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# The Effects of Acceptance and Commitment Therapy on Parents of Children Diagnosed with Autism

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# Walden University

College of Social and Behavioral Sciences

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Walden University 2015

# Abstract

Effects of Acceptance and Commitment Therapy for Parents of Children with Autism

by

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BA, California State University, Sacramento 1997MS, California State University, San Jose, 2000

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Psychology

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#### Abstract

The number of children who display characteristics of autism in the United States has been on the rise. Not only do children diagnosed with autism experience difficulties related to the defining characteristics of autism, but parents of children diagnosed with autism commonly experience negative consequences as well. Parents of a child diagnosed with autism more often report symptoms of depression, stress, and reduced quality of life than their do counterparts with neuro-typical children. These traits have the potential to negatively impact the parents' capacity to assist their child in receiving needed treatment and can limit the ability of the parents to learn and utilize effective strategies to assist their child in their future development. Guided by the relational frame theory, this study investigated the effects that acceptance and commitment therapy (ACT) might have on parents who have a child diagnosed with autism within California. The dependent variables were stress, depression, and quality of life. The independent variable was treatment, with 3 intervention levels: ACT, behavior analytic training, and a no treatment control group. A quasi-experimental, non-equivalent, pretest-posttest design was used to examine the variables among a sample of 57 parents of children diagnosed with autism. Given concerns meeting assumptions of normality, Kruskal-Wallis was the statistical procedure used. The overall/change score for Quality of Life was significant at the .01 level across treatment levels. The findings of this study could serve to allow the parents of a child diagnosed with autism to interact more fully and meaningfully with their child and to provide the parents with a venue for which to address challenges they may be experiencing related to their child's disability.

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#### Dedication

It is with much love that I dedicate this dissertation to my family. My husband and children have demonstrated immeasurable patience and understanding during this intense time of focus. Personal resources are exhausted when working on a Ph.D., and my family has worked together to combat those challenges and encouraged me to continue this journey to the end. My husband's words of encouragement and unwavering support have not only helped me through these challenging times, but have also been my lifeline when I was not sure I could continue. There have been many life changes along the way and we have grown closer as a family because of them. Completion of this dissertation and Ph.D. is not only an accomplishment for myself, but for my husband and children as well. I would also like to dedicate this dissertation to my parents who instilled in me the values of hard work and the importance of education from childhood. With my family and parents, I share this success.

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# Chapter 1: Introduction to the Study

The frequency of children diagnosed with autism spectrum disorder is on the rise. In the United States, in 2006, the estimated prevalence of a child obtaining a diagnosis on the autism spectrum was 1:110 (Rice, 2009). The core features of autism include impairments in social interaction, impairments in verbal and nonverbal communication, impairments in self-help skills, and the display of repetitive, stereotypical behavior (Meadan, Halle, & Ebata, 2010). The behavioral repertoire and core features associated with a diagnosis of autism affect not only a child's ability to interact successfully with the environment and society, but also have a tremendous impact on the family structure (Meadan et al., 2010). Compared with parents of typically developing children, parents of children diagnosed with autism, especially mothers, reported higher levels of stress (Benson & Karlof, 2009; Blackledge & Hayes, 2006; Davis & Carter, 2008; Meadan et al., 2010) and more frequent perceived symptoms of depression (Benson & Karlof, 2009).

A child diagnosed with autism may not be able to communicate his/her wants and needs to others, and may demonstrate delays in social skills. Delays in communication and socialization can be observed by the child lacking the ability to demonstrate communicative intent, lacking the ability to initiate and maintain conversation, displaying difficulty in developing friendships, and displaying difficulty understanding the context of the conversational language (Ruser et al., 2007). Because of these deficits, family members may be left guessing what the child feels, thinks, and needs, and may endure strangers in the community not understanding why the child is engaged in socially

inappropriate behavior. The lack of ability to understand and verbally engage with their child has the potential to lead to frustration on both the parent and child's behalf. Another characteristic of autism is impairment in self-help and play skills. A child who lacks self-help and play skills, such as the ability to independently toilet, feed, and entertain oneself, will likely require another individual to complete these activities for them and to be available to structure the child's day, so they remain engaged (Jasmin et al., 2009). The time requirement involved in completing self-help skills for, or with, one's child and the level of their child's independence is one of the many concerns for parents of children diagnosed with autism (Jasmin et al., 2009).

In this study, I addressed the gap in the research by examining the variable of quality of life of parents of a child diagnosed with autism as well as comparing treatment programs in reference to the variable, quality of life. In 2006, Blackledge and Hayes found that parents of a child diagnosed with autism reported elevated levels of stress and depression. In this study, I will expand upon the findings of Blackledge and Hayes and will compare outcomes of parents who participate in different treatment programs.

Detailed discussion regarding current literature is reviewed in Chapter 2.

#### **Problem Statement**

The number of children diagnosed with autism has increased over the past decade. In 2006 on average, 1 in 110 children carried a diagnosis on the autism spectrum (Rice, 2009). These findings indicated a 57% increase from the number of children diagnosed with autism in 2002 (Rice, 2009). Not only are the core features of autism detrimental to the individual carrying the diagnosis, but these effects also have a tremendous impact on

the family system. Parents of children diagnosed with autism have been reported to display a higher degree of stress and increased perceived levels of depression compared with parents of typically developing children, as well as parents who have children with other disabilities including down syndrome, mental retardation, cerebral palsy, and attention deficit hyperactivity disorder (Blackledge & Hayes, 2006; Lee, Harrington, Louie, & Newschaffer, 2008).

While much of the literature has been focused on designing interventions to address the core characteristics of autism, limited research has focused on designing effective interventions for parents of children diagnosed with autism. Interventions based on the theoretical framework of behavior analysis are frequently recommended for children diagnosed with autism (Schwichtenberg & Poehlmann, 2007). Although the outcomes of behavior analytical programs typically focus on increasing the child's skill level and reducing problematic behaviors, parent involvement may also be a key component of a behavior analytic program. Schwichtenberg and Poehlmann (2007) looked at the intensity of behavior analytic programming for children diagnosed with autism as related to family stress and well being. Schwichtenberg and Poehlmann found that parents whose child participated in home-based behavior analytic therapy reported elevated levels of depression and stress.

Given that behavior analysis is a commonly recommended treatment for children diagnosed with autism, it is important to understand how this therapy affects the family as a whole. According to the Lanterman Developmental Disabilities Services Act (Department of Developmental Services [DDS], 2011) in California, parents of a child

diagnosed with autism are required to complete group parent training in behavior analytic theory prior to their child receiving services funded by a Regional Center. Regional Centers are state funded agencies in California, which provide assessments, supports, and allocate services to individuals meeting certain criteria for developmental delays (DDS, 2011).

Acceptance and Commitment Therapy (ACT) is considered a cognitive-behavioral model of therapy, which focuses on teaching acceptance of one's thoughts, feelings, and emotions, along with being mindful of one's internal dialogue (Blackledge & Hayes, 2006). Blackledge and Hayes (2006) examined the effects of ACT on parents of children diagnosed with autism in regards to perceived levels of depression and distress. While the findings of this research provided promising support for ACT as an effective intervention for parents of children diagnosed with autism, the study had several limitations, including the lack of a control group other than those parents who did not receive services. In 2010, Keen, Couzens, Muspratt, and Rodgers implemented a parent-focused intervention, hypothesizing that parental levels of stress would decrease following increased parenting competence. While the findings of this study supported the hypothesis that parental stress decreased as parents became more confident with their parenting abilities, the focus of the study was on increasing the parent's ability to interact effectively with their child, not on identifying an effective intervention for parents to address their own symptoms of stress. To fill the research gap, this study seeks to compare levels of depression, stress, and quality of life of parents who receive different models of group parent training.

### **Purpose of the Study**

The purpose of this quantitative research study is to investigate the effects that ACT might have on parents of children diagnosed with autism compared to parents of children diagnosed with autism who participate in group behavioral intervention training, and parents of children diagnosed with autism who have not received behavioral intervention or ACT. In this quantitative study, all participants will complete pre and post measurements assessing perceived levels of stress, depression, and quality of life. A more detailed outline of the research methodologies will be presented in Chapter 3.

# **Nature of the Study**

In this study, I used a quantitative approach, in which data will be gathered in numerical form. A quantitative approach is appropriate when the research questions seek to gain information that can be realized through the use of a questionnaire or survey, when the results can be numerically coded, and when associations between variables is sought (Gelo, Braakmann, & Benetka, 2008). In this study, primary data were collected through a number of questionnaires and inventories including the Parenting Stress Index Short Form (Abidin, 1995) which purports to measure stress in the parent-child relationship, consists of 36 questions on a Likert-type scale ranging from 1 (*strongly agree*) to 5 (*strongly disagree*).

In addition, I used the Beck Depression Inventory-II (Beck, Steer, & Brown, 1996) which purports to measure the existence and severity of symptoms of depression using a Likert-type scale consisting of 21 questions and values ranging from 0 to 3. The Quality of Life Inventory (Frisch, 1994) was also used, which provided a brief overview of

quality of life across 16 domains, and consists of a 3-point Likert-type scale for importance, and 6-point Likert-type scale for satisfaction. Lastly, to measure internal process change, an ACT specific questionnaire, the Acceptance and Action Questionnaire-II (Bond et al., in press) was provided to participants which consisted of 9 questions on a Likert-type scale ranging from 1 (*never true*) to 7 (*always true*). The advantage of using a survey questionnaire is that information was gathered in a standardized way across participants reducing subjectivity and bias because the researcher's opinions will not influence the participants' answers (Edwards, 2010).

Individuals who have been enrolled to receive behavior analytic or ACT training were recruited to participate in this study. Participants in the treatment group received 15 hours of group parent training in ACT or 15 hours of group parent training in behavior analytic theory. Participants in the no treatment control group were parents who were not enrolled in and have not received either of the above treatments. ACT and behavior analytic theory have some commonalities as they both incorporate behavioral principles, with behavior analytic theory closely following principles of behavior analysis while ACT incorporates more of a cognitive behavioral treatment model. Thus, both treatments focus on identifying behavior and taking action to address that behavior.

All participants were parents of children diagnosed with autism, wherein the child was between the ages of 36 months through adulthood and their child carries a diagnosis of autism. Specifics on the study methodology are discussed further in Chapter 3.

# **Research Questions and Hypotheses**

In this quantitative study, the relationship between the dependent variables: stress, depression, and quality of life, and the independent variable: treatment, were examined. There were three treatment levels: ACT, behavior analytic training, and a no treatment control group. The participants in the ACT treatment group received 15 hours of group based ACT training. This training provided the participants with the ability to accept their thoughts, realize the relationship between thoughts and actions, and establish a value system for which the participant may begin to engage in behavior related to that value system. Participants in the behavior analytic group received 15 hours of group based treatment in behavior analytic principles for which the primary purpose was to increase parental ability to effectively interact with their child utilizing the principles taught during the group parent training. Lastly, the no treatment control group consisted of participants who have not received training in ACT or behavior analytic theory.

### **Research Question**

The research question for this study was: Are differences between ACT, behavior analytic treatment, and a no treatment control group in regards to stress, depression, and quality of life in parents of children diagnosed with autism?

# **Hypotheses**

 $H_01$ : There will be no difference between the overall/total post test score related to depression, as measured by the Beck Depression Inventory-II, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

H<sub>a</sub>1: There will be a difference between the overall/total post test score related to depression, as measured by the Beck Depression Inventory-II, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

H<sub>0</sub>2: There will be no difference between the overall/total post test score related to stress, as measured by the Parenting Stress Index-Short Form, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

H<sub>a</sub>2: There will be a difference between the overall/total post test score related to stress, as measured by the Parenting Stress Index-Short Form, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

H<sub>0</sub>3: There will be no difference between the overall/total post test score related to quality of life, as measured by the Quality of Life Inventory, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

H<sub>a</sub>3: There will be a difference between the overall/total post test score related to quality of life, as measured by the Quality of Life Inventory, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

#### **Theoretical Base**

The theoretical foundation of this research study was relational frame theory (RFT; Hayes, Barnes-Holmes, & Roche, 2001). RFT is a way to account for the development of human cognition and language (Hayes et al., 2001). RFT asserts, stated here in simplistic terms, that relationships result from prior learning and associations (Hayes et al., 2001). For example, if a child has learned that a round red fruit is called an apple, the child may then infer that an apple is a round, red fruit. In symbols, this inference is A = B, then B = A. These types of learned and inferred relationships can become very complex depending upon the number of variables involved. For example, if Jack (A) is older than Sherry (B) and Jack is younger than Hailey (C) one may infer that Sherry is younger than Hailey (B = C), that Hailey is older than Sherry (C = B), and that Sherry is younger than both Jack and Hailey (B = A + C).

This type of relational frame is not limited to early developmental leaning, but also to internal thoughts, feelings, emotions, and assumptions (Torneke, Luciano, & Salas, 2008). An example is an individual who is fearful of heights. In the situation where an individual is high off the ground, increased heart rate, rapid breathing, and increased sweat production may occur. In an attempt to distract one from thinking about being high off the ground, the individual may begin to think of an enjoyable activity such as lying on the sand by the ocean. However, when thinking of lying on the sand by the ocean, the fear reaction is still in place and the individual still realizes the situation of being high off the ground. Soon lying on the sand by the ocean may become associated with ones fear of heights, and therefore in the future, lying on the sand by the ocean may evoke a fear

reaction. In this way, RFT asserts that unlikely negative associations can be made even when the stimuli share no similarities (Torneke et al., 2008).

RFT informs ACT in that it provides a theoretical framework for the processes underlying changes in language and cognition. ACT, therefore, is a way of applying RTF in that ACT focuses on accepting ones thoughts, feelings, and private events, understanding how different stimuli may have come to be associated, providing avenues for disassociating those stimuli, setting goals, and then acting in ways which ultimately match those goals (Blackledge, Moran, & Ellis, 2009). While there have been multiple empirical studies on ACT, only one study has focused on parents of children diagnosed with autism. This research seeks further explored the effects of ACT on parents of children diagnosed with autism compared to those individuals who participate in other treatment modalities.

### **Definition of Terms**

Acceptance and commitment therapy – an intervention that incorporates acceptance and mindfulness strategies, value orientation, and behavior change, which ultimately increases psychological flexibility (Hayes, Luoma, Bond, Masuda, & Lillis, 2006).

Autism —a pervasive developmental disorder as defined in the DSM-IV or Diagnostic and Statistical Manual of Mental Disorders — Fourth Edition-TR (DSM-IV-TR: American Psychiatric Association, 2000), and includes impairment in social interaction, impairment in communication, and repetitive, stereotypic behaviors.

Daily living skills – self-care tasks such as bathing, toileting, and leisure skills, which allow an individual to be more independent within their daily environment (Jasmin et al, 2009).

*Depression* – the display or perception of increased sadness, fatigue, irritability, hopelessness, and fearfulness (Benson & Karlof, 2009).

Developmental delays – delay in two or more areas of development that are significantly below the expected mean (Tervo, R.C., 2010).

Externalizing behavior - behavior that is outwardly displayed, such as verbal and nonverbal refusal to comply with requests, tantrum behavior, and other outward expression of behavior, which typically draws negative attention in the public setting.

Pervasive developmental disorder – umbrella under which specific diagnoses, such as autism, pervasive developmental disorder-not otherwise specified, Aspergers disorder, Rett's syndrome, and childhood disintegrative disorder are listed (DSM-IV-TR, 2000).

*Private event* - internal thoughts, feelings, beliefs, rules, and conditional statements of an individual (Guadiano, 2010).

Psychological flexibility – ability to contact and remain in engaged with difficult situations or memories without attempting to change one's thoughts, feelings, or beliefs about it (Hayes et al., 2006).

Relational frame theory – an account of the development and structure of human language and cognition and the theoretical foundation for which ACT was formed (Hayes, 2008).

Sense of coherence - the ability to utilize available resources and effective coping strategies in order to cope with life stressors (Mak et al., 2007).

Typically developing – also referred to as neuro typical, typical developing individuals meet developmental milestones similar to same age peers in the absence of significant delays.

Quality of life - an individual interpretation of one's life in regards to coherence with their values, culture, family situations, spiritual values, economics, and general expectations (Lee et al., 2008).

### **Assumptions and Limitations of the Study**

# **Assumptions**

My first assumption in this study was that participants would answer the questionnaires truthfully. I also assumed that the questionnaires would be completed by the participants and not another individual, and that the participants in the treatment groups would attend to the information presented and would utilize the skills taught outside of treatment hours during the course of the intervention. Additionally, I assumed that the treatment provided to the participants will accurately reflect what has been proposed in this study regarding treatment model, hours, and identified timeline.

#### Limitations

One limitation of the study was that demographics were limited to families of children diagnosed with autism who lived in the greater Sacramento, CA area. Therefore, generalizability to families outside of that area may be limited. Participants were eligible for the study based on their child's reported diagnosis of autism; however, I did not

employ measures to confirm the diagnosis. Data collection was based on parent questionnaires that may or may not accurately reflect true levels of stress, depression, or quality of life. Lastly, I was unable to truly assess participants understanding of the information presented, which may or may not, have an effect on the posttest scores.

# Significance of the Study

The effects of parental depression, stress, and poor quality of life can be detrimental to the entire family. Cohen and Semple (2009), in their study of parents who reported symptoms of depression and those that did not report symptoms of depression, found that those who reported symptoms of depression displayed decreased parental sensitivity to their child, meaning they were less likely to notice and react to the subtle needs of their child. Decreased parenting sensitivity was associated with a lag in child school readiness skills, lag in expressive language abilities, and lag in understanding of receptive or spoken language (Cohen & Semple, 2009). Additionally, elevated behavioral difficulties and antisocial behavior were reported in school-age children whose mother reported symptoms of depression (Cohen & Semple, 2009).

Likewise, parents of a child with a disability who employ problem-focused coping strategies using cognitive and behavioral techniques reported higher levels of emotional well being and increased positive parent-child relations (Head & Abbeduto, 2007).

MacDonald and Hastings (2008) found that fathers who reported being more present in the moment and centered on their relationship with their child also reported more involvement in parenting roles, tasks, and child socialization. The establishment of a supportive, caring, and encouraging family environment can positively contribute to a

child's development and can lead to increased capability of the child and family in accepting and accessing required treatment (Head & Abbeduto, 2007).

In this study, I identified whether participation in ACT was likely to affect parental psychological wellness, specifically levels of stress, depression, and quality of life. This is significant because the research by Head and Abbeduto (2007), MacDonald and Hastings (2008) and Cohen and Semple (2009) found that not only does parental well being affect the parents of a child with a disability, but also can negatively impact the child, potentially decreasing the child's ability to develop school readiness skills including receptive and expressive language and can serve to promote antisocial behavior. In addition, parents who reported higher levels of stress and depression were less likely to realize and react to their child's needs (Cohen & Semple, 2009). This information is significant since the burden of caring for a child with a disability is different, and can be greater than, caring for a typically developing child.

While there is ample research on parents of children with various disabilities in regards to perceived levels of stress and depression, and the effects of these variables on both parents and their child, there is limited research specifically on parents of children diagnosed with autism. I addressed the gap in the literature in that it may identify an effective treatment for parents of children diagnosed with autism which could result in reduce parental levels of stress, perceived levels of depression, and increased overall quality of life. Furthermore, previous literature on ACT and parents of children with autism did not include a control group, which is addressed within the methodology section of this research.

The research findings have the potential to contribute to positive social change by identifying a treatment option, which can serve to reduce parental levels of stress and depression, while improving one's quality of life. The results of increased parental well being may also bring about a positive change in their child diagnosed with autism, which is a future area of study. Additionally, insight into effective treatment options for parents of children diagnosed with autism can further assist practitioners in making recommendations for parents once their child has received a diagnosis of autism. Thus far, there has been minimal research on effective treatments for parents of children diagnosed with autism. This study can supply information as to effective treatment options. The gap in the literature will be further explored in Chapter 2.

## Summary

While there are many resources and interventions designed to address difficulties that individuals diagnosed with autism experience, few researchers have focused on interventions for parents of children diagnosed with autism. Effective interventions for parents of children diagnosed with autism are essential, especially given that these parents are more likely to display greater amounts of stress and increased symptoms of depression than their counterparts with typically developing children (Blackledge & Hayes, 2006). The effects of high levels of stress have been reported to be negatively correlated with quality of life for parents of children with disabilities, which can produce barriers in the parent's ability to support their child in accessing needed services (Blackledge & Hayes, 2006). Therefore, the need for an effective intervention to address parental levels of stress, depression, and quality of life is crucial.

The following four chapters will include a more detailed discussion of this study, including Chapter 2 where I will summarize current literature in regards to stress, depression, and quality of life of parents of a child diagnosed with autism, ACT, and the underlying theory of ACT. Chapter 3 will include a discussion of the research design, participants, method, procedures, data collection, and treatment. In Chapter 4, I will present the analysis of the data, and in Chapter 5, a final discussion of the research findings, including limitations and future recommendations is discussed.

# Chapter 2: Literature Review

#### Introduction

The number of children diagnosed with autism is increasing. In 2006, the average number of children in the United States who received a diagnosis on the autism spectrum was estimated to be 1 in 110 (Rice, 2009). This number represented a 57% increase from the number of children diagnosed with autism in 2002 (Rice, 2009). Individuals with a diagnosis of autism are commonly described as displaying significant deficits in social, communication, and self-help skills as well as behavioral excesses, specifically that of repetitive-type behavior (Rice, 2009).

A diagnosis of child autism also has an effect on families, health care systems, and educational systems. Recent researchers have indicated that the lifelong economic cost for raising a child diagnosed with autism is 3.2 million dollars (Ganz, 2007). In addition to the financial effects on a family and society relative to raising a child diagnosed with autism are the emotional and physical effects.

Parents of children diagnosed with autism display greater amounts of stress and report increased symptoms of depression than their counterparts with typically developing children (Blackledge & Hayes, 2006). The effects of high levels of stress have been reported to be negatively correlated with quality of life for parents of children with disabilities, which can produce barriers in the parent's ability to support their child in accessing needed services (Blackledge & Hayes, 2006). The purpose of this study is to examine the relationship between three sets of parents of children diagnosed with autism:

(a) parents who receive ACT in regard to their perceived levels of stress, depression, and

quality of life; (b) parents who receive group parent training in basic behavior analytic principles designed to increase parental effectiveness and interactions with their child; and (c) parents who do not receive additional training. In Chapter 2, I will examine the current literature as related to parents of a child with autism and their perceived levels of stress, depression, and quality of life. This chapter will also include the literature regarding the effectiveness of ACT as a treatment modality and explore relational frame theory (RFT), on which ACT reasoning is based.

### **Compilation of Literature**

For this review, I located published articles using PsycINFO database, EBSCO, ProQuest, Academic Search Premier, Google Scholar, and the Contextual Psychology website. Primary off line sources for books were from my personal library and from the local library. Significant key words and concepts included *ACT*, *depression*, *stress*, *quality of life*, *parents*, *autism*, and *disability*. The terms *parents of children with disability* were also paired with these key terms. Sources from 2005 through 2011 were included in the review as were older sources if they were identified as essential to the study. Saturation of the literature was achieved by references within significant articles being reviewed and searched until the same articles and authors were appearing within various literature searches.

# **Depression, Stress, and Quality of Life**

# **Depression**

Having a child diagnosed with autism brings unexpected changes and complexities to a family's life. While some families may adapt to the changes and complexities with

sensitivity and understanding, others may grieve the loss of the child they were expecting to raise. The disconnect between expectations versus reality can lead parents to express feelings of shock, sorrow, resentment, and guilt (Bumin, Gunal, & Tukel, 2008). Having a child with a disability also commonly leads to changes within the family structure and roles, which can lead to increased parental stress and anxiety (Bumin et al., 2008). For example, many parents of a child diagnosed with autism must choose between working or giving up their employment to stay home in order for services to be delivered to their child (Lee et al., 2008). Changes to the family roles and expectations can further elevate parental stress and anxiety, which according to Lee et al., have been related to one's perceived quality of life.

Individuals experiencing symptoms of depression report increased sadness, fatigue, irritability, hopelesness, and fearfulness (Benson & Karlof, 2009). Parents who experience symptoms of depression have less positive parent-child relationships and interactions, which can eventually lead to increased disengagement between the parent and child (Cohen & Semple, 2009). In addition, the literature has demonstrated a negative correlation between the perceived amount of stress a parent experiences and perceived symptoms of depression (Davis & Carter, 2008). Davis and Carter found that 39% of mothers of a child who carry a diagnosis of autism report clinically significant levels of depression.

In addition, both mothers and fathers of a child diagnosed with autism experience elevated levels of stress, however, the level of stress reported by mothers were slightly, but not significantly, higher than those reported by fathers (Davis & Carter, 2008).

Benson and Karlof reported similar results, finding no significant difference between mothers and fathers of a child diagnosed with autism in regard to the amount of perceived psychological distress and symptoms of depression experienced. The research by Davis and Carter (2008) and Benson and Karlof (2009) provide information that there is a relationship between having a child diagnosed with autism and an increase in parental stress levels and depression which both mothers and fathers uniformly experience.

The findings of the study by Benson and Karlof (2009) regarding the percentage of mothers of a child diagnosed with autism who report clinically significant levels of depression are significant because they allude to the fact that parents of children diagnosed with autism experience higher levels of depression than parents of typically developing children. Given the prevalence of 1:110 children diagnosed with autism in the United States in 2006 (Rice, 2009), it is imperative that parents of children diagnosed with autism have the ability to effectively raise their child, have the mental ability to develop a positive relationship with their child, and display positive beliefs about the future (Mak, Ho, & Law, 2007). The extent to which the parent's mental well being is intact could ultimately affect the child's ability to access needed services, thus improving the child's development (Head & Abbeduto, 2007).

#### **Stress**

Compared with parents of typically developing children and with parents of children with mental retardation, parents of children diagnosed with autism display elevated levels of parenting stress (Baker-Ericzen, Brookman-Frazze, & Stahmer, 2005; Benson & Karlof, 2009; Weiss, 2002). While symptoms of depression are more prevalent in

mothers of children diagnosed with autism than fathers, both mothers and fathers report elevated levels of stress (Davis & Carter, 2008). Deficits and delays in a child's social abilities and parental perception of their closeness to, and ability to understand their child, have been associated with maternal and paternal stress, while a child's self-regulatory difficulties including eating, sleeping, and emotional regulation problems were associated with maternal stress (Davis & Carter, 2008). However, the preeminent predictor of parental stress was shown to be the child's social abilities, with decreased social ability correlated with increased parental levels of stress (Davis & Carter, 2008).

Likewise, the child's externalizing problematic behavior was also associated with increased parental stress (Davis & Carter, 2008). Externalizing problematic behavior is defined as behavior that is outwardly displayed by the child, such as verbal and nonverbal refusal to comply with requests, tantrum behavior, aggression, and other outward displays of expression that typically draw negative attention in the public setting, are difficult to manage, and are typically correlated with impaired academic and social development (Baker, Grant, & Morlock, 2008). Benson and Karlof (2009) also found that high levels of parental stress were associated with a child's dependency upon their parents, portraying a correlation between decreased ability of the child to independently complete daily living skills and increase in parental stress. Further, Davis and Carter (2008) found that a child's cognitive functioning and communication difficulties were not necessarily sole predictors of increased parental stress.

Overall, many predictors of parental stress related to a child diagnosed with autism have been shown to affect both the mother and father equally. While Davis and Carter

(2008) found that the best predictor of parental stress is the extent to which the child is unable to socialize with others, the authors did not specifically define socializing behavior. It would be reasonable to infer that socialization includes the ability to effectively communicate with others; however, this hypothesis may not be valid since child communication abilities were not found to be a salient predictor of parental stress according to Davis and Carter. Additional research in this area could focus on conducting a factor analysis to identify specifically which child characteristics are decidedly correlated with parental stress and which combinations of characteristics lead to systematic changes in parental levels of stress. Defining the terminology used within the method section of the literature will be beneficial to ensure that researchers are comparing and analyzing variables in a consistent manner across future studies.

While the literature has demonstrated that parental stress is positively correlated with the level of severity of their child's social ability, self-regulation ability, and the display of externalizing behavior problems, there is a lack of information regarding the specific child characteristics which cause the most stress for parents of a child diagnosed with autism. Hastings et al. (2005), suggested using the Autism Behavior Checklist as a measurement tool to identify autism symptomology, and proposed that it is the degree of autism symptomology which is correlated with parental stress, not necessarily child specific individual characteristics. The Autism Behavior Checklist asks 57 questions, which are divided into 5 categories of symptomology, including sensory, relating, body and object use, language, and social/self-help (Krug, Arik, & Almond, 1980). This

information is important because it provides an avenue for future research to further address the factors associated in parental stress and raising a child diagnosed with autism.

The Aggravation in Parenting Scale has been used to assess parental stress. This scale is reported to measure parental feelings about life sacrifices, difficulties, frustration, and anger associated with caring for their child (Schieve, Blumberg, Rice, Visse, & Boyle, 2007). These parental feelings of stress may be exaggerated based upon their child's display of externalizing problematic behavior, challenges in communication, difficulties in self-care, and challenges related to social skills (Schieve et al., 2007). Compared with parents of typically developing children and children with developmental disabilities other than autism, parents of children diagnosed with autism were more likely to report that their child was harder to care for than other children; they were bothered by the behaviors their child exhibited; and felt they gave up more of their life for their child than expected (Schieve et al., 2007). Elevation in these areas led to overall exaggerated scores on the Aggrevation and Parenting Scale (Schieve et al., 2007). While the Aggrevation in Parenting Scale does not include the word "stress" in the title, it does report on variables which could correlate with parental stress levels.

Given the increased levels of stress families of a child diagnosed with autism report, it is important to identify strategies to effectively reduce stress levels. Mak, Ho, and Law (2007) found that, specifically for parents of a child with a disability, the adoption of an optimistic outlook was instrumental in the ability to effectively cope with stress. Mak et al. (2007) looked at the sense of coherence and level of stress in mothers of a child diagnosed with autism. Sense of coherence was defined as the ability to utilize available

resources and effective coping strategies in order to cope with life stressors (Mak et al., 2007). Participants included 150 mothers who had at least one child diagnosed with autism and who were recruited from parent associations in Hong Kong (Mak et al., 2007). Participants completed several questionnaires including the Childhood Autism Rating Scale, Sense of Coherence Scale, Parent-Attitude Survey Scales, and Parenting Distress subscale of the Parenting Stress Index Short Form (Mak et al., 2007). Results of the analysis of data indicated that mothers with high levels of sense of coherence reported lower levels of stress, regardless of the severity of their child's disability, utilized available resources, developed effective coping strategies, and held a positive attitude about life (Mak et al., 2007). Overall these findings indicated that a mothers' ability to seek out and utilize available resources and develop effective coping strategies to deal with stress ultimately allow a parent to establish a positive belief about their child and life circumstances.

Paczkowski and Baker (2008) looked at mother's love and acceptance for their child with a disability and positive belief in their child's future influenced their relationship with their child, as well as how these positive beliefs affected their child's behaviors. The researchers hypothesized that (a) higher levels of stress would be positively correlated with higher levels of problematic behaviors, (b) positive beliefs would be a mediating factor in child problematic behaviors, and (c) higher levels of positive belief would be negatively coorelated with lower levels of stress (Paczkowski & Baker, 2008). One-hundred and sixty-seven parent participants from Pennsylvania and California with at least one child between ages 30 to 39 months, who was diagnosed with developmental

delays, excluding autism, and were ambulatory, were included in the study (Paczkowski & Baker, 2008). This research was a longitudinal study in which measures of self-mastery, life orientation, family impact, and child behavior were completed for the child at ages 3, 5, and 7 years (Paczkowski & Baker, 2008). The findings of the study indicated that higher levels of positive belief were associated with lower levels of parental stress (Paczkowiski & Baker, 2008). Additionally, mothers who reported higher levels of positive belief frequently had children who displayed fewer problematic behaviors (Paczkowiski & Baker, 2008). One limitation to this research was that the positive belief variable was viewed by the researchers to be a static trait and, therefore, only assessed when the child was age 3 years (Paczkowski & Baker, 2008). Because this variable was only assessed once during the longitudinal study, the researchers noted that correlations should be interpreted with caution, as it is unknown whether this variable changed over time, thus having an effect on the levels of parental stress and child problematic behavior upon follow up (Paczkowski & Baker, 2008).

To further the research on the relationship between stress and parental well-being,

Pottie and Ingram (2008) conducted a longitudinal study in which they hypothesized that

parents who reported higher levels of stress were more likely to utilize strategies

including withdrawal, helplessness, escape, worrying, and blaming on a daily basis while
those who reported lower levels of stress were able to effectively manage stress through

utilizing strategies including being problem focused, seeking support from others,
regulating one's emotions, compromising with others, and utilizing positive reframing
techniques. The findings confirmed the original hypothesis that coping responses

correlated with daily mood and levels of stress in that coping strategies including positive focus, social support, positive reframing, emotional regulation, and compromise were correlated with a more positive daily mood, while coping strategies which consisted of escape, blaming, withdrawal, and helplessness were correlated with primarily negative daily mood (Pottie & Ingram, 2008). To further expand upon these findings, Pottie, Cohen, and Ingram (2008) analyzed the data gathered by Pottie and Ingram (2008) in a different manner and found that additional predictors of daily mood did not include other environmental effects, such as the level of social support parents received, interactions with others who are unsupportive, and the display of child externalizing problematic behaviors.

Parents play a significant role in providing care, overseeing services, and supporting the development of their child (Mak et al., 2007). Uniformly, mothers of a child diagnosed with autism report slightly greater perceived levels of stress and depression compared to fathers (Davis & Carter, 2008). However, levels of stress and depression in both mother and father are elevated compared to those parents without children with a disabilty (Davis & Carter, 2008).

While some origins of stress are related to environment, living conditions, employment, and socioeconomic status, elevated stress levels also result from the problematic behavior and difficulties associated with having a child with a disability (Davis & Carter, 2008). Specifically, parents of children diagnosed with autism reported increased levels of stress resulting from their child's dependence on their parents, their child's deficits in social abilities, self regulation difficulties, and displays of externalizing

problematic behaviors (Benson & Karlof, 2009). Based on parents' pivotal role in their child's development and because of the higher perceived levels of depression and stress identified in parents of children diagnosed with autism (Davis & Carter, 2008), it is essential that parents are able to manage their own levels of stress and psychological well being. Additionally, perceived levels of depression and stress can play a role in affecting an individual's quality of life. Quality of life is important to study as it is an individual interpretation of one's life in regards to their environment (Lee et al., 2008).

### **Quality of Life**

Quality of life has been defined through the literature as how closely an individual's behavior and response to situations are in alignment with their values, culture, family situations, spiritual values, economics, and general expectations (Lee et al., 2008). This is a multidimensional concept incorporating physical and mental health, social relationships, level of independence, personal beliefs, cohesiveness with their environment, and a sense of belonging (Lee et al., 2008). Quality of life, therefore, is an individual perception of one's life compared to their interactions with the environment. While perceived levels of stress and depression can contribute to perception of quality of life and bonding and interactions with their child with developmental disabilities, little research has been conducted on the quality of life of parents of a child diagnosed with autism. Overall, quality of life studies have attempted to define how an individual's perception of life may change when they have a child with a disability, such as down syndrome, attention deficit hyperactivity disorder, and other disabilities, and how those

perceptions can impact various life domains (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006).

Based on the literature demonstrating that child problematic behaviors can contribute to parents perceived level of stress and symptoms of depression, one may infer that parents of children diagnosed with autism experience decreased quality of life compared to families without a child with a disability because of the inherent characteristics of the diagnosis and associated problematic behavior. Mungo, Ruta, D'Arrigo, and Mazzone (2007) looked at the quality of life of mothers and fathers of children with various disabilities, including pervasive developmental disorder-not otherwise specified, under which is autism is classified, mental retardation, cerebral palsy, and typically developing children. The findings indicated that fathers of children with pervasive developmental disorder-not otherwise specified reported decreased quality of life in the social relationship and psychological well being domains compared to parents of children diagnosed with mental retardation, cerebral palsy, and those without a disability (Mungo et al., 2007). Mothers of a child diagnosed with pervasive developmental disorder-not otherwise specified reported decreased quality of life in the areas of social relationships, physical well being, mental health, and overall quality of life compared to all other groups (Mungo et al., 2007). Mungo et al. hypothesized that the report of lower quality of life in parents of a child diagnosed with pervasive developmental disorder-not otherwise specified compared to other groups could partly be explained based upon the higher rate of stress those parents experienced compared to others, and the severe developmental disorder and behavioral difficulties their child may exhibit.

Thus far information has been presented in regards to the psychological well being of parents of children with various disabilities. Allik, Larsson, and Smedje (2006) looked at perceived quality of life of parents of children diagnosed with Aspergers syndrome and high functioning autism compared to those of typically developing children. Aspergers syndrome and high functioning autism are terms which are sometimes used interchangeably with Aspergers syndrome included as a pervasive developmental disorder in the Diagnostic and Statistical Manual-IV-TM (American Psychiatric Association [DSM-IV-TR],2000). Allik et al. (2006) found that parents of children diagnosed with Aspergers syndrome and high functioning autism reported decreased quality of life, which was negatively correlated with child symptoms of hyperactivity and externalizing behavior problems (Allik et al., 2006). Compared with parents of children diagnosed with down syndrome, parents of children diagnosed with Aspergers syndrome and high functioning autism were significantly more likely to isolate themselves, reported less free time, reported lower level of leisure and enjoyment of life, and reported lower financial earnings (Brown et al., 2006). Compilation of this research provides information that parents of children with a disability within the classification of pervasive developmental disorder, including children diagnosed with pervasive developmental disorder-not otherwise specified, Aspergers syndrome or high functioning autism, and autism, report decreased quality of life compared with both parents of typically developing children and parents of children with other disabilities including down syndrome, mental retardation, and cerebral palsy.

While much of the research has addressed children with disabilities and parental quality of life, little research has been conducted specifically on families of children diagnosed with autism in regards to parental quality of life. The single research conducted within this area was by Lee et al. (2008). The researchers analyzed crosssectional parental-report data from the National Survey of Children's Health, which asked questions regarding quality of life in parents of children age 3 through 17 years who were reported to carry a diagnosis of either autism, attention deficit hyperactivity disorder, or were typically developing (Lee et al., 2008). One limitation in this study was the questions asked were not in line with the definition of quality of life as provided by previous researchers, nor were standardized questionnaires used (Lee et al., 2008). Instead, questions related to the burden of caring for their child, family outings, family meals, religious services, employment, days of missed school, social activity, repeating a grade, independence, and community service were asked (Lee et al., 2008). The findings from this study indicated that the behavior of parents of a child diagnosed with autism were different from those of the comparison groups in that parents of a child diagnosed with autism were significantly less likely to attend religious services, were significantly less likely to participate in social outings, and were significantly more likely to quit their job in order to care for their child (Lee et al., 2008). Additionally, children diagnosed with autism were more likely to be absent from school and were more likely to repeat a grade (Lee et al., 2008). The association between parental and child behaviors was correlated with a significant increase in the burden of caring for a child with autism

compared to the comparison groups, and all above stated variables contributed to overall lower levels of quality of life for these parents (Lee et al., 2008).

Overal, research findings demonstrated increased levels of stress, increased perceived levels of depression, and reduced quality of life in parents of children diagnosed with autism than those of typically developing children or children with other varying diagnoses. Specifically, Bumin et al. (2008) found that, in mothers of children with a disability, anxiety and depression were variables which negatively affected one's quality of life. Lee et al. (2008) found that the overall burden of caring for a child diagnosed with autism can negatively contribute to one's perceived quality of life. These findings are significant compared to families of children with other disabilities such as down syndrome, mental retardation, cerebral palsy, and attention deficit hyperactivity disorder (Lee et al., 2008). Furthermore, these findings have been found to be correlated with the child's externalizing behavior problems and lack of pro social behavior, not necessarily severity or degree of child autistic characteristics (Davis & Carter, 2008). Based upon this information, it may be beneficial for parents to learn to engage in mindful and accepting parent-child interactions in order to further accept their child and develop an outlook more in line with their values, ultimately reducing their own levels of stress, symptoms of depression, and increasing their overall quality of life.

# **Relational Frame Theory**

Relational Frame Theory (RFT) is the theoretical foundation on which ACT was formed. ACT is a mindfulness-based psychological intervention rooted in RFT, considered by its founder to be a"third wave" behavioral approach incorporating

equivalence training, rule following, and internal dialogue (Hayes et al., 2001). RFT asserts that during early language development, children begin to arbitrarily associate stimuli and through multiple exemplar training wherein the cues for associations are blurred and generalized to unrelated stimuli (Torneke et al., 2008). The result is that individuals relate stimuli to associations which were previously unlearned and share no formal properties (Torneke et al., 2008). For example, a young girl lives with her mother, who has said that the girl's father is a bad person. The child may then arbitrarily associate all men with being "bad people"; therefore, if a friend of the child lives with the friend's father, her friend's father is also a "bad person." From there, other unlearned associations, and ultimately personal rules, are likely to be made such as "all fathers are bad and should go to jail" or "kids shouldn't live with their fathers because they are bad." To further understand RFT, one must understand that RFT is based on the assumption that individuals learn to relate stimuli that do not share the same properties, thus forming arbitrary stimuli relations (A=B and B=C, then A=C), and these stimuli relations can be generalized to new stimuli without training (A=D) (Ruiz, 2010). These unrelated rules and relationships can be directly related to one's internal dialogue including passing thoughts, feelings, and emotions (Ruiz, 2010). For example, while at work an individual received depressing life changing news. The work area (A) becomes associated with depression (B), and the thought "I am depressed" (B) comes associated with the literal thinking of "I = depression" (C). This thinking ultimately is associated with "As long as I work, I will always be depressed" (A=C). These relationships may involve negative

thoughts and feelings, which cannot be prevented; however, one's internal dialogue can steer the direction of one's behavior and the generalization of that behavior (Ruiz, 2010).

Experimental avoidance is a byproduct of RFT, which predicts that when an individual is experiencing some type of discomfort, the individual may attempt to escape aversive private events, thoughts, feelings, and behaviors (Boulanger, Hayes, & Pistorello, 2010). Experimental avoidance occurs when one purposefully attempts to change their negative private events associated with various environmental contingencies (Vilardaga, Hayes, & Schelin, 2007). A private event is defined as a person's internal thoughts, feelings, beliefs, rules, and conditional statements (Guadiano, 2010). Experimental avoidance implies that thoughts, feelings, or memories can be negatively associated with various events; therefore, pain is not avoidable just by removing oneself from the situation (Vilardaga et al., 2007). As an individual attempts to control or eliminate pain by thinking about it, one's own verbal processes become negatively associated with the painful memory; thus the individual is unable to escape the pain as it is no longer the environment that elicits the memories, but instead one's own thought process (Vilardaga et al., 2007). In this role, experimental avoidance is a pain-building process rather than a pain-reducing process (Vilardaga et al., 2007).

In the previous example, the individual would hypothetically avoid going into work, thus worsening the depression and further ingraining the negative self-belief of "I = work = depression." This behavior of experimental avoidance is negatively reinforced as it causes a decrease in the aversive event and maintains the irrational thinking.

Experimental avoidance or attempting to escape negative thoughts and feelings is

reinforced by the behavior an individual displays, such as the refusal to go to work allows an individual to escape the negative thoughts and feelings that have become associated with going to work. Because the associations an individual makes eventually develop into personal "rules" (i.e., As long as I go to work, I will be depressed"), experimental avoidance can cause difficulty when an individual's thinking becomes inflexible, avoiding the feared private event and not allowing oneself to come in contact with the aversive thoughts and feelings (Ruiz, 2010). While the development of personal rules allows an individual to organize behavior, it can also serve to inhibit the individual from accepting and being present in the moment, instead becoming trapped in overly rigid verbal rules and subsequent behavior (Blackledge, 2007).

ACT aims to allow the individual a venue to fully come in contact with the feared aversive private events and to allow the memory of those events to remain in ones consciousness (Ruiz, 2010). Instead of attempting to control and change the private event, ACT utilizes strategies, which allow the individual to experience the feared event, identify their role in the event, and how their private thoughts are connected with the event, define and clarify their values, and begin to act in ways which are in line with those identified values (Ruiz, 2010). This process is said to decrease experimental avoidance.

### **Acceptance and Commitment Therapy**

The effect of parental depression, stress, and decreased perception of quality of life has the potential to be detrimental to the entire family. A study of parents who reported symptoms of depression and those who did not report symptoms of depression found that

those who reported symptoms of depression displayed decreased sensitivity to their child, meaning they were less likely to notice and react to the subtle needs of their child (Cohen & Semple, 2009). Decreased parenting sensitivity was associated with a decrease in the child's school readiness skills, decrease in child's expressive language abilities, and decrease in understanding of receptive language (Cohen & Semple, 2009). Additionally, school-age children with a mother who reported symptoms of depression displayed elevated behavioral difficulties and antisocial behavior (Cohen & Semple, 2009). While most of the research on mindfulness and disabilities has focused on either mothers or both parents collectively, mindful parenting is also relevant for fathers of children with a disability. Parents of a child with a disability who employ problem focused coping strategies using cognitive and behavioral techniques report higher levels of emotional well being and increased positive parent child relations (Head & Abbeduto, 2007). MacDonald and Hastings (2008) found that fathers who reported being more present in the moment and centered on their relationship with their child also reported more involvement in parenting roles, tasks, and child socialization. The establishment of a supportive, caring, and positive family environment can positively contribute to a child's development and ability for both the child and family to more easily access needed treatment (Head & Abbeduto, 2007).

Mindfulness based strategies have been established as an effective intervention to reduce symptoms of depression in adults, reduce parental stress, and enhance parental perception of quality of life (Cohen & Semple, 2009). Mindfulness interventions focus on conscious awareness of the present moment while demonstrating a nonjudgmental

attitude towards the experience (Cohen & Semple, 2009). Baer (2003) conducted a metaanalylsis to evaluate the effectiveness of mindfulness based therapies on depression and found that 74% of those individuals who received mindfulness training reported better outcomes with regards to level of perceived depression than those in control groups.

ACT is based on the foundation of RFT discussed previously, and incorporates mindfulness and acceptance, along with cognitive behavioral processes to promote psychological flexibility (Hayes, 2008). Unlike traditional cognitive-behavioral therapy, ACT does not attempt to control thoughts and feelings or explain underlying reason for them (Cullen 2008). Instead, ACT aims to increase psychological flexibility by encouraging the individual to be present in the moment, come in contact with, and embrace difficult internal states and feelings (Cullen, 2008). Thus, ACT was constructed as a way of focusing on one's private events which have become negatively associated with environmental contingencies and overt behaviors (Hayes, 2008). The processes behind ACT includes experimental avoidance, cognitive defusion, contact with the present moment, values, and commitment (Hayes, 2008).

Cognitive fusion refers to the domination of one's own internal thoughts and feelings over their behavior in the absence of self-monitoring and regulation (Bond et al., 2006). The inverse of cognitive fusion is cognitive defusion, which is the process of becoming aware of difficult feelings, allowing those feelings to be present, and eventually embracing and accepting them; thus reducing experimental avoidance (Cullen, 2008). Cognitive defusion is a technique involving the practicing of, and experiencing of, one's events, memories, thoughts, and feelings and allowing those cognitive processes to be

viewed as a perspective rather than a fact (Ruiz, 2010). Within ACT, cognitive defusion includes exposing thoughts as just thoughts, not rules to follow (Blackledge, 2007). Cognitive defusion disrupts the chain of negative, rule based behavior, allowing an individual to be aware of the internal events, thoughts, or feelings, identify them as positive or negative, and proceed to make value based decisions (Bond et al., 2006). Cognitive defusion thus promotes greater perspective taking and understanding of one's thoughts. Psychological flexibility is the ability to allow oneself to feel, remember, and discuss difficult events without defensiveness and the cognitive flexibility to adapt to changes (Gaudiano, 2010). There are many strategies to assist this process such as utilizing relaxation techniques, saying a difficult word or thought quickly, and talking about it aloud (Cullen, 2008). The more that a feeling or thought becomes accepted, the more likely that the suffering associated with the feeling or thought will diminish (Cullen, 2008).

As referenced above, acceptance of the negative thoughts and emotions and commitment to working toward aligning ones thoughts and behaviors, is a key component in ACT (Hayes et al., 2006). Acceptance does not mean the individual accepts their internal thoughts and feelings as presented and acts upon those internal stimuli; instead, acceptance refers to the ability to remain in contact with ones negative thoughts and feelings, accepting those thoughts as relevant, but not tied to the way one must then behave (Bond et al., 2006). In this way, the individual allows oneself to engage with the painful thoughts and feelings without suppressing, avoiding, or escaping it (Bond et al., 2006).

Clarifying and understanding one's own values, and committing to an action, is part of the final ACT process (Cullen, 2008). In this sense, one's self-chosen values are defined and acknowledged as goals to work towards. Through the process of cognitive defusion and acceptance, one learns to evaluate their internal thoughts and feelings, eventually allowing one to analyze whether their thoughts and feelings are in line with their values, and mindfully attending to the behavior one chooses to then display (Bond et al., 2006). One of the outcomes measured by ACT is if the individual is acting in accordance to their identified values (Cullen, 2008).

### **Literature on Acceptance and Commitment Therapy**

Since its inception, the effectiveness of ACT in addressing varying diagnoses and conditions has been studied. Additional empirical research has been conducted on the underlying theory of ACT to ensure that the process change procedures occurring within ACT therapy are in accordance with RFT. The findings in the literature have verified ACT to be an effective technique when addressing a number of conditions in adults, including conditions stemming from the work environment, marital discord, and varying forms of psychopathology (Murrell & Scherarth, 2006). A meta-analysis of 18 studies was reviewed wherein the inclusion selection required ACT as the treatment, randomly or consecutively assigned groups, and a control group (Powers, Zum Vorde Sive Vording, & Emmelkamp, 2009). Results of the meta-analysis demonstrated that greater benefits were demonstrated through ACT than all control conditions, waiting lists, and psychological placebos across all targeted disorders except for the treatment of individuals diagnosed with both anxiety and depression (Powers et al., 2009). In the

literature, effect sizes were not observed to differ significantly based upon time, meaning that effect sizes were similar for a one day ACT workshop as a 12-week ACT workshop (Powers et al., 2009). Based upon the overall effect sizes identified in the meta analysis, which ranged from medium to large treatment effects, ACT has been recognized by Division 12 of the American Psychological Association as an empirically validated treatment for depression in adults (Powers et al., 2009). The question regarding the effectiveness of ACT over other established treatments such as cognitive therapy and cognitive behavioral therapy are still unanswered and additional research is needed in this area.

While multiple studies have been conducted on the use of ACT with adults, there have been very few studies which focus on children and parents with only one study analyzing the effectiveness of ACT on parents of children diagnosed with autism.

Blackledge and Hayes (2006) looked at the effectiveness of a 2-day, 14-hour, group ACT training on parents of children diagnosed with autism in regards to the parent's perceived level of depression and distress before and after the ACT training. In this research, 20 participants were recruited within California and completed pre and post measures, including the Global Severity Index from the Brief Symptom Inventory, the Beck Depression Inventory, the General Health Questionnaire, the Parental Locus of Control Scale, and the Acceptance and Action Questionnaire—9-item version (Blackledge & Hayes, 2006). A within subjects, repeated measures design, was used where data was collected on the specified variables twice prior to the intervention and twice subsequent to the intervention (Blackledge & Hayes, 2006). Data analysis revealed improvement in

perceived levels of depression and distress in the participants between the pre and post tests with greater improvement in those individuals who were at or slightly above the depression cutoff than those that reported more extensive levels of depression and distress; however, the overall improvement was not clinically significant (Blackledge & Hayes, 2006). This study was the first to assess and identify the use of ACT as a potentially effective training for parents of children with autism which resulted in decreased percieved levels of depression and distress, with outcomes being maintained over a three month period.

Key limitations included the lack of control group, limited sample size, and the utilization of ACT strategies that were not specific to the parent-child relationship (Blackledge & Hayes, 2006). The lack of a control group elicits question of whether the treatment had an actual effect because no other group was used for comparison. The research by Blackledge and Hayes (2006) could have been strengthened by the inclusion of a control group and using a quasi-experimental design, which could have included a treatment group and a control group in which participants received a different treatment modality. The research by Blackledge and Hayes also had a limited sample size, which is a limitation because the sample of participants may not be representative of the population as a whole and the margin of error is larger resulting in decreased confidence in the findings. Lastly, the ACT strategies used were not specific to the parent-child relationship (Blackledge & Hayes, 2006). ACT provides a number of different strategies and variations of strategies one can use during treatment. These strategies are to be chosen based on the core process targeted, such as cognitive defusion, acceptance,

defining values, and commitment (Blackledge & Hayes, 2006). While the researchers chose strategies based upon targeted core processes, time, and ease of administration, specific strategies chosen with the purpose of enhancing the parent-child relationship may have been beneficial and could then be replicated in future studies.

Singh, Lancioni, Winston, Singh, Curtis, and Wahler, (2007) conducted a study with mothers of children diagnosed with autism in which the mothers were taught specific mindfulness strategies aimed at increasing the parent-child relationship. This study took place over 12 weeks, but unlike the findings in the study by Blackledge and Hayes (2006), was conducted in individual sessions (Singh et al., 2007). At the end of the study, the mothers reported increased satisfaction with their parenting abilities and increased satisfaction with their relationships with their child (Singh et al., 2007). Singh et al. (2007) reported a negative correlation between parental outcomes and child behavior, finding that after the 12 week parental intervention, parents reported that their child displaying decreased levels of aggression, non-compliance, and self-injury. While this study was based upon mindfulness training and not specifically all the components of ACT, the findings are relevant based upon the fact that ACT incorporated mindfulness and acceptance as founding principles of therapy.

# **Summary**

The family's response to their child receiving a diagnosis of autism can play an important role in their ability to implement recommended treatment plans and allow their child access to beneficial resources that could assist in supporting future development.

The family's response is especially important given the elevated rate at which children

are diagnosed with autism and the subsequent financial impact on the community (Rice, 2009). The development of a mindful and positive parent-child relationship, where the parents of a child diagnosed with autism gain the ability to utilize available resources and develop effective coping strategies in order to cope with life stressors (Mak et al., 2007) appear to be important to meet this end objective. Having a child diagnosed with autism brings unexpected changes and complexities to a family's life. While some families may adapt with sensitivity and understanding, others may grieve the loss of the child they were expecting to raise. The inability to display hope regarding their child and future and the lack of ability to effectively utilize available resources may lead a parent to experience higher levels of stress and perceived levels of depression, which could ultimately lead to reduced quality of life compared with those parents without a child with a disability (Blackledge & Hayes, 2006; Bumin et al., 2008; Davis & Carter, 2008).

ACT may be a way to counteract parental feelings of stress, depression, and decreased quality of life. While ACT has been utilized for more than 20 years, just recently a number of strong methodological randomized control studies have been conducted (Cullen, 2008). The results of these studies have demonstrated positive outcomes in addressing a number of conditions in adults, including conditions stemming from the work environment, marital discord, and varying forms of psychopathology (Murrell & Scherarth, 2006). Additionally, Blackledge and Hayes (2006) found that ACT was relatively successful for parents of children diagnosed with autism in reducing perceived levels of stress and depression.

While ACT has primarily resulted in benefits for those participating in the training more so than participants in control conditions, psychological placebos, and on waiting lists, and has been recognized by the Division 12 of the American Psychological Association as an empirically validated treatment for depression (Powers et al., 2009), these studies have been relatively limited in scope, duration, and sample size (Cullen, 2008). In 2006, Blackledge and Hayes found that parents of a child diagnosed with autism reported elevated levels of stress and depression. In this study, I expanded upon the findings of Blackledge and Hayes and the area of ACT by addressing the additional variable of quality of life. I also incorporated an additional treatment group consisting of parents who participate in group behavior analytic training, as well as a non-treatment control group consisting of parents who are not receiving additional supports, so that the effectiveness across treatment groups could be analyzed.

### Chapter 3: Research Method

#### Introduction

As of 2015, only one researcher has looked at the effects of Acceptance and Commitment Therapy (ACT) as a viable option to address perceived symptoms of depression and stress in parents of children diagnosed with autism (Blackledge & Hayes, 2006). This quantitative study expanded on those findings by addressing the variable quality of life and comparing outcomes for participants from different treatment groups. Contained in this chapter is a detailed outline of the research design approach, including the settings in which the treatment occurred, the population from which the sample was drawn, the instruments used to assess changes in the dependent variables, how the data was collected, and the statistical procedures used to analyze the data.

### **Research Design and Approach**

In this study, I used a quasi-experimental, nonequivalent, pretest-posttest design to examine these variables. The dependent variables were stress, depression, and quality of life. The independent variable was treatment, with three intervention levels: ACT, behavior analytic training, and a no treatment control group. If the groups were identified as being similar based upon the pretest scores, the pretest score was the covariate, eliminating "time" from consideration. If this was the case, a one-factor ANCOVA would be the statistical procedure utilized. However, if the groups were not similar based upon the pre-test scores, time was considered an independent variable and a two-factor ANOVA would be used.

In a quasi-experimental design, assignment to treatment groups is not random, nor can the groups be completely controlled for intervening variables, thus classifying this type of design as a nonequivalent group design (Jensen, Fast, Taylor, & Maier, 2008). In this type of design, which is commonly used in the educational setting, a control group is compared with an unrelated treatment group for which different individuals teach the group interventions (Randler & Bogner, 2008). Consistent with a nonequivalent group design, in this study I utilized intact groups, which included those individuals who were already enrolled to participate in ACT treatment through a community agency or were enrolled with a community agency to receive group parent training in behavior analytic treatment. I also recruited participants for the treatment control group. All participants, regardless of which group they were in, completed a set of questionnaires at two different times during the course of this study.

### **Setting and Sample**

### **Population**

The participants in this study were parents of a child no younger than 36 months and carry a diagnosis of autism. Participants resided in Northern and Central California, specifically Sacramento and surrounding cities, San Joaquin Valley, Yuba, and Sutter regions. Participants for the 15-hour ACT and behavior analytic treatment were recruited from agencies which provided this type of treatment and for which these parents had already sought out services. Participants for the no-treatment control group were recruited through fliers posted in the following locations: San Juan Unified School District, and parent groups such as Families for Early Autism Treatment and Warmline.

### **Data Collection and Analysis**

# **Sampling Method**

The agencies, school district, regional center, and parent groups from which participants were identified were chosen based on their location and interaction with parents of children who have a diagnosis of autism, as well as the type of services they provide. Specific individuals within each recruitment facilities were identified and designated to receive information about the study. Fliers about the study were provided to those individuals. Additionally, fliers were posted in general meeting areas around these facilities to further recruit participants for the no-treatment control group.

I did not use random sampling for this study because the sampling procedure cannot be the same for each population given that some families were already enrolled to receive group parent training in behavior analytic treatment of ACT. Instead, this study utilized a convenience sample in which participants were recruited based on their willingness to complete the requested surveys. All individuals who meet the criteria for selection were eligible to be included within the study. Because I did not use random sampling, I paid special attention to those who may have been underrepresented in the sample. To adjust for this limitation, the population was narrowly defined, and the study took place in a controlled setting.

### Sample Size

I used Java Applets for Power and Sample Size ([Computer Software], Lenth, 2006) for ANOVA design to identify the number of participants needed in order to detect a significant treatment effect. Given a power of .80, an alpha of .05, and expected small

effect size, I identified that a minimum of 10 participants per treatment method were necessary for this study. However, I desired the sample mean to be representative of the population mean; therefore the number of participants included within this study was be increased to 20, which is in line with the number of participants used in the research conducted by Blackledge and Hayes (2006). To plan for participant dropout rate, a minimum of 30 participants per treatment method were recruited. Additionally, due to potential extraneous variables unaccounted for, as well as the limited amount of treatment provided, I expected that the difference between the mean values of the treatment groups would be small.

### **Eligibility Criteria**

To be eligible for participation in this study, participants must have had a child diagnosed with autism. The child must have been between the ages of 36 months and 12 years. Parents reported that they can read and speak fluent English. Confirmation of criteria being met was based upon parent report that their child carries a diagnosis of autism, that their child is eligible for special education services based on their diagnosis of autism, and/or that their child is a consumer of regional center, a state funded agency which assesses, diagnoses, and coordinates services for individuals with disabilities based upon their diagnosis of autism. Supporting documentation of diagnosis was not requested.

### **Sample Characteristics**

I recruited participants for the no-treatment control group from locally formed parent groups for families with a child diagnosed with autism and local school districts.

Participants for the treatment groups were identified through local agencies with already intact treatment groups. Demographic characteristics were asked of the parents.

Descriptive statistics were provided once the participants were identified.

#### **Treatment**

Treatments for both groups was provided by an outside agency. Participants in ACT attended a 15-hour group training program on ACT. The duration of each session was 3 hours, with a 20-minute break after 90 minutes of each session. Since this was a group training format, six to 10 participants were grouped together at a time. I continued to recruit participants until the population sample size had been reached. The 15 hour training was broken down into 5 sessions. Each session included discussion on the topic at hand, therapeutic interventions that participants were guided through, vignette applications, and weekly homework. Week one focused on providing an introduction to ACT, discussion and exercises surrounding the topic of avoidance and control. Week two focused on one's internal language and how language affects actions. Week three's topic expanded on being in the moment with one's thoughts and building awareness of self. Week four's discussion focused on practicing mindfulness and clarifying values. The final week focused on aligning the participant's actions with their values. The ACT training took place in a conference room located within the agency facility.

Participants receiving treatment in behavior analytic theory attended a 15-hour group training program on behavior analytic strategies aimed at providing the participants increased knowledge and ability to more effectively interact with their child. Each session was 3 hours in length with six to 10 participants grouped together at a time. I

recruited participants until the population sample size has been reached. Each week focused on a different teaching principle including the foundation of teaching skills to a child, including how to target a skill, establishing steps, choosing reinforcers, and setting the stage. Skills teaching techniques such as identifying appropriate expectations, using reinforcement to establish motivation, systematically targeting steps to teach, and shaping and fading of prompts used to teach skills was addressed. Lastly, gaining compliance, identifying functions of behaviors, and addressing behavior management problems was discussed. At the final week, a summary of the previous 4 weeks was provided. Both the ACT and behavior analytic treatment sessions were largely based upon lecture and group discussion, but also incorporated role playing, feedback, and homework. The behavior analytic training took place in a conference room located within the agency facility.

After I conducted a thorough internet search and conversing with a number of professionals in the field of psychology, I was not able to identify a local agency or individual who identified themselves as displaying the knowledge, ability, or willingness to provide group parent training in both behavior analysis and ACT. Therefore, I recruited participants for this study from more than one agency and different individuals provided the two levels of treatments. The qualifications of the trainer for each treatment varied depending upon the agencies' requirements concerning academic and applied knowledge base.

### **Instrumentation and Materials**

### **Instruments**

**Demographic Questionnaire.** A brief demographic questionnaire was developed and completed by the participants (Appendix A). The questionnaire included information related to the participant's age, gender, marital status, ethnicity, education level, and any previous experience with ACT or behavior analytic theory, as well as the participant's child's age, gender, diagnosis, and age at diagnosis. I used data from the questionnaire to see if the groups were balanced in terms of these demographics.

**Evaluation of Trainer Questionnaire.** In order to identify potential differences in trainer characteristics, which could account for variability in post-test scores, participants in the two treatment groups completed a short questionnaire in which they rated the trainer on specified characteristics and presentation style (Appendix B).

Beck Depression Inventory-II (BDI-II; Beck, Steer, & Brown, 1996). The Beck Depression Inventory-II purports to measure symptoms corresponding with depression as identified within the DSM-IV (Beck et al., 1996). The Beck Depression Inventory-II is a 21-item self-report inventory which is designed to be administered to an individual or group of people ages 13 years and older (Beck et al., 1996). The inventory is reported to take between 5-10 minutes to administer where respondents answer questions about how they have felt during the past 2 weeks, based on a 4-point Likert-type scale ranging from symptoms not being present (0) to severe display of symptoms (3) (Beck et al., 1996). The content items measured within the Beck Depression Inventory-II include areas related to a loss or change in feelings, such as a loss or change in interest, energy,

pleasure, appetite, concentration, or sleep, and negative self-concept such as self-dislike, self-criticism, feelings of worthlessness, and a focus on past failure or guilt (Farmer, 2001).

The administrator scores the Beck Depression Inventory-II by summing the ratings for each question, with a maximum score of 63 being possible (Beck et al., 1996). Cut scores for identifying the probability of depression were identified through a group of patients from the University of Pennsylvania who were grouped into four sectors which included individuals who were reported to be mildly depressed, moderately depressed, severely depressed, and non depressed (Beck et al., 1996). From this sample, optimal cut scores identifying sensitivity to each of the four ranges were established and were slightly lowered by Beck et al. (1996) in order to reduce the number of false positives.

Additional sample groups were used to investigate the measurement techniques and characteristics of the Beck Depression Inventory-II (Beck et al., 1996). This sample included a total of 500 individuals across four different psychiatric outpatient clinics and one university (Beck et al., 1996). From this sample, reliability and validity were assessed. In regards to internal reliability, the coefficient alpha of the Beck Depression Inventory-II was .93, indicating significance at the .05 level, with the lowest correlation being .27, and the highest correlation being .74 (Beck et al., 1996). Test-retest reliability was stable over a 1-week interval at the .93 level (Arbisi, 2001). In a recent study which examined Acceptance and Commitment Therapy verses Progressive Relaxation Training for obsessive-compulsive disorder the test-retest reliability was consistent with previous findings at .90 (Twohig et al., 2010).

Content and construct validity of the Beck Depression Inventory-II were assessed. The Beck Depression Inventory-II is a revision of the original Beck Depression Inventory-II and, therefore, questions were modified based on previous research of the Beck Depression Inventory-IA and to be in line with DSM-IV criteria for depression (Beck et al., 1996). The construct validity between the Beck Depression Inventory-II and the Beck Depression Inventory-IA was .93 and convergent validity of the Beck Depression Inventory-II was positively related to the Beck Hopelessness Scale (r = .68), the Scale for Suicide Ideation (r = .37), and the Hamilton Psychiatric Rating Scale for Depression-Revised (r = .71) (Beck et al., 1996; Arbisi, 2001).

Quality of Life Inventory (QOLI; Frisch, 1994). The Quality of Life Inventory purports to provide a broad, yet brief, impression of the overall life satisfaction of the respondent (Frisch, 1994). This 32-item, pencil and paper administration inventory, appropriate for use with individuals age 18 years and older (Frisch, 1994). This inventory is reported to take approximately 5 minutes to complete.

The Quality of Life Inventory includes concepts related to the quality of life across 16 different life domains, including health, self-esteem, goals and values, money, work, play, leaning, creativity, helping, love, friends, children, relatives, home, neighborhood, and community (Frisch, 1994). Within each of the 16 life domains, respondents are presented with information related to the specific life domain, and are asked to rate the importance of that life domain, and their level of satisfaction within that life domain (Frisch, 1994). Level of importance is rated on a 3-point scale ranging from zero to two, and satisfaction is rated on a 6-point scale ranging from -3 to +3 (Frisch, 1994).

Satisfaction scores are calculated by multiplying the importance of the scores to obtain a total of 16 weighted satisfaction scores (Barnes, 2001). These scores are then added together to produce an overall Quality of Life Inventory score (Barnes, 2001). The test booklet provides instruction regarding conversion of the total raw score to a T-score and percentile, which leads to an overall life satisfaction classification ranging from very low to high (Barnes, 2001).

Standardization of the Quality of Life Inventory was realized through a nonclinical population in the United States, with racial and ethnic composition matching that of the U.S. census in 1990 (Frisch, 1994). Participants were placed in groups, asked to complete the Quality of Life Inventory and at least one other self-report life satisfaction inventory, with the final standardization sample consisting of self-reports from 798 individuals (Frisch, 1994). A two-way analysis of variance (ANOVA) was used to analyze any differences between gender, race, and ethnicity (Frisch, 1994). The findings indicated that there was not a significant difference between gender, or genders and race and ethnic groups on test scores (Frisch, 1994). However, a significant difference was noted for test scores within race and ethnic groups, with a post hoc test indicating that the Hispanic group scored significantly higher than individuals of dissimilar race and ethnicity, indicating an above average quality of life for Hispanics (Frisch, 1994).

The reliability coefficient of the Quality of Life Inventory was reported to be .73 which was obtained from 55 participants who engaged in a 2-week test-retest procedure (Frisch, 1994). Frisch (1994) reported this reliability coefficient to be significant at p < .001. Convergent validity of the Quality of Life Inventory was assessed through data

from two other measures of life satisfaction and presented with moderate correlation of .25, which is significant at p < .001 (Barnes, 2001). Sensitivity to clinical treatment was addressed through treatment of 13 individuals diagnosed as clinically depressed (Frisch, 1994). These individuals received cognitive behavioral treatment weekly, for 15 weeks (Frisch, 1994). An ANOVA was used to detect the effect of treatment on the pre-test and post-test scores of the Quality of Life Inventory, the Beck Depression Inventory, and the Hamilton Rating Scale for Depression, resulting in a statistically significant main effect from pre-test to post-test, demonstrating that the Quality of Life Inventory is sensitive to changes in depression after treatment.

Parenting Stress Index, Third Edition – Short Form (PSI-SF, Abidin, 1995). The Parenting Stress Index-Short Form is a standardized measure which purports to identify the perceived levels of stress, and ability to effectively manage that stress, of parents of children between 1 month to 12 years old (Abidin, 1995). The Parenting Stress Index-Short Form is a pencil and paper measure containing 36 items, which are rated on a 5-point Likert-type scale ranging from *strongly agree* to *strongly disagree* (Abidin, 1995). This inventory is reported to take approximately 10 minutes to complete and is appropriate for parents age 18-60 years old (Abidin, 1995).

The Parenting Stress Index-Short Form provides a total stress score and three subscale scores related to parental distress, parent-child dysfunctional interactions, and difficult child (Abidin, 1995). The total stress score identifies the level of parental stress experienced across the three domains and does not assess stress experienced across other life roles and events such as spousal relationships, financial situation, socioeconomic

status, and the like (Abidin, 1995). The parental stress subscale measures ones perceived levels of stress as related to the parental role, including but not limited to parenting competence, social support, and symptoms of depression (Abidin, 1995). The parent-child dysfunctional interaction looks at the parent-child relationships and parents expectations and interactions with their child (Abidin, 1995). The difficult child subscale focuses on behavioral characteristics of the child which the parents may display difficulty in managing (Abidin, 1995).

Scores are calculated by calculating subscale scores in order to identify a total stress score (Abidin, 1995). Raw scores are then converted to percentiles, with the normal range of scores falling within the 15<sup>th</sup> through 80<sup>th</sup> percentiles and high scores being those identified above the 85<sup>th</sup> percentile (Abidin, 1995). The defensive responding scale is a measure of validity which assists in identifying if an individual is trying to minimize or deny problems (Abidin, 1995).

Validation of the Parenting Stress Index-Short Form included 800 participants who were primarily Caucasian and married mothers of young children (Abidin, 1995). The Parenting Stress Index-Short Form was provided to these mothers mainly at well-baby visits or routine medical screenings. It should be noted that the validation of the Parenting Stress Index-Short Form included parents' perception of their levels of stress related to the three subscale areas but no direct interaction between parent and their child was observed in order to identify if perception and observation of behavior were consistent (Haskett, Ahern, Ward, & Allaire, 2006). A factor analysis was also conducted between the Parenting Stress Index and the Parenting Stress Index-Short Form and correlations on

the total scores were high (Abidin, 1995). Regarding reliability, the test re-test was conducted over a 6 month period and found to be reliable at the .79 level for parental distress and up to .90 for total stress (Abidin, 1995).

Haskett et al. (2006) conducted a study of the psychometric properties of the Parenting Stress Index-Short Form. In this study, scores from 185 of the participants who completed the Parenting Stress Index-Short Form were analyzed (Haskett et al., 2006). The population in this study differed than that in the study conducted by Abidin (1995). Specifically, Haskett et al. recruited some parents who had a history of child abuse; who were from different cultural backgrounds, including African American, Hispanic, and Caucasian; and who had children who were older than the children in the study by Abidin (1995). The results of Haskett et al. study provide additional support for the different subscales, indicating they are measuring different dimensions of parental stress. Additionally, teacher report and school observations were made six-months after the parent completed the Parenting Stress Index-Short Form in order to assess the quality of child/peer interactions (Haskett et al., 2006). The researchers were unable to identify child specific characteristics from the Parenting Stress Index-Short Form based upon observation and teacher report at a six-month interval; however there was a high level of agreement between parental test-retest scores at the six-month interval, demonstrating reliability of scores over time (Haskett et al., 2006).

# **Recruitment and Confidentiality**

### Recruitment

For the treatment groups, I contacted representatives from local agencies and, upon consent to conduct research within their agency, community partner letters were drafted and signed. I provided information about the study to the community partners and they presented information about the study to individuals who meet the qualifications to participate. I included in the introductory letter this researcher's phone number and email address so that the potential participants could contact me if they were interested in participating in the study. Upon contact by the participant, I explained informed consent, explained the instruments, explained confidentiality, and requested the participant's contact information.

### **Confidentiality**

Once I received the informed consent and participant's contact information, a brief demographics questionnaire, and four assessment tools were given each participant. The informed consent form included a brief background of the study, information regarding confidentiality and limits of confidentiality, the voluntary nature of the study, ethical constructs and procedures of the study, how the information is expected to be used, the approximate time frame needed to complete the questionnaires, the assessment tools utilized in the study, and information about the researcher (see Appendix D). The demographic data included information related to the participant's age, gender, marital status, ethnicity, education level, and any previous experience with ACT or behavior analytic theory, as well as the participant's child's age, gender, diagnosis, and age at

diagnosis. This information was gained in order to determine the similarity of each treatment group. At the end of the intervention, I again met with the participants and requested they complete the assessment tools again.

I maintained confidentiality during this process by coding the participant's questionnaires and keeping their informed consents and coded questionnaires separate. No identifying information, such as names and contact information were on the instruments

### **No-Treatment Control Group**

In order to recruit participants for the no-treatment control group, I posted fliers at a local school district and with parent groups (see Appendix C). This researcher's information was included in the flyer and interested individuals who meet the qualifications for the study were requested to contact me. Upon initial contact, I explained the study and informed consent to the participant and request their email address. No other personal health information was requested of the participants.

Once I received all self-report instruments from the participants, I hand scored as directed by the corresponding manuals and entered into the Statistical Package for Social Sciences (SPSS, 19.0 computer software program) for data analysis.

### **Data Analysis**

In this study, I used a quasi-experimental design to analyze the independent variable of treatment, and the dependent variables of stress, depression, and quality of life. The independent variable has three levels of treatment: ACT, behavior analytic treatment, and a no-treatment control. In order to address each of the research questions, and assuming

the pre-test scores among the groups are similar, an independent measure, analysis of covariance (ANCOVA) was expected to be used. Independent measure means that a different participant sample was used for each treatment group. The sample size (n = 20) was the same for each participant group.

ANCOVA is a statistical technique, which controls for variation in an extraneous variable, or covariate, and is commonly used in nonexperimental designs where random assignment is not permissible (Culpepper & Aguinis, 2011). In this way, ANCOVA adjusts the variance in the dependent variables to what they would be assuming that all participants had equal scores on the covariate (pre-test). This allows the covariate to be removed as a possible reason for variance.

In order for an ANCOVA to be appropriate, certain assumptions must have been met. The main assumptions of ANCOVA are that 1) each of the observations will be independent, 2) the dependent variables and the covariate will be interval units of measurement, 3) the populations will be normally distributed and have the same variance, 4), there will be independence between the covariate and treatment effect, and 5) there will be homogeneity of the regression slopes (Simonoff, 2011). The first three assumptions are also true for ANOVA to be used. Therefore, if assumption four was violated, then ANOVA was the statistical procedure recommended to be used instead of ANCOVA.

Since an ANCOVA only provides information in regards to a relationship between the dependent variables and covariate, a comparison test such as Tukey Honestly Significant Comparison Test was expected to be conducted to test for direction and

differences between treatment groups. Tukey Honestly Significant Comparison Test is appropriate for use with both ANOVA and ANCOVA, because the test utilizes a stepwise comparison, it is appropriate to use with multiple treatment levels. This was computed through SPSS Version 19, computer software.

# **Research Question and Hypotheses**

### **Research Question**

When using an ANCOVA, the research questions address whether an individual belonging to one group is expected to change at a different rate than an individual belonging to another group, given the similarity in pre-test scores. The research question for this study asks if there are differences between ACT, behavior analytic treatment, and a no-treatment control group in regards to stress, depression, and quality of life in parents of children diagnosed with autism?

### **Hypotheses**

Since ANCOVA is the statistical procedure of choice, the hypotheses for this study discovered whether the adjusted group means for the dependent variables differ significantly from each other across treatment levels.

 $H_01$ : There will be no difference between the overall/total post test score related to depression, as measured by the Beck Depression Inventory-II, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

H<sub>a</sub>1: There will be a difference between the overall/total post test score related to depression, as measured by the Beck Depression Inventory-II, across treatment levels

(ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

 $H_02$ : There will be no difference between the overall/total post test score related to stress, as measured by the Parenting Stress Index-Short Form, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

H<sub>a</sub>2: There will be a difference between the overall/total post test score related to stress, as measured by the Parenting Stress Index-Short Form, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

 $H_03$ : There will be no difference between the overall/total post test score related to quality of life, as measured by the Quality of Life Inventory, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

H<sub>a</sub>3: There will be a difference between the overall/total post test score related to quality of life, as measured by the Quality of Life Inventory, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

### **Protection of Participant Rights**

The participants in this study were adults, older than age 18 years, and precautions were made to ensure their confidentiality. I used procedures that were in compliance with the Institutional Review Board of Walden University as well as the ethical procedures for

research identified through the Regional Centers utilized in this study. I ensured that I received written consent from each participant, prior to participation in the study, which included, confidentiality, limits of confidentiality, use of the data, and right to withdraw from the study at any time without recourse. All participants and instruments were coded by number, allowing inventories and consent to be linked, but without revealing any of the participant's personal health information. Results of individual inventories were shared with anyone outside of researcher and Walden University. Participation was completely voluntary; participants were not paid for their time, and there was no foreseeable risks for participants to take part in this study.

### **Dissemination of Findings**

This study has the potential to provide an effective intervention for parents of children diagnosed with autism in regards to parental levels of stress, depression, and quality of life. Given the impact of this research, findings will be shared through poster presentations at conferences related to autism and behavior, such as California Association for Behavior Analysis and Association for Behavior Analysis International, shared at parent groups for parents of children diagnosed with autism, and at the agencies for which participants were recruited. Participants were made aware that they can contact the researcher and request finding information or they may view the findings at the agency where they received the initial flier. Additionally, the findings of the research will be provided to the founders of ACT and requested for acceptance on their website Association for Conceptual Behavioral Science. Finally, the research will attempt to be published in a peer-reviewed journal.

# **Summary**

Within this chapter, I outlined the research design and methodology. I proposed a quasi-experimental, non-equivalent, pretest-posttest, group design. Participants for the three treatment levels were identified from intact groups and were recruited for the notreatment control group. Pre- and post-intervention scores from the assessment measures were be analyzed using SPSS (19.0) computer software. Results of the data analysis will be discussed in Chapter 4.

## Chapter 4: Results

#### Introduction

This section will include information related to data collection procedures, time periods for data collection and participant recruitment, demographics, and data fidelity. I will report the results of the study, and summarized answers to research questions.

The purpose of this quantitative research study was to investigate the effects that ACT might have on parents of children diagnosed with autism compared to parents of children diagnosed with autism who participated in group behavioral intervention training, and parents of children diagnosed with autism who have not received behavioral intervention or ACT. Sixty parents participated in the study. After a series of analyses, 57 were used for the hypothesis testing.

Given similarity in groups based upon the pretest scores, a one-factor ANCOVA was to be used as the statistical analysis. If the groups were not similar based upon the pre-test scores, ANOVA would be used as the statistical analysis. The following are the original hypotheses presented in Chapter 3.

H<sub>0</sub>1: There will be no difference between the overall/total post test score related to depression, as measured by the Beck Depression Inventory-II, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

H<sub>0</sub>2: There will be no difference between the overall/total post test score related to stress, as measured by the Parenting Stress Index-Short Form, across treatment levels

(ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

 $H_03$ : There will be no difference between the overall/total post test score related to quality of life, as measured by the Quality of Life Inventory, across treatment levels (ACT, behavior analytic training, no-treatment control), when controlling for pretest score as the covariate.

In order to utilize ANCOVA as the statistical measurement, assumptions of normality needed to be met. The main assumptions of ANCOVA are that (a) each of the observations will be independent, (b) the dependent variables and the covariate will be interval units of measurement, (c) the populations will be normally distributed and have the same variance, (d) there will be independence between the covariate and treatment effect, and (e) there will be homogeneity of the regression slopes (Simonoff, 2011).

When examining the data, I identified 41 outliers. I analyzed these outliers and made the decision to eliminate three data points based upon inconsistency in participant responding. To test assumptions of normality, I used the Shapiro-Wilk for each of the three outcome measures (BDI, PSI, and QOL) and for each of the three groups of respondents (ABA, ACT, and Control). I performed these tests after adjusting the sample size and data from the three outliers were deleted. In all, I found that 15 of the 27 Shapiro-Wilk tests were significant, suggesting that the groups come from populations that are not normally distributed.

Given the concerns meeting normality assumptions for ANCOVA and ANOVA, as well the fact that the PSI presents data expressed in percentile scores, which is not an

interval unit of measurement, I made the decision to use Kruskal-Wallis, a nonparametric test. Kruskal-Wallis is a rank-based analysis of variance that does not require normality in groups, determines statistical significance between two or more groups of independent variables, and is commonly used as an alternative to ANOVA (Creswell, 2009). The dependent variable is change from pretest to posttest.

H<sub>0</sub>1: There will be no difference in changes from pretest to posttest for the overall/total posttest score related to depression, as measured by the Beck Depression Inventory-II, across treatment groups (ACT, behavior analytic training, no-treatment control).

 $H_02$ : There will be no difference in changes from pretest to posttest for the overall/total posttest score related to stress, as measured by the Parenting Stress Index-Short Form, across treatment groups (ACT, behavior analytic training, no-treatment control).

 $H_03$ : There will be no difference in changes from pretest to posttest for the overall/total posttest score related to quality of life, as measured by the Quality of Life Inventory, across treatment groups (ACT, behavior analytic training, no-treatment control).

## **Data Collection and Treatment Fidelity**

Sixty parents participated in this research study. I recruited forty of these participants from intact groups, meaning participants in a workshop focused on ACT or Applied Behavior Analysis. I recruited the remaining 10 participants from the community and had not received training in either ACT or Applied Behavior Analysis. I recruited participants

from March 2012 through May 2014, with data collection occurring between November 2012 and May 2014.

The data collection method that I used in this research was a survey. A problem inherent to the survey approach is that people have the right to refuse to participate, which can result in selection bias (Creswell, 2009). The participants in this study took the time to answer, and others chose not to answer, for a host of reasons unknown to the researcher. Additionally, the sample size for this study was taken from a small geographic region in Sacramento, California. Attitudes and services in California may be different than in other areas of the country.

Response bias could also be present. Although the participants were informed that all responses would be confidential and coded to ensure anonymity, the participants may still have desired to present themselves in a favorable light, and could have been inclined to adjust their responses to accord with what they believed to be socially acceptable (Creswell, 2009). Given these reasons, it could not be ascertained whether the sample in this study is representative of the population.

All participants were parents and/or caregivers of an individual diagnosed with Autism Spectrum Disorder. The age range of the individual with Autism Spectrum Disorder was originally 36 months-12 years. However, given the length of time recruitment took, in order to maximize recruitment measures, the age range of the individuals with Autism Spectrum Disorder was broadened to encompass the lifespan (birth through to adulthood). Pre- and post-measures were either mailed to participants, or handed to them in person prior to and at the end of the ACT and Applied Behavior

Analysis training dates. Informed consent was obtained from each participant, and the questionnaires were numerically coded in order to maintain confidentiality.

The training model the identified trainer used in the ACT and Applied Behavior

Analysis workshop was a "2+1" model wherein training was delivered over a total of
three sessions. Two of the training sessions took place over the course of one weekend,
and the third training session occurred approximately four weeks later. The rationale for
this model was that it would give participants time to work the processes, encounter
barriers, get help from each other, and then receive reinforcement and/or coaching from
the trainer and the group upon returning. Bond and Bunce (2000) demonstrated
therapeutic effectiveness with ACT training in regards to stress in the workplace when
utilizing this format. In 2002, Bond and Hayes demonstrated therapeutic effectiveness
utilizing the "2+1" model with ACT training in regards to leadership in the workplace, as
did Flaxman and Bond (2010). There were no adverse events related to the ACT or
Applied Behavior Analysis interventions.

## **Descriptive Statistics**

There were initially 70 individuals who chose to participate in this study. However, I eliminated 10 of those participants prior to data analysis. Of those 10 participants that were eliminated, I eliminated six participants from the control group due to lack of completion of the posttest measurement. I eliminated three participants from the ACT group and one from the ABA group due to lack of completion of the posttest measurements. I then analyzed the data from the pre- and post-test measurements for the remaining 60 participants. Upon initial review of the data, there seemed to be extreme

scores present, which raised question regarding potential data entry error. Therefore the BDI, PSI and QOL from each participant were re-scored in order to ensure scoring accuracy. Five of these scores changed based upon the cleaning of this data.

Next, I examined the data for outliers. I created a series of box plots to determine the presence of outliers for each of the three outcome measures (BDI, PSI, and QOL) for their pretest, posttest, and change scores. A *low outlier* was any value that was 1.5 times the interquartile range (IQR) below the first quartile (25th percentile) while a *high outlier* was any value that was 1.5 times the IQR above the third quartile, or 75th percentile (e.g., Creswell, 2009). For the nine boxplots pertaining to the three BDI scores, nine outliers were found based upon their change scores. For the nine boxplots pertaining to the three PSI scores, 25 outliers were found. For the nine boxplots pertaining to the QOL scores, seven outliers were found, totaling 41 outliers in all.

I then examined each of the 41 outliers. Examination included reviewing the pre and post measurements, ensuring all measurements were completed in their entirety, and there were no data entry errors. I also examined the validity scale for the PSI, which confirmed that none of the participants scored within the *defensive responding* range. Consistency in pretest to posttest responding was evaluated for each of the outliers. Inconsistent responding, across either two or three of the measurements was noted for three of the outliers, which raised concern regarding the validity of responding on those measurements. Based upon this examination, the decision was made to exclude the data related to three outliers, ultimately reducing the number of participants included in the statistical analysis from N = 60 to N = 57.

Table 1 displays the frequency counts for selected variables. There were initially equal numbers of parents (n = 20) across the three groups, however upon analyzing the outliers, inconsistent reporting seemed to exist from three of the individuals, therefore those data points were removed from the findings. This resulted in 20 individuals in the ABA group, 18 individuals in the ACT group, and 19 individuals in the control group (n = 57).

Table 1 Frequency Counts for Selected Variables (N = 57)

Variable	Category	n	%
Group			
	ABA	20	35.1
	ACT	18	31.6
	Control	19	33.3
Parent's Gender			
	Female	43	75.4
	Male	14	24.6
Parent's Marital Status			
	Divorced/Separated	8	14.0
	Married	41	71.9
Parent's Race/Ethnicity	Single	8	14.0
	Asian	7	12.3
	Caucasian	35	61.4
	Hispanic	5	8.8
	Other	10	17.6
Parent's Education			
	HS Diploma or less	12 24	21.0 42.1

	Some college		
	Bachelor's	9	15.8
	Master's	12	21.1
Child's Gender			
	Female	12	21.1
	Male	45	78.9
Child's Age in Months <sup>a</sup>			
	24 to 48 months	13	23.2
	49 to 72 months	16	28.4
	73 to 120 months	13	23.2
	121 to 384 months	15	26.7
Child's Diagnosis			
	Autism	44	77.4
	Asperger's Syndrome	9	15.9
	PDD-NOS	2	3.5
	Other	2	3.5

Note. a = Age in Months: M = 100.51, SD = 76.40. Age in Years: M = 8.54, SD = 6.37

Many more mothers participated (75.4%) than did fathers (24.6%), with most participants (71.9%) being married and Caucasian (61.4%). Educational levels among the parents varied widely, and 36.9% of the respondents had earned at least a bachelor's degree. Most of the diagnosed children (78.9%) were male. Ages of children at diagnosis ranged from 24 to 384 months (2 to 32 years) with a mean age of 8.54 years old (*SD* = 6.37). The majority of parents (77.4%) had a child diagnosed solely with Autism Spectrum Disorder, 15.9% of the parents had a child diagnosed with Asperger's Syndrome, while 3.5% of parents had a child diagnosed with Autism Spectrum Disorder and another comorbid diagnosis (see Table 1).

Table 2 displays the descriptive statistics for the primary dependent variables (Beck Depression Inventory (BDI), Parenting Stress Index (PSI), and Quality of Life Inventory (QOL). The parent's BDI score had an average decline (pretest minus posttest) of M = 1.65 (SD = 6.83). The parent's PSI score had an average decline of M = 1.67 (SD = 10.09). In addition, the parent's QOL score had an average increase (posttest minus pretest) of M = 2.37 (SD = 24.66).

Table 2  $\label{eq:decomposition} Descriptive \ Statistics \ for \ the \ Primary \ Dependent \ Variables \ (N=57)$ 

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Variable	M	SD	Low	High
BDI pretest score	11.60	8.09	0.00	36.00
BDI posttest score	9.95	8.93	0.00	43.00
BDI decline <sup>a</sup>	1.65	6.83	-14.00	24.00
PSI pretest stress	86.95	19.22	18.00	99.00
PSI posttest stress	85.28	21.65	10.00	99.00
PSI decline <sup>a</sup>	1.67	10.09	-27.00	45.00
QOL pretest score	33.02	26.46	1.00	98.00
QOL posttest score	35.39	25.99	2.00	99.00
QOL increase <sup>b</sup>	2.37	24.66	-72.00	66.00

Note. <sup>a</sup> = Decline = Pretest score minus posttest score; <sup>b</sup> = Increase = Posttest score minus pretest score; BDI refers to Beck Depression Inventory. PSI refers to Parenting Stress Index (Short Form). QOL refers to Quality of Life Inventory

Decline scores were used for the BDI and PSI because lower scores were considered to be more favorable, meaning a decrease in depression and stress (Abidin, 1983; Beck, Steer, & Brown, 1996) while an increase score was calculated for the QOL because higher QOL scores were deemed to be more favorable, indicating increased satisfaction with ones quality of life (Frisch, 1994).

The standard deviations for the BDI, PSI, and QOL were considerably larger than their mean change scores (between approximately four to 10 times larger). This could suggest a wide range of variability, either increase or decrease, in the sample (Table 2). Table 3 displays the BDI category scores at pretest and posttest. Minimal depression was present in 70.2% of parents at pretest and in 78.9% at posttest (Table 3).

Table 3

BDI Category Scores (N = 57)

Variable	Category	n	%
BDI pretest range			
-	Minimal	40	70.2
	Mild	11	19.3
	Moderate	3	5.3
	Severe	3	5.3
BDI posttest range			
r	Minimal	45	78.9
	Mild	5	8.8
	Moderate	4	7.0
	Severe	3	5.3

Note. BDI refers to Beck Depression Inventory.

## **Answering the Research Question and Hypotheses**

The primary research question I focused on in this study is whether there were differences in change scores from pretest to posttest between ACT, behavior analytic treatment, and a no-treatment control group in regards to stress, depression, and quality of life in parents of children diagnosed with autism. I created boxplots to identify the presence of outliers for each of the three outcome measures. In total, I identified 41 outliers in the dataset. I assessed normality by using the Shapiro Wilk test. The Shapiro-Wilk test were calculated for each of the three outcome measures (BDI, PSI, and QOL) and for each of the three groups of respondents (ABA, ACT, and Control). Inspection of the Shapiro-Wilk tests for BDI found three of nine tests to be statistically significant.

For the PSI scores, I identified that eight of nine tests were significant, and for QOL scores, four of nine were significant. In total, 15 of the 27 Shapiro-Wilk tests were significant, suggesting that the groups come from populations that are not normally distributed. Given the number of outliers identified by the boxplots, review of the data and identified inconsistent reporting, as well as the information gained from the Shapiro Wilk test, decision was made to eliminate three of outliers, bringing the number of participants to N = 57. Given the concerns meeting normality assumptions for ANCOVA and ANOVA, the statistical measurement used to analyze the data was Kruskal-Wallis, a nonparametric test. Kruskal-Wallis is a rank-based test that does not require normality in groups, and can be used to determine statistical significance between two or more groups of independent variables, and is commonly used as an alternative to ANOVA (Creswell, 2009).

Means and standard deviations (SDs) were reported for the three Kruskal-Wallis tables (Tables 4, 5, and 6) because the standard summary statistics provided in the SPSS printouts for Kruskal-Wallis tests are "mean ranks." Mean ranks are largely uninterpretable, and not particularly useful, to most readers (especially the change scores) so a decision was made to report the means and SDs to provide a better level of understanding for the reader. That being said, the mean ranks were still used by SPSS to calculate the relevant chi-square distributions displayed in the tables.

To reduce the likelihood of Family-wise Type 1 errors, a. Bonferroni correction was applied to the overall alpha level in this study. Given three tests of significance for this

study (Tables, 4, 5, 6), and a critical p value of .05, the alpha level was reduced from  $\alpha$  < .05 to  $\alpha$  < .02.

Null hypothesis 1 predicted that,  $H_01$ : There will be no difference in changes from pretest to posttest for the overall/total posttest score related to depression, as measured by the Beck Depression Inventory-II, across treatment groups (ACT, behavior analytic training, no-treatment control). Table 4 displays the Kruskal-Wallis tests for the BDI decline scores comparing the three groups of participants, as well as the central tendencies for the pretest and posttest scores. The BDI decline score was not significant, thus providing support to retain the null hypothesis (Table 4).

Table 4 Kruskal-Wallis Tests for the BDI Scores Based on Group (N = 57)

Score	Group	n	М	SD	$\chi^2$	p
BDI Pre Score						
	1. ABA	20	13.35	10.56		
	2. ACT	18	11.72	8.09		
	3. Control	19	9.63	4.06		
BDI Post Score						
	1. ABA	20	11.60	12.96		
	2. ACT	18	8.78	6.32		
	3. Control	19	9.32	5.33		
BDI Decline <sup>a</sup>					1.20	.55
	1. ABA	20	1.75	8.91		
	2. ACT	18	2.94	6.20		
	3. Control	19	0.32	4.64		

<sup>&</sup>lt;sup>a</sup> Decline = Pretest score minus posttest score.

Null hypothesis 2 predicted that,  $H_02$ : there will be no difference in changes from pretest to posttest for the overall/total posttest score related to stress, as measured by the Parenting Stress Index-Short Form, across treatment groups (ACT, behavior analytic training, no-treatment control).

Table 5 displays the Kruskal-Wallis tests for the PSI decline scores, as well as the central tendency for the PSI pretest and posttest scores. The PSI decline score was not significant, thus providing support to retain the null hypothesis (Table 5).

Table 5 Kruskal-Wallis Tests for the PSI Scores Based on Group (N = 57)

Score	Group	n	M	SD	$\chi^2$	<i>p</i>
PSI Pre Score						
	1. ABA	20	83.30	24.29		
	2. ACT	18	92.44	9.53		
	3. Control	19	85.58	19.84		
PSI Post Score						
	1. ABA	20	82.75	27.74		
	2. ACT	18	87.94	19.45		
	3. Control	19	85.42	16.58		
PSI Decline <sup>a</sup>					1.95	.38
	1. ABA	20	0.55	10.06		
	2. ACT	18	4.50	11.14		
	3. Control	19	0.16	8.98		

<sup>&</sup>lt;sup>a</sup> Decline = Pretest score minus posttest score.

Null hypothesis 3 predicted that, H<sub>0</sub>3: there will be no difference in changes from pretest to posttest for the overall/total posttest score related to quality of life, as measured by the Quality of Life Inventory, across treatment groups (ACT, behavior analytic training, no-treatment control).

Table 6 displays the Kruskal-Wallis tests for the QOL increase scores, as well as measures of central tendency for the pretest and posttest scores. The PSI increase score was significant (p = .001). Inspection of the table found that parents in the ACT group had higher increase scores (M = 19.33) than either ABA parents (M = -1.80) or control group parents had (M = -9.32) (Table 6).

Table 6 Kruskal-Wallis Tests for the QOL Scores Based on Group (N = 57)

Score	Group	n	М	SD	$\chi^2$	р
QOL Pre Score						
	1. ABA	20	32.80	26.73		
	2. ACT	18	24.56	24.57		
	3. Control	19	41.26	26.66		
QOL Post Score						
	1. ABA	20	31.00	29.46		
	2. ACT	18	43.89	24.72		
	3. Control	19	31.95	22.40		
QOL Increase <sup>a</sup>					16.24	.00
	1. ABA	20	-1.80	23.63		
	2. ACT	18	19.33	21.49		
	3. Control	19	-9.32	20.39		

<sup>&</sup>lt;sup>a</sup> Increase = Posttest score minus pretest score.

## **Results Summary**

In summary, in this study I recruited and used data from 57 parents to investigate effects of ACT on parents of children diagnosed with autism compared to parents of children diagnosed with autism who participated in group behavioral intervention training, and parents of children diagnosed with autism did not receive behavioral intervention or ACT. Hypothesis 1 (overall/total change score as measured by the BDI) was not supported (Table 4). Hypothesis 2 (overall/total change score as measured by the PSI) was not supported (Table 5). Hypothesis 3 (overall/total change score as measured by the QOL) was supported (Table 6). In the final Chapter, I compared these findings to the existing literature, drew conclusions and implications, and made a series of recommendations.

## Chapter 5: Discussion, Conclusions, and Recommendations

#### Introduction

The purpose of this research study was to investigate the effects that ACT might have on parents of children diagnosed with autism. ACT results were compared with parents of children diagnosed with autism who participated in group behavioral intervention training, and parents of children diagnosed with autism who did not receive behavioral intervention or ACT. Sixty parents participated in the study.

The primary research questions for this study asked if there were differences between ACT, behavior analytic training, and a no treatment control group in regards to parental levels of stress, depression, and quality of life. This is the first study of its kind where a researcher compared ACT and ABA treatment relating to changes in parental levels of depression, stress, and quality of life.

Parents who have a child with a disability have mental health challenges. Having a child with a disability can lead parents to feel shock, sorrow, resentment, and guilt, along with changing expectations about family structure and roles (Bumin, Gunal, & Tukel, 2008). Davis and Carter (2008) found that 39% of mothers of a child with autism reported clinically significant depression levels. Benson and Karlof (2009) reported similar findings as that of Davis and Carter, indicating that parents of a child diagnosed with autism reported symptoms of depression at congruent levels.

The parents in this study had lower levels of depression than those reported by Davis and Carter (2008) and Benson and Karlof (2009). Based upon the results of the BDI,

70.2.7 % of parents in this study reported minimal levels of depression, while 19.3% reported mild levels, and 10.6% reported moderate to severe levels of depression.

Parents in this study exhibited lower levels of stress than is reported in the literature. According to Abidin (1995), parents who receive total stress scores on the PSI between the 15<sup>th</sup>-80<sup>th</sup> percentiles are within the normal range, while lower than the 15<sup>th</sup> percentile equates to extremely low levels of stress, and above the 80% percentile equates to extremely high levels of stress. In this study, .02% of parents reported extremely high levels of stress, while 40% reported stress levels within normal range, and 58% reported extremely low levels of stress. However, self-reported levels of stress should not be overlooked, as Abidin found that research and clinical experience suggests that extremely low levels of stress may be present when there is dysfunction within the parent-child relationship, as can be the case when parenting a child with a disability.

Knowledge about parental levels of depression and stress are important because parents who experience symptoms of depression and stress frequently have less positive parent-child relationships and interactions, which can eventually lead to increased discord within the family unit (Cohen & Semple, 2009). Additionally, parents of children diagnosed with autism report that their child was more difficult to care for than other children, that the child's externalizing behaviors were difficult for the parents, and that parents feel that their life sacrifices were more than had been expected (Davis & Carter, 2008; Schieve, Blumberg, Rise, Visse, & Boyle, 2007). All of these factors can lead to a diminished quality of life for the parents of children diagnosed with autism.

### **Interpretation of Findings**

Blackledge and Hayes (2006) claimed that parents of children diagnosed with autism seem to experience higher levels of depression than their counterparts who have typically developing children. Current research suggests this is true, particularly for mothers of a child who has a diagnosis of autism: Davis and Carter (2008) found that 39% of mothers who have a child diagnosed with autism reported significant levels of depression.

In this study, the Null Hypothesis 1 ( $H_01$ ) predicted there will be no difference in changes from pretest to posttest for the overall/total posttest score related to depression, as measured by the Beck Depression Inventory-II, across treatment groups (ACT, behavior analytic training, no-treatment control). The findings of this study retained the null hypothesis, indicating no significant differences in depression change scores based on group.

Although no other research has compared ACT and ABA treatment groups, Baer's meta analysis (2003) found that individuals who participated in mindfulness based therapies reported better outcomes in regards to levels of depression than those in a control group. This was supported by Powers et al. (2009) who found that individuals who participated specifically in ACT accessed greater benefits overall than those in the control conditions, waiting lists, and those receiving psychological placebos. Excluded from this were individuals who suffered from severe depression and/or a combination of anxiety and depression (Powers et al.). Cohen and Semple (2009) found that mindfulness based strategies have been established as an effective intervention in reducing symptoms of depression, reducing stress, and enhancing perception of quality of life.

Findings from the literature seems to support ACT and/or general mindfulness based therapies as an effective treatment for depression. In addition, has been recognized by Division 12 of the American Psychological Association as an empirically validated treatment for depression in adults (Powers et all, 2009). However, the results of this study found no significant differences based on BDI change scores.

This result is similar to that found by Blackledge and Hayes (2006). Blackledge and Hayes looked at the effectiveness of a 2-day, 14 hour, group ACT training on parents of children diagnosed with autism. They used pre and post tools, to measure parents perceived level of depression and distress. Blackledge and Hayes found that participants who were slightly above the depression cutoff reported better outcomes in regards to perceived levels of depression and distress from pre to post measures. However, the overall improvement was not clinically significant.

The lack of significant change from pretest to posttest BDI scores of this study seems to contradict findings in the literature which support ACT and/or general mindfulness based therapy as an effective treatment for depression. One possible reason for this contradiction could be the complexity of the population of this study given that the participants were parents of a child diagnosed with ASD. It is possible that the unique underlying life and family stressors of this population may play a role in presentation of depression, which was not identified or specifically addressed through the study.

In addition, Blackledge and Hayes (2006) also used participants of a child with ASD, and although they reported lower levels of depression after ACT, the differences were not clinically significant. Neither this study, nor the study by Blackledge and Hayes, utilized

ACT strategies specifically focused on the parent/child relationship or the acceptance of life change given a child with ASD. Lack of specificity of ACT training to the population at hand could account for these apparently contradictory findings from the literature.

The literature shows that parents of children diagnosed with autism experience greater stress levels than parents with typically developing children (Baker-Ericzen, Brookman-Frazze, & Stahmer, 2005; Benson & Karlof, 2009; Blackledge & Hayes, 2006; Weiss, 2002). While mothers of a child diagnosed with autism seem to experience higher levels of depression than fathers, both mothers and fathers seem to experience high levels of stress fairly uniformly (Davis & Carter, 2008). While there may be many reasons for this, some studies have suggested that the change in family structure and roles each family member plays is a contributing factor to increased stress levels and anxiety (Bumin et al., 2008).

In this study, the Null Hypothesis 2 (H<sub>0</sub>2) predicted there would be no difference in changes from pretest to posttest for the overall/total posttest score related to depression, as measured by the Parenting Stress Index, across treatment groups (ACT, behavior analytic training, no-treatment control). The findings of this study retained the null hypothesis, indicating no significant differences in stress change scores based on group. This is the first study of its kind to compare ACT and ABA treatment as they relate to changes in parental levels of stress.

Although this is the first study to compare parental levels of stress based upon treatment groups, research on mindfulness based strategies have been established as an effective intervention inducing stress (Cohen & Semple, 2009). This is in direct contrast

to the findings of this study, which indicated no significant change in perceived levels of stress, based on treatment group. The lack of significant change in perceived levels of stress from pretest to posttest PSI scores of this study seem to contradict the findings in the literature.

One possible reason for this contradiction could be the complexity of the population in this study, given that the participants were parents of a child diagnosed with ASD. It is possible that the unique underlying life and family stressors of this population may not have been fully identified, and ACT strategies were not focused specifically on stressors relating to the parent/child relationship. The lack of specificity of ACT training to the population at hand could account for the apparent contradictory findings from the literature.

Previous researchers have hypothesized that higher levels of stress and depression negatively correlate with quality of life (Blackledge & Hayes, 2006). That is, the more an individual suffers from stress and depression, the poorer they will report their quality of life to be. Having a child with a disability seems to negatively affect parents' perceptions about various life domains, including social relationships, psychological well being, physical well being, and mental health (Brown, MacAdam-Crisp, Wang, & Larocci, 2006). Ultimately, this can result in increased social isolation, decreased free time, lower levels of leisure and enjoyment of life, and lower financial earnings (Brown et al., 2006). Mindfulness based strategies have been established as an effective treatment to not only decrease depression in adults, to reduce parental stress, but also to enhance parental perceptions of quality of life (Cohen & Semple, 2009).

In this study, the Null Hypothesis 3 (H<sub>0</sub>3) predicted there will be no difference in changes from pretest to posttest for the overall/total post test score related to depression, as measured by the Quality of Life Inventory, across treatment groups (ACT, behavior analytic training, no-treatment control). This study found a significant difference at the .02 level related to the QOL change score, across treatment levels. This supported the alternative hypothesis (H<sub>a</sub>3), and is consistent with that presented by Cohen and Semple (2009), who stated that mindfulness based strategies have been established as an effective intervention in enhancing perception of quality of life. These findings were also compatible with the findings of Singh, Lancioni, Winston, Singh, Curtis, and Wahler (2007), who found that when mothers of children diagnosed with autism were taught specific mindfulness strategies aimed at improving the parent-child relationship, their satisfaction with their parenting abilities and relationship with their child increased.

It is interesting that although there was no significant difference from pretest to post test for the overall/total change scores related to depression and stress, there was significant improvement related to quality of life. It is possible that an individual's quality of life as related to having a child diagnosed with autism is disconnected from the variables that lead to parental levels of depression and stress. Additionally, it is also possible that while general ACT or ABA training is sufficient when focusing on quality of life concepts, the specific variables related to parental levels of depression and stress may need to be further explored. Based upon that information, services could then be designed specifically to address those variables identified as playing an important role in the development of parental levels of depression and stress. The findings of this study

also brings to the foreground the question of the cohesiveness between the three assessment measures utilized and whether they truly captured the essence of the challenges that parents of a child diagnosed with ASD experience.

## **Limitations of the Study**

Limitations of this study include the small sample size used across the groups, lack of consistency in instrumentation across previous research studies and lack of operational definition of quality of life across previous studies. The sample size of this study (*N* = 57) was not large. The larger the sample size the greater the chance of reaching significance increases. This is because a larger sample is said to more reliably reflect the population mean (Creswell, 2009). However, the sample size matched that used by Blackledge and Hayes (2006). In addition to the above limitations, the use of percentile scores for the QOL presented challenges as related to statistical analysis procedures. Percentiles provide information regarding a relative position and are not a linear transformation from raw scores. Therefore, the magnitude or difference from pre to post test scores is unknown. While the QOL utilizes percentiles, this is not the best approach for use in research and with this said, the findings related to QOL change scores should be interpreted with caution.

The findings of this study differed from the consensus found in the literature. A contributing factor to that, and a limitation of this study, is that there has not been consistency in the instruments used. Lack of consistency in measures used to assess depression, stress, and quality of life, makes it difficult to compare findings from one study to another. This lack of consistency not only pertains to the instrumentation used,

but also to operational definitions. For example, quality of life is defined differently across comparative studies, which is problematic because the definition of quality of life in this study may differ to that of other studies.

Additionally, this study included any parent who had a child with a diagnosis under the Autism Spectrum umbrella, and presentation of these individuals can differ greatly. Likewise, this study did not place limits on the child's age at time of diagnosis, functioning or developmental level, or severity of internalizing or externalizing behaviors. These are variables that have the potential to play a part in the parent's levels of depression, stress, and quality of life. In fact, it may be that these variables have a more direct influence on the complexities of parental levels of depression, stress, and quality of life than has been demonstrated in the current literature. The specific variables which contribute to parental levels of depression, stress, and quality of life were not identified within this study and the ACT training provided was not specifically designed to address challenges within the parent/child relationship, but instead was based upon general ACT principles.

This study is unique in that it is the first to analyze change scores based on treatment groups, in regards to depression, stress, and quality of life. The findings of this study found that there were no significant differences in change scores related to depression and stress, based on participation in ACT or Applied Behavior Analysis workshops.

These findings are contradictory when compared with seminal articles, which support ACT as an empirically based treatment effective in reducing levels of depression and stress. Although there was no significant differences related to depression and stress,

there was a significant difference from pretest to posttest for the overall/total change scores related to quality of life. It is possible that an individual's quality of life as related to having a child diagnosed with autism is disconnected from the variables that lead to parental levels of depression and stress. Additionally, it is also possible that while general ACT or ABA training is sufficient when focusing on quality of life concepts, the specific variables related to parental levels of depression and stress may need to be further explored. The findings of this study also bring to question the cohesiveness between the three assessment measures utilized and if they truly captured the essence of the challenges that parents of a child diagnosed with ASD experience.

While the findings of this study established that participation in ACT and Applied Behavior Analysis did not reduce levels of stress and depression, there was significant improvement in the participant's perception of their quality of life. In the literature, higher levels of stress and depression seemed to be linked to lower perception of quality of life. Thus, changing levels of stress and depression subsequently tends to increase quality of life. It is interesting that in this study, change levels of depression and stress remained constant across treatment groups, however quality of life improved, independent from change scores related to stress and depression.

## **Implications**

The effects of parental depression, stress, and poor quality of life can be detrimental to the entire family. Cohen and Semple (2002) found that parents who reported symptoms of depression displayed decreased parental sensitivity to their child, meaning they were less likely to notice and react to the subtle needs of their child. Decreased parenting

sensitivity was associated with a lag in child school readiness skills, lag in expressive language abilities, and lag in understanding of receptive or spoken language (Cohen & Semple, 2009). In contrast, parents of a child with a disability who employ problem-focused coping strategies using cognitive and behavioral techniques reported higher levels of emotional well being and increased positive parent-child relations (Head & Abbeduto, 2007). MacDonald and Hastings (2008) found that fathers who reported being more present in the moment and centered on their relationship with their child also reported more involvement in parenting roles, tasks, and child socialization. The establishment of a supportive, caring, and encouraging family environment can positively contribute to a child's development and can lead to increased capability of the child and family in accepting and accessing required treatment (Head & Abbeduto, 2007).

The findings of this study demonstrated that parental levels of quality of life can change. This research addresses the gap in the literature, and provides support for treatment for the parents of children diagnosed with autism. This is imperative because parental mental health has been demonstrated to not only impact child behaviors and the parent/child attachment process, but also responsiveness and adherence with regards to accessing needed treatment. This contributes to positive social change for parents of children diagnosed with autism. Additionally, insight into effective treatment options for parents of children diagnosed with autism can further assist practitioners in making recommendations for parents once their child has received an autism diagnosis.

#### Recommendations

Given the literature surveyed and the findings of this research, parents of children diagnosed with autism seem to experience elevated levels of depression and stress, and decreased quality of life. The findings of this study indicate that quality of life is improved at a significant level for parents who receive treatment. The unknown is the relationship between stress, depression, and quality of life, as well as which treatment group caused the significant changes in quality of life. Previous research hypothesized that higher levels of depression and stress would lead to reduced quality of life. It could be said that if one increases their quality of life, levels of stress and depression would subsequently lift, or visa versa. However, while the findings of this research identified a significant change in quality of life, the change scores for depression and stress were not significant. Thus, there seem to be other factors involved in the relationship between depression, stress, and quality of life. Future research questions could focus on analyzing demographics of parents of children diagnosed with autism compared to depression, stress, and quality of life to identify if there is a variable correlating with depression, stress, or quality of life. Future research questions could also look at child factors such as the display of internalizing or externalizing behavior as related to parental levels of depression, stress, and quality of life. Specific to ACT treatment, a follow up study could measure changes in parental levels of depression, stress, and quality of life compared to changes in their child's attachment, learning acquisition rate, and internalizing and externalizing behaviors. Lastly, future research questions could examine if ACT strategies specific to the parent-child relationship affected levels of depression, stress,

and quality of life more so than ACT strategies that were not specific to the parent-child relationship. This could also include a follow up measure to see if changes in the variables were maintained over time.

Given the results of this study, on a macro level, it may be prudent to advocate for increased availability of services for parents of children diagnosed with autism in order to address parental levels of depression, stress, and quality of life. On a micro level, health care professionals may want to take a proactive stance in identifying parental challenges, such as stress, depression, and quality of life, which could have an impact on the child's development. Based on the results of this study, practitioners working with parents of children diagnosed with autism may see benefits from incorporating strategies focused on increasing parental quality of life into their treatment planning and implementation.

### **Conclusion**

The number of children who display characteristics of autism in the United States has been on the rise (CDC, 2014). Not only do children diagnosed with autism experience difficulties related to the defining characteristics of autism, but parents of children diagnosed with autism commonly experience negative consequences as well. Parents of a child diagnosed with autism more often report symptoms of depression, stress, and reduced quality of life than their counterparts with neurotypical children. These traits have the potential to negatively affect parents' capacity to assist their child in receiving needed treatment and can limit the ability of parents to learn and utilize effective strategies to assist their child in their future development.

The foundation of this study was based on relational frame theory and investigated the effects that ACT might have on parents who have a child diagnosed with autism within California. The dependent variables were stress, depression, and quality of life. The independent variable was treatment, with three intervention levels: ACT, behavior analytic training, and a no treatment control group. A quasi-experimental, non-equivalent, pretest-posttest design was used to examine the variables.

 $H_01$ : There will be no difference in changes from pretest to posttest for the overall/total posttest score related to depression, as measured by the Beck Depression Inventory-II, across treatment groups (ACT, behavior analytic training, no-treatment control).

 $H_02$ : There will be no difference in changes from pretest to posttest for the overall/total posttest score related to stress, as measured by the Parenting Stress Index-Short Form, across treatment groups (ACT, behavior analytic training, no-treatment control).

H<sub>0</sub>3: There will be no difference in changes from pretest to posttest for the overall/total posttest score related to quality of life, as measured by the Quality of Life Inventory, across treatment groups (ACT, behavior analytic training, no-treatment control).

Given perceived variability in responding, the change scores were analyzed, using the Kruskal-Wallis, a non-parametric test. According to the results of the Kruskal-Wallis pretest, posttest and decline scores for the BDI and PSI, no significant differences were found. The findings provided support to retain the null hypothesis  $H_01$  and  $H_02$ .

However, significant differences were found for the QOL increase score. The significant findings of the Kruskal-Wallis test provided support to reject the null hypothesis H<sub>0</sub>3.

According to the literature, parents of children diagnosed with autism seem to experience heightened levels of depression, stress, and reduced quality of life.

Identification of an effective treatment to reduce parental levels of depression, stress, and increase quality of life could provide parents with a venue through which to address challenges they may be experiencing related to their child's disability and may subsequently lead to more meaningfully interactions between parents and child.

According to the results of this study, quality of life can be improved at a significant level for parents of children diagnosed with ASD. Given this information, once a child is diagnosed with autism, it may be prudent to advocate for services for parents in order to proactively address known correlations of stress, depression, and reduced quality of life. Additionally, practitioners working with parents of children diagnosed with autism may see benefits from incorporating ACT strategies into their treatment planning and implementation.

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# Appendix A: Demographic Questionnaire

De	ar					
Ple	ease answer all of the following	questions:				
Participant/Parent:		Child:				
1.	Are you over 18: YesNo_	1. Age:mos				
2.	Male: Female:	2. Male:Female:				
3.	Marital Status:	3. Diagnosis:				
	Married:	4. Age at Diagnosis:yrsmos				
	Divorced/Separated:					
	Single:					
4.	Ethnicity:					
	Asian:	Caucasian:				
	Hispanic:	African American:				
	Native American:	Other:				
5.	Education					
	HS Diploma:	Some College:				
	Bachelor's Degree:	Master's Degree:				
	Other:					
6.	Have you ever received Acceptance and Commitment Therapy before?					
7.	Have you ever received training in applied behavior analysis where the purpose					
	was to increase your ability to more effectively interact with your child?					
8.	Are you currently enrolled in o	or receiving any other therapies?				
	If yes, what?					

# Appendix B: Evaluation of Trainer

# **Evaluation of Trainer Questionnaire**

Name of Trainer:	C	lass:		)ate:	
Please check the box that you believe	is most a	occurately	reflects	the class:	
	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
The trainer was prepared for each					
class					
The trainer answered questions and					
clarified content					
The balance between instruction and					
participation was good					
The trainer spoke in a soft or muffled					
voice					
The trainer maintained good eye					
contact with the learners					
The trainer used language					
understandable to the learners					
The trainer looked tired and bored					
The trainer presented in an					
unprofessional manner.					
Overall, I am confident with the					
trainer's skill level					
Overall, I am satisfied with the trainer					
	1	1	1	1	1

Appendix C: Flier

# RESEARCH OPPORTUNITY

# FOR PARENTS OF A CHILD DIAGNOSED WITH AUTISM Doctoral Dissertation

Are you the parent of a child diagnosed with Autism?

Is your child between the ages of 36 months and 12 years?

If so, please consider being a research participant!

Your participation is crucial in the expansion and development of effective services for parents of children diagnosed with autism!

## Participants needed:

- 1. Parent(s) who are on a waiting list for services or are not currently receiving any services
- 2. Parent(s) who have not received group parent training in behavior analysis or Acceptance and Commitment Therapy

### FOR ADDITIONAL INFORMATION CONTACT

Dawn Montgomery xxx-xxx Cell

### Appendix D: Informed Consent

# INFORMED CONSENT FORM FOR A RESEARCH STUDY OF Effects of Acceptance and Commitment Therapy for Parents of Children with Autism

You are invited to take part in a research study conducted by Dawn Montgomery, who is a doctoral student in clinical psychology at Walden University. This research study will explore the effects of Acceptance and Commitment Therapy for Parents of Children Diagnosed with Autism compared to the effects of individuals who participate in alternative treatment programs. You have been selected to participate in this study because you have a child diagnosed with autism between the ages of 3 years and adulthood.

This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

**Background Information:** The purpose of this study is to investigate the effects that Acceptance and Commitment Therapy might have on parents of children diagnosed with autism compared to parents of children diagnosed with autism who participate in behavior analytic training and those who have not received either service.

**Procedures:** In order to participate in this study, you must be a parent of a child diagnosed with autism wherein the child is no younger than three years of age. Additionally, you must have no prior history of participating in group training on behavior analytic principles or acceptance and commitment therapy.

If you agree to be in this study, you will be asked to commit to the following: Inventories: To be completed twice during a 6 week period Completing all of the below self-report measures should take between 40 - 55 minutes

- Complete a brief demographics questionnaire
- Complete the Beck Depression Inventory-II (BDI-II) which is a self-report measuring perceived levels of depression.
- Complete the Quality of Life Inventory (QOLI) which is a self-report measuring overall life satisfaction.
- Complete the Parenting Stress Index Short Form (PSI-SF) which is a self-report measuring perceived levels of stress and effectiveness in dealing with stress.
- Participants in a treatment group additionally complete the Rate the Trainer Questionnaire

**Voluntary Nature of the Study:** Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you want to be in the study. No individual who provides the treatment or has referred you to this study will treat you differently if you decide not to be in the study. If you decide to participate in the study, you can still change your mind at any point and stop. You may also choose to skip any questions that you feel are too personal.

**Risks and Benefits of Being in the Study:** The risks of participating in the study are minimal, yet some of the content of the survey questions may be somewhat emotionally upsetting. The benefits to you include the knowledge that your participation in this research will advance the field and positively contribute to identifying potentially effective treatments for parents of children with autism.

**Compensation:** Participation in this study is entirely voluntary. You will not be compensated for your time or participation.

**Confidentiality:** Any information you provide will be kept entirely confidential. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or any other identifying information in any reports of the study. The self-report measures you complete will not contain any identifying information with the exception of a coded number. A coded number is used only so that the researcher is able to contact you should there be any concerns regarding risk for depression.

Contacts and Questions: If you have any questions at any time or would like a copy of the results upon study completion, you may contact the researcher, Dawn Montgomery, at xxx-xxx-xxxx or xxx.xxxx@xxxx.xxxx. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-xxx-xxxx, extension xxxx. Walden University's approval number for this study is 03-15-12-0055558, which will expire on 02/11/2015.

You may keep a copy of this informed consent form for your records.

### **Statement of Consent:**

I have read the above information and I feel I understand the study well enough to make an informed decision about my involvement. By signing below, I am agreeing to the terms described above.						
Printed Name of Participant:						
Date of Consent: Phone Number:						
Address:	_					
Participant's Signature:						
Researcher's Signature:						