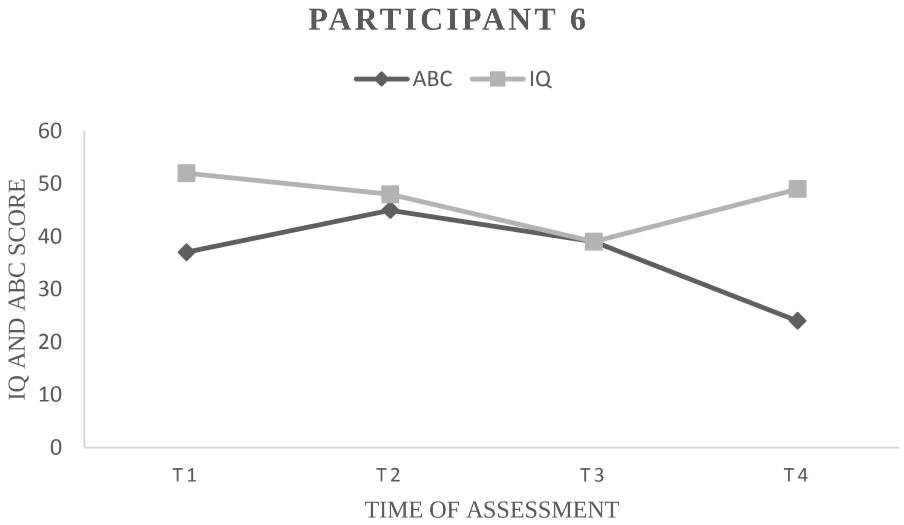


Figure 7.

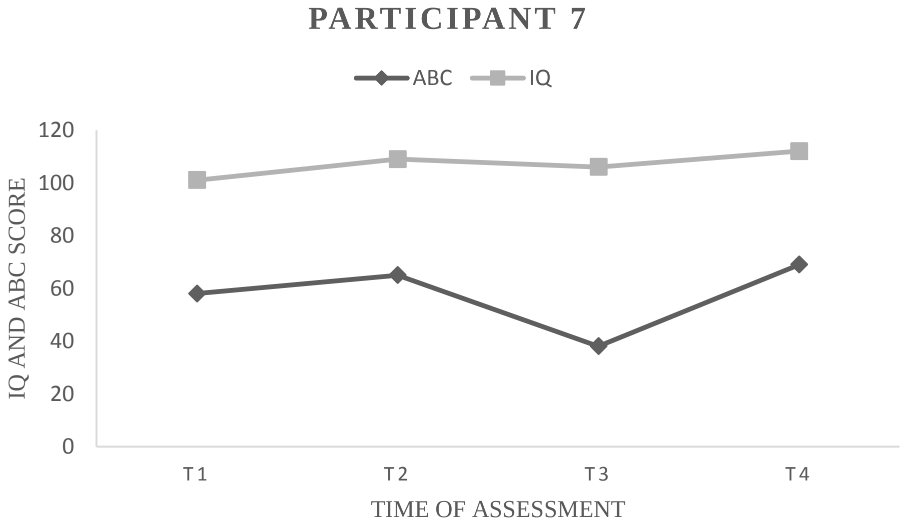


Figure 8.

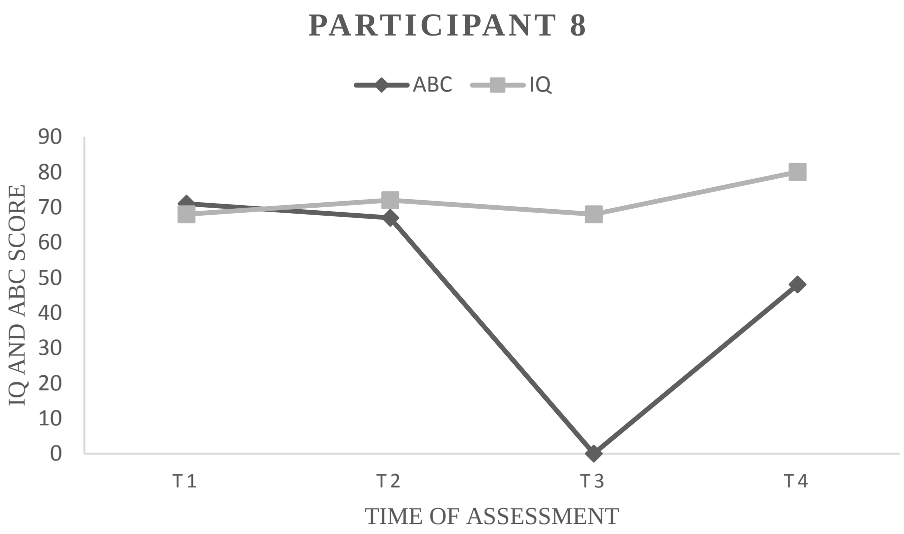


Figure 9.

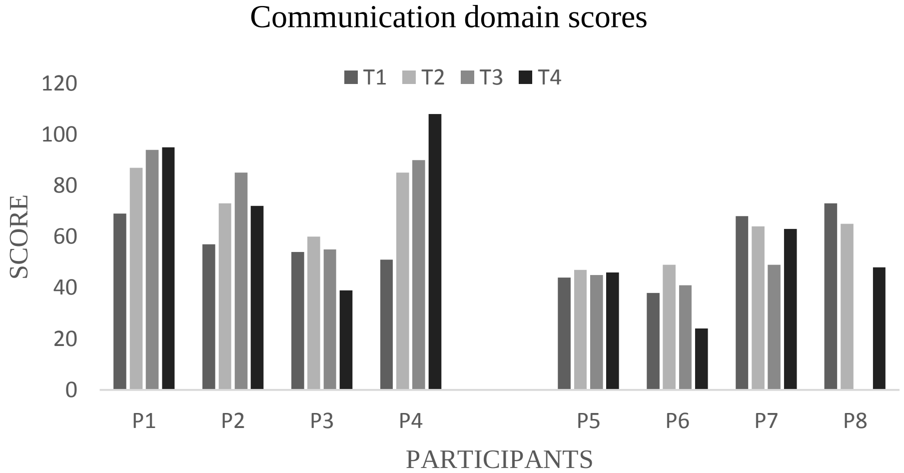


Figure 10.

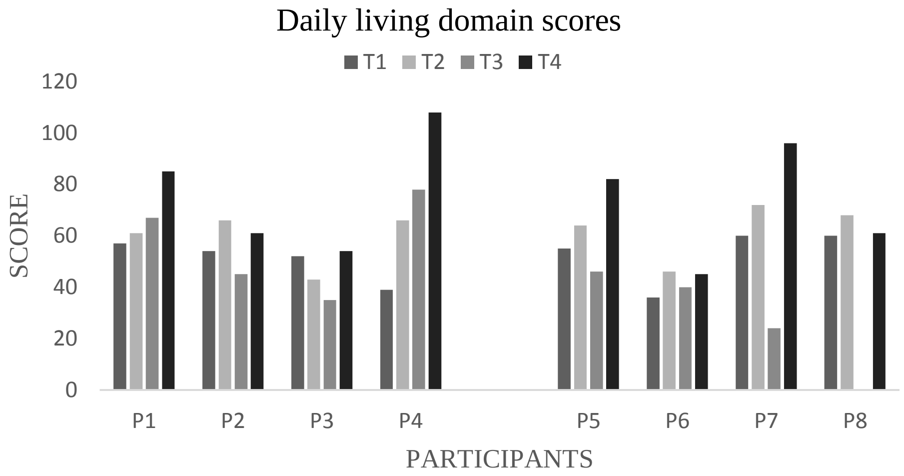


Figure 11.

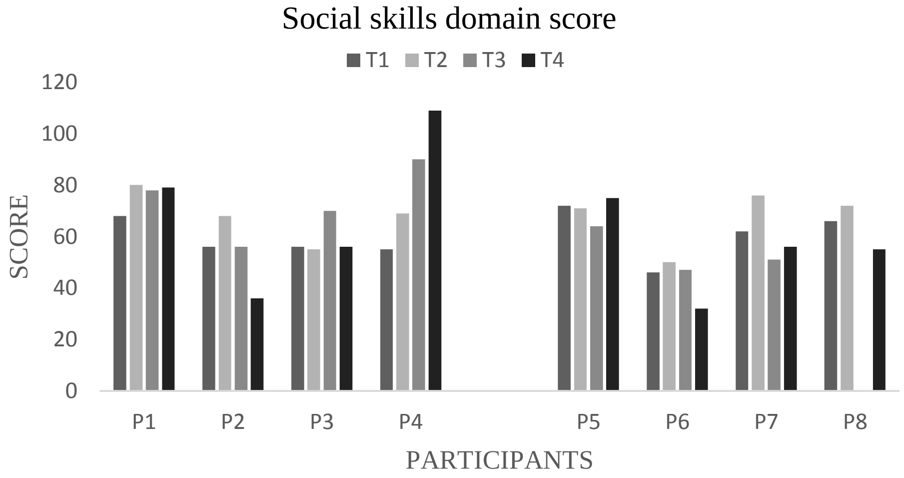


Figure 12.

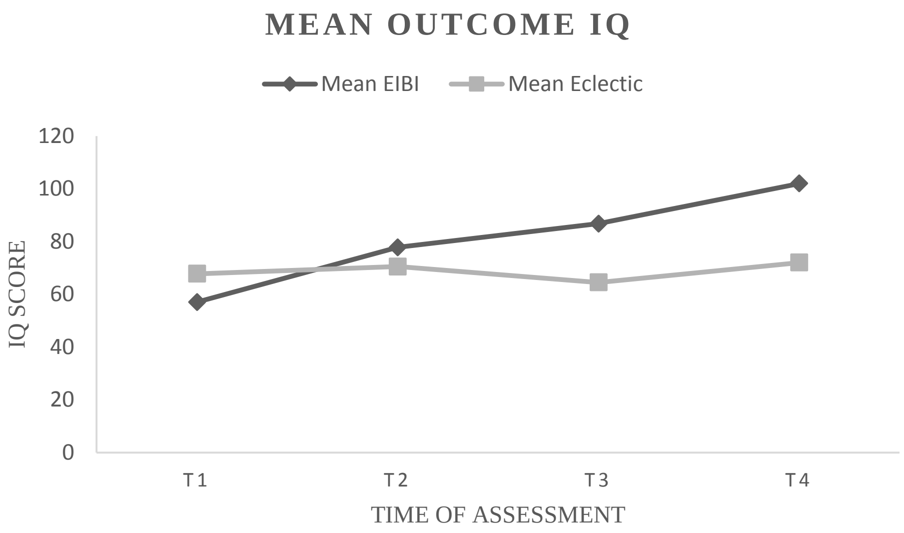
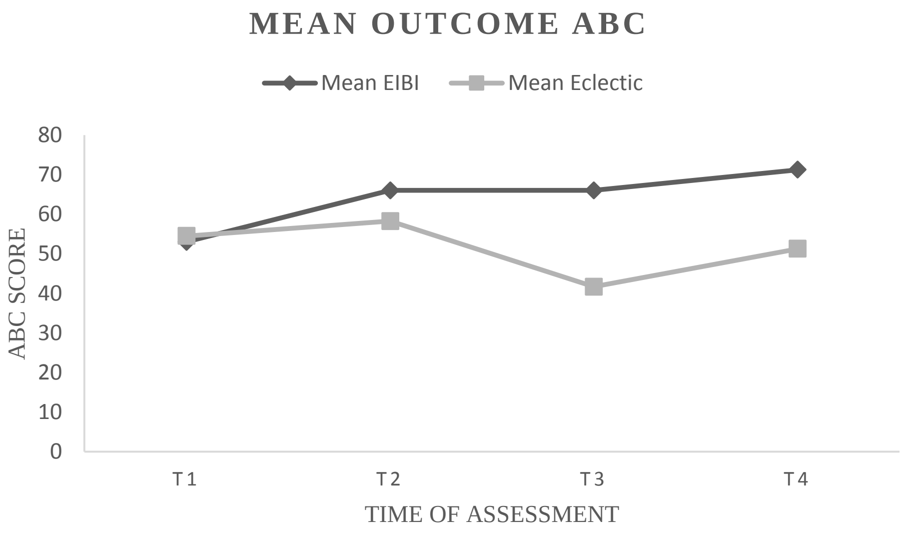


Figure 13.



REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Gjøril Bergva	22845529	03.07.2013	2013/1025/REK sør-øst D
			Deres dato:	**Deres referanse:**
			28.05.2013	

Vår referanse må oppgis ved alle henvendelser

Til Svein Eikeseth

2013/1025 Utfall hos voksne personer med autismespekterforstyrrelser som mottok systematisk opplæring i barnehagen og tidlig grunnskole

Forskningsansvarlig: Høgskolen i Oslo og Akershus
Prosjektleder: Svein Eikeseth

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 13.06.2013. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikklovens § 4.

Prosjektomtale

Bakgrunnen for studien er at det er begrenset kunnskap om utviklingen til barn med autisme som har fått ulike typer behandling som barn. Målet med studien er å følge opp 25 barn med autismespekterforstyrrelser som i førskolealder og tidlig skolealder ble allokert til enten intensiv atferdsanalytisk opplæring (N=13) eller annen spesialpedagogisk opplæring (N=12) uten randomisering. Tidligere studier har vist forskjeller mellom de to gruppene fram til åtte år. Formålet med denne studien er å undersøke hvordan det har gått med disse to gruppene mht autismesymptomer og fungering i voksen alder. Deltagerne vil bli undersøkt med Autism Diagnostic Obervation Schedule (ADOS), WAIS og Vineland Adaptive Behavior Scale, og fyller ut et spørreskjema som blant annet spør om demografiske forhold, andre diagnoser og sosialt nettverk.

Vurdering

Prosjektet har tidligere vært vurdert av komiteen i to omganger (REK-referanse 2013/435). Søker har nå sendt inn en ny søknad, der komiteens kommentarer i tidligere behandling av prosjektet er tatt til følge. Det er utarbeidet en tilfredsstillende forskningsprotokoll, omfang av veiledning er angitt og honoraret har en akseptabel størrelse.

Komiteen har ingen innvendinger til studien slik den nå er fremlagt. Komiteen har imidlertid noen kommentarer til informasjonsskrivet:
-Skrivet må tones ned når det gjelder fordeler. Den potensielle deltageren blir fortalt at informasjonen deres vil gjøre tiltakene for barn med autisme bedre. Det er det ikke holdepunkter for å si. Fordelene må heller ikke ramses opp, og betaling må ikke framheves som en fordel, heller ikke overfor mennesker med autisme. Det er også uheldig at vurdering av diagnose blir framhevet som noe positivt. ADOS blir ikke regnet som tilstrekkelig til å sette en autismespekterdiagnose, og det går ikke fram av søknaden at det skal foretas noen mer omfattende diagnostisering.
-Det opplyses om at data blir anonymisert. I dette tilfellet vil det være riktig å si at data er avidentifisert, som innebærer at man kan finne tilbake til hvem opplysningene gjelder ved hjelp av en nøkkel eller kode. Dersom opplysningene er anonymisert finnes det ingen nøkkel eller kode som gjør det mulig å koble opplysningene sammen igjen.

På denne bakgrunn setter komiteen følgende vilkår for godkjenning:
-Informasjonsskrivet skal revideres i tråd med ovennevnte kommentarer og sendes komiteen til orientering.

Vedtak
Med hjemmel i helseforskningsloven § 9 jf. 33 godkjenner komiteen at prosjektet gjennomføres under forutsetning av at ovennevnte vilkår oppfylles.

I tillegg til vilkår som fremgår av dette vedtaket, er godkjenningen gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknad og protokoll, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 02.03.2015. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 02.03.2020. Forskningsfilen skal oppbevares avidentifisert, dvs. atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse og omsorgssektoren».

Dersom det skal gjøres vesentlige endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK.

Prosjektet skal sende sluttmelding på eget skjema, senest et halvt år etter prosjektslutt.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst D. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst D, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn på korrekt skjema via vår saksportal: http://helseforskning.etikkom.no. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Stein A. Evensen
Professor dr. med.
Leder

Gjøril Bergva
Rådgiver

Kopi til: postmottak@hioa.no

Forespørsel om deltakelse i forskningsprosjektet

«Undersøkelse av voksne personer som fikk diagnosen autisme som barn og mottok systematisk opplæring»

Bakgrunn og hensikt

Da du var mindre fikk du systematisk atferdsanalytisk opplæring i barnehagen og på skolen. Vi ønsker å finne ut hvordan det går med deg, nå når du har blitt voksen.

Dette er en forespørsel til deg om å delta i en forskningsstudie for å undersøke utfallet av opplæringen du mottok i barnehagen og tidlig grunnskole. Studien vil undersøke to grupper av personer som fikk diagnosen autisme som barn, hvor den ene gruppen fikk systematisk atferdsanalytisk opplæring og den andre fikk systematisk spesialpedagogisk opplæring. Vi ønsker å undersøke ved å sammenligne resultatene fra de to gruppene, om det er forskjell på hvordan det har gått med dere etter at dere ble voksne ut i fra hvilken type opplæring dere fikk. For å finne ut om det er forskjell mellom og innenfor gruppene, trenger vi at du gjennomfører to tester sammen med en psykolog og spesialpedagog, samt at du fyller ut et spørreskjema. Dine foresatte mottar forespørsel fra oss om å delta i samme studie hvor de blir bedt om å bidra ved å gjennomføre et intervju. Opplysningene om deg som navn og fødselsdato vil bli avidentifisert, som innebærer at man kun kan finne tilbake til hvem opplysningene gjelder ved hjelp av en kode. Det er bare autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Opplysningene om deg kan ikke spores tilbake til deg når studien er ferdig.

Den informasjonen du kan gi er svært verdifull. Den kan blant annet bidra til at tilbudet som gis til små barn med autisme blir bedre.

Effekten av tidlig og systematisk opplæring for barn med autisme er godt dokumentert gjennom flere studier både nasjonalt og internasjonalt. Om resultatene vises også i voksne alder, gjenstår det å fremskaffe mer kunnskap om.

Hensikten med studien er å gjøre kunnskapen fra studien kjent for andre som er tilknyttet opplæring og omsorg for personer med autisme. Dette gjøres ved å publisere en forskningsrapport med en statistisk analyse av resultatene fra testene i et internasjonalt tidsskrift.

Hva innebærer studien?

Vi ønsker nå å gjennomføre et forskningsprosjekt for å finne ut hvordan det går med voksne personer som mottok systematisk opplæring, enten atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller tidlig grunnskole, og om det er forskjeller mellom de to gruppene ut i fra hvilken type opplæring de fikk.

Hvis du velger å delta i studien vil dette innebære to dager med tester, en test pr. dag gjennomført av psykologspesialist og spesialpedagog, samt utfylling av et spørreskjema. Dine foresatte eller nærmeste pårørende vil bli forespurt om å gjennomføre et intervju, Vineland Adaptive Behavior Scales—Second Edition. Testingen vil foregå hjemme hos deg.

Høgskolen i Oslo og Akershus og Glenne regionale senter for autisme vil stå for testingen. Testene vil kartlegge kognitive ferdigheter (IQ), og tilpasningsferdigheter, som for eksempel sosiale ferdigheter og selvhjelpsferdigheter. Det vil også gjøres en ny diagnostisk vurdering knyttet til autismeproblematikk. De testene som blir benyttet er vanlig å bruke til utredning av personer med autisme og er standardiserte psykologiske/pedagogiske tester. Testene heter ADOS (Autism Diagnostic Observation Schedule), WAIS III (Wechsler Adult Intelligence Scale), og Vineland Adaptive Behavior Scales—Second Edition. Testene innebærer at du og en annen person som er psykolog, sitter ved et bord og snakker sammen. Du må også svare på spørsmål og løse oppgaver sammen med denne personen. Spørreskjemaet kan du fylle ut selv, få hjelp til å fylle ut av noen du kjenner godt, eller at noen som du kjenner godt kan fylle ut for deg. Det tar om lag 2 timer å gjennomføre ADOS, 2 - 3 timer å gjennomføre WAIS III. Dine foresatte eller nærmeste pårørende vil måtte beregne 1 – 2 timer til å gjennomføre Vinelandintervjuet. Du må altså påregne å bruke 2 – 3 timer den ene dagen og 3 – 4 timer den andre dagen de dagene testingen skal skje.

Resultatene av testene gis til deg i en samtale med psykolog, hvis du vil. Du kan også få resultatene skriftlig når studien er ferdig.

Du eller personer som kjenner deg godt kan få en veiledningssesjon av psykolog når du har fått resultatene. Veiledningen vil ta utgangspunkt i resultatene, og vil innebære forslag til ferdigheter du kan trene på eller hvordan det kan tilpasses bedre rundt deg i hverdagen. Dette inngår ikke som ledd i prosjektet, men er et tilbud til deg. Du har anledning til å avslå dette tilbudet dersom du ikke synes det er nødvendig.

Som takk for ditt bidrag og at du setter av tid til denne undersøkelsen, kan du velge mellom en økonomisk kompensasjon på kr. 300, gavekort på et kjøpesenter pålydende kr. 300 eller kinobilletter til en 3D-film for to personer.

Mulige fordeler og ulemper ved å delta

Mulige fordeler ved å delta i studien kan være at du får mulighet til å bidra til at det fremkommer mer kunnskap knyttet til opplæring av barn med autisme. Du vil videre få resultater av tre tester, noe som kan være verdifull informasjon for deg og eventuelt dine nærmeste. Dessuten vil resultatene danne grunnlaget for veiledningen du tilbys med en psykolog.

Mulige ulemper kan være at du må avsette tid til gjennomføring av testene.

Hva skjer med testene og informasjonen om deg?

Testene som blir tatt og all informasjonen som registreres om deg skal brukes kun slik som beskrevet i hensikten med studien.

Alle opplysningene og testene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger og tester gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg.

Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien, men senest innen 01.10.2014. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side og sender denne tilbake til oss i den ferdigfrankerte konvolutten som medfølger. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte prosjektansvarlig Svein Eikeseth på 922 10 988 (svein.eikeseth@hioa.no).

Ytterligere informasjon om studien finnes i kapittel ***A*** – *utdypende forklaring av hva studien innebærer.*

Ytterligere informasjon om personvern og forsikring finnes i kapittel B – *Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltagelse er:

- Deltakeren mottok systematisk opplæring, atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller i tidlig grunnskole med bakgrunn i en autismeproblematikk.
- Denne opplæringen fant sted for om lag 15 - 20 år siden.

Tidsskjema:

- Etter at du har meldt din interesse for deltagelse vil du bli innkalt til testing og utredning, og du vil samtidig bli bedt om å fylle ut et spørreskjema.
- Testing og utredning gjennomføres i løpet av ca. 5 timer hjemme hos deg.
- Testing er planlagt gjennomført vinteren 2013 / 2014.
- Du vil få invitasjon til samtale om testresultatene i etterkant, samt tilbys en veiledningssesjon med psykolog.

Kapittel B - Personvern

Personvern

Opplysninger som registreres om deg er testprotokoller (kognitive ferdigheter, tilpasningsferdigheter og diagnose). Disse testprotokollene vil ikke inneholde opplysninger som kan identifisere deg (dvs. de vil ikke inneholde navn eller fødselsnummer). Testprotokollene vil identifiseres kun ved et identifikasjonsnummer.

I tillegg vil det foreligge en liste som har både personopplysninger og identifikasjonsnummer. Denne listen vil oppbevares separat fra testene og vil kun være tilgjengelig for autorisert personell.

Rett til innsyn og sletting av opplysninger om deg og sletting av tester

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi:

Studien er finansiert gjennom forskningsmidler fra Regionalt fagmiljø for autisme, ADHD, Tourettes syndrom og narkolepsi Helse Sør-Øst.

Informasjon om utfallet av studien

Etter prosjektets slutt vil alle deltagere bli invitert til en oppsummerende presentasjon av resultatene.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien (fylles ut på testdagen)

(Signert, rolle i studien, dato)

Forespørsel om deltakelse i forskningsprosjektet

«Undersøkelse av voksne personer som fikk diagnosen autisme som barn og mottok systematisk opplæring»

Bakgrunn og hensikt

Da din sønn var mindre fikk han systematisk atferdsanalytisk opplæring i barnehagen og på skolen. Vi ønsker å finne ut hvordan det går med han, nå når han har blitt voksen.

Dette er en forespørsel til deg som foresatte om å delta i en forskningsstudie, sammen med din sønn, for å undersøke utfallet av opplæringen han mottok i barnehagen og tidlig grunnskole. Studien vil undersøke to grupper av personer som fikk diagnosen autisme som barn, hvor den ene gruppen fikk systematisk atferdsanalytisk opplæring og den andre fikk systematisk spesialpedagogisk opplæring. Vi ønsker å undersøke ved å sammenligne resultatene fra de to gruppene, om det er forskjell på hvordan det har gått med dem etter at de ble voksne ut i fra hvilken type opplæring de fikk. For å finne ut om det er forskjell mellom og innenfor gruppene, trenger vi at du gjennomfører et intervju sammen med en testperson som er spesialpedagog. Din sønn får også denne forespørselen og han vil bli spurt om å gjennomføre en test med psykologspesialist og en test med spesialpedagog. Opplysningene om deg og din sønn, som navn og fødselsdato vil bli avidentifisert, noe som innebærer at man kun kan finne tilbake til hvem opplysningene gjelder ved hjelp av en kode. Det er bare autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg og din sønn. Opplysningene om deg og din sønn kan ikke spores tilbake til dere når studien er ferdig.

Den informasjonen du og din sønn kan gi er svært verdifull. Den kan blant annet bidra til at tilbudet som gis til små barn med autisme blir bedre.

Effekten av tidlig og systematisk opplæring for barn med autisme er godt dokumentert gjennom flere studier både nasjonalt og internasjonalt. Om resultatene vises også i voksne alder, gjenstår det å fremskaffe mer kunnskap om.

Hensikten med studien er å gjøre kunnskapen fra studien kjent for andre som er tilknyttet opplæring og omsorg for personer med autisme. Dette gjøres ved å publisere en forskningsrapport med en statistisk analyse av resultatene fra testene i et internasjonalt tidsskrift.

Hva innebærer studien?

Vi ønsker nå å gjennomføre et forskningsprosjekt for å finne ut hvordan det går med voksne personer som mottok systematisk opplæring, enten atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller tidlig grunnskole, og om det er forskjeller mellom de to gruppene ut i fra hvilken type opplæring de fikk.

Hvis du og din sønn velger å delta i studien vil dette innebære to dager med tester, en test pr. dag gjennomført av psykologspesialist og spesialpedagog, samt utfylling av et spørreskjema for din sønn. For deg som foresatt vil det innebære å gjennomføre et intervju, Vineland Adaptive Behavior Scales—Second Edition. Testingen vil foregå hjemme hos din sønn.

Høgskolen i Oslo og Akershus og Glenne regionale senter for autisme vil stå for testingen. Testene vil kartlegge kognitive ferdigheter (IQ), og tilpasningsferdigheter, som for eksempel sosiale ferdigheter og selvhjelpsferdigheter. Det vil også gjøres en ny diagnostisk vurdering knyttet til autismeproblematikk. De testene som blir benyttet er vanlig å bruke til utredning av personer med autisme og er standardiserte

psykologiske/pedagogiske tester. Testene heter ADOS (Autism Diagnostic Observation Schedule), WAIS III (Wechsler Adult Intelligence Scale), og Vineland Adaptive Behavior Scales—Second Edition. Testene innebærer at din sønn og en annen person som er psykolog, sitter ved et bord og snakker sammen. Han må også svare på spørsmål og løse oppgaver sammen med denne personen. Spørreskjemaet kan han fylle ut selv, få hjelp til å fylle ut av noen han kjenner godt, eller at noen som han kjenner godt kan fylle ut for ham. Det tar om lag 2 timer å gjennomføre ADOS, 2 - 3 timer å gjennomføre WAIS III. Du som foresatt vil måtte beregne 1 – 2 timer til å gjennomføre Vinelandintervjuet. Din sønn må altså påregne å bruke 2 – 3 timer den ene dagen og 3 – 4 timer den andre dagen de dagene testingen skal skje.

Resultatene av testene gis til din sønn i en samtale med psykolog, hvis han vil. Han kan også få resultatene skriftlig når studien er ferdig.

Din sønn eller personer som kjenner han godt kan få en veiledningssesjon av psykolog når han har fått resultatene. Veiledningen vil ta utgangspunkt i resultatene, og vil innebære forslag til ferdigheter han kan trene på eller hvordan det kan tilpasses bedre rundt han i hverdagen. Dette inngår ikke som ledd i prosjektet, men er et tilbud til han. Han har anledning til å avslå dette tilbudet dersom dette ikke ansees som nødvendig.

Som takk for deres bidrag og at dere setter av tid til denne undersøkelsen, kan din sønn velge mellom en økonomisk kompensasjon på kr. 300, gavekort på et kjøpesenter pålydende kr. 300 eller kinobilletter for en 3D-film for to personer.

Mulige fordeler og ulemper ved å delta

Mulige fordeler ved å delta i studien kan være at du og din sønn får mulighet til å bidra til at det fremkommer mer kunnskap knyttet til opplæring av barn med autisme. Din sønn vil videre få resultater av tre tester, noe som kan være verdifull informasjon for han og eventuelt hans nærmeste. Dessuten vil resultatene danne grunnlaget for veiledningen han tilbys med en psykolog.

Mulige ulemper kan være at du og din sønn må avsette tid til gjennomføring av testene.

Hva skjer med testene og informasjonen om deg?

Testene som blir tatt og all informasjonen som registreres om din sønn skal brukes kun slik som beskrevet i hensikten med studien.

Alle opplysningene og testene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter din sønn til hans opplysninger og tester gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til han.

Det vil ikke være mulig å identifisere han i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Din sønn kan når som helst og uten å oppgi noen grunn trekke sitt samtykke til å delta i studien, men senest innen 01.10.2014. Dersom din sønn ønsker å delta og du som foresatt ønsker å bidra ved å delta i intervju, undertegner du samtykkeerklæringen på siste side og sender denne tilbake til oss i den ferdigfrankerte konvolutten som medfølger. Om dere nå sier ja til å delta, kan dere senere trekke tilbake samtykket uten at det påvirker din sønns øvrige behandling.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte prosjektansvarlig Svein Eikeseth på 922 10 988 (svein.eikeseth@hioa.no).

Ytterligere informasjon om studien finnes i kapittel *A* – *utdypende forklaring av hva studien innebærer.*

Ytterligere informasjon om personvern og forsikring finnes i kapittel B – *Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltagelse er:

- Deltakeren mottok systematisk opplæring, atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller i tidlig grunnskole med bakgrunn i en autismeproblematikk.
- Denne opplæringen fant sted for om lag 15 - 20 år siden.

Tidsskjema:

- Etter at du og din sønn har meldt deres interesse for deltagelse vil din sønn bli innkalt til testing og utredning, og han vil samtidig bli bedt om å fylle ut et spørreskjema. Du som foresatt vi bli innkalt til intervju.
- Testing og utredning gjennomføres i løpet av inntil 5 timer hjemme hos din sønn.
- Testing er planlagt gjennomført vinteren 2013 / 2014.
- Din sønn vil få invitasjon til samtale om testresultatene i etterkant, samt tilbys en veiledningssesjon med psykolog.

Kapittel B - Personvern

Personvern
Opplysninger som registreres om deg og din sønn er testprotokoller (kognitive ferdigheter, tilpasningsferdigheter og diagnose). Disse testprotokollene vil ikke inneholde opplysninger som kan identifisere dere (dvs. de vil ikke inneholde navn eller fødselsnummer). Testprotokollene vil identifiseres kun ved et identifikasjonsnummer.

I tillegg vil det foreligge en liste som har både personopplysninger og identifikasjonsnummer. Denne listen vil oppbevares separat fra testene og vil kun være tilgjengelig for autorisert personell.

Rett til innsyn og sletting av opplysninger om deg og sletting av tester
Hvis du og din sønn sier ja til å delta i studien, har dere rett til å få innsyn i hvilke opplysninger som er registrert om dere. Dere har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du eller din sønn trekker dere fra studien, kan dere kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi:
Studien er finansiert gjennom forskningsmidler fra Regionalt fagmiljø for autisme, ADHD, Tourettes syndrom og narkolepsi Helse Sør-Øst

Informasjon om utfallet av studien
Etter prosjektets slutt vil alle deltagere bli invitert til en oppsummerende presentasjon av resultatene.

Samtykke til deltakelse i studien

Jeg, foresatt til ____________________________________, er villig til å delta i studien

\---
(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien (fylles ut på testdagen)

\---
(Signert, rolle i studien, dato)

Forespørsel om deltakelse i forskningsprosjektet

«Undersøkelse av voksne personer som fikk diagnosen autisme som barn og mottok systematisk opplæring»

Bakgrunn og hensikt

Da din datter var mindre fikk hun systematisk atferdsanalytisk opplæring i barnehagen og på skolen. Vi ønsker å finne ut hvordan det går med henne, nå når hun har blitt voksen.

Dette er en forespørsel til deg som foresatte om å delta i en forskningsstudie, sammen med din datter, for å undersøke utfallet av opplæringen hun mottok i barnehagen og tidlig grunnskole. Studien vil undersøke to grupper av personer som fikk diagnosen autisme som barn, hvor den ene gruppen fikk systematisk atferdsanalytisk opplæring og den andre fikk systematisk spesialpedagogisk opplæring. Vi ønsker å undersøke ved å sammenligne resultatene fra de to gruppene, om det er forskjell på hvordan det har gått med dem etter at de ble voksne ut i fra hvilken type opplæring de fikk. For å finne ut om det er forskjell mellom og innenfor gruppene, trenger vi at du gjennomfører et intervju sammen med en testperson som er spesialpedagog. Din datter får også denne forespørselen og hun vil bli spurt om å gjennomføre en test med psykologspesialist og en test med spesialpedagog. Opplysningene om deg og din datter, som navn og fødselsdato vil bli avidentifisert, noe som innebærer at man kun kan finne tilbake til hvem opplysningene gjelder ved hjelp av en kode. Det er bare autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg og din datter. Opplysningene om deg og din datter kan ikke spores tilbake til dere når studien er ferdig.

Den informasjonen du og din datter kan gi er svært verdifull. Den kan blant annet bidra til at tilbudet som gis til små barn med autisme blir bedre.

Effekten av tidlig og systematisk opplæring for barn med autisme er godt dokumentert gjennom flere studier både nasjonalt og internasjonalt. Om resultatene vises også i voksne alder, gjenstår det å fremskaffe mer kunnskap om.

Hensikten med studien er å gjøre kunnskapen fra studien kjent for andre som er tilknyttet opplæring og omsorg for personer med autisme. Dette gjøres ved å publisere en forskningsrapport med en statistisk analyse av resultatene fra testene i et internasjonalt tidsskrift.

Hva innebærer studien?

Vi ønsker nå å gjennomføre et forskningsprosjekt for å finne ut hvordan det går med voksne personer som mottok systematisk opplæring, enten atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller tidlig grunnskole, og om det er forskjeller mellom de to gruppene ut i fra hvilken type opplæring de fikk.

Hvis du og din datter velger å delta i studien vil dette innebære to dager med tester, en test pr. dag gjennomført av psykologspesialist og spesialpedagog, samt utfylling av et spørreskjema for din datter. For deg som foresatt vil det innebære å gjennomføre et intervju, Vineland Adaptive Behavior Scales—Second Edition. Testingen vil foregå hjemme hos din datter.

Høgskolen i Oslo og Akershus og Glenne regionale senter for autisme vil stå for testingen. Testene vil kartlegge kognitive ferdigheter (IQ), og tilpasningsferdigheter, som for eksempel sosiale ferdigheter og selvhjelpsferdigheter. Det vil også gjøres en ny diagnostisk vurdering knyttet til autismeproblematikk. De testene som blir benyttet er vanlig å bruke til utredning av personer med autisme og er standardiserte

psykologiske/pedagogiske tester. Testene heter ADOS (Autism Diagnostic Observation Schedule), WAIS III (Wechsler Adult Intelligence Scale), og Vineland Adaptive Behavior Scales—Second Edition. Testene innebærer at din datter og en annen person som er psykolog, sitter ved et bord og snakker sammen. Hun må også svare på spørsmål og løse oppgaver sammen med denne personen. Spørreskjemaet kan hun fylle ut selv, få hjelp til å fylle ut av noen hun kjenner godt, eller at noen som hun kjenner godt kan fylle ut for henne. Det tar om lag 2 timer å gjennomføre ADOS, 2 - 3 timer å gjennomføre WAIS III. Du som foresatt vil måtte beregne 1 – 2 timer til å gjennomføre Vinelandintervjuet. Din datter må altså påregne å bruke 2 – 3 timer den ene dagen og 3 – 4 timer den andre dagen de dagene testingen skal skje.

Resultatene av testene gis til din datter i en samtale med psykolog, hvis hun vil. Hun kan også få resultatene skriftlig når studien er ferdig.

Din datter eller personer som kjenner henne godt kan få en veiledningssesjon av psykolog når hun har fått resultatene. Veiledningen vil ta utgangspunkt i resultatene, og vil innebære forslag til ferdigheter hun kan trene på eller hvordan det kan tilpasses bedre rundt henne i hverdagen. Dette inngår ikke som ledd i prosjektet, men er et tilbud til henne. Hun har anledning til å avslå dette tilbudet dersom dette ikke ansees som nødvendig.

Som takk for deres bidrag og at dere setter av tid til denne undersøkelsen, kan din datter velge mellom en økonomisk kompensasjon på kr. 300, gavekort på et kjøpesenter pålydende kr. 300 eller kinobilletter for en 3D-film for to personer.

Mulige fordeler og ulemper ved å delta

Mulige fordeler ved å delta i studien kan være at du og din datter får mulighet til å bidra til at det fremkommer mer kunnskap knyttet til opplæring av barn med autisme. Din datter vil videre få resultater av tre tester, noe som kan være verdifull informasjon for henne og eventuelt hennes nærmeste. Dessuten vil resultatene danne grunnlaget for veiledningen hun tilbys med en psykolog.

Mulige ulemper kan være at du og din datter må avsette tid til gjennomføring av testene**.**

Hva skjer med testene og informasjonen om din datter?

Testene som blir tatt og all informasjonen som registreres om din datter skal brukes kun slik som beskrevet i hensikten med studien.

Alle opplysningene og testene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter din datter til hennes opplysninger og tester gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til henne.

Det vil ikke være mulig å identifisere henne i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Din datter kan når som helst og uten å oppgi noen grunn trekke sitt samtykke til å delta i studien, men senest innen 01.10.2014. Dersom din datter ønsker å delta og du som foresatt ønsker å bidra ved å delta i intervju, undertegner du samtykkeerklæringen på siste side og sender denne tilbake til oss i den ferdigfrankerte konvolutten som medfølger. Om dere nå sier ja til å delta, kan dere senere trekke tilbake samtykket uten at det påvirker din datters øvrige behandling.

Dersom du eller din datter senere ønsker å trekke dere eller har spørsmål til studien, kan dere kontakte prosjektansvarlig Svein Eikeseth på 922 10 988 (svein.eikeseth@hioa.no).

Ytterligere informasjon om studien finnes i kapittel *A* – *utdypende forklaring av hva studien innebærer.*

Ytterligere informasjon om personvern og forsikring finnes i kapittel B – *Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltagelse er:
- Deltakeren mottok systematisk opplæring, atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller i tidlig grunnskole med bakgrunn i en autismeproblematikk.
- Denne opplæringen fant sted for om lag 15 - 20 år siden.

Tidsskjema:
- Etter at du og din datter har meldt deres interesse for deltagelse vil din datter bli innkalt til testing og utredning, og hun vil samtidig bli bedt om å fylle ut et spørreskjema. Du som foresatt vi bli innkalt til intervju.
- Testing og utredning gjennomføres i løpet av inntil 5 timer hjemme hos din datter.
- Testing er planlagt gjennomført vinteren 2013 / 2014.
- Din datter vil få invitasjon til samtale om testresultatene i etterkant, samt tilbys en veiledningssesjon med psykolog.

Kapittel B - Personvern

Personvern
Opplysninger som registreres om deg og din datter er testprotokoller (kognitive ferdigheter, tilpasningsferdigheter og diagnose). Disse testprotokollene vil ikke inneholde opplysninger som kan identifisere dere (dvs. de vil ikke inneholde navn eller fødselsnummer). Testprotokollene vil identifiseres kun ved et identifikasjonsnummer.

I tillegg vil det foreligge en liste som har både personopplysninger og identifikasjonsnummer. Denne listen vil oppbevares separat fra testene og vil kun være tilgjengelig for autorisert personell.

Rett til innsyn og sletting av opplysninger om deg og sletting av tester
Hvis du og din datter sier ja til å delta i studien, har dere rett til å få innsyn i hvilke opplysninger som er registrert om dere. Dere har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du eller din datter trekker dere fra studien, kan dere kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi:
Studien er finansiert gjennom forskningsmidler fra Regionalt fagmiljø for autisme, ADHD, Tourettes syndrom og narkolepsi Helse Sør-Øst

Informasjon om utfallet av studien
Etter prosjektets slutt vil alle deltagere bli invitert til en oppsummerende presentasjon av resultatene.

Samtykke til deltakelse i studien

Jeg, foresatt til ____________________________________, er villig til å delta i studien

----
(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien (fylles ut på testdagen)

(Signert, rolle i studien, dato)

Forespørsel om deltakelse i forskningsprosjektet

«Undersøkelse av voksne personer som fikk diagnosen autisme som barn og mottok systematisk opplæring»

Bakgrunn og hensikt

Da du var mindre fikk du systematisk spesialpedagogisk opplæring i barnehagen og på skolen. Vi ønsker å finne ut hvordan det går med deg, nå når du har blitt voksen.

Dette er en forespørsel til deg om å delta i en forskningsstudie for å undersøke utfallet av opplæringen du mottok i barnehagen og tidlig grunnskole. Studien vil undersøke to grupper av personer som fikk diagnosen autisme som barn, hvor den ene gruppen fikk systematisk atferdsanalytisk opplæring og den andre fikk systematisk spesialpedagogisk opplæring. Vi ønsker å undersøke ved å sammenligne resultatene fra de to gruppene, om det er forskjell på hvordan det har gått med dere etter at dere ble voksne ut i fra hvilken type opplæring dere fikk. For å finne ut om det er forskjell mellom og innenfor gruppene, trenger vi at du gjennomfører to tester sammen med en psykolog og spesialpedagog, samt at du fyller ut et spørreskjema. Dine foresatte mottar forespørsel fra oss om å delta i samme studie hvor de blir bedt om å bidra ved å gjennomføre et intervju. Opplysningene om deg som navn og fødselsdato vil bli avidentifisert, som innebærer at man kun kan finne tilbake til hvem opplysningene gjelder ved hjelp av en kode. Det er bare autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Opplysningene om deg kan ikke spores tilbake til deg når studien er ferdig.

Den informasjonen du kan gi er svært verdifull. Den kan blant annet bidra til at tilbudet som gis til små barn med autisme blir bedre.

Effekten av tidlig og systematisk opplæring for barn med autisme er godt dokumentert gjennom flere studier både nasjonalt og internasjonalt. Om resultatene vises også i voksne alder, gjenstår det å fremskaffe mer kunnskap om.

Hensikten med studien er å gjøre kunnskapen fra studien kjent for andre som er tilknyttet opplæring og omsorg for personer med autisme. Dette gjøres ved å publisere en forskningsrapport med en statistisk analyse av resultatene fra testene i et internasjonalt tidsskrift.

Hva innebærer studien?

Vi ønsker nå å gjennomføre et forskningsprosjekt for å finne ut hvordan det går med voksne personer som mottok systematisk opplæring, enten atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller tidlig grunnskole, og om det er forskjeller mellom de to gruppene ut i fra hvilken type opplæring de fikk.

Hvis du velger å delta i studien vil dette innebære to dager med tester, en test pr. dag gjennomført av psykologspesialist og spesialpedagog, samt utfylling av et spørreskjema. Dine foresatte eller nærmeste pårørende vil bli forespurt om å gjennomføre et intervju, Vineland Adaptive Behavior Scales—Second Edition. Testingen vil foregå hjemme hos deg.

Høgskolen i Oslo og Akershus og Glenne regionale senter for autisme vil stå for testingen. Testene vil kartlegge kognitive ferdigheter (IQ), og tilpasningsferdigheter, som for eksempel sosiale ferdigheter og selvhjelpsferdigheter. Det vil også gjøres en ny diagnostisk vurdering knyttet til autismeproblematikk. De testene som blir benyttet er vanlig å bruke til utredning av personer med autisme og er standardiserte psykologiske/pedagogiske tester. Testene heter ADOS (Autism Diagnostic Observation Schedule), WAIS III (Wechsler Adult Intelligence Scale), og Vineland Adaptive Behavior Scales—Second Edition. Testene innebærer at du og en annen person som er psykolog, sitter ved et bord og snakker sammen. Du må også svare på spørsmål og løse oppgaver sammen med denne personen. Spørreskjemaet kan du fylle ut selv, få hjelp til å fylle ut av noen du kjenner godt, eller at noen som du kjenner godt kan fylle ut for deg. Det tar om lag 2 timer å gjennomføre ADOS, 2 - 3 timer å gjennomføre WAIS III. Dine foresatte eller nærmeste pårørende vil måtte beregne 1 – 2 timer til å gjennomføre Vinelandintervjuet. Du må altså páregne å bruke 2 – 3 timer den ene dagen og 3 – 4 timer den andre dagen de dagene testingen skal skje.

Resultatene av testene gis til deg i en samtale med psykolog, hvis du vil. Du kan også få resultatene skriftlig når studien er ferdig.

Du eller personer som kjenner deg godt kan få en veiledningssesjon av psykolog når du har fått resultatene. Veiledningen vil ta utgangspunkt i resultatene, og vil innebære forslag til ferdigheter du kan trene på eller hvordan det kan tilpasses bedre rundt deg i hverdagen. Dette inngår ikke som ledd i prosjektet, men er et tilbud til deg. Du har anledning til å avslå dette tilbudet dersom du ikke synes det er nødvendig.

Som takk for ditt bidrag og at du setter av tid til denne undersøkelsen, kan du velge mellom en økonomisk kompensasjon på kr. 300, gavekort på et kjøpesenter pålydende kr. 300 eller kinobilletter til en 3D-film for to personer.

Mulige fordeler og ulemper ved å delta

Mulige fordeler ved å delta i studien kan være at du får mulighet til å bidra til at det fremkommer mer kunnskap knyttet til opplæring av barn med autisme. Du vil videre få resultater av tre tester, noe som kan være verdifull informasjon for deg og eventuelt dine nærmeste. Dessuten vil resultatene danne grunnlaget for veiledningen du tilbys med en psykolog.

Mulige ulemper kan være at du må avsette tid til gjennomføring av testene**.**

Hva skjer med testene og informasjonen om deg?

Testene som blir tatt og all informasjonen som registreres om deg skal brukes kun slik som beskrevet i hensikten med studien.

Alle opplysningene og testene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger og tester gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg.

Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien, men senest innen 01.10.2014. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side og sender denne tilbake til oss i den ferdigfrankerte konvolutten som medfølger. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte prosjektansvarlig Svein Eikeseth på 922 10 988 (svein.eikeseth@hioa.no).

Ytterligere informasjon om studien finnes i kapittel ***A*** *– utdypende forklaring av hva studien innebærer.*

Ytterligere informasjon om personvern og forsikring finnes i kapittel B – *Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltagelse er:

- Deltakeren mottok systematisk opplæring, atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller i tidlig grunnskole med bakgrunn i en autismeproblematikk.
- Denne opplæringen fant sted for om lag 15 - 20 år siden.

Tidsskjema:

- Etter at du har meldt din interesse for deltagelse vil du bli innkalt til testing og utredning, og du vil samtidig bli bedt om å fylle ut et spørreskjema.
- Testing og utredning gjennomføres i løpet av ca. 5 timer hjemme hos deg.
- Testing er planlagt gjennomført vinteren 2013 / 2014.
- Du vil få invitasjon til samtale om testresultatene i etterkant, samt tilbys en veiledningssesjon med psykolog.

Kapittel B - Personvern

Personvern

Opplysninger som registreres om deg er testprotokoller (kognitive ferdigheter, tilpasningsferdigheter og diagnose). Disse testprotokollene vil ikke inneholde opplysninger som kan identifisere deg (dvs. de vil ikke inneholde navn eller fødselsnummer). Testprotokollene vil identifiseres kun ved et identifikasjonsnummer.

I tillegg vil det foreligge en liste som har både personopplysninger og identifikasjonsnummer. Denne listen vil oppbevares separat fra testene og vil kun være tilgjengelig for autorisert personell.

Rett til innsyn og sletting av opplysninger om deg og sletting av tester

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi:

Studien er finansiert gjennom forskningsmidler fra Regionalt fagmiljø for autisme, ADHD, Tourettes syndrom og narkolepsi Helse Sør-Øst.

Informasjon om utfallet av studien

Etter prosjektets slutt vil alle deltagere bli invitert til en oppsummerende presentasjon av resultatene.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien (fylles ut på testdagen)

(Signert, rolle i studien, dato)

Forespørsel om deltakelse i forskningsprosjektet

«Undersøkelse av voksne personer som fikk diagnosen autisme som barn og mottok systematisk opplæring»

Bakgrunn og hensikt
Da din sønn var mindre fikk han systematisk spesialpedagogisk opplæring i barnehagen og på skolen. Vi ønsker å finne ut hvordan det går med han, nå når han har blitt voksen.

Dette er en forespørsel til deg som foresatte om å delta i en forskningsstudie, sammen med din sønn, for å undersøke utfallet av opplæringen han mottok i barnehagen og tidlig grunnskole. Studien vil undersøke to grupper av personer som fikk diagnosen autisme som barn, hvor den ene gruppen fikk systematisk atferdsanalytisk opplæring og den andre fikk systematisk spesialpedagogisk opplæring. Vi ønsker å undersøke ved å sammenligne resultatene fra de to gruppene, om det er forskjell på hvordan det har gått med dem etter at de ble voksne ut i fra hvilken type opplæring de fikk. For å finne ut om det er forskjell mellom og innenfor gruppene, trenger vi at du gjennomfører et intervju sammen med en testperson som er spesialpedagog. Din sønn får også denne forespørselen og han vil bli spurt om å gjennomføre en test med psykologspesialist og en test med spesialpedagog. Opplysningene om deg og din sønn, som navn og fødselsdato vil bli avidentifisert, noe som innebærer at man kun kan finne tilbake til hvem opplysningene gjelder ved hjelp av en kode. Det er bare autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg og din sønn. Opplysningene om deg og din sønn kan ikke spores tilbake til dere når studien er ferdig.

Den informasjonen du og din sønn kan gi er svært verdifull. Den kan blant annet bidra til at tilbudet som gis til små barn med autisme blir bedre.

Effekten av tidlig og systematisk opplæring for barn med autisme er godt dokumentert gjennom flere studier både nasjonalt og internasjonalt. Om resultatene vises også i voksne alder, gjenstår det å fremskaffe mer kunnskap om.

Hensikten med studien er å gjøre kunnskapen fra studien kjent for andre som er tilknyttet opplæring og omsorg for personer med autisme. Dette gjøres ved å publisere en forskningsrapport med en statistisk analyse av resultatene fra testene i et internasjonalt tidsskrift.

Hva innebærer studien?
Vi ønsker nå å gjennomføre et forskningsprosjekt for å finne ut hvordan det går med voksne personer som mottok systematisk opplæring, enten atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller tidlig grunnskole, og om det er forskjeller mellom de to gruppene ut i fra hvilken type opplæring de fikk.

Hvis du og din sønn velger å delta i studien vil dette innebære to dager med tester, en test pr. dag gjennomført av psykologspesialist og spesialpedagog, samt utfylling av et spørreskjema for din sønn. For deg som foresatt vil det innebære å gjennomføre et intervju, Vineland Adaptive Behavior Scales—Second Edition. Testingen vil foregå hjemme hos din sønn.

Høgskolen i Oslo og Akershus og Glenne regionale senter for autisme vil stå for testingen. Testene vil kartlegge kognitive ferdigheter (IQ), og tilpasningsferdigheter, som for eksempel sosiale ferdigheter og selvhjelpsferdigheter. Det vil også gjøres en ny diagnostisk vurdering knyttet til autismeproblematikk. De testene som blir benyttet er vanlig å bruke til utredning av personer med autisme og er standardiserte

psykologiske/pedagogiske tester. Testene heter ADOS (Autism Diagnostic Observation Schedule), WAIS III (Wechsler Adult Intelligence Scale), og Vineland Adaptive Behavior Scales—Second Edition. Testene innebærer at din sønn og en annen person som er psykolog, sitter ved et bord og snakker sammen. Han må også svare på spørsmål og løse oppgaver sammen med denne personen. Spørreskjemaet kan han fylle ut selv, få hjelp til å fylle ut av noen han kjenner godt, eller at noen som han kjenner godt kan fylle ut for ham. Det tar om lag 2 timer å gjennomføre ADOS, 2 - 3 timer å gjennomføre WAIS III. Du som foresatt vil måtte beregne 1 – 2 timer til å gjennomføre Vinelandintervjuet. Din sønn må altså påregne å bruke 2 – 3 timer den ene dagen og 3 – 4 timer den andre dagen de dagene testingen skal skje.

Resultatene av testene gis til din sønn i en samtale med psykolog, hvis han vil. Han kan også få resultatene skriftlig når studien er ferdig.

Din sønn eller personer som kjenner han godt kan få en veiledningssesjon av psykolog når han har fått resultatene. Veiledningen vil ta utgangspunkt i resultatene, og vil innebære forslag til ferdigheter han kan trene på eller hvordan det kan tilpasses bedre rundt han i hverdagen. Dette inngår ikke som ledd i prosjektet, men er et tilbud til han. Han har anledning til å avslå dette tilbudet dersom dette ikke ansees som nødvendig.

Som takk for deres bidrag og at dere setter av tid til denne undersøkelsen, kan din sønn velge mellom en økonomisk kompensasjon på kr. 300, gavekort på et kjøpesenter pålydende kr. 300 eller kinobilletter for en 3D-film for to personer.

Mulige fordeler og ulemper ved å delta

Mulige fordeler ved å delta i studien kan være at du og din sønn får mulighet til å bidra til at det fremkommer mer kunnskap knyttet til opplæring av barn med autisme. Din sønn vil videre få resultater av tre tester, noe som kan være verdifull informasjon for han og eventuelt hans nærmeste. Dessuten vil resultatene danne grunnlaget for veiledningen han tilbys med en psykolog.

Mulige ulemper kan være at du og din sønn må avsette tid til gjennomføring av testene**.**

Hva skjer med testene og informasjonen om deg?

Testene som blir tatt og all informasjonen som registreres om din sønn skal brukes kun slik som beskrevet i hensikten med studien.

Alle opplysningene og testene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter din sønn til hans opplysninger og tester gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til han.

Det vil ikke være mulig å identifisere han i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Din sønn kan når som helst og uten å oppgi noen grunn trekke sitt samtykke til å delta i studien, men senest innen 01.10.2014. Dersom din sønn ønsker å delta og du som foresatt ønsker å bidra ved å delta i intervju, undertegner du samtykkeerklæringen på siste side og sender denne tilbake til oss i den ferdigfrankerte konvolutten som medfølger. Om dere nå sier ja til å delta, kan dere senere trekke tilbake samtykket uten at det påvirker din sønns øvrige behandling.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte prosjektansvarlig Svein Eikeseth på 922 10 988 (svein.eikeseth@hioa.no).

Ytterligere informasjon om studien finnes i kapittel ***A*** – *utdypende forklaring av hva studien innebærer.*

Ytterligere informasjon om personvern og forsikring finnes i kapittel B – *Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltagelse er:

- Deltakeren mottok systematisk opplæring, atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller i tidlig grunnskole med bakgrunn i en autismeproblematikk.
- Denne opplæringen fant sted for om lag 15 - 20 år siden.

Tidsskjema:

- Etter at du og din sønn har meldt deres interesse for deltagelse vil din sønn bli innkalt til testing og utredning, og han vil samtidig bli bedt om å fylle ut et spørreskjema. Du som foresatt vi bli innkalt til intervju.
- Testing og utredning gjennomføres i løpet av inntil 5 timer hjemme hos din sønn.
- Testing er planlagt gjennomført vinteren 2013 / 2014.
- Din sønn vil få invitasjon til samtale om testresultatene i etterkant, samt tilbys en veiledningssesjon med psykolog.

Kapittel B - Personvern

Personvern

Opplysninger som registreres om deg og din sønn er testprotokoller (kognitive ferdigheter, tilpasningsferdigheter og diagnose). Disse testprotokollene vil ikke inneholde opplysninger som kan identifisere dere (dvs. de vil ikke inneholde navn eller fødselsnummer). Testprotokollene vil identifiseres kun ved et identifikasjonsnummer.

I tillegg vil det foreligge en liste som har både personopplysninger og identifikasjonsnummer. Denne listen vil oppbevares separat fra testene og vil kun være tilgjengelig for autorisert personell.

Rett til innsyn og sletting av opplysninger om deg og sletting av tester

Hvis du og din sønn sier ja til å delta i studien, har dere rett til å få innsyn i hvilke opplysninger som er registrert om dere. Dere har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du eller din sønn trekker dere fra studien, kan dere kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi:

Studien er finansiert gjennom forskningsmidler fra Regionalt fagmiljø for autisme, ADHD, Tourettes syndrom og narkolepsi Helse Sør-Øst

Informasjon om utfallet av studien

Etter prosjektets slutt vil alle deltagere bli invitert til en oppsummerende presentasjon av resultatene.

Samtykke til deltakelse i studien

Jeg, foresatt til ____________________________________, er villig til å delta i studien

----
(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien (fylles ut på testdagen)

(Signert, rolle i studien, dato)

Forespørsel om deltakelse i forskningsprosjektet

«Undersøkelse av voksne personer som fikk diagnosen autisme som barn og mottok systematisk opplæring»

Bakgrunn og hensikt
Da din datter var mindre fikk hun systematisk spesialpedagogisk opplæring i barnehagen og på skolen. Vi ønsker å finne ut hvordan det går med henne, nå når hun har blitt voksen.

Dette er en forespørsel til deg som foresatte om å delta i en forskningsstudie, sammen med din datter, for å undersøke utfallet av opplæringen hun mottok i barnehagen og tidlig grunnskole. Studien vil undersøke to grupper av personer som fikk diagnosen autisme som barn, hvor den ene gruppen fikk systematisk atferdsanalytisk opplæring og den andre fikk systematisk spesialpedagogisk opplæring. Vi ønsker å undersøke ved å sammenligne resultatene fra de to gruppene, om det er forskjell på hvordan det har gått med dem etter at de ble voksne ut i fra hvilken type opplæring de fikk. For å finne ut om det er forskjell mellom og innenfor gruppene, trenger vi at du gjennomfører et intervju sammen med en testperson som er spesialpedagog. Din datter får også denne forespørselen og hun vil bli spurt om å gjennomføre en test med psykologspesialist og en test med spesialpedagog. Opplysningene om deg og din datter, som navn og fødselsdato vil bli avidentifisert, noe som innebærer at man kun kan finne tilbake til hvem opplysningene gjelder ved hjelp av en kode. Det er bare autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg og din datter. Opplysningene om deg og din datter kan ikke spores tilbake til dere når studien er ferdig.

Den informasjonen du og din datter kan gi er svært verdifull. Den kan blant annet bidra til at tilbudet som gis til små barn med autisme blir bedre.

Effekten av tidlig og systematisk opplæring for barn med autisme er godt dokumentert gjennom flere studier både nasjonalt og internasjonalt. Om resultatene vises også i voksne alder, gjenstår det å fremskaffe mer kunnskap om.

Hensikten med studien er å gjøre kunnskapen fra studien kjent for andre som er tilknyttet opplæring og omsorg for personer med autisme. Dette gjøres ved å publisere en forskningsrapport med en statistisk analyse av resultatene fra testene i et internasjonalt tidsskrift.

Hva innebærer studien?
Vi ønsker nå å gjennomføre et forskningsprosjekt for å finne ut hvordan det går med voksne personer som mottok systematisk opplæring, enten atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller tidlig grunnskole, og om det er forskjeller mellom de to gruppene ut i fra hvilken type opplæring de fikk.

Hvis du og din datter velger å delta i studien vil dette innebære to dager med tester, en test pr. dag gjennomført av psykologspesialist og spesialpedagog, samt utfylling av et spørreskjema for din datter. For deg som foresatt vil det innebære å gjennomføre et intervju, Vineland Adaptive Behavior Scales—Second Edition. Testingen vil foregå hjemme hos din datter.

Høgskolen i Oslo og Akershus og Glenne regionale senter for autisme vil stå for testingen. Testene vil kartlegge kognitive ferdigheter (IQ), og tilpasningsferdigheter, som for eksempel sosiale ferdigheter og selvhjelpsferdigheter. Det vil også gjøres en ny diagnostisk vurdering knyttet til autismeproblematikk. De testene som blir benyttet er vanlig å bruke til utredning av personer med autisme og er standardiserte

psykologiske/pedagogiske tester. Testene heter ADOS (Autism Diagnostic Observation Schedule), WAIS III (Wechsler Adult Intelligence Scale), og Vineland Adaptive Behavior Scales—Second Edition. Testene innebærer at din datter og en annen person som er psykolog, sitter ved et bord og snakker sammen. Hun må også svare på spørsmål og løse oppgaver sammen med denne personen. Spørreskjemaet kan hun fylle ut selv, få hjelp til å fylle ut av noen hun kjenner godt, eller at noen som hun kjenner godt kan fylle ut for henne. Det tar om lag 2 timer å gjennomføre ADOS, 2 - 3 timer å gjennomføre WAIS III. Du som foresatt vil måtte beregne 1 – 2 timer til å gjennomføre Vinelandintervjuet. Din datter må altså påregne å bruke 2 – 3 timer den ene dagen og 3 – 4 timer den andre dagen de dagene testingen skal skje.

Resultatene av testene gis til din datter i en samtale med psykolog, hvis hun vil. Hun kan også få resultatene skriftlig når studien er ferdig.

Din datter eller personer som kjenner henne godt kan få en veiledningssesjon av psykolog når hun har fått resultatene. Veiledningen vil ta utgangspunkt i resultatene, og vil innebære forslag til ferdigheter hun kan trene på eller hvordan det kan tilpasses bedre rundt henne i hverdagen. Dette inngår ikke som ledd i prosjektet, men er et tilbud til henne. Hun har anledning til å avslå dette tilbudet dersom dette ikke ansees som nødvendig.

Som takk for deres bidrag og at dere setter av tid til denne undersøkelsen, kan din datter velge mellom en økonomisk kompensasjon på kr. 300, gavekort på et kjøpesenter pålydende kr. 300 eller kinobilletter for en 3D-film for to personer.

Mulige fordeler og ulemper ved å delta

Mulige fordeler ved å delta i studien kan være at du og din datter får mulighet til å bidra til at det fremkommer mer kunnskap knyttet til opplæring av barn med autisme. Din datter vil videre få resultater av tre tester, noe som kan være verdifull informasjon for henne og eventuelt hennes nærmeste. Dessuten vil resultatene danne grunnlaget for veiledningen hun tilbys med en psykolog.

Mulige ulemper kan være at du og din datter må avsette tid til gjennomføring av testene**.**

Hva skjer med testene og informasjonen om din datter?

Testene som blir tatt og all informasjonen som registreres om din datter skal brukes kun slik som beskrevet i hensikten med studien.

Alle opplysningene og testene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter din datter til hennes opplysninger og tester gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til henne.

Det vil ikke være mulig å identifisere henne i resultatene av studien når disse publiseres.

Frivillig deltakelse

Det er frivillig å delta i studien. Din datter kan når som helst og uten å oppgi noen grunn trekke sitt samtykke til å delta i studien, men senest innen 01.10.2014. Dersom din datter ønsker å delta og du som foresatt ønsker å bidra ved å delta i intervju, undertegner du samtykkeerklæringen på siste side og sender denne tilbake til oss i den ferdigfrankerte konvolutten som medfølger. Om dere nå sier ja til å delta, kan dere senere trekke tilbake samtykket uten at det påvirker din datters øvrige behandling.

Dersom du eller din datter senere ønsker å trekke dere eller har spørsmål til studien, kan dere kontakte prosjektansvarlig Svein Eikeseth på 922 10 988 (svein.eikeseth@hioa.no).

Ytterligere informasjon om studien finnes i kapittel ***A*** – *utdypende forklaring av hva studien innebærer.*

Ytterligere informasjon om personvern og forsikring finnes i kapittel B – *Personvern, økonomi og forsikring.*

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltagelse er:

- Deltakeren mottok systematisk opplæring, atferdsanalytisk eller spesialpedagogisk, i barnehagen og / eller i tidlig grunnskole med bakgrunn i en autismeproblematikk.
- Denne opplæringen fant sted for om lag 15 - 20 år siden.

Tidsskjema:

- Etter at du og din datter har meldt deres interesse for deltagelse vil din datter bli innkalt til testing og utredning, og hun vil samtidig bli bedt om å fylle ut et spørreskjema. Du som foresatt vi bli innkalt til intervju.
- Testing og utredning gjennomføres i løpet av inntil 5 timer hjemme hos din datter.
- Testing er planlagt gjennomført vinteren 2013 / 2014.
- Din datter vil få invitasjon til samtale om testresultatene i etterkant, samt tilbys en veiledningssesjon med psykolog.

Kapittel B - Personvern

Personvern
Opplysninger som registreres om deg og din datter er testprotokoller (kognitive ferdigheter, tilpasningsferdigheter og diagnose). Disse testprotokollene vil ikke inneholde opplysninger som kan identifisere dere (dvs. de vil ikke inneholde navn eller fødselsnummer). Testprotokollene vil identifiseres kun ved et identifikasjonsnummer.

I tillegg vil det foreligge en liste som har både personopplysninger og identifikasjonsnummer. Denne listen vil oppbevares separat fra testene og vil kun være tilgjengelig for autorisert personell.

Rett til innsyn og sletting av opplysninger om deg og sletting av tester
Hvis du og din datter sier ja til å delta i studien, har dere rett til å få innsyn i hvilke opplysninger som er registrert om dere. Dere har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du eller din datter trekker dere fra studien, kan dere kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi:
Studien er finansiert gjennom forskningsmidler fra Regionalt fagmiljø for autisme, ADHD, Tourettes syndrom og narkolepsi Helse Sør-Øst

Informasjon om utfallet av studien
Etter prosjektets slutt vil alle deltagere bli invitert til en oppsummerende presentasjon av resultatene.

Samtykke til deltakelse i studien

Jeg, foresatt til ___________________________________, er villig til å delta i studien

----
(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien (fylles ut på testdagen)

(Signert, rolle i studien, dato)

Spørreskjema for innhenting av opplysninger i forbindelse med forskningsprosjektet

”Utfall hos voksne personer med autismespekterforstyrrelser som mottok systematisk opplæring i barnehagen og tidlig grunnskole”.

Navn: ____________________

Alder: ____________________

Utfyllingsdato: ____________________

Instrukser:

Fyll ut opplysningsrubrikkene overfor før du begynner med spørreskjemaet.

Dette spørreskjemaet inneholder 14 spørsmål. Sett kryss i ruten for det utsagnet som passer best i forhold til spørsmålet (du kan sette flere kryss og skrive utfyllende, hvis nødvendig). Der det ikke er avkrysning, skriv kort svaret på spørsmålet i ruten.

1. Hvem fyller ut skjemaet? (skriv i ruten nedenfor)

2. Hvordan bor du? (sett x)

☐	I eget hus
☐	I egen leilighet
☐	Hos foreldre (foresatte)
☐	I kommunal bolig uten bemanning
☐	I kommunal bolig med bemanning. Spesifiser omfanget av bemanningen:
☐	Annet, spesifiser:

3. Hvis du får bistand fra det offentlige hjelpeapparatet, hvilken type bistand får du? (sett x og skriv utfyllende nedenfor)

☐ Miljøterapeutisk bistand ukentlig i hjemmet
☐ Miljøterapeutisk bistand daglig i hjemmet
☐ Heldøgns omsorg
☐ Arbeid med bistand
☐ Dagsenter
☐ Hjemmehjelp
☐ Hjemmesykepleie
☐ Støttekontakt
☐ Brukerstyrt personlig assistent
☐ Økonomi - / gjeldsrådgivning
☐ Annen type rådgivning
☐ Psykolog / psykiater

Eventuelt andre typer bistand, beskriv kort:

4. Er du gift eller er du i et forhold? (sett x)

☐ Ja, jeg er gift
☐ Ja, jeg har samboer
☐ Ja, jeg har kjæreste
☐ Nei

5. Har du barn? (sett x)

☐ Ja
☐ Nei

6. Har du venner / sosial omgangskrets? (sett x)

☐ Ingen venner
☐ En venn
☐ To eller flere venner
☐ Annet, spesifiser:

7. Hvilken type skolegang har du fullført, og var det behov for spesialpedagogiske tiltak? (sett x)

Type skolegang		Spesialpedagogisk bistand		
		I stor grad	I mindre grad	Ingen
☐	Grunnskole – barneskole	☐	☐	☐
☐	Grunnskole - ungdomsskole	☐	☐	☐
☐	Videregående skole – studiespesialisering	☐	☐	☐
☐	Videregående skole – yrkesrettet	☐	☐	☐
☐	Lærlingtid	☐	☐	☐
☐	Folkehøgskole	☐	☐	☐
☐	Voksenopplæring	☐	☐	☐
☐	Høgskole / universitet	☐	☐	☐
☐	Annet, spesifiser:			

8. Hvis du har en utdannelse, hvilken tittel har du? (skriv i ruten nedenfor)

9. Jobber du? (sett x)

☐ Ja
☐ Nei

10. Mottar du trygdeytelser eller annen bistand fra NAV? (sett x og skriv i ruten nedenfor)

☐ Nei
☐ Ja, spesifiser:

11. Hvis du har jobb, hva jobber du som? (skriv i ruten nedenfor)

12. Hvis du har jobb, hva slags arbeidsforhold er du i? (sett x eller skriv i ruten nedenfor)

☐	Selvstendig næringsdrivende
☐	Ansatt / engasjert i privat sektor
☐	Ansatt / engasjert i offentlig sektor
☐	Ansatt / engasjert i privat eller offentlig sektor med bistand
☐	Ansatt i vernet bedrift
☐	Annet, spesifiser:

13. Hvilke(n) diagnose(r) har du nå? (skriv i ruten nedenfor)

14. Har du sertifikat for bil?

☐	Ja
☐	Nei
☐	Er i gang med kjøreundervisning