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Reducing the Impact of Disabilities in Developing Nations: Implications from a Parent Delivered Behavioral Intervention in Macedonia

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Reducing the Impact of Autism in Developing Countries: Implications of a Parent-Delivered Behavioral Intervention in Macedonia

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ABSTRACT

Reducing the Impact of Autism in Developing Countries: Implications of a Parent-Delivered Behavioral Intervention in Macedonia

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Autism spectrum disorder (ASD) is recognized the world over as a major public health issue. Autism is highly prevalent, persists across the lifespan, and is characterized by behaviors that can profoundly impair typical functioning. Interventions based on behavioral strategies have proven effective, but there are significant barriers to care, including cost, intensity of treatment, and access to qualified practitioners. The impact of ASD and obstacles to appropriate care are magnified by systemic limitations in developing countries. Parent training holds promise as a method of disseminating therapy to underserved areas.

This study investigated the effectiveness of a pyramidal parent training intervention in Macedonia. Fifteen parents of children with ASD were trained in three specific strategies for promoting prosocial skills: eye contact, compliance, reducing restricted repetitive behaviors (RRB). Parents reported daily ratings of these skills and their own confidence, action or engagement, and family distress. Participants were ethnic Macedonians from the capital of Skopje with at least one child with ASD between the ages of 2 and 13 years.

This study utilized a single case research design. Data were collected per and post intervention using an interrupted time series design. Individual response was analyzed visually and Tau U effect sizes were calculated. Moderator and mediator effect was considered following the method initially established by Gaynor and Harris (2008). Effect sizes were small but significant for the group overall for all variables except restricted repetitive behaviors (RRB). The program was especially effective for younger children, those with comorbid hyperactivity, those with low to moderate symptomology, and those with no prior special education services.

Keywords: autism spectrum disorder, pervasive developmental disorders, behavior modification, developing nations, interpersonal competence, parent workshops, family environment

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To my family, near and far, thank you for believing in me and bearing with the long hours, random stresses, and general chaos of grad school life. Extra special love and gratitude to my amazing husband, Todd, for coming along at just the right time to serve as sounding board and editor (and for being generally fantastic.) To my darling children, thank you for coming on this journey with me with very little complaining and very much excitement. May we all do a better job of meeting your needs and those of all exceptional children—and may we ever remember that all children are exceptional.

And finally, for my Mum:

Well, I'm very fond of Daddy, but he hasn't time to play,
And I'm very fond of Mummy, but she sometimes goes away,
And I'm often cross with Nanny when she wants to brush my hair…
But Binker's always Binker, and is certain to be there.

A.A. Milne

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DESCRIPTION OF THESIS STRUCTURE

This thesis, *Reducing the Impact of Autism in Developing Countries: Implications of a Parent-delivered Behavioral Intervention in Macedonia*, is written in a hybrid format. The hybrid format combines aspects of thesis and journal publication requirements. The preliminary pages of the thesis reflect requirements for submission to the university. The thesis report is presented as a journal article, and conforms to length and style requirements for submission to education journals. The literature review, including references, is included as Appendix A. Instruments and training protocols are included as Appendices B and C, respectively. Appendix D includes tables reporting participant data.

Introduction

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder characterized by persistent deficits in communication and social interaction (American Psychiatric Association, 2013). Individuals with ASD often exhibit problematic behaviors associated with lack of emotional regulation, distractibility, and irregular activity and thought patterns (Lainhart, 1999; Leyfer et al., 2006). These antisocial and disruptive behaviors often result in substantial impairment for both the individual and their family (Kheir et al., 2012).

The World Health Organization (2017) reported the global prevalence of ASD is 1 in 160 children. The disorder is viewed as a substantial public health issue due to the level of impairment and its persistence across the lifespan (Leyfer et al., 2006; Simonoff et al., 2008). Financial and human costs associated with ASD include cost of treatment, non medical costs such as respite care and accomodations at home and school, and indirect costs in terms of loss of human potential and productivity of both the individual and their caregivers (Ganz & Ganz, 2007). Families of individuals with ASD face costs such as loss of time for career and leisure opportunities, loss of income due to caregiving responsibilities, and out of pocket expenses for care and intervention (Jarbrink, Fambonne, & Knapp, 2003; Rosano, Mancini, Solipaca, & Solipaca, 2009).

A number of factors complicate the treatment of individuals with ASD. One such factor is the prevalence of comorbid disorders, most notably Attention Deficit/Hyperactivity Disorder (ADHD). A recent study found that 59% of children with ASD also had a diagnosis of ADHD (Stevens, Peng, Barnard-Brak, & Barnard Brak, 2016). Another factor is the need to provide these individuals with costly social services, including education, employment, medical care, and

support services. In the United States, total societal cost of care for individuals with ASD is estimated to be between $268 billion USD (Leigh & Du, 2015).

Individuals with comorbid ASD and ADHD can display a nexus of additional symptoms that further impact quality of life and complicate intervention (Stevens et al., 2016). These can include distractibility, forgetfulness, over-activity, impulsivity, inability to inhibit unwanted behavior, deficits in working memory, difficulty activating and maintaining attention, lack of motivation and persistence, inability to organize or prioritize, and executive function deficits (American Psychiatric Association, 2013; Greenbaum & Markel, 2001; Stahr, Cushing, Lane, & Fox, 2006; Storer, Evans, & Langberg, 2014).

Individuals with ASD face significant challenges which impact both their own quality of life and that of their families. This impact is amplified in developing countries, where issues associated with less infrastructure, weaker economies, and less advanced health care systems present additional challenges that negatively impact access to treatment.

The Former Yugoslav Republic of Macedonia, a country in southeast Europe the size of the U.S. state of Vermont, is typical of developing nations. Unemployment is high at 27% and more than 30% of the population lives below the poverty line (State Statistical Office, 2017). The already struggling economy has been further strained in recent years by the arrival of large numbers refugees from the Middle East, totaling more than 750,000 in 2015 alone ("Migrant crisis: Migration to Europe explained in seven charts - BBC News," 2016). Macedonia reports a significantly higher rate of disability than developed countries. Although the educational system is extensive, with free public education provided for 13 years, data suggest children with significant disabilities are underserved. Only 10.7% of children have access to early childhood education, there are no schools specifically dedicated to educating children with ASD, and just

1% of Macedonian children receive special education (Gottleib, Maenner, Cappa, & Durkin, 2008). As of 2016, there was a significant lack of psychologists and education specialists; only 21% of Macedonian children with ASD were receiving behavioral therapy, and 12% were receiving no treatment of any kind (Salomone et al., 2016). These statistics place Macedonia in the bottom third of European countries in access to treatment, lagging significantly behind other East European nations (Salomone et al., 2016).

Families in developing nations thus face a difficult set of circumstances. They and their children with ASD face serious impacts to quality of life, while access to treatment is hampered by a number of factors. Noting the effect of these obstacles to care, researchers considered if non-clinicians could be trained to adequately administer therapeutic interventions in their homes, providing effective treatment at essentially no cost and immune to infrastructure limitations. Studies show that non-professionals, including parents, can be as successful in conducting interventions as practitioners if provided adequate training and support (Koegel, Bimbela, Schreibman, & Schreibman, 1996; Suppo & Floyd, 2012; Suppo & Mayton, 2014).

The Republic of Macedonia (Macedonia), a country in southeast Europe, reflects these characteristics of developing countries. As such, life in Macedonia presents specific challenges for people living with ASD. Macedonia reports a significantly higher rate of disability than developed countries, but access to treatment is severely limited, as noted previously. These statistics place Macedonia in the bottom third of European countries in access to treatment, lagging significantly behind even other East European nations (Salomone et al., 2016). These characteristics qualify Macedonia as a location for investigating the efficacy of pyramidal parent training in ABA techniques in developing countries.

Pyramidal parent training is an effective method of providing training (Hansen et al., 2017; Kuhn, Lerman, Vorndran, & Vorndran, 2003; Neef, 1995). This model involves parents with knowledge of a therapeutic approach training other parents, who then go on to train other parents. Pyramidal parent training is an economical way to provide treatment to underserved populations (Kuhn et al., 2003; Loughrey et al., 2014; Neef, 1995; Symon & Symon, 2005).

Applied Behavioral Analysis (ABA) is an effective therapy for individuals with ASD. ABA has been recommended by the U.S. Surgeon General, the National Academy of Sciences, and the American Academy of Pediatrics (Granpeesheh, Tarbox, & Dixon, 2009). ABA uses the principles of behavioral science to design interventions to supplant problem behaviors with more acceptable ones (Cooper, Heward, William, & Cooper, 2007; Granpeesheh et al., 2009).

Efficacy of ABA treatment appears to be related to early intervention, high intensity, and broad scope. Intervention is most effective when implemented in early childhood, when the scope of the training involves all problem behaviors rather than focusing on only one, and when training is intense or 40 hours per week (Granpeesheh, et al., 2009).

Given the impact of ASD and obstacles to care within developing countries, development of effective, low cost interventions that can be made available to currently underserved populations should be a priority. ABA interventions are accepted as effective, and pyramidal parent training has proven successful at providing parents with training necessary to implement behavioral interventions. This study investigated the effects of an ABA-based, parent-delivered intervention on symptom expression in children and behavior of their parents.

Statement of the Problem

Autism is a widely prevalent disorder that affects at least 80 million people around the world. It impairs typical function in the individual, negatively impacting educational, social,

emotional, and career activities across the lifespan. Symptoms are destructive to all family members' quality of life. There are effective techniques for reduction of problematic symptoms and improvement of quality of life for individuals and their families, and yet a majority of individuals with ASD are not benefitting from these interventions. Particularly in developing countries, issues of access, cost, infrastructure limitations, lack of providers, and scope of intervention serve as insurmountable barriers between children with ASD and treatment that could drastically change their lives and the lives of their family members. Identifying effective, economical treatment that can reduce the impact of ASD on individuals and families and increase social integration is vital. ABA based interventions have proven effective, though costly. Previous studies in the United States have shown that parents can be taught to deliver ABA interventions. Research into pyramidal training has shown that parents in the United States can successfully train other parents to deliver other therapies. This suggests that pyramidal parent training is a potential route to extend provision of ABA services in developing countries, overcoming current systemic barriers. Further investigation is needed to determine the feasibility of this approach.

Statement of Purpose

The purpose of this study was to investigate the effect of a parent-delivered behavioral intervention designed to increase social behaviors and decrease restricted repetitive behaviors in children with ASD in a developing country.

Research Questions

1. To what extent is an ABA-based parent training effective in increasing parent perception of eye contact, compliance and restricted repetitive behaviors (RRBs) in children with ASD?

2. To what extent is the parent training effective in increasing parental confidence and parental action and reducing stress in families with children with ASD?
3. How do age of child, degree of symptomology, level of hyperactivity, and extent of pre-existing services moderate the effectiveness of the intervention?
4. How do self-rated parent action and observed skill acquisition mediate the effectiveness of the intervention?

Given the extensive data on parent training and behavior analytic interventions in children with ASD and hyperactivity, we believed this intervention would be successful in reducing hyperactivity and increasing eye contact in this population. Parent training would also improve child compliance. Considering that parents report child behavior, isolation due to child behavior, and lack of knowledge of how to shape behavior are stressors, we believed that training parents in behavioral techniques would increase parental confidence and decrease family stress. However, given that ASD is a spectrum disorder, there is a great deal of variance in the severity and presentation of symptoms. Consequently, effects of interventions in this field often vary widely between individuals (Zachor & Ben Itzchak, 2010). We expect results of our study to follow this pattern as well.

Method

To answer the research questions, we conducted this study in conjunction with a larger project researching pyramidal parent training in Macedonia. Data were collected utilizing an interrupted time series design. This research model utilizes multiple data point collected before and after introduction of an intervention to assess effect size. This section outlines the participants, settings, instruments, and procedures used.

Participants

Participants were recruited through social media and email contacts of the Macedonian Scientific Study for Autism, a support and advocacy group connected with the Saints Cyril and Methodius University in Skopje. The study was approved by Brigham Young University's Institutional Review Board for Human Subjects, and all participants signed an approved Informed Consent Form, translated into Macedonian. Initially, 20 parents (including two married couples) enrolled in the study, representing 18 children with autism and related disorders. Only one parent from the married couples completed assessments evaluating their children. Two parents did not complete pre-intervention measures, one parent was dissatisfied with the intervention and refused to complete post-intervention measures, and one parent was hospitalized due to illness and was unable to complete the intervention. In all, 17 parents representing 15 children completed the study. All were ethnic Macedonians between the ages of 2 and 13 (mean age = 9; *SD* = 3.7). The participants included 3 females and 12 males, all participants had a diagnosis of autism. Eight participants were reported to have at least one additional diagnosis; one additional diagnosis was hyperactivity. None of the participants had an official diagnosis of ADHD. This is likely due to differences in diagnostic norms in Macedonia and a prevailing approach in earlier years against dual diagnosis of ASD and ADHD (American Psychiatric Association, 2013). Despite the lack of formal diagnosis, seven participants reported clinically significant (above average) levels of hyperactivity in their children on the pre-treatment *Strengths and Difficulties Questionnaire* (SDQ; Goodman, 1997).

Parents were asked to report on prior therapies or special education services received by their children with ASD. Of the 15 participants who completed the study, five received no treatment services, three received one service, the remaining seven received two or more

services. These services included special education support (seven participants), daily special education kindergarten (five participants), speech therapy (six participants), physical therapy (two participants); one participant received music therapy.

All participants were current residents of Skopje, the capital of Macedonia. All but two child participants had been born in Skopje; the remaining participants were born in Veles and Shtip, both urban centers with populations of roughly 50,000. Eleven participants were living in families with married parents. Two participants were children whose parents were divorced, and two parents did not provide their marital status. All parents had at least completed technical high school; nine had completed undergraduate degrees; two had completed post graduate programs. Though statistical data on educational attainment is scarce, some evidence suggests that this group is likely better educated than a significant portion of the population. Though Macedonian law mandates high school attendance to at least age 14, the Educational Policy and Data Center reported in 2014 that Macedonia literacy rates place the nation in the 11th percentile among European and Central Asian nations. The same report placed Macedonia in the 8th percentile (in the same group of nations) in regards to the number of children out of school. Poorer and more rural populations had the lowest rates of school attendance and literacy. Parents received $20 United State Dollars (USD) as compensation for participation. Demographic data are summarized in Table 1.

Table 1
Participant Demographics (*N* = 15)

Variable	Total	Males	Females
Participants			
Parents	15	5	10
Children	15	12	3
Parents Marital Status			
Married	11	3	8
Divorced	2	1	1
Unknown	2	1	1
Parent Education			
High School	4	1	3
College	9	3	6
Postgraduate	2	1	1
Age of Child			
0-3	2	2	-
4-6	3	2	1
7-9	3	1	2
10-14	7	7	-
Diagnosis			
ASD only	6	5	1
1 addl diagnosis	8	6	2
Multiple addl	1	1	-
Receiving therapy?			
No therapy	5	4	1
1 service	3	2	1
>1 service	7	6	1
Therapies received			
SPED	7	6	1
SPED kindergrtn	5	4	1
Speech	6	4	2
PT	2	1	1
Other	1	-	1

Setting

The setting for this study is Skopje, capital of the Republic of Macedonia. Parents training consisted of two meetings. The first meeting provided an overview of the principles of behavioral intervention, led by an individual with a PhD in behavior analysis, and discussion of individual family needs. The second meeting was a single three-hour pyramidal training workshop in implementing the intervention. Training was conducted in a hotel conference room of approximately 1500 square feet. Intervention was then conducted by parents in their homes in Skopje, Veles, and Štip.

Macedonia was chosen as the setting for a number of reasons. This research was conducted as part of a larger, established study, which provided convenient access to participants. More importantly, as discussed fully in the literature review in Appendix A, Macedonia has a fairly unique combination of characteristics of both developed and developing countries. Located in Europe, Macedonia is relatively easy to travel to and a level of infrastructure that facilitates research, while still exhibiting the characteristics of developed nations that tend to act as barriers to treatment of children with ASD (high level of unemployment, low income, access to both practitioners and transportation, inadequate educational opportunities).

Measures

Parent training. Parents were trained in intervention techniques as part of a larger study on pyramidal parent training. Interventions were based on applied behavioral analysis (ABA) techniques and designed to reduce problem behaviors, including non-compliance, lack of eye contact, and restricted repetitive behaviors. Parents received instruction in the fundamentals of ABA delivered by a U.S. university professor in English and translated into Macedonian. Parents

were trained to implement the specific intervention strategies by either a master's-level practitioner or a parent who had been trained previously and assessed as able to train with fidelity. Fidelity was established through observation; data were recorded on the Task Analysis Form. Training consisted of instruction, modeling, and role play, and was conducted in Macedonian by native speakers. Training materials were provided in Macedonian. Training sessions were filmed on iPads. Evaluation was conducted during and at the end of the training to measure the level of pre-existing familiarity with the strategies and to ensure that the parent had learned the intervention and could implement it with fidelity. Training sessions were also observed and evaluated for training and implementation fidelity. A statistically significant number of training sessions were evaluated later via video to measure interobserver agreement. Both live and video observations were conducted by fluent speakers of Macedonian.

Demographics questionnaire. Parents completed a demographics questionnaire prior to attending the first training. The questionnaire collected basic information such as names, birthdates and places, ages, and ethnicities of parents and their children with ASD, as well as the parents' marital status, educational attainment, and names and ages of any other children. Additionally, parents provided information regarding their child's diagnosis, symptoms, and educational and therapeutic services provided.

Task analysis form. The task analysis form was used to document training, assess parent competence and confirm program acquisition. Data were collected at three time points for each parent: prior to training, during training and after training. Observers were undergraduate and master's level students who were fluent in Macedonian. They evaluated participants on performance of task components and quality of implementation on a five-point Likert scale. Data

were analyzed to establish change in skill level, pre to post training, and ability to implement the intervention with fidelity. A copy of the task analysis form is included in Appendix B.

Strengths and Difficulties Questionnaire (SDQ). Information regarding level of ASD and comorbid symptoms and impact on family life was collected pre and post treatment via the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997). The SDQ is a rating scale which evaluates social and psychological function in children between the ages of 3 and 16 years. There are two versions, one for teachers and another for parents. This study utilized the parent version. The SDQ consists of 25 questions focused on five areas of behavior: emotional regulation, conduct, hyperactivity-inattention, peer interaction, and prosocial behaviors. Parents rate their children's behavior on a 3-point Likert scale. In 2010, a meta-analysis of more than 40 studies confirmed satisfactory reliability and validity ratings for the SDQ (Stone et al., 2010). The SDQ is used extensively in translation for research overseas; reliability and validity ratings are generally maintained across cultures (Kersten et al., 2016). Copies of the *SDQ* are available free online from the following website: [www.sdqinfo.com].

***Daily Behavior Rating* (DBR) scale.** The *Daily Behavior Rating* (DBR), based upon Chafouleas, Riley-Tilman, and Christ's (2009) *Direct Behavior Rating Scale*, asks parents to rate daily occurrence of specific behaviors. In this study, data were collected on three child behaviors (compliance/following directions, eye contact, and restricted repetitive behaviors) and two parent behaviors (action and confidence). Participants estimated the amount of time their children exhibited each behavior as a percentage of total time. The self-rating feature for parent behaviors features a ten-point Likert scale where zero represents no confidence or no action and 10 represents complete confidence or extreme action. Parents completed the DBR daily for the 10 days directly prior to and directly after parent training. Due to the constraints of international

research, no independent verification of parent rating on the DBR was possible. A copy of the DBR is included in Appendix B.

Procedures

Parent training. Parents were trained in intervention techniques as part of a larger study on pyramidal parent training. Interventions were based on ABA techniques and designed to reduce three problem behaviors: non-compliance, lack of eye contact, and restricted repetitive behaviors. Parents received instruction in the fundamentals of ABA from a university professor. Parents were taught the basic concepts of reinforcement and function of behavior.

Training was conducted according to a pyramidal model. Participants were grouped in sets of three parents with one trainer. Trainers were native Macedonian master's level practitioners. The pyramidal model in this instance consisted of three tiers. Tier 1 involved a participant (Participant 1) being trained by the trainer. After Participant 1 demonstrated the ability to implement the intervention with fidelity (competence), as assessed using the Task Analysis Form, he or she conducted the training for Participant 2. After demonstrating competence, Participant 2 trained Participant 3 until Participant 3 achieved competence.

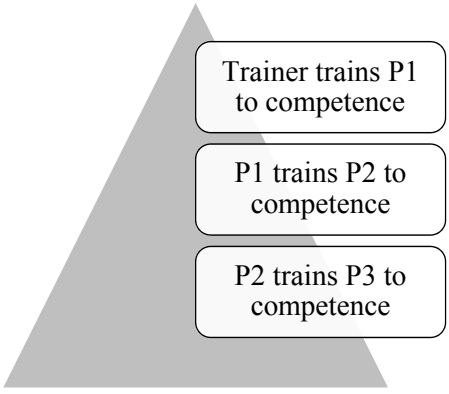

Figure 1. Pyramidal parent training flow chart. This figure illustrates the pyramidal training process.

Training method. Training consisted of a pretest simulation, instruction, modeling, and role play. The pretest simulation allowed for evaluation of pre-existing familiarity with the strategies. Instruction included definition of the strategy, theoretical rationale for the intervention, and instruction in how to implement the strategy. The trainer modeled the strategy. Finally, the role play provided guided practice as the participant took the role of a parent implementing the intervention with the trainer in the role of child; the trainer provided prompts, as necessary, until the participant achieved competence. Complete training scripts are included in Appendix C; a summary of skills taught in each module is provided in Table 2

All training and was conducted in Macedonian by native speakers. Training materials were provided in Macedonian. Training sessions were filmed on iPads. Training sessions were also observed and evaluated for training and implementation fidelity. A statistically significant number of training sessions were evaluated later via video to measure interobserver agreement. Both live and video observations were conducted by fluent speakers of Macedonian.

Compliance module. The training for increasing compliance, *Verbal Praise for Compliance,* taught four steps for improving compliance: look at the child, smile and have a pleasant expression, enthusiastically use positive words to describe what the child did right, very the words used to praise and praise frequently.

Eye contact module. The training for increasing eye contact, *Prompting Eye Contact When Children Request,* taught five steps: find a highly preferred item for the child to request, create motivation to request the item by blocking or limiting access, prompt the child (if necessary) to make eye contact when they make a request, praise and provide the item when the child makes a request while making eye contact.

Restricted repetitive behaviors. The training for reducing restricted repetitive behaviors, *Response Interruption and Redirection,* taught five steps: identify both a restricted repetitive behavior to target and a competing behavior (behavior that cannot be performed simultaneously with target behavior), gain the child's attention while they are doing the target behavior, verbally prompt the competing behavior, verbally and/or physically prompt the competing behavior if the child does not comply, and praise the competing behavior.

Table 2
Skill Steps

Praising Compliance (PC)
Definition: When a child follows a parent directive within 10 s, the parent says a positive statement using an enthusiastic tone of voice and pleasant facial expression

1. Parent looks at experimenter.
2. Parent waits 10 s for compliance.
3. Parent provides a directive.
4. Parent says a positive statement with
   (a) an enthusiastic tone of voice.
   (b) and a pleasant facial expression.

Teaching Eye Contact (TEC)
Definition: When the child makes a request without providing eye contact, the parent utilizes a prompting procedure to evoke the child's eye contact.

1. When the child does not provide eye contact when making a request:
2. Parent waits 5 s for eye contact.
3. Parent prompts eye contact.
4. Item is presented contingent upon eye contact.
5. Parent praises eye contact.
6. Parent makes eye contact with the child.

Response Interruption and Redirection (RIR)
Definition: When the child engages in stereotypic behaviors, the parent directs the child to a competing motor task. The parent uses a prompting procedure to teach the child the motor task.

1. When the child engages in motor stereotypy:
2. Parent provides a verbal direction to motor task.
3. Parent models the motor task.
4. Parent provides a verbal prompt to engage in the motor task.
5. Parent provides a physical prompt to engage in the motor task.
6. Parent provides praise contingent on engagement in motor task.

Design. This study utilized a quasi-experimental, interrupted time-series design to evaluate the effects of parent training. Multiple measures of symptom levels were taken prior to parent training. These included one administration of the SDQ and 10 consecutive daily reports via the DBR in the period immediately preceding training. Data from these sources were used to establish baseline levels. Participants were randomly assigned to one of three training groups. Training groups ran essentially concurrently, as the parent trainings were conducted on three consecutive evenings. Within each training group, parents were randomly assigned to one of three training tiers. Multiple measures of symptom level were collected post-training, including one administration of the SDQ at one month post-training, and 10 consecutive daily reports via the DBR in the period immediately following parent training.

Analysis

Traditionally, analysis of moderator and mediator variables was limited to studies with large sample sizes. However, in 2008, Gaynor & Harris developed a method for investigating mediator and moderator effects in the context of single case design. The process has been utilized in prior studies since and found reliable (Lemmens, Muller, Arntz, & Huibers, 2016; Maric, Wiers, & Prins, 2012; Martens, 2014). The approach requires a specific methodology in order to overcome the limitations of small sample size. Data collection and analysis were conducted to satisfy these four requirements of valid single case research design (See *Figure 1* for overview of methodology and analysis). First, it was established that participants acquired knowledge of the intervention to a sufficient degree to allow accurate delivery. Second, an appropriate temporal relationship between treatment and outcome was established. More simply put, change in the dependent variables was shown to postdate implementation of the intervention. Third, positive change in both the mediator and dependent variable was

demonstrated. Fourth, a link between the putative mediator and the change in the dependent variable was established. This was generally accomplished through attention to the temporal order of change, i.e., change in the mediator variable can be shown to predate change in the dependent variable (Gaynor & Harris, 2008).

Participant naiveté and receipt of treatment. As outlined by Gaynor and Harris (2008), the first step is to establish participant naiveté and verify receipt of treatment at a level sufficient to establish competence. Participants are considered naïve when they have no previous knowledge of the intervention (Colman, 2008). Parent competence refers to the parent's ability to implement the intervention with fidelity. Intervention fidelity is a measure of how accurately a participant implements the strategies taught in the intervention (Resnick et al., 2005). Essentially, this step establishes that the treatment was a new provision and that the participants had developed an adequate level of proficiency in implementing the intervention. Additionally, for the purposes of our study, we needed to establish receipt of treatment by the children by verifying that parents not only learned the intervention, but also implemented the strategies at home.

A number of measures established participant naiveté. At intake, parents reported on previous services received. During training, treatment novelty was confirmed via observation of role plays at baseline and after training. Observers evaluated the parents' knowledge the intervention and quality of implementation. Observations were conducted by undergraduate research assistants who spoke fluent Macedonian and were recorded on a task analysis form. A second trained and fluent researcher evaluated these measures via video to establish interobserver agreement. Receipt of treatment was secondarily verified through video and photographic documentation of attendance at the training.

Due to the constraints of international research, we were unable to conduct a direct observation of implementation at home. We established treatment implementation through visual analysis of pre- and post-training parent activity and confidence levels reported on the DBR to assess changes in trend, level, and variability. Increase in activity and confidence post-training was assumed to indicate implementation.

Improved outcome after treatment. In accordance with Gaynor and Harris's (2008) methodology, a temporal relationship between treatment and positive outcome must be established next. This is typically accomplished by determining that improvement in one or more outcome variables followed treatment implementation (Gaynor & Harris, 2008). In this case, treatment was the ABA-based intervention taught in the parent training. The outcome variables were defined as symptom expression in the children with ASD (hyperactivity, eye contact, compliance, and restricted repetitive behaviors) and family distress. This requirement was met by documenting a change in symptom expression from pre-treatment to post-treatment levels. Using data collected on the SDQ and the DBR, we conducted visual analysis of changes in level, trend, and variability between pre- and post-treatment symptomology and behavior to evaluate change in dependent variables.

Positive change in mediator(s) after treatment. According to Gaynor and Harris (2008), once improvement on the dependent variable(s) is confirmed, positive change on the putative mediator (aspect related to the study) must be documented, and this change must be shown to follow treatment implementation. In this study, predicted mediators were parent effectiveness, as measured by parent confidence and parent action, and degree of skill acquisition. Visual analysis of the DBR and SDQ provided documentation that change in the

putative mediators predated change in the dependent variables. Data were evaluated for changes in level, trend, and variability.

Relationship between mediator and outcome. In the Gaynor and Harris (2008) model, the last step in establishing mediator effect is to document a relationship between mediator(s) and outcome. Mediators are the mechanisms of action through which the intervention is effective; therefore, consistent change in mediator and dependent variables supports the hypothesized relationship, as long as mediator change precedes dependent variable change (Gaynor & Harris, 2008). Visual analysis of the DBR and SDQ provided documentation that change in the putative mediators predated change in the dependent variables. Data were evaluated for changes in level, trend, and variability. Treatment effect size was computed using Tau-U to enable group analysis. Tau-U is a statistical process for evaluating non overlap of data points between phases as well as trend within phases (Parker, Vannest, Davis, & Sauber, 2011)

Relationship between moderator and outcome. Predicted moderators (variables inherent in the participants that affect outcome) were age of child, severity of ASD symptomology overall, level of hyperactivity, and extent of pre-existing services. Pre-intervention data from the DBR and the SDQ were evaluated to divide participants into groups along these variables. Treatment effect size was computed using Tau-U to enable group analysis.

Results

This study investigated the effects of a parent-delivered behavioral intervention on children and parents impacted by ASD in a developing country. Overall, the intervention proved successful in effecting positive change in both children and parents. Child behaviors were generally more responsive to intervention than were parent factors. Consistent with previous research, response to intervention was highly variable by individual, with a general trend toward

individuals with mild to moderate impairment being more responsive than those with more severe impairment (Granpeesheh et al., 2009). This section will discuss in detail the results of data analysis in relation to each of the four research questions.

Research Question 1: Child Factors

The first research question investigated the effect of the intervention on parent perceptions of three symptoms of ASD in their child: amount of eye contact, level of compliance, and expression of RRBs. To answer this question, this section will describe trends in behavior during the 10 days immediately post-intervention as compared to baseline. Graphs of individual results are listed in Appendix D and results are summarized in Figure 2. Results of Tau-U analysis are reported in Table 3.

Overall effect. Overall, the intervention was effective in changing behavior in the child participants, according to their parent's perception. All participants showed some positive change in behavior over baseline levels as noted by a change in trend, level, or variability. More than half (n = 8) showed positive changes in all three aspects for at least one of the behaviors. In terms of Tau-U effect size, effect was minimal for eye contact and compliance (Tau-U = 0.26 and 0.28, respectively, $p < .001$) and small (Tau-U = -0.11) for reduction of RRBs.

Effect on eye contact. Visual analysis showed four of the 15 participants (27%) demonstrated positive changes in level, trend and variability; 14 participants (93%) showed change on at least one aspect; and one participant (6%) showed no positive change.

Tau-U analysis showed that the intervention was most effective for children with less eye contact at baseline compared to children with higher levels at baseline. Participants were divided into two groups by initial level of eye contact compared to the group mean. Effect size was

minimal (Tau-U = 0.15, $p > .05$) for children with higher than average eye contact, and large (Tau-U = .96, $p < .001$) for children with lower than average eye contact.

Effect on compliance. Visual analysis showed six of the 15 participants (43%) with positive changes in level, trend and variability; 14 participants (93%) showed change on at least one aspect; only one participant (7%) showed no positive change on any of the identified variables.

Tau-U analysis showed that the intervention was markedly more effective for children with low levels of compliance at baseline. Participants were grouped by compliance in relation to the group mean. Effect size was large (Tau-U = 1, $p < .001$) for children with low initial compliance, minimally negative (Tau-U = -.12, $p > .05$) for children with high initial compliance.

Table 3
Child Variables

	Tau-U	*p*
Eye Contact		
Overall	0.26	.00
High Initial	0.15	.57
Low Initial	0.96	.00
Restricted Repetitive Behavior		
Overall	-0.11	.14
High Initial	-0.41	.12
Low Initial	0.52	.05
Compliance		
Overall	0.28	.00
High Initial	-0.12	.65
Low Initial	1.00	.00

Effect on restricted repetitive behavior. Visual analysis demonstrated two of 15 participants (13%) showed positive changes in level, trend and variability; 14 participants (100%) showed change on at least one aspect. One participant showed no evidence of RRB in either baseline or intervention phases and was excluded from analysis for this variable.

Tau-U analysis showed that the intervention was markedly more effective for children with high levels of RRBs at baseline. Participants were divided into two groups in relation to initial group mean for RRBs. It should be noted that RRBs are considered impairing and thus a reduction in behavior, reflected by a negative effect size, is desirable. Effect size was moderate for increased RRB (Tau-U = .52, $p < .05$) for children with low levels of RRB, while behavior was minimally reduced (Tau-U = -.41, $p < .05$) in children with high levels of RRBs.

	Eye Contact				Compliance				RRB		
Child	Level	Trend	Var.		Level	Trend	Var.		Level	Trend	Var.
W1	X	X	X		X	X	X		X	X	
W2		X	X		X	X	X		X	X	X
W4[a]	X	X			X		X				X
W6	X		X		X	X	X		X	X	X
W9	X	X	X		X	X	X				X
T1	X		X						X	X	
T2			X		X						X
T3	X				X		X		X		X
T4			X			X	X				X
T5			X			X	X				
M1	X	X	X			X	X			X	X
M2	X	X			X	X	X			X	
M4	X	X	X		X	X					X
M5					X	X	X		X		X
M6	X	X			X		X				X
Note. Var. refers to variability </= baseline.											
[a] no change day to day through baseline and intervention.											

Figure 2. Visual analysis of child variables.

Research Question 2: Parent Factors

The second research question addressed the effect of the intervention on two measures of parent competence, amount of parenting action, the level of parent's confidence in their own ability to parent, and perception of family distress levels. To answer this question, this section will describe trends in levels of action and confidence during the 10 days immediately post-intervention as compared to baseline. This section will also discuss changes in family distress rating from pre- to post-intervention. Graphs of individual results are listed in Appendix D and results are summarized in Figure 3. Results of Tau-U analysis are reported in Table 4.

Overall effect. Overall, the intervention was effective in changing parent behavior. Measures of parent action and parent confidence were analyzed visually and through Tau-U statistical analysis. Due to a lack of post-intervention data, one participant was dropped from analysis. All 14 remaining participants showed some positive change in behavior over baseline levels as noted by a change in trend, level, or variability. More than half (n = 8) showed positive changes in all three aspects for at least one of the behaviors. Tau-U effect size was minimal for parent action and confidence (Tau-U = .28, $p < .001$ for each measure); effect size for family distress was minimal for the group as a whole (Tau-U = -.08, $p > .05$*).* Four of the 14 participants (29%) showed large effect size in at least one symptom; three participants (20%) showed moderate effect size in at least one symptom; and three participants showed minimal to negative effect size in both symptoms.

Effect on parent confidence. Visual analysis showed four of the 14 participants (29%) experienced positive changes in level, trend and variability; 13 participants (93%) showed positive change on at least one aspect.

Tau-U analysis showed that parents with low initial confidence derived the most benefit from the intervention. Participants were grouped in relation to the initial group mean. Effect size was minimal (Tau-U = .20, $p < .05$) for parents with higher confidence, large (Tau-U = .67, $p < .05$) for parents with low initial confidence.

Effect on action. Visual analysis showed six of the 14 participants (43%) demonstrated positive changes in level, trend and variability; 12 participants (86%) showed change on at least one aspect.

Tau-U analysis showed that the participants who were initially less active parents derived the most benefit from the intervention. Participants were grouped in relation to the initial group mean. Effect size was large (Tau-U = 1, $p < .001$) for parents with activity less than the group mean, minimally negative effect size (Tau-U = -.14, $p > .05$) for parents who were more active initially.

Effect on family distress. Family distress reflects an undesirable situation, thus negative effect sizes signal an improvement in family function. Effect size for the group overall was minimal, -.08 ($p > .05$). Families with high initial distress had a minimal negative effect size (-.27, $p = .33$), representing some improvement in distress. Families with lower than average distress had a minimal positive effect size (.17, $p > .05$), indicative of a rise in family stress.

Table 4
Parent Variables

	Tau-U	*p*
Parental Confidence		
Overall	0.28	.00
High Initial	0.20	.48
Low Initial	0.67	.05
Parental Action		
Overall	0.28	.00
High Initial	-0.14	.60
Low Initial	1.00	.00
Family Distress		
Overall	-0.08	.71
High Initial	-0.27	.33
Low Initial	0.17	.63

Research Question 3: Moderators

The third research question regarded the proposed moderating effect of five variables: age of child, degree of overall symptomology, initial level of hyperactivity, history of special education services and parent's educational level. This section will report results of Tau-U analysis of these effects.

Child's age. Participants were sorted into four groups by age: 0–3 years, 4–6 years, 7–9 years and 10–14 years. Combined Tau-U effect sizes were computed for each group. The results of this analysis are listed in Table 5.

With the exception of RRB, average overall effect size for the intervention was minimal (Tau-U = .28, $p < 001$). Although the response was not strictly consistent, there were significant differences in effect by age group. For parent variables, 4–6 year olds showed the greatest response, with moderate effect size in both action and confidence. The 7–9 year old group also showed greater response than the norm for parental action, with a moderate effect size. The 0–3 year old group showed substantially greater response in parent confidence (Tau-U = .40, $p <$

.05). The oldest group, 10–14 year olds, consistently underperformed, with effect size lower than the norm for both variables.

Effect sizes for the group overall were minimal for all three child variables (eye contact, RRB and compliance.) With regard to eye contact and compliance, the youngest group, 0–3 year olds, consistently outperformed the overall group. Response among other groups was generally unremarkable compared to the overall group, with three exceptions. Performing above the norm were the oldest group, 10–14 year olds (Tau-U = .39, $p < .001$). The 4–6 year olds underperformed the group in eye contact (Tau-U = 0.12, $p < .05$). The 7–9 year olds showed a negative response to intervention for compliance (Tau-U = -.03, $p > .05$).

	Action				Confidence		
Child	Level Δ	Trend Δ	Vrblty		Level Δ	Trend Δ	Vrblty
W1a			X		X	X	X
W2		X	X			X	X
W4[b]	X	X[c]	X				X
W6	X	X	X		X	X	X
W9	X	X	X		X	X	X
T1	no data post intervention				no data post intervention		
T2	X	X				X	
T3	X		X				X
T4		X	X		X		X
T5[a]	X	X	X			X	
M1[d]		X	X		X	X	X
M2	X	X	X		X	X	
M4					X	X	
M5	X	X	X			X	X
M6		X					

Note. Vrblty refers to variability </= baseline
[a]no change (action) day to day through baseline and intervention. W1 responded at max for each day. T5, M5 reported at max for 19 of 20 days.
[b]no change (confidence) day to day through baseline and intervention.
[c]action reported as 100% for all days post intervention
[d]No pre intervention action data, trend and variability reported for intervention phase; confidence reported as max for all post intervention days.

Figure 3. Visual analysis of parent variables.

Table 5
Moderator Effect, Child's Age

	Tau-U	*p*
Child's age x action		
0-3	0.21	.29
4-6	0.51	.01
7-9	0.64	.02
10-14	0.16	.18
All participants	0.28	.00
Child's age x confidence		
0-3	0.40	.04
4-6	0.59	.00
7-9	0.05	.81
10-14	0.18	.07
All participants	0.28	.00
Child's age x RRB		
0-3	0.24	.21
4-6	0.40	.01
7-9	-0.47	.02
10-14	-0.32	.00
All participants	-0.11	.14
Child's age x eye contact		
0-3	0.57	.00
4-6	0.12	.45
7-9	0.27	.09
10-14	0.25	.01
All participants	0.26	.00
Child's age x compliance		
0-3	0.45	.02
4-6	0.23	.13
7-9	-0.03	.83
10-14	0.39	.00
All participants	0.28	.00

RRB was a unique case in terms of both data and response pattern. First, because RRBs are an undesirable behavior, reduction of RRB expression was the goal of the intervention. Thus, negative effect size represented the desired response. Overall effect size for RRB was -.11, a

minimal reduction. The two older groups showed greater than average response to intervention (Tau-U = -.32 to -.47, $p < 05$).

Degree of symptomology. The moderating effect of level of initial symptomology on child and parent variables was evaluated through Tau-U analysis. Participants were divided into two groups, low and high, based on level of symptoms reported by parents at intake. Combined Tau-U effect sizes were computed for each group. Results of this analysis are listed in Table 6.

Table 6
Moderator Effect, Initial Symptomology

	Tau-U	*p*
Initial symptomology x action		
Low	0.50	.00
High	-0.23	.14
Action all participants	0.28	.00
Initial symptomology x confidence		
Low	0.56	.00
High	-0.09	.40
Confidence all participants	0.28	.00
Initial symptomology x RRB		
Low	-0.17	.07
High	-0.02	.86
RRB all participants	-0.11	.14
Initial symptomology x eye contact		
Low	0.53	.00
High	-0.04	.67
Eye contact all participants	0.26	.00
Initial symptomology x compliance		
Low	0.41	.00
High	0.14	.16
Compliance all participants	0.28	.00

Across all measures, children with lower symptomology showed greater response to intervention than those with greater symptomology. Tau-U effect sizes ranged from -.17 (RRB) to .56 (parental confidence) for the *low symptomology* group. Although effect sizes for the *high symptomology* group ranged -.23 ($p < .05$) for parental action to .14 ($p < .05$) for compliance for the *high symptomology* group, effect size for eye contact, confidence, and RRB were negligible.

Hyperactivity as moderator of treatment effect. The moderating effect of hyperactivity on child and parent variables was evaluated through Tau-U analysis. Participants were divided into two groups, *low* and *high* based on level of hyperactivity reported by parents at intake. The results of this analysis are listed in Table 7.

Table 7
Moderator Effect, Hyperactivity

	Tau-U	*p*
Hyperactivity x action		
Low	-0.03	.76
High	0.73	.00
All participants	0.28	.00
Hyperactivity x confidence		
Low	0.22	.02
High	0.35	.00
All participants	0.28	.00
Hyperactivity x RRB		
Low	-0.07	.44
High	-0.15	.17
All participants	-0.11	.14
Hyperactivity x eye contact		
Low	0.08	.37
High	0.47	.00
All participants	0.26	.00
Hyperactivity x compliance		
Low	0.13	.17
High	0.46	.00
All participants	0.28	.00

For every measure effect size was markedly larger for the *high* group compared to the *low* group and the group overall. Effect size for the group overall for parent confidence, parent action, child eye contact and compliance was minimal (Tau-U = .28, $p < .001$). For the *high* group, effect size ranged from minimal for action (Tau-U = .35, $p < .001$) to large for confidence, (Tau-U = .73, $p < .001$). Effect sizes for the *low* group were consistently minimal, with Tau-U ranging from -.03 ($p > .05$) for action to .22 ($p < .05$) for confidence.

Pre-existing services as moderator of treatment effect. The moderating effect of prior exposure to special education services was evaluated through Tau-U analysis. Participants were divided into two groups based on parent report of prior receipt of special education services or other therapies. The groups were labelled *no services* and *prior services*. The results of this analysis are listed in Table 8.

Effect size was greatest in the *no services* group compared to the group as a whole and the *prior services* group in all but one variable. Effect size for action, confidence, RRB and eye contact ranged from .32 to .34 (-.32 for RRB), compared to the average of .28 for the group as a whole (-.11 for RRB). The *prior services* group had effect sizes ranging from .06 (RRB) to .24 (action). One variable was a notable exception; effect size for compliance was .49 for the *prior services* group, compared to the overall group at .28 and the *no services* group at .06. Size for parent action for all individuals was minimal (.28, $p < .001$). When parent action and prior services were combined, both groups had minimal effect sizes; 0.34 ($p = .001$) for the *no services* group, 0.24 ($p < .05$) for the *prior services* group.

Table 8
Moderator Effect, Prior Services

	Tau-U	*p*
Services X action		
No	0.34	.01
Yes	0.24	.03
All participants	0.28	.00
Services X confidence		
No	0.36	.00
Yes	0.19	.06
All participants	0.28	.00
Services X RRB		
No	-0.32	.00
Yes	0.06	.55
All participants	-0.11	.14
Services X eye contact		
No	0.32	.00
Yes	0.21	.03
All participants	0.26	.00
Services X compliance		
No	0.06	.57
Yes	0.49	.00
All participants	0.28	.00

Parent's education as moderator effect. The moderating effect of the parent's level of education on child and parent variables was evaluated through Tau-U analysis. Participants were divided into three groups based on parent self-report of highest level of educational attainment. The groups were labelled *high school* (for those who reported attending either tech or academic high school), *college* (for those who attended three or four year college), and *postgraduate* (for any study beyond the college degree.) The results of this analysis are listed in Table 9.

On every variable, parents with more education showed greater effect sizes than parents with less education. In all but one variable (eye contact), parents with postgraduate education had

larger effect sizes than parents with a college degree. Effect sizes for parents with high school degrees ranged from .12 for RRB (representing a minimal increase in RRB) to .15 for parental action. For college graduates, the range was similar to that of the group overall, -.16 (RRB) to .36 (eye contact). Effect sizes for postgraduate parents ranged from .21 (RRB) to 1.00 (action).

Table 9
Moderator Effect, Parent's Educational Level

	Tau-U	*p*
Educational level x action		
High school	0.01	.96
College	0.26	.01
Postgraduate	1.00	.00
Action all participants	0.28	.00
Educational level x confidence		
High school	0.15	.26
College	0.27	.00
Postgraduate	0.56	.00
Confidence all participants	0.28	.00
Educational level x RRB		
High school	0.12	.43
College	-0.16	.07
Postgraduate	-0.21	.26
RRB all participants	-0.11	.14
Educational level x eye contact		
High school	0.09	.48
College	0.36	.00
Postgraduate	0.21	.27
Eye contact all participants	0.26	.00
Educational level x compliance		
High school	0.02	.86
College	0.32	.00
Postgraduate	0.65	.00
Compliance all participants	0.28	.00

Research Question 4: Mediators

The fourth research question asked about the effects of two proposed mediators of outcome: level of parent action and level of skill acquired by the parent. In accordance with the methodology developed by Gaynor and Harris (2008), documentation of mediating effect involves four steps. First, receipt of novel treatment (in this case the intervention) must be established. For this study, parents were assessed for knowledge of the steps of each intervention and the quality of their implementation of the intervention before and after training. These ratings are reported in Table 10. Improvement in either knowledge or quality of implementation satisfied both aspects of this step. Two participants (T3 and T4) did not gain in either aspect for eye contact and have been excluded from further analysis for this intervention.

The second step in this methodology requires documentation of change in outcome as signaled by a change in an outcome variable. Effect size for variable by individual is reported in Table 11. Participants with negative, zero, or negligible effect size (Tau-U < .15) for a variable were excluded from further analysis for this variable.

Table 10
Receipt of Treatment

	Praise		Eye contact		Redirecting	
Participant	Steps	Quality	Steps	Quality	Steps	Quality
W1	2	12	2	12	2	19
W2	4	22	2	20	3	20
W4	3	21	1	21	2	13
W6	0	6	2	4	2	19
W9	2	16	1	8	1	1
T1	2	12	3	12	2	13
T2	0	4	1	2	0	4
T3	3	12	-2	-14	3	15
T4	0	2	0	-3	5	27
T5	5	16	1	12	2	2
M1	1	2	1	6	2	6
M2	0	5	0	5	-1	10
M4	2	8	4	10	2	14
M5	2	10	0	9	1	7
M6	3	8	5	8	1	19

Table 11
Effectiveness by Individual, Child Variables

	Eye con	RRB[a]	Comp
M1	0.19	0.80	-0.71
T5	0.00		-0.34
T2	-0.30	0.23	0.21
M5	-0.30	-0.40	0.02
T1	0.16	-0.27	-0.23
M6	0.52	0.21	-0.05
W2	-0.44	0.20	1.00
M4	0.67	0.68	0.46
W1	-0.05	-0.60	0.10
W9	0.46	0.18	0.92
W6	0.62	-0.64	0.35
W4	1.00	0.00	1.00
M2	1.00	-0.92	0.92
T3	Excluded	-0.28	0.43
T4	Excluded	-0.74	0.05

[a]*Negative effect size indicates decrease in RRB.*

The third step in Gaynor and Harris's (2008) methodology requires documentation of change in the putative mediator after the intervention. The two proposed mediators in this study were level of parent action and degree of acquisition of the intervention. Effect size for change in parent action is reported in Table 12. Three participants reported maximum action for all 20 reported days (baseline and post intervention). An additional four participants noted a reduction in action post-intervention and one participant had a negligible effect size of .04. The remaining four participants satisfied the criteria for this step. Skill acquisition was defined by the level of change in skill and quality of implementation from pre- to post-intervention. Acquisition data are summarized in Table 13. All remaining participants showed acquisition of skill. They have been divided into categories based on degree of skill acquisition relative to the group mean for further analysis.

Table 12
Parental Action

Participant	*Tau-U*	*p* value
W2	-0.62	0.02
M6	-0.30	0.26
T4	-0.18	0.50
T2	-0.09	0.77
M4	0.04	0.88
T3	0.40	0.16
W6	0.64	0.02
W4	0.68	0.01
W9	1.00	0.00
M2	1.21	0.00

Note. W1, T5, and M5 were excluded because participants reported maximum action for entire reporting period.

The final step in this methodology requires documentation of that the change in the outcome variable did not precede change in the proposed mediator. Changes in parent action and each child outcome variable were graphed together and assessed for temporality; for the second

proposed mediator, degree of acquisition, documentation of temporality mirrors the process undertaken in question one. Both sets of graphs are presented in Appendix D. Acquisition happened at one time point, the day of training, and was not variable over time. The temporal relationship of the two variables can be assessed through visual analysis. For both proposed mediators, all remaining cases met the temporality criteria.

Table 13
Degree of Acquisition

Compliance/Praise		Eye Contact		RRB/Redirecting	
Part	Acq	Part	Acq	Part	Acq
Far below average (>1 SD below the mean)					
M1	3	T3	-16	W9	2
T4	2	T4	-3		
Below average (>.5 SD below the mean)					
M2	5	T2	3	T2	4
T2	4			T5	4
W6	6				
Average (within .5 SD of the mean)					
M4	10	M1	7	M1	8
M5	12	M2	7	M2	9
M6	11	M4	14	M4	16
T1	14	M5	9	M5	8
T3	15	M6	13	T1	15
W1	14	T5	13	W4	15
		W1	14		
		W6	6		
		W9	9		
Above average (>.5 SD above the mean)					
W9	18	T1	15	M6	20
				T3	18
Far above average (>1 SD above the mean)					
T5	21	W2	22	T4	32
W2	26	W4	22	W1	21
W4	24			W2	23
				W6	21

Discussion

This study examined the effects of a parent-delivered ABA intervention for children with ASD in Macedonia. Research has established the effectiveness of ABA interventions in the ASD population, but many families are unable to benefit from this therapy due to limitations to access related to cost, availability of providers, and intensity of intervention (Granpeesheh et al., 2009). Studies have shown success in teaching parents in the U.S. to provide this type of intervention, but these studies have not been extended to foreign countries (Anan, Warner, McGillivary, Chong, & Hines, 2008). Families in developing nations such as Macedonia are at increased disadvantage with regard to effective intervention due to infrastructure deficits, differences in attitude toward disability, and limitations of health care systems (Salamone, et al., 2016). The development of effective interventions that can be taught to and then implemented by parents of children with ASD can help to bridge this access gap.

In response to this need, this study sought first to determine if parent-delivered ABA techniques were effective in Macedonia, and second, to evaluate factors that moderated and mediated the intervention's effectiveness. The data show that, overall, the intervention was effective in improving eye contact and compliance in children with ASD and was effective in reducing RRBs in some children. Additionally, the intervention improved parent action and confidence in dealing with challenging behaviors associated with ASD. Moderating effects of several characteristics were identified. Level of parent action was found to be a substantial mediator of effect. Consistent with results of other studies of ASD, responses across all measures were highly variable, likely due to the highly individualized expression of ASD as a spectrum

disorder (Granpeesheh et al., 2009). This section will discuss the study's results in relation to research questions, as well as limitations to the current research and suggestions for future research.

Research Question 1: Effect on Child Behaviors

Results showed that the intervention was effective in increasing both eye contact and compliance in children with ASD. This effect was greatest in children with low levels of eye contact and compliance prior to intervention. Although the intervention was not effective at reducing levels of restricted repetitive behaviors for the group overall, it did show some effect for children with high levels of RRB prior to intervention. This discrepancy may demonstrate that RRBs are unconscious behaviors or are maintained by automatic reinforcement, and thus less responsive to modification. Given these findings, this study suggests the use of this intervention to reduce impairment among children with ASD. More important, these results suggest that the intervention may be particularly effective for children who are highly impacted by individual symptoms.

Research Question 2: Effect on Parent Behaviors

The intervention had mixed effects on parent behaviors. Overall, parent confidence and action increased after the intervention. The effect on confidence was substantially greater for parents who had low confidence and low action entering the intervention. However, parent confidence increased only slightly, while parent action showed greater increase. It is possible that action levels reflect a person's general approach to parenting and are not very susceptible to change, while confidence is reflective of a lack of knowledge or strategy which can be affected. These findings may also be an artifact of this particular sample. The participants were recruited from among the membership of a university group for autism research and support. Thus, the

sample was assumed to include parents who were already both active and informed. Greater benefits might reasonably be expected from parents who are more naïve to intervention.

Fox, Vaughn, Wyatt, & Dunlap (2002) found that lack of effective discipline strategies was a major source of parental stress, suggesting that provision of strategies would result in reduced stress. Specifically, impaired communication and problem behavior are predictors of increased stress (Lee et al., 2008). The intervention was designed to address these two factors. It is thus surprising that the intervention appeared to have had essentially no effect on family distress levels. Families with low initial levels actually showed increased distress in the period immediately after the intervention. This may be a transient consequence of the intervention, as the implementation of new strategies by newly confident parents, fresh from training, serves to disrupt the status quo. Heightened conflict within the family is known to increase symptomology in children with ASD, which in turn is known to increase family problems (Graetz, 2010; Harpin, 2005). If implementation of the intervention was the source of additional stress, we would expect to see distress levels begin to decline as the family assimilates to the new strategy and as children respond to the intervention with decreased symptomology.

Consistent with the general trend, the intervention was more successful in reducing distress in families that reported high levels of distress pre-intervention.

Research Question 3: Potential Moderators

Child's age. The effect of the intervention was clearly moderated by the age of the child. Although neither the magnitude nor the direction of effect was consistent across variables, considerable differences were noted between age groups.

On both parent measures, the intervention proved most effective in younger children. Parental action increased most in parents of children between four and nine years old, while

parental confidence was most affected for parents of children six and under. The minimal effect on action for children three and under may be attributed to the nature of development. Fewer demands are required of children of this age group than for older children and they are less divergent from typically developing peers. The smaller difference between children and their peers and lower social and behavioral demands requires less action from the parents. On the other hand, parents with children in this age group are likely dealing with a fairly recent diagnosis, struggling with uncertainty and attempting to adjust to the demands of raising a non-typical child. The intervention met these needs, as reflected in the results. For both parent domains, the oldest age group showed only minimal movement, likely due to the fact that parents and children are usually more set in their roles and routines at later ages.

The importance and effectiveness of early intervention is well established in the literature (Drew et al., 2002; Webb et al., 2014). This study further supports the benefit of early intervention, as younger children overall showed greater response than older individuals. A direct implication of this finding is support for early adoption of ABA techniques; indirectly, the study supports the importance of early identification of ASD to enable early intervention.

Interestingly, the two oldest groups showed the greatest reduction in restricted repetitive behaviors, while RRBs increased in the two younger groups. This may be unique to this particular sample. A large number of older participants had high levels of RRBs, and as already stated, the intervention was most effective in children with high initial level of RRBs. As would be expected, the remaining child variables (eye contact and compliance) were most affected in the youngest children, with minimal effect observed in the other age groups.

Symptomology. Level of initial combined symptomology served as a moderator of intervention effect. In all parent and child variables, children with lower combined

symptomology had greater response to intervention than those with higher symptomology**,** consistent with findings of other researchers (Zachor & Ben Itzchak, 2010). This result was likely due to the impact of greater impairment of children with higher symptomology. The implication of this result is that the intervention is likely not a good fit for children with greater impairment as these children typically need more intense therapy.

This result at first glance appears contradictory to earlier results that showed the intervention to be effective in children with high levels of symptoms. The distinction lies in the definition of symptomology. The earlier result looked at symptoms individually; an individual participant may have low levels of eye contact but be relatively unimpaired in other areas. When analyzing for moderator effects, symptomology as a whole was considered. Thus, participants with high symptomology expressed high levels of impairment in multiple areas, resulting in a higher level of impairment overall.

Hyperactivity. Hyperactivity was found to be a moderator of effect. Across all measures, high levels of initial hyperactivity correlated with greater effect size, while low levels of initial hyperactivity correlated with essentially no response to intervention. The connection between hyperactivity and effect was especially notable in parental action, eye contact, and compliance. ADHD is a commonly comorbid with ASD, and this combination adds to individual impairment, reduced quality of life, and added stress in the family (Harpin, 2005). The results of this study suggest that this intervention may be particularly effective for treating comorbid ASD and ADHD.

Prior services. One area of concern driving this study was the need to extend effective therapies to populations with limited or no access to intervention. Results of this study showed that access to prior services was not a moderator of effect size. In fact, on multiple measures,

children and parents with no prior history of special services had greater response to intervention that those who had accessed services. The encouraging implication is that the program may be effective in areas that are currently underserved or completely unserved.

Parent education. For parent variables, response to intervention increased as the educational level of the parent increased. This pattern held for child variables with the exception of eye contact, in which the highest effect was seen in the college group. Smallest effect size was seen consistently in the group with the lowest educational attainment. This result was unexpected, as it was assumed that parents with higher educational attainment were more likely to have the resources to access therapy through research or greater socioeconomic status. Unfortunately, this result suggests that the intervention may not be well suited to expansion into the rest of Macedonia and other parts of the developing world, where educational attainment is lower than in the study sample. The intervention materials were written and training presented by people in graduate school programs and university professors. In addition, training was conducted quite quickly, in one session, and relied substantially on written materials. It is possible that this combination of methods may be ill suited to people with lower levels of education or literacy. Care should be given in the future to adapting materials and presentations to a slower pace, lower reading levels and include more repetition and practice, which may adjust for different learning abilities.

Research Question 4: Potential Mediators

Parent Action. It was predicted that intervention effectiveness would be related to level of parent action, but this variable was found to have a mediating effect for only four participants for eye contact and compliance and only two participants for RRB. Mediator analysis was constrained because some parents did not complete post-intervention ratings, as well as by the

fact that ratings were not independently verified and not operationally defined. Additionally, three parents rated themselves as being maximally active for all 20 days on which they reported. Although these issues require that results be interpreted with caution, it is worth noting that in every instance where parent action increased, eye contact and compliance had noticeable increases. In contrast, among participants who did not increase in action, only 3 out of 15 (20%) increased in both eye contact and compliance. When parent action increased, 9 of the 15 of children showed decreased RRB. With no increase in parental action, the proportion was reversed: 10 of children did not show decreased RRB. It would appear that level of parent action was a considerable factor in the success of this intervention.

Acquisition of intervention. Analysis of the effect of acquisition of the intervention showed that this variable had no stable effect on child outcomes. Although initially surprising, this result may point to the effectiveness of training. Differences in acquisition were small, and the majority of parents were able to achieve mastery of the strategies, the only exception being two parents in one of the three interventions. This resulted in a fairly homogenous group of parents with regard to skill acquisition. Future research should perhaps focus on implementation of strategies rather than skill acquisition.

Implications for Practitioners

Implementation of an intervention similar to the one in this study may address many of the issues faced by individuals, families, and societies dealing with the impact of ASD. ABA techniques in general and this intervention specifically were effective in reducing challenging behavior associated with ASD. The intervention focuses on providing behavioral tools to parents, who report lack of appropriate parenting strategies as a major source of stress (Fox, 2002). The intervention is extremely low cost, providing positive impact without increasing the already

burdensome outlay of public and private resources (Ganz, 2006). This is of particular importance in developing countries, where treatment of youth with disabilities is of low priority compared to more pressing public health concerns (Durkin, 2002).

Cost and intensity of commitment are obstacles that prevent families from accessing ABA therapy, despite evidence supporting this approach for children with ASD (Suppo & Floyd, 2012). This intervention suggests that benefits of ABA therapy can be achieved by parents within the family setting, reducing both barriers. Thus, this study may support parent training in ABA approaches as a valid and effective method of providing therapy in situations where access to ABA therapists is precluded. Though constrained in scope, this study suggests in concert with previous findings that parents can be effective even in the absence of continuing consultation with professionals (Granpeesheh et al., 2009; Suppo & Floyd, 2012).

This study was set in a developing country, but the findings may inform school psychology practice in the United States, as well. The National Association of School Psychologists identified behavioral coaching, parent training, development of pro-social skills and the promotion of dependable parenting practices and home interventions as integral parts of the school psychology practice model (National Association of School Psychologists, 2010). This study supports provision of parent training in behavioral techniques as an effective tool for school psychologists in accomplishing these goals.

Limitations and Future Directions

This study is limited by a number of factors associated with international research. Chief among these is the inability to verify diagnosis of ASD. Differences exist in standards and practices related to diagnosis between the United States and Macedonia, and this, combined with limited time in-country, precluded an independent verification of diagnosis. Though the study

design included a survey of symptoms that allowed for some substantiation, future research will be strengthened by standardized verification of diagnosis.

Parent report of variables was not standardized or operationally defined, lending a degree of subjectivity to data. Additionally, there was no independent assessment of variable levels either pre- or post-intervention, leading to over reliance on parent report. Again, this was a factor of restrictions inherent in international research, including limited time in country. Results would have been strengthened by in situ observations, operationalized definitions, and training for parents in rating symptoms and behaviors.

The study did not provide a measure of social validity. An informal measure of social validity can be assumed from the willingness of most adult participants to continue in the study and provide post-intervention data. Only one participant actively refused to continue participation in the project due to lack of perceived utility. One other participant did not complete post-intervention measures because she was in the hospital. Future studies should consider including measures of social validity.

Sample size and diversity is another limitation of this study. As a convenience sample identified from members of an advocacy group attached to a university in a major metropolitan area, this sample is over-representative of educated, urban, middle class, active parents with access to information and services regarding ASD and therapies beneficial for children with ASD. Even within this small and fairly privileged sample, distinct differences were observed between groups defined by education level, suggesting that the results of this study may not generalize well. Particularly considering the needs of other populations, notably less urban and lower socioeconomic status, future studies should seek to include greater diversity.

The short-term nature of this study suggests another area for future research. Data were collected for 10 days directly post-intervention with a parent rating measure conducted one month post-intervention. It is possible that results in several areas, notably parent confidence, family distress, and parent action may be susceptible to change over time. Additionally, given the rigidity and aversion to change common to ASD, child variables are susceptible to response to intervention that may not have continued over time. Thus, future research should include data collection and follow up over a longer period of time to note long term effects of the intervention.

Conclusion

The results of this study suggest a number of conclusions. First, parents in Macedonia were capable of developing competence in ABA interventions. Second, these interventions were effective in improving common symptoms of ASD in children in Macedonia. Third, a number of factors moderated intervention effect, and are thus likely to predict populations that are more likely to benefit from the intervention. Fourth, as a complex system involving unique individuals, there are multiple factors which mediated intervention effect. Among these were parent action and degree of acquisition. However, there appear to be other factors that combined to determine response to intervention.

In conclusion, we feel this study strongly supports the use of parent-delivered intervention to extend the benefits of ABA therapy to children with ASD in developing countries and other environments in which the therapy might not otherwise be available. ABA has been established empirically as an effective therapy for children with ASD. However, people in developing countries, including Macedonia, have trouble overcoming barriers to ABA therapy, including a lack of therapists, lack of coverage for services, and the cost, duration and intensity

of treatment. Although further research is required to verify and extend the findings of this study, our results show that parents were able to deliver ABA therapy at an effective level, suggesting that this may be a route to provision of therapy to people and areas without current access.

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APPENDIX A: REVIEW OF LITERATURE

Introduction

ASD is recognized across the globe as a public health concern due to high rates of prevalence and the level of impact the disorder has on the individual, their family, and community services (Simonoff et al., 2008). Determining exact prevalence rates globally is complicated by the fact that there is no internationally accepted standard of diagnosis or method of data collection (Metts, 2004). Conservative estimates are that ASD occurs in at least 1% of the population globally (Simonoff et al., 2008). The World Health Organization puts the overall global prevalence at 1 in 160 children, with incidence rates ranging widely between countries. In the United States, the prevalence rate nationwide is estimated to be between 1 in 45 and 1 in 88 (Wingate et al., 2014; Pastor & Reuben, 2008). Incidence of ASD varies between genders, ethnic groups, locations, and socio-economic levels (Baio, 2012; Developmental, 2014). Identifying effective and economical methods to moderate symptoms of ASD will improve individual outcomes and reduce societal costs. To do this, it is vital to understand what is known about Autism Spectrum Disorder (ASD) and its impact on individuals, families, and society, as well as what aspects of intervention have proven effective in reducing this impact. Additionally, when considering international applications, it is important to address the status of individuals with disabilities in developing countries such as the Former Yugoslav Republic of Macedonia.

Autism Spectrum Disorder

According to the DSM 5 (2013), Autism Spectrum Disorder is a lifelong neurodevelopmental disorder characterized by persistent deficits in communication and social interaction. Individuals with ASD exhibit repetitive behaviors and restricted interests. Although symptoms can range from mild to severe, the disorder is marked by significant impairment in

function within typical environments. The disorder may or may be accompanied by intellectual disability (American Psychiatric Association, 2013). Individuals with ASD often exhibit problematic behaviors associated with lack of emotional regulation, distractibility, and irregular activity and thought patterns (Lainhart, 1999; Leyfer et al., 2006).

The symptoms associated with ASD affect individuals and their communities in a number of ways. The disorder is a substantial public health consideration due to its persistence across the lifespan combined with the degree of functional impairment experienced by individuals with the condition. (Leyfer et al., 2006; Simonoff et al., 2008). Financial and human costs associated with ASD include cost of treatment, non medical costs such as respite care or accomodations to home and school, and indirect costs in terms of loss of human potential and productivity of both the individual and their caregivers (Ganz & Ganz, 2007). Contributing to this societal impact is the current lack of effective and economical therapies available to moderate symptomology and reduce functional impairment (Ganz & Ganz 2007; Leyfer et al., 2006). An understanding of the impact of ASD on individuals, families, and societies in order to appreciate the need for effective intervention.

Impact on individuals. Individuals with ASD often exhibit antisocial and disruptive behaviors, including tantrums, self-injury, aggression, restricted interests, and rigid repetitive behavior rituals (Lee, Harrington, Louie, & Newschaffer, 2008) These symptoms often result in social, academic, and individual impairment for both individual and their family (Kheir et al., 2012).

In childhood, these symptoms often lead to social isolation, low levels of independence, and poor academic attainment compared to peers, both those who are typically developing and other children with developmental disabilities. Children with ASD are also more likely than their peers to experience bullying, repeat a grade, and acquire excessive absences (Chamak & Bonniau, 2016; Curran, Sharples, White, Knapp, & Knapp, 2001; Lee et al., 2008).

Longitudinal studies of individuals with ASD reveal a lifelong pattern of impairment and lack of Quality of Life (QOL) compared to peers (Farley et al., 2009) . The World Health Organization has found that people with ASD experience discrimination and stigma and are the victims of human rights violations (Skevington, Lotfy, & O'Connell, 2004). In terms of employment (competitive or sheltered), marriage/dating, independent living, high school graduation and postsecondary education, individuals with ASD experience lower success rates and are less independent than non disabled peers (Chamak & Bonniau, 2016; Engström, Ekström, & Emilsson, 2003; Farley et al., 2009). Farley et al. (2009) found that 73% of individuals required a moderate to high level of assistance, meaning they required daily practical assistance in basic activities of daily living. Participation in school for children and adolescents and employment for adults is key to financial and psychosocial well being. A majority of people with impairing disabilities are unemployed or underemployed, and consequently lose the attendant financial, social and personal benefits (Ramadani & Madzova, 2013).

Impact on families. The impacts of ASD on family standard of living is well recognized (Jarbrink, Fambonne & Knapp, 2003). Families of individuals with ASD must weather social, financial, and employment-related costs. Due to the lifelong nature of the disorder, these issues continue to impact parents and families well past the usual age of independence, typically affecting siblings and other extended family who must take over care of the individual as parents

age and eventually die. Globally, most to all of care required by individuals affected by ASD is provided by immediate family (Jarbrink et al, 2003; Järbrink & Knapp, 2001; Lee et al., 2008; Rosano, Mancini, Solipaca, & Solipaca, 2009). Costs borne by family include loss of time for career and leisure opportunities, loss of income related to time devoted to caregiving, and out of pocket expenses for care and intervention, transportation costs for educational and treatment opportunities, cost of medications, repair of damage, respite and child care expenses, and adaptive aids (Jarbrink et al., 2003; Rosano et al., 2009). In part due to these issues, it is estimated that families spend three times more to raise a child with a disability than a typically developing child. Jarbrink and Krister (2003) found the cost to families to be £397 GBP ($515 USD) per week. Ganz and Ganz (2007) estimated the lifetime cost of care (direct and indirect medical and non-medical costs) for a person with autism to be $3.2 million USD, with a cost of just under $1 million USD in lost economic opportunity to parents alone.

Not surprisingly, studies have found a correlation between disability and poverty. One study found that 28% of families with children with disabilities were living below the poverty level, compared to 16% of families with no children with disabilities. (Emerson & Emerson, 2007; Park, Turnbull, & Turnbull, 2002; Rosano et al., 2009).

Not all impacts are monetary in nature. ASD associated with compromised quality of life for both the individuals diagnosed and their families (Chamak & Bonniau, 2016). In a recent study, all parents reported that caring for their child had negatively impacted their careers, increased personal stress (notably regarding child rearing and financial issues), reduced time for personal pursuits, and greater family and personal distress, including depression and suicidal ideation (Chamak & Bonniau, 2016; Fox, Vaughn, Wyatte, & Dunlap, 2002; Jarbrink et al., 2003; Lee et al., 2008; Mugno et al., 2007; Suppo & Floyd, 2012). Parents of individuals with

ASD report higher levels of isolation, as stigma and intolerance of idiosyncratic behaviors lead families to avoid social contact outside the home, including avoidance of religious meetings (Fox et al., 2002). Park, Turnbull and Turnbull (2002) identify three factors that define quality of life at the family level: all family members have their needs met, enjoy family together time and have opportunities to pursue their own goals. Clearly, life on the spectrum impacts all three of these aspects.

Impact on the family is correlated with the diagnosed individual's ability to communicate: family stress decreases as communication skills increase (Lee et al., 2008). Similar correlations exist with behavior; considering that behavior is a primary cause of stress, decreasing problem behavior is connected to decreased family stress. Conversely, research showed that increased stress among caregivers is linked to increased intensity of symptoms in the individual diagnosed with ASD (Graetz, 2010; Suppo & Floyd, 2012).

Impact on society. There are tremendous societal costs associated with ASD. Education, social services, employment, and medical systems expend substantial resources to serve affected individuals and their families. In a 2001 study of the economic impact of autism in the UK, Jarbrink and Krister (2003) found the cost to communities to be £425 GBP ($551 USD) per individual per week. This amount includes cost of special education services, therapy services, transportation and independent living services, when applicable. In the United States and the United Kingdom, total societal cost per annum is estimated in the tens of billions; one study assessed the cost in the US to be $35 billion USD per year (Elsabbagh, Divan, Koh, & Kim, 2012; Ganz, 2006; Ganz & Ganz, 2007). Considering the prevalence of ASD and the magnitude of the disorder's impact on individuals, families and communities, development of effective and economical interventions is essential. It is important to consider implications on intervention

design of common characteristics of the disorder, including symptomology, sources of parental stress, and the significance of comorbid disorders such as Attention Deficit/Hyperactivity Disorder (ADHD).

Implications for intervention. Such interventions should aim to increase independence of the individual, reduce familial stress, and enable greater integration of both into the larger society. Communication skill deficits and restricted repetitive behaviors both significantly impact independence and integration; thus, research should seek to improve function in both areas. In a 2002 study, Fox and associates found that a major source of parental stress was a lack of effective discipline strategies. Parents reported that typical approaches to discipline (time out, ignoring, earning/losing activities or rewards) did not seem to work for their children with ASD, and that they did not know how else to respond. Thus, providing parents with effective strategies for shaping their children's behavior should positively impact family stress.

Comorbidity

Further complicating the treatment of individuals with ASD is the existence of comorbid disorders. A significant number of individuals with ASD exhibit additional neuropsychiatric symptoms that increase functional impairment (Leyfer et al., 2006). Of these comorbid conditions, hyperactivity and ADHD are the most prevalent (Leyfer et al, 2006). A recent study found that 53% of children with ASD exhibit hyperactivity, impulsivity, and/or other subclinical aspects of ADHD, with more than half of that number, 29%, meeting the diagnostic criteria for ADHD (Leyfer et al., 2006). Wozniak et al. (1997) placed the level of ADHD symptoms among individuals with ASD between 29% and 73%. In this subpopulation, inattention was found to be particularly apparent in nonpreferred activities. In many individuals, this coincided with activities that are important to daily function and academic attainment, such as school,

homework, and other intellectually demanding activities (Leyfer et al., 2006). The most recent update of the DSM recognized the relevance of this comorbidity by updating diagnostic criteria to allow for the concurrent diagnosis of ASD and ADHD (American Psychiatric Association, 2013)

Attention Deficit Hyperactivity Disorder/ADHD. Individuals with ADHD can display a nexus of additional symptoms that impact appropriate role function. These can include distractibility, forgetfulness, over-activity, impulsivity, inability to inhibit unwanted behavior, deficits in working memory, difficulty activating and maintaining attention, lack of motivation and persistence, inability to organize or prioritize, and executive function deficits (American Psychiatric Association, 2013; Greenbaum & Markel, 2001; Stahr, Cushing, Lane, & Fox, 2006; Storer, Evans, & Langberg, 2014). This behavioral and cognitive dysfunction impacts individuals with ADHD and their families.

Impact on individuals. The person with ADHD experiences difficulty attaining educational and professional success, requires a greater than average share of educational and social resources and reports lower levels of self-esteem, self-efficacy and satisfaction than typical peers (Barkley, 1997; DuPaul, Weyandt, & Janusis, 2011; Kessler, Adler, & Barkley, 2006). These symptoms adversely affect school performance in a variety of ways. Students with ADHD often come to class unprepared, fail to begin tasks in a timely manner, neglect to write down assignments, struggle to maintain effort, and have difficulty organizing time and materials (Meyer & Kelley, 2008). These behaviors limit acquisition of skills and negatively impact relationships with peers and teachers. They commonly underachieve academically, performing below expectation both in the classroom and on standardized tests (Barkley, 1997; DuPaul et al., 2011). Students with ADHD are also more likely to be retained, have poorer school attendance

and are less likely to graduate from high school than their peers (Barkley, Murphy, & Fischer, 2010; DuPaul et al., 2011). These findings are particularly concerning given the evidence ADHD, like ASD, does not significantly resolve with age and is related to relationship and employment issues later in life (Trout, Lienemann, & Reid, 2007).

Students with ADHD present a burden on the school system as a whole. Behaviors common to children with ADHD are disruptive and negatively impact attention and attainment for both the child affected and other students in the classroom; additionally, the behavioral and academic needs of student with ADHD can reduce whole class instructional time by monopolizing teacher attention (Barkley et al., 2011).

The negative impact of ADHD can persist throughout adulthood. Adult individuals with ADHD exhibit increased rates of unemployment and divorce, as well as unhealthy habits such as poor nutrition, inadequate sleep, and smoking (Fayyad et al., 2007; Kessler et al., 2006).

Impact on families. Families of individuals with ADHD experience heightened levels of stress (Harpin, 2005). Parents report conflicts over organization and time management, chores, homework, task initiation, attention to detail, remembering directions, and emotional regulation (Greenbaum & Markel, 2001; Kessler et al., 2006). This heightened level of conflict may explain the increased levels of family and marital problems and parent-child dysfunction reported by families of children with ADHD (Harpin, 2005). Research has shown that parental stress levels are intensified by a lack of parent skill and by the presence of one or more comorbid disorders. (Greenbaum & Markel, 2001; Harpin, 2005).

ASD and ADHD are two common disorders that can significantly impair function and quality of life for the individual and their families. Unfortunately, these two conditions often occur together, compounding the disruption to individual, family, and community life. The

confluence of symptoms associated with these two disorders require additional services in order to enable individuals to participate in education and their communities. Significant research has been directed to developing interventions to address problematic behavior in ASD and ADHD, separately, but there is little research focusing on treatment outcomes for individuals with both disorders.

Intervention

Many options exist to address problematic behavior associated with autism. Most are not backed by empirical research. However, the efficacy of Applied Behavioral Analysis (ABA) in treating individuals with ASD has been established in hundreds of published studies. ABA is recognized as effective by the U.S. Surgeon General, the National Academy of Sciences, and the American Academy of Pediatrics (Granpeesheh, Tarbox, & Dixon, 2009). However, it is important to understand Applied Behavior Analysis (ABA), its efficacy, obstacles to implementation, and characteristics of effective parent training programs.

Applied Behavioral Analysis. Applied Behavioral Analysis uses the principles of behaviorism to define the function of behavior and design interventions to supplant problem behaviors with more acceptable ones (Granpeesheh et al., 2009). Behaviorism posits that all behavior is maintained by consequences and that consequences can be manipulated in order to shape behavior. ABA involves analysis of an individual's behavior through direct and indirect observation to determine the cause, function, and reinforcing influences contributing to that behavior. Environmental factors can then be changed to increase expression of desired behaviors and decrease expression of problem behaviors (Cooper, Heward, William, & Cooper, 2007; Granpeesheh et al., 2009).

Efficacy of ABA. ABA interventions have proven effective across genders, ages, and symptom typology and severity. Treatment has been shown to produce gains in IQ and improvement in adaptive function, represented by movement from more severe to less severe classification and placement in general education environments. As might be expected when working with a spectrum disorder, response to treatment was found to be highly variable, but in the aggregate, nearly 75% of participants experienced gains in at least one area, and these gains were maintained over time. Efficacy of ABA treatment appears to be related to early intervention, intensity, duration, consistency, and scope. Although gains were statistically significant with as few as 10 hours a week of intervention, improvement increased with additional hours of intervention. Similarly, intervention was most effective when implemented in early childhood, with gains decreasing with age. Effects increased as the time of intervention lengthened. They were most pronounced when the scope of the training involved all problem behaviors rather than focusing on only one. Although individuals were serviced by "disparate" providers, the nature of the provider had no effect on treatment outcome. In fact, a consultative approach, in which caregivers were trained by professionals to implement treatment day-to-day, was found to be as effective as professional implementation (Granpeesheh et al., 2009; Suppo & Floyd, 2012).

Obstacles to implementation. ABA is proven effective, but the nature of the treatment presents significant obstacles to implementation. Granpeesheh et al. (2009) found that, for optimal effect, ABA therapy should be conducted 40 hours per week for as long as possible (best results were garnered in an intervention that was conducted for 4 years.) For many families, that level of commitment and time are difficult. In the United States, additional obstacles include cost and availability of ABA. Insurance does not, as a rule, cover the cost of ABA treatment, which is

often several hundred dollars per hour. Additionally, the number of ABA professionals cannot keep up with the demand nationwide, meaning access is to a large extent determined by location (Suppo & Floyd, 2012).

Parent training. Noting the effect of these obstacles to care, researchers considered if parents and other nonprofessional caregivers could be trained to adequately administer therapeutic interventions. It is well established that, if provided appropriate support, non-professionals can be as successful in conducting interventions as practitioners (Koegel, Bimbela, Schreibman & Schreibman, 1996). These results have been obtained across multiple modes of training and for diverse types of intervention (Anan, Warner, McGillivary,Chong, & Hines, 2008; Ingersoll & Dvortcsak, 2006; Suppo & Floyd, 2012; Suppo & Mayton, 2014). Parents have been successfully trained in clinics and in their own homes, by practitioners and non-practitioners, in person and via website, video, and printed materials. Effective teaching methods include role playing, modeling, and coaching (Suppo & Floyd, 2012; Suppo & Mayton, 2014).

Through these training methods, parents have been able to effect positive changes in a wide variety of behaviors, including increasing functional communication (both verbal and non-verbal), joint attention, eye contact, and adaptive function. The parents themselves have noted positive outcomes related to their own feelings of competence, reduced stress, increased positive interactions with their children (Anan et al., 2008; Meadan, Ostrosky, Zaghlawan, Yu, & Yu, 2009; Moes & Frea, 2002; Reagon & Higbee, 2009; Solomon, Howard, & Brit'ny, 2015; Vismara, Colombi, & Rogers, 2009).

An important benefit to parent-delivered intervention is the ability to fit training and delivery into the family schedule (Suppo & Floyd, 2012). This is an especially important factor considering that increased intensity and duration of intervention produces greater results in

children with ASD. Furthermore, parent training surpasses other modes of intervention in relation to the locus of intervention and its effect on generalization. Treatment of individuals with autism is often complicated by a noted difficulty to generalize skills across settings. Teaching of skills in natural environments is particularly important in children with ASD, and is a natural component of parent training models (Meadan et al., 2009). Parent-delivered training that focuses on improving social and communication skills may be especially impactful for individuals with ASD.

Pyramidal Training. Parent training has shown promise in overcoming some obstacles to ABA intervention. However, parent training was initially dependent on availability of qualified trainers. Issues of cost, limited numbers of ABA therapists and proximity remained obstacles to parent training. Researchers investigated the potential of pyramidal training networks as a method for disseminating training to otherwise underserved populations (Hansen et al., 2017). A pyramidal training model involves successive tiers of trainers and trainees. The primary tier involves lay people being trained by professionals. Once the primary tier demonstrates mastery, they train tier 2. Initial results indicate that parents are capable of both acquiring ABA skills and subsequently teaching them to others (Hansen et al., 2017).

Improving Social Skills

The body of research into ASD showed a hopeful trend. Lifetime outcomes for adults with ASD have been rising as society has become more aware of their needs (Gray, 2009). Specifically, outcomes have become more positive with the opening of increased opportunities for work and education (Eaves & Ho, 2008). This suggests that interventions that improve prosocial behavior and greater integration into society could lead to improved lifetime outcomes.

Prosocial skills. A primary characteristic of ASD is difficulty in developing social relationships (American Psychiatric Association, 2013). Interventions aimed at reducing the impact of ASD must address this lack of prosocial skills. Studies support teaching joint attention and eye contact as primary prosocial skills (Charman, 2003; Drew et al., 2002).

Joint attention is the sharing of attention to an object or occurrence between two individuals. Examples of joint attention are pointing and following another's gaze. Improvement in joint attention (and the related skill of imitation) leads to improved language and communication skills (Charman, 2003; Drew et al., 2002).

Initiating, responding to, and maintaining eye contact are important precursors to other social skills (Jeffries, Crosland, & Miltenberger, 2016). Eye contact is also recognized as an essential component of attention, a role which makes eye contact important in learning and mastery of academic and life skills. Lack of eye contact is a hallmark symptom of ASD; issues of attention impair attainment in children with ADHD (American Psychiatric Association, 2013).

Communication skills. Research has determined that improved language abilities are key to allowing individuals with ASD to achieve positive outcomes, expanding independent living and attainment of educational and employment goals. In contrast, more severe communication impacts are associated with poor outcomes (Chamak & Bonniau, 2016; Drew et al., 2002; Lee et al., 2008). This suggests that interventions aimed at improving quality of life should address communication deficits. It is important to understand the role of early intervention in addressing these deficits.

Early implementation. Research clearly showed that intervention in early childhood correlates with greater reduction in symptomology and functional impairment for individuals with ASD (Drew et al., 2002; Webb, Jones, Kelly, & Dawson, 2014). The social and

communication deficits expressed by children with ASD interfere with attainment of early developmental milestones that are predictors of later success (Wodka, Mathy, & Kalb, 2013). Due to brain development in early childhood, opportunities for skill development exist at this stage of maturity that may not be available later in life. Early intervention leads to early integration into typical educational and social settings, which may enable children with ASD to make greater gains (Webb et al., 2014). As vital as it is to improve the lives of individuals with ASD in the United States, the importance of these gains takes on greater significance when considered in light of the status of people with disabilities in the developing world.

The Status of People with Disabilities in Developing Countries

The need for interventions for individuals with ASD/ADHD is clear. The condition is prevalent, permanent, and problematic. It impacts, often to a great extent, both the individual and their family, carrying the burden of financial, social, career, and psychological costs. These impacts are difficult to manage without specialized help and last throughout the individual's life. Although effective treatments exist, to date, access to them in the United States is limited by the cost of treatment, intensity and duration of treatment, and access to qualified practitioners. The situation faced by individuals with ASD/ADHD and their families in developing countries is far bleaker.

There is currently no standard protocol for determining the status of a country as either developed, developing, or least developed. In general, the latter terms connote nations in which levels of infrastructure, industrialization, income, and quality of life are lagging. Typically, global institutions, including the United Nations, the World Trade Organization, and the International Monetary Fund, make the determination slightly differently, depending on their objectives and member nations. Commonly, the classification includes income level (either

Gross Domestic Product or Per Capita Income), indicators of public health (infant mortality rate, life expectancy at birth), and, in the case of the United Nations, educational opportunities (Nielsen, 2011). The World Bank (2016) defines developing countries as those having a per capita income of less than $12, 475 USD.

As discussed earlier, individuals with ASD face significant challenges which impact both their own quality of life and that of their families. This impact is amplified in developing countries. Countries with less infrastructure, weaker economies, and less advanced health care systems present additional challenges to people with disabilities and their caregivers. Extensive research on quality of life for people with disabilities in developing countries exposes trends that are worrisome.

Although exact numbers vary between specific countries and differ slightly depending on statistical methodology, the trend is clear: disability rates are significantly higher in developing nations than in higher income countries (Durkin, 2002). A number of potential factors increase the prevalence of disabilities in developing countries. These range from increased prenatal exposure to toxins (due to poor sanitation, poor air and water quality), cultural and religious attitudes toward child bearing (mothers bearing children earlier and/or later in life), limited access to effective health care, unhealthy birth practices, and lack of implementation of prevention measures. Prevalence rates gain impact when one considers global birth rates: 80% of births each year occur in developing and less developed countries (Durkin, 2002).

Treatment of children with disabilities is impacted in developing countries by “a tendency among health providers to view childhood disabilities as a low priority” (Durkin, 2002, p 206), possibly due to the prevalence of other, more tractable conditions, but also potentially related to increased infant and child mortality rates (Durkin, 2002; UNICEF, 2001).

Additionally, developing countries tend to face limitations in health and education services that negatively impact access to treatment; in countries where basic health care can be hard to access, specialized treatment for children with disabilities may be non-existent.

Developing countries have higher poverty rates than developed countries. Durkin (2002) found that low socioeconomic status is "the strongest and most consistent predictor" (p. 210) of intellectual disability throughout the world. In addition to increasing the likelihood of a cognitive disability, low income presents additional barriers to treatment. Beyond the simple cost of treatment, there are attendant travel, time and supply costs. These costs can multiply in developing countries, where health system limitations may require extensive travel to treatment centers. Lack of income may also make intervention a low priority within the family, as basic survival and procurement activities usually take precedence over treatment (Durkin, 2002; Park et al., 2002).

Status of Persons with Disabilities in Macedonia

By all parameters for classifying countries as developing or less developed, the Former Yugoslav Republic of Macedonia is a developing country. As such, life in Macedonia presents specific challenges for people living with ASD. To understand these challenges, it is necessary to know about the country, the incidence of disabilities, prevailing cultural attitudes toward the disabled, as well as access to education, treatment and employment.

Macedonia. Macedonia is a small country (roughly the same size as the U.S. state of Vermont) in southeast Europe. It is bordered by Serbia and Kosovo to the North, Bulgaria to the East, Greece to the south, and Albania to the West. As reported by the Central Intelligence Agency (2016), demographically, Macedonia is dominated by two primary ethnic groups. The population is majority Macedonian, with a sizeable (25%) Albanian minority. Language and

religion are in keeping with the ethnic divide, Macedonian and Orthodox for the majority, with a minority of Albanian Muslims. Life expectancy at birth is 76, with a relatively high (for Europe) infant mortality rate of 7.5/1,000. Health expenditures are 6.5% of GDP, which ranks Macedonia 79th in the world; physician density is 2.6/1,000. The educational system is extensive, with free public education provided for 13 years. Macedonia's economy is primarily service related. Unemployment is high at 27% and more than 30% of the population lives below the poverty line. (For comparison, the United States spends 17.1% of GDP on health care, has 5.2% unemployment, and 15% of people living in poverty.). Macedonia's location just north of Greece on the land route between the Middle East and Europe has made it, in recent years, a primary transit point for refugees from Syria. Starting in 2015 and continuing through September of 2016, Macedonia saw 477,931 refugee arrivals, further straining the already struggling economy (CIA, 2015).

Incidence of disability. Macedonia reports a significantly higher rate of disability than developed countries. In 2005, nationwide prevalence rates averaged 10% of children between the ages of 2 and 9 years old. Identification rates were essentially stable between urban and rural populations. However, incidence was almost twice as high in families who were at or below the median income level (State Statistical Office, 2007).

Cultural acceptance of disability. There is a strong negative social stigma regarding people with disabilities in Macedonia. Parents report feeling judged because of their child's behavior or condition, and describe avoiding social interactions because of their child's behavior. Ramadani and Madzova (2013) found that stigma pervades adult interactions as well, as seen in negative stereotypes among employers and a general societal outlook that individuals with disabilities are not full members of society and are treated as objects of charity. The same study

found that Macedonians tend to treat individuals with disabilities as children, regardless of actual age or ability.

Education. Although education is comprehensive and includes services for children with disabilities starting as early as 8 months, data suggest children with significant disabilities are underserved. Gottlieb et al. (2009) reported for UNICEF that only 10.7% of children have access to early childhood education. This statistic is particularly concerning in relation to children with ASD given the known impact of early intervention on maximizing positive outcomes.

In Macedonia, children with mild disabilities are educated with typically developing peers in the neighborhood school, while children with more profound impairments are educated in special schools. There are no schools specifically dedicated to educating children with ASD. Data from 2010/2011 show that just .5% of children were attending special schools, while Gottleib, Maenner, Cappa, & Durkin (2009) reported just 1% of Macedonian children qualified for special education. These rates are far lower than prevalence estimates would predict (Ramadani & Madzova, 2013; Ramo-Akgun, Stanojkovska-Trajkovska, & Petrov, 2011).

Access to treatment. Access to treatment is problematic and highly dependent on location, with populations in urban centers more likely to have opportunities for treatment (Suppo & Floyd, 2012). Macedonia suffers from a lack of psychologists and education specialists, which further impacts attainment of effective intervention. In 2008, Jimerson found there were no professionals functioning as school psychologists in Macedonia. In a recent study by Salomone et al. (2016), only 21% of Macedonian children with ASD were receiving behavioral therapy, and 12% were receiving no treatment of any kind. These statistics place Macedonia in the bottom third of European countries in access to treatment, lagging significantly behind even other East European nations (Salomone et al., 2016)

Employment. Although the Macedonian government is taking steps to move the country towards greater inclusion, individuals with disabilities are typically excluded from the work force and the financial and psychosocial benefits derived from employment. Currently, the only employment options for individuals with significant disabilities are sheltered work environments. More then one third of welfare recipients in Macedonia are individuals with disabilities (Ramadani & Madzova, 2013).

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APPENDIX B: INSTRUMENTS

Institutional Review Board
for Human Subjects

Brigham Young University
A-285 ASB Provo, Utah 84602
(801) 422-3841 / Fax: (801) 422-0620

October 10, 2016

Professor Blake Hansen

340-C MCKB

Campus Mail

Re: X 16007

Parent Training in Southeast Europe: Strengthening Families of Children with Autism in Macedonia

Dear Professor Blake Hansen

This is to inform you that Brigham Young University's Institutional Review Board has reviewed your Amendment dated 10-5-2016 for the above captioned study. The changes to the study have been approved.

Your approval is contingent upon the receipt of the following:
- So that our files are complete, please forward the email exchange with Dr. Yudelevich.

A copy of the Informed Consent Document, approved as of 10-10-2016 is enclosed. No other consent form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject must be given a copy of the signed consent form.

The approved period for the study ends on 1-19-2017. Any additional modifications in the research protocol, study site, personnel, or consent form during this time period must first be reviewed and approved by the IRB.

If you have any questions, please let us know. We wish you well with your research.

Sincerely,

Robert Ridge, PhD, Chair
Sandee Aina, MPA, Administrator
Institutional Review Board for Human Subjects

Согласност за учество во истражување

Вовед

Ова истражување е спроведено од Blake Hansen, Доцент професор на „ Brigham Young“ универзитет, Прово, Јута, САД, со цел да се пронајдат најефективните методи за учење на родителите на деца со посебни потреби како да се справат со едноставни но истовремено и предизвикувачки однесувања кои се појавуваат кај нивните деца како и способности за учење. Вие сте поканети да учествувате бидејќи имате дете со посебни потреби.

Процедури

Доколку се согласите да учествувате во истражувањето, ова е распоредот на активностите кои следат:

- Приближно помеѓу 1-ви и 7-ми Април, ќе бидете повикани на информативна сесија за истражувањето и обуката. Ќе бидете информирани за истражувањето и ќе биде побарано од вас да пополните неколку формулари. Оваа активност би траела околу 30 минути. Ќе бидете дополнително известени за времето и локацијата каде што ќе се одржи информативната сесија.
- За време на информативната сесија ќе Ви биде доделен формулар кој ќе треба да го пополнувате во текот на 10 дена. Формуларот би го пополниле за помалку од 5 минути секој ден.
- Помеѓу 7-ми и 24-ти Април би можеле да направите видео снимка од вашата интеракција со вашето дете. Видео снимката би требало да е помалку од 5 минути.
- Приближно помеѓу 25-ти и 27-ми април ќе се одржи двочасовна обука. Ќе бидете снимани за време на обуката. Ќе биде побарано од вас да пополните неколку формулари. Ќе бидете дополнително известени за времето и локацијата каде што ќе се одржи обуката.
- Помеѓу 1-ви и 31-ви мај ќе биде побарано од вас повторно да пополнувате формулар во текот на 10 дена. Формуларот би го пополниле за помалку од 5 минути секој ден.
- Помеѓу 1-ви и 31-ви мај би можеле да направите видео снимка од вашата интеракција со вашето дете. Видео снимката би требало да е помалку од 5 минути.
- Прибложно помеѓу 1-ви и 7-ми јуни ќе биде побарано од вас да пополните неколку формулари. Ќе биде побарано од вас да дадете краток извештај за истражувањето и обуката и да го споделите вашето мислење.
- Ние ќе ги обезбедиме сите материјали и ќе бидеме достапни за да Ви одговориме на сите прашања кои ќе ни ги поставите.

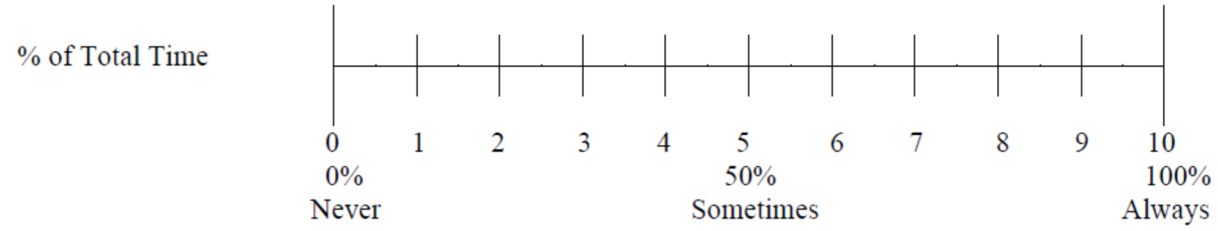
Ризици/Непријатности

Постои мал ризик за губење на приватноста преку овој истражувачки процес. Истражувачот ќе го ублажи овој ризик со тоа што нема да се користи вашето име и презиме туку целата ваша документација ќе биде нумерирана со број. Ќе ги споделуваме видео снимките со други личности само доколку вие се согласите на тоа.

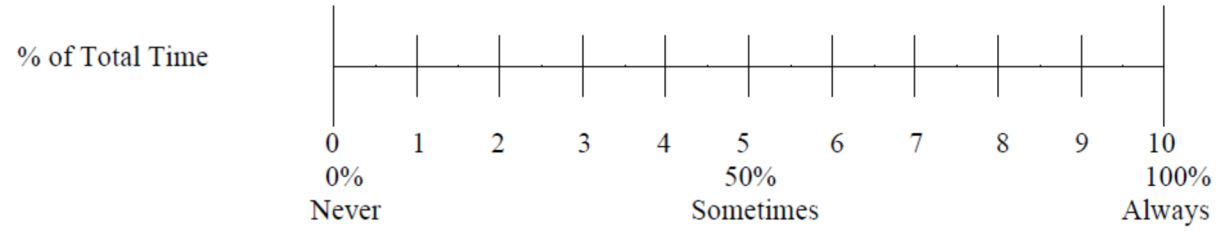
Daily Behavior Rating (DBR)

Your name: _____
Date: _____
Directions: Place a mark along the line that best reflects the percentage of total time that your child exhibited each behavior.

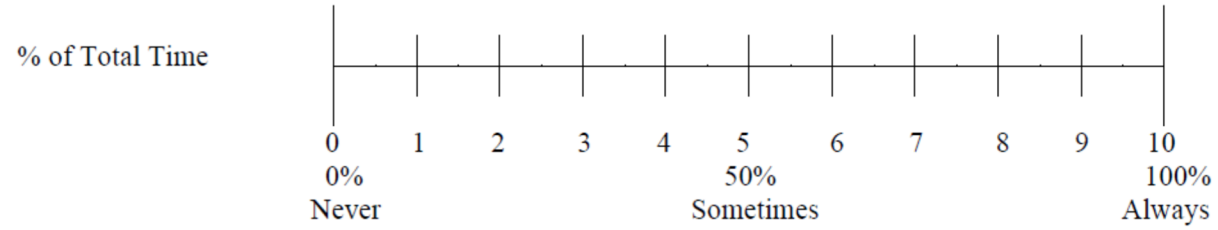
Compliant (following directions)



Eye Contact



Repetitive Behaviors



Behavior	Rate confidence in ability to manage behavior (0 – 10; 0 = no confidence, 10 = complete confidence)	How much action did you take to change these behaviors? (0 – 10; 0 = no action; 10 = extreme amounts of action)
Compliance		
Eye Contact		
Repetitive Behaviors		

Demographics Questionnaire

Your full name: _____

Your date of birth: _____

Your city of birth: _____

Your relationship to the child: _____

Your race/ethnicity: _____

Your child's full name: _____

Your child's date of birth: _____

Your child's city of birth: _____

Your child's race/ethnicity: _____

Please describe your child's disability: _____

Please describe your child's challenging behaviors:

Please describe your child's repetitive behaviors:

How many siblings does your child have and what are their ages and genders?

What is the highest level of education you have obtained:

[ ] Some high school
[ ] High school diploma
[ ] Some college or technical school
[ ] 2 year college or technical school certificate/diploma
[ ] Bachelor's degree
[ ] Some graduate school
[ ] Master's degree or equivalent
[ ] Doctoral degree (including PhD, MD, JD, EdD, etc).

Please list the educational services that your child receives and how many hours of services your child receives:

Service (example, speech therapy, reading, math, behavior, etc.)	Frequency	Number of Minutes
1.	Daily, Weekly, Monthly, Yearly	
2.	Daily, Weekly, Monthly, Yearly	
3.	Daily, Weekly, Monthly, Yearly	
4.	Daily, Weekly, Monthly, Yearly	
5.	Daily, Weekly, Monthly, Yearly	
6.	Daily, Weekly, Monthly, Yearly	
7.	Daily, Weekly, Monthly, Yearly	
8.	Daily, Weekly, Monthly, Yearly	
9.	Daily, Weekly, Monthly, Yearly	
10.	Daily, Weekly, Monthly, Yearly	

APPENDIX C: TRAINING PROTOCOLS

Verbal Praise for Compliance

When training, read the *italicized* words aloud.

Materials
Toy

Definition and Rationale
Noncompliance (not following directions) is among the most common problem behaviors in children with disabilities. The first skill we are going to learn is verbal praise for following directions. Verbal praise is when an adult says a positive comment after a child does something well. Verbal praise is important because it helps children learn. Praise is based on a principle called "positive reinforcement." Positive reinforcement is a consequence that increases a behavior. Therefore, if you want a child to do something more often, praise the behavior you want to see more often.

Step 1 – Determine which Behaviors to Praise
The first step is to determine which behaviors you are going to praise. The behaviors can be anything including behaviors such as eye contact and following directions. Verbal praise is useful for many behaviors.

Step 2 – Steps for Providing Praise

When your child does the behavior you want to praise:

1. *Look at your child.*
2. *Smile or have a pleasant look on your face.*
3. *Using an enthusiastic tone of voice, say a positive word (such as good job! Nice work!). You may also say what the child did well (for example, nice work! I like how you cleaned up your toys!)*
4. *Vary the words you use to praise. For example, say different words each time you praise, rather than saying "good job!" each time.*
5. *Praise frequently.*

Let's practice.

Step 3 - Practice
Place the toy on the floor.

Tell me to pick up this item. After I pick up the item, use a verbal praise.

Parent should tell you to pick up the item, but if they don't prompt them to do so.
Pick up the item.
Once you pick up the item, the parent should offer praise. If they don't, prompt them to do so by saying, *praise me for doing so*.

Parents have completed training when they demonstrate praise by:

(1) Looking at you
(2) Saying what you did well
(3) Using a nice voice
(4) Having a smile or pleasant look on their face

Prompting Eye Contact When Children Request

Materials
Toy

Definition and Rationale
The second skill we are going to learn is prompting eye contact. Even though eye contact is important for social interactions, many children with disabilities have difficulty giving eye contact. Therefore, it is important to teach children with disabilities to provide eye contact.

Step 1 – Find something that the child can request
The first step is to determine an item motivates the child that he/she can request with words, pictures or signs. Items can be toys, food, or any other item that the child prefers.

Step 2 – Create motivation to request the item
Once you have determined what motivates the child, block access or place the item out of the child's reach, but so they can see it. Wait for the child to request the item or prompt them to do so. The focus is on creating language and eye contact so do not have all preferred items available all of the time.

Step 3 – If the child provides eye contact when requesting the item.
If the child provides eye contact to indicate that he/she would like the item, provide the item without delay and tell the child "good job" or another positive statement after they provide eye contact.

Step 4 – If the child does not provide eye contact when requesting the item.
If the child does not provide eye contact, then wait 5 seconds. If the child does not provide eye contact after 5 seconds, prompt them to do so by saying: "look at me." If they do provide eye contact after a prompt, provide the item and tell the child good job or another positive statement after they provide eye contact.

Step 5 – Guided Practice
Let's practice.

Here is the item I like [provide item].
Hold the item out of reach.
As I request the item make sure I am providing eye contact. If I do not provide eye contact, wait 5 seconds. If I do not provide eye contact after 5 seconds, then say: "look at me". After I give you eye contact, tell me I did a nice job providing eye contact.

Parents have completed training when they can:

1. Withhold the item after a request until eye contact is provided by you
2. Prompting you to look at them if you aren't providing eye contact after 5 seconds
3. Praising you when you look at them.

Training Script: Response Interruption and Redirection

Definition and Rationale:
The skill we are going to learn is redirecting repetitive behaviors. Repetitive behaviors are common in children with developmental disabilities. They include usual hand movements, rocking, making noises repeatedly, biting fingernails, and some forms of self injury. One way to reduce repetitive behaviors is to redirect them and provide an alternative form of stimulation.

Step 1 – Identify repetitive behaviors and a competing behavior.

a. *Identify a behavior your child does repetitively.*
b. *Notice what parts of their body are used to perform this repetitive behavior.*
c. *Identify a task that uses the same parts of their body that they move repetitively.*
    - *For example, if your child shakes his hands in front of his eyes, you would select a task that uses his hands. This could be a high five, handshake, drawing, or giving him a toy. If your child makes repetitive noises, you could ask them to tell you their name or age.*

Step 2 – Gain the child's attention.

a. *Watch for your child to do the repetitive behavior.*
b. *When they are doing that repetitive behavior, get your child's attention or eye contact by saying their name.*

Step 3 – Verbal prompt for competing behavior.

a. *Ask your child to do the replacement activity or use the replacement item. Use a calm voice.*

Step 4 – Directing the child to the competing behavior.

a. *If your child does not stop the repetitive behavior or does not engage in the activity, then show your child how to do it. If the behavior does not stop, gently prompt your child by placing your hand over theirs and gently directing them to the task.*

Step 5 – Praise competing behavior.

a. *Praise your child when he/she does the task.*

Step 6 – Practice.

b. *Let's practice. Redirect my hands when I'm waving them.*

Start moving your fingers in front of your eyes. Do not play with the toy until the parent physically prompts you or hands you the toy.

Parent has completed training when he/she:

(1) Tells you to play with the toy.
(2) If you don't do play with the toy after the parent tells you to, the parent hands you the toy or physically prompts you.
(3) Praises you for playing with the toy.

APPENDIX D: TABLES

Parental Confidence

Results reported on the Daily Behavior Rating scale (DBR) for the 10 days immediately prior to and after parent training.

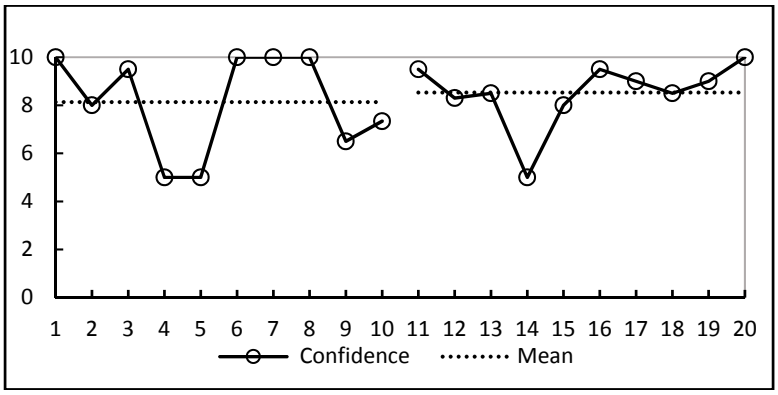


Figure E1. Confidence data for participant W1

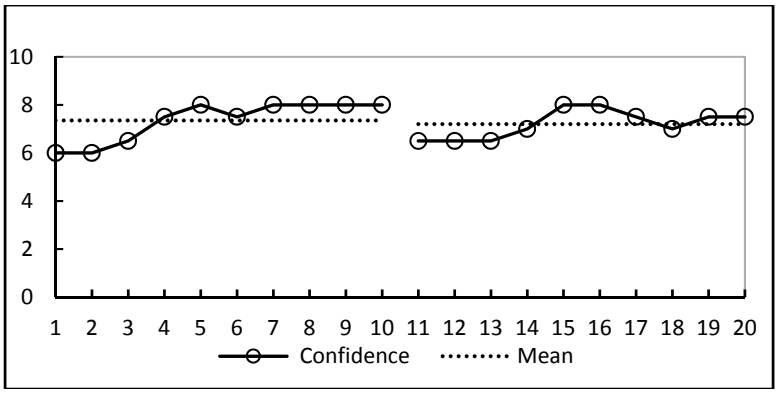


Figure E2. Confidence data for participant W2

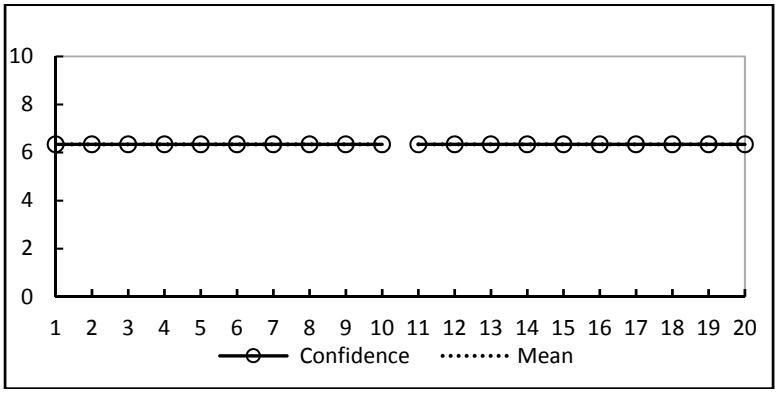


Figure E3. Confidence data for participant W4

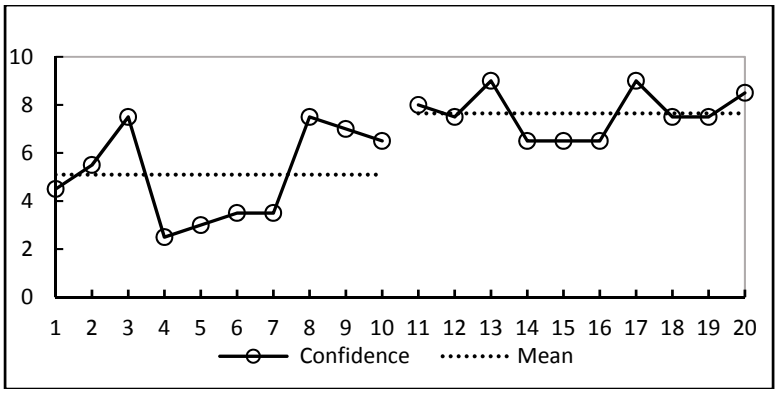


Figure E4. Confidence data for participant W6

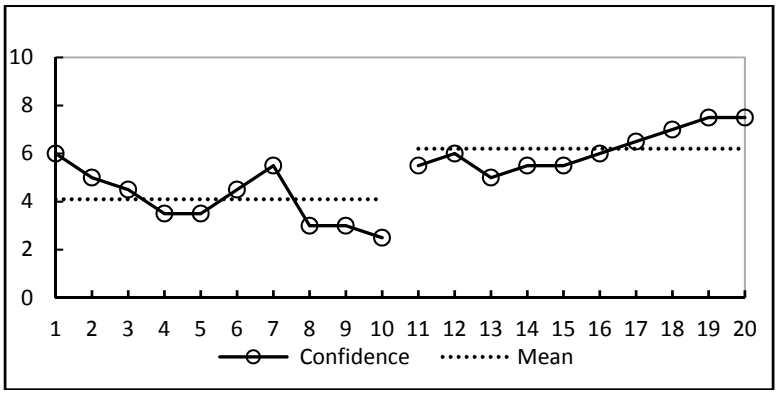


Figure E5. Confidence data for participant W9

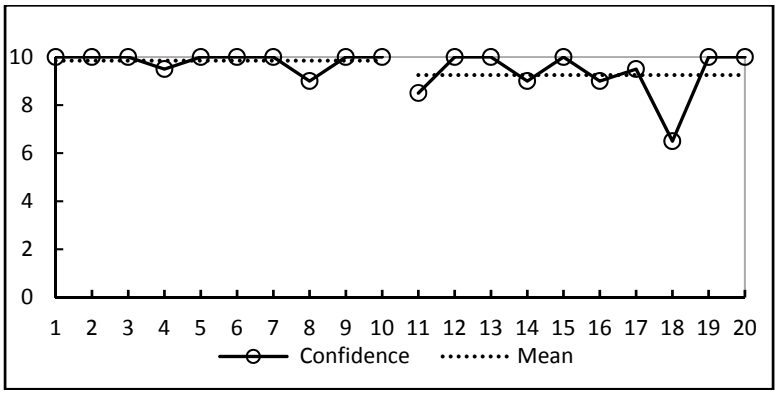


Figure E6. Confidence data for participant T2

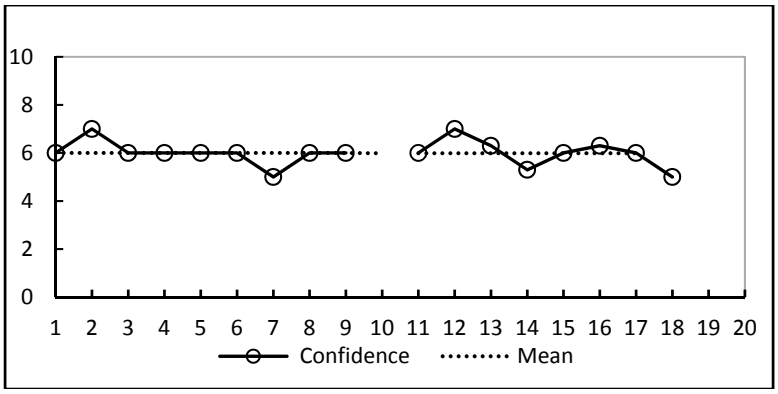


Figure E7. Confidence data for participant T3

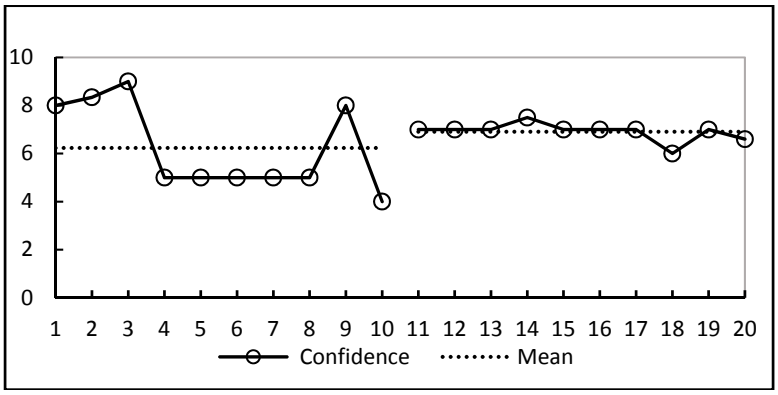


Figure E8. Confidence data for participant T4

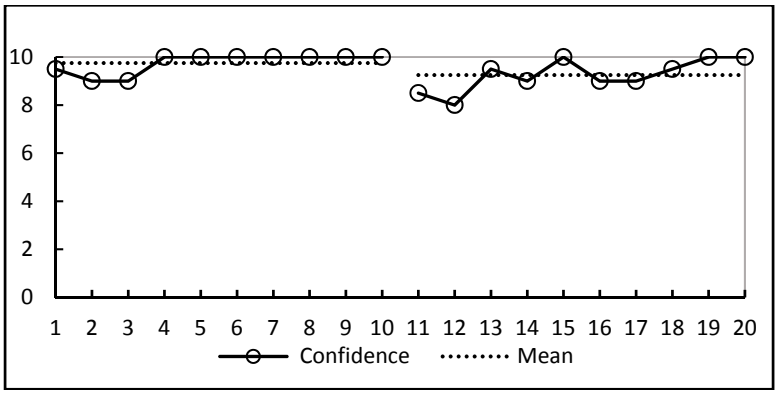


Figure E9. Confidence data for participant T5

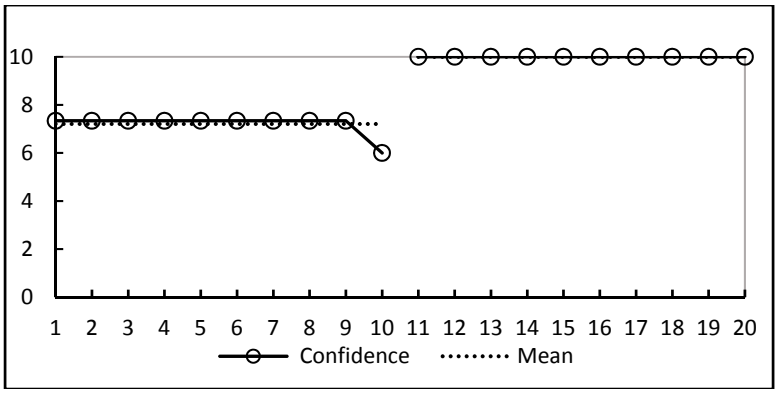


Figure E10. Confidence data for participant M1

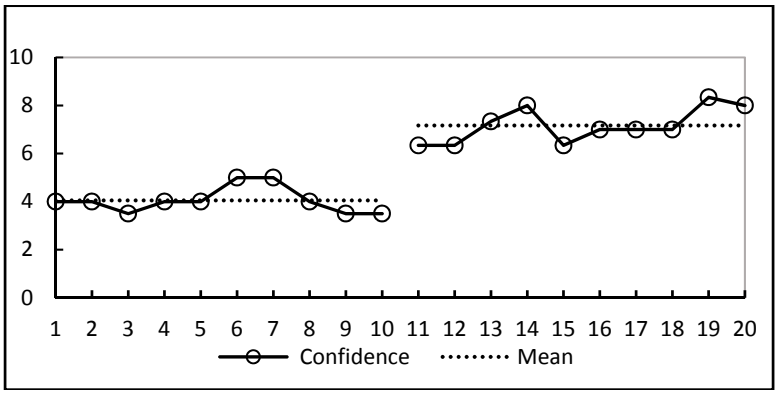


Figure E12. Confidence data for participant M2

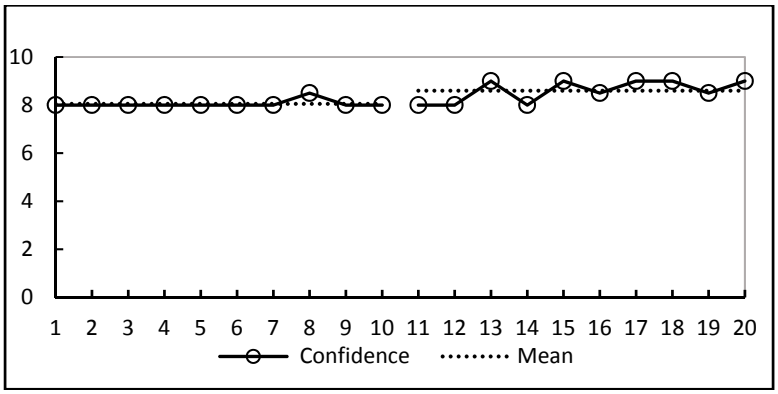


Figure E13. Confidence data for participant M4

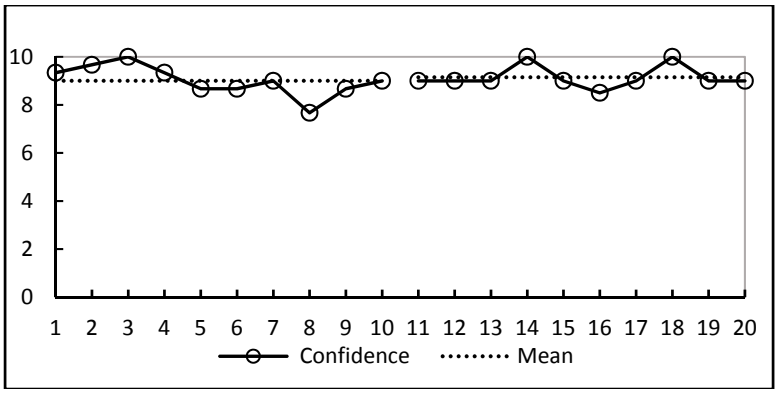


Figure E14. Confidence data for participant M5

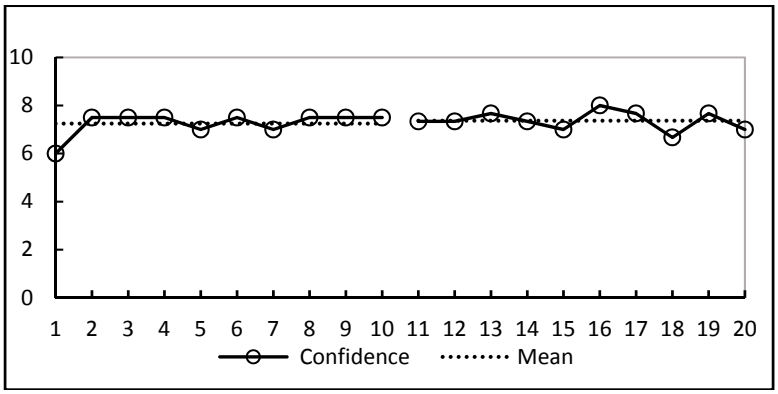


Figure E15. Confidence data for participant M6

Parental Action

Results reported on the Daily Behavior Rating scale (DBR) for the ten days immediately prior to and after parent training.

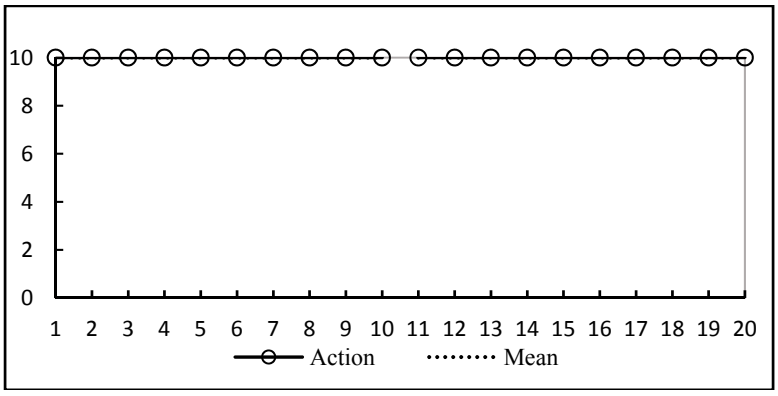


Figure E16. Action data for participant W1

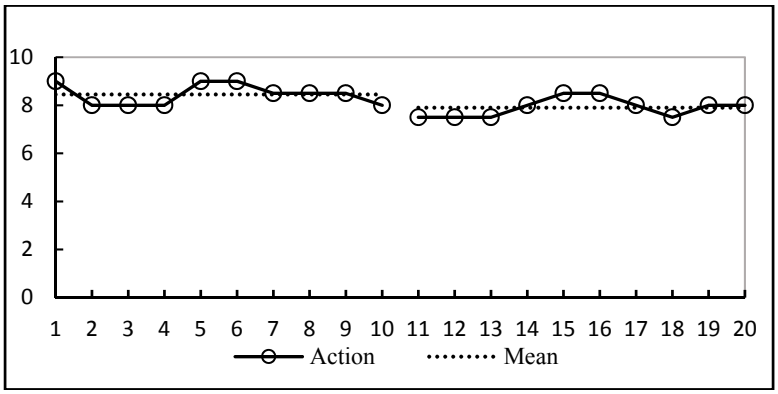


Figure E17. Confidence data for participant W2

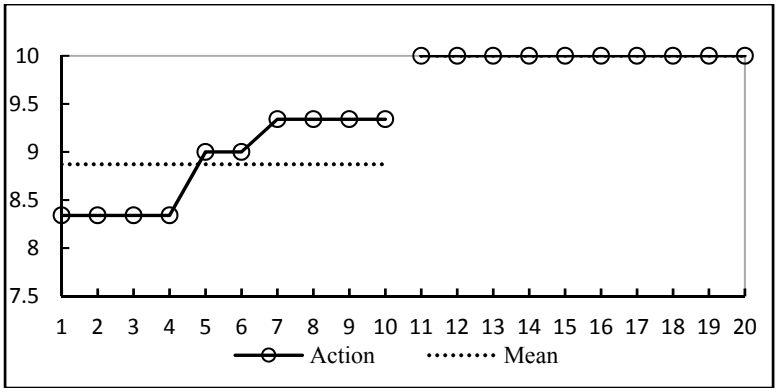


Figure E18. Action data for participant W4

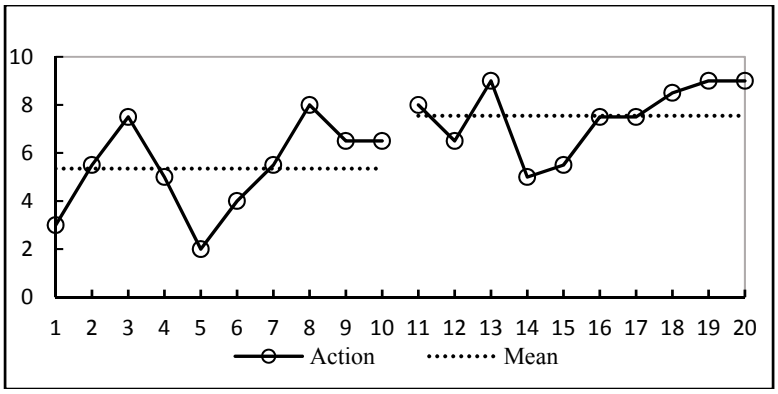


Figure E19. Action data for participant W6

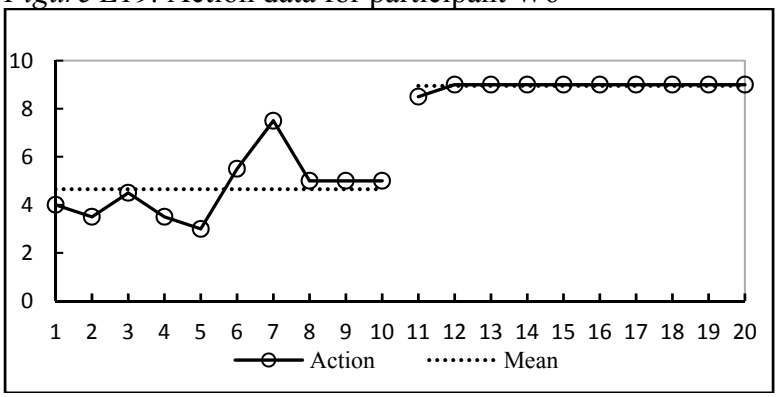


Figure E20. Action data for participant W9

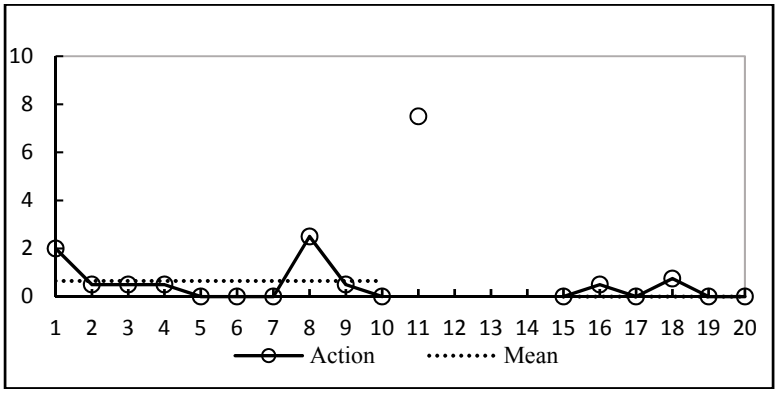


Figure E21. Action data for participant T2

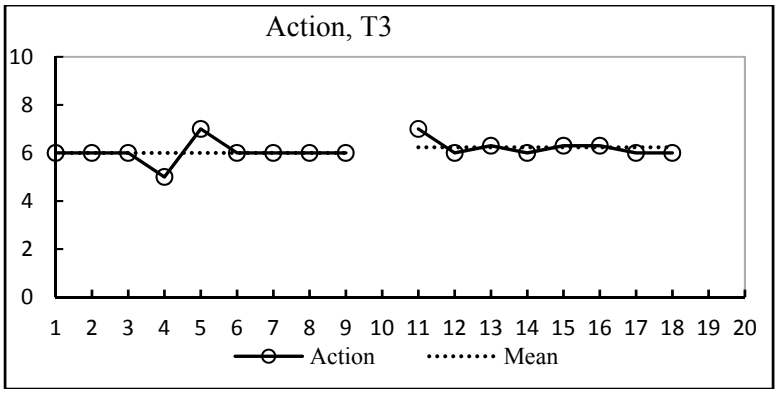


Figure E22. Action data for participant T3

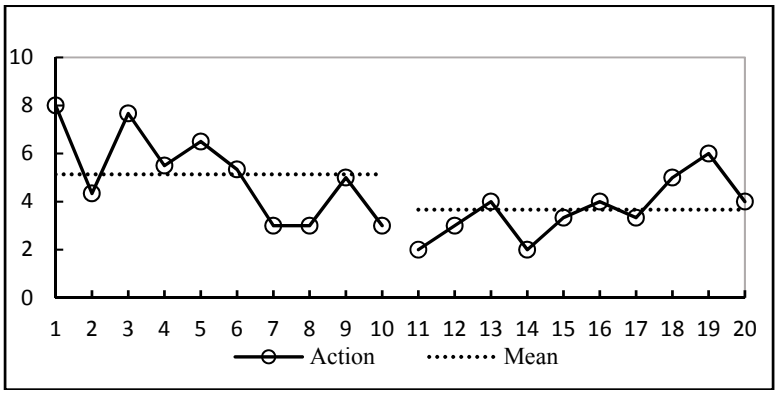


Figure E23. Action data for participant T4

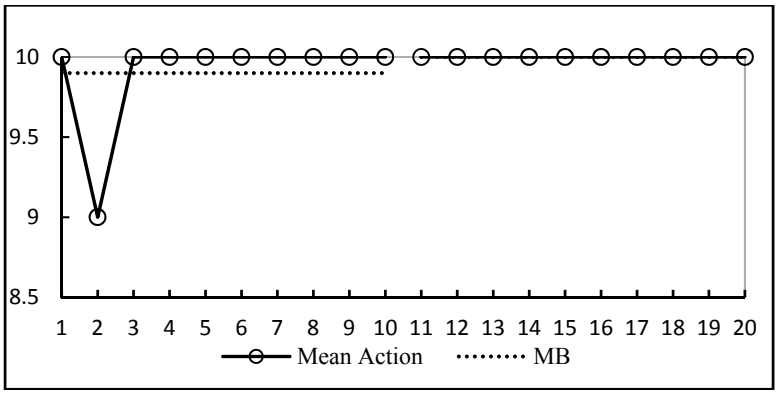


Figure E24. Action data for participant T5

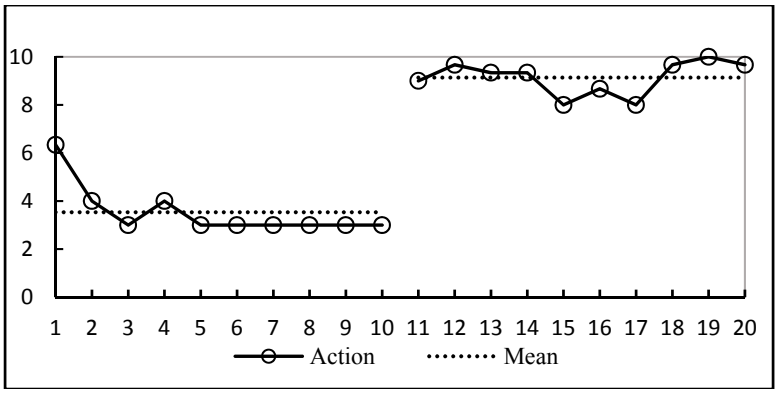


Figure E25. Action data for participant M2

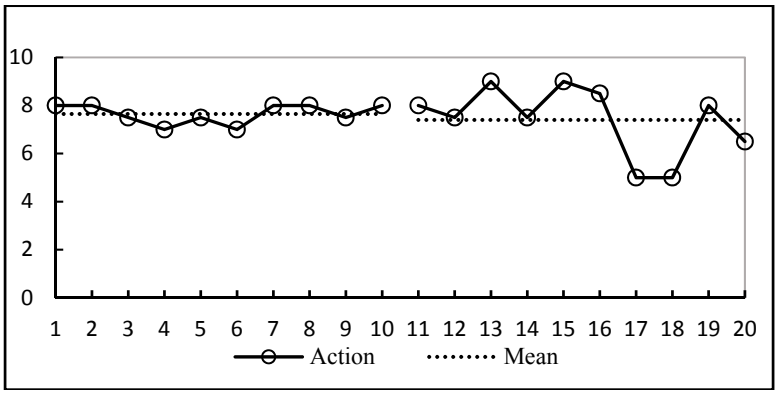


Figure E26. Action data for participant M4

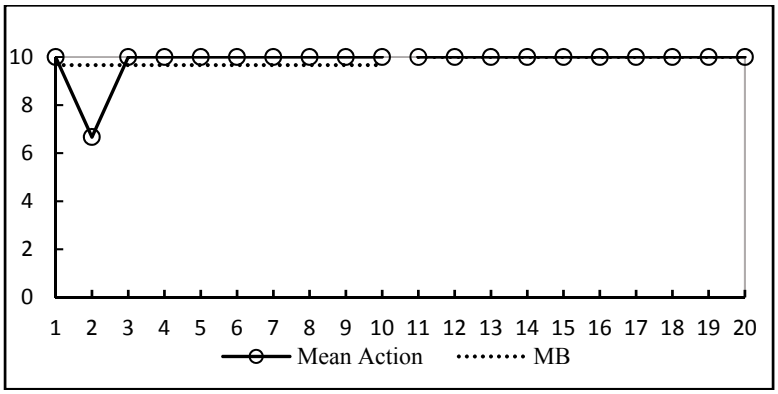


Figure E27. Action data for participant M5

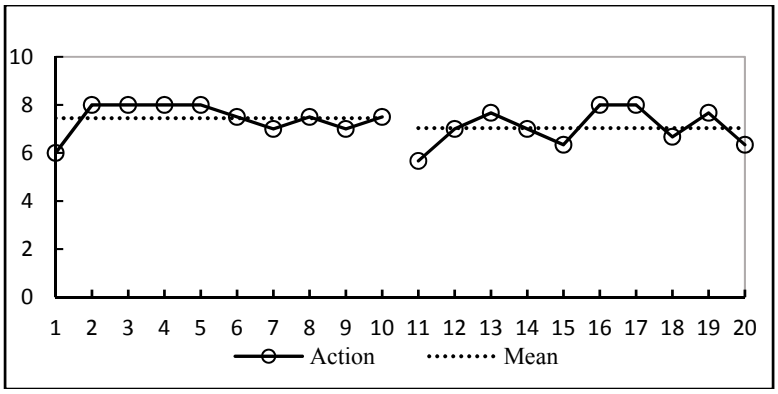


Figure E28. Action data for participant M6

Eye contact

Results reported on the Daily Behavior Rating scale (DBR) for the ten days immediately prior to and after parent training.

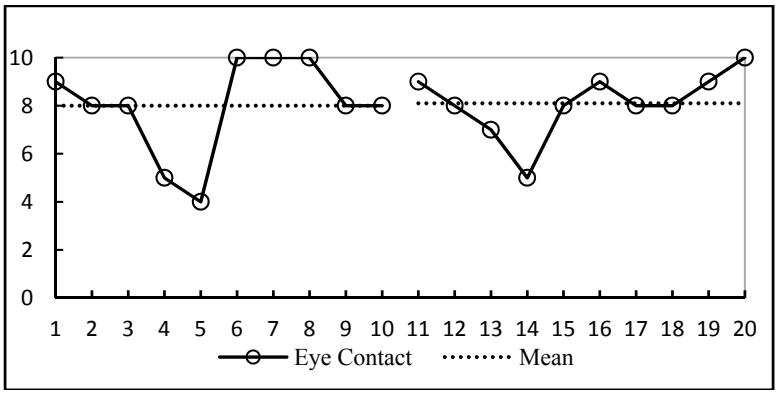


Figure E29. Eye Contact data for participant W1

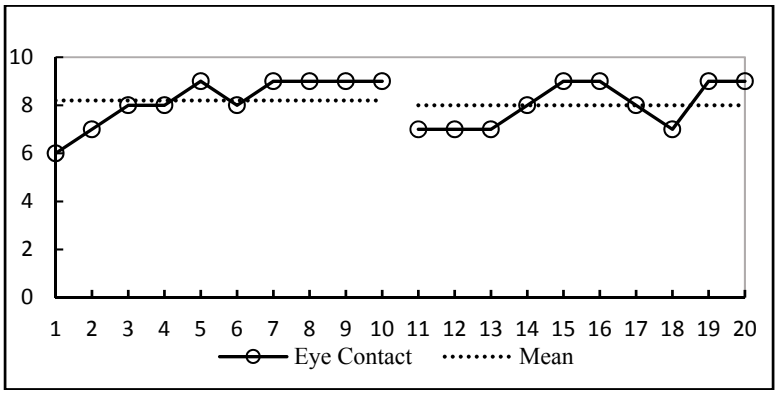


Figure E30. Eye contact data for participant W2

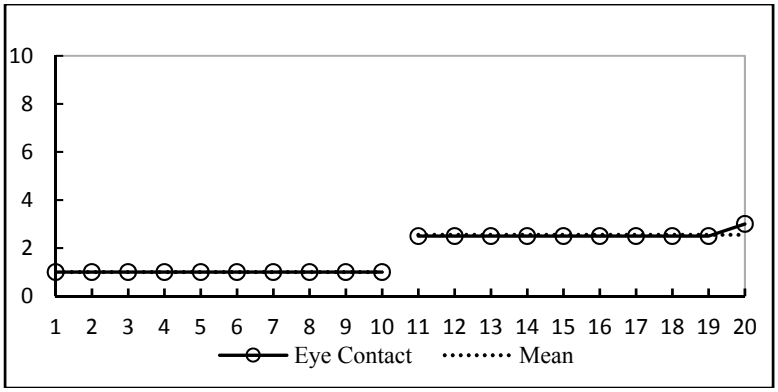


Figure E31. Eye contact data for participant W4

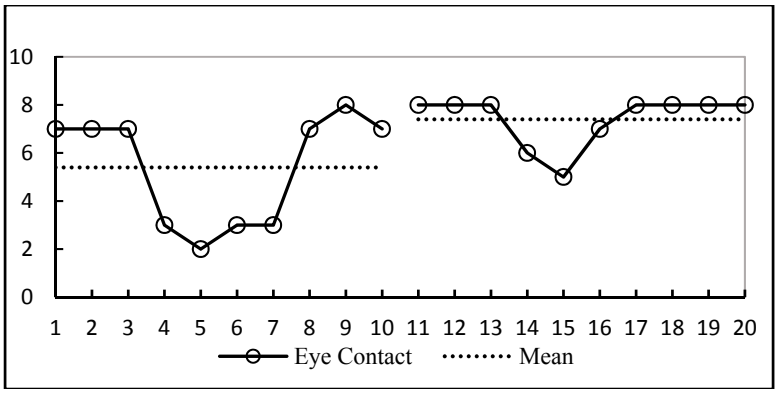


Figure E32. Eye contact data for participant W6

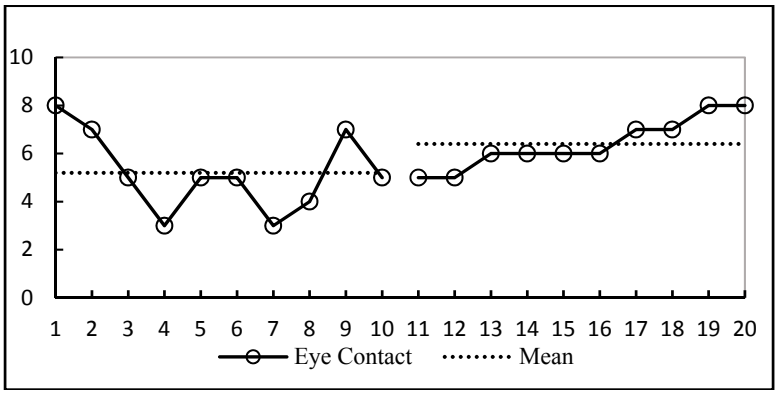


Figure E33. Eye contact data for participant W9

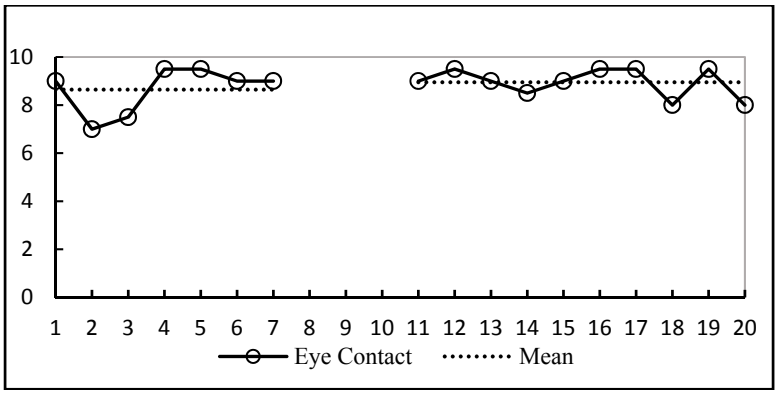


Figure E34. Eye contact data for participant T1

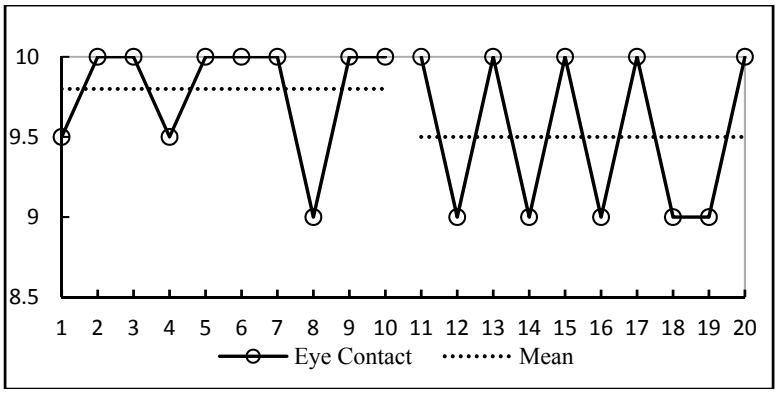


Figure E35. Eye contact data for participant T2

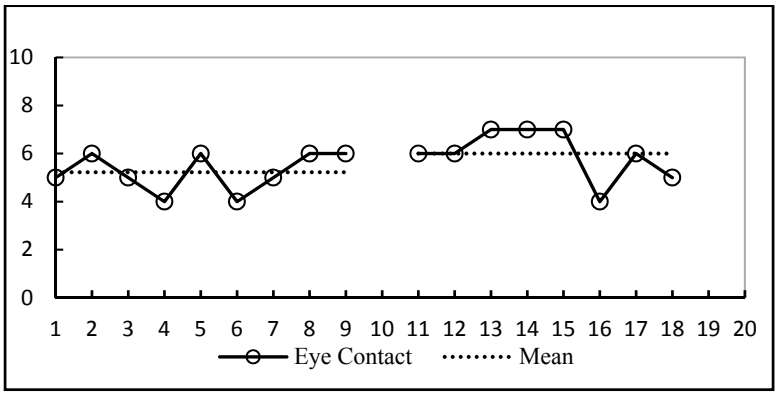


Figure E36. Eye contact data for participant T3

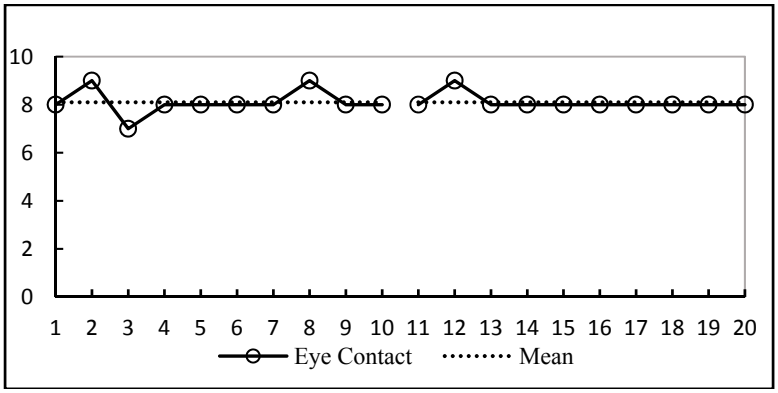


Figure E37. Eye contact data for participant T4

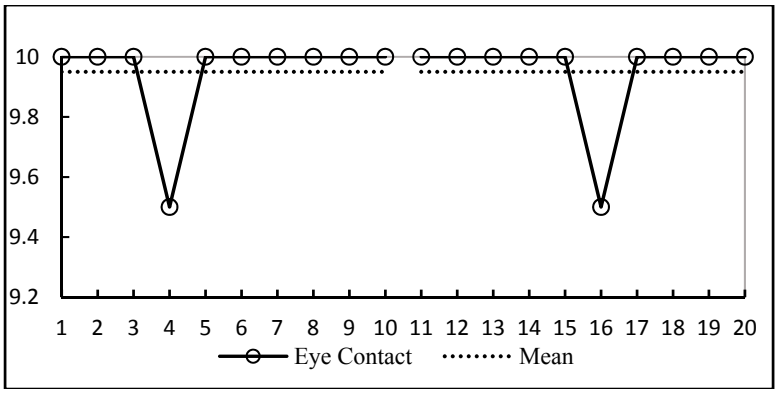


Figure E38. Eye contact data for participant T5

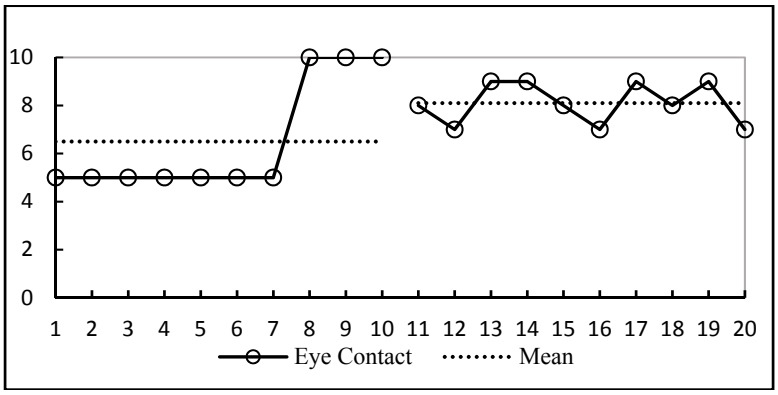


Figure E39. Eye contact data for participant M1

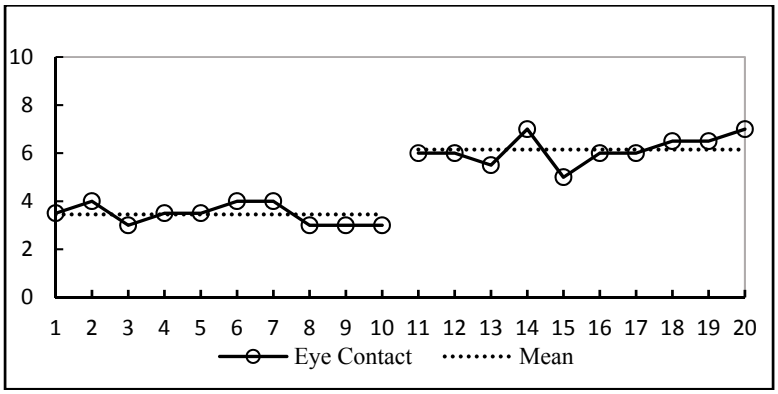


Figure E40. Eye contact data for participant M2

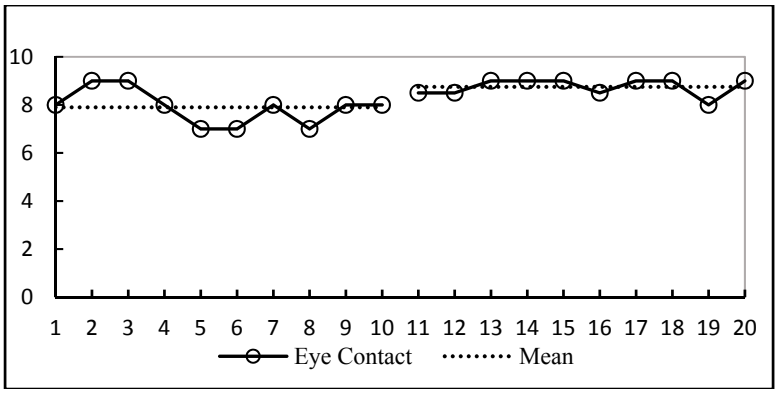


Figure E41. Eye contact data for participant M4

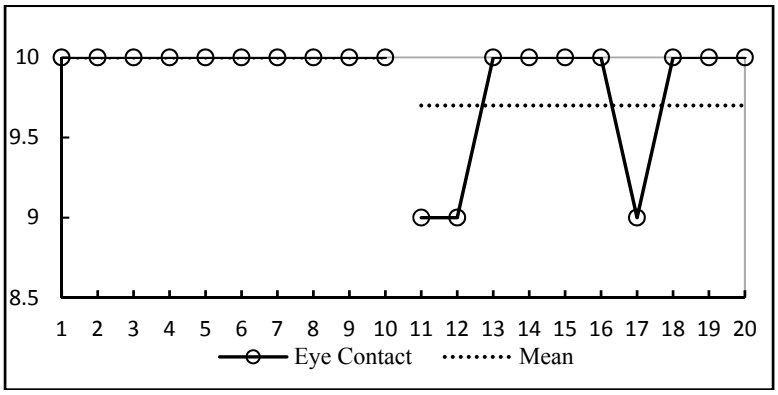


Figure E42. Eye contact data for participant M5

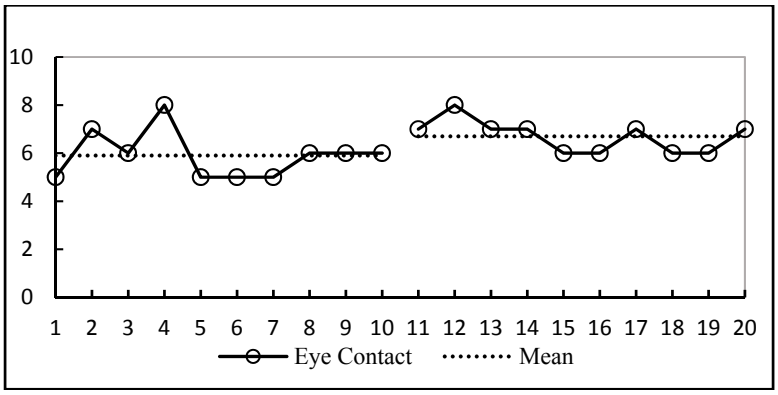


Figure E43. Eye contact data for participant M6

Compliance

Results reported on the Daily Behavior Rating scale (DBR) for the ten days immediately prior to and after parent training.

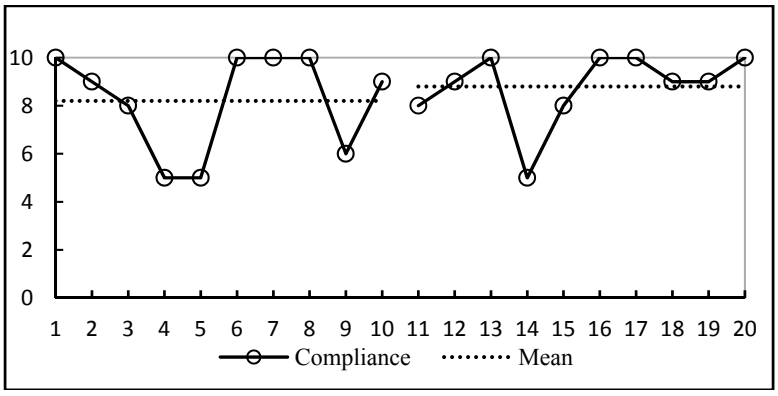


Figure E44. Compliance data for participant W1

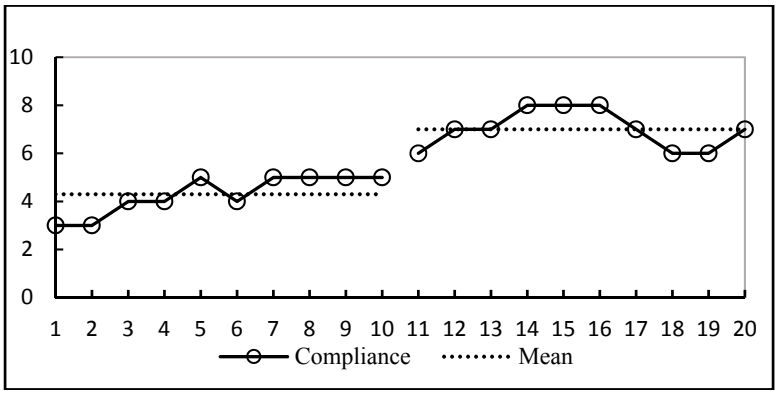


Figure E45. Compliance data for participant W2

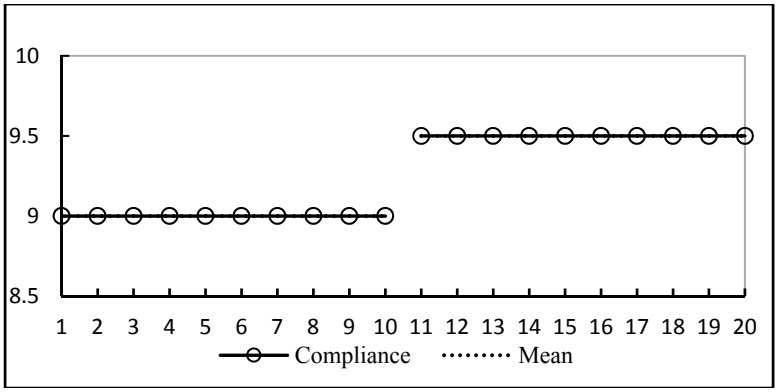


Figure E46. Compliance data for participant W4

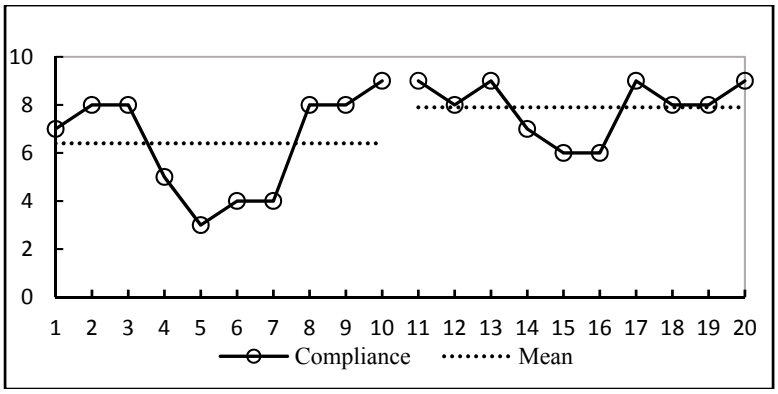


Figure E47. Compliance data for participant W6

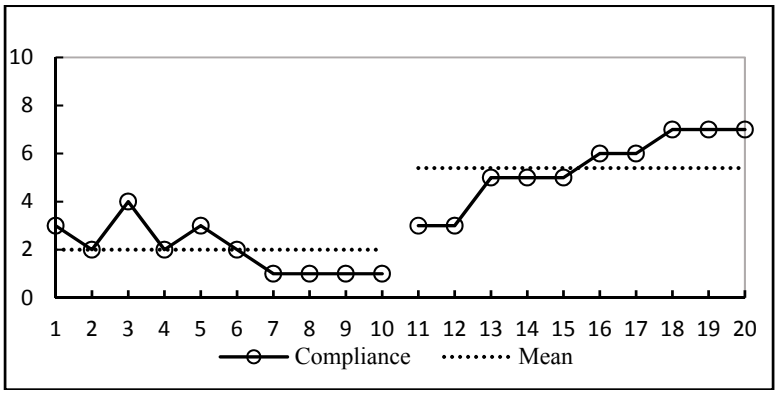


Figure E48. Compliance data for participant W9

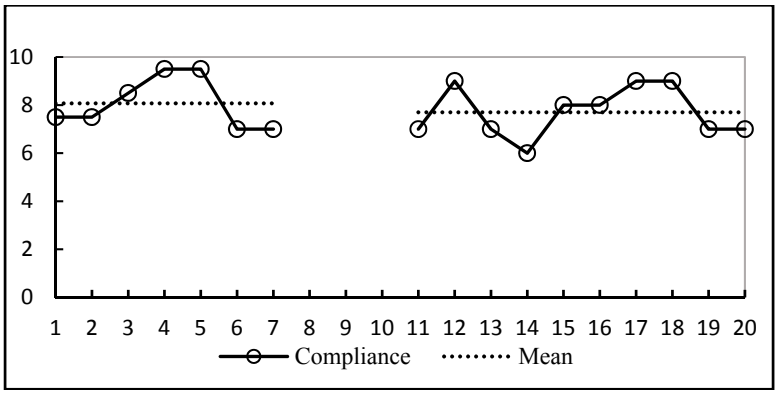


Figure E49. Compliance data for participant T1

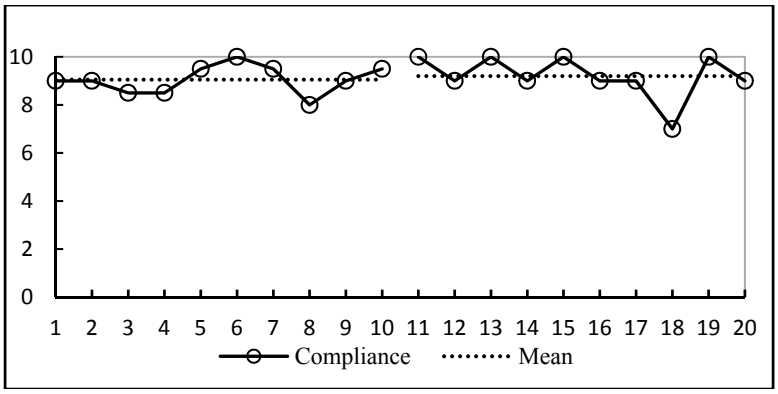


Figure E50. Compliance data for participant T2

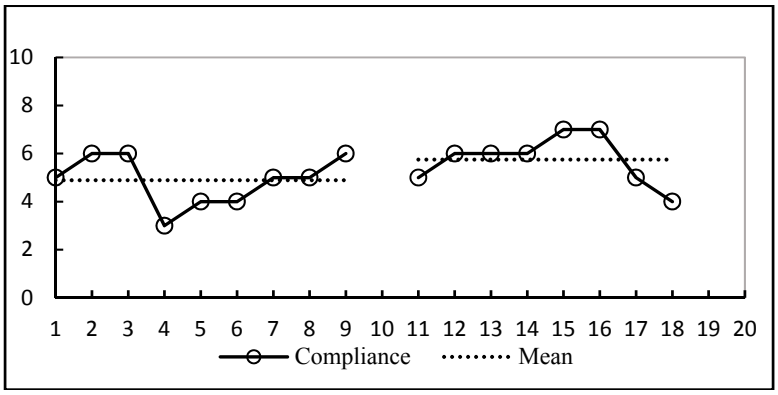


Figure E51. Compliance data for participant T3

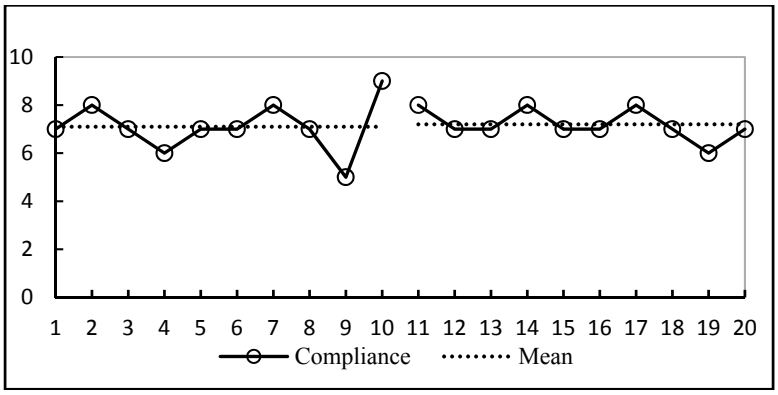


Figure E52. Compliance data for participant T4

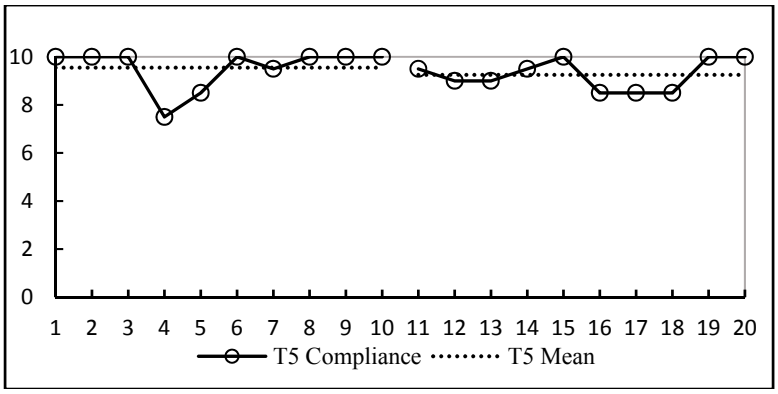


Figure E53. Compliance data for participant T5

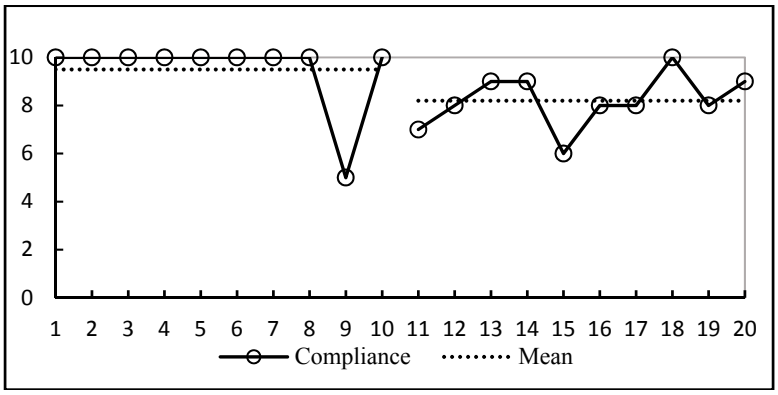


Figure E54. Compliance data for participant M1

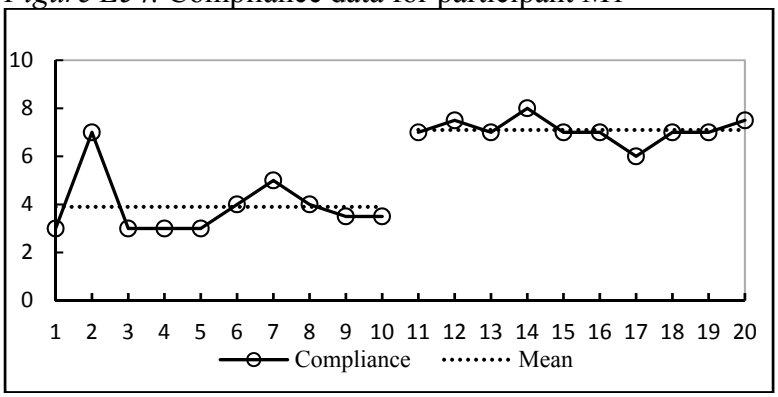


Figure E55. Compliance data for participant M2

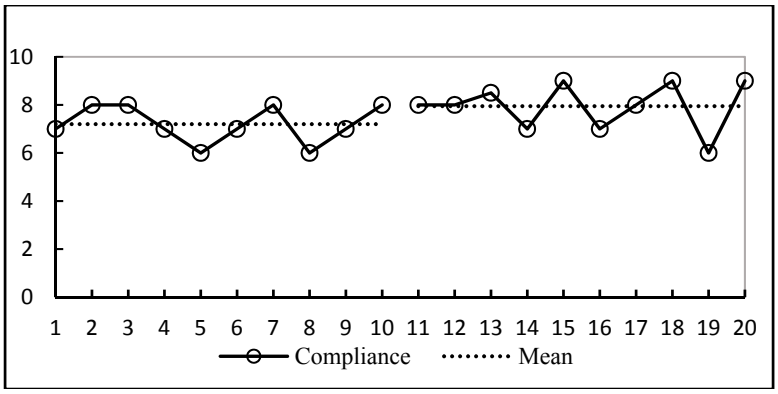


Figure E56. Compliance data for participant M4

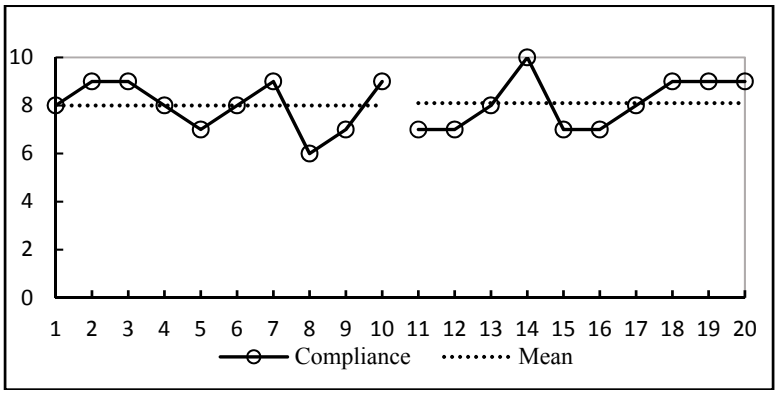


Figure E57. Compliance data for participant M5

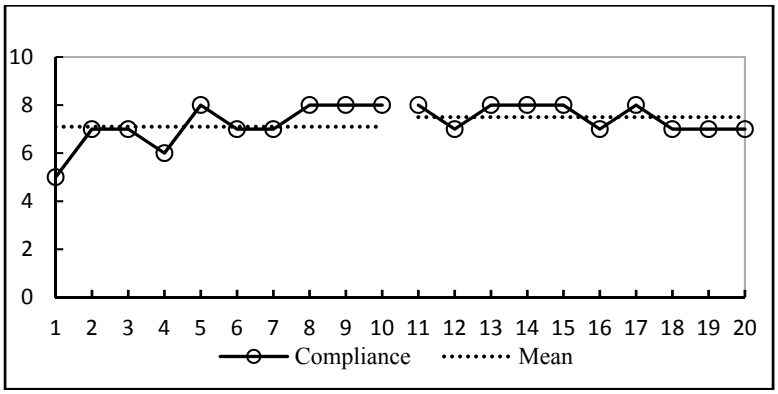


Figure E58. Compliance data for participant M6

Restricted Repetitive Behaviors

Results reported on the Daily Behavior Rating scale (DBR) for the ten days immediately prior to and after parent training.

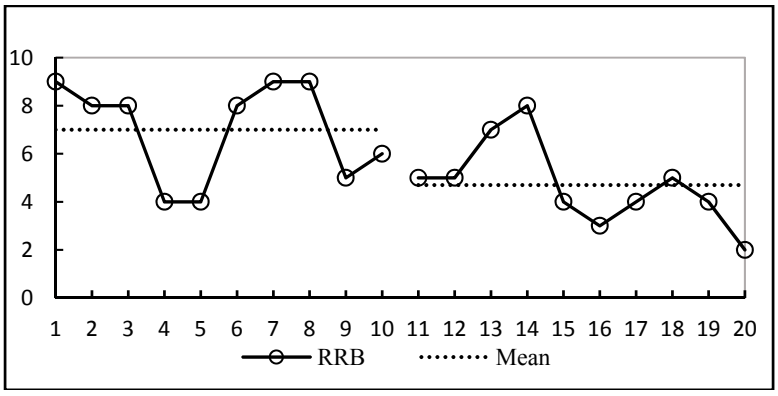


Figure E59. Restricted and repetitive behaviors data for participant W1

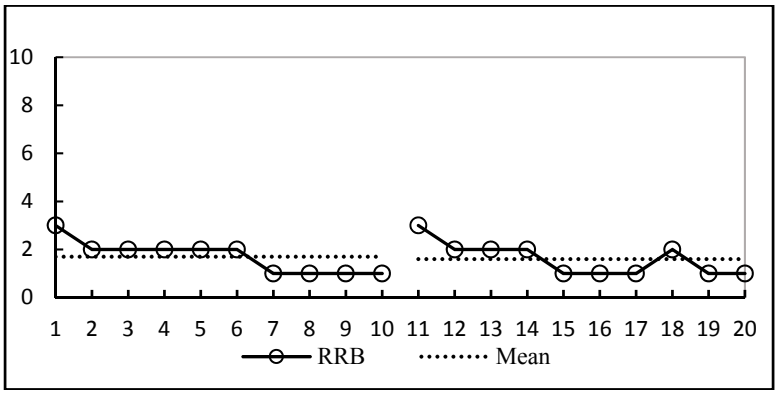


Figure E60. Restricted and repetitive behaviors data for participant W2

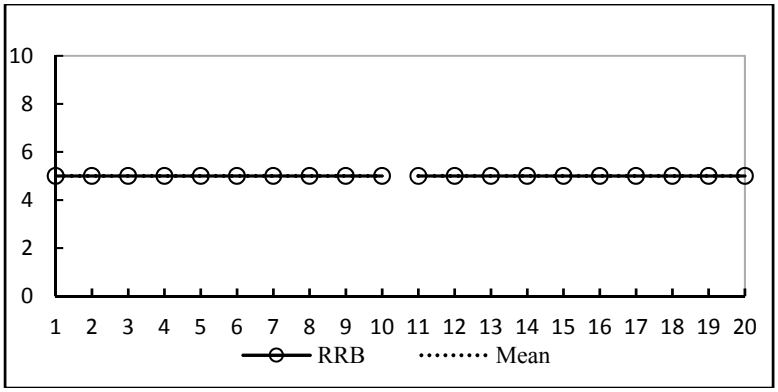


Figure E61. Restricted and repetitive behaviors data for participant W4

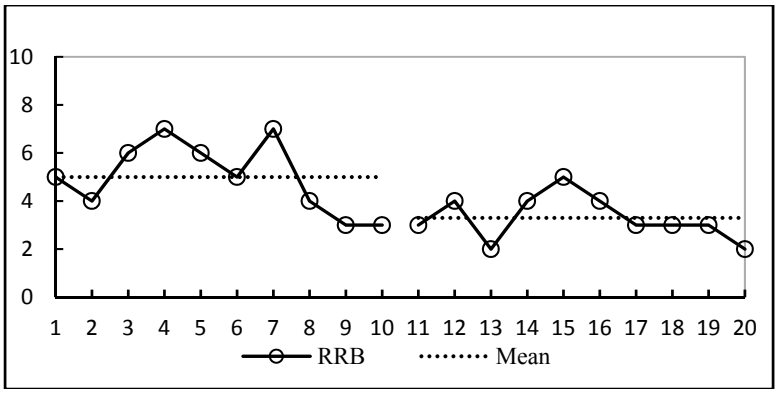


Figure E62. Restricted and repetitive behaviors data for participant W6

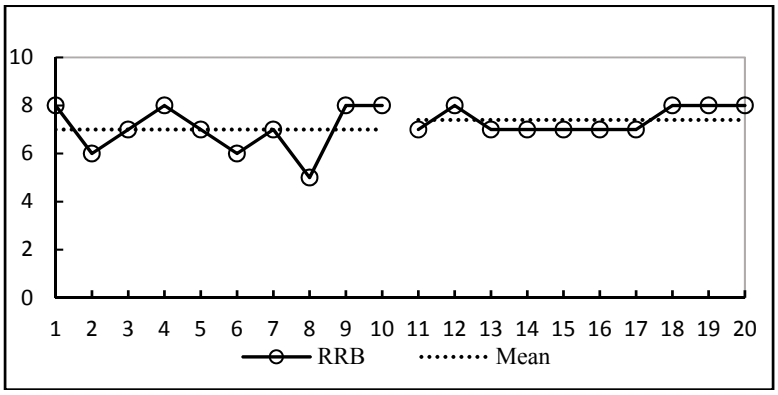


Figure E63. Restricted and repetitive behaviors data for participant W9

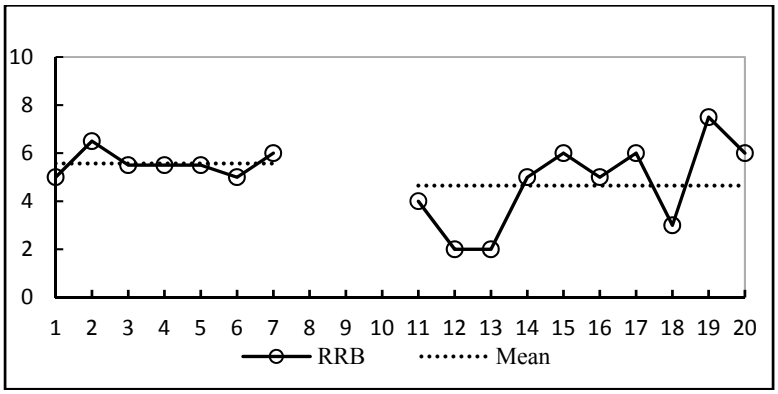


Figure E64. Restricted and repetitive behaviors data for participant T1

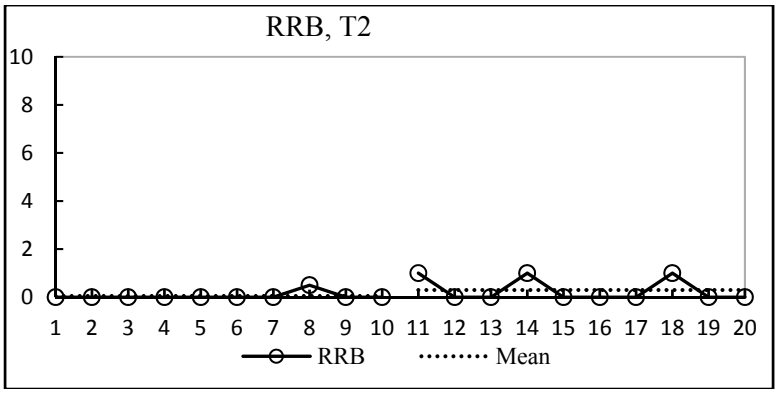


Figure E65. Restricted and repetitive behaviors data for participant T2

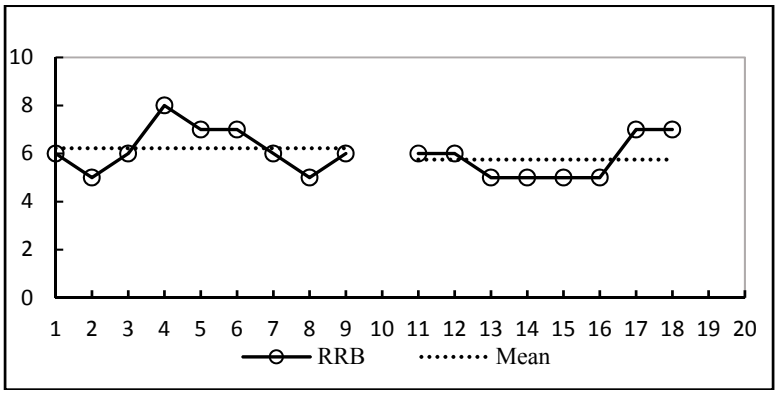


Figure E66. Restricted and repetitive behaviors data for participant T3

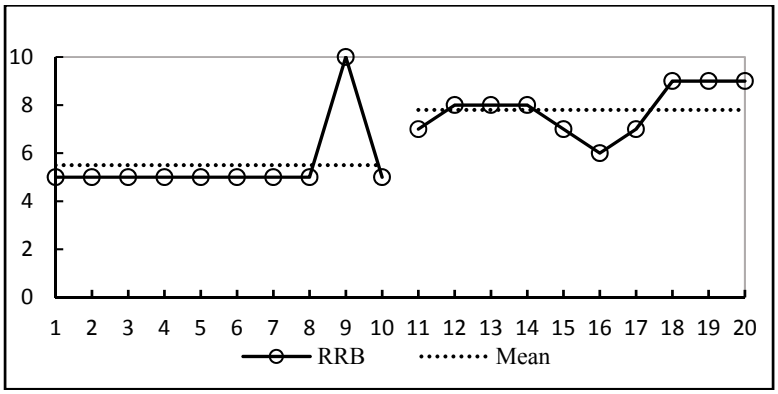


Figure E67. Restricted and repetitive behaviors data for participant M1

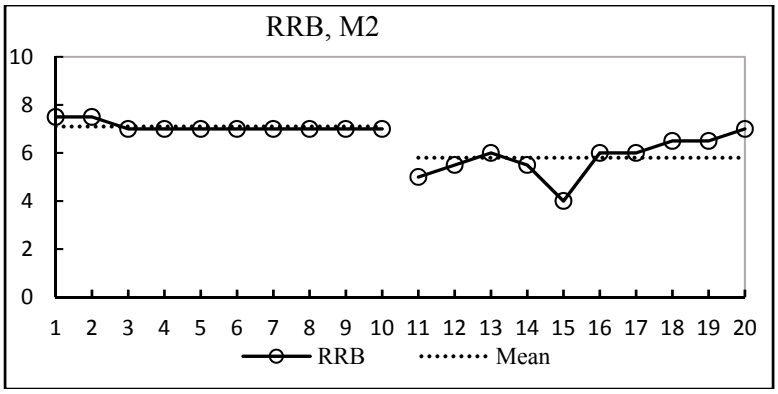


Figure E68. Restricted and repetitive behaviors data for participant M2

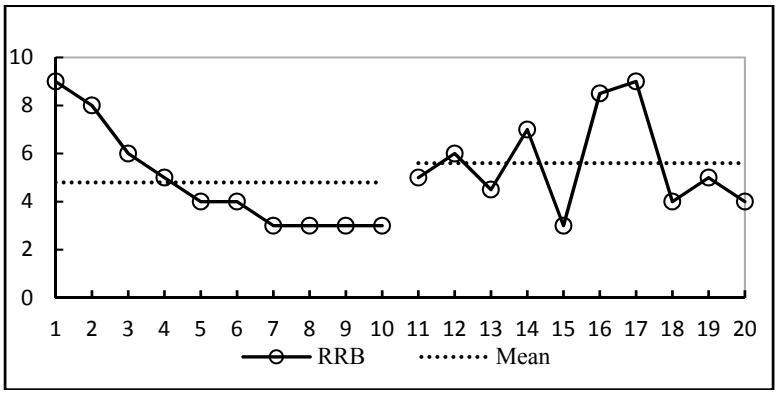


Figure E69. Restricted and repetitive behaviors data for participant M4

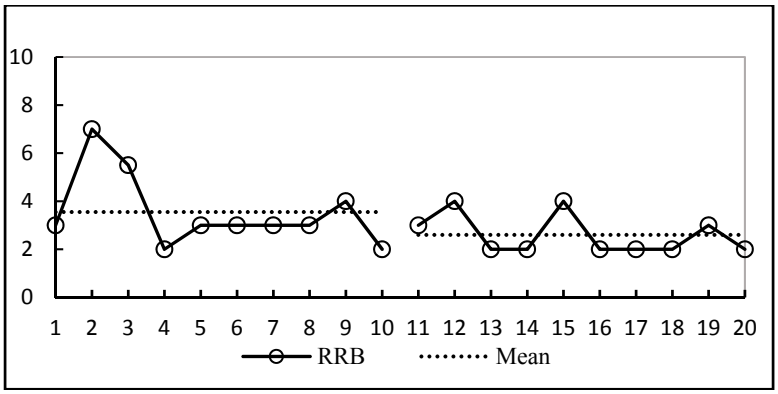


Figure E70. Restricted and repetitive behaviors data for participant M5

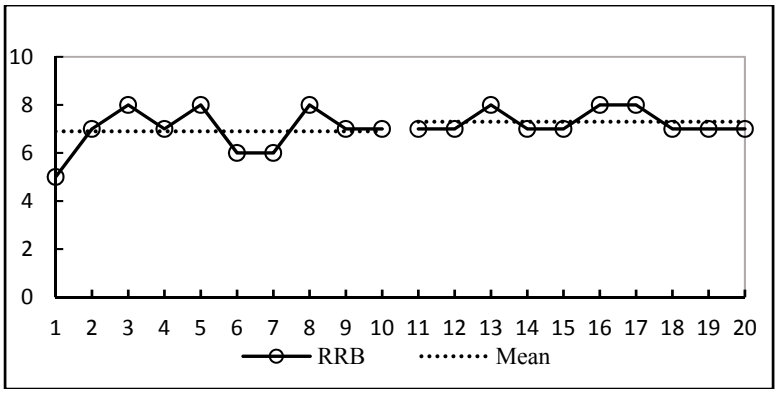


Figure E71. Restricted and repetitive behaviors data for participant M6