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# Assessing Parent Involvement In Applied Behavior Analysis Treatment For Children With Autism

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**ASSESSING PARENT INVOLVMENT IN APPLIED BEHAVIOR ANALYSIS  
TREATMENT FOR CHILDREN WITH AUTISM**

by

**KRISTA M. CLANCY**

**DISSERTATION**

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of:

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MAJOR: EDUCATIONAL PSYCHOLOGY

Approved By:

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Advisor

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Date

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## **DEDICATION**

This project is dedicated to the countless families who I have worked with over the years for their determination to obtain the best outcomes for their children with autism. They have pushed me to continuously improve treatment and training for myself and the staff I supervise.

## ACKNOWLEDGEMENTS

I would like to acknowledge and thank the efforts and patience of my committee members. Specifically, I would like to thank Cheryl Somers, Ph. D., who acted as chair of my committee for all of her guidance and support. I learned a tremendous amount by going through this process and appreciate the effort and feedback that she gave. It allowed me to develop skills in research and writing that I will benefit from throughout my career. I also wanted to thank Diane Chugani, Ph. D., who has acted as a mentor to me for the last nine years. Her mentorship has helped me understand treatment and training from a family perspective and has made me more understanding and compassionate. Finally, I would also like to acknowledge my other committee members, Barry Markman, Ph. D., and Francesca Pernice-Duca, Ph. D., who have been mentors in my work and education. This committee has guided me and modeled for me so many important skills that have contributed to my understanding and implementation of treatment, my day to day interactions with professionals and clients, and my ability to understand research. I have learned so much in this program and in my clinical work. The process of going through a Ph.D. program and completing a dissertation offers amazing growth opportunities. It has been both challenging and rewarding.

I also want to acknowledge the collaborative efforts of all the staff at the autism center, for their support in administering the parent measures used in this study and providing the parent trainings. I also want to thank Abbie Solish, Ph. D. and Adrienne Perry, Ph. D for their work in in parent involvement and for allowing me to use the Parent Involvement Questionnaire. Lastly, I would like to thank my husband, John Clancy and my children Jordan and Lily Kennedy for all the support they have given me and the patience they have had for me in this process. I could not have done this without their help.

## TABLE OF CONTENTS

DEDICATION .....	ii
ACKNOWLEDGEMENTS.....	iii
CHAPTER 1 INTRODUCTION.....	1
Parent Involvement.....	1
Parent Stress.....	4
Parent Self-Efficacy .....	5
Treatment Acceptability .....	6
Limitations of Past Research and Purpose of the Current Study.....	7
CHAPTER 2 LITERATURE REVIEW .....	10
Applied Behavior Analysis.....	10
Parent Involvement.....	13
Parent Stress.....	17
Parent Self-Efficacy .....	20
Treatment Acceptability .....	22
Parent Training .....	24
CHAPTER 3 METHOD.....	30
Participants.....	30
Procedure .....	32
Parent stress.....	34
Parent self-efficacy .....	36
Treatment acceptability.....	36
Parent involvement.....	37

Data Analysis.....	38
CHAPTER 4 RESULTS .....	40
Preliminary Analyses.....	40
Research Question 1: .....	42
Research Question 2: .....	46
Research Question 3 .....	49
Research Question 4 .....	51
Á Posteriori Qualitative Analysis .....	52
CHAPTER 5 DISCUSSION.....	55
Limitations.....	59
Summary, Implications, and Conclusions .....	63
APPENDIX A PARENT SENSE OF COMPETENCY – EFFICACY SUBSCALE .....	64
APPENDIX B TREATMENT EVALUATION INVENTORY – SHORT FORM.....	65
APPENDIX C PARENT STRESS INDEX – SHORT FORM .....	66
APPENDIX D PARENT INVOLVMENT QUESTIONNAIRE – PARENT VERSION .....	67
APPENDIX E PARENT INVOVLMENT QUESTIONNAIRE – THERAPIST VERSION .....	78
APPENDIX F PARENT/CHILD INFORMATION SURVEY – PARENT VERSION.....	84
APPENDIX G PARENT/CHILD INFORMATION SURVEY – THERAPIST VERSION.....	86
APPENDIX H INFORMED CONSENT - PARENT .....	87
APPENDIX I INFORMED CONSENT - THERPIST .....	93
APPENDIX J ORAL CONSENT SCRIPT .....	99

REFERENCES.....	100
ABSTRACT.....	116
AUTOBIOGRAPHICAL STATEMENT .....	118

## LIST OF TABLES

Table 1 Statistical Analyses.....	39
Table 2 Descriptive Statistics and Correlations Between Pre- and Post-Test Measures.....	41
Table 3 Pearson Correlation Matrix for All Measures.....	42
Table 4 Mixed Design ANOVA Results for Parent Training Effects on Parent Stress.....	43
Table 5 Mixed Design ANOVA Results for Parent Training Effects on Parent Self-Efficacy .....	44
Table 6 Mixed Design ANOVA Results for Parent Training Effects on Treatment Acceptability .....	45
Table 7 ANOVA Results for Parent Involvement – Parent Report.....	45
Table 8 ANOVA Results for Parent Involvement – Therapist Report .....	46
Table 9 Multiple Linear Regression Model – Parent Involvement – Parent Report .....	47
Table 10 Multiple Linear Regression Model – Parent Involvement – Therapist Report.....	48
Table 11 Multiple Linear Regression Model – Parent Involvement with Parallel Predictor Scales .....	49
Table 12 Hierarchical Linear Regression Model – Relationship Between Parent Involvement and Parent Training.....	51



## CHAPTER 1 INTRODUCTION

Applied Behavior Analysis (ABA) is used for treatment of children with Autism Spectrum Disorder (ASD). It has been empirically shown to significantly reduce the debilitating effects of autism (Ben-Itzhak & Zachor, 2011; Eldevick, Hastings, Hughes, Jahr, Eikeseth, & Cross, 2009; Howlin, Magiati & Charman, 2009; Reichow & Wolery, 2009). There is a necessary parent component that has been reported as a significant factor contributing to the outcome and longevity of the treatment effects (Anderson & Romanczyk, 1999; Dawson & Osterling, 1997). However, many parents do not participate in treatment at recommended levels or drop out of treatment for their children before their behavior problems and deficits are resolved (Matson, Mahan & Matson, 2009; Miller & Prinz, 2003). Parents report adherence to treatment recommendations between 50-80% even on strategies in which they have been trained and demonstrated competency (Moore & Symons, 2011). This can be even lower when there have been no rigorous training procedures for parents. Overall rates of patient non-adherence to physician recommendations are between 24% (e.g., Dimatteo, 2004) and 50% (e.g., Sabate, 2003). Since parent involvement is a variable that contributes to treatment efficacy, it is important to focus on areas to target for intervention that support parent involvement in treatment.

### **Parent Involvement**

Many studies report parent involvement as a part of the treatment design (Lovaas, 1987; MacDonald, Parry-Cruwys, Dupere & Ahearn, 2014; Smith, et al., 2010). Most researchers hypothesize that treatment outcomes are largely related to a parent's training and ability to promote changes across environments. Parents can provide learning opportunities outside of the treatment sessions that will assist with skill building, generalization, and coordination of care (Drew, et al., 2002; Kasari, Gulgrund, Paparella, Hellman & Berry, 2015; Laski, Charlop & Schriebman, 1988;

Smith, et al., 2010). Parent training programs can offer a way to provide intervention in the home, which will help to improve the way the child interacts with the family and in the community. When parents use these skills in the home with their children, it is likely to lead to improvements in their children's behavior problems, functional communication (Koegel, Stiebel, & Koegel, 1998), flexibility and adaptability, parent-child relationships (Solomon, Ono, Timmer, & Goodlin-Jones, 2008), and overall family harmony and well-being in everyday life (Koegel, Bimbela, & Schriebman, 1996; Koegel et al, 1998).

Adherence to treatment recommendations, especially recommendations to implement procedures in the home, is a problem in ABA treatment (Cordisco, Strain, & Depew, 1988; Moore & Symons, 2011). Due to the extensive number of hours and the long commitment, many families may not participate in treatment at all, or at the recommended dosage necessary to get the optimal results. In addition to parent involvement, there are also difficulties with how involvement in treatment is defined and conflicting perceptions between the levels of involvement as viewed by the parents versus the therapist (Solish, 2010; Solish & Perry, 2008). There are cognitive-behavioral constructs such as parent stress, self-efficacy (Benson, 2015), and treatment acceptability (Bradshaw 2015; Steiner, Gengoux & Koegel, 2015; Kazdin & Wassell, 1999; Moore & Symons, 2011) that are hypothesized to be associated with parent motivation and ability to engage and follow through with treatment recommendations (Solish, 2010; Solish & Perry 2008). The success of a treatment plan relies on a therapist's ability to identify enablers and barriers to treatment including perceptions of those involved and contextual factors that can pose as barriers (Sanders & Kirby, 2012). The primary purpose of this study was to determine if parents who received a parent intervention targeted to improve their stress, self-efficacy, and treatment acceptability would result in improved parent involvement in their children's ABA treatment.

Additionally, by assessing the parent stress, self-efficacy, and treatment acceptability in participants, information was obtained regarding how strongly each of these variables explained variance in parent involvement. This information was collected to further inform therapists about motivational variables that could be directly targeted in treatment with parents to improve involvement in their children's ABA treatment.

Studies that have focused on parent mental health and family functioning have shown that these variables can be used to help parents reframe their perceptions of their children and the intervention (Bristol, Gallagher, & Holt, 1993; Keen, Couzens, Muspratt, & Rodger, 2010). Several studies have also demonstrated decreases in stress following parent education to manage difficult behavior (Keen et al., 2010; Koegel, et al., 1998; Singer, Ethridge & Aldna, 2007; Solomon et al., 2008; Tonge et al., 2006). Kuhn and Carter (2006) measured these effects on the extent to which parents assume an active role in their children's development by using strategies that promote positive interactions and reduce maladaptive behaviors. In their study, Kuhn and Carter (2006) found that parent self-efficacy was correlated with assuming a more active role in treatment. Also, parents who reported reduced beliefs of parent self-efficacy benefited more by trainings that were professionally guided rather than self-guided education in improving their self-efficacy (Keen et al., 2010), indicating the need for a more structured intervention approach (Tavil, 2010). Furthermore, adherence to treatment, including involvement with their children's therapy in the form of attending meetings, completing homework assignments and using the skills learned in therapy in the home environment, is closely tied to a parent's belief in the effectiveness of the intervention (Moore & Symons, 2011). How parents process their children's disability and treatments that are available can play a role in mediating stress, self-efficacy, and the belief in the effectiveness of the treatment (Hassall & Rose, 2005; Hastings & Brown, 2002; Moore & Symons,

2001). The clinical implications of considering parent and family variables could improve parent involvement in treatment, resulting in greater gains for children participating in ABA treatment and improved mental health and family functioning for the entire family system.

### **Parent Stress**

Stress has been shown to negatively impact parent involvement in treatment (Osborne & Reed, 2010), child learning (Robbins, Dunlap, & Plenis, 1991), problematic behavior in children (Hastings & Brown, 2002) and social, mental and health problems in parents (LeCavlier, Leone, & Wiltz, 2006). Studies of parents of children with ASD have demonstrated higher levels of stress than parents of children who are typical or those with other disabilities (Benson, 2015; Hastings & Johnson, 2001). An estimated 39% of mothers and 28% of fathers of children with ASD are reported to experience clinically significant stress in relation to parenting children with ASD (Davis & Carter, 2008). Over 90% of parents who have children with ASD reported that they were sometimes unable to effectively deal with their children's behavior and nearly half of the parents reported feeling severely anxious (Bitsika & Sharpley, 2004). The stress of having a child with ASD can affect family recreation, finances, emotional well-being of the parents, interpersonal relationships within the immediate family, the extended family and the community (Plenis, Robbins, & Dunlap, 1988). It can also erode the effectiveness of ASD interventions (Osborn, McHugh, Saunders, & Reed, 2008).

Results are mixed in the literature regarding the effects of ABA on stress in parents and the family. Some report no difference in the stress levels between those who are involved in treatment and those who are not (Hastings & Johnson, 2001; Remington et al, 2007). Others report an increase in stress, especially when parents are responsible for implementation of the treatment themselves (Osborne et al., 2008; Schwichtenberg & Poehlmann, 2007). However, it may be less

about the ABA treatment and more about variables associated with the thoughts, beliefs, and situational stressors of the family members (Schauss, Chase, & Hawkins, 1997). Keen and colleagues (2010) demonstrated a reduction of an average of 7.8 points on the Parenting Stress Index (PSI) for parents whose children were recently diagnosed with ASD who participated in a parent training intervention. Singer, Ethridge, and Aldana (2007) compared different types of parent education interventions and found that a combined method of using behavior management and coping skills trainings was significantly more effective than either focusing on behavior management or coping skills alone in reducing family distress. Some families perceive ABA as intrusive, demanding and disruptive to the family routine (Granger, des Rivieres-Pigeon, Sabourin, & Forget, 2012). How parents perceive their involvement may have to do with how supportive, adaptive, and cohesive the family unit is (Herring et al., 2006; Manning, Wainwright, & Bennett, 2011). It is important to measure stress in parents when they enter treatment to determine whether parent stress is present at clinical levels. When parents report clinically significant levels of stress, it can function as a barrier to treatment in many different ways. It is also important to determine how stress and parent involvement are related and to gain more information about if and how parent involvement improves if clinically significant stress is resolved.

### **Parent Self-Efficacy**

Parent self-efficacy is a key component of parent involvement. Self-efficacy beliefs can vary across different activities, task demands, situations, characteristics, contexts and conditions (Bandura, 1997). The more self-efficacy you have for a particular task, the more likely you are to attempt that task, try harder to accomplish it and persist even when the task is difficult (LeFrançois, 2012). The relationship between parent self-efficacy and involvement suggests that parents who are more confident in providing intervention are more likely to engage in those behaviors (Solish

& Perry, 2008). Devising strategies to increase parent self-efficacy could maximize the benefits of the treatment by increasing the motivation of parents to become more involved in treatment. Parent training in ABA has also been linked to increases in parent self-efficacy (Hastings & Symes, 2002; Keen, et al., 2010; Solish & Perry, 2008).

Parent involvement in treatment often consists of tasks assigned to parents to complete aspects of treatment in the home, complete fidelity training involving live or video recorded observations of parents implementing strategies, completing data collection tasks and making changes to parent-child interactions. How confident a parent feels in performing these tasks can impact how likely they are to complete them. Therapists often report problems with parents not completing or returning assignments such as data or video clips, avoiding live training sessions and implementing certain treatment strategies with their children. By embedding strategies targeting improvement of parent self-efficacy in a treatment plan, an ABA provider may improve parent motivation to attend training meetings and implement treatment procedures in the home and the community more consistently. Furthermore, having a better understanding of how parent self-efficacy impacts different types of involvement and if treatment strategies targeting parent self-efficacy can improve parent involvement, can help solve a common problem in ABA treatment.

### **Treatment Acceptability**

Treatment acceptability is defined as judgments by a layperson, client, and others about whether treatment procedures are appropriate, fair, and reasonable (Kazdin, 1980). When treatments are viewed as acceptable they are more likely to be adhered to than those that are viewed as not acceptable (Kazdin, 1980; Miltenburger, 1990). Treatment acceptability is a factor that, at least partially, mediates clinical outcomes by influencing decisions regarding treatment such as when to terminate and client compliance to treatment recommendations (Tarnowski & Simmonian,

1992). Factors that influence treatment acceptability can include characteristics of the treatment, child, and parent. Parents of children who have more severe behavior tend to view behavioral interventions as more acceptable (Choi & Kovshoff, 2013). Parents who perceived their children's behavior as being unrelated to the parent's influence are less likely to judge a behavioral treatment as acceptable (Mah & Johnson, 2008; Thorton & Calam, 2011). Cultural factors such as stigma or whether the targeted goals and strategies are culturally relevant can also influence the acceptability of treatment (Sanders & Kirby, 2012). Another variable that may improve acceptability of a treatment is to clarify with the parent at the onset of treatment the variables that influence treatment outcomes (Sanders & Kirby, 2012). Parents who perceive the treatment to be ineffective are more likely to drop out of treatment (Matson, et al., 2009). Therefore, when developing treatment, it is necessary to include the family in the development of goals and strategies and gather opinions from the parents and the extended family members who will interact with the child about the appropriateness of the treatment, as well as, the progress toward goals that have been made.

### **Limitations of Past Research and Purpose of the Current Study**

Many studies have assessed barriers to treatment such as parent stress, self-efficacy, and treatment acceptability. However, there is limited research to show how these variables interact with each other and if they help to explain variance in parent involvement in a clinical population. Research on how treatment targeted toward the parent can change beliefs and perceptions of their stress, self-efficacy, and treatment acceptability and whether those changes will lead to improvement in parent involvement is also lacking. Additionally, because these variables have been shown to affect parent involvement in treatment, there is a need to extend that knowledge to devise, implement, and evaluate a tailored intervention designed to improve parent involvement

in treatment. Furthermore, analysis of these constructs and the effects that parent training has on parents in a clinical treatment setting rather than those that have agreed to participate in parent training as part of a randomized-controlled trial research design, will extend knowledge on how parent choice in treatment affects outcome. Therefore, a major goal of the proposed study is to compare two groups of parents whose children participated in ABA. The treatment group opted to attend a parent-training targeted to reduce stress; increase self-efficacy, and increase treatment acceptability of ABA. The comparison group was parents who had a child(ren) receiving ABA services but opted not to attend parent-training. The two groups were compared for the effect the training had on parent stress, self-efficacy, treatment acceptability, and parent involvement. We will also analyze self-reported scores of parent stress, self-efficacy, and treatment acceptability to determine which, if any, can explain variance in parent involvement as a way to help guide treatment.

Based on the above literature review and perceived limitations of prior research, the following are the aims of this research.

Research Question 1: What are the effects of the parent training on parent stress, self-efficacy, treatment acceptability, and parent involvement with ABA treatment?

Research Question 2: To what extent do parent stress, self-efficacy, and treatment acceptability explain variance in parent involvement in ABA treatment for their children?

Research Question 3: How well does the group parent training explain variance in parent involvement above and beyond parent stress, self-efficacy, and treatment acceptability?

Research Question 4: If a relationship is found between the group parent training and parent involvement then is it moderated by parent stress, self-efficacy, and treatment acceptability levels?

It was hypothesized that by teaching parents to better communicate with their family and



support providers and deal with stressful situations including problem behaviors of their children, there would be a positive effect on parent perception of their stress and self-efficacy in relation to parenting a child with ASD. It is also hypothesized that by providing knowledge of ASD, background information, and the rationale about the treatment parents were being offered, it would improve the acceptability of using ABA strategies with their children, leading to increased usage of the treatment strategies and improvement in child outcomes. These outcomes are expected to provide those who work with children with ASD and their families more successful assessment and treatment strategies to improve parent involvement in their children's treatment plans. By learning more about how these variables are related and how to improve parent motivation, children will benefit with the improved outcomes that have been demonstrated by having parents involved in treatment.

## CHAPTER 2 LITERATURE REVIEW

### Applied Behavior Analysis

Early intervention is a necessary component of successful treatment of severe developmental disabilities and ASD. It is the recommended choice of treatment for children with ASD (Eldevik, et al., 2009; Rogers & Vismara, 2008; Reichow & Wolery, 2009). ABA is considered a “well-established” treatment and children who receive ABA make more significant gains than control groups on standardized intelligence and adaptive functioning measures (Eikeseth, 2009). These findings have also been replicated in a large-scale study using data at the population level (Freeman & Perry, 2010). ABA provided at the right dosage and implemented to fidelity is more effective than those treatments that are at minimal hours or those that are combined with other treatments in an eclectic approach (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Reichow & Wolery, 2009). Eldevik and colleagues (2009) conducted a meta-analysis using the raw data of 34 studies including 9 controlled designs and found a large effect size for changes in intellectual functioning (1.10) and a moderate effect size for adaptive functioning (.66). When behavior analytic strategies are used they have been considered highly effective by parents and parents report substantial satisfaction in making progress toward obtaining their children’s goals (Dillenburger, Keenan, Gallagher & McElhinney, 2004).

The American Academy of Pediatrics (2007) recommends Early Intensive Behavioral Intervention (EIBI) of no less than 25 hours per week of intervention for children with ASD beginning as soon as the child is identified as having ASD. It is recommended that ABA programs have the following components to reach the most optimal results: 1) address each child’s unique deficit areas, 2) have a low student-teacher ratio (one on one in most cases), 3) include a family component, and 4) include ongoing assessment of and revision of goals for the treatment plan

(Reichow & Wolery, 2009). Recent research even shows benefits for infants at risk of developing ASD (Bradshaw et al., 2015). Furthermore, teaching parents skills in ABA techniques can help with generalization, improvement of parent-child interactions and family functioning (Koegel et al., 1996; Koegel et al., 1998; Singer et al., 2007; Solomon et al., 2008; Tonge et al., 2006) and increased intervention hours have been shown to have a significant positive effect on treatment outcomes (Lovaas, 1987; Matson et al., 2012; Myers & Plauche Johnson, 2007).

When translating evidence-based treatment to clinical practice there are often changes in key variables from what has been reported in the literature to what occurs at the population level such as hours of intervention and adherence to treatment recommendations, including parent involvement. Three critical dimensions of treatment include the strength, integrity and effectiveness of the treatment (Yeaton & Sechrest, 1981). Parents often vary in the best practice recommendations in the number of hours of intervention they choose for their child, what other interventions they choose to also have their child participate in and how involved they are in the treatment. These are key variables that are likely to change the outcome of the treatment. Efficacious interventions for ASD are rarely adopted or successfully implemented as designed in public mental health systems (Dingfelder & Mandell, 2011). Adherence to treatment can include attending appointments, making lifestyle changes, parents having their children take medications on a specific schedule, and performing home-based therapeutic activities for themselves or their children (Moore & Symes, 2011). Variables associated with treatment adherence can include parent beliefs (Ajzen, 1991), information about what they are being asked to do (Fisher, Fisher, Amico & Harman, 2006), personal or family stressors, practical obstacles that include traveling and time, their relationship with the therapist and their ability to engage in the behaviors as prescribed by the therapist (Kazdin & Wassell, 1999). When parents are not seeing the outcomes

they had hoped for this can further decrease motivation for them and their children to fully participate in the treatment (Yeaton & Sechrest, 1981). Many studies have shown the effectiveness of parent involvement with children with ABA treatment. However, with the added benefits of parent involvement for the parents and their children, therapists are often confused as to why parents are sometimes uninvolved, difficult to engage or resistant to therapy. There may be practical barriers to treatment including the perception that treatment is too demanding, treatment is not relevant to their child, or poor therapeutic alliance with the therapist (Kazdin & Wassell, 1999) that can be directly targeted in treatment, which may have a positive effect on involvement.

The social motivation for a parent to engage in therapeutic activities may lay in part in their perception of social support from their significant others (Fisher et al., 2006). Family system models of stress and cohesion can be used to analyze why some parents might choose to be involved in treatment and why some may not (Hassell & Rose, 2005; Lavee & Olson, 1991; Siman-Tov & Kaniel, 2001). Siman-Tov and Kaniel (2001) examined a multivariate family systems model in an attempt to explain these phenomena. The four variates assessed included parent stress, resources, and adjustment; and the child's ASD symptom severity. They found that a parent's ability to cope with the stress of having a child with ASD was largely dependent on their sense of cohesion, their perception of the locus of control, their social support and the quality of their marriage. Lavee and Olson (1991) reviewed the resiliency model and circumplex family model to stress and adaption. These models suggest that all families have stress and how well they cope with stress depends on how adaptable and cohesive they are as a family, how many stressors they encounter, and the intensity of those stressors. An additional model of stress and the family focuses on how parental cognition can play a role in how adaptable a family is to the demands they experience (Hassall & Rose, 2005). This model focuses on the family interaction, resources, and

child characteristics as variables that affect responses to stress, and also specific characteristics about how the parent perceives stressors and their beliefs toward them (Mash & Johnston, 1990). For therapists in the field, it is imperative a transactional model of intervention focusing on both the child in treatment and the family is considered in order to get better treatment results that will be fully utilized and sustained within the family.

### **Parent Involvement**

Parent involvement is one of the necessary components of successful ABA treatment programs. Parent activities that are related to involvement can include attending educational or planning meetings, workshops and trainings about ASD and ABA; promoting the integration of treatment goals into the home and school environments; coordinating care between treatment team members, educational team members and other professionals that treat the child for medical or comorbid issues; observing during treatment; participating in ongoing evaluations and goal development for treatment progress; and engaging with their children using strategies prescribed in the treatment (Solish, Perry, & Shine, 2015).

Parent cognitions can be related to parenting behaviors, (Hassell, Rose, & McDonald, 2005; Kuhn & Carter, 2006) including how involved they are in treatment. There is also a lot of variability across parents' involvement in treatment (Mahoney & Powell, 1998). How supportive a parent views their family and community can also determine how effective they view themselves as a behavior change agent for their child. This can further influence their perceived efficacy as a parent (Moore & Symons, 2011; Solish & Perry, 2008). Parents of children with difficult behavior and intellectual disability often show decreased parent self-efficacy (Hassal et al., 2005) and increased levels of stress (Bitsika & Sharpley, 2004; Davis & Carter, 2008; Osborne & Reed, 2010; Tomanik, Harris, & Hawkins, 2004; Woodman, Mawdsley, & Hauser-Cram, 2015). Further

research is needed to clarify causal relationships between parent cognition and treatment (Hassell & Rose, 2005).

Research on parent involvement in the intervention of children with ASD is limited. Few studies examine the effects of parent and family involvement as a whole (Benson, 2015). In order to benefit from the outcomes as they are reported in the literature, clinical treatment must include a parent involvement component and have a dosage in hours similar to those in successful research. Typically, researchers focus on variables such as demographic information to describe treatment adherence (Becker & Maiman, 1975). However, these variables are not malleable and give therapists no hypotheses or strategies on how to make changes within their practice to remediate this problem. Choosing to participate with treatment, take medication, or show up to an appointment is controlled by the motivation of the person involved in treatment. Our thoughts, perceptions, and beliefs can change our motivation to engage in certain behaviors (Ryan & Deci, 2008; Dweck, 1986; Moes & Frea, 2002; Schauss et al., 1997; Weiner, 2008). When treatment providers consider how parents view the perceived effects of treatment and outside variables that impact the family, it will offer a better understanding of parent motivation as a potential barrier to ABA treatment.

As a way to improve the definition and measurement of parent involvement, Solish and Perry (2008) developed the Parent Involvement Questionnaire. This tool identified a good fitting four factor model of parent involvement in the following domains: 1) conducting formal intensive behavior intervention sessions with their children, 2) assisting with their children's program development, 3) participating with training on strategies used in treatment for their children and related to their children's diagnosis, and 4) involvement with the treatment agency in other ways such as volunteering and participating in agency activities and meetings (Solish et al., 2015). By

defining these four factors it added to the literature by providing therapists and researchers a better way to define parent involvement. This would improve the therapist's ability to add treatment goals to improve involvement and measure ways in which involvement was affected by these goals. Solish and Perry (2008) also identified several predictive variables associated with parent involvement. They reported involvement was negatively correlated with stress, and positively correlated with belief in the appropriateness of intensive behavioral intervention for their children. Belief in intensive behavioral intervention was also positively correlated with knowledge of ASD and ABA. A higher rate of perceived knowledge was also correlated with self-efficacy and stress was negatively correlated with self-efficacy. They concluded that self-efficacy was the only direct predictor of involvement, although belief and stress indirectly impacted involvement through their effect on self-efficacy (Solish, 2010).

A therapist version of the Parent Involvement Questionnaire was also developed. This was a shorter version of the Parent Involvement Questionnaire–Parent version with fewer, more general questions. Therapists were asked to rate parents separately when working with two parents from the same family. Perry and Solish (2008) found that there were significant differences between how parents and therapists rated their involvement. They suggested this was an issue in perception and that the information should be used to tailor treatment to reflect potential differences in how involvement is perceived by parents and therapists and that therapists may need to expand their view of what involvement is and tailor it for each family. Little is known about how the differences between the views of the parents and the therapist's affect treatment (Dillenburger, Keenan, Doherty, Byrne, & Gallager, 2010). It will be beneficial to have more information as to what the differences are in views and how these differences may impact collaboration between therapists and parents.

Typically, evidence-based parenting programs are able to show a positive outcome during randomized-controlled trials, but they have weak effects when used at the population level. Sanders and Kirby (2012) report that at the population level participation rates are often low, with high dropout rates or social stigma associated with participation of the recommended treatment. In order to obtain better outcomes for evidence-based treatment in a more widely accessible population group it will be necessary to consider the perceptions of the people who need to access it, the characteristics of the populations that practitioners want to use the treatment with, and the context in which the treatment will be used (Berwick, 2003; Greenhalgh, Robert, Macfarland, Bate, & Kyriakdou, 2004; Rogers, 2003).

When considering the variability between families that participate with recommended treatment and those who do not, we must better explain where the variability comes from in order to improve treatment outcomes. Barriers to treatment often can be accounted for in parent attributions of the child, the treatment, and parents themselves. Attribution is a person's perception of a situation and the causal factors framing that situation. An example of incorporating this concept into treatment is with the Stepping Stone Triple P program. Stepping Stones Triple P is a well-established parent-training program with widespread use that was adapted for parents of children with ASD. A study was conducted on the acceptability of this treatment by assessing parent views of the program after watching an educational DVD on the treatment (Whittingham, Sorronoff, & Sheffield, 2006). This study demonstrated that parent misattributions of children's behavior was a barrier to treatment acceptability in that when parents viewed the children's behavior as attributed to a stable trait such as ASD, rather than it being a modifiable behavior, they were less likely to find a behavior change technique usable. Parents also identified this program as one that was used for only younger and lower functioning children. Therefore, parents of higher



functioning or older children were less likely to find this treatment acceptable for their child. This study illustrates the necessity of evaluating parents' thoughts and beliefs about the treatment prior to its implementation as a way to improve treatment adherence.

### **Parent Stress**

Stress and adjustment of parents is not associated with demographic variables such as age of child or parents, number of siblings and income but more with the way that the child's symptoms present (Donnenberg & Baker, 1993) and psychological variables in the parent (Hastings & Johnson, 2001). Family systems theory suggests that parents' response to stress may have more to do with how many stress demands they have encountered and how flexible and adaptable the family members are in dealing with those stressors. A parent's cognitive appraisals and level of adaption, social support, marital happiness, family social climate and ability to engage in effective coping strategies all influence stress levels in parents (Hassell et al., 2005).

Parents of children with ASD are reported to have higher levels of stress than parents of typical children or other children with developmental disabilities (Benson, 2015; Hastings & Johnson, 2001). This is particularly true for mothers of children with ASD (Tomanick et al. 2004). There are mixed results on whether child behavior problems create or increase stress levels for parents (Tomanik et al., 2004). Tomanick and colleagues (2004) evaluated 60 mothers of children diagnosed with pervasive development disorder (now ASD according to DSM-V) and found that 2/3<sup>rd</sup> of the scores were significantly elevated. They also attempted to differentiate the type of behaviors that were reported by mothers to cause the most stress. They reported that mothers who experienced the greatest stress with their children rated their children as more irritable, lethargic, socially withdrawn, hyperactive, non-compliant, unable to communicate, interact with others or care for themselves. These are often primary symptoms of an ASD diagnosis (American

Psychological Association, 2013). Parents might believe that when their children engage in these behaviors, they are unsuccessful at meeting their children's emotional needs or unable to effectively engage with them. This can lead to increased levels of stress in the parent, particularly when their children are young (Woodman et al., 2015). Caregiver demands associated with raising a child with ASD can be excessive and can significantly influence how the family interacts and structures their daily activities (Moes & Frea, 2002).

Parents of children who have more severe symptoms of ASD report higher elevations of stress than those with less significant ASD symptoms (Hastings & Johnson, 2001). Communication impairment, uneven cognitive abilities and problems in social relationships are related to the stress that parents of children with ASD report (Bebko, Konstantareas & Springer, 1987). Children with high rates of externalizing behaviors also elevate reported stress levels of parents, especially fathers, (Davis & Carter, 2008; Donnenberg & Baker, 1993; Solomon, et al., 2008) and accounts for 32% of variance in the Parenting Stress Index–Short Form. (Tomanik et al, 2004). Mothers report an increased amount of stress associated with their children when they display problems with self-regulation such as emotions, sleeping and eating problems (Beck, Hastings, Daley, & Stevenson, 2004; Schwichtenberg & Poehlmann, 2007). Parents experiencing high levels of stress have less perceived involvement and poorer reported communication with their children (Osborne & Reed, 2010). High parent stress has a negative impact on child learning (Robbins et al., 1991). High levels in parenting stress can also lead to inconsistent discipline practices, lack of appropriate structure and guidance, and unrealistic expectations for the child (Crawford & Manassis, 2011). Parents of older children also report higher rates of stress (Davis & Carter, 2008). These behavioral and emotional problems have been shown to be stable within families and persist into adolescence and adulthood (Herring et al., 2006).

Parent stress can function as both an antecedent and a consequence to child problem behavior (Neece et al., 2012). Parents of children with behavior problems at 3 years of age report feeling more stress when the child is 5 and parents with higher reported rates of stress when their child is 3 years of age reported more behavior problems in their children at 5 years of age. This suggests that stress in parents influence problem behavior in their children and behavior problems in children influence stress in their parents (Woodman et al., 2015). Parent stress levels are also related to adaptive coping strategies, informal social support sources and beliefs about the efficacy of the intervention and their ability to parent their children effectively (Hastings & Johnson, 2001; Hastings & Symes, 2002). According to stress and coping theory, parents become stressed because of their secondary appraisals of the stressor and when they believe they do not have sufficient resources to effectively cope with the stressor (Beresford, 1994). Parents of children with more severe behavior problems are more likely to be pessimistic in their beliefs about the ability for treatment to make positive outcomes. However, higher parent self-efficacy levels are associated with reduced pessimism and stress even when ASD symptoms are high (Hastings & Johnson, 2001; Hastings & Symes, 2002). This bi-directional effect changes the nature of the parent-child relationship in a way that often results in a lack of feeling efficacious as a parent, leading to subjective negative feelings, perceived social isolation, parent health problems, and feelings of restriction in the parenting role (Lecavlier et al., 2006; Neece et al., 2012).

ABA is often stated to have intense requirements for families and this has been cited as a critique, which adds to the family stressors related to ASD (Schwichtenberg & Peohlmann, 2007). Parents are often encouraged to take on the role of therapist or teacher within the ABA program as part of their involvement in the treatment (Maurice, Green, & Luce, 1996). When the parents are in the role of therapist or teacher they have reported an increased level of stress when those

hours are too high (Schwichtenberg & Poelmann, 2007). Robbins, Dunlap and Plienis (1991) found that pre-intervention stress levels are the strongest predictors of parent stress during ABA treatment. Increased levels of stress can counteract the effects of the ABA intervention (Osborne et al., 2008). Further evidence suggests that stress mediates the impact of ASD severity and support on maternal therapeutic self-efficacy (Hastings & Brown, 2002; Hastings & Symes, 2002; Kuhn & Carter, 2006). When developing an ABA intervention, it is beneficial to consider what stressors the family is dealing with and how much and what type of involvement might be good to maximize the benefits of parent involvement without making matters worse for the family by demanding too much from them. It may be necessary for the therapist to recommend additional services such as counseling or other stress reduction strategies as part of the treatment in order to help families cope when they participate with more intensive ABA intervention programs (Osborn et al, 2008).

### **Parent Self-Efficacy**

Adult efficacy is related to several factors including lasting partnerships, marital relationships, career, financial resources, and parenthood (Bandura, 1997). Bandura (1997) discusses self-efficacy at length in his book *Self-Efficacy: The Exercise of Control* about how efficacy impacts the lives of people and variables that impact it. Parent self-efficacy is defined as a parent's feelings of competency in a caretaking role. Self-efficacy can mediate the role between thought and action by influencing persistence and engagement in specific parenting tasks. Bandura (1997) lists several variables that can lead to reduced efficacy in parenting including: not having an effective parenting model, not having strong parent-child attachment, lack of external social support, difficult child temperament, and having children who suffer from ongoing or severe health problems.

Ohan, Leung and Johnson (2000) reported that fathers have lower self-efficacy scores when

their children have higher rates of externalizing behaviors, whereas mothers have lower self-efficacy scores when their children have higher internalizing problems. Rogers and Matthews (2004) reported a slight negative correlation between overactive parenting style and self-efficacy but no correlation between self-efficacy and depression, anxiety or stress for either mothers or fathers. In 2008, Gilmore and Cuskelly found that efficacy accounted for 22.7% of variance in the Parenting Sense of Competency Scale. Mothers reported higher self-efficacy than fathers, but fathers' scores tend to be higher when they are over the age of 50. The severity of the child's problem behavior is seen as a negative predictor for parent self-efficacy, but support from ABA treatment is seen as a positive predictor (Hastings & Symes, 2002; Ohan, Leung & Johnson, 2000).

Parent self-efficacy has been shown to be an important factor in promoting positive well-being in parents and their parenting practices (Hastings & Brown, 2002; Jones & Prinz, 2005; Weiss et al., 2013). In fact, it has been shown to be the only direct predictor of parent involvement (Solish, 2010). One factor associated with increased levels of reported self-efficacy is education for parents of children with ASD, especially when the child is suffering from severe problem behavior (Benson, 2015). Studies have shown an increase in parent self-efficacy levels for parents of children with intellectual disabilities following training focused on the use of treatment strategies for managing behavior for children with intellectual disabilities (Hudson et al, 2003). Family-based interventions designed to provide support to families and focus on parent cognitions may enhance parent self-efficacy (Kuhn & Carter, 2006).

When considering treatment for children with ASD we must also consider the effects parent self-efficacy can have on the outcomes of the treatment for their children. As stated previously, parent implementation of therapeutic strategies and data collection in the home is an integral part of ABA treatment, but it is not always adhered to. Parents' beliefs about their ability to take on a

therapeutic role may predict their ability and willingness to act as therapists for their children's program (Hastings & Symes, 2002). It was reported that parents are able to demonstrate fidelity with ABA procedures and they report satisfaction with the intervention (Bradshaw et al, 2015). If treatment focused on ways to improve self-efficacy in parents, it could lead to an increase in parent involvement, which in turn could improve the overall outcome for the child and family. Self-efficacy in a particular area can also be related to the quality and amount of training, support and supervision one gets (Hastings & Symes, 2002). Determining how efficacious parents feel about performing certain parenting and treatment related tasks can help to guide a therapist on the type and amount of support they need to successfully help a family make a therapeutic change in the home environment.

### **Treatment Acceptability**

Treatments that are effective can vary on their acceptability (Kazdin, 1980). Treatment acceptability is a factor that can impact the outcome of treatment success for children receiving ABA. Finding a good fit between the characteristics of the treatment and what will be acceptable and identified as useful to the population targeted for treatment is necessary for treatment adherence (Sanders & Kirby, 2012). Sanders and Kirby (2012) report several factors that increase the likelihood of getting a good fit between the consumer and the treatment. These include building a relationship with the consumer groups that will be using the services, soliciting input from those using the service and clarifying those variables that influence access and completion of treatment programs to their fidelity. In their publication, they focus on the client as a consumer of services. This is appropriate when considering the choices that clients have in whether or not to participate with treatment or parts of treatment as recommended by the therapist.

In 1978, Wolf published an article questioning the concept of social validity when using

ABA procedures. This concept focuses on how socially important a treatment is in terms of the goals, procedures, and the effects of the treatment. Considerations of social importance can be assessed in terms of ethics, cost, practicality of the treatment procedures, and the use of the treatment. If parents do not see the treatment as socially valid for their children, they will have little value for the treatment and this will impact their motivation to engage or persist with treatment. This can be especially true if they are experiencing high levels of stress or low levels of self-efficacy. In 1980, Kazdin began to consider this concept in terms of acceptability of treatment. He defined acceptability as the judgments about treatment procedures by non-professionals, lay-persons, clients, and other potential consumers about the treatment. He further extended the idea of acceptability to assess how fair, reasonable, and non-intrusive a treatment was. He also focused on the idea of whether or not the treatment met conventional notions about what the treatment “should be”. Treatment must be effective and accepted by those who are implementing it (Miltenberger, 1990).

Some research has been conducted to evaluate typical responses of lay-people regarding their thoughts about behavioral interventions. Mothers tend to prefer positive discipline techniques to negative ones as a way to reduce inappropriate behavior (Jones, Eyberg, Adams, & Boggs, 1998). Behavioral procedures are typically more acceptable to those parents who have children with more severe behavioral problems and to those staff who are more behaviorally oriented (Tarnowski, Rasnake, Mulick, & Kelly, 1989). Positive reinforcement is the most acceptable behavioral treatment followed by response cost, time out, differential attention, overcorrection and spanking as the least acceptable (Jones et al., 1998). Other considerations regarding treatment acceptability can include the severity of the problem behavior, the treatment approach, the side effects of a treatment, the time needed to implement the treatment, and the cost of treatment

(Reimers, Wackers, & Koepple, 1987).

Families may be at risk for dropping out or not fully adhering to treatment if they have serious doubts about the effectiveness of the intervention (Hastings & Johnson, 2001). Providing education regarding the rationale of a treatment can change the acceptability of the treatment (Singh & Katz, 1985; Tingstrom, 1989). The Stepping Stone Triple P program incorporated educational components and the researchers measured the changes in parent attributions following education on the program. Parents reported higher rates of acceptability to treatment after viewing the Stepping Stones informational video (Whittingham et al., 2006). The researchers recommend that in clinical settings, therapists spend more time educating the families about the parent training program, its rationale and what is being targeted to increase buy-in on how usable it is for their children before beginning the treatment. Similarly, Singh and Katz (1985) evaluated the effects of a 5-hour lecture on using behavioral interventions with children to undergraduates and demonstrated an increase in the acceptability levels of behavioral interventions following the lecture. Providing performance training for treatment can also influence the acceptability of a procedure. In a study conducted by Reimers and Wacker (1988), parents were coached to use a behavioral procedure with their children and then reassessed for their acceptability ratings after a month and found increases in acceptability of the procedures. In conclusion, describing the rationale, educating consumers, and exposing them to treatments prior to the expectation that they implement the procedure can improve their acceptability of the procedure and ultimately increase the likelihood that they will adhere to it.

### **Parent Training**

Research consistently shows that parents are able to develop skills using ABA techniques that result in more effective treatment for their children (Matson et al., 2009). Successful



behavioral intervention for children with ASD that have parents implement therapeutic activities with their children focus on training parents to recognize and define specific behaviors for data collection, establish specific consequences for problem behavior in the home and community settings, and maintain consistent programming across settings (Matson et al., 2009). Often parents are trained to increase overall compliance with their children, implement skill acquisition procedures to facilitate learning with their children, and implement procedures targeted to reduce specific behavior problems (Johnson et al., 2007). Providing a detailed manual for parents can help to increase the fidelity of the treatment and training procedures (Johnson et al., 2007). Parents who can implement procedures as prescribed across settings and maintain the consistency of the treatment are less likely to seek help for their children in the future (Forehand, Steefe, Furey, & Walley, 1983).

Parent training and intervention programs often focus on the outcomes of children and fail to consider how parent and family variables might impact the overall treatment outcomes. Controlled studies have demonstrated that parent training can lead to improved child communication, increased maternal knowledge of ASD, enhanced maternal communication style, and improved parent-child interaction (McConachie & Diggle, 2007). However, results of randomized controlled trials of parent education programs are mixed (Tonge, Brereton, Kiomall, Mckinnon, & Rinehart, 2014). Parents are often able to perform the skills but do not effectively use them after they are learned (Mahoney & Powell, 1998; Moore & Symons, 2011). There are also many issues with transferring the skills learned in treatment across settings (Cordisco, Strain, & Depew, 1988). This variability in implementation might be due more to the attitudes and beliefs of the parents rather than just their ability to perform the tasks asked.

The Stepping Stone Triple P parenting program has been available for the last 30 years. In

this model parents are trained in small groups of 4-5 that are paired up based on similar functioning of their children. They are provided training in group and individual sessions based on a manualized training program. This program has demonstrated improvements in parent reported child behavior problems and parent reports of knowledge, skill, and confidence (Sanders, 2009). The focus of the Stepping Stone Triple P parenting program is to help parents learn to provide positive attention and to manage problem behavior in their children by considering the function of their children's behavior. This parent-training program was modified to specifically target families with children who had disabilities in 2003 and again for parents of children with ASD in 2006 (Whittingham, Sofronoff, Sheffield, & Sanders, 2009). Outcomes of this parent-training program have been associated with acceptance and satisfaction (Sanders, 1999). The Stepping Stone Triple P program has an impressive body of outcome data showing statistically significant decreases in behavior of children that has been shown to maintain over time (Sanders, 1999; Sanders, Mazzucchelli, & Studman, 2004; Whittingham et al., 2009).

Tonge, Brereton, Kiomall, MacKinnon, King, and Rinehart (2006) conducted a randomized controlled study of two types of parent interventions. They aimed to compare the effects of a parent education and behavior management intervention as compared to a counseling intervention program. The parent education and behavior management intervention included topics such as features of ASD diagnosis, managing behavior and change, teaching new skills, improving social interaction and communication, services available in the community, parental stress, grief and mental health, sibling, family, and community responses to ASD. The other was an intervention in which the sessions had no training or homework and the emphasis was on nondirective interactive discussion and counseling. They found that both treatments resulted in significant progressive improvement in the overall mental health of the parents involved,

especially with those parents who reported the highest levels of mental health problems. However, the educational and behavior management intervention group was more effective in also alleviating anxiety, insomnia, somatic symptoms and family dysfunction at a 6 month follow up.

Kasari, Gulrud, Paparella, Helleman, and Berry (2015) studied the effects of parent-mediated interventions for toddlers with autism. They developed two parent-training models. One training model focused on psycho-education, which targeted a behavior management and skill development; stress; and family variables that commonly impact treatment such as; siblings, and family and community responses to diagnosis. This training was provided in a didactic model. The parents in the other group were exposed to a hands-on training approach targeted at improving core deficits of ASD such as joint attention, symbolic play, engagement and regulation. Active coaching was used in one-on-one settings to teach parents these skills. They found that parents who participated in the hands-on model had children that gained more skills in joint attention and functional play and generalized those skills to new environments. Parents in both groups reported high levels of stress with nearly 50% of the parents rating their stress in clinical ranges. Parents in the psycho-educational group reduced stress levels, but the hands-on group did not. The authors concluded that future studies may want to evaluate the effects of a combined parent training where both the parent skills and their family stressors are targeted within a treatment model.

Measures of child behavior problems, parent stress, behavior, and negative beliefs and emotions tend to persist and stay stable over time. However, early support and intervention can improve child behavior problems, negative emotions, and parent beliefs resulting in improved family functioning (Herring et al., 2006). When examining the effects of parent stress, self-efficacy, and treatment acceptability we see that there seems to be a bi-directional effect between the family's ability to function and the stress and support they receive. Parent training can have a

positive impact on parent stress and self-efficacy (Keen et al., 2009). Using psycho-educational programs focused on the functioning of family systems and helping families better adapt to the stressors of having a child with ASD may lead to improvement in their perception of the family situation and change a parent's view of their ability to effectively parent their child (Lavee & Olson, 1991). Interventions addressing both the children's behavior and the parents' well-being are likely to promote better results than focusing on either separately (Singer et al., 2007).

When assessing the functioning of a family you can see that ABA may add additional stressors if the family is not prepared for this additional burden. However, ABA therapy has also been shown in certain situations to reduce stress. It is hypothesized that the underlying premise of the treatment assists parents in gaining efficacy in parenting a child with ASD by focusing on teaching parents new, more successful ways to interact, teach and discipline their children. This can also result in a reduction of stress for the family by reducing the problem behaviors the children are engaging in and increasing the communication and adaptive skills, enabling parents to experience relief by moving their children forward developmentally. Creating these positive outcomes for their children can reduce the pile up effects to the family, which usually is exacerbated as children with behavior problems grow and become a greater burden to the family unit.

When families enter a treatment situation with their children they come with their own sets of strengths and weaknesses, communication styles, access to community resources, and perceptions of how their children with disabilities are functioning within their family. What ideas they have about these things has an impact on the family unit. Pre-intervention education on the disorder including, what the treatment will look like and the time and effort needed by the family may help to increase the understanding on how their children's disabilities and subsequent

treatment will impact the family as a whole. Giving parents a better understanding of what they need to do in order to make treatment gains, why it is important, and how the treatment pertains to their children specifically can help with parent acceptance of treatment recommendations. Also, assisting the family in constructing a support system within their family and in the community, as well as, focusing on effective communication within those support relationships can help with sustaining the necessary changes that will result in treating a child with ASD successfully. These preemptive measures of family treatment can set the children's treatment off in a positive direction rather than starting treatment and then resolving issues with failed commitment and involvement that are likely to arise in a number of families that attempt ABA treatment for their children with ASD.

A missing link in the literature is how parent training can impact parent stress, self-efficacy, and treatment acceptability in clinical practice (McConchie & Diggle, 2007). More research must be completed at the population level where community resources are used to assess the outcomes within current treatment systems with funding that is typically available for these types of services and families are able to choose treatment as they would in a typical clinical setting. Furthermore, there is little discussion in the literature about how parent training packages can impact parent involvement in their children's intervention. By assessing the outcomes in a clinical setting, researchers will have a better idea of how the randomized controlled studies have translated to a real clinical population.

## CHAPTER 3 METHOD

### Participants

In this sample, a total of 113 parents were contacted to participate in the study. These parents were comprised of current and past clients of the autism center during the time period when the parent training seminars were available. They were recruited from an ABA treatment facility in the Midwestern United States with multiple center-based locations in a metropolitan area. Of those contacted, 33 were unreachable, 17 declined to participate, 23 agreed to participate during a recruitment phone call, but did not return the materials, and a total of 40 (n=40) parents returned the written consent and parent involvement survey. 18 of the 40 participants who consented had participated in the parent training seminars and 22 had not.

This was a quasi-experimental design study with two groups: 1) 18 parents who elected to participate with the group parent intervention program as part of their children's standard care of treatment who functioned as a treatment group, and 2) 22 parents who elected not to participate in the group parent intervention program who functioned as a comparison group. Of those who consented, several had missing data from their file or had not yet had follow up data on the parent report measures collected as part of the client's standard care of treatment. Because these measures were not available in all the client files, it resulted in a decreased number of participant's data run for each analysis. Each analysis was run with the most complete data set available for the measures being analyzed. Based on the completeness of the client treatment files, samples ranged from 15-18 in the treatment group and 12-13 in the comparison group for analyses comparing the groups.

The participants were asked a number of demographic questions at the time of the study, including socio-economic status (SES), age, gender, race, education, marital status, family size, and living arrangements of the family members. The SES was determined based on the insurance

type presented for the care of the child (Medicaid or private insurance). The overall percentage of parents of low SES (Medicaid) was 17.5% of the total parent group. The age of the participants was broken down by father and mother into 6 categories with 1 being less than 21, 2 being 21-30, 3 being 31-40, 4 being 41-50, 5 being 51-60, and 6 being over 60. Of participants who reported their age, the majority of fathers were 4 (41-50) ( $n = 17$ , 44%) and mothers were 3 (31-40) ( $n = 19$ , 50%) years of age. The gender of the participant's children was overwhelming male at 90% ( $n = 36$ ) and 10% ( $n = 4$ ) being female. Of the participants who identified their race, the majority of the participants identified as either Caucasian ( $n = 21$ , 58%) or African American ( $n = 7$ , 19.4%), with the remaining sample being Asian ( $n = 3$ , 8%), Hispanic ( $n = 2$ , 5%), and other ( $n = 1$ , 3%). Education level was obtained for parents. Data for the mothers was as follows: 8% graduated from high school, 8% having some college, 15% having an associate's degree, 49% having a bachelor's degree, 18% having a master's degree, and 3% having a doctorate degree. Data for the fathers was as follows: 3% having some high school, 8% graduated from high school, 10% having some college, 10% having an associate's degree, 26% having a bachelor's degree, 23% having a master's degree, 15% having a doctorate degree and 5% reporting other type of degree/certification. 78% of the parents were married, 5% were single, 2.5% were cohabitating, 10% were divorced, and 5% were widowed. Family size accounting for number of children ranged from 1-6 with a mean number of children being 2.5 and a median of 2. Of the participating families, 31 reported their children lived with both parents. For those who reported a split family, 20% of parents reported having their child spend 50% of their time with each parent and 60% reported having their child spend the majority of time with their mother and 20% with their father.

Parents were also asked to provide information about how much time their children spent in treatment per week and how much time they spent in treatment with the consultant per week as

part of their children's treatment. The average number of hours their children spent in treatment per month was 87 with a median of 67. 18% of the children spent 20-40 hours in treatment per month, 29% spent 41-60 hours in treatment per month, 12% spent 61-80 hours in treatment per month, 24% spent 81-100 hours in treatment per month, and 18% spent more than 100 hours in treatment per month. The parents reported spending an average of 3.36 hours per month with their children's therapists with a median of 4. 38% of the parents spent 0-2 hours per month with their children's therapist, 59% spent 3-5 hours with their children's therapist, and 3% spent over 6 hours per month with their children's therapist.

### **Procedure**

The cognitive-behavioral group parent intervention offered to the parents by the autism center was a 16-hour training designed to provide parents with the following: knowledge and understanding of their child's diagnosis and treatment, skills for improved family planning, communication and coping skills, training on ways to better manage behavior and improve skill building in their children, and assistance with how to access community resources. This intervention was scheduled in eight two-hour sessions for parents in small groups. The content covered in each session was manualized to include the topics listed above with both in-session and home activities to allow further practice of the skills taught. Additionally, parents were encouraged to participate and share information amongst the group to enhance learning and the shared experience for the members.

The topics for the sessions include the following: 1) ASD diagnosis and symptoms; how to observe specific feature of ASD in each child; how symptoms and treatment changes based on the age of the child; genetic causes of ASD and other medical conditions that frequently co-occur with ASD; and how to recognize evidence-based treatment. 2) The effects having a child with



ASD has on a family; how the family members can adapt to meet the changing needs of their family following a diagnosis; understanding typical development; and determining goals for children based on their strengths and weaknesses. 3) How to observe and determine functions of behavior. 4) Changing behavior through motivation and reinforcement. 5) Improving compliance and disciplinary practices. 6) Assessing skills to promote teaching and collaborating with the school. 7) Decreasing stress; improving communication between family members; and improving sleep habits. 8) Working collaboratively with treatment providers to develop a treatment plan and improving communication with treatment team members.

This was a voluntary treatment option that was offered to all parents who had children enrolled in ABA therapy at the treatment center. Some parents chose to participate in this treatment option, while others did not. All parents of children involved in ABA treatment at the treatment center were asked to be evaluated in terms of their perceived stress, self-efficacy, and treatment acceptability levels, as part of their children's standard care of treatment at each six-month interval when their children's plans were reviewed. These tools were used to guide the therapists' interaction with parents, to improve the quality of service for the children and their families and to assess additional barriers that may affect outcomes for their children.

In this study, those measures were used to assess changes in parent stress, self-efficacy, and treatment acceptability levels. There was some variation of how the measures were used clinically with each client. Most often there was one reporter for each of the children's measures in the client file. However, whether the reporter was the mother or father was not indicated. If there was more than one reporter for the same measure of the same assessment period, those scores were averaged to indicted one score only for each measurement time. There were also some instances where not all measures were used at each assessment period. If this occurred then the

measures available from that assessment period were used for the analyses, resulting in differing numbers of overall assessments for each of the measures extracted from the files. Furthermore, the individual scoring sheets were not available for review, only the total score for each measure was available for extraction from the treatment plan in the client files. Therefore, analysis of the measures for this current sample are limited by the data available in the client files.

Additional data was collected on parent involvement by both the parent and therapist on children whose parents consented to participate in the study. These forms were filled out by one member of the family for the parent forms and by the children's therapist who was most knowledgeable about the case. One of the challenges with collecting the data for this portion of the study was the inconsistency with staff. There was a high turn-over rate at the center for therapists working as behavior analysts. In this clinical setting, there were often multiple therapists who worked with each client and it was left up to the team to determine who the best reporter would be. There were also situations where the therapist for the child was no longer employed and unable to be reached. Therefore, data for those children did not include the therapist measure.

For those who consented, surveys were completed and their records were reviewed for treatment measures for parent stress, self-efficacy, and treatment acceptability (PSI-SF, PSOC Efficacy subscale, and the TEI-SF), demographic data and their amount of participation in treatment. The university IRB approved all procedures.

## **Measures**

**Parent stress.** Parent stress was measured using the Parenting Stress Index–Short Form (PSI-SF). The PSI-SF has been commonly used to evaluate program outcomes with high-risk populations (Abidin, 2012). The PSI-SF has 36 items scored on a five point Likert-type scale with items being rated as 1= Strongly Agree, 2=Agree, 3=Not Sure, 4=Disagree, and 5=Strongly

Disagree. There are three subscales in the 4<sup>th</sup> edition including: a) Parent Distress, focusing on the parent's personal adjustment to parenting (e.g., "I feel trapped by my responsibilities as a parent"), b) Parent-Child Dysfunctional Interaction, focusing on whether or not the quality of parent-child interactions meet the parent's expectations (e.g., "When playing, my child doesn't giggle or laugh"), and c) Difficult Child, focusing on the parent's perceptions of whether the child's behaviors are perceived as normal by the parent (e.g., "My child gets upset easily, over the smallest things").

To calculate the scores, raw scores are totaled based on their domains and converted to percentile ranks and/or T scores based on the manual tables. The percentile rank is the primary interpretive measure. Scores in the 16<sup>th</sup>-84<sup>th</sup> percentiles are considered in the normal range, those in the 85<sup>th</sup>-89<sup>th</sup> percentile are considered in the high range and any score in the 90<sup>th</sup> percentile or above are considered clinically significant. Scores can be examined over all or by domain to determine if they fall within the clinical range. Defensiveness can also be determined for scores of less than 24. Scores that are classified defensive should be interpreted with caution. The overall PSI-SF test has a high internal consistency of .84, .85 for parenting distress, .68 for parent-child dysfunctional interaction, and .78 for the difficult child subscales (Tomanik et al., 2004). Test-retest reliability is stable across 1-3 month intervals; it has displayed predictive validity across cultures and demonstrated stability and validity of factor structure (Abidin, 2012). In this study, retrospective data was obtained in the form of total raw scores and percentile ranks that were extracted from the treatment plans. The scales were already computed by the client's therapist as part of their standard care treatment and the computed scores were reported in their treatment plans. Thus, the individual item scores were not available. The treatment plans were made available for this study and the computed scores were examined to determine the if raw scores

changed over time.

**Parent self-efficacy.** Parent self-efficacy was measured by the self-efficacy subscale of the Parenting Sense of Competence Scale (PSOC) (Johnston & Mash, 1989). The PSOC is a 17-item questionnaire developed to assess parenting self-esteem with items being rated on a 6-point Likert-type scale ranging from 1= Strongly Disagree, 2= Disagree, 3= Neutral, 4 = Agree, and 5 = Strongly Agree (e.g., “I meet my own personal expectations for expertise in caring for my child”). The PSOC has two subscales (satisfaction and efficacy). Only the 8-item efficacy subscale was used in this study (questions 1, 2, 3, 5, 6, 7, 9, & 10). The efficacy subscale represents competence, problem solving, and capability in the parenting role (Johnston & Mash, 1989). This is the most frequently used tool to assess parent self-efficacy as linked to treatment success (Jones & Prinz, 2005; Črnčee, Barnett, & Matthey, 2010). Average mean efficacy scores range from 3.24-4.12 and the higher the score on this assessment the stronger the indication of parent self-esteem (Rogers & Matthews, 2004). The internal consistency for the PSOC Efficacy subscale is high ranging between .76-.88 (Lovejoy, Verda, & Hays, 1997; Johnston & Mash 1989). In this study, retrospective data was obtained in the form of total scores that were extracted from the treatment plans. The scales were computed by the client’s therapist as part of their standard care treatment and the computed scores were reported in their treatment plans. The treatment plans were made available for this study and the computed scores were examined to determine if raw scores changed over time.

**Treatment acceptability.** The Treatment Evaluation Inventory–Short Form (TEI–SF) was used to measure the belief of a parent that ABA is a good treatment for their child (Kelley, Heffer, Gresham, & Elliott, 1989). It is used most often in clinical research with parents of children with behavior problems and to monitor treatment acceptability within a treatment study (Finn & Sladeczek, 2001). It was modified from the Treatment Evaluation Inventory (Kazdin, 1980) to

reduce the number of items and simplify the wording. At that time, it was also changed from a seven-point to a five-point Likert-type scale (Kelly et al., 1989). The TEI-SF is a 9-item measure, which uses a five-point Likert-type scale with items being rated as 1= Strongly Disagree, 2= Disagree, 3= Neutral, 4 = Agree, and 5 = Strongly Agree (e.g., “I believe the treatment will likely result in permanent improvement”). Acceptability of the psychometric properties of the TEI-SF has been demonstrated to show discriminative validity (Jones et al., 1998; Kelly et al, 1989; Finn & Sladeczek, 2001). It has good internal consistency at .85 and the internal consistency scores for the TEI-SF ratings for acceptability of a parent-focused versus a child focused intervention were high at  $\alpha = .90$  and  $\alpha = .91$  (Choi & Kovshoff, 2013). Items are summed with number six being a reverse score. A total of 27 indicates a moderate acceptance of treatment level with a range of 9-45 for the assessment tool (Jones et al., 1998; Kelly et al., 1989). In this study, retrospective data was obtained in the form of total scores that were extracted from the treatment plans. The scales were computed by the client’s therapist as part of their standard care treatment and the computed scores were reported in their treatment plans. The treatment plans were made available for this study and the computed scores were examined to determine if raw scores changed over time.

**Parent involvement.** The Parent Involvement Questionnaire was used to measure the level of involvement of parents who participated in ABA for their children with ASD. Both the parent and the therapist working with the parent assessed parent involvement using the parent and the therapist version of the tool. It is scored on a five-point Likert-type scale with items being rated in general as one being at the low range of choices and five being at the high range of choices, short answer, and true or false questions. Three latent variables were identified for the scale: involvement, self-efficacy, and belief in intensive behavioral intervention. It has six subscales including: parent involvement and five predictor scales: self-efficacy, perception of child progress,

belief in intensive behavioral intervention, knowledge, and stress.

The parent involvement subscale is broken into three domains; Agency Involvement (e.g., “Please indicate how often you do the following things: Communicate directly with your child’s IBI program staff either on the phone or in person”), Training Involvement (e.g., “Indicate how often you do the following things; Seek out information about autism and IBI”), and Child Program Involvement (e.g., “To what extent do you try to generalize your child’s academic skills”) (Solish, 2010). Seventy-two percent of variance in the Parent Involvement Questionnaire was accounted for in self-efficacy, 25% of the variation was accounted for in belief, and 67% of variance was accounted for in involvement (Solish, 2010). The parent involvement subscale has an internal consistency rating of between .72-.95. The five predictor scales: self-efficacy, perception of child progress, belief in intensive behavioral intervention, knowledge, and stress have an internal consistency rating of between .72-.92 (Solish, 2010). This assessment was administered as part of the study and was not part of the standard care of treatment. Therefore, individual items were available to determine internal reliability coefficients for this sample. In the current sample, the Cronbach’s alpha internal reliability coefficients were .89 for both the parent and therapist reports. In this study, the Overall Involvement Subscale was used to compare means of the treatment and comparison group scores and the Self-Efficacy, Belief in IBI, and Parent Stress predictor scales were used for the third regression analyses as *á posteriori* analysis in research question two.

### **Data Analysis**

The statistical package IBM SPSS was used for analyses. A criterion alpha level of .05 was used to determine statistical significance. A significance level of .05 leaves a 5% probability that the results of the study were generated randomly, and a 95% probability that they are not due to chance. Table 1 provides an overview of the analyses used to assess the research questions.

Table 1  
Statistical Analyses

Research Questions	Variables	Statistical Analysis
Preliminary analysis will be run using ANOVA to test for differences in parent involvement, stress, efficacy, and treatment acceptability by various demographics including SES, marital status, and family size. The purpose will be to determine if any demographics should be controlled for in the main study analyses.		
Research question 1: What are the effects of the parent training on parent stress, self-efficacy, treatment acceptability, and parent involvement with ABA treatment?	<p><b>1) Mixed Design ANOVA</b>  <u>Dependent Variables (pre and post-test)</u>            —Parent stress            —Self-efficacy            —Treatment acceptability  <u>Independent Variable</u>            —Time            —Group (treatment vs. comparison)</p> <p><b>2) ANOVA</b>  <u>Dependent Variable (post test)</u>            —Parent involvement parent            —Parent involvement therapist  <u>Independent Variable</u>            —Group (treatment vs. comparison)</p>	<p>1) Three Mixed Design ANOVAs to assess parent stress, self-efficacy, and treatment acceptability            2) Two ANOVAs to assess parent involvement by parent and therapist report</p>
Research question 2: To what extent do parent stress, self-efficacy, and treatment acceptability predict parent involvement in ABA treatment with their children?	<p><u>Predictor Variables</u>            —Parent reported stress            — Self-efficacy            —Treatment acceptability  <u>Criterion Variables</u>            —Parental involvement parent            —Parent involvement therapist</p>	Two Multiple Regression Analyses
Research question 3: How well does the group parent training explain variance in parent involvement above and beyond parent stress, self-efficacy and treatment acceptability?	<p><u>Predictor Variables at Step 1</u>            —Parent report stress            —Self-efficacy            —Treatment acceptability  <u>Predictor Variables at Step 2</u>            —Parent training  <u>Criterion Variable</u>            —Parent involvement</p>	Hierarchical linear regression analysis
Research question 4: If a relationship is found between the group parent training and parent involvement then is it moderated by parent stress, self-efficacy, and treatment acceptability levels?	<p><u>Predictor variable:</u>            —Parent training  <u>Moderating variables:</u>            — Parent stress            — Self-efficacy            —Treatment acceptability  <u>Criterion variable:</u>            —Parent involvement</p>	Three hierarchical linear regression analyses, one with each moderating variable separately.

## CHAPTER 4 RESULTS

The purpose of this study was to compare two groups of parents whose children participated in ABA on their levels of stress, self-efficacy, treatment acceptability, and the parents' level of involvement in their children's treatment, and to assess variables that may explain some of the variance in parent involvement. Parents in the treatment group participated in a voluntary parent training and the comparison group were parents who elected not to participate in the voluntary training. The first objective of the study was to assess the effects of the parent training. The second objective was to determine how much parent stress, self-efficacy, and treatment acceptability explained variance in their involvement in their children's treatment. The third objective was to determine what affects the parent training had on the model. Lastly, if parent training was found to explain some of the variance in parent involvement, the objective was to determine if the effects of the parent training on parent involvement was moderated by any of those predictor variables. The results of the data analyses used to test the four hypotheses developed for this study are presented in this chapter.

### Preliminary Analyses

Preliminary analyses were conducted using an Analysis of Variance (ANOVA) to compare the treatment and comparison groups for differences in parent stress, self-efficacy, treatment acceptability, and parent involvement by various demographics including socio-economic status (SES), age of parent and child, child gender and race, parent education, marital status, family size, hours of service, severity of child behavior, and cognitive level. These analyses were mostly nonsignificant and only showed main effects for treatment acceptability scores by father's level of education ( $F(1, 3) = 10.73, p < .05$ ) and by child's level of problem behavior ( $F(1, 3) = 16.35, p < .05$ ). These differences were not the focus of the study, however, and thus were controlled for in



the primary analyses. The overall means and standard deviations for all measures and correlations between pre- and post-test measures, for the treatment and comparison groups are included in Table 2. Correlations between all study variables are included in Table 3.

Table 2

*Descriptive Statistics and Correlations Between Pre- and Post-Test Measures*

Treatment	Pretest		Posttest		n	95% CI for Mean Difference	r	t	df	p
	M	SD	M	SD						
Stress	86.83	16.17	80.08	20.91	12	-7.60, 8.39	.38	1.04	11	.38
Efficacy	27.73	6.00	29.64	6.55	11	-3.72, 1.83	.91**	-2.35	10	.00
Acceptability	29.75	3.57	33.17	4.28	12	-5.68, 0.61	.60*	-3.33	11	.04
Inv-Parent			70.8	17.0	18	62.6, 78.9				
Inv-Therapist			86.6	15.9	16	78.3, 94.8				

  

Comparison	Pretest		Posttest		n	95% CI for Mean Difference	r	t	df	p
	M	SD	M	SD						
Efficacy	29.72	5.49	30.78	4.53	18	-3.94, 1.83	.34	-.77	17	.17
Acceptability	31.67	5.06	33.61	4.13	18	-4.50, 0.61	.39	-1.61	17	.11
Stress	85.83	19.37	83.62	16.42	18	-3.94, 8.39	.77**	0.76	17	.00
Inv-Parent			77.54	16.66	13	67.96, 87.11				
Inv-Therapist			73.15	16.31	13	63.10, 82.31				

Note. Inv=Involvement; \* $p \leq .05$ ; \*\* $p \leq .01$

Next, a correlation analysis was conducted among all of the constructs measured within the study. The results in Table 3 indicate that parent self-efficacy was significantly correlated with parent stress. This analysis revealed no other significant correlations between the measures.

Table 3

*Pearson Correlation Matrix for All Measures*

Variables	Stress	Efficacy	Accept	Involve-parent	Involve-therapist
Stress		.02*	.10	.23	.12
Efficacy			.44	.96	.97
Acceptability				.72	.31
Involve-Parent					.67
Involve-therapist					

Involve=Involvement, Acceptability = Treatment Acceptability; \* $p \leq .05$ ; \*\* $p \leq .01$

**Research Question 1: What are the effects of the parent training on parent stress, self-efficacy, treatment acceptability, and involvement in ABA treatment?**

To answer this question, three separate Mixed Design ANOVAs were run to determine if there were statistically significant pre–post changes in the scores in parent stress, self-efficacy, and treatment acceptability for the treatment group compared to the comparison group. This approach was selected as most appropriate given the relatively small sample size. For each analysis, two independent variables were entered – a within–subject variable (time 1 vs time 2) and a between–subject variable (treatment vs comparison group). The dependent variable for each separate analysis were parent stress, self-efficacy, and treatment acceptability.

First, the Mixed Design ANOVA analytic strategy was applied to parent stress. Table 4 provides the results indicating no statistically significant main effect on stress between the treatment and the comparison group,  $F(1, 28) = 3.31, p = .080$ , partial  $\eta^2 = .10$ . There was no statistically significant change in scores across time  $F(1, 28) = 1.39, p = .249$ , partial  $\eta^2 = .05$ , or in the interaction of the group difference over time  $F(1, 28) = 2.97, p = .096$ , partial  $\eta^2 = .10$ . These results indicate that stress remained stable regardless of time or treatment.

Table 4

*Mixed Design ANOVA Results for Parent Training Effects on Parent Stress*

Source	SS	df	MS	F
Between Subjects				
Treatment	1436.00	1	1436.00	3.31
Error	12,151.35	28	434.98	
Within Subjects				
Difference (pre-post)	169.47	1	169.47	1.38
Difference X Group	362.00	1	362.00	2.97
Error	3419.68	28	122.10	

\* $p \leq .05$ ; \*\* $p \leq .01$

A second analysis was used to assess the effects of the parent training seminars on parent self-efficacy. Table 5 provides the results indicating a statistically significant main effect between the treatment and comparison groups,  $F(1, 27) = 6.76, p < .05$ , partial  $\eta^2 = .20$ . However, there was no statistically significant change in scores across time,  $F(1, 27) = 1.04, p = .317$ , partial  $\eta^2 = .04$  or in the interaction between the group differences over time  $F(1, 27) = .34, p = .565$ , partial  $\eta^2 = .01$ . These results suggest that there were differences between the groups, but not necessarily due to the treatment.

Table 5

*Mixed Design ANOVA Results for Parent Training Effects on Parent Self-Efficacy*

Source	SS	df	MS	F
Between Subjects				
Treatment	275.97	1	275.97	6.76*
Error	1102.93	27	40.85	
Within Subjects				
Difference (pre-post)	13.32	1	13.32	1.04
Difference X Group	4.36	1	4.36	.34
Error	345.58	27	12.80	

\* $p \leq .05$ ; \*\* $p \leq .01$

A third analysis was run to assess the effects of the parent training seminars on treatment acceptability. Because the preliminary analyses revealed significant differences in treatment acceptability by father's level of education and child problem behaviors, these variables were included as covariates. However, results were not significant, likely due to the small sample size, which would lower the power to detect effects. Therefore, analyses were run without the covariates in order to increase power. Table 6 provides the results indicating that there was no statistically significant main effect between the treatment and comparison groups,  $F(1, 27) = 2.27$ ,  $p = .144$ , partial  $\eta^2 = .08$ . However, there was a significant effect for treatment acceptability both when you consider time alone,  $F(1, 27) = 11.56$ ,  $p < .01$ , partial  $\eta^2 = .30$ , and when you consider the interaction between time and the treatment group,  $F(1, 27) = 14.03$ ,  $p < .001$ , partial  $\eta^2 = .34$ . These results indicate that there were no statistically significant differences between the groups, but over time the parents scores did improve significantly.

Table 6

*Mixed Design ANOVA Results for Parent Training Effects on Treatment Acceptability*

Source	SS	df	MS	F
Between Subjects				
Treatment	61.78	1	61.78	2.27
Error	736.60	27	27.28	
Within Subjects				
Difference (pre-post)	85.36	1	85.36	11.56**
Difference X Group	103.57	1	103.57	14.03**
Error	199.36	27	7.38	

Note. Accept=Treatment Acceptability; \* $p \leq .05$ ; \*\* $p \leq .01$

Finally, analyses were run for parent involvement. However, because parent involvement was a post-test only variable, no change in time could be evaluated. Instead, the analyses targeted differences between the two groups at that single post-test time point. Parent involvement was assessed by two different measures – parent self-assessment and therapist assessment. Therefore, two separate ANOVAs were run. Table 7 provides the results indicating no statistically significant difference for parent involvement when rated by the parents between the treatment group and the comparison group,  $F(1, 29) = 1.21, p = .280, \eta_p^2 = .04$ .

Table 7

*ANOVA Results for Parent Involvement – Parent Report*

Source	SS	df	MS	F
Between Subjects				
Treatment	345.01	1	345.01	1.21
Error	8264.34	29	285.98	

\* $p \leq .05$ ; \*\* $p \leq .01$

Another ANOVA was run to compare the scores between groups for parent involvement

rated by the therapists. Table 8 provides the results indicating statistically significant differences between the parent training group and the comparison group on parent involvement when rated by the therapists,  $F(1, 27) = 4.98, p < .05, \eta p^2 = .16$ .

Table 8

*ANOVA Results for Parent Involvement – Therapist Report*

Source	SS	df	MS	F
Between Subjects				
Treatment	1290.54	1	1290.54	4.98*
Error	6989.63	27	258.88	

\* $p \leq .05$ ; \*\* $p \leq .01$

**Research Question 2: To what extent do parent stress, self-efficacy, and treatment acceptability explain variance in parent involvement in ABA treatment with their children?**

In order to address research question two, a series of multiple linear regression analyses were run to assess the relationship between parent involvement and a) parent stress, b) self-efficacy, and c) treatment acceptability. These analyses were used to determine how much the predictor variables (parent stress, self-efficacy, and treatment acceptability) explained a significant amount of variance in the criterion variable (parent involvement) as reported by parents and their therapists. In the first analysis, parent stress, self-efficacy, and treatment acceptability were entered simultaneously at step 1 and the parent report of parent involvement being the criterion variable. Table 9 provides results indicating that parent stress, self-efficacy, and treatment acceptability, did not explain variance in parent involvement as reported by the parents,  $R^2 = .09, F(3, 26) = .81, p = .502$ .

Table 9

*Multiple Linear Regression Model – Parent Involvement – Parent Report*

Variable	<i>B</i>	<i>SE B</i>	$\beta$	t-Value
Constant	109.02	41.29		2.64
Efficacy	-.39	.65	-.12	-.59
Acceptability	-.06	.77	-.01	-.07
Stress	-.28	.18	-.32	-1.51
Group				
$R^2$			.09	
$R^2(\text{adj})$			-.02	
F			.81	
df			3, 26	

\* $p \leq .05$ ; \*\* $p \leq .01$

The second analysis was conducted using the same predictor variables as above (parent stress, self-efficacy, and treatment acceptability) and the criterion variable of parent involvement as reported by the therapists. The post-test data from the parent measures were entered simultaneously at step one and the therapist report of parent involvement was entered as the criterion variable. Table 10 provides the results indicating that parent stress, self-efficacy, and treatment acceptability did not explain variance in parent involvement as reported by the therapists,  $R^2 = .11$ ,  $F(3, 24) = 1.01$ ,  $p = .407$ .

Table 10

*Multiple Linear Regression Model – Parent Involvement – Therapist Report*

Variable	<i>B</i>	<i>SE B</i>	$\beta$	t-Value
Constant	99.14	42.56		2.33
Efficacy	-.50	.68	-.16	-.74
Acceptability	.55	.83	-.14	.67
Stress	-.26	.19	-.30	-1.38
<b>Group</b>				
R <sup>2</sup>			.11	
R <sup>2</sup> (adj)			.00	
F			1.01	
df			3, 24	

\* $p \leq .05$ ; \*\* $p \leq .01$

When the findings were insignificant for the above regression analysis using the measures from research question one, a posteriori follow up regression analyses was conducted, with different measures for parent stress, self-efficacy, and treatment acceptability as the predictor variables in the regression analyses. The reason behind this follow up analysis, was to assess if results could be replicated to explain variance in parent involvement if the same scales were used to measure parent stress, self-efficacy, and treatment acceptability as those in the original study assessing parent involvement with parents of children enrolled in ABA treatment Using the Parent Involvement Questionnaire (Solish, 2010).

This analysis incorporated additional available data that was similar to, though different enough than, the original measures to run additional analyses incorporating them. These parallel measures were available from the parents who filled out the parent involvement survey as part of the study. These were not measures that were collected as part of the standard care treatment. They were only collected when parents consented to the study as part of the parent involvement



survey. As described in Chapter 3, the parent involvement survey was made up of 6 subscales (the overall involvement subscale that was used for the parent involvement measure collected for this study) and five additional subscales, three of which also measured parent stress, self-efficacy, and treatment acceptability. The predictor variables from the new data measuring parent stress, self-efficacy, and treatment acceptability were entered simultaneously at step 1 and parent involvement was entered as the criterion variable. Table 11 provides the results that showed parent stress, self-efficacy, and treatment acceptability explained 49% of variance in parent involvement,  $R^2 = .49$ ,  $F(3, 36) = 11.52, p < .001$ .

Table 11

*Multiple Linear Regression Model – Parent Involvement with Parallel Predictor Scales*

Variable	B	SE B	$\beta$	t-Value
Constant	18.93	15.81		1.20
Self-Efficacy	.95	.18	.66	5.28**
Acceptability	-.00	.15	-.00	1.00
Parent Stress	-.31	.22	-.17	.17
R <sup>2</sup>			.49	
R <sup>2</sup> (adj)			.45	
F			11.52	
df			3, 36	

\* $p \leq .05$ ; \*\* $p \leq .01$

The analysis was not run with the therapist report because there was no predictor scale for parent self-efficacy on the therapist version of the Parent Involvement Questionnaire.

**Research Question 3: How well does the group parent training explain variance in parent involvement above and beyond parent stress, self-efficacy, and treatment acceptability?**

The third regression analyses from question two above, using the additional available data

on parent stress, self-efficacy, and treatment acceptability, were used to answer research question three. This analysis could only be run because a significant amount of variance in parent involvement could be explained by running the regression analysis with the additional data collected as part of the parent involvement survey. If the third regression analysis was not significant, this analysis would not have been conducted. Thus, using the measures in the *a posteriori* analyses in research question 2, and based on the results from those analyses above, a hierarchical linear regression analysis was conducted to ascertain whether or not participation in parent training explained variance in parent involvement above and beyond that explained by stress, self-efficacy, and treatment acceptability.

Parent stress, self-efficacy, and treatment acceptability were entered at step one, participation in the parent training seminar was entered at step two (yes/no), and parent involvement was entered as the criterion variable. Table 12 provides the results, which indicate that parent stress, self-efficacy, and treatment acceptability explained 45.5% of variance in parent involvement, with parent self-efficacy being the statistically significant contributor in the model. When adding parent training at step two, variance explained by the model significantly increased to 47.1%,  $R^2 = .47$ ,  $F(4, 26) = 5.78$ ,  $p < .01$ . This change was above and beyond step one by 1.6%,  $R^2$  change = .16,  $p < .01$ ).

Table 12

*Hierarchical Linear Regression Model – Relationship Between Parent Involvement and Parent Training*

Variable	Model 1				Model 2			
	<i>B</i>	<i>SE B</i>	$\beta$	t-Value	<i>B</i>	<i>SE B</i>	$\beta$	t-Value
Constant	8.90	21.98		.41	7.76	22.12		.35
Self-Efficacy	1.08	.24	.66	4.59**	1.07	.24	.65	4.49**
Acceptability	-.02	.17	-.02	-.11	.02	.18	.02	.11
Stress	-.20	.28	-.10	-.70	-.20	.17	-.24	-1.17
Group					-4.47	5.16	-.13	-.87
R <sup>2</sup>			.46				.47	
R <sup>2</sup> (adj)			.40				.39	
F			7.53				5.78	
df			3, 27				4, 26	

\* $p \leq .05$ ; \*\* $p \leq .01$

**Research Question 4: If a relationship is found between the group parent training and parent involvement, then is it moderated by parent stress, self-efficacy, and treatment acceptability levels?**

Three hierarchical linear regression analyses were used to determine if parent stress, self-efficacy, or treatment acceptability were moderating the relations between parent training and parent involvement. An interaction term (product term) was created between each predictor variable (parent stress, self-efficacy, and treatment acceptability) and parent training. The product term was entered in step two of each hierarchical regression analysis to observe a change in variance explained.

First, parent stress was examined as a moderator of the relation between parent training and parent involvement. The predictor variables parent training and parent stress were entered in

the first step of the regression analysis and parent involvement was entered as the dependent/criterion variable. In the second step, the interaction term (parent training \* parent stress) was entered. There was no significant change in the model,  $\Delta R^2 = .12$ ,  $F(3, 27) = .176$ ,  $p = .178$  between steps 1 and 2. Thus, overall parent stress was not a significant moderator.

In the second analysis, parent self-efficacy was examined as a moderator of the relation between parent training and parent involvement. The predictor variables parent training and parent self-efficacy were entered in the first step of the regression analysis and parent involvement was entered as the dependent/criterion variable. In the second step, the interaction term (parent training \* parent self-efficacy) was entered. The interaction term explained a significant amount of variance in the model,  $\Delta R^2 = .00$ ,  $F(3, 27) = 7.87$ ,  $p < .001$  between steps 1 and 2. Thus, overall parent self-efficacy was a significant moderator of the relations between parent training and parent involvement.

In the third analysis, treatment acceptability was examined as a moderator of the relation between parent training and parent involvement. The predictor variables parent training and treatment acceptability were entered in the first step of the regression analysis and parent involvement was entered as the dependent/criterion variable. In the second step, the interaction term (parent training \* treatment acceptability) was entered. There was no significant change in the model,  $\Delta R^2 = .01$ ,  $F(3, 27) = .47$ ,  $p = .703$  between steps 1 and 2. Thus, overall treatment acceptability was not a significant moderator.

### **Á Posteriori Qualitative Analysis**

Because of the small sample size in this study, we also capitalized on available qualitative data to help glean more information about the motivation of the parents to participate in the parent training seminars and variables they reported effect their ability to be involved with their children's

treatment. Written narrative data was collected as part of the Parent Involvement Questionnaire (parents report) and the demographic data collection sheet provided to the parent participants as part of the study. Parents were given open-ended questions and asked to reflect on things that made it easier or harder to be involved in their children's treatment. From the 40 Parent Involvement Questionnaires that were returned from each family, 35 parents commented on things that made their involvement in treatment easier and 28 parents commented on things that made involvement more difficult. Parents were also asked to comment on why they did, or did not attend the parent training seminars that were offered at the clinic. From the 40 demographic forms returned, 29 parents provided comments for this question.

Many of the parents reported that support from their families was something that was helpful (n=13). An additional 10 parents reported that their financial situation and/or the passing of legislation that allowed them to access insurance coverage for services was helpful. Several others reported that their work was flexible, part-time, or they were able to have a spouse stay at home, which helped with their ability to be involved (n=6). A few found that it was helpful to receive adaptations or support that was provided from the clinic or their therapist, such as changing the time or location of treatment and helping the family obtain transportation services (n=4). One parent commented on the improvement in their child's behavior as a variable that made it easier for them to be involved. Finally, one parent commented on his/her self-determination as a variable that helped with involvement in treatment. Barriers included family or other commitments (n=16), work responsibilities (n=9), the distance to the treatment facility (n=3), financial constraints (n=2), and their child's behavior (n=1).

Most parents described their motivation for attending the parent training seminars as a way to learn more about ASD or ABA treatment (n=16). Some parents reported that they were

motivated to enroll in the training to have more contact with other parents (n=3). One parent reported that he/she enrolled to improve self-advocacy. One parent reported that he/she enrolled in the parent training seminars but the training did not meet his/her expectation. The seven other parents who did not enroll in the parent training seminars indicated that they did not enroll due to schedule conflicts.

## CHAPTER 5 DISCUSSION

Parent involvement is an important component in ABA therapy outcomes (Anderson & Romanczyk, 1999; Dawson & Osterling, 1997). Drop-out rates (Matson, et al, 2009; Miller & Prinz, 2003) and adherence to treatment recommendations (Moore & Symons, 2011) are areas of concern for therapists implementing ABA for children with ASD and their families. Knowing how parent motivation affects their involvement in treatment and how to reduce barriers to treatment that affect involvement can help therapists better translate research findings to clinical settings. This is very pertinent information because, in clinical settings, parents often have more flexibility in the way that ABA is implemented than is permitted in research settings. Parents often choose less therapy hours and may avoid implementation of certain recommendations for generalization or other treatment strategies that may impact the positive outcome of treatment.

Given all of this, the purpose of this study was to evaluate the effects of a parent training intervention, run in a clinical setting and designed to change parent perceptions of their stress, self-efficacy, and treatment acceptability, and to assess how much variance in parent involvement can be explained by these variables. This clinical setting offered an eight-week parent training seminar where constructs including parent stress, self-efficacy, and treatment acceptability were targeted and measured as part of the clinical data collected on each client. In this setting, parents were able to choose to participate in the parent training seminars as a supplement to their children's ABA services at the center. Despite well-reasoned intentions, key limitations of this study include the quasi-experimental design and especially the relatively small sample size. Therefore, all interpretations based on these analyses will not be able to be generalized to the larger population. The outcomes of these analyses, identified limitations, implications, and recommendations based on the outcome of the analyses will be discussed.

In the literature there are many group treatment programs targeted toward parent stress (Keen, et al., 2010; Singer, et al., 2007). However, results of these studies have been mixed (Hastings & Johnson, 2001; Remington et al., 2007). This parent training treatment showed that there was little to no change in parent stress within subjects or between groups with this sample. When considering stress, this parent training intervention was not an effective treatment strategy for changing parents' stress levels.

A major finding in this study was that there were significant improvements in both parent self-efficacy and treatment acceptability in the treatment group as indicated in Table 2. This is consistent with previous research that indicated that parent self-efficacy (Benson, 2015; Hudson, et al., 2003; Kuhn & Carter, 2006) and treatment acceptability (Sanders, 1999; Whittingham, et al., 2009) can be improved with parent training. However, in the current sample, when comparing the differences in gains between the groups, the average gains of the treatment group were not significantly different than the average gains of the comparison group. One reason for this finding could be differences in parent levels of self-efficacy and treatment acceptability between the groups before treatment.

In attempting to understand the differences between the groups prior to treatment, the design of the study is a significant limitation. The quasi-experimental design of this study served to create a confounding effect, due to self-selection to the group, that could contribute to the group differences. The descriptive analyses indicated the comparison group had higher pre-test scores in the areas of parent self-efficacy, treatment acceptability, and parent involvement (Table 2). Therefore, there may have been something about the beliefs of the population that impacted their choice of whether or not to participate in the treatment group.

The *á posteriori* analysis provided some insight into why parents decided to attend the



parent training. Most parents stated that they chose to attend the parent training seminars in order to gain additional information on ASD and ABA as a way to better implement treatment. These statements support the idea that parents who were interested in learning more would also be parents with lower scores on the treatment acceptability and self-efficacy measures. Parents who felt more confident in their ability to parent their children with ASD and those who felt they already understood ABA may be less likely to elect to participate in training where they would learn those skills.

It could also be that the lack of significant effect indicates that the parent training seminars were not implemented to fidelity or targeted areas of concern to the parents of this sample. Other than the one parent who indicated that he/she was not satisfied with the parent training, there is no other data to indicate whether the parents felt that the training was helpful or effective. There was also no additional information as to why other parents did not attend other than schedule conflicts. These variables may be helpful to evaluate further in the future, as they may provide useful information to improve the outcome of the trainings and stimulate more people to attend.

When assessing the impact that the treatment had on parent involvement, two measures were analyzed—parent and therapist report. Although a strong conclusion cannot be made because of the quasi-experimental design of the study and the very small sample size, findings indicated that the treatment group was rated as having significantly higher levels of involvement by the therapists, but not by the parents themselves. Parents in the treatment group actually reported themselves as having less involvement than those in the comparison group. Therapists rated parents who participated in the parent training seminars as more involved. Therapists may view participation in the parent training seminars as a sign of greater involvement, or it could be that the parent training seminars “teach” the parents to do things that therapists rate as being more

involved. This data does confirm there are differences in how parents and therapists rate involvement of parents (Solish, 2010; Solish & Perry, 2008), but not the extent or reason for those differences.

Multiple regression analyses assessing the relationship between parent involvement and 1) parent stress, 2) self-efficacy, and 3) treatment acceptability did not indicate significant results when retrospective data from the client files data were used to measure parent stress, self-efficacy, and treatment acceptability. This led to further analysis to determine if the variance in parent involvement could be explained using the additional data collected in the parent involvement survey on parent stress, self-efficacy, and treatment acceptability from the study participants. The follow up analysis, using the measures on the parent involvement survey, was able to explain 49% of variance in parent involvement. These results suggest that the levels of parent stress, self-efficacy, and treatment acceptability may be important constructs to consider when attempting to improve parent involvement. However, the measures collected as part of the parent involvement survey may be a better tool to measure parent stress, self-efficacy, and treatment acceptability for those treating parents of children enrolled in ABA treatment, as compared to the measures collected as part of the treatment in the clinical setting.

A follow up hierarchical regression analysis using the measures for parent stress, self-efficacy, and treatment acceptability collected as part of the parent involvement survey were used to determine if parent training explained variance in parent involvement above and beyond what was already explained by parent stress, self-efficacy, and treatment acceptability. This analysis indicated that there was additional variance explained by parent training in parent involvement. This indicated that there was some benefit to the parent training in regards to parent involvement.

A further analysis was then conducted to see what effect parent stress, self-efficacy, and

treatment acceptability had as a moderator on the relationship between parent training and parent involvement. Results from this analysis indicated that variance explained in parent involvement by parent training was dependent on parent self-efficacy. Parent self-efficacy was indicated as the major contributor to the variance explained in parent involvement and, as noted above, self-efficacy also improved significantly in the parent training group. Additionally, understanding that parent self-efficacy moderates the relationship between parent training and parent involvement helps to explain those results. This indicates that parent training could be expected to have a positive effect on parent involvement only if a parent's self-efficacy is low. Parents with high self-efficacy are more likely to be involved in treatment already, possibly thereby making the parent training less effective in improving parent involvement.

Parent self-efficacy is likely an important construct to include in a therapist's assessment for the parents when developing ABA treatment for children with ASD. When parents have lower self-efficacy, they are less likely to be involved in their child's ABA treatment. Also if parents have lower self-efficacy, they are more likely to benefit from a parent training intervention. Furthermore, it may be helpful to assess the utility of the measures that were used in the study. The original measures used in the clinical setting to collect data from the parents on self-efficacy (Parenting Sense of Competency Efficacy Subscale) did not explain the variance in parent involvement. It may be beneficial to determine if the self-efficacy scale on the parent involvement survey may be a better indicator of potential problems with parent involvement and a more sensitive measure for change after intervention. Although this may not have been a focus of this study it may prove to be important in future research in this area.

### **Limitations and Direction for Future Research**

When considering the data analysis from this study, above and beyond the aforementioned

quasi-experimental design and very small sample size, there are limitations including using a clinical population for research. With this sample, a retrospective analysis of outcome data was used to gain perspective on how evidence-based treatment procedures are translated to the population level. This form of data collection proved challenging in gaining accurate and complete information consistent with the research design. In this setting, some parents attended the parent seminars for only a portion of the training. Also some therapists did not complete the follow up data according to the protocol because it did not meet a clinical need of the client at the time and parents refused or failed to return certain assessments during treatment. This affected the ability to retrieve accurate data on all the measures and ultimately reduced the sample size. Although these challenges are not ideal for sound research, the way treatment is utilized at the population level is an important topic to study. We need to better identify how treatment is being implemented in clinical settings and whether the outcomes of the evidence-based treatment are similar at this level.

Further limitations of the study include the lack of measures that indicate parent satisfaction/social validation of the training and fidelity of the implementation of the treatment program. It would be beneficial to include a social validation or a satisfaction survey for the parents to complete following the parent training seminars. This could help to inform the therapists about how valuable the parents perceived the training they obtained. There may also be a need to improve the implementation process with the staff running the programs in the clinical settings. Some considerations for implementation of a multi-center program, such as this, would be to offer training and oversight of the program for the therapist running the parent training intervention and integrity checks of the program during its implementation. From a research standpoint these are important variables to consider, but in a clinical setting, these aspects often go overlooked. At this center, there were manuals created with the curriculum content for the group lectures and

programed activities, but there still may have been differences in the skills that the therapists had in implementing the parent training seminars and these may have affected the change scores for the parents on the measures. Recommendations for future research or for those who attempt to implement large scale trainings across multiple centers would be to have some level of oversight for the implementation across therapists and locations to ensure that each time the treatment is run, it is run to fidelity.

Finally, researchers should consider whether the measures being used to assess parent self-efficacy and treatment acceptability are the most appropriate for this population. In this study, results were different when the regression analysis was conducted with the clinical data collected from the client files verses the parallel data collected from the parent involvement survey. Although the Parent Involvement Questionnaire has not been widely used in the assessment of involvement, it may be something that ABA therapists want to use as a treatment tool to identify potential barriers to treatment and to measure outcomes of change in parent perceptions following parent intervention. Further analysis should be conducted to compare these measures and their appropriateness for different populations. If we could identify tools that will more effectively guide treatment choices and give therapists a better understanding of how to help those who are most resistant to treatment, we would see improved client outcomes for all, and not just those who are most susceptible to change.

In order to better manage data collection, improve fidelity of implementation of parent training, and consider the parent satisfaction data; a more comprehensive manual could be developed including how to complete data collection to measure change, when the measures should be administered, and how to interpret the measures. Further information on how to modify the parent curriculum based on the interpretation of the measures could be included in the manual

to provide the therapists in the clinical setting background information about these barriers to treatment. It would be beneficial to construct a fidelity measure for both the implementation of the training in group and individual sessions that could provide information about the implementation of the parent training components based on therapist performance. Finally identifying a parent satisfaction measure to add to the treatment manual will assist therapists and researchers in understanding how the parents feel about the training they received and if it is valuable to them.

To better understand the discrepancies in the results of the measures in predicting parent involvement, further research would need to be conducted on the measures themselves. Knowing which measures show the best utility in detecting stress, self-efficacy, and treatment acceptability in parents of children with ASD in ABA treatment and acquiring an improved ability to predict when parent involvement will be a challenge could improve the outcomes for the children in ABA treatment. Further analysis should be conducted comparing the measures for their utility with this population. Once the ability of the measures to accurately predict when areas of stress, self-efficacy, and treatment acceptability are potential issues for the parents is determined, this information could be added to the comprehensive manual for parent training.

When considering the research design itself, future research in the clinical setting could be more controlled by having the measures administered as part of the research protocol rather than utilizing retrospective data analysis from the child's treatment file. It is likely that a longitudinal design where the training components are embedded into the treatment goals over time would reduce the confounds of outside influence from the potential differences in parent goals from the ABA treatment. Providing these treatment components as part of the parents' individual treatment could result in a larger sample size and a more simplified way to collect the data and give parents

opportunity to participate without scheduling problems and self-selection confounds of a quasi-experimental design. It is important that research is conducted in clinical setting to determine what is happening in treatment at the population level and how effective day to day clinical practice is in achieving the same results as those obtained in controlled research designs.

### **Summary, Implications, and Conclusions**

There may have been some benefit provided by the parent training seminars. Many families signed up for the program to learn more about the diagnosis and treatment for their children. Further analysis of the group parent training can help identify ways in which the treatment could be improved. Also, parent self-efficacy was identified as a major contributor in explaining variance in parent involvement. Developing parent training and treatment interventions focused on improving parent self-efficacy within areas where parent involvement is weak could result in improvement of parent involvement in those areas. Furthermore, teaching therapists about tools that may be beneficial for measuring parent involvement, stress, self-efficacy, and treatment acceptability could result in improved therapeutic relationships and realistic expectations for involvement for parents based on their family situations. This could be important in improving treatment outcomes for children in ABA programs.

Although this was a small sample size and is not possible to be conclusive, the data does provide some valuable information about some of the issues in translating research to the population level. A greater focus on how to improve translation of research to practice could improve the outcomes for consumers. Assessing how consistent clinical work is with research could result in more meaningful change in treatment. Furthermore, training and fidelity measures on the implementation of evidence-based treatment in clinic settings and the barriers to implementing it will likely improve the outcomes of those treatments at the population level.

## APPENDIX A

**PARENT SENSE OF COMPETENCY – EFFICACY SUBSCALE**

## PARENTING SENSE OF COMPETENCE SCALE (PSOC), EFFICACY SUBSCALE

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired.	_____	_____	_____	_____	_____
2. I would make a fine model for a new mother/father to follow in order to learn what she/he would need to know in order to be a good parent.	_____	_____	_____	_____	_____
3. Being a parent is manageable, and any problems are easily solved.	_____	_____	_____	_____	_____
5. I meet my own personal expectations for expertise in caring for my child.	_____	_____	_____	_____	_____
6. If anyone can find the answer to what is troubling my child, I am the one.	_____	_____	_____	_____	_____
7. Considering how long I have been a mother/father, I feel thoroughly familiar with this role.	_____	_____	_____	_____	_____
9. I honestly believe I have all the skills necessary to be a good mother/father, to my child.	_____	_____	_____	_____	_____
10. Being a good mother/father is a reward in itself.	_____	_____	_____	_____	_____



## APPENDIX B TREATMENT EVALUATION INVENTORY – SHORT FORM

### TREATMENT EVALUATION INVENTORY SHORT FORM (TEI-SF)

Please complete the items listed below by placing a checkmark on the line next to each question that best indicates how you feel about the treatment. Please read the items very carefully because a checkmark accidentally placed on one space rather than another may not represent the meaning you intended.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I find this treatment to be an acceptable way of dealing with the child's problem behavior.	_____	_____	_____	_____	_____
2. I would be willing to use this procedure if I had to change the child's problem behavior.	_____	_____	_____	_____	_____
3. I believe that it would be acceptable to use this treatment without children's consent.	_____	_____	_____	_____	_____
4. I like the procedure used in this treatment.	_____	_____	_____	_____	_____
5. I believe this treatment is likely to be effective.	_____	_____	_____	_____	_____
6. I believe the child will experience discomfort during the treatment.	_____	_____	_____	_____	_____
7. I believe this treatment is likely to result in permanent improvement.	_____	_____	_____	_____	_____
8. I believe it would be acceptable to use this treatment with individuals who cannot choose treatments for themselves.	_____	_____	_____	_____	_____

**APPENDIX C**  
**PARENT STRESS INDEX – SHORT FORM**  
Could not be included because of copyright

## APPENDIX D

### PARENT INVOLVMENT QUESTIONNAIRE – PARENT VERSION

Participating agency: \_\_\_\_\_

1

#### Parent Involvement Questionnaire – Parent Version

*This questionnaire has several different sections. Each section has its own set of instructions. The first section is included to help us to understand the background of individuals who agree to participate in our study. In the case of a two parent family, one person can fill out the information for both partners. If at any point throughout the questionnaire you feel that a question does not apply to you, please feel free to write not applicable (n/a). If you write n/a we would appreciate if you could tell us why the question is not applicable. Feel free to add other comments if you wish.*

Date questionnaire completed: \_\_\_\_\_

- ◆ Completed by/relationship to child:

- |                                 |  |
|---------------------------------|--|
| <input type="checkbox"/> Mother | <input type="checkbox"/> Male guardian   |
| <input type="checkbox"/> Father | <input type="checkbox"/> Female guardian |

- ◆ What is your family constellation?

- Married/Common Law
- Single-Parent
- Other (e.g., grandparent or other family member living in the house) please describe: \_\_\_\_\_

- ◆ What is the highest level of education you (and your partner) have completed?

Mother/female guardian

- Elementary school
- Some high school
- High school
- Some college/university
- College/technical diploma
- Undergraduate degree
- Professional/graduate degree

Father/male guardian

- Elementary school
- Some high school
- High school
- Some college/university
- College/technical diploma
- Undergraduate degree
- Professional/graduate degree

- ◆ What is your (and your partner's) occupation? (please be specific):

Mother/female guardian \_\_\_\_\_

Father/male guardian \_\_\_\_\_

- ◆ Do you (and your partner) work outside the home?

Mother/female guardian

- Part-time
- Full-time
- No paid employment

Father/male guardian

- Part-time
- Full-time
- No paid employment

- ◆ What is your (and your partner's) country of birth?

Mother/female guardian \_\_\_\_\_

Father/male guardian \_\_\_\_\_

- ◆ If applicable, what is your (and your partner's) date of entry into Canada?

Mother/female guardian \_\_\_\_\_

Father/male guardian \_\_\_\_\_

- ♦ What is your (and your partner's) first language?

Mother/female guardian \_\_\_\_\_ Father/male guardian \_\_\_\_\_

- ♦ What language(s) do you speak in the home?
  - English
  - English and \_\_\_\_\_
  - \_\_\_\_\_ only

**PART I**

**Agency Involvement**

*This section refers to your involvement with your child's service provider and/or the staff who work with your child providing IBI. For questions 1-6 please indicate how often you do the following things:*

1. Communicate directly with your child's IBI program staff either on the phone or in person?

1	2	3	4	5
never		sometimes (once per week)		frequently (daily)

2. Read and write in your child's communication book (corresponding with his/her IBI staff?)

1	2	3	4	5	n/a
never		sometimes (once per week)		frequently (daily)	my child does not have a communication book

3. Watch your child in therapy sessions? (\*fill out "a" if your child has primarily home-based therapy OR "b" if your child has primarily centre-based therapy)

a) home-based therapy

1	2	3	4	5
never		sometimes (once per week)		frequently (daily)

**\*OR**

b) centre-based therapy

1	2	3	4	5
never		sometimes (on some occasions)	(on every possible occasion)	frequently

4. Attend review meetings and have input into goal setting about your child's IBI program?

1	2	3	4	5
never		sometimes (on some occasions)	(on every possible occasion)	frequently

5. Read material and do homework given to you by the IBI staff?

1	2	3	4	5
never		sometimes (on some occasions)	(on every possible occasion)	frequently

6. Please provide your best estimate of how many hours per week you are involved with your child's IBI agency:

0	1-3	3-5	5-7	7 or more
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**Keeping your answers to questions 1-6 in mind, please answer questions 7-10**

7. How *difficult* do you find it to be involved in your child's IBI agency?

1                      2                      3                      4                      5  
not at all                      moderately                      extremely

8. How *effective* do you think you are at being involved in your child's IBI agency?

1                      2                      3                      4                      5  
not at all                      moderately                      extremely

9. How *confident* do you feel being involved in your child's IBI agency?

1                      2                      3                      4                      5  
not at all                      moderately                      extremely

10. How much do you feel your involvement in your child's IBI agency *makes a difference* in his/her progress?

1                      2                      3                      4                      5  
not at all                      moderately                      extremely

### **Training Involvement**

*Questions 11-16 refer to your involvement in training activities related to autism and IBI. Please indicate how often you do the following things:*

11. Have individual coaching and feedback from your child's IBI program staff?

1                      2                      3                      4                      5  
never                      sometimes                      frequently  
(at least monthly)                      (at least weekly)

12. Seek out information about autism and IBI (e.g., searching the internet, going to the library, reading articles, etc.)?

1                      2                      3                      4                      5  
never                      sometimes                      frequently  
(at least monthly)                      (at least once a week)

13. How many hours of behavioural parent training courses have you attended (e.g., a course with other parents and a group leader, such as Jumpstart, where parents are taught behavioural principles like reinforcement, prompting, and task analysis)?

0                      1-10                      11-20                      21-30                      31 or more

14. How many hours of behavioural lectures, presentations, workshops, and/or conferences have you attended (e.g., where you have been taught advanced behavioural techniques, or you have learned about research on behavioural intervention)?

0                      1-10                      11-20                      21-30                      31 or more

15. How many formal university/college courses have you taken about autism or IBI?

1                      2                      3                      4                      5  
none                      one complete                      formal degree, diploma  
semester course                      or certificate in related field

16. Please provide your best estimate of how many hours per week you are involved in training related to autism and IBI:

0                      1-3                      3-5                      5-7                      7 or more

***Keeping your answers to questions 11-16 in mind, please answer questions 17-20***

17. How *difficult* do you find it to be involved in training activities about autism and IBI?

1	2	3	4	5
not at all		moderately		extremely

18. How *effective* do you think you are at being involved in training activities about autism and IBI?

1	2	3	4	5
not at all		moderately		extremely

19. How *confident* do you feel being involved in training activities about autism and IBI?

1	2	3	4	5
not at all		moderately		extremely

20. How much do you feel your involvement in training activities about autism and IBI *makes a difference* in his/her progress?

1	2	3	4	5
not at all		moderately		extremely

### Child Program Involvement

***In this next section we are going to ask whether you do formal IBI sessions with your child in specific areas. Some parents do formal IBI sessions using exactly the same methods as the staff. Other parents try to work on the same skills in a more naturalistic way in every day life to promote generalization of the skills. Some parents do both and some do neither. For questions 21-31 please indicate how often you do the following:***

\*Remember...

**Formal IBI sessions** = structured teaching with specific instructional goals and some form of data collection

**Generalization** = using IBI principles to teach the same goals but in a flexible way and/or in every day situations

### Academic Skills

21. To what extent do you do formal IBI sessions focusing on your child's **academic skills**? (e.g., letter identification, counting, printing, math, reading, etc. in a structured teaching situation)

1	2	3	4	5	n/a
never		sometimes		frequently	child is not working on academic skills

22. To what extent do you try to generalize your child's **academic skills**? (e.g., if you at the grocery store and you are working on counting do you ask your child to put 5 apples into a bag?)

1	2	3	4	5	n/a
never		sometimes		frequently	child is not working on academic skills

### Social and Play Skills

23. To what extent do you do formal IBI sessions focusing on your child's **social and play skills**? (e.g., turn-taking, sharing, asking another child to play in a structured teaching situation)

1	2	3	4	5
never		sometimes		frequently

24. To what extent do you try to generalize your child's **social and play skills**? (e.g., if turn-taking is your goal and you are at the park and another child is on the slide do you help encourage your child to wait his/her turn to go down the slide?)

1	2	3	4	5
never		sometimes		frequently

Communication Skills

25. To what extent do you do formal IBI sessions focusing on your child's **communication skills**? (e.g., requesting, labeling, responding to questions, following directions, etc. in a structured teaching situation)

1	2	3	4	5
never		sometimes		frequently

26. To what extent do you try to generalize your child's **communication skills**? (e.g., if you have been working on labeling do you encourage your child to ask for the items he/she wants at dinner time)

1	2	3	4	5
never		sometimes		frequently

Self-help skills

27. To what extent do you do formal IBI sessions focusing on your child's **self-help skills**? (e.g., toileting, dressing, tooth-brushing, etc. in a structured teaching situation)

1	2	3	4	5
never		sometimes		frequently

28. To what extent do you try to generalize your child's **self-help skills**? (e.g., if you are working on a toileting program do you encourage your child to follow the same routine when using the toilet in a variety of locations?)

1	2	3	4	5
never		sometimes		frequently

29. Please provide your best estimate of how many hours per week you are implementing formal IBI sessions:

0	1-3	4-6	7-9	10 or more
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30. Please provide your best estimate of how many hours per week you are deliberately generalizing skills that your child is working on:

0	1-3	4-6	7-9	10 or more
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31. How familiar are you with your child's specific IBI program goals? (e.g., if your child is working on a colors program, would you be familiar with which specific colors he/she had mastered and which ones he/she is still trying to acquire?)

1	2	3	4	5
not at all		moderately		extremely

Formal IBI sessions

32. How *difficult* do you find it to conduct formal IBI sessions with your child?

1	2	3	4	5	n/a
not at all		moderately		extremely	I do not implement formal sessions

33. How *effective* do you think you are at conducting formal IBI sessions with your child?

1	2	3	4	5	n/a
not at all		moderately		extremely	I do not implement formal sessions

34. How *confident* do you feel conducting formal IBI session with your child?

1	2	3	4	5	n/a
not at all		moderately		extremely	I do not implement formal sessions

35. How much do you feel your involvement in formal IBI sessions with your child *makes a difference* in his/her progress?

1	2	3	4	5	n/a
not at all		moderately		extremely	I do not implement formal sessions

#### Generalization

36. How *difficult* do you find it to promote generalization of skills your child is learning in IBI into daily life?

1	2	3	4	5	n/a
not at all		moderately		extremely	I do not promote generalization

37. How *effective* do you think you are at promoting generalization of skills learned in IBI into daily life?

1	2	3	4	5	n/a
not at all		moderately		extremely	I do not promote generalization

38. How *confident* do you feel promoting generalization of skills into daily life?

1	2	3	4	5	n/a
not at all		moderately		extremely	I do not promote generalization

39. How much do you feel your involvement in promoting generalization of skills into daily life *makes a difference* in your child's progress?

1	2	3	4	5	n/a
not at all		moderately		extremely	I do not promote generalization

#### Problem Behaviours

40. If your child has problem behaviours (e.g., tantruming, self-injury, aggression), to what extent do you try to handle them in the same manner as the IBI program staff do?

1	2	3	4	5	n/a
never		sometimes		frequently	child does not have problem behaviours

41. How *difficult* do you find it trying to handle problem behaviours in the same manner as the IBI staff do?

1	2	3	4	5	n/a
not at all		moderately		extremely	child does not have problem behaviours

42. How *effective* do you think you are at handling problem behaviours in the same manner as the IBI staff do?

1	2	3	4	5	n/a
not at all		moderately		extremely	child does not have problem behaviours



43. How *confident* do you feel in your ability to handle problem behaviours in the same manner as the IBI staff do?

1	2	3	4	5	n/a
not at all		moderately		extremely	child does not have problem behaviours

44. How much do you feel your involvement in handling problem behaviours in the same way as the IBI staff do *makes a difference* in your child's progress?

1	2	3	4	5	n/a
not at all		moderately		extremely	child does not have problem behaviours

## **PART II**

For questions 45 and 46, please use the following criteria to rate your child's abilities:

- 1 (low) = nonverbal and delays in all areas
- 3 (medium) = some language and delays in many areas
- 5 (high) = verbal and some skills on par with children his/her age

45. How would you rate your child's functioning when he/she entered the IBI program?

1	2	3	4	5
low		medium		high

46. How would you rate your child's functioning now?

1	2	3	4	5
low		medium		high

47. Your child's level of functioning could change (up or down) for many reasons (e.g., IBI, other interventions, natural developmental changes, etc.) To what extent would you say that the change in your child's functioning, if any, is related to your child's participation in an IBI program?

1	2	3	4	5	n/a
not at all		moderately		extremely	no change

For questions 48-52 please circle the number/statement that best corresponds with your child's progress:

48. How would you rate your child's improvement in **social and play skills** since the IBI program began?

1	2	3	4	5
got worse	no improvement	slightly improved	somewhat improved	substantially improved

49. How would you rate your child's improvement in **academic skills** since the IBI program began?

1	2	3	4	5	n/a
got worse	no improvement	slightly improved	somewhat improved	substantially improved	child is not working on academic skills

50. How would you rate your child's improvement in **communication skills** since the IBI program began?

1	2	3	4	5
got worse	no improvement	slightly improved	somewhat improved	substantially improved

51. How would you rate your child's improvement in **self-help skills** since the IBI program began?

1	2	3	4	5
got	no	slightly	somewhat	substantially
worse	improvement	improved	improved	improved

52. How would you rate your child's improvement in **problem behaviours** since the IBI program began?

1	2	3	4	5	n/a
got	no	slightly	somewhat	substantially	child does not
worse	improvement	improved	improved	improved	have any problem behaviours

### **PART III**

*For questions 53-65 please use the following rating scale to circle the statement that best corresponds with your belief:*

<b>SA = Strongly Agree</b>	<b>A = Agree</b>	<b>NS = Not Sure</b>	<b>D = Disagree</b>	<b>SD = Strongly Disagree</b>
53. I believe that IBI is a major breakthrough in the treatment of autism.				SA A NS D SD
54. I am convinced that IBI will turn out to be another false miracle like other "miracle cures" for autism.				SA A NS D SD
55. I believe that IBI is likely to result in permanent improvement for children with autism.				SA A NS D SD
56. I feel comfortable with the procedures and techniques used in IBI therapy.				SA A NS D SD
57. I am skeptical about 'success stories' that I hear about the use of IBI for children with autism.				SA A NS D SD
58. I believe that IBI helps children with autism to improve more than any other form of intervention.				SA A NS D SD
59. No matter what, I will always continue to use behavioural principles with my child with autism.				SA A NS D SD
60. I intend to continue to pay for IBI for my child with autism even when/if public funding becomes unavailable.				SA A NS D SD
61. I believe that IBI will help my child to develop better <b>social and play skills</b> .				SA A NS D SD
62. I believe that IBI will help my child to develop better <b>academic skills</b> .				SA A NS D SD
63. I believe that IBI will help my child to develop better <b>communication skills</b> .				SA A NS D SD
64. I believe that IBI will help my child to develop better <b>self-help skills</b> .				SA A NS D SD
65. I believe that IBI will help to eliminate or reduce my child's <b>problem behaviour</b> (e.g., tantruming, self-injury, and/or aggression).				n/a SA A NS D SD

### **PART IV**

*We understand that raising a child with autism can be a challenge for parents, and can lead to a variety of both positive and negative feelings/consequences. Please answer the following two sets of questions.*

*For questions 66-95 please use the same rating scale as in the previous section:*

<b>SA = Strongly Agree</b>	<b>A = Agree</b>	<b>NS = Not Sure</b>	<b>D = Disagree</b>	<b>SD = Strongly Disagree</b>
66. I often have the feeling that I cannot handle things very well.				SA A NS D SD
67. I find myself giving up more of my life to meet my children's needs than I ever expected.				SA A NS D SD
68. I feel trapped by my responsibilities as a parent.				SA A NS D SD
69. Since having this child, I have been unable to do new and different things.				SA A NS D SD

70. Since having a child, I feel that I am almost never able to do things that I like to do. SA A NS D SD
71. I am unhappy with the last purchase of clothing I made for myself. SA A NS D SD
72. There are quite a few things that bother me about my life. SA A NS D SD
73. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend). SA A NS D SD
74. I feel alone and without friends. SA A NS D SD
75. When I go to a party, I usually expect not to enjoy myself. SA A NS D SD
76. I am not as interested in people as I used to be. SA A NS D SD
77. I don't enjoy things as I used to. SA A NS D SD

*The following statements express how some parents feel they have been CHANGED through the experience of parenting a child with special needs. Please use the same rating scale as above:*

78. I have learned to speak out for my child SA A NS D SD
79. I have learned that I can achieve rather than feel powerless SA A NS D SD
80. I am more compassionate toward others SA A NS D SD
81. I have made a career change, which has lead to greater vocational satisfaction SA A NS D SD
82. I am stronger as a person SA A NS D SD
83. I am more confident SA A NS D SD
84. I take better care of myself SA A NS D SD
85. I have stronger spiritual convictions now (e.g., personal spirituality, faith in god) SA A NS D SD
86. I have made many close friends with people I would have never met otherwise SA A NS D SD
87. I have learned to see life from a different perspective (learned what it is like to live in someone else's shoes) SA A NS D SD
88. I have made a difference in the lives of other people (through advocacy/promoting changes) SA A NS D SD
89. I make the most out of each day rather than living for the future SA A NS D SD
90. I celebrate life more now (rather than just merely surviving day to day) SA A NS D SD
91. I have a different and more authentic view of what it means to be successful in life SA A NS D SD
92. I have learned what is really important and valuable in life SA A NS D SD
93. I have developed new skills that have helped me to do a better job in my career/vocation SA A NS D SD
94. I have developed attitudes that have helped me to do a better job in my chosen career/vocation SA A NS D SD
95. My marriage has emerged stronger SA A NS D SD

96. How would you rate your stress level **before** your child started his/her IBI program?

1 2 3 4 5  
low medium high

97. How would you rate your stress level **now**?

1 2 3 4 5  
low medium high

98. People's stress levels may change (up or down) for many reasons (e.g., financial problems, death in the family, increase in supports available, exciting child accomplishments). To what extent would you say that your change in stress level, if any, is related to your child's participation in an IBI program?

1                      2                      3                      4                      5                      n/a  
not at all                      moderately                      extremely                      no change

#### **PART V**

99. Compared to the general population, how would you rate your knowledge about autism as a developmental disorder?

1                      2                      3                      4                      5  
low                      medium                      high

100. Compared to the general population, how would you rate your knowledge about the principles of IBI?

1                      2                      3                      4                      5  
low                      medium                      high

#### **Autism**

*Please circle either "True"(T) or "False"(F) for questions 101-111. We encourage you to make your best guess, but if you are completely unsure of an answer you may circle "Don't Know"(DK)*

- |   |   |   |    |
|---|---|---|----|
| 101. Autism is an extremely rare disorder.  | T | F | DK |
| 102. The earliest signs of autism include poor response to being called by name and lack of pointing.                               | T | F | DK |
| 103. Children with autism are good at understanding the thoughts, feelings, and intentions of other people.                         | T | F | DK |
| 104. Children with autism do not always, but may, have intellectual disability.   | T | F | DK |
| 105. Autism affects children of all racial, ethnic and social class backgrounds with equal frequency.                               | T | F | DK |
| 106. Children with autism range from being nonverbal to being verbal.   | T | F | DK |
| 107. Autism involves a qualitative impairment in communication and social interaction, but no stereotyped or repetitive behaviours. | T | F | DK |
| 108. Children with autism are known to have a wide variety of interests and good social skills.                                     | T | F | DK |
| 109. Children with autism may communicate using sign language or pictures.  | T | F | DK |
| 110. Children with autism usually engage in play that looks like that of other children their age.                                  | T | F | DK |

#### **IBI**

*Please circle either "True"(T) or "False"(F) for questions 111-120. We encourage you to make your best guess, but if you are completely unsure of an answer you may circle "Don't Know"(DK)*

- |  |   |   |    |
|--|---|---|----|
| 111. After a child has mastered a task with prompting, prompts should be faded so that the child can eventually demonstrate the skill independently. | T | F | DK |
| 112. In IBI it is often best to teach the child a complex task by breaking it down into parts rather than teaching the task as a whole.              | T | F | DK |



## APPENDIX E

### PARENT INVOLVEMENT QUESTIONNAIRE – THERAPIST VERSION

#### *Parent Involvement Questionnaire – Therapist Version*

Participant number \_\_\_\_\_

#### Parent Involvement Questionnaire – Therapist Version

*This questionnaire has several different sections. Each section has its own set of instructions. The first section will provide us with some background information about you and your experience in the IBI field. The remaining questions are about the family that you are currently working with. Some questions ask you to rate the mother/female guardian and the father/male guardian separately. If you work with a single-parent family then please leave the other parent blank. However, if you work with a two-parent family, please try your best to rate both parents, even if you do not know one of them very well. If you feel that a question does not apply to you and/or the family that you work with please write n/a.*

#### **Therapist General Information**

- What is your role?     Senior Therapist (ST)
- Instructor Therapist (IT)
- Other (please specify) \_\_\_\_\_
- How long have you been working in the IBI field? \_\_\_\_\_
- How many families of children with autism have you worked with? \_\_\_\_\_
- How long have you been working with the family in question? \_\_\_\_\_

#### **Part 1**

*For questions 1-5a please use the rating scale below to answer how often the mother and/or father of the child with autism does each of the following*

	1	2	3	4	5
	never		once per week		daily
				<u>Mother/Female guardian</u>	<u>Father/Male guardian</u>
1) Communicates directly with you either on the phone or in person				1 2 3 4 5	1 2 3 4 5
2) Reads and Writes in their child's communication book				1 2 3 4 5	1 2 3 4 5
3) Does formal IBI sessions with her/his child				1 2 3 4 5	1 2 3 4 5
4) Promotes the generalization of skills that the child is learning in IBI in daily life				1 2 3 4 5	1 2 3 4 5

5a) \* If home-based, watches her/his child in Therapy sessions 1 2 3 4 5 1 2 3 4 5

*For questions 5b-10 please use the rating scale below to answer how often the mother and/or father of the child with autism does each of the following*

	1	2	3	4	5
	never		on some occasions		on every possible occasion
				<u>Mother/Female guardian</u>	<u>Father/Male guardian</u>
5b) * If center-based, watches her/his child in therapy sessions				1 2 3 4 5	1 2 3 4 5
6) Attends review meetings and has input into goal setting for their child				1 2 3 4 5	1 2 3 4 5
7) Reads material and/or does homework that you give them				1 2 3 4 5	1 2 3 4 5
8) Attends conferences and parent training sessions				1 2 3 4 5	1 2 3 4 5
9) Has individual coaching and feedback from the IBI program staff				1 2 3 4 5	1 2 3 4 5
10) Tries to handle problem behaviors in the same manner as the IBI staff				1 2 3 4 5	1 2 3 4 5
11) Please provide your best estimate of how many hours per week the child's mother/female guardian is involved with the IBI agency	0	1-3	3-5	5-7	7 or more
12) Please provide your best estimate of how many hours per week the child's father/male guardian is involved in the IBI agency	0	1-3	3-5	5-7	7 or more
13) Please provide your best estimate of how many hours per week the child's mother/female guardian implements formal IBI sessions with her child	0	1-3	3-5	5-7	7 or more
14) Please provide your best estimate of how many hours per week the child's father/male guardian implements formal IBI sessions with his child	0	1-3	3-5	5-7	7 or more

0                  1-3                  3-5                  5-7                  7 or more

15) Please provide your best estimate of how many hours per week the child's mother/female guardian works on deliberately generalizing skills that the child is learning in therapy

0                  1-3                  3-5                  5-7                  7 or more

16) Please provide your best estimate of how many hours per week the child's father/male guardian works on deliberately generalizing skills that the child is learning in therapy

0                  1-3                  3-5                  5-7                  7 or more

17) How familiar would you say the child's mother/female guardian is with her child's specific IBI program goals

1                  2                  3                  4                  5  
not at all                  somewhat                  extremely

18) How familiar would you say the child's father/male guardian is with his child's specific IBI program goals

1                  2                  3                  4                  5  
not at all                  somewhat                  extremely

*For questions 19 and 20 please use the rating scale below to answer the following*

1                  2                  3                  4                  5  
not at all                  somewhat                  extremely

19) How effective is the child's parent at implementing the principles of IBI

	<u>Mother/Female guardian</u>					<u>Father/Male guardian</u>				
	1	2	3	4	5	1	2	3	4	5

20) How confident do you believe the child's parent is in their ability to implement the principles of IBI

	1	2	3	4	5	1	2	3	4	5
--	---	---	---	---	---	---	---	---	---	---

**Part 2**

*For questions 21 and 22, please use the criteria below to rate the child's abilities*

- 1 (low) = nonverbal and delays in all areas
- 3 (medium) = some language and delays in many areas
- 5 (high) = verbal and some skills on par with children his/her age



*Although you may not have known each child at the start of his/her intervention, based on your current knowledge (from the child's treatment file and/or through speaking with other staff) please provide us with your best estimate of the following*

21) How would you rate the child's functioning when he/she entered the program?

1	2	3	4	5
low		medium		high

22) How would you rate the child's functioning now?

1	2	3	4	5
low		medium		high

23) How would you rate the child's improvement in the social and play skills since the IBI program began?

1	2	3	4	5
got worse	no improvement	slightly improved	somewhat improved	extremely improved

24) How would you rate the child's improvement in academic skills since the IBI program began?

1	2	3	4	5
got worse	no improvement	slightly improved	somewhat improved	extremely improved

25) How would you rate the child's improvement in communication since the IBI program began?

1	2	3	4	5
got worse	no improvement	slightly improved	somewhat improved	extremely improved

26) How would you rate the child's improvement in self-help skills since the IBI program began?

1	2	3	4	5
got worse	no improvement	slightly improved	somewhat improved	extremely improved

27) How would you rate the child's improvement in problem behavior since the IBI program began?

1	2	3	4	5
got	no	slightly	somewhat	extremely
worse	improvement	improved	improved	improved

**PART 3**

28) How strongly would you say the child's mother/female guardian believes in IBI as the intervention of choice for her child?

1	2	3	4	5
not at all		somewhat		extremely

29) How strongly would you say the child's father/male guardian believes in IBI as the intervention of choice for his child?

1	2	3	4	5
not at all		somewhat		extremely

**PART 4**

*For questions 30-32 please use the rating scale below to answer the following*

1	2	3	4	5	n/a
not at all		moderately		extremely	did not know family at intake

	<u>Mother/Female guardian</u>					<u>Father/Male guardian</u>				
	1	2	3	4	5	1	2	3	4	5
30) If you knew the parent at intake, How stressed did the parent seem?										
31) How stressed does the parent seem now?										
32) To what extent would you say that a change in the parent's stress level, if any, is related to their child's participation in an IBI program?										

**PART 5**

*For questions 33 and 34 please use the rating scale below to answer the following*

1	2	3	4	5
low		medium		high

	<u>Mother/Female guardian</u>	<u>Father/Male guardian</u>
33) How would you rate the parent's knowledge of autism?	1 2 3 4 5	1 2 3 4 5

34) How would you rate the parent's knowledge of IBI?	1 2 3 4 5	1 2 3 4 5
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35) Please comment on any other parent or family factors which you believe positively affect the quality of IBI that the child receives (i.e. support from extended family or friends, financial resources, etc.)

Mother/female guardian

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Father/male guardian

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36) Please comment on any other parent or family factors which you believe detract from/negatively affect the quality of IBI that the child receives (i.e. support from extended family or friends, financial resources, etc.)

Mother/female guardian

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Father/male guardian

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Thank you for taking time to complete this questionnaire!

This survey has been taken from the dissertation "Parent's Involvement in Behavioural Intervention For Their Children with Autism" by Abbie J. Solish

**APPENDIX F  
PARENT/CHILD INFORMATION SURVEY – PARENT VERSION**

The information you provide will be used for research purposes only. Your responses will remain confidential. You have the right to not answer any or all of the questions.

**Childs Name:** \_\_\_\_\_

**Mothers Name:** \_\_\_\_\_

**Fathers Name:** \_\_\_\_\_

**Mothers Date of birth:** \_\_\_\_\_

**Fathers Date of birth:** \_\_\_\_\_

**Marital Status:**

<input type="checkbox"/> Single	<input type="checkbox"/> Cohabiting	<input type="checkbox"/> Married	<input type="checkbox"/> Divorced	<input type="checkbox"/> Widowed	<input type="checkbox"/> Other
---------------------------------	-------------------------------------	----------------------------------	-----------------------------------	----------------------------------	--------------------------------

**If applicable, how many hours a week does your child spend at:**

Mothers home: \_\_\_\_\_

Fathers home: \_\_\_\_\_

**Please list the total number of siblings your child has (full and/or half):** \_\_\_\_\_

**How many family members live in the** \_\_\_\_\_ **Mothers home:** \_\_\_\_\_ **Fathers**  
**home:** \_\_\_\_\_

**Mother highest education completed:**

<input type="checkbox"/> Some High School	<input type="checkbox"/> High School	<input type="checkbox"/> Some College	<input type="checkbox"/> Associates Degree
<input type="checkbox"/> Bachelor's Degree	<input type="checkbox"/> Master's Degree	<input type="checkbox"/> Doctorate Degree	<input type="checkbox"/> Other

**Father highest education completed:**

<input type="checkbox"/> Some High School	<input type="checkbox"/> High School	<input type="checkbox"/> Some College	<input type="checkbox"/> Associates Degree
<input type="checkbox"/> Bachelor's Degree	<input type="checkbox"/> Master's Degree	<input type="checkbox"/> Doctorate Degree	<input type="checkbox"/> Other

**Please list any other type of treatment your child has received for Autism:**

<b>Treatment type/name</b>	<b>Hours of treatment per week</b>	<b># of mos/yrs spent in treatment</b>

**How many hours of direct service does your child receive on average per month at UPAC:**

\_\_\_\_\_

**How many hours do you and/or your spouse spend in contact with your child's consultant per month:** \_\_\_\_\_

**Please tell us why you did or did not choose to participate in the parent training course offered by UPAC?**

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**Thank you for your participation!**

**APPENDIX G**  
**PARENT/CHILD INFORMATION SURVEY – THERAPIST VERSION**

The information you provide will be used for research purposes only. Your responses will remain confidential. You have the right to not answer any or all of the questions.

**Your Name:** \_\_\_\_\_

**Childs Name:** \_\_\_\_\_

**How many hours of direct service does this child receive on average per month at UPAC:**

\_\_\_\_\_

**How many hours do you spend in contact with this child's parent(s) on average per month:**

\_\_\_\_\_

**What is this child's level of problem behaviors?**

1	2	3
Low	Moderate	Severe
(No significant focus on behavior as part of the child's plan/no significant scores on CBCL or other behavior measures)	(behavior reductions incorporated into treatment plan but are not main focus/ borderline range scores on the CBCL or other behavior measures)	(behavior reductions are main focus of treatment plan/clinical range scores on the CBCL or other behavior measures)

**What is this child's level of cognitive impairment?**

1	2	3	4
Within the normal Range of development (on the VABS or other cognitive measure)	Within 1 standard deviations below the mean on the (on the VABS or other cognitive measure)	Within 2 standard deviations below the mean on the (on the VABS or other cognitive measure)	Within 3+ standard deviations below the mean on the (on the VABS or other cognitive measure)

**Thank you for your participation!**

## APPENDIX H INFORMED CONSENT - PARENT

### Behavioral Research Informed Consent

Title of Study: Assessing Parent Involvement in Applied Behavior Analysis  
Treatment for Children with Autism

Principal Investigator (PI): Krista Clancy  
Wayne State University College of Education  
University Pediatricians Autism Center  
21600 Novi Rd. Suite 800  
Novi, MI 48375  
(248) 305-6172

Co-investigator: Katie Gersky  
University Pediatricians Autism Center

When we say “you” in this consent form, we mean you or your child. “We” means the researchers and other staff.

### Purpose

You are being asked to be in a research study of parent involvement in Applied Behavior Analysis treatment for children with autism because your child has a diagnosis of Autism Spectrum Disorder and receives or has received intensive behavioral intervention services through University Pediatricians Autism Center. This study is being conducted at Wayne State University. The estimated number of study participants to be enrolled at Wayne State University is 150. **Please read this form and ask any questions you may have before agreeing to be in the study.**

In this research study, we are studying whether parent involvement is related to the amount of stress a parent feels, their feelings of how confident they are in their ability to parent their child with autism and their belief in the effectiveness of Applied Behavior Analysis (ABA) as a treatment for their child with autism. We are also studying whether a voluntary parent education seminar offered at University Pediatricians Autism Center as an optional part of your standard care of treatment is effective in changing levels of stress, confidence in parenting and beliefs in ABA change after participating in this intervention and what factors may influence a parents/guardians choice to participate in this intervention.

### Study Procedures

Potential participants for this study will be identified by the therapists working at University Pediatricians Autism Center and be provided with an information sheet explaining the study. For those interested in participating a member of the research team will obtain consent from the parent/guardian following review of this document.

If a parent/guardian of a child at University Pediatricians Autism Center they will be asked to consent to the following procedures: 1). Allow research staff to access your child’s treatment file

to extract data related to the study including assessment scores, time in treatment, attendance for different treatment options at University Pediatricians Autism Center facility and demographic information 2). Agree to complete the Parent Involvement Questionnaire – Parent Version and 3). Allow your child’s therapist to participate by completing the Parent Involvement Questionnaire – Therapist Version.

You may choose to participate in all three parts of the study or only the portions you choose. By choosing to participate with the Parent Involvement Questionnaire you will be asked to complete a survey which will take approximately 30 minutes of your time to complete. If you consent to the other portions of the study there will be no additional requirements from you or your child. All other data will be extracted from your child’s file for their standard of care treatment. This may include private health information such as your child’s name and service provision information, parent participation rating by your therapist and attendance of different services by you and your child. All information that is obtained from University Pediatricians Autism Center will be coded and de-identified.

All information you provide or obtained from you or your child will remain confidential. It will not be shared with any persons or agencies in its identifiable form. All identifying information that appears on materials will be immediately removed. Hard copies of consent forms will be stored in a locked file cabinet in a locked office space at University Pediatricians Autism Center. All data from the study will be presented in a manner that does not reveal you or your child’s identity, except as may be required by law. Any forms or protocols that reveal your child’s identity will be destroyed at the end of the study. If you choose to withdraw your child from the study all collected data will be destroyed at that time.

### **Benefits**

The possible benefits to your child for taking part in this research study are the direct suggestions for future instructional planning that can assist with increase opportunities for you to be involved with your child’s treatment. This information could be useful for informing intervention at University Pediatricians Autism Center and be a valuable addition to your child’s treatment program. Your participation will also give information on potential barriers parents experience with parent involvement and ways to overcome those barriers.

### **Risks**

There are no anticipated risks to your involvement in this study. Most of the information will be directly extracted from your child’s treatment file and all sources of data outside of the Parent Involvement Questionnaire is already part of your child’s standard care of treatment. There may be risks involved from taking part in this study that are not known to researchers at this time.

### **Study Costs**

Participation in this study will be of no cost to you outside of your regular therapy expense.

### **Compensation**

No compensation will be provided to participants of this study.



### **Research Related Injuries**

In the event that this research related activity results in an injury, treatment will be made available including first aid, emergency treatment, and follow-up care as needed. Care for such will be billed in the ordinary manner to you or your insurance company. No reimbursement, compensation, or free medical care is offered by Wayne State University's University Pediatricians Autism Center. If you think that you have suffered a research related injury, contact the PI right away at (248) 305-6172.

### **Confidentiality**

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Institutional Review Board (IRB) at Wayne State University, or federal agencies with appropriate regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records. When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity.

### **Voluntary Participation/Withdrawal**

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you decide to take part in the study you can later change your mind and withdraw from the study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

The PI may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study

### **Questions**

If you have any questions about this study now or in the future, you may contact Krista Clancy or one of her research team members at the following phone number (248) 305-6172. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

### **Consent to Participate in a Research Study**

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

---

 Signature of participant

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 Date

---

 Printed name of participant

---

 Time

---

 Signature of person obtaining consent

---

 Date

---

 Printed name of person obtaining consent

---

 Time

### **HIPAA Authorization**

A federal regulation, known as the “Health Insurance Portability and Accountability Act (HIPAA)” gives you certain rights concerning the use and disclosure (sharing with others) of your Protected Health Information (PHI). This regulation provides safeguards for the privacy and security of your information. Your permission (authorization) is required for the use and sharing of any protected health information collected as part of this research study. If you are not willing to sign this authorization to use and/or disclose your PHI by the research team, you will not be eligible to take part in this research study.

The principal investigator (PI) and her research team will use your medical records and information created or collected as part of this research study. Your PHI is important for the PI and her research team in order to collect information about you and your child during the study, to be able to contact you if needed, and to provide treatments to you during the study, if required. The PI may send out your study related health information to the sponsor or other entities involved in this study.

Your medical records, which may contain information that directly identifies you, may be reviewed by representatives from groups identified below. The purpose of these reviews is to assure the study is being conducted properly, that data is being obtained correctly or for other uses authorized by law. These reviews occur at the study site or in the PI’s research office and can take place anytime during the study or after the study has ended.

**The PHI that will be “USED”** for this research includes the following: name, assessment scores, elements of dates, participation ratings, treatment attendance information and any unique identifying numbers or characteristics or code.

**The PHI that will be “DISCLOSED”** or shared with others for this research includes the following: No identifying information will be removed or disclosed to individuals outside those authorized to view this information and members of the research team. All PHI information will remain at University Pediatricians Autism Center. Only deidentified data will be removed.

Your study information may be **used** or **shared** with the following people or groups:

- The PI, co-investigators, and key personnel of WSU associated with the research project
- WSU's Institutional Review Boards (IRB)
- Other collaborating academic research institutions, which include: University Pediatricians autism Center
- Federal agencies with appropriate regulatory oversight (e.g., FDA, OHRP, OCR, etc.) may review your records

Once your information has been released according to this Authorization, it could be released again and may no longer be protected by the HIPAA regulations.

This Authorization does not expire. The research team may need to correct it or provide missing information about you even after the study has ended, and your medical records may be needed to assist in this process.

During your participation in this study you will have access to your medical record and any study information that is part of that record. The PI is not required to release research information that is not part of your medical record.

You may withdraw (take back) your permission for the **use** and **disclosure** of your PHI for this research at anytime, by **writing** to the PI at the address on the first page of this form. Even if you withdraw your permission, the PI for the research project may still use your PHI that was collected prior to your written request if that information is necessary to the study. If you withdraw your permission for use of your PHI, you will also be withdrawn from the research project. Withdrawing your authorization **will not** affect the health care that will be provided by the Detroit Medical Center and/or the WSU School of Medicine Practice Plans.

#### **Authorization to use and disclose PHI**

- ❖ By signing this document, you are authorizing the PI to **use** and **disclose** PHI collected about you for the research purposes as described above.

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Signature of participant

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Date

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Printed name of participant

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- ❖ For participants unable to give Authorization, the following individual is acting on behalf of the research participant (e.g., children, mentally impaired, etc.).

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Signature of authorized representative

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Date

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Printed name of authorized representative

Relationship to the participant

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Signature of person obtaining Authorization

Date

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Printed name of person obtaining Authorization

Time

## APPENDIX I INFORMED CONSENT - THERPIST

### Behavioral Research Informed Consent

Title of Study: Assessing Parent Involvement in Applied Behavior Analysis  
Treatment for Children with Autism

Principal Investigator (PI): Krista Clancy  
Wayne State University College of Education  
University Pediatricians Autism Center  
21600 Novi Rd. Suite 800  
Novi, MI 48375  
(248) 305-6172

Co-investigator: Katie Gersky  
University Pediatricians Autism Center

When we say “you” in this consent form, we mean you or your child. “We” means the researchers and other staff.

#### **Purpose**

You are being asked to be in a research study of parent involvement in Applied Behavior Analysis treatment for children with autism because your child has a diagnosis of Autism Spectrum Disorder and receives or has received intensive behavioral intervention services through University Pediatricians Autism Center. This study is being conducted at Wayne State University. The estimated number of study participants to be enrolled at Wayne State University is 150. **Please read this form and ask any questions you may have before agreeing to be in the study.**

In this research study, we are studying whether parent involvement is related to the amount of stress a parent feels, their feelings of how confident they are in their ability to parent their child with autism and their belief in the effectiveness of Applied Behavior Analysis (ABA) as a treatment for their child with autism. We are also studying whether a voluntary parent education seminar offered at University Pediatricians Autism Center as an optional part of your standard care of treatment is effective in changing levels of stress, confidence in parenting and beliefs in ABA change after participating in this intervention and what factors may influence a parents/guardians choice to participate in this intervention.

#### **Study Procedures**

Potential participants for this study will be identified by the therapists working at University Pediatricians Autism Center and be provided with an information sheet explaining the study. For those interested in participating a member of the research team will obtain consent from the parent/guardian following review of this document.

If a parent/guardian of a child at University Pediatricians Autism Center they will be asked to consent to the following procedures: 1). Allow research staff to access your child’s treatment file

to extract data related to the study including assessment scores, time in treatment, attendance for different treatment options at University Pediatricians Autism Center facility and demographic information 2). Agree to complete the Parent Involvement Questionnaire – Parent Version and 3). Allow your child’s therapist to participate by completing the Parent Involvement Questionnaire – Therapist Version.

You may choose to participate in all three parts of the study or only the portions you choose. By choosing to participate with the Parent Involvement Questionnaire you will be asked to complete a survey which will take approximately 30 minutes of your time to complete. If you consent to the other portions of the study there will be no additional requirements from you or your child. All other data will be extracted from your child’s file for their standard of care treatment. This may include private health information such as your child’s name and service provision information, parent participation rating by your therapist and attendance of different services by you and your child. All information that is obtained from University Pediatricians Autism Center will be coded and de-identified.

All information you provide or obtained from you or your child will remain confidential. It will not be shared with any persons or agencies in its identifiable form. All identifying information that appears on materials will be immediately removed. Hard copies of consent forms will be stored in a locked file cabinet in a locked office space at University Pediatricians Autism Center. All data from the study will be presented in a manner that does not reveal you or your child’s identity, except as may be required by law. Any forms or protocols that reveal your child’s identity will be destroyed at the end of the study. If you choose to withdraw your child from the study all collected data will be destroyed at that time.

### **Benefits**

The possible benefits to your child for taking part in this research study are the direct suggestions for future instructional planning that can assist with increase opportunities for you to be involved with your child’s treatment. This information could be useful for informing intervention at University Pediatricians Autism Center and be a valuable addition to your child’s treatment program. Your participation will also give information on potential barriers parents experience with parent involvement and ways to overcome those barriers.

### **Risks**

There are no anticipated risks to your involvement in this study. Most of the information will be directly extracted from your child’s treatment file and all sources of data outside of the Parent Involvement Questionnaire is already part of your child’s standard care of treatment. There may be risks involved from taking part in this study that are not known to researchers at this time.

### **Study Costs**

Participation in this study will be of no cost to you outside of your regular therapy expense.

### **Compensation**

No compensation will be provided to participants of this study.

### **Research Related Injuries**

In the event that this research related activity results in an injury, treatment will be made available including first aid, emergency treatment, and follow-up care as needed. Care for such will be billed in the ordinary manner to you or your insurance company. No reimbursement, compensation, or free medical care is offered by Wayne State University's University Pediatricians Autism Center. If you think that you have suffered a research related injury, contact the PI right away at (248) 305-6172.

### **Confidentiality**

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Institutional Review Board (IRB) at Wayne State University, or federal agencies with appropriate regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records. When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity.

### **Voluntary Participation/Withdrawal**

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you decide to take part in the study you can later change your mind and withdraw from the study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

The PI may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study

### **Questions**

If you have any questions about this study now or in the future, you may contact Krista Clancy or one of her research team members at the following phone number (248) 305-6172. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

### **Consent to Participate in a Research Study**

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

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 Signature of participant

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 Date

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 Printed name of participant

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 Time

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 Signature of person obtaining consent

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 Date

---

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---

 Time

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Signature of participant

Date

---

Printed name of participant

- ❖ For participants unable to give Authorization, the following individual is acting on behalf of the research participant (e.g., children, mentally impaired, etc.).

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Signature of authorized representative

Date

---

Printed name of authorized representative  
participant

Relationship to the

---

Signature of person obtaining Authorization

Date

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Printed name of person obtaining Authorization

Time

**APPENDIX J  
ORAL CONSENT SCRIPT**

Good [Morning/Afternoon] – my name is \_\_\_\_\_ and I am the principal investigator/research assistant on the research team at University Pediatricians Autism Center (UPAC). I am calling to ask you if you would be willing to participate in a study regarding parent involvement because your child receives(ed) ABA treatment at UPAC. The purpose of this study is to provide data about the how parents are involved in treatment, what some of the barriers are to parent involvement and ways to help parents overcome those barriers to involvement.

Your participation in this study is completely voluntary and involves completing a parent involvement questionnaire, providing consent for your child’s therapist to complete a parent involvement questionnaire in relation to your child’s treatment and for the research staff to review your child’s chart to extract assessment scores and attendance information regarding different services options provided at UPAC. You can consent to only one, two or all three of the data collection measures requested (to complete the parent survey, have the survey completed on your child’s treatment, and allow the research team access to your child’s treatment data in their client file). If you choose to complete the survey it will take about 30 minutes. If you choose to consent to the other two options it will take no additional involvement from you. This research has minimum risks and aims to benefit the UPAC staff by helping them to better understand how they can improve the care they deliver. There is no compensation for your time, but we hope the study will benefit future patients if we can better understand ways to promote parent involvement in treatment.

Please know that I will do everything I can to protect your privacy. Your identity or personal information will not be disclosed in any publication that may result from the initiative. Surveys and chart data will be stored in a secure location.

Do you have any questions regarding anything I’ve mentioned or this study, overall? [Discuss questions]

**Would you like to move forward with participating in this study?**

YES

NO

**[If yes] Would you be willing to sign a consent that provides more information about the study at your next office visit?**

YES

NO

Upon completion of this phone script, should you have further questions, you may contact the Principal Investigator, Krista Clancy, MS, LLP BCBA, at 248-305-6172.

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**ABSTRACT****ASSESSING PARENT INVOLVMENT IN APPLIED BEHAVIOR ANALYSIS  
TREATMENT FOR CHILDREN WITH AUTISM**

by

**KRISTA M. CLANCY****May 2017****Advisor:** Dr. Cheryl Leigh Somers**Major:** Educational Psychology**Degree:** Doctor of Philosophy

The purpose of this study was to compare two groups of parents whose children participated in ABA on their levels of stress, self-efficacy, treatment acceptability, and parents' level of involvement in their children's treatment, and to assess variables that may explain variance in parent involvement. Parents in the treatment group participated in a voluntary parent training (n=18) and the comparison group were parents who elected not to participate in the voluntary training (n=22). This was a quasi-experimental design study where parents and their therapists completed a survey regarding parents' involvement in their children's treatment programs. Additional parent measures collected as part of the children's treatment were also reviewed to assess changes in parent stress, self-efficacy, and treatment acceptability.

A major finding in this study was that there were significant improvements in both parent self-efficacy and treatment acceptability in the treatment group. However, when comparing the differences in gains between the groups, the average gains of the treatment group were not significantly different than those of the comparison group. Findings also indicated that the treatment group was rated as having significantly higher levels of involvement by the therapists,

but not by the parents themselves.

Multiple regression analyses assessing the relationship between parent involvement and 1) parent stress, 2) self-efficacy, and 3) treatment acceptability did not indicate significant results when retrospective data from the client files were used to measure parent stress, self-efficacy, and treatment acceptability. However, a follow up regression analysis, using additional measures, was able to explain 49% of variance in parent involvement. These results suggest that the levels of parent stress, self-efficacy, and treatment acceptability may be important constructs to consider when attempting to improve parent involvement.

Results of a hierarchical regression analysis suggested that parent training explained variance in parent involvement above and beyond what was already explained by parent stress, self-efficacy, and treatment acceptability. Further results indicated that variance explained in parent involvement by parent training was dependent on self-efficacy. This indicated that there was some benefit to the parent training in regards to parent involvement and that self-efficacy was a major contributor to the relationship between parent training and parent involvement. Meaning and significance of results, in light of limitations such as small sample size, are discussed.

## **AUTOBIOGRAPHICAL STATEMENT**

I have worked with families and their children with disabilities for almost 20 years. Over time I have learned that building a relationship with those you work with is one of the most important aspects of treatment. I have had the privilege of working in both the homes of families, client's communities, and clinical settings. This has enhanced my understanding of how these environments can affect treatment outcomes and the changes in interactions and relationships that must be considered when providing treatment in different settings. I have also had many experiences where I have worked as a mentor, instructor, or supervisor to students and staff who are working in the field of applied behavior analysis. By holding positions where I was able to gain both the perspective of the clients and the therapists who work with them, I have been able to help identify areas where there are gaps in practice.

This project has helped me to acquire improved analytical skills. I am grateful to have the ability to better assess problems in treatment and hypothesize potential solutions for improvement. I would like to spend more time and effort focusing on how to improve my skills, as well as, help others improve theirs in order to provide more effective treatment and training for those who need it the most. After completing this training program my intention is to continue to focus on improvements in treatment and training. I hold both teaching and clinical positions where I am able to have an impact on many families by helping to provide training and feedback to many clinicians and future clinicians. My goal is to improve the focus on parent's and family's needs as a way to improve outcomes for the client. Furthermore, I am now in a position with my current appointment to the State of Michigan Autism Council where I can have an even greater influence on how to improve the systems of service throughout the state. I am anxious to use my new skills acquired in my Ph. D. program to improve my future work.