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# The impact of a group-based acceptance and commitment therapy intervention on parents of children diagnosed with an autism spectrum disorder

Jennifer D. Kowalkowski

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The Impact of a Group-Based Acceptance and Commitment Therapy Intervention on Parents of  
Children Diagnosed with an Autism Spectrum Disorder

by

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Dissertation

Submitted to the Department of Psychology

Eastern Michigan University

in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Clinical Psychology

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June 25, 2012

Ypsilanti, Michigan

## Dedication

*When you change the way you look at things, the things you look at change. — Wayne Dyer*

This dissertation is dedicated to every parent of a child with an autism spectrum disorder. To the many families I have known personally, particularly the mothers who graciously provided their time for this study, I am deeply indebted to you for letting me learn and grow from your experiences. I am forever in awe of the passion and devotion you show to your families.

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## Abstract

Parents of children diagnosed with an autism spectrum disorder face significant stressors and challenges; however, little research has investigated ways to effectively address their psychological distress and adjustment issues. This study used a between-subject and within-subject repeated measures design to test the effects of an 8-week Acceptance and Commitment Therapy (ACT) or treatment as usual (TAU) group. Treatment completers included 13 mothers in the ACT condition and 4 mothers in TAU. They were assessed three weeks before the intervention, one week after, and three months post-intervention. Limited data for between-group comparison demonstrated only a significant difference on the frequency scale of the Automatic Thoughts Questionnaire (ATQ), in which frequency of automatic thoughts increased for mothers in the TAU condition. For mothers in the ACT condition only, repeated measures ANOVAs revealed significant decreases from baseline to post-intervention on the Parental Distress Index of the Parental Stress Index-Short Form. Baseline to post-intervention decreases were seen for the GSI of the Brief Symptom Inventory-18 (BSI-18), with some regression to baseline at follow-up but overall reductions maintained. Similar significant findings were also demonstrated with increases in the Positive Aspects of Caregiving and decreases in the ATQ total score and the believability scale.

No statistically significant changes were seen on the Depression Index of BSI-18, the Acceptance and Action Questionnaire II, or the Five Facets of Mindfulness Questionnaire. In exploratory analysis, experiential avoidance correlated positively with multiple scales of a self-administered measure of executive functioning, including a measure of one's ability to shift attention rapidly. Additionally, mothers who reported significantly greater levels of externalizing problem behaviors also reported significantly higher degrees of parental distress. This research

suggests that an ACT-based treatment delivered in group format may be of assistance in helping parents better adjust to the difficulties in raising children with autism.

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## **Chapter 1: Introduction**

### **Background**

The prevalence of autism spectrum disorders has increased markedly over the past few decades, with current estimates at one in every 88 births (Centers for Disease Control and Prevention [CDC], 2012; Fombonne, 2003). Individuals with autism spectrum disorders (ASD) often display marked social impairment, communication deficits, and rigid patterns of behavior (DSM-IV-TR, 2000). Parenting a child with ASD is often a difficult and stressful experience. In addition to problems in communication abilities, children with ASD often exhibit behavioral excesses (e.g., tantrums or self-stimulatory behaviors) that increase the challenge of parenting these children. The parents of these children appear to be at a great risk for psychosocial difficulties due to the difficult nature of the disorder (Lecavalier, Leone, & Wiltz, 2006), significant financial stressors (Johnson & Hastings, 2002; DeMyer, 1979), and the demanding lifestyle required to care for a child with such a disability. These parents have also been found to engage in maladaptive coping styles (Hastings & Johnson, 2003; Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005), experience increased marital conflict (DeMyer, 1979), and have a reduced perception of social support (Higgins, Bailey, & Pearce, 2005).

Parents of children with ASD tend to report more stress than parents of children without disabilities or with other disabilities (e.g., Down's syndrome, chronic physical conditions; Dumas, Wolf, Fisman, & Culligan, 1991; Phetrasuwan & Miles, 2009) regardless of geographic location or symptom severity (Koege, Schreibman, L., Loos, L. M., Dirlich-Wilhelm, H., et al., 1992). Parental depression is already a strong correlate of typical parenting stress (e.g., Gelfand, Teti, & Fox, 1992; Maxted, Dickstein, Miller-Loncar, High, Spritz, Liu, & Lester, 2005) and is often exacerbated when a child is diagnosed with an ASD (Hastings et al., 2005). Mothers of

children with ASD have typically reported higher levels of depression than fathers (Hastings et al., 2005; Olsson & Hwang, 2001), which makes them a clinical population in need of intervention.

However, researchers have identified a number of factors that might serve a protective role in reducing the amount of stress and burden experienced by these parents. Factors such as the presence of both parents at home (Beckman, 1983) and acceptance and understanding of the child's condition (Denhoff & Holden, 1971) have been found to correlate with more successful coping and adjustment. Active avoidance coping (e.g., using alcohol/drugs, blaming or criticizing self, giving up trying to deal with it) is associated with more stress, anxiety, and depression for mothers and fathers (Hastings et al., 2005), whereas positive coping is negatively correlated with depression (e.g., making jokes about the situation, looking for something good in a situation, learning to live with it, getting comfort or understanding from someone). Providing parents of children with ASD strategies to increase adaptive coping skills (e.g., acceptance of their reality) appears to be a potentially effective way to prevent and treat of stress, burden, and/or depression.

Unfortunately, the extensive intervention efforts afforded to alleviate symptoms of ASD for children with the disorder have not been readily extended to their parents/caregivers. Beyond the literature that focuses on teaching parents training to manage behavior problems, increase socialization, and facilitate academic and communications skills (Anan, Warner, McGillivray, Chong, & Hines, 2008; Nefdt, Koegel, Singer, & Gerber, 2010), little empirical research has investigated effective means of supporting parents of children with autism in terms of coping skills, associated psychopathology, and stress. An early study involved a short-term group therapeutic approach, which combined elements of behavior management training (focused on

the child's behavior) with a forum for sharing experiences and concerns (Samit, 1996). Other interventions have also included elements of coping skills, but typically as a supplement to child-specific parental skills training (Micheli, 1999). Another intervention took the form of a mutual support group (Davidson & Dosser, 1982); however, all interventions examined were methodologically weak.

A therapeutic approach called Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999) offers an alternative to skills training and traditional forms of psychotherapy. ACT has historically addressed disorders such as anxiety and depression but seems to address the persistent problems of parenting children diagnosed with autism. ACT was developed primarily to treat individuals with chronic levels of distress that have debilitating effects on functioning in multiple life domains. ACT cuts across conventional DSM-IV diagnostic categories to minimize a client's use of ineffective processes (which are referred to as *cognitive fusion* and *experiential avoidance*) that arguably underlie many diagnosable conditions. ACT has been established as an effective treatment for a multitude of disorders (e.g., depression, anxiety, smoking cessation, chronic pain, psychosis; Öst, 2008; Powers, Vörding, & Emmelkamp, 2009). Since parents of children with ASD have a well documented use of ineffective coping skills, an intervention that addresses avoidance of experiences that create uncomfortable emotional responses (i.e. guilt, fear) is uniquely fitting. ACT works to increase a client's psychological flexibility, attentiveness to the present moment, and the establishment of and engagement in personal values.

The efficacy of using ACT within this population has been tested only once in the experimental literature (Blackledge & Hayes, 2006). The researchers implemented a 2-day group ACT workshop for 20 parents of children diagnosed with autism. Although the study did have

considerable weaknesses (e.g., lack of experimental control with use of a control group), the results suggested promising effectiveness. Analyses revealed pre-to-post improvements on a measure of depression, a general health questionnaire, and process measures such as experiential avoidance.

### **Purpose and Objectives**

The proposed intervention expanded upon a previous efficacy study (i.e., Blackledge & Hayes, 2006) in three ways: (1) incorporated randomization and the addition of a TAU group to demonstrate further experimental control, (2) expanded outcome measures, and (3) used group-based intervention in eight consecutive 1.5 hour sessions rather than an intensive weekend workshop. The main objective for this project was to further determine the feasibility of a group-based ACT intervention in a novel population (mothers of children with ASD). An additional objective for this pilot study was to not only examine the effect of such acceptance-based treatments on the negative aspects of caregiving (i.e. burden/stress, depression) but to also assess change in the parent's subjective experience of positive aspects of caregiving (e.g., finding meaning in their experience of caregiving). Additionally, this study included an investigation of the relationship of a neurocognitive measure of executive functioning (BRIEF-A) with a measure of psychological inflexibility (AAQ-II), as this concept had not been previously established within the literature.

### **Research Questions/Hypotheses**

The primary aim of this project was to examine the effects of a group-based ACT intervention on a measure of parental stress, a measure of positive affect, and the anxiety/depression scales of a measure of psychological distress. The intervention group was intended to be compared to TAU; however, due to significant dropout rates in the second wave,

the TAU group was terminated following the first wave. Thus, repeated measures on the ACT group members served as their own control. The first hypothesis for this study was that the mothers in the intervention group would have a statistically lower report of psychological dysfunction at follow-up (as measured by a total scale score on the global severity index and anxiety and depression scales of the BSI-18) than at baseline and of the TAU. A second hypothesis was that the ACT group would also report less subjective stress (as measured by the PSI-SF Parental Distress scale score) at follow-up than at baseline and of the TAU. Third, it was hypothesized that mothers in the ACT group would endorse a significantly greater number of positive aspects of caregiving (as measured by the PAC total score) at follow-up than at their baseline levels and of the TAU group.

A secondary aim of this intervention was to examine the role of ACT-specific processes in the intervention. It was hypothesized that mothers in the ACT group would demonstrate lower levels of experiential avoidance (as measured by the AAQ-II total score) at follow-up than their baseline levels and those of the TAU group, as well as significant reductions in the believability of their thoughts (as measured by the total score of the B scale on the ATQ). It was also hypothesized that the ACT group would endorse more indicators of mindfulness (as measured by the total score of the FFMQ) at follow-up than their baseline levels and those of the TAU.

An additional research question that was examined was the correlation between the severities of the children's behavioral problems (as measured on the BASC-2 scales) on the mothers' levels of distress at various time points (baseline, post, and follow-up). It was hypothesized that mothers who report greater amounts of parental distress (Parental Distress scale on PSI-SF) would also report greater degrees of behavioral problems for their children (a positive correlation). The researchers also examined the correlation between the total score on a

measure of psychological flexibility (AAQ-II) and a neurocognitive measure of executive functioning (BRIEF-A). It was hypothesized that the AAQ-II scores would correlate positively significantly with the scores on the BRIEF-A, in particular the scale measuring one's ability to shift attention from one thing to another.

## Chapter 2: Review of the Literature

In the literature review that follows, the general characteristics of autism spectrum disorders, diagnosis, and common challenges associated with these disorders are discussed. The following section discusses characteristics of parents of children with autism, including factors influencing general distress, parental stress, and psychopathology. This is followed by a review of the treatment literature for reducing stress and psychopathology in these parents, followed by a discussion of the plausibility of a novel application of Acceptance and Commitment Therapy within this population. Finally, the review concludes with a detailed review of the theoretical and empirical literature regarding Acceptance and Commitment Therapy and the applicability of this intervention for parents of children with autism spectrum disorders.

### Autism Spectrum Disorders

The term *autism spectrum disorder* (ASD) is often used to describe a range of diagnostic disorders that stem from general impairment in social interaction and communication skills. This term encompasses the more classic Autistic disorder, Asperger syndrome (which has similar characteristics but lacks delays in cognitive development and language), and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), which is typically diagnosed if the individual does not meet criterion for either of the other disorders (DSM-IV-TR, 2000). The prevalence of ASD has increased markedly over the past few decades and is now considered one of the most common developmental disabilities (Newschaffer et al., 2007), with current estimates of 1 in every 88 births (CDC, 2012; Fombonne, 2003). This neurobiological disorder is believed to occur in virtually all racial and ethnic groups and across all levels of socioeconomic status; however, it is almost 5 times more likely to occur in boys than in girls (CDC, 2012).

Although the majority of cases of ASD have no known cause, approximately 10% of children have an identifiable genetic, neurologic, or metabolic disorder (e.g., Fragile X; CDC, 2012).

Parenting a child with ASD is often a difficult and stressful experience. The stress and burden placed on the parents of these children can most clearly be articulated by examining the common characteristics of these disorders. Many individuals with ASD will display characteristics such as marked social impairment, communication deficits, and rigid patterns of behavior (DSM-IV-TR, 2000). In addition to problems in communication abilities, children with ASD often exhibit behavioral excesses (e.g., tantrums or self-stimulatory behaviors) that increase the challenge of parenting these children.

### **Characteristics of Parents of Children with an ASD**

The parents of these children appear to be at a great risk for psychosocial difficulties due to the difficult nature of the disorder (Lecavalier, Leone, & Wiltz, 2006), significant financial stressors (Johnson & Hastings, 2002; DeMyer, 1979), and the demanding lifestyle required to care for a child with such a disability. These parents have also been found to engage in maladaptive coping styles (Hastings & Johnson, 2003; Hastings et al., 2005), experience increased marital conflict (DeMyer, 1979), and have a reduced perception of social support (Higgins, Bailey, & Pearce, 2005). While the population of focus for this study is parents of children with ASD, this literature review is broadened to include research on general parenting distress and experiences of parents of children with developmental disabilities because the scope of specifically ASD is still limited in the literature base.

**General distress.** The experience of parenting, more generally, has been documented to produce a considerable amount of stress within a family (Deater-Deckard & Scarr, 1996), stress that arises from the demands of being a parent. This stress has been defined as “a set of processes

that lead to aversive psychological and physiological reactions arising from attempts to adapt to the demands of parenthood” (Deater-Deckard, 2004, p. 6). Although all parents deal with some degree of stress, the likelihood of that stress to be chronic and affect their well-being increases when parenting a child with special needs (Dyson, 1993). The overarching concept of such stress has been measured by researchers in a multitude of ways; however, there are a few assessment devices that have the ability to specifically measure the stress associated with parenting, including the Parental Stress Scale (Berry & Jones, 1995) and the Parenting Stress Index (Abidin, 1995). The latter is a more detailed assessment measure and has been used in a number of studies, including some with children with developmental disabilities (Doneberg & Baker, 1993; Kazdin, 1990; Moran, Pederson, Pettot, & Krupka, 1992; Robbins, Dunlap, & Plienis, 1991). In one particular study, researchers found that parents of children with ASD who reported their child to be more difficult to handle were less engaged and reported higher stress levels (Kasari & Sigman, 1997).

Parents of children with ASD tend to report more stress than parents of children without disabilities or with other disabilities (e.g., Down’s syndrome, chronic physical conditions; Dumas et al., 1991; Moran et al., 1992; Phetrasuwan & Miles, 2009) regardless of geographic location or symptom severity (Koegel et al., 1992). There is also growing support that indicates that parenting stress not only produces negative effects for the parents but also affects their parenting style (Abidin, 1995; Crnic & Low, 2002). Parents of children with ASD have been found to score high in aggravation measures, as compared to parents of typical children (Schieve, Blumberg, Rice, Visser, & Boyle, 2007), and parents who report greater levels of stress tend to use more negative parenting practices (e.g., harsh discipline, rejection), which has been associated with more problematic behaviors in their children (Dodge, Pettit, & Bates, 1994).

**Psychopathology.** It is widely documented that parents of children with ASD exhibit higher rates of psychopathology, particularly clinical depression and anxiety. Parental depression is already a strong correlate of typical parenting stress (e.g., Gelfand et al., 1992; Maxted et al., 2005) and is often exacerbated by incurring the diagnosis of ASD within a family (Hastings et al., 2005). Mothers of children with ASD have typically reported higher levels of depression than fathers (Hastings et al. 2005; Olsson & Hwang 2001), which make them a clinical population in need of intervention. Bitsika and Sharpley (2004) reported that more than half the parents in their study (n=107) endorsed symptoms of being highly anxious, and two thirds of the individuals met criterion for clinical depression. Research also indicates a five-times-greater incidence of bipolar disorder in parents of children with ASD than in the general population (DeLong & Dwyer, 1998). Despite these alarming rates of psychopathology, it is still not completely clear if these clinical conditions precede the diagnosis of ASD (and possibly contribute to it), arise in response to it, or a combination of both.

In addition to the well-documented psychopathology that plagues these families, there are a multitude of emotions that come with the experiences involved in parenting a child with ASD. Upon learning of their child's condition, parents report experiencing emotions such as "alarm, ambivalence, denial, guilt, grief, shame, self pity, sorrow, depression, and a wish for their child's death" (Price-Bonham & Addison, 1978, p. 223). Additionally, the parents' sense of responsibility and self-blame often results in feelings of guilt, shame, hatred, and anger directed both toward themselves and possibly their partners (Konstantareas, 1990). Parents might also feel emotions associated with grief and loss over the "idealized non-disabled" child their child may have been if not for their disability (McCubbin, Cauble, & Patterson, 1982). These emotions, coupled with higher rates of depression and anxiety, have the potential to drastically

compromise a parent's ability to manage their daily affairs, care for their children, and engage in the lives they have dreamed of living.

### **Sources of Stress for Parents**

Many researchers have speculated on the specific sources of stress for families of children of ASD and, more generally, parents of children with disabilities. Although many studies have examined only the correlation between stress and parenting a child with special needs, some researchers have investigated direct relationships with specific stressors that are often unique to these families.

**Stress associated with ASD diagnosis and treatment.** Despite a recent decline in age at diagnosis sparked by demand for more efficient diagnostic techniques (Johnson & Meyers, 2007; Kleinman, Ventola, Pandey, Verbalis, Barton, Hodgson, et al., 2008), many children are still not diagnosed until much later in childhood than parents would have liked (Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006). Some parents may feel guilt and stress regarding the “wasted treatment time” prior to diagnosis, especially considering that more than 80% of parents report recognizing symptoms by 24 months of age (De Giacomini & Fombonne, 1998). Mothers, generally the primary caregivers, also tend to have stressful concerns over the permanency of the condition, future occupational prospects, poor acceptance of autistic behaviors by society, very low levels of social support, and the restrictions placed on other family members by the autistic child (DeMyer, 1979; Holroyd & McArthur, Sanders & Morgan, 1997).

Although there is no known cure for autism spectrum disorders, many families seek to alleviate the symptoms of the disorder with one or more therapies or treatments. With hundreds of available treatments, caregivers often experience distress and confusion in selecting the appropriate interventions for their children (Woodgate, Ateah, & Secco, 2008). Many

interventions require families to hire professionals or therapists to perform various services with their child (e.g., occupational therapy, speech therapy), which adds the additional stress of bringing strangers into one's home and family affairs.

One of the most empirically validated treatments for symptoms of ASD is applied behavior analysis (ABA; Granpeesheh, Tarbox, & Dixon, 2009). Based on learning theory, behavioral principles (i.e., reinforcement, shaping, and fading) are applied to the individual behavioral deficits and excesses experienced by the individual with autism. ABA treatments have notably been recommended for children with ASD at intensity levels ranging from 20 to 40 hours per week. Many intervention hours are actually conducted in the home, and in an effort to save on costs, some therapists will provide training (followed by close oversight) to the caregivers so that they may implement the interventions with the children themselves (Anan et al., 2008). The added responsibility of managing (and often participating in) such intensive and long-term treatment does not come without both positive and negative consequences. Schwichtenberg and Poehlmann (2007) found that caregivers of children with ASD participating in home-based ABA program tended to endorse more symptoms of depression than mothers of children with other disabilities and report more personal strain when their children were receiving more hours of ABA intervention.

However, there is also evidence to suggest that when parents and caregivers of children with autism are actively involved in their child's educational programming, the prognosis for both caregiver and child are significantly better (Koegel, Schreibman, O'Neil, & Burke, 1983). Tonge and colleagues (2006) found greater improvement in parental mental health (e.g., anxiety, insomnia, and somatic symptoms) for parents who participated in a parent education and behavior management intervention than for those who received a more general counseling

intervention. Keen and colleagues (2010) found reduced child-related parenting stress and increased parental self-efficacy when parents were given a skills-based intervention directed at helping their children. Despite commonly held beliefs, this benefit experienced by parents does not actually appear to stem from greater perceived control over their life events, as the locus of control literature has not supported a mediational role between stress and psychological functioning (Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007). Furthermore, it has been demonstrated that families who report greater beliefs in the efficacious nature of the treatments being implemented with their children tend to report lower levels of stress, suggesting that engaging in empirically-validated treatments may serve as a protective factor for family stress (Hastings & Johnson, 2003).

Finding ways to help parents manage their chronic stress appears to not only benefit parental well-being but also child functioning. For instance, mothers of children with externalizing behavior problems who perceived them as less adaptable, less acceptable, and more moody tended to have greater stress levels and premature termination from treatment (Kazdin, 1990). In fact, in a study examining the relationship of stress and progress in treatment, the researchers concluded that higher maternal stress levels were correlated with less progress in treatment for their child with ASD (Robbins, Dunlap, & Plienis, 1991).

**Financial stressors.** Another common source of stress associated with the diagnosis of ASD is the amount of financial responsibility that families are expected to endure. Although some families receive federal or state funding or insurance coverage for some treatments, the vast majority of families spend a considerable amount “out of pocket.” Intensive behavioral intervention programs can cost up to \$60,000 per year (Butter, Wynne, & Mulick, 2003). Families might also incur high costs related to the care for their child with special needs (e.g.,

more expensive daycare options) and may often have to take time off from work to respond to their child's needs, resulting in loss of pay and, sometimes, friction with their employer. Beyond the costs associated with treatment, it is estimated that the lifetime incremental societal cost of each individual with ASD is approximately \$32 million (Ganz, 2007), and average medical expenditures were more than 4 times greater for those with ASD than for those without (Shimabukuro, Grosse, & Rice, 2008).

**Parenting versus caregiving.** Although the act of parenting is generally not thought of as an experience in caregiving, the term (and its rich research base) might actually be applicable in the context of parenting a child with special needs. The act of caregiving can be defined in multiple ways. The *Family Caregiver Alliance* (2005) defines a caregiver (CG) as anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help. The act of caregiving has been categorized into two main categories, informal and formal CG's. Informal CG's represent the majority of CG's and refers to unpaid individuals such as family members, friends, and neighbors who provide care. According to the *Family Caregiver Alliance*, these individuals "can be either primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately" (2005, p. 1). For most families coping with ASD, the child's mother serves the role of primary caregiver (Howard, 1978). This is contrasted with formal caregivers who are typically either paid care providers within a service system or volunteers (e.g., behavioral tutors, respite workers; Fradkin & Heath, 1992; McConnell & Riggs, 1994).

Many children with ASD require constant supervision to prevent self-injury or harm, assistance in activities of daily living past the preschool years, and caregivers who are skilled at managing their difficult behavioral problems (Matson & Nebel-Schwalm, 2007). There is a

strong and stable positive correlation between externalizing behavior problems and caregiver stress (Lecavalier, Leone, & Wiltz, 2005), which adds difficulty to the act of caregiving for these children. In fact, Doneberg and Baker (1993) found that parents of children with externalizing behavior problems and parents of children with ASD report similar amounts of stress, both of which are significantly higher than those of typically developing children. Mothers of children with ASD also report the necessity of constant care as a significant source of stress within their families (Bouma & Schweitzer, 1990), with caregivers of children with ASD spending as many as 60 hours per week or more involved in caring and supporting their child as a result of their diagnosis (Jabrink, Fombonne, & Knapp, 2003; Tunali & Power, 2002). An analysis of parenting a child with special needs as a caregiving experience may result in an expanded literature base from which generating treatments and assessment measures is broadened.

**Marital and interpersonal difficulties.** Caregivers who report receiving higher amounts of informal social support tend to report lower levels of stress (Hastings & Johnson, 2003). It has been demonstrated that a lack of social support, unsupportive interactions, and disruptive child behaviors are predictors of daily mood (Pottie, Cohen, Ingram, 2009). It is also commonly known that social support processes are generally considered to function as buffers to the effects of stress and to enhance personal well-being (Cohen & Wills, 1985). Unfortunately, these parents often find themselves in situations that place significant strain on their interpersonal relationships with others, such as the inability to go particular places because of their child's externalizing behaviors or lack of socialization time due to obligations with their child's treatment. This strain often results in feelings of rejection and isolation from their communities (Davidson & Dossier, 1982; Intagliata & Doyle, 1984; Kazak & Wilcox, 1984; Trute & Hauch, 1988) and negative

reactions/embarrassment with friends due to their children's behavior (McCubbin, Cauble, & Patterson, 1992).

Similar difficulties arise within their own homes, as parents of children with ASD report lower marital happiness, less family cohesion, and more difficulties in family adaptability than comparison norm groups (Higgins, Bailey, & Pearce, 2005). Most mothers of children with ASD consider themselves less satisfied in their marriages than mothers of non-disabled children (DeMyer, 1979). However, research in this area has produced mixed results. A recent study conducted at the Kennedy Krieger Institute has debunked the commonly referenced 80% divorce rate amongst these families, suggesting the contrary: that autism does not result in higher divorce rates (Kennedy Krieger Institute, 2010).

**Personal expectations and appraisals.** Some researchers believe that the stress of parenting is interlinked with parents' personal expectations. For instance, if a parent has particular expectations about the necessary resources to meet the demands they face (e.g., competence, support from family members), stress may occur when they do not find the available resources in their environment (Goldstein, 1995). This might occur with parents of children with ASD if they feel they are unable to get acquire the knowledge needed to help their children or the support required to implement the treatments they believe will help the disorder.

Appraisals, particularly negative ones, regarding their own competency and adaptability also add to the distress experienced by the parents of children diagnosed with ASD.

Approximately a third of the mothers of children diagnosed with autism were uncertain if they would be able to be a competent mother to their children (DeMyer, 1979; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981). These mothers tend to feel less competent as parents and perceive their families as less adaptable than mothers of non-disabled children and even other

developmentally disabled children (Rodrigue, Morgan, & Geffken, 1990). Frey, Greenberg, and Fewell (1989) also found that parents who made negative appraisals of difficulties in their families relative to difficulties faced in other families tended to experience the most stress. Furthermore, fathers who perceived less control over family well-being, and mothers who blamed themselves more frequently for family problems, both tended to report more distress than their counterparts.

These findings suggest a striking truth that is often experienced by families afflicted with ASD: negative appraisals and beliefs about the difficulties of raising these children and the reduced control over their life events may actually be quite logical and accurate. Given the significant sources of stress, financial burden, intensive caregiving responsibility, and social isolation associated with their lifestyle, it may be an evitable reality for some of these families. This realization is particularly important when evaluating treatment options (discussed further in a later section), especially when one of the most common treatments for anxiety and depression (i.e. CBT) often involves a process of coaching clients to address what often appear to be irrational or illogical beliefs.

**Coping and quality of life.** An important model to consider when evaluating how individuals manage the stress associated with their caregiving experience is the stress process model (Lazarus & Folkman, 1984), which serves as the theoretical underpinning of many caregiver intervention studies. This model states that individuals are constantly appraising their transactions with their environment. Transactions that are appraised as stressful require coping to regulate distress. Coping responses can be adaptive (problem-focused coping) or non-adaptive (avoidance-coping). Coping processes lead to an event outcome (e.g., favorable resolution, unfavorable resolution, or no resolution). Emotion is generated through the process of appraisal,

coping, and event outcomes. A favorable outcome is more likely to lead to positive emotions during the caregiving experience. Unsatisfactory outcomes are more likely to lead to additional distress.

Caregivers of children with ASD who engage in adaptive coping strategies are more likely to report experiencing lower stress levels (Hastings & Johnson, 2003), whereas active avoidance coping (e.g., alcohol/drugs, blame or criticize self, give up trying to deal with it) has been associated with more stress, anxiety, and depression for both mothers and fathers (Hastings et al., 2005; Lyons, Leon, Phelps, & Dunleavy, 2010). The same researchers have also found religious/denial coping associated with depression for mothers and depression and anxiety in fathers, and they note that positive coping is negatively correlated with depression (e.g., making jokes about the situation, looking for something good in a situation, making fun of a situation, learning to live with it, getting comfort or understanding from someone). Mothers of children with ASD tend to use self-blame and wish fulfillment as coping techniques more frequently than mothers of non-disabled children (Rodrigue, Morgan, & Geffken, 1990). Parents who blame themselves for their child's condition cope less effectively than those who do not blame themselves (Frey et al., 1989).

Additionally, greater levels of daily positive mood are associated with more emotional and instrumental support and less parenting stress and unsupportive interactions, whereas greater daily negative moods are associated with less emotional support and more parenting stress, unsupportive interactions, and disruptive child behaviors (Pottie et al., 2008). Based on this research, Pottie and colleagues (2008) advocate treatments for parents that include the identification of interpersonal processes that enhance psychological well-being.

## **Protective Factors for Stress**

Following growing concerns regarding the inadequacies of the stress process model to account for reported positive outcomes by caregivers, Folkman (1997) published a revised stress process model. This model was published with considerable empirical support and incorporates meaning-based coping (e.g., positive reappraisal, revised goals, spiritual beliefs, focus on positive aspects of caregiving), as mediators of the impact of negative event outcomes (e.g., unfavorable or no resolution) on resulting emotions. The impact of this revised theoretical model has been great, encouraging many researchers to obtain more support for this conceptualization of the caregiving experience.

Psychological researchers might identify a number of these positive factors as serving a protective role in reducing the amount of stress and burden experienced. Therefore, factors such as social support, marital satisfaction, belief in treatment efficacy, and coping strategies may all serve a protective role against additional stress in the family functioning. In support of this notion, research has found that the presence of both parents at home (Beckman, 1983) and acceptance and understanding of the child's condition (Denhoff & Holden, 1971) are correlated with more successful coping and adjustment. Providing parents of children with autism skills to increase adaptive coping skills (e.g., acceptance of their reality) appears to be a potentially effective focus for the prevention and treatment of stress, burden, and/or depression.

The experience of being a caregiver for children with ASD may also result in some personal growth for the individual. Although many terms have been used to describe these perceived positive aspects of caregiving (e.g., rewards, gratification, benefits, positive impact, positive impact), the experience is more generally termed the "perceived benefit phenomena" (McMillan, 1999) and typically defined as the rewards and satisfaction derived from the

caregiving relationship (Tarlow et al., 2004). This approach provides a broader view of the caregiving experience, one that, according to caregivers, more accurately reflects the “bittersweet” nature of this unique circumstance. Studied more extensively in other populations (e.g., dementia, cancer; Farran, 1997; Kramer, 1997; Rapp & Chao, 2000), this concept is slowly being investigated with caregivers of children with ASD (Corman, 2009). Further research in this area is certainly warranted, and some suggest that intervention strategies should look at helping families understand the perceived benefits (Rapanaro, Bartu, & Lee, 2008).

### **Treatments for Parents of Children with an ASD**

Unfortunately the extensive intervention efforts afforded to alleviate symptoms of ASD for children with the disorder have not been readily extended to their parents/caregivers. Beyond the literature that focuses on teaching parents skills to manage behavior problems, increase socialization, and facilitate academic and communications skills (Anan et al., 2008; Nefdt et al., 2010), few empirical studies have investigated effective means of supporting parents of children with ASD in terms of coping skills, associated psychopathology, and stress. This is a surprising finding, considering the documented degree of stress and psychological dysfunction plaguing this population. Due to the lack of attention in this area, the literature base presented in this review includes research conducted with both parents of children with ASD as well as those with developmental disabilities more generally.

A study conducted by Micheli (1999) was designed to “... broaden the scope of parent training to go beyond the current needs of the child and the application of behavioral techniques and enable parents to foresee future difficulties, cope with change in family needs, and gain knowledge of techniques involved in more general parenting skills” (p. 100). Treatment was conducted in a group format, lasted six sessions, and began with a broad introduction to ASD

and general guidelines for consistency and structure in the home environment. The following three sessions provided an overview of reinforcement principles and the use of time limits, as well as goal setting for different domains of the child's life. In the final session, the researchers reported the delivery of information regarding their coping skills, with an emphasis on emotion identification and regulation. Despite subjective reports from the parents that the treatment was beneficial, the researchers did not use any formal assessment measures to assess effectiveness.

A similar study by Samit (1996) was designed to teach behavior management techniques to parents of children with ASD, while also incorporating a forum for parents to share experiences and concerns. The author notes that the purpose of the forum was to help parents learn "acceptance of the child as he or she was" (Samit, 1996, p. 24). The intervention was delivered on a weekly basis to both parents and extended family members/support staff. The topics discussed each week were selected by the therapists but were noted to be in response to parental concerns. This author did not provide any objective assessment either, thus not allowing conclusions to be drawn regarding its effectiveness.

Another intervention took the form of a mutual support group (Davidson & Dosser, 1982) designed specifically for families of developmentally disabled infants, termed the *Parents Helper Program*. This intervention utilized parent-to-parent support by establishing relationships between parents of developmentally disabled children who were thought to have made healthy transitions to their new lifestyle as parents of children with disabilities with parents of infants just starting in the process. Parents selected as "peer-helpers" underwent a training program that "emphasized the basic elements of successful counseling" and "the nature of various types of developmental disabilities that may be encountered through referrals" (Davidson & Dosser, 1982, p. 297). Unfortunately, despite parental report of an enjoyed experience, this study exhibits

the same methodological flaws as the previous research due to the lack of formal assessment processes.

Even though parent facilitated interventions (e.g., support groups) are a common model of intervention for these families, empirical investigations of their evaluation data are rarely reported (Hastings & Beck, 2008). A noted exception to this trend is a model called the Parent-to-Parent movement (Santelli & Marquis, 1993; Santelli, Poyadue, & Young, 2001). This model is run primarily by parents, with some support from professionals who provide training in supportive techniques. Based on referrals from the community, parents are matched up with “supporter” parents, typically based on child diagnosis, and are provided emotional supports and resources primarily through telephone contact. Singer and colleagues (1999) conducted a controlled trial of this model that was randomized with a waiting list control. Limited outcome measures were used, and the researchers did not use standardized measures to assess for parental stress and mental health well-being. However, the parents did report a positive impact on their family unit and positive gains in their progress toward desired goals.

Beyond the work conducted specifically with parents of children with ASD, additional studies with more general intellectual disabilities populations have demonstrated more methodological rigor. A comprehensive treatment program (Singer, Irvin, & Hawkins, 1988) compared randomized groups of 8-10 parents against a treatment as usual control (case management and weekly respite care services) using a 16-hour treatment package consisting of self-monitoring, muscle relaxation, cognitive restructuring, parental support groups, individual therapy for depression/anxiety, and parent training. The package also included the application of an early version of ACT, called Comprehensive Distancing, which was applied as the individual depression treatment protocol. Results indicated significant reductions in the treatment group for

state and trait anxiety, as well as reduced depression scores, while waitlist participants' scores on these measures increased during the same time period; these results maintained at 1-year follow-up. A less comprehensive study (Nixon & Singer, 1993) used a 10-hour CBT intervention focused on remediating cognitive distortions that contribute to self-blame and guilt to evaluate change pre-intervention and post-intervention intervention and compared to a waitlist control. Results suggested significant reductions in guilt, internal attributions, automatic negative thoughts, and depression.

Gammon and Rose (1991) combined a cognitive restructuring intervention with components of problem solving skills, goal setting, and interpersonal skills training in their evaluation of mothers of children with developmental disabilities receiving a 10-week group-based intervention. Compared to a no-treatment control, individuals in the CBT group demonstrated greater reductions in stress and some evidence of improvements in problem-solving abilities and interpersonal skills (assessed via role play). Greaves (1997) conducted a novel study, which included a head-to-head comparison of Rational Emotive Therapy (RET), Applied Behavior Analysis, and a no-treatment control group for mothers of children with Down's syndrome. During 8 weekly sessions, the RET group focused on core irrational beliefs, whereas the ABA group focused on behavioral parenting skills. Following treatment, mothers in the RET group reported significantly reduced stress, while the other groups indicated no change.

In summary, there is clearly a lack of scientific investigation of effective treatments for this population, which becomes grimmer when looking for treatments for parents of children with ASD specifically. Many studies are lacking methodological rigor (e.g., including no comparison group or weak controls such as waitlists, small sample sizes). The majority of interventions used either some type of parent support group or a combination of CBT-type

interventions. Only one study (Greaves, 1997) compared two active treatments in a head-to-head comparison trial, a necessary element of scientific query in this area.

### **Choosing an Appropriate Treatment**

Although it would appear ideal to use a comprehensive treatment package, similar to the one suggested by Singer and colleagues (1989) to address a host of difficulties for these families with a multi-method approach, the reality is such that a treatment package would likely be too costly and taxing on one agency to deliver. Furthermore, families with limited financial resources and even more limitations on available “free time” may find it very difficult to devote considerable time and effort to a treatment for themselves, despite the necessity. Even though a comprehensive treatment package might not be feasible for the larger community at this time, this does not mean that further empirical investigations of individual treatment components should falter.

Regardless of the higher prevalence of psychological disorders such as depression and anxiety within this population, many parents may benefit from treatment, despite not meeting criterion for a clinical disorder. Thus, when evaluating treatments it is important to consider those treatments empirically-validated for these disorders as well as ones that might best address the specific issues facing this population. Given the above literature review, it appears that traditional behavioral parenting may improve parenting skills but does not necessarily reduce stress and burden for the parents. It also seems that, despite their popularity, there is not empirical evidence for the use of support groups to significantly reduce parental stress.

It does appear that a variety of cognitive-behavioral techniques may be effective, although treatment packages make it difficult to ascertain which elements were successful for producing change. As previously mentioned, a possible caveat to using techniques such as

cognitive restructuring within this population is that oftentimes the irrational belief that needs to be “restructured” is not necessarily that irrational (e.g., the hard work and effort necessary for treatment of ASD or the financial burden faced). However, there is evidence suggesting that maternal acceptance may be bi-directionally related to factors of negative adjustment for parents of children with intellectual disabilities, suggesting that acceptance-based interventions may promote more positive adjustment within these families (Lloyd & Hastings, 2008). A therapeutic approach called Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999) offers an alternative to skills training and traditional forms of psychotherapy and may be applicable to address issues experienced by parents of children diagnosed with an ASD. ACT was developed primarily to treat individuals with chronic levels of distress that have debilitating effects on functioning in multiple life domains. ACT attempts to cut across conventional DSM-IV diagnostic categories to minimize a clients’ use of ineffective processes (e.g., termed cognitive fusion and experiential avoidance) that arguably underlie many diagnosable conditions. ACT has been established as an effective treatment for a multitude of disorders (e.g., depression, anxiety, smoking cessation, chronic pain, psychosis) (Öst, 2008; Powers, Vörding, & Emmelkamp, 2009). Given the ineffective coping skills consistently documented in the literature, such as avoidance strategies, an intervention that addresses avoiding experiences that create uncomfortable emotional responses (i.e. guilt, fear) seems uniquely fitting for parents of children with ASD.

### **Acceptance and Commitment Therapy**

Within the past few decades, a multitude of distinctly different, and often difficult to categorize, therapeutic interventions have arisen, *seemingly* from within the cognitive-behavioral framework. These therapies have been said to expand upon previous generational frameworks

(i.e., first and second wave of behavior therapy) and are collectively described as the “third wave” (Hayes, 2004). Interventions that are considered to constitute this “third wave” are functional analytic psychotherapy (FAP; Kohlenberg & Tsai, 1991), integrative behavioral couples therapy (IBCT; Jacobson & Christensen, 1996), dialectical behavior therapy (DBT; Linehan, 1993), mindfulness-based cognitive therapy (MBCT; Segal, Williams, & Teasdale, 2002), and acceptance and commitment therapy (ACT; Hayes et al., 1999).

“Third wave” therapies maintain a core set of differences from other behavioral and cognitive therapies (e.g. an emphasis on contextual and experiential change strategies, incorporation of mindfulness, and the acceptance of private experiences). DiGiuseppe (2008) raises the question of general common factors amongst all first generation behavioral approaches and similarly in third wave approaches, suggesting that these interventions may actually be more similar than different. Although this debate is not prominent within the ACT literature, it is certainly something to be considered.

ACT is rooted in the pragmatic functional contextualism philosophy, a “specific variety of contextualism that has as its goal the prediction, and influence of actions, with precision scope and depth” (Hayes et al., 2006, p. 4). This form of contextualism, where focus is on the ongoing events viewed in their natural context, underlines much of third generation behaviorism (Biglan & Hayes, 1996). The theoretical underpinnings of the ACT model are also unique in that they are based on a basic research program in language and cognition, referred to as Relational Frame Theory (RFT; Hayes et al., 2001), which was discussed previously. Due to the strong conceptual link between basic and applied research, many of the core components of ACT can be manipulated experimentally, allowing for greater scientific investigation (for a review, see Ruiz,

2010). According to one of the developers, Steven Hayes, “ACT is neither from the first wave of behavior therapy nor the second, although it builds upon both” (2004, p. 645).

First introduced in the literature as Comprehensive Distancing (Zettle & Hayes, 1982), the earlier model of ACT was named after aspects of the therapeutic approach that was similar to the “distancing” component in Beck’s protocols for Cognitive Therapy (Butler et al., 2006). Much of the original Comprehensive Distancing material was incorporated into the current version of ACT with some expansions (e.g., values identification and clarification work, the addition of observer self exercises, and a greater emphasis on the use of the creative hopelessness technique; Zettle, 2005).

**The ACT model.** The current ACT model consists of six core processes that are most often presented in a diagram termed the *Hexaflex* (see Figure 1), which assists in highlighting the interconnectedness of the various treatment components (Hayes et al., 1999). The four processes on the left side of the model speak to the core principles of acceptance and mindfulness inherent in the model, whereas those on the right side primarily address commitment and behavior change processes. At the core of the ACT model is *psychological flexibility*, which is posited as the primary goal of ACT (Hayes, Strosahl et al., 2004; Pull, 2008; Wilson & Murrell, 2004). It has been defined as “the ability to contact the present moment more fully as a conscious human being, and to either change or persist when doing so serves valued ends” (Hayes, et al., 2004, p. 5). From an ACT perspective, individuals do not get to choose which emotions they have; however, they do have the opportunity to choose how they interact with those emotions (Hayes et al., 1999). Therefore, if presented with the opportunity to alter the rigid and inflexible patterns that have developed in their thoughts and feelings, they allow more room for more flexible and presumably psychologically healthier responding (Wilson & Murrell, 2004).

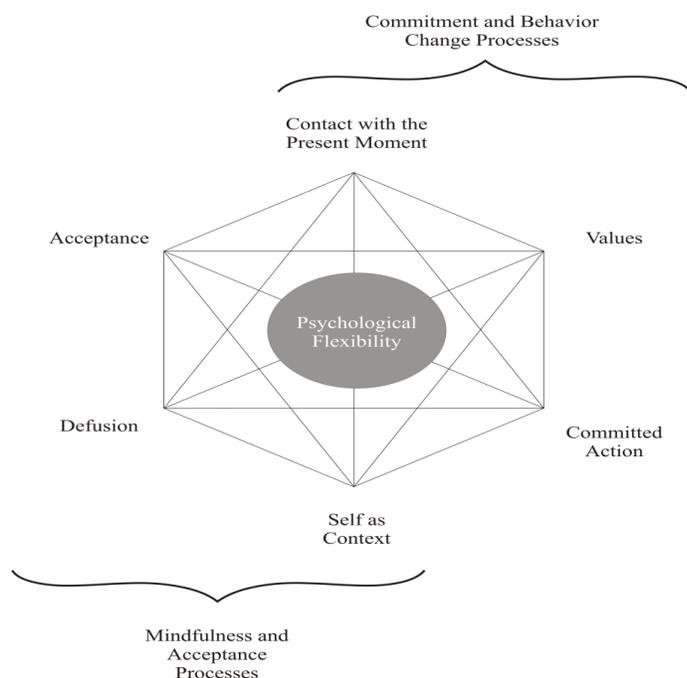
**Acceptance.** One core process is acceptance, the alternative to experiential avoidance. Experiential avoidance (EA) is a term used to define a functional class of behaviors that represent generally negative evaluations of private events (e.g., uncomfortable feelings or thoughts) as well as an unwillingness to experience such events. Individuals who experience EA often have clear patterns of intentional efforts to control or escape these private events (or conditions that occasion them), a cycle that is thought to be maintained by negative reinforcement (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). Although in moderation it is functional, EA “becomes problematic when a person relies on it rigidly and nearly exclusively, without regard to situational appropriateness” (Schumalz & Murrell, 2010, p. 186).

When working on acceptance, the focus is to help assess whether or not a client’s current strategies for managing life and its many stressors are working; if not, then clients are encouraged to cease the struggle they are creating and consider acceptance as a possible alternative (i.e., a technique termed “creative hopelessness”; Bach & Moran, 2008). ACT’s philosophy is to create the willingness to experience what cannot be changed (e.g., private experiences such as guilt felt when a client is unable to accommodate a request from a family member), coupled with the encouragement to change what can be modified (e.g., one’s context, degree of action in valued directions; Wilson & Murrell, 2004).

**Cognitive defusion.** Therapists address maladaptive cognitive fusion that may be impeding the clients’ ability to make regular contact with the present moment or engage in committed action through specific techniques. Clients learn to notice words (emotions, thoughts) for what they are (i.e., sounds associated with meanings and emotional functions) and not for what they say they are (i.e., realities that might bind the client to particular thoughts or beliefs; Wilson & Sandoz, 2008). There are a number of techniques used to accomplish this goal, many

of which are supported by basic RFT literature (Blackledge, 2007). For example, a client may be encouraged to use *deliteration* (i.e., saying a meaningful word, such as “incompetent” over and over) until the functions previously associated with that word are weakened.

***Self as context.*** As clients work to overcome attachments to a conceptualized self, they learn to distinguish between the “self” that serves as a holding space or framework from which psychological activity takes place and the “self” that is intimately linked with the thoughts, feelings, and emotions of their personal history (Valdivia-Salas, Sheppard, & Forsyth, 2009). This therapeutic process is directly linked with the basic RFT literature regarding relational frames, with recent evidence suggesting that this aspect of self is related to the fluency of specific frames (e.g., I versus You, Here versus There; McHugh, Barnes-Holmes, & Barnes-Holmes, 2004). Cognitive neuroscientists are also interested in exploring the neural correlates associated with self-referential behavior and have posed ideas for future research involving an fMRI paradigm to explore this concept (Tagini & Raffone, 2010).



*Figure 1.* Hexaflex: ACT Model of Treatment Processes

***Contact with the present moment.*** In this core process, clients are taught to engage with the “here and now” by embracing both the ongoing environment and physiological events with a non-judgmental and purely observation stance (Hayes et al., 1996). The object is to have clients experience their world in a more direct nature, heightening their sensitivity to the current opportunities for life engagement in valued areas. This emphasis on engaging with the present moment is where ACT incorporates a number of mindfulness techniques. Benefits of mindfulness training have been demonstrated independently of the ACT protocol, reviews of which suggest that mindfulness training is associated with significant improvements in functioning across multiple realms of physical and psychological well-being (Baer, 2003; Kabat-Zinn, 1990; Shapiro, Carlson, Astin, & Freedman, 2006).

Mindfulness has also been linked to a variety of neural correlates (Corcoran, Farb, Anderson, & Segal, 2009). When engaged in mindfulness meditation, preliminary findings

suggest that individuals show increased theta and alpha power bands and decreases in overall wave frequency (Andresen, 2000). Individuals with long-term mindfulness practice demonstrate more flexible emotion regulation patterns, which are thought to be due to engagement of the frontal cortical structures, specifically changes to the anterior cingulate cortex and dorsolateral prefrontal area (Cahn & Polich, 2006). Although it appears that mindfulness does target specific brain areas, these same areas (e.g., emotion and emotional regulation) have also been implicated in other forms of intervention, specifically psychotherapy (Chiesa, Brambilla, & Serretti, 2010). Recent research also suggests that long-time meditators display a significantly larger volume of hippocampal, orbito-frontal cortex, thalamus, and inferior temporal gyrus tissues than a non-meditating group when scanned using high resolution MRI (Luders, Toga, Lepore, & Gaser, 2009). The researchers suggest that increased gray matter may provide evidence for more developed cortical areas for these individuals, providing a neuronal framework for their perceived enhanced ability for emotion regulation and well adjusted demeanor toward life. Hölzel and colleagues (2011) recently published a very informative review paper that highlights the proposed mechanisms of action involved in mindfulness meditation.

**Values.** From an ACT perspective, values are the “individual dynamic ongoing patterns of behavior in different life domains that organize behavior and provide a sense of direction” (Valdivia-Salas et al., 2009, p. 325). Therapists attempt to help clients discover and define what matters most to them in their lives (i.e., what are they passionate about) in a variety of domains (e.g., career, family, community; Dahl & Lundgren, 2006). The process of affirming values appears to have a biological correlate as well; researchers have found that participants who were given a values-affirmation task had significantly lower cortisol responses to stress than those

who received a control task, suggesting that reflecting on personal values may keep neuroendocrine and psychological response to stress at lower levels (Creswell et al., 2005).

**Committed action.** Once a client is able to recognize and state his or her personal values, a major goal of therapy focuses on helping the client engage in committed actions toward those valued paths. Some of this work may appear functionally similar to first wave behavior approaches, like behavioral activation. Bach and Moran (2008, p. 152-153) nicely summarize how committed action can pull together the whole therapeutic approach: “When a client is given an orientation to committed action—defined as behavior in the service of values, defused from unhelpful rules and verbal events, executed in contact with the present moment, while accepting physiological and cognitive responses elicited during that situation—the client has a better platform from which to take her first step toward clinical improvement.”

**Modalities of treatment.** The most frequently tested model of the ACT intervention is delivered in an individual therapy format, generally from 1 to 48 sessions ( $M = 12.1$ ), spanning between 1 and 16 weeks ( $M = 5.2$ ), with total treatment hours ranging from 3 to 24 ( $M=6.6$ ; Hayes, Pankey, Gifford, Batten, & Quiñones, 2002; Öst, 2008). Active treatment components can either be delivered in a more traditional therapy formats or presented in a workshop fashion (e.g., Blackledge & Hayes, 2006), and the coverage of core processes tends to overlap throughout sessions, depending on when particular needs are demonstrated (Bach & Moran, 2008).

Although many of the clinical trials are focused on an individual therapy format of treatment, there is considerable evidence for the application of the ACT model in a group format (Blackledge & Hayes, 2006; Bond & Bunce, 2000; Glaser, Blackledge, Shepherd, & Deane, 2009; Hayes, Bissett et al., 2004; Hayes, Wilson, et al., 2004; Zettle & Raines, 1989). Self-help

manuals are another form of treatment available for those seeking an ACT-based approach, and manuals have been published for parenting (Coyne & Murrell, 2009; McCurry, 2009), relationships (Walser & Westrup, 2009), depression (Robinson & Strosahl, 2008), anxiety (Forsyth & Eifert, 2008), chronic pain (Dahl & Lundgren, 2006), and general distress (Harris, 2008; Hayes & Smith, 2005), among others. Despite popularity within clinical psychology, there are mixed opinions regarding whether these books are able to help clients suffering with a variety of psychological disorders (Redding, Herbert, Forman, & Gaudiano, 2008). A recent RCT evaluated the efficacy of an ACT self-help book, as compared to a wait list control, for individuals with chronic pain and found support for the success of this method with improved quality of life and decreased anxiety (Johnston, Foster, Shennan, Starkey, & Johnson, 2010). Further investigations may shed light on the effectiveness of this approach for a variety of clinical populations, particularly in remote locations where availability of ACT therapists is scarce.

### **Empirical Literature for ACT**

**Reviews of the literature.** The most unique aspect of the ACT literature is the wide variety of clinical applications that have been studied over the past 25 years. Unlike applications of other psychotherapy approaches where researchers initially apply a specific treatment for a specific diagnosis (i.e., DBT for Borderline Personality Disorder), ACT's empirical literature base ranges across diagnostic categorizations and a multitude of delivery formats. The earliest formal review of the ACT literature, conducted by Hayes and colleagues (2004), evaluated the published outcome data for ACT, as well as other third-wave treatments such as DBT and FAP. The authors sought to address claims from within the behavior therapy domain (Corrigan, 2001) that the applications of third wave therapies are "getting ahead of the data." After evaluating the

eight published RCTs (23 empirical papers overall), the authors concluded that ACT researchers have not overstated their claims and that although the research is limited, the model appears to have promising results for a wide range of conditions (Hayes, Masuda, et al., 2004).

In the first meta-analysis conducted by an independent researcher to the ACT literature base, Öst (2008) found a mean effect size (ES) of 0.68, ( $z = 5.11$ ,  $p < 0.0001$ ), with a large ES demonstrated with wait list control groups and moderate ES when compared with treatment as usual and active treatments. This was updated again by Powers, Vörding, and Emmelkamp (2009); with 5 additional RCTs, the researchers found that ACT continues to outperform control conditions on both primary and secondary outcome measures at post-treatment and follow-up compared to waitlist controls or TAU conditions. However, when compared to established treatment conditions, the authors concluded that ACT was not significantly more effective than established treatments (e.g., CBT). This was noted particularly in the treatment of distress problems (anxiety/depression), likely because they included the most head-to-head comparison studies. The effect sizes were calculated using Hedges'  $g$ ; overall ES was determined to be  $g = 0.42$ , 95% CI = 0.23–0.60 and  $g = 0.18$ , 95% CI = –0.06 to 0.42;  $p = 0.13$ , when compared with established treatments. Although there were considerable debates between Powers and ACT researchers within the literature (Levin & Hayes, 2009; Powers & Emmelkamp, 2009), no consensus was determined regarding the accuracy of some aspects of the originally published analysis and thus should be interpreted with some caution.

**Randomized controlled trials for ACT in clinical populations.** To date, empirical evidence for ACT has been demonstrated in 18 published RCTs applied to roughly 14 different psychological conditions and disorders (Öst, 2008; Powers, Vörding et al., 2009; Ruiz, 2010). Arguably, the most efficacy research has been conducted in the area of depression. In the first

small RCT by Zettle & Hayes (1986), 18 depressed female adults were randomized into either an ACT or CT condition. Following 12 sessions, participants in the ACT group had greater reductions in symptoms of depression and the presence of automatic thoughts than those in the CT condition, and these results were maintained at a 2-month follow-up. A similar study (Zettle & Rains, 1989) analyzed a group-based 12-week ACT treatment, in comparison with a CT group and partial CT group for 31 depressed adult females. Results indicated that all three groups showed significant, but equivalent, reductions in depression both at post-treatment and 2-month follow-up. Mediation analysis in these studies also demonstrated that changes in cognitive fusion mediated treatment effects for the ACT groups but not for the CT groups, thus suggesting the two therapeutic approaches may be effective by different means.

Forman, Herbert, Moitra, Yeomans, and Geller (2007) completed a larger RCT of 101 individuals who reported moderate to severe levels of anxiety *or* depression and randomized them into an ACT and CT group. After receiving a varied amount of individual treatment sessions (mean = 15 sessions), CT and ACT groups both showed clinically significant, yet equal, reductions in measures of anxiety and depression (Forman et al., 2007). Lappalainen and colleagues (2007) found that ACT was significantly more effective than the control group in reducing general distress and symptoms of depression in their RCT. ACT has been found to be superior to a placebo psychotherapy condition for both drug refractory epilepsy (compared to supportive therapy; Lundgren, Dahl, Melin, & Kies, 2006; Lundgren, Dahl, Yardi, & Melin, 2008) and workplace stress (compared to Innovation Promotion Program; Bond & Bunce, 2000). Lundgren and colleagues (2006) found that the combination of ACT and anticonvulsant medication, as compared to a similar supportive therapy condition, was able to produce significant results in quality of life and seizure frequency/duration with a 9-hour intervention

delivered over a 4-week period. These results were maintained over both a 6-month and 12-month follow-up. Similar reductions in a seizure index were found when ACT was compared to professional yoga sessions, although both conditions significantly improved the participants' quality of life. This suggests that complementary treatments, such as ACT or yoga, may provide benefit to individuals with chronic disorders such as epilepsy (Lundgren et al., 2008).

ACT has also been demonstrated as more effective than a treatment-as-usual (TAU) group for prevention of rehospitalization of psychotic patients (Bach & Hayes, 2002), stress and pain (Dahl, Wilson, & Nilsson, 2004), borderline personality disorders (Gratz & Gunderson, 2006), and diabetes (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007). Various ACT treatment packages have also been demonstrated to be effective with chronic pain (Vowles, McCracken, & Eccleston, 2007), polysubstance abuse (Hayes, Wilson et al., 2004), trichotillomania (Woods, Wetterneck, & Flessner, 2006), weight control (Lillis, Hayes, Bunting, & Masuda, 2009), methamphetamine use (Smout et al., 2010), mathematics anxiety (Zettle, 2003), and smoking cessation (Gifford et al., 2004). Although these empirical studies differ in respect to length and format of treatment and populations treated, the basic components of the ACT intervention remain throughout the various studies.

**Randomized controlled trials for ACT in non-clinical populations.** Despite the lack of inclusion in the current meta-analyses of the literature (see Ost, 2008; Powers, Vörding et al., 2009), there are some notable RCTs conducted with non-clinical populations. These novel applications further solidify the wide-ranging relevance of an ACT framework for many facets of psychology. Lappalainen and colleagues (2007) conducted a small RCT to compare the impact of individualized treatment provided by trainee clinicians based on either a traditional CBT model or the experimental ACT model. Twenty-eight participants were randomized to one of the

two approaches and were seen by one of 14 different therapists (Lappalainen et al., 2007). Despite the trainees' initial discomfort with the ACT knowledge-base (and fear associated with using it), the participants treated in the ACT condition demonstrated greater symptom reduction than the CBT group and appeared to improve on acceptance measures better than CBT (although CBT methods more rapidly improved client self-confidence levels). Another series of studies (which will be discussed at length in the diversity section) have investigated the role of ACT-based workshops on the impact of attitudes in a variety of populations. These include studies to increase willingness amongst counselors to recommend evidence-based pharmacotherapy treatments (Varra, Hayes, Roget, & Fisher, 2008), address racial prejudices in the classroom (Lillis & Hayes, 2007), and reduce stigma toward individuals with psychological disorders (Masuda et al., 2007).

**Additional relevant research.** When analyzing the empirical ACT literature base, there is also much relevance to the previously discussed correlational research, more than 30 longitudinal and mediational studies, and component studies of ACT core processes (e.g., Korn, 1997; Metzler, Biglan, Noell, Ary, & Ochs, 2000). Conceptual applications of ACT have been proposed for religious coping with cancer (Karekla & Constantinou, 2010) and terrorism (Dixon, Dymond, Rehfeldt, Roche, & Zlomke, 2003), among others.

### **Evidence for and Barriers to Effectiveness**

In addition to more traditional outcome measures (e.g., reductions in depression, anxiety), some RCTs have focused on somewhat unconventional instruments to measure change. Bach and Hayes (2002) applied a brief ACT intervention to individuals with psychosis. Post-treatment assessments found that the ACT group had a rehospitalization rate half that of the TAU group. Interestingly, they did not show the expected decline in experiencing symptoms of delusions and

hallucinations; however, they did report lower symptom believability. This finding provides additional evidence for the uniqueness of an ACT conceptualization of treatment, demonstrating that symptom reduction is not always necessary to reduce suffering in clients.

Another advantage of this treatment approach is the evidence that demonstrates ACT's effectiveness in a variety of formats and sometimes with relatively short duration of intervention. Powers, Vörding et al. (2009) did not find a significant dose-response relationship; thus, short ACT workshops showed similar effects sizes to longer-term psychotherapy. For instance, Lundgren and colleagues (2006) found positive impact on epileptic patients for a year following a 9-hour ACT intervention and the impact of a 4-hour intervention made on chronic pain patients maintained at a 6-month follow-up (Dahl, Wilson, & Nilsson, 2004). This is particularly powerful in our current era of managed care, where efficient *and* effective treatments are coveted (Hayes, 1995).

Potential barriers to the effectiveness of ACT research include some significant aspects of the research methodology, training and implementation issues, and critical opinions from within the behavior analytic tradition. Although research methodology will be covered in a later section, it is important to mention that smaller sample sizes, a lack of treatment adherence and therapist competence information, and a lack of head-to-head effectiveness studies with gold standard treatments are all potential barriers to the credibility of this research. Waltz and Hayes (2010) also caution practitioners to not always assume that a client's barriers revolve around fusion or experiential avoidance-based difficulties, as they readily admit that some difficulties do not stem from this conceptualization. They encourage the use of role-play or other in-vivo exercises in order to assess the possible need for more basic behavioral skills training (e.g., assertive or social skills training) to address such deficits.

ACT has also been characterized as “nothing new” or “old hat” from many in the psychological community, some suggesting ACT is simply a re-packaging of earlier psychotherapy approaches (Arch & Craske, 2008; Asmundson, & Hadjistavropoulos, 2006; Corrigan, 2001; Hofmann, & Asmundson, 2008). Specific elements of ACT, such as the emphasis on the present-moment and focused actions, have been criticized as having come straight from humanistic or constructivist approaches such as Gestalt Therapy, narrative psychology, or Morita Therapy (Hoffman & Asmundson, 2008). Although critical analysis is complementary toward the scientific process, it does appear that some researchers have taken to making attacks/arguments against ACT/RFT without a full understanding (i.e. investment of time) of the treatment philosophy and underlying science. ACT proponents have responded swiftly and specifically to these criticisms, which appear to be a strong tactic for “setting the record straight”; however, this trend is still a concern (e.g., Hayes, 2002). ACT researchers have also responded to the debates surrounding differences between ACT and older approaches to psychotherapy and related disciplines on topics such as spirituality (Hayes, 1984) and Buddhism (Hayes, 2002).

### **Applicability of ACT to Parents of Children with an ASD**

ACT works to increase clients’ psychological flexibility, attentiveness to the present moment, and the establishment and engagement in personal values. ACT also incorporates elements of mindfulness, which are intended to help the parents become more present and focused on their daily lives and give them the ability to make directed actions toward valued life domains. Interestingly, these same techniques have been explored somewhat in the parenting and caregiving literature. Mindful parenting teaches parents how to use mindfulness, breathing, and body awareness to change their parental behavior and have healthy interactions with their

children (O'Brien, 2008). This treatment is in the early stages of validation (Cohen & Semple, 2010) but has been documented to improve child compliance and parental happiness and satisfaction in children with ADHD (Singh, Singh, Lancioni, Singh, Winton, & Adkins, 2010), among a few other populations. Research also suggests superior communication achievement in children with ASD who have parents who are more responsive (often as a result of being more present and aware; Siller & Sigman, 2002). These results, coupled with Lloyd & Hastings' (2008) findings regarding maternal acceptance and avoidance-based coping, reveal the potential application of an acceptance-based intervention for parents of children with ASD.

To our knowledge, the efficacy of using ACT within this specific population has been tested only once in the experimental literature (Blackledge & Hayes, 2006), although the results are suggestive of possible use in this area. The researchers implemented a 2-day, 14 total hours, group ACT workshop for 20 parents of children diagnosed with autism. The treatment involved a brief application of the key components of the ACT protocol, which are described in greater detail in a later section.

The parents were assessed 3 weeks before treatment, 1 week before, 1 week after, and at a 3-month follow-up. The researchers found no significant changes in participants while waiting for treatment, while pre-intervention to post-intervention measures indicated a decrease in scores on the Beck Depression Inventory-II, as well as decreases on a global psychological distress measure (Global Severity Index of the Brief Symptom Inventory). They also found pre-intervention to post-intervention changes on some ACT-specific process measures of experiential avoidance and cognitive fusion. Although the study did have considerable weaknesses (e.g., reduced experimental control), the results suggested promising effectiveness.

As evidenced in Blackledge and Hayes's (2006) initial empirical investigation of ACT within this population, there are a number of factors that support the applicability of the intervention. Starting with the initial diagnosis, parents may experience a host of emotions in response to receiving the news their child has been diagnosed with a developmental disability. They may feel guilt regarding their perceived role in the diagnosis, fear of what the future may hold, or grief over the "idealized child" they no longer feel is a possibility. As a result of the literature suggesting that the earlier the child's diagnosis, the more treatment gains they will generally demonstrate (Dunlap, 1999; Goin & Myers, 2004), parents might feel an immense amount of pressure to pursue treatment options as soon as possible. Parents also face challenges in their role of their child's treatment, including managing chaotic scheduling of therapist and appointments, as well as actually serving as a therapist to their child in some interventions (Anan et al., 2008; Greenspan & Wieder, 1999).

Additional intense emotions may arise when parents are required to implement difficult behavior management strategies in response to their child's maladaptive behaviors. These situations are highly susceptible to experiential avoidance, as it is often more reinforcing in the short-term to disengage from one's child than cope with the intense emotions and pervasive negative thoughts that often arise. Research indicates that parents of children with ASD are less likely to participate in social events that might typically bring a family a sense of support and belonging (e.g., religious services) than families affected by ADHD or non-affected controls (Lee, Harrington, Louie, & Newschaffer, 2008). By helping parents learn techniques of willingness/acceptance and cognitive defusion, some of these barriers to fully living their lives might be identified and addressed.

Cognitive defusion also seems applicable in helping parents gain some flexibility with potentially distressing cognitive appraisals of their situations (e.g., comparing their child to other children, beliefs about their ability to manage their situations, feelings of victimization or blame). Mindfulness strategies and value clarification exercises may also serve to provide an alternative to avoidance that allows parents to move in the direction of valued life domains in a manner that is present-focused and full of integrity.

## Chapter 3: Methods

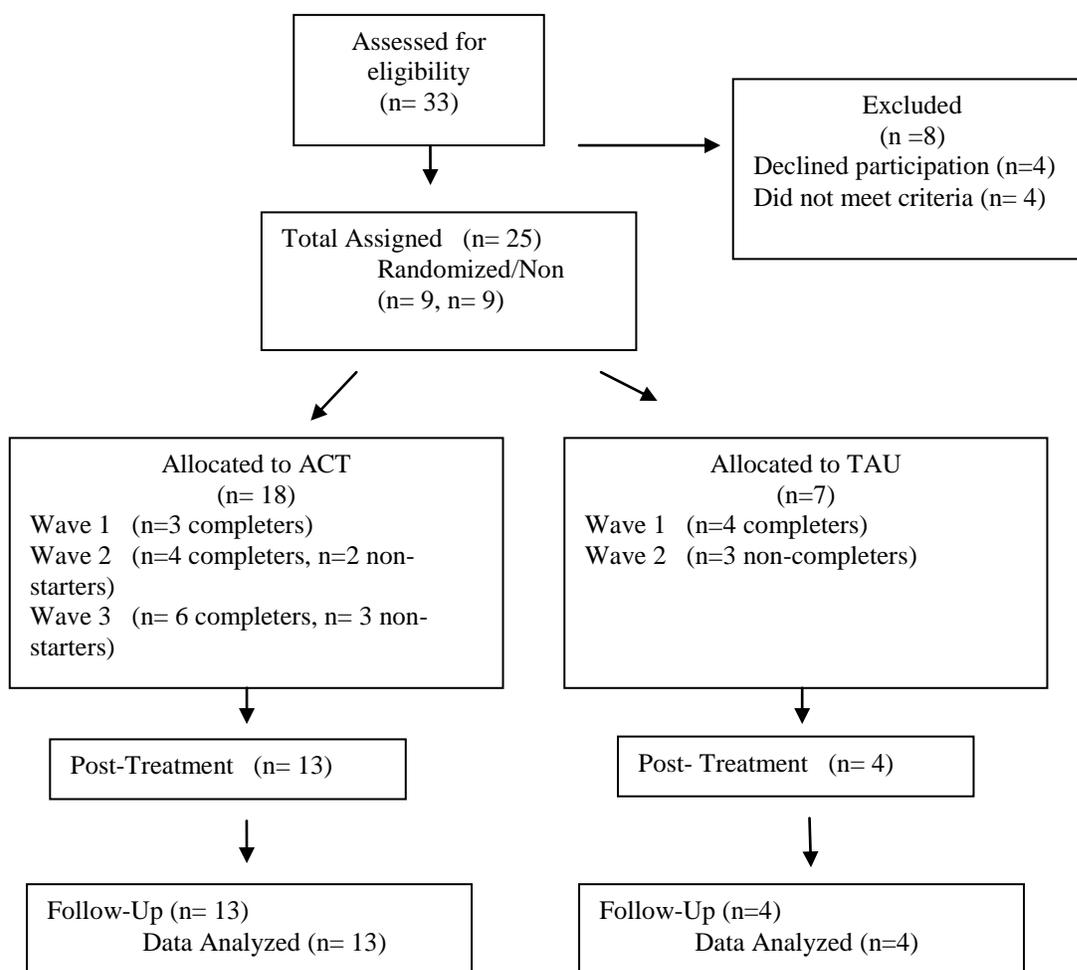
### Participants

The participants of this study included 17 mothers of children with ASD who were initially randomized into two groups, an ACT-based treatment group and a TAU support group. The first wave of treatment included 3 participants in the ACT group and 4 in the TAU group. The second wave of treatment was started when the first wave was in the 6th week of treatment and consisted of 4 in the ACT group and 3 assigned to the TAU group. Unfortunately, the 3 participants in the TAU group withdrew (for reasons discussed below) prior to completing the treatment. In the third wave of the study, 6 participants were assigned solely to the ACT group. The participants occasionally were excused from group sessions due to illness or vacation. No participants missed more than two sessions during the 8-week treatment, and the average of missed sessions was one per participant. Figure 2 provides the flow of participant recruitment and treatment completion.

**Recruitment.** Participants for this study were recruited from direct referrals through the local community agencies (e.g., Autism Collaborative Center, Autism Ask), hospitals (e.g., Beaumont Health System's Center for Human Development, Detroit Medical Center's Children's Hospital), and schools (e.g., Royal Oak School District, Clawson School District, Bloomfield Hills School District).

***Beaumont Health System's Center for Human Development.*** The Center for Human Development is located in Berkley, Michigan. This center uses an interdisciplinary approach to evaluate and treat children and adolescents who show evidence of or are at risk for disorders such as autism spectrum disorders, attention deficit disorders, emotional impairment, and social

dysfunction. Potential participants were recruited through medical staff's direct contact with families who met criterion for the study.



*Figure 2.* Participant Flow Diagram

An additional component of the Center for Human Development is the HOPE Center, which provides hands-on parent education to the families of children with autism spectrum disorders and other developmental disabilities. Families who participate in this program are asked to participate in an email list, which is HIPPA compliant. To date, there are approximately 350-400 families who receive notifications sent out through this email list. Demographics on these individual families vary greatly; however, the majority of the families either have

participated or currently are participating in behavioral treatment services. Additionally, the HOPE Center maintains a social networking webpage that was accessed for recruiting purposes.

***Autism Ask.*** Autism Ask is a newly formed community agency, located in Waterford, Michigan. Founders Stephanie Harlan and Beth Kimmel state that the organization's mission is to provide advocacy, support, and knowledge to the autism spectrum community through resource provision, direct service, and autism awareness materials. Participants were contacted directly by agency staff and/or through their website.

***Autism Collaborative Center.*** This center is housed within Eastern Michigan University and provides assessment, intervention, and referrals services to individuals with Autism Spectrum Disorders across the lifespan. They offer interdisciplinary services (e.g., psychology, social work, special education, occupational therapy) that are provided primarily by Eastern Michigan University faculty, staff, and students. Potential participants were contacted through the center's staff members and flyers available at the center.

***University of Michigan's Autism & Communication Disorders Center (UMACC).*** UMACC is a center that primarily provides research, training, and diagnostic assessment services to individuals within the autism spectrum community. Located in Ann Arbor, Michigan, the center also provides some brief intervention services for social skills and parent training.

***Private practice groups.*** Participants were also recruited from a few local private practice groups that work with children and families. These contacts came from individual psychologists who are familiar with the entry criterion for the study and passed along study information to interested families. All of these psychologists were located in the Metro Detroit area.

***Local school districts.*** Participants were also recruited by sending information and flyers to psychologists/social workers for local school districts (within a 15-mile radius of Berkley,

Michigan). The researcher followed up with these professionals in order to answer any questions regarding the study and who was eligible to participate.

**Inclusion/Exclusion Criteria.** Individuals were eligible for entry if (1) they were the biological or adoptive mother (and primary caregiver) of a child with a diagnosis of an autism spectrum disorder, (2) the child was 2-11 years of age inclusive, (3) they spoke English, and (4) they planned to live in the area for at least 6 months.

Individuals were excluded from the study if (1) they were involved in a concurrent clinical trial of psychosocial interventions for parents/caregivers or (2) they (or their child/spouse) had active major medical issues such as cancer, organ transplant, and so on.

**Retention Strategies.** The following strategies were used to maximize participant retention: 1) payment of a \$10 gift card (to a choice of either Target or Meijer) for each completed assessment battery (pre-intervention, post-intervention, and follow-up); 2) telephone screening times scheduled at the convenience of the parent; 3) thank-you notes following each assessment; and 4) close monitoring of reasons for discontinuation.

## **Procedures**

**Participant screening and group assignment.** Parents who were interested in participating in the study contacted the researcher by phone or email. A time to conduct the telephone screening was arranged for each interested individual. Once an individual had been screened and deemed eligible for this project, the researcher asked the mother if she still wished to participate. If she expressed continued interest in the study, the researcher explained the procedures involved with completing the initial baseline measures.

The individual received a packet in the mail, complete with these measures, detailed instructions, and a self-addressed stamped envelope for easy return of the materials to the

researcher's attention at William Beaumont Hospital. These completed materials were required to be returned prior to official enrollment in the project. Participants also received a copy of the consent form to review prior to the first group meeting; however, they were not formally asked to sign the form until the first meeting, allowing ample opportunity for questions and concerns to be addressed by the researcher.

Once the baseline data had been collected, participants for the first wave of treatment were randomly assigned to a treatment condition. The design of the study was originally conceptualized as a randomized, two-group 2 x 2 mixed model design with 1) a group-based Acceptance and Commitment Therapy (ACT) intervention and 2) a TAU support group. For a variety of reasons, Wave 2 of the TAU was ceased after three weeks. These reasons included negative informal feedback from wave 1 participants and requests to withdraw their participation from all of the wave 2 participants (two due to dissatisfaction with the TAU format and one for personal reasons). The remaining recruited participants were assigned solely to the ACT treatment group (wave 3).

**Group-based ACT.** Those assigned to the treatment group took part in an 8-week workshop based on principles and procedures of Acceptance and Commitment Therapy provided by the primary researcher. The treatment manual (See Appendix A) for this intervention was based on previous ACT work with this population (Blackledge & Hayes, 2006) and established models for group-based treatment within the ACT literature (see Gifford et al., 2004).

**Week 1.** The researcher began the initial contact with each prospective participant in a group format of approximately 20-25 minutes. The introduction to the research study included general features of participation and the reasons why the ACT-based intervention was believed to be useful to help parents of children with ASD. The participants who agreed to participation,

which turned out to be all individuals across all three waves, signed the consent forms after questions were answered. The remaining allotment of the 90-minute session detailed the merits of the ACT treatment (e.g., the empirical literature which supports application of ACT to diverse populations and the fundamental assumption that psychological distress is inherent within the human condition and a normal part of life). Next, the therapist led a discussion among the participants designed to enhance motivation for the participation and normalizing the workshop format (e.g., destigmatizing their preconceptions of psychological treatment), followed by a caveat that although homework may not be assigned each week, their active use of skills outside the workshop sessions would ensure a greater degree of progress toward their goals.

The session concluded with an assessment of the specific goals that participants hoped to accomplish through the workshop. Their stated goals were combined on a whiteboard and divided into two categories (i.e. “Feeling better/thinking better” and “Living what I value more often/more effectively”). The purpose of this categorization was to orient the participants to the fact that although the workshop would address some of the unpleasant thoughts and feelings they might have, a large portion of the work would reside in identifying what was meaningful in their lives and how they could work toward these often overlooked values.

**Week 2.** During the second session of treatment, participants were asked to build upon the previous week’s exercise about personal goals. Participants were asked to complete an initial Values Assessment Form (see Appendix C). After a brief exploration of how these values might help guide treatment, the therapist began the initial phase of ACT treatment, “Creative Hopelessness.” Through group discussion, participants were asked to describe the unpleasant feelings they encountered in their daily lives and generate a verbal list (which was combined into categories on the whiteboard) of the ways they coped with these feelings. Answers were

categorized into active versus emotion/thought-focused strategies, and the effectiveness of these styles of coping was discussed. The session concluded by laying the groundwork for the idea that harmful and non-constructive attempts to control unpleasant thoughts and feelings may actually be more problematic than simply experiencing those thoughts/feelings (use of “Man in the Hole” metaphor to illustrate that although they are doing something over and over, it does not appear to be working; Hayes, Strosahl, & Wilson, 1999, pp. 101-102).

**Week 3.** The third session of treatment began by engaging the participants in a review of the problematic nature of the control (or “need to change”) agenda. The remainder of the session included additional didactic material, metaphors, and an experiential exercise to fully orient participants to the concept of the control agenda within their own lives (e.g., participants identified ways they have tried to control their emotions, such as through overeating or alcohol use). Standard ACT exercises were used to illustrate these concepts (e.g., Chinese Handcuffs to illustrate that no matter how hard a person pulls them apart, relief can be found when actually working with the resistance or pushing; “If you aren’t willing to have it, you’ve got it” metaphor to clarify the paradoxical nature of attempting to control emotional states). This metaphor is as follows:

The situation here is something like those "Chinese handcuffs" we played with as kids. Have you ever seen one? It is a tube of woven straw about as big as your index finger. You push both index fingers in, one on each end, and as you pull them back out, the straw catches and tightens. The harder you pull, the smaller the tube gets and the tighter it holds your fingers. You'd have to pull your fingers out of their sockets to get them out by pulling them once they've been caught. Maybe this situation is something like that. Maybe these tubes are like life itself. There is

no healthy way to get out of life, and any attempt to do so just restricts the room you have to move. With this little tube, the only way to get some room is to push you fingers in, which makes the tube bigger. That may be hard to do at first, because everything your mind tells you to do casts the issue in terms "in and out" not "tight and loose." But your experience is telling you that if the issue is "in and out," then things will be tight. Maybe you need to come at this situation from a whole different angle than what your mind tells you to do with your psychological experiences (Hayes, Strosahl, & Wilson, 1999, p. 105).

Next, the therapist helped participants understand the underpinnings of the control agenda (e.g., the cultural and historical roots of how verbal rules and beliefs become part of one's cognitive network are made clear with the Computer programming metaphor) and normal occurrence of such unpleasant thoughts/feelings. Additional techniques (e.g., "tug of war with a monster") were used to illustrate the notion that although attempting to control unpleasant thoughts and feelings tends to make things worse, participants might have another option (Hayes, 1987, p. 366; Hayes, Strosahl, & Wilson, 1999, p. 109).

**Week 4.** During the fourth week of treatment, the therapist covered the ACT notion that the human ability for language may actually be at the core of our suffering. Using metaphors and exercises, the therapist illustrated the significant differences between direct experiences and "talked about" direct experiences (i.e. evaluations). Finally, participants were guided into an experiential exercise to practice defusing problematic thoughts (e.g., variation of the "Milk" exercise, "Say it and don't believe it"). In the Milk exercise, participants explored various properties of something common, such as milk (white, creamy, etc.) followed by a repetition of the word aloud by all group members for 2-3 consecutive minutes until the "meaning" is gone.

Participants recognized that like much of language, the “meaning” attached to various words/sounds can be manipulated.

**Week 5.** The fifth week’s session covered various aspects of mindfulness training, beginning with a very simple exercise where participants were instructed to focus on physical sensations (e.g., breathing) within their bodies as they occurred. This exercise gave them some framework for a discussion of the difference between direct experience and the verbal explanations of those experiences. The participants also engaged in some more advanced mindfulness exercises (e.g., an exercise intended to help participants notice their continuous stream of thoughts without becoming reactive toward them). The session concluded with an introduction, via metaphors and interactive discussion, of the ACT concept of willingness or acceptance. Willingness was described as an action, rather than an emotional state, which was most effectively demonstrated with the participants each time they chose to participate in an illustrative exercise during the sessions.

**Week 6.** In the sixth week, the ACT group reviewed the concept of willingness and used additional exercises to clarify the idea that pain is a part of the normal human experience, and although difficult at times, that pain is something that can be accepted without adding further suffering. The quicksand metaphor (Hayes & Smith, 2005, 3-4) was used illustrate the difference between struggling with pain (results in further sinking), while fully experiencing the sensations (e.g., full contact with the sand) is similar to willingness and creates an option for survival. Participants were then taught to identify their evaluative thoughts and began to define them as something different than the content of the thoughts themselves (e.g., using metaphors such as “Soldiers in a Parade,” “Passengers on the Bus,” and the “Observer Exercise”). A discussion regarding the use of acceptance as an alternative to control and a means to more meaningful

pursuit of valued life directions followed. The session concluded with a series of exercises (e.g., “Physicalizing Exercise,” “Eye Contact,” “Looking for Mr. Discomfort,” and “Tin Can Monster”) that were intended to provide participants with practice in identifying and accepting unpleasant experiences. For instance, the “Eye Contact” exercise involved asking participants to pair up, sit across from each other (knees touching), and maintain eye contact for a prolonged period of time (2-3 minutes). The exercise allowed participants to observe their own reactions (both emotions and thoughts) while engaging in willingness to participate in a traditionally uncomfortable experience.

**Week 7.** The seventh session began with a review of the initial week’s values clarification exercise followed by a didactic instruction/ discussion of the aspects of values clarification (i.e. what it is, what it is not) and clarification of key terms (e.g., goals, barriers, actions). Participants further clarified their individual values through the “What do you want your life to stand for?” exercise. A detailed discussion of their experiences with this exercise was held to address any concerns or confusion regarding this concept.

**Week 8.** The final session focused on generating perseverance in committed action, particularly when participants were faced with events (i.e. barriers), which typically would undermine their behavior in a given context. One metaphor that was useful in exploring this concept with the mothers was the Gardening Metaphor, which is presented here in its entirety:

Imagine that you selected a spot to plant a garden. You worked the soil, planted the seeds, and waited for them to sprout. Meanwhile you started noticing a spot just across the road, which also looked like a good spot—maybe even a better spot. So then you pulled up your vegetables, and went across the street and planted another garden there. Then you noticed another spot, which looked even

better. Values are like where you plant your garden. You can grow some things very quickly, but some things require time and dedication. So the question is “Do you want to live on lettuce, or do you want to live on something more substantial—potatoes, beets, or the like?” You can’t find out how things work in gardens when you have to pull up stakes again and again. Now of course, if you stay in the same spot you’ll start to notice its imperfections. Maybe the ground isn’t quite as level as it looked when you started, or the water has to be carried a ways. Some things you plant may seem to take forever to come up. It is times like these that your mind will tell you that “you should have planted elsewhere,” “this will probably never work,” “it was stupid of you to think you could grow anything here,” etc. The choice to garden here allows you to water and weed and hoe, even when these thoughts and feelings show up. (Hayes, Strosahl, & Wilson 1999, p. 220)

Participants were also provided an opportunity to ask questions about the treatment procedures and receive feedback about any of the concepts discussed throughout the workshops. An interactive discussion of the ways in which skills are used in their natural environments followed. They also received a set of handouts that were designed to help them practice ACT principles and remain oriented to the ACT perspective (see Blackledge & Hayes, 2006).

**TAU group.** Participants assigned to the TAU control condition were assessed on the same schedule as the individuals in the ACT group. The TAU was formatted similarly to a traditional support group (see TAU treatment manual in Appendix B). This format was chosen for this intervention because it is currently the most common form of support/therapy provided to parents of children with autism throughout the United States. Although most university- and

center-based treatment facilities do not currently offer specific psychological treatment for these parents, it is relatively common to offer some form of support group, typically once a month (versus weekly).

The support group ran for the same length as the active treatment group (1.5 hours for 8 weeks). The group was run by a master's level mental health professional who served primarily as the group facilitator. The topics and format for discussion were decided primarily by the participants, as they were encouraged during the first session to choose topics for the 8 weekly sessions. The topics chosen by the first wave of participating included topics such as managing stressful situations, dealing with siblings and extended family, preparing for the future, marital issues, treatment options, and self-care. The participants were encouraged to share their personal experiences with each other regarding each topic, and the facilitator helped guide the conversation and maintain a dynamic flow. The participants were also informed that the primary focus was a peer-to-peer model, where they assisted each other with solutions to commonly shared problems and situations. Participants were not provided guidance or advice by the facilitator. After the first wave of treatment in the TAU group, the researchers received some negative feedback about the nature of the support group. Following the start of the second wave of the TAU, unfortunate circumstances and dissatisfaction with the nature of the TAU resulted in all three participants requesting removal from the study. Thus, the second wave of TAU completed only three treatment sessions and is not included in the data analysis. After these events, the decision was made to assign future participants to only the ACT condition and focus on a repeated measures design.

**Staff/Therapist Training.** The first author was a graduate student in an APA-accredited clinical psychology doctoral program and served as the therapist for all participants in the ACT

condition. The therapist, a Caucasian female, had didactic and clinical experience with ACT. In addition, she engaged in study-specific preparations that included detailed reading and discussion of Blackledge & Hayes's (2006) treatment manual (obtained from the first author), a 1-day intensive workshop on the delivery of ACT interventions to parents of children with autism, and significant supervision for issues encountered during the treatment phase of this project. The facilitators for the TAU groups (wave 1 and wave 2) were two different Caucasian females, both of whom had master's degrees in clinical psychology and experience working with families of children with autism. They received training from the primary researcher on treatment protocols detailed in the TAU manual.

## **Measures**

The assessments were completed at baseline (3 weeks prior to treatment starting), approximately 3 weeks after the final treatment session, and at 3 months after the post-treatment questionnaire was completed (i.e., 3 month follow-up). The assessment battery required approximately 1.5 hours to complete and was completed by the participant without the assistance of the examiner. All assessments were mailed directly to the participant's home, complete with a self-addressed, stamped envelope for easy return of the materials.

*Screening and demographics.* This section describes measures used to screen participants for the inclusion and exclusion criterion, as well as provide detailed demographic information.

*Telephone screening form.* Participants were screened for the study using a brief questionnaire designed specifically for use in this study. It assessed variables related to inclusion and exclusion criteria, such as age, race, sex, relationship of the participant to the child with autism spectrum disorder, and brief medical history.

***Demographic characteristics.*** The demographics questionnaire was included in the initial assessment at baseline. The questions included some information previously assessed with the telephone screening form but functioned as a more elaborate mechanism for obtaining background information. Demographic variables included race, mother's age, years of education, relationship to the child, and SES. Additionally, it assessed living arrangements, type and age of child's diagnosis, treatments sought previously for child and participant, and other relevant concepts. (See Appendix C).

***Post-Treatment Questionnaire.*** This was a 5-item questionnaire developed by the first author to assess participants' satisfaction with the intervention (either ACT or TAU). The questionnaire was assessed as part of the post-intervention assessment. The questionnaire asked participants to rate on a scale of 1 to 5 ("not at all" to "very much") aspects of treatment, including how useful they found the intervention, how helpful the group leader was, how helpful the techniques discussed were, how likely they would be to recommend the intervention to a friend, and overall satisfaction with the group. Participants were also provided space to express what they liked most and least about the groups, as well as what they would like to see happen differently.

***Process Measures.*** These process measures were self-report instruments intended to measure the therapeutic mechanisms of change believed to be active in ACT, specifically experiential avoidance, cognitive fusion, and the presence and degree of believability of automatic thoughts.

***Acceptance and Action Questionnaire-II (AAQ-II).*** The Acceptance and Action Questionnaire-II is a revised 7-item unpublished version of the original measure (Bond, Hayes, Baer, Carpenter, Guenole, Orcutt, Waltz, & Zettle, 2011). Although many ACT studies have

used the AAQ-I, there were considerable drawbacks to the measures, including comprehension and reliability issues (Bonds et al., 2011). Initially the AAQ-II was conceptualized as a two-factor solution using 10 questions for scoring, but upon the recent publication of the revised AAQ-II, the authors strongly advocate for use of the 7-item version only. They base this recommendation on recent analyses that concluded the two-factor solution was purely due to a method effect and did not actually represent a second dimension. Thus, the current AAQ-II has preliminary psychometric data generated from six datasets ( $N = 206-854$ ), appears to be one-dimensional in nature, and correlates well ( $r = .97$ ) with the original AAQ-I.

Reliability indices are improved from the AAQ (mean alpha coefficient is .84; range from .78 to .88) and the 3- and 12-month test–retest reliability is .81 and .79, respectively. Criterion-related validity was also established with measures of depression, anxiety, and thought suppression (Bond et al., 2011). Berman, Wheaton, McGrath, and Abramowitz (2010) found convergent validity between AAQ-II and a measure of anxiety sensitivity, noting that anxiety sensitivity predicted severity independently of EA for the physical concerns dimension of the measure. The AAQ-II is scored by summing the seven items, with higher scores indicating greater degrees of psychological inflexibility, with a maximum score of 49. To our knowledge, clinically significant cut-offs have not yet been established in the literature, but some means can be drawn from the validation samples. In a non-clinical sample of undergraduate students ( $N = 206$ ), the mean score was 21.41 ( $SD = 7.97$ ; Bond et al., 2011). In a second sample of nonclinical undergraduates ( $N = 433$ ), the researchers found a slightly lower mean ( $M = 17.34$ ;  $SD = 4.37$ ) and similar results in a sample ( $N = 538$ ) of bank employees ( $M = 18.53$ ;  $SD = 7.52$ ). These results are compared to a sample ( $N = 290$ ) of individuals presenting for outpatient services for substance

misuse ( $M = 28.34$ ,  $SD = 9.92$ ), which represent much greater levels of psychological inflexibility.

***The Automatic Thoughts Questionnaire.*** This scale (ATQ; 30 items; Cronbach alpha = .97; Hollon & Kendall, 1980) measures the frequency of automatic negative statements about the self. Frequency ratings are made on a 7-point Likert scale (1 = “never” to 7 = “always”). The ATQ version that was used was a modified version (see Blackledge & Hayes, 2006), which includes believability of automatic thoughts (1 = “not at all believable” to 7 = “completely believable”). Both frequency (ATQ-F) and believability scale (ATQ-B) totals are the sum of the 30 items; however, analysis of each scale separately is common in the literature. Scores range from 30 to 210, and higher scores on the ATQ-F indicate greater frequency of negative statements. Previous research indicates that nonpatients tend to score in the 40 to 60 range ( $M = 52.91$ ,  $SD = 18.18$ ), while depressed patients typically scored over 90 (Dozois, Covin, & Brinker, 2003). Higher scores on the ATQ-B indicate more believability of these automatic thoughts, given that they occurred.

For the purposes of this study, both ATQ-B and ATQ-F scores were analyzed to examine the cognitive defusion process. For the ATQ-B scale, respondents rate the degree to which they believe 30 different thoughts associated with depression, such as “I’m not good,” “I can’t stand this anymore,” and “My future is bleak.” Previous research has shown that the internal reliability of the believability of thoughts scale added to the ATQ is also excellent (Cronbach’s alpha = .96; Bissett, 2002). The ATQ-B has also been shown to covary with ACT outcomes (Zettle & Hayes, 1986) and to covary with such applied problems as severity of substance abuse (Bissett, 2002).

***Five Facet Mindfulness Questionnaire (FFMQ).*** The FFMQ (Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006) is a 39-item measure designed to assess five distinct aspects of

mindfulness: observing, describing, acting with awareness, non-judging of inner experience, and non-reactivity to inner experience. The instrument combines items from five different self-report measures, using both an exploratory and confirmatory factor analysis to identify the five-factor solution (Baer et al., 2006). The FFMQ has also undergone additional construct validation and was found to correlate significantly with well-being, meditation experience, and psychological symptoms (Baer et al., 2008). Although new and somewhat lengthier, this scale demonstrates considerable promise for researchers attempting to tap into the whole construct.

**Outcome Measures.** These measures were chosen to measure specific outcomes that are expected to change following an acceptance-based treatment such as ACT.

***Brief Symptom Inventory-18 (BSI-18).*** The BSI-18 (Derogatis, 2000) is an 18-item self-administered measure that provides information on participants' overall psychological distress and Global Severity Index, as well as scales of somatization, depression, and anxiety. The measure takes approximately four minutes to complete, requires a 6<sup>th</sup> grade reading level, and is available in both pencil-and-paper and computer format, although the former was used exclusively for this project. The developers of the BSI-18 use the term *caseness* to identify individuals with clinically significant emotional distress levels. Specifically, *caseness* refers to having either a GSI *t* score greater than 63, or having two or more symptom dimension *t* scores greater than 60.

***Positive Aspects of Caregiving (PAC).*** PAC was measured with a nine-item pencil-and-paper instrument that assesses CGs' subjectively perceived gains from, desirable aspects of, or positive affective returns from providing care for their loved one (Roff et al., 2004). Respondents are asked to rate the extent to which they agree or disagree (1 = *disagree a lot*, 5 = *agree a lot*) with statements such as "The care recipient made me feel more useful." The measure has been

tested in a large and diverse sample of caregivers of dementia patients (Tarlow et al., 2004) and has shown good psychometric properties ( $\alpha = 0.93$ ). This study sought to determine its applicability in measuring perceived gains within this population with a simple modification (replacing the term *care recipient* with *child*; See Appendix C).

***Parental Stress Index-Short Form (PSI-SF)***. The Parenting Stress Index is a 36-item paper-and-pencil self-report instrument (Abidin, 1995) that takes less than 10 minutes to complete. Respondents are asked to rate each item on a 5-point scale (ranging from strongly agree to strongly disagree) for most items, although some items require a different format of responding. Scoring of the PSI begins with the validity scale, Defensive Responding, where scores of 10 or less may indicate that the respondent is answering test items in a defensive manner, and caution should be used when interpreting their scores. A Total Stress score and other subscales are scored next by summing items endorsed on the profile sheet and using normative data to collect scores. A total stress score, the primary outcome measure for the study, above a raw score of 90 (at or above the 90 percentile) is indicative of a parent who is experiencing clinically significant levels of stress. It has also been suggested that a score of 33 on the Parental Distress Index, roughly the 85<sup>th</sup> percentile is a valid cut point for clinical significance (Zaidman-Zait et al., 2011).

The full-length version of the PSI (as compared with this short form) measures factors within both child and parent domains. High scores within the child domain suggest child characteristics that make it difficult for parents to fulfill their parenting role; subscales include Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability. High scores within the parent domain may suggest sources of stress and potential dysfunction of the parent-child system related to dimensions of the parent's functioning;

subscales include Competence, Isolation, Attachment, Health, Role Restriction, Depression, and Spouse. The PSI Short-Form is based on a factor analysis of the full-length version, which indicated a 3-factor solution (Castaldi, 1990) and now includes three subscales: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child.

Although full empirical validity of the PSI Short-Form has not been established, it is helpful to look at data from the full-length measure. The PSI was standardized for use with parents of children ranging in age from one month to 12 years. Normative data were collected from 2,633 mothers and 200 fathers. The measure has been validated in a variety of U.S. samples and used in transcultural research involving diverse populations (Pearson & Chan, 1993; Brigas & Lafreniere, & Abidin, 1995). Internal consistency for this measure is good; coefficients range from .70 to .84 for all subscales, while coefficients for the two larger domains (parent and child) and total stress were .90 and above. Test-retest reliability has also been established by a number of studies, with testing intervals ranging from 3 weeks to 1 year.

**Child behavior measure.** The Behavior Assessment Systems for Children (BASC-2) was chosen in order to obtain information about the parents' report of their child with ASD's possible behavioral difficulties. The BASC-2 is a "multimethod, multidimensional system used to evaluate the behavior and self perceptions of children and young adults aged 2 through 25 years of age (Reynolds & Kamphaus, 2004, p. 1). The multidimensional nature of the BASC-2 allows for measurement of both adaptive and maladaptive behaviors (clinical) and is considered an effective tool in the evaluation of behavior in children (Merydith, 2001; Stein, 2007). Administration is based on the age of the child with separate forms for preschoolers aged 2-5, children aged 6-11, and adolescents age 12-21 years. Although the BASC-2 allows for multiple informants, for the purpose of this study, only the Parent Rating Scale (PRS) was used.

The PRS of the BASC-2 provides the choice of four options for the frequency of each observable behavior (*never to almost always*), takes approximately 10-20 minutes to complete, and includes three important validity scales (e.g., F index, response pattern index, and consistency index). The main variables used in this study were the Externalizing Problems Composite (subscales include Hyperactivity, Aggression, and Conduct Problems), Internalizing Problems Composite (subscales include Anxiety, Depression, and Somatization), and the Behavioral Symptom Index. Standard scores are reported for each of the composites; each score has a mean of 50 and standard deviation of 10. Higher scores indicate the presence of clinically significant behavior ( $t$  score = 70 or higher) or the presence of a behavior that is at risk for the development of clinically significant behavior ( $t$  score = 60-69).

Internal consistency is very good for composite scores with coefficient alphas over .90 and good for individual subscales (all over .80 for all age ranges). High temporal stability (range from low .80's to low .90's) has been demonstrated across all age ranges, with intervals ranging from 9 to 70 days. Validity has been established through factor analytic findings and concurrent validity. The PRS correlates moderately well ( $r = .73$  to  $.84$ ) with another measures of parent-rated child behavior, the Achenbach System of Empirically Based Assessment Child Behavior Checklist.

**Convergent validity measure.** In order to obtain further validity information on the unpublished AAQ-II, a measure of cognitive flexibility and executive functioning was selected for correlational testing. The Behavior Rating Inventory of Executive Functioning-Adult Version (BRIEF-A; Roth, Isquith, & Gioia, 2005) is a 75-item self-administered method of capturing information regarding an adult's self-regulation and executive functioning in his/her everyday environment. It is designed for individuals aged 18-90 years and takes approximately 15 minutes

to complete. Respondents are asked to select from three choices (never, sometimes, and always) for each item. Clinically significant scores are equal or greater to a *t*-score of 65, indicating that they experience less executive functioning skills. Reliability of the BRIEF-A is moderate to high and ranges from .73 to .90. Inter-rater agreement between the self-report (used in this study) and informant report version range from .44 to .68 and is considered low-moderate. For purposes of this study, composite scores were used to measure convergent and/or discriminant validity with the AAQ-II.

The BRIEF-A is based on the original BRIEF and is composed of nine clinical scales, which form two broader indexes, Behavioral Regulation (BRI) and Metacognition (MI). The BRI index is composed of four scales: Inhibit, Shift, Emotional Control, and Self-Monitor. This index is said to capture one's ability to maintain appropriate regulatory control of one's own behavior and emotional responses. The MI index is thought to reflect the person's ability to initiate activity and generate problem-solving ideas, sustain working memory, plan and organize problem-solving approaches, and monitor successes and failures in problem solving. This index is composed of five scales: Initiate, Working Memory, Plan/Organize, Task Monitor, and Organization of Materials. These indexes combine to form an overall summary score, the Global Executive Composite. The measure also includes three validity scales (Negativity, Inconsistency, and Infrequency). Of particular interest for this study is the Shift scale, which assesses a person's ability to move with ease from one situation, activity, or aspect of a problem to another as the circumstances demand.

### **Data Analysis**

The data collected for this study were analyzed using SPSS for Windows. Descriptive statistics were used to analyze the demographic data. Statistical procedures were modeled from

current statistical methodology guidelines (Maxwell & Delaney, 2004). The original intent for this study was to use a 2x2 mixed design analysis-of-variance (ANOVA) test for differences in the means of outcome variable both between groups and within groups. However, due to the premature termination of the TAU comparison group, the most relevant results were the repeated measures ANOVAs for the within-group effect. The between-groups effects compare the group receiving the ACT intervention and the TAU group. This grouping factor is a fixed between-groups effect. The within-subject effects were analyzed using the subjects' scores from the pre-intervention, post-intervention and follow-up assessment batteries. These were repeated effects and included a comparison of group means on three primary outcome measures (PSI-SF, BSI-18 scales, and PAC) and three secondary analyses on three process measures (AAQ-II, ATQ, and FFMQ).

We expected to find a significant between-groups effect for all dependent variables, indicating that at follow-up, individuals in the treatment group reported significantly lower endorsement of negative affect measures (BSI-18 anxiety and depression, PSI-SF, AAQ-II, AAQ, scale B) and gave significantly higher endorsements of positive measures (PAC, FFMQ). It was also expected that individuals in the within-subjects main effect of dependent measure scores would be significant, thus indicating there was a significant reduction in post-treatment negative affect scores as compared with pre-intervention-treatment scores, as well as a significant increase in post-treatment positive affect scores as compared with pre-intervention-treatment scores.

## Chapter 4: Results

### Characteristics of the Sample

Treatment completers were women who were primarily between 40-49 years of age (58.8%), with the rest of participants falling in the 30-39 years of age range (42.2%). The majority of women were Caucasian (76.5%; African American, 11.8%; Hispanic, 11.8%). They averaged 16 years of education, an equivalent of a bachelor's degree (high school diploma, 5.9%; associate's degree, 17.6%; master's degree, 35.3%; professional degree, 11.8%). Most were married (94.1%; divorced/separated, 5.9%). Approximately half of the participants reported working for wages (52.9%), while the other half reported being a housewife as their occupation (47.1%). All mothers reported having only one child diagnosed with ASD, with half of the children between 6 and 7 years (52.9%; range from 4-11 years old). The majority of mothers reported one other child in the home (58.8; two other children, 41.2%). Most children were first diagnosed at either age 3 (29.4%) or 4 (29.4%) with an ASD (88.2%; Asperger's Disorder, 5.9%; Pervasive Developmental Disorder-NOS, 5.9%).

Parents reported that their children received their diagnosis from a variety of professionals: school professional team (29.4%), psychologist (29.4%), neurologist (17.6%), pediatrician (11.8%), and other (11.8%). The majority of participants endorsed approximately four different treatment interventions for their children at the current time (23.5; range from 1-11 different interventions). The majority of mothers reported that their child with ASD was not currently participating in intensive applied behavior analytic interventions (64.7%) and reported seeking previous counseling/psychotherapy experiences for themselves (58.8%).

A summary of the means for individuals in the both conditions of the study can be found in Table 1. Overall, it is clear that the sample used for this study was non-clinical on most

measured dimensions of inflexibility or psychopathology, but they did experience significant parental distress. This finding is not a surprise, given the lack of specific inclusion criterion related to psychopathology (e.g., anxiety or depression).

Table 1

*Summary Statistics for ACT Group*

	N	Minimum	Maximum	Mean	SD
<b>Parental Distress Index- Short Form</b>					
Parental Distress Time 1	13	18	46	34.46	8.838
Parental Distress Time 2	13	17	47	33.85	8.754
Parental Distress Time 3	13	15	39	29.38	8.931
<b>Brief Symptom Inventory-18</b>					
Global Severity Time 1	13	42	66	55.46	6.553
Global Severity Time 2	13	33	67	49.92	10.112
Global Severity Time 3	13	33	63	50.77	10.142
Depression scale Time 1	13	40	65	55.62	7.489
Depression scale Time 2	13	40	67	51.31	10.070
Depression scale Time 3	13	40	63	51.69	8.702
Anxiety scale Time 1	13	39	69	54.62	8.780
Anxiety scale Time 2	13	38	69	52.15	10/652
Anxiety scale Time 3	13	38	69	51.38	9.588
Somatization scale Time 1	13	41	63	50.92	7.815
Somatization scale Time 2	13	41	63	47.62	7.752
Somatization scale Time 3	13	41	63	49.62	9.170
<b>Acceptance and Action Questionnaire- II</b>					
Total score Time 1	13	9	43	18.38	6.117
Total score Time 2	13	9	34	18.69	6.613
Total Score Time 3	13	8	30	19.08	7.182
<b>Automatic Thoughts Questionnaire</b>					
Frequency Scale Time 1	13	34	79	56.77	15.573
Frequency Scale Time 2	13	34	77	54.92	13.893
Frequency Scale Time 3	13	33	83	51.46	14.802
Believability Scale Time 1	13	33	111	69.31	23.969
Believability Scale Time 2	13	35	75	56.77	14.773
Believability Scale Time 3	13	30	75	51.23	13.893
Total score Time 1	13	67	162	126.08	31.855
Total score Time 2	13	70	148	111.69	28.894
Total score Time 3	13	63	164	103.46	29.932
<b>Positive Aspects of Caregiving</b>					
Total score Time 1	13	12	45	31.62	9.534
Total score Time 2	13	12	45	32.54	8.368
Total score Time 3	13	18	45	35.54	7.090
<b>Five Facets of Mindfulness Questionnaire</b>					
Total score Time 1	13	97	169	128.15	19.027
Total score Time 2	13	107	174	131.31	20.370
Total score Time 3	13	109	169	131.85	16.268

## Analysis of Outcomes

**Univariate summaries.** The statistical analysis involved examining repeated measures ANOVAs for several scales related to parental distress and psychopathology, with measurements taken at three points in time: pre-intervention, post-intervention, and follow-up. In addition to comparing baseline to two subsequent post-intervention measures, a comparison was made between two treatment groups: ACT and TAU. The TAU group was measured only pre-intervention- and post-intervention, with no follow-up for only wave 1 participants (n=4), so the repeated measures ANOVAs with the between-subjects group factor are based on two points in time.

An important assumption underlying ANOVA is that the dependent variable is distributed normally. To investigate this assumption, box plots were fit to each of the scales serving as the dependent variables. Box plots indicate normality when the median line falls in the center of the box, with the box representing the inter-quartile range (25<sup>th</sup> to 75<sup>th</sup> percentile of the data). The whiskers extend to the highest and lowest values, assuming these are within an area equal to 1.5 times the inter-quartile range. The whiskers should appear relatively equal in length on both sides of the box. In addition, there should not be very many outliers, defined as observations beyond the whiskers. Figure 3 shows box plots for the Parental Distress scale of the PSI-SF at each point in time (1 = baseline, 2 = post-intervention, 3 = follow-up). The first two time points come close to normality, though the median line shows an upwards skew at t=2. The third point shows an even larger skew. None of the time points show outliers.

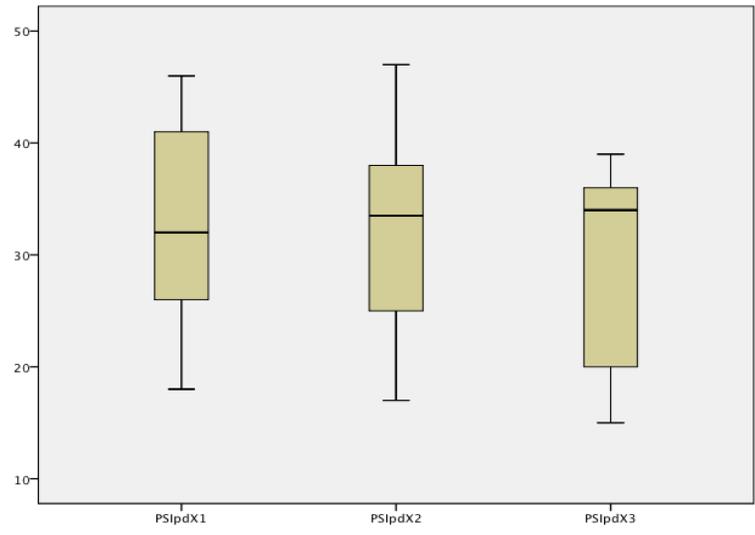


Figure 3. Box plots for the Parental Distress scale of the PSI-SF

Figure 4 displays box plots for the Global Severity Index of the BSI-18. The largest skew appears at t=1, where the median line was closer to the higher end of the box and where there is a single outlier. T=2 show more symmetry, albeit with the median line closer to the lower end of the box. For t=3, the median line is closer to the high end of the scale, while the lower whisker extends much further than the higher end.

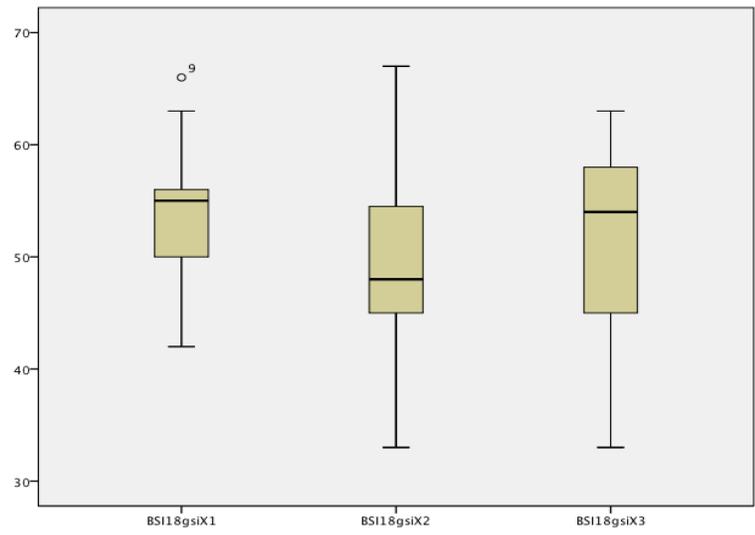
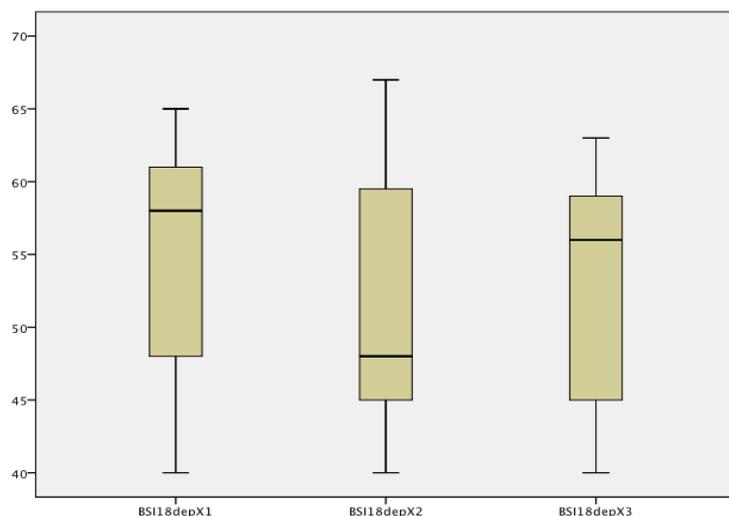


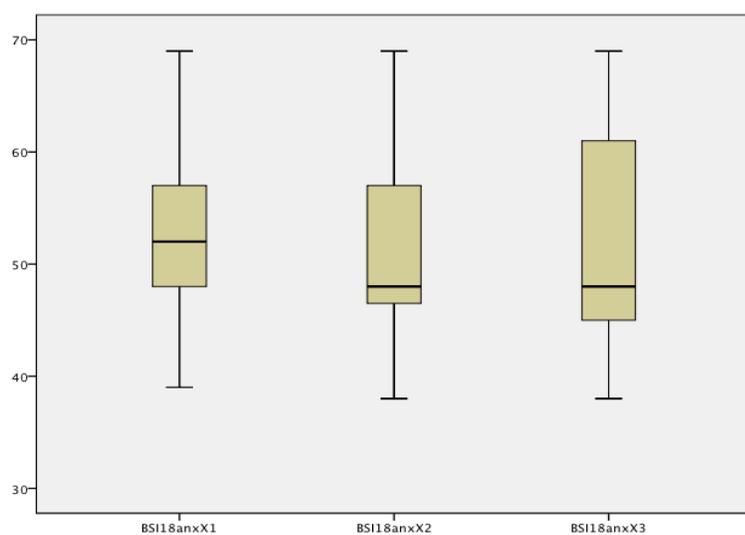
Figure 4. Box plots for the Global Severity Index of the BSI-18

Figure 5 shows box plots for the Depression Scale on the BSI-18. The median line at  $t=1$  and  $t=3$  is closer to the top of the box, while it is closer to the bottom at  $t=2$ . The whiskers are longer on the low end of the scale at  $t=1$  and longer on the high end at  $t=2$ .



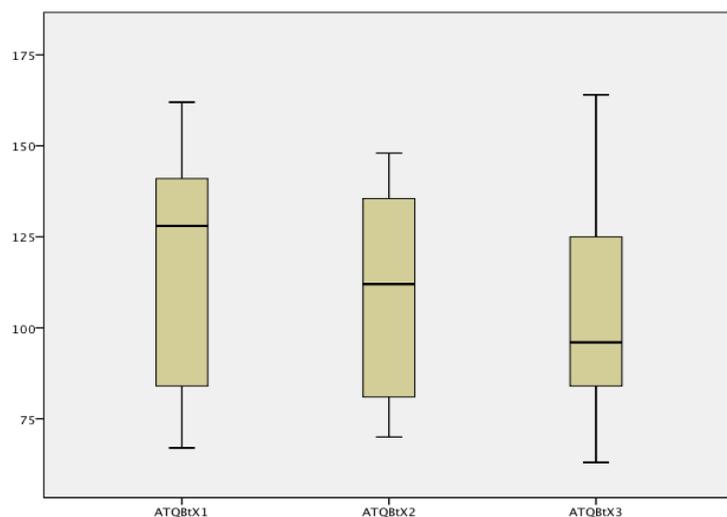
*Figure 5.* Box plots for the Depression Scale on the BSI-18

Figure 6 shows results for the Anxiety Scale on the BSI-18. The plot at  $t=1$  is closest to normal. At both  $t=2$  and  $t=3$ , the median line falls closer to the low end of the scale. There are no outliers for any of the three points in time.



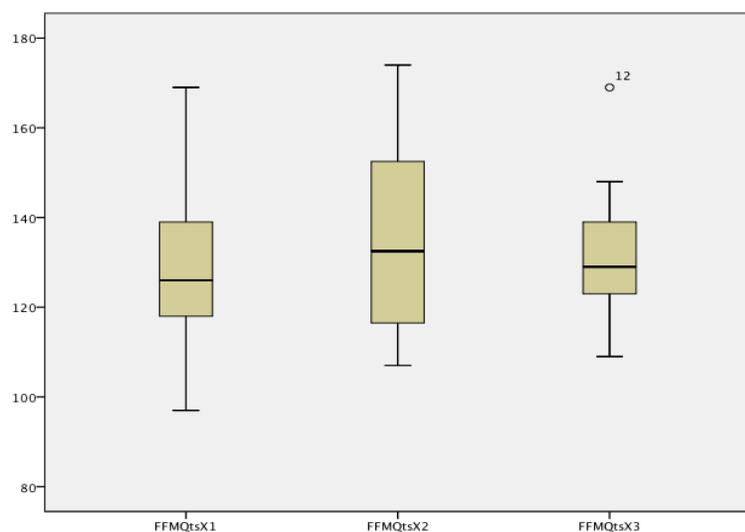
*Figure 6.* Box plots for Anxiety Scale on the BSI-18

Figure 7 refers to the Believability scale of the ATQ. The pre-intervention-intervention measurement shows a modest skew towards the top end of the scale. The middle measurement is approximately normally distributed. The last measurement has a median towards the lower end of the scale but whiskers that extend a little higher than lower. There are no outliers.

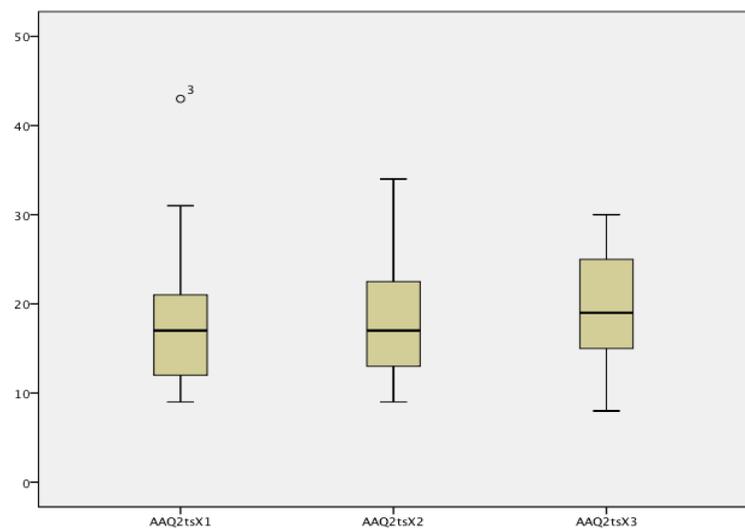


*Figure 7.* Box plots for the Believability scale of the ATQ

The next figure looks at the total scale score on the FFMQ. The plots appear relatively symmetric at all three time points, with the exception of a single outlier at follow-up. Figure 9 represents box plots for the total score on the AAQ-II. There is one outlier at the pre-intervention measurement, and a slight upward skew at  $t=1$  and  $t=2$ . Otherwise, the plots look close to normal.



*Figure 8.* Box plots for total score on the FFMQ



*Figure 9.* Box plots for total score on the AAQ-II

Finally, Figure 10 considers the total score on the PAC measure. There is an outlier at  $t=2$ , but the follow-up measurements show the clearest deviations from normality. The whiskers are almost equal to the inter-quartile range, and there are several outliers. Observation 8 is listed as a particularly large outlier.

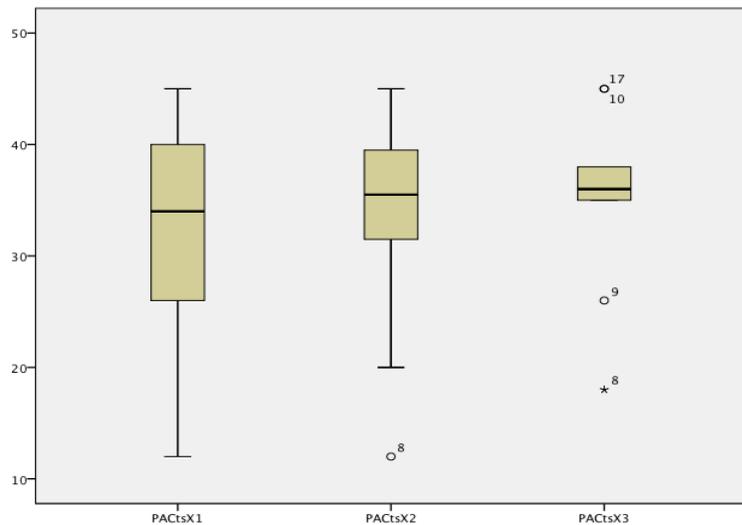


Figure 10. Box plots for total score on the PAC

Across each of these variables, the distributions are not perfectly normal for all three time points. In the messy real world, perfect normality is often not met, especially in smaller samples. Nonetheless, these scales have all been previously tested for validity and reliability. Hence, because the observations are overwhelmingly “near” normal, no transformations were applied. However, extra care should be taken when drawing inferences about the PAC scale, since, particularly at follow-up, normality seems to be most suspect.

**Repeated measures ANOVA: Within-subjects factor only.** Another important assumption underlying repeated measures ANOVA is that the error covariance matrix follows a structure known as *sphericity*. If this assumption is violated, it becomes necessary to make an adjustment to the F-tests when looking at the significance of a within-subjects factor.

Alternatively, one can consider multivariate tests, which test the null hypothesis that the means on the dependent variables (i.e. each time point) are equal between groups. Multivariate tests – such as Pillai’s Trace, Wilks’ Lambda, Hotelling’s Trace, and Roy’s Largest Root – do not require that the sphericity assumption be met. Table 2 shows results of Wilks’ lambda for the

multivariate equality of means test (with only one factor in the model, all four test statistics yield the same result).

Table 2

*Wilks' Lambda Test of Within Subjects Factor (Time) for Each Dependent Variable*

DV	$\Lambda$	F	df 1	df 2	p	Eta-squared	Power
PSI-PD	.485	5.834	2	11	.019	.515	.760
BSI-GSI	.489	5.755	2	11	.019	.511	.754
BSI-SOM	.815	1.247	2	11	.325	.348	.217
BSI-DEP	.652	2.941	2	11	.095	.348	.457
BSI-ANX	.792	1.448	2	11	.277	.208	.246
AAQ-II	.983	.097	2	11	.908	.017	.061
PAC	.477	6.039	2	11	.017	.523	.775
ATQ	.490	5.726	2	11	.020	.510	.752
ATQ-F	.652	2.936	2	11	.095	.348	.217
ATQ-B	.458	6.518	2	11	.014	.542	.807
FFMQ	.930	.413	2	11	.672	.070	.101

Note. Each row represents separate repeated-measures ANOVA.

Table 2 presents eight different tests; hence there is an increased probability of incorrectly rejecting a null. Before taking this possibility into account, half of the tests were significant at the .05 level. These were the measurements for PSI-PD ( $F = 5.834$ ,  $df = 2, 11$ ,  $p = .019$ ), BSI GSI ( $F = 5.755$ ,  $df = 2, 11$ ,  $p = .019$ ), PAC ( $F = 6.039$ ,  $df = 2, 11$ ,  $p = .017$ ), ATQ ( $F = 5.726$ ,  $df = 2, 11$ ,  $p = .020$ ), and ATQ-B ( $F = 6.518$ ,  $df = 2, 11$ ,  $p = .014$ ). BSI-DEP ( $F = 2.941$ ,  $df = 2, 11$ ,  $p = .095$ ) and the ATQ-F ( $F = 2.936$ ,  $df = 2, 11$ ,  $p = .095$ ) are significant at the more generous .10 cut-off level.

If one were to make a Bonferroni adjustment to the required  $p$ -value for significance, thus requiring a  $p$ -value of less than  $.05/8 = .006$  or  $.10/8 = .013$ , none of the tests would remain significant. However, this seems to be overly conservative, given that half (or more than half) of

the tests were significant before the adjustment. Thus, post-hoc tests were carried out on each of the significant measures.

Table 3

*Post-hoc Tests for Each Significant ANOVA*

Time	Comparison	Mean Diff.	SE	p	95% CI	
<b>PSI-PD</b>						
1	2	.615	1.352	1.000	-3.142	4.373
	3	5.077*	1.504	.017	.896	9.258
<b>BSI- GSI</b>						
1	2	5.538*	1.992	.050	.001	11.076
	3	4.692	1.992	.109	-.843	10.228
<b>BSI-DEP</b>						
1	2	4.308	2.205	.224	-1.822	10.438
	3	3.923	2.147	.278	-2.044	9.890
<b>PAC</b>						
1	2	-.923	1.879	1.000	-6.146	4.300
	3	-3.923	1.681	.113	-8.596	.750
<b>ATQ-B</b>						
1	2	12.538	7.366	.343	-7.934	33.011
	3	18.077	6.740	.060	-.657	36.811
<b>ATQ-F</b>						
1	2	1.846	1.970	1.000	-3.631	7.323
	3	5.308	2.104	.080	-.541	11.156
<b>ATQ</b>						
1	2	14.385	7.696	.259	-7.006	35.775
	3	22.615*	6.892	.020	3.460	41.770

Note. P-values are Bonferroni adjusted. \*  $p < .50$ .

Table 3 presents results for each follow-up contrast, where the p-values have already been adjusted using the Bonferroni method. Beginning with Parental Distress scale on the PSI-SF, the difference between time 1 and time 2 is not significant ( $p \approx 1.00$ ). However, there is a significant difference between pre-intervention and follow-up scores ( $p = .017$ ). This is evident from a plot of the estimated marginal means, as shown in Figure 11. The average score at

baseline in the figure is 34.46 ( $SE = 2.45$ ), dropping only to 33.85 ( $SE = 2.43$ ) after the intervention. By follow-up, though, the average has dropped by 5.08 to 29.36 (2.48).

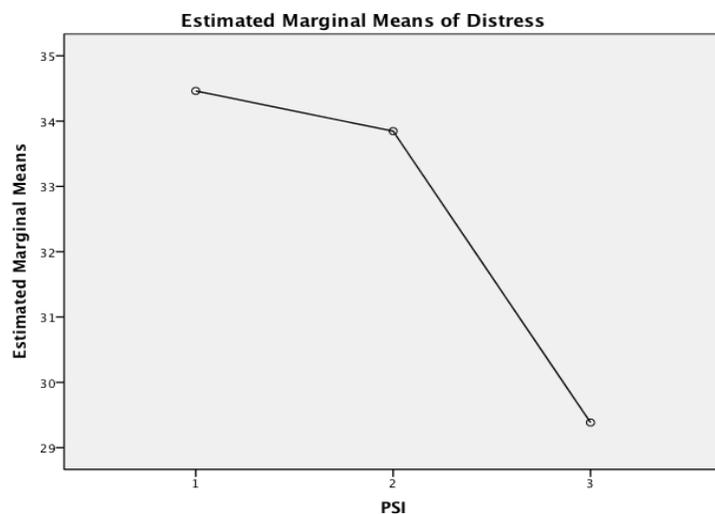


Figure 11. Plot of means for the Parental Distress scale on the PSI-SF

For the Global Stress Index of the BSI-18, the significant difference is between baseline and the post-intervention measurement ( $p = .05$ ). This is illustrated in Figure 12. The average at baseline is 55.46 ( $SE = 1.82$ ), which drops by 5.54 to 49.92 ( $SE = 2.80$ ) at the next measurement. There is a slight regression towards baseline at follow-up ( $\mu = 50.77$ ,  $SE = 2.81$ ). Although the difference between baseline and follow-up is not significant ( $p = .109$ ), the measurement still shows improvement relative to the first measurement.

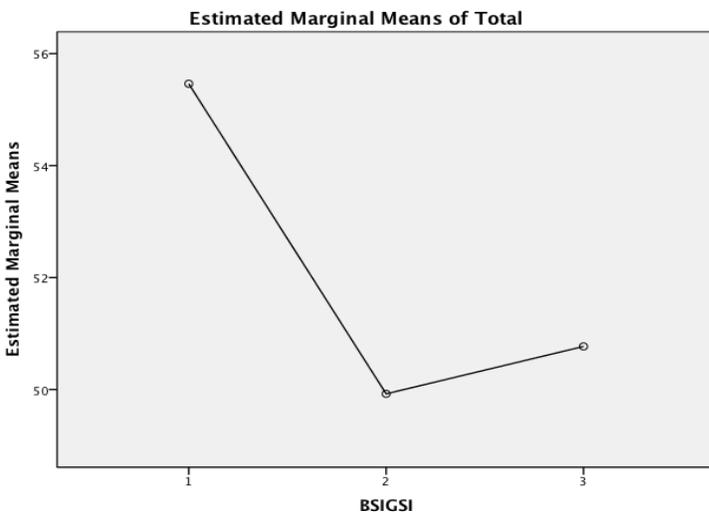


Figure 12. Plot of means for the Global Severity Index scale on the BSI-18

Figure 13 shows the means for Depression scale of the BSI-18. The averages do show improvement from pre-intervention ( $\mu = 55.62$ ,  $SE = 2.08$ ) compared to the post-intervention measurement ( $\mu = 51.31$ ,  $SE = 2.79$ ) and follow-up ( $\mu = 51.69$ ,  $SE = 2.41$ ). However, these are not significant after adjusting for the simultaneity of the tests ( $p = .224$  and  $p = .278$ , respectively). The lack of significance is not surprising given that the Depression scale results were only significant at the more generous .10 cut-off level. Nonetheless, although not statistically distinguishable from zero, the results show some improvement after the intervention that remained at follow-up.

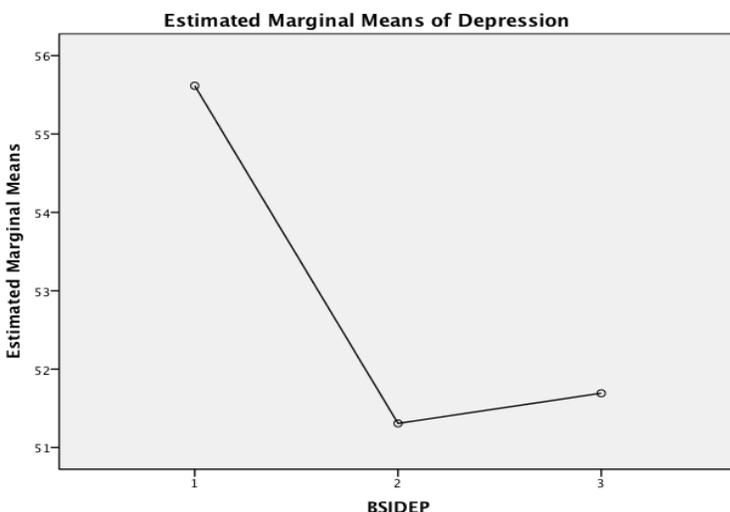


Figure 13. Plot of means for the Depression scale on the BSI-18

The next significant measurement was for the total on the PAC, displayed in Figure 14. The mean at the pre-intervention-measurement was 31.62 ( $SE = 2.79$ ), which increased to 32.54 ( $SE = 2.36$ ) at post-intervention and 35.54 ( $SE = 1.97$ ) at follow-up. However, the pre-intervention to post-intervention result was not significant ( $p \approx 1.00$ ), nor was the pre-intervention to follow-up comparison ( $p = .113$ ). Instead, the significant ANOVA was due to the comparison between post-intervention and follow-up ( $p = .034$ ). The reason post-intervention versus follow-up was significant whereas pre-intervention versus follow-up was not is due to the differences in variances at each time point as seen in Figure 10. It was noted then that inferences about these measurements should be made with caution, and that warning clearly holds here. Setting aside the significance testing, however, there is a clear upward trend in the means as time progresses.

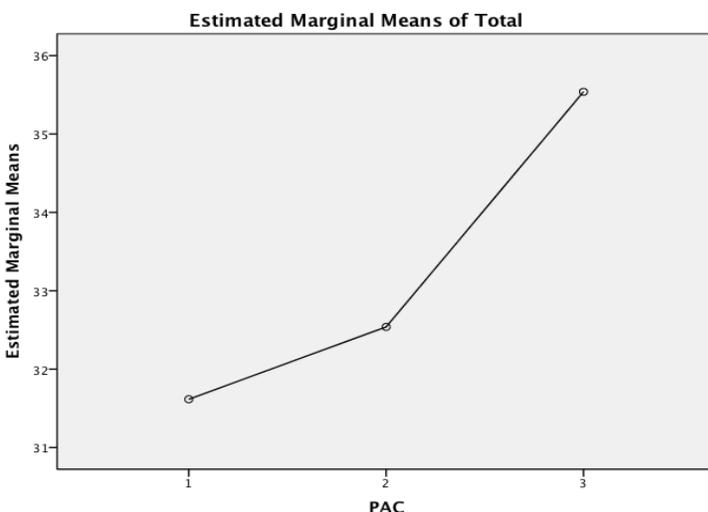


Figure 14. Plot of means for the total score on the PAC

The final measurement to be considered is the ATQ. For the total score (believability and frequency scale) variable, the average at the pre-intervention-measurement was 126.08 ( $SE = 7.97$ ). This changed to 111.69 ( $SE = 8.38$ ) at post-intervention and 103.46 ( $SE = 8.30$ ) at follow-up. The pre-intervention and post-intervention comparison was not significant ( $p = .259$ ), but the pre-intervention and follow-up comparison was ( $p = .020$ ). The means are plotted in Figure 15. On the Frequency scale of this measure, results were only significant at the .10 level ( $F = 2.936$ ,  $df = 2, 11$ ,  $p = .095$ ). These results can be examined in Figure 16. Figure 17 shows that the Believability scale of the ATQ measure demonstrates a significant Wilks' lambda for the believability scale ( $F = 6.518$ ,  $df = 2, 11$ ,  $p = .014$ ); however, despite clear visual trends, post-hoc tests for believability and frequency scales with Bonferroni-adjusted  $p$ -values suggest none of the contrasts are significant at the .05 level.

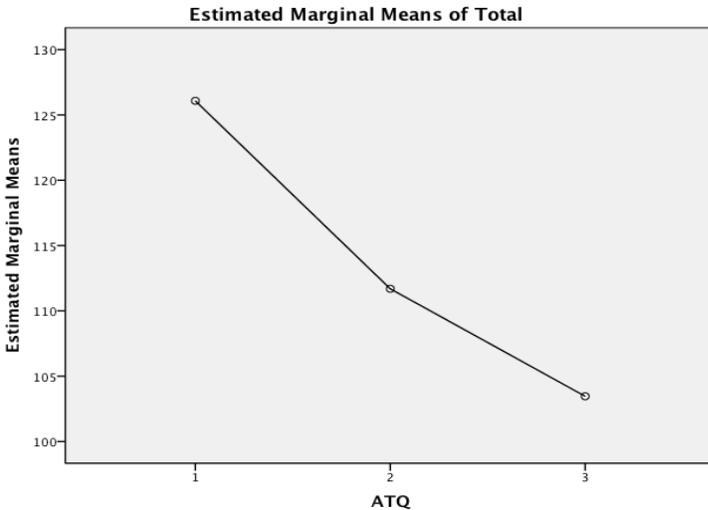


Figure 15. Plot of means for the total score on the ATQ

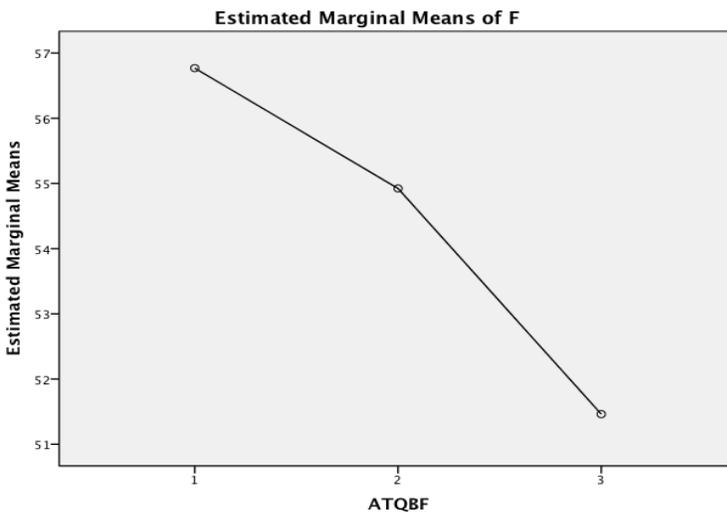


Figure 16. Plot of means for the Frequency scale on the ATQ

**Repeated measures ANOVA with between-subjects factor.** The next step was to compare ACT participants with the TAU group to determine if there were any significant differences in the trends between groups. This analysis is more limited due to the fact that there were only four control participants and there was no follow-up for the control. Because there are only two time points available, the sphericity assumption is automatically met.

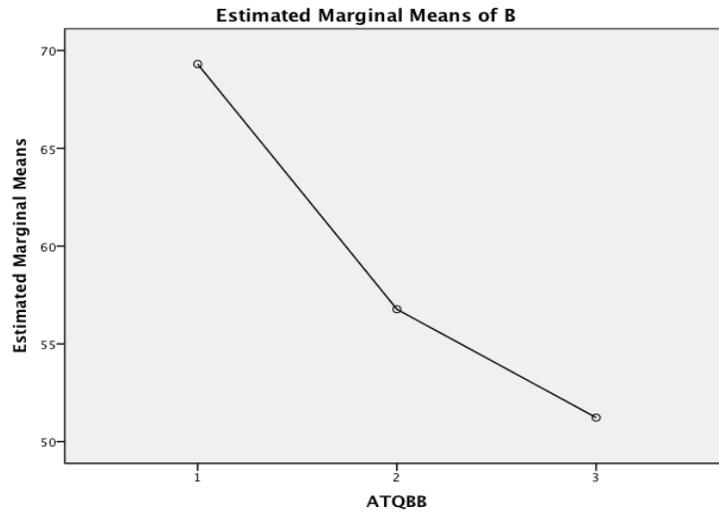


Figure 17. Plot of means for the Frequency scale on the ATQ

Table 4

*Tests of Group Factor and Time-Group Interaction*

	F	p	Partial $\eta^2$	Power
<b>PSI-PD</b>				
Group	2.872	.112	.170	.352
Grp X Time	.424	.526	.029	.093
<b>BSI GSI</b>				
Group	.954	.345	.064	.149
Grp X Time	.523	.481	.036	.104
<b>BSI-DEP</b>				
Group	.878	.365	.059	.141
Grp X Time	.373	.551	.026	.088
<b>BSI-ANX</b>				
Group	.721	.410	.049	.124
Grp X Time	.115	.740	.008	.062
<b>BSI-SOM</b>				
Group	2.868	.113	.170	.351
Grp X Time	.004	.951	.000	.050
<b>AAQ-II</b>				
Group	.665	.429	.045	.118
Grp X Time	.652	.433	.044	.117
<b>PAC</b>				
Group	1.945	.185	.122	.255
Grp X Time	.098	.759	.007	.060
<b>ATQ</b>				
Group	2.663	.125	.160	.330
Grp X Time	1.726	.210	.110	.232
<b>ATQ-F</b>				
Group	1.358	.263	.088	0.192
Grp X Time	3.811	.071	.214	.444
<b>ATQ-B</b>				
Group	3.143	.098	.183	.379
Grp X Time	.629	.441	.043	.115
<b>FFMQ</b>				
Group	1.289	.275	.084	.185
Grp X Time	.570	.463	.039	.108

Note. Degrees of freedom for F-tests = 1, 14.

Table 4 presents the results of the repeated measures ANOVA with group as a between-subjects factor. A significant effect for the group main effect would signify that, across both

measurements, the ACT and control groups have different means on the respective scale. A significant interaction would mean that ACT participants change from pre-intervention to post-intervention at a different rate compared to the control group.

As the table makes clear, however, none of the effects are significant, with the exception of the ATQ-F ( $F = 3.811$ ,  $df = 1, 14$ ,  $p = .071$ ) when using the more generous cutoff of .10. This is not surprising given the very small number of control participants. The power column makes clear that there are not enough subjects to find a significant effect for many of the variables. The highest level of power is only .379, which occurs for the group main effect for the ATQ-B measurement. For a significant result, interpretation is that the change in scores between time 1 and time 2 is larger for one group than the other. Figure 18 demonstrates that it is the control group that changed faster on the ATQ-F measure.

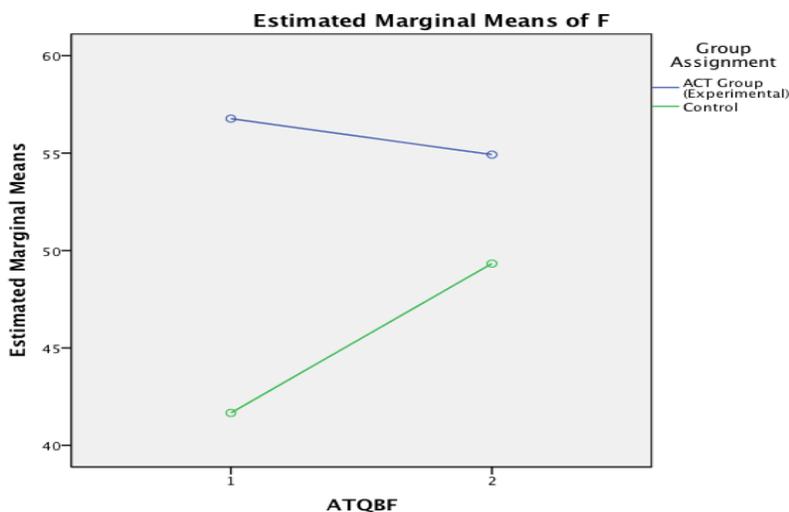


Figure 18. Means for Time X Group Interaction on ATQ-F

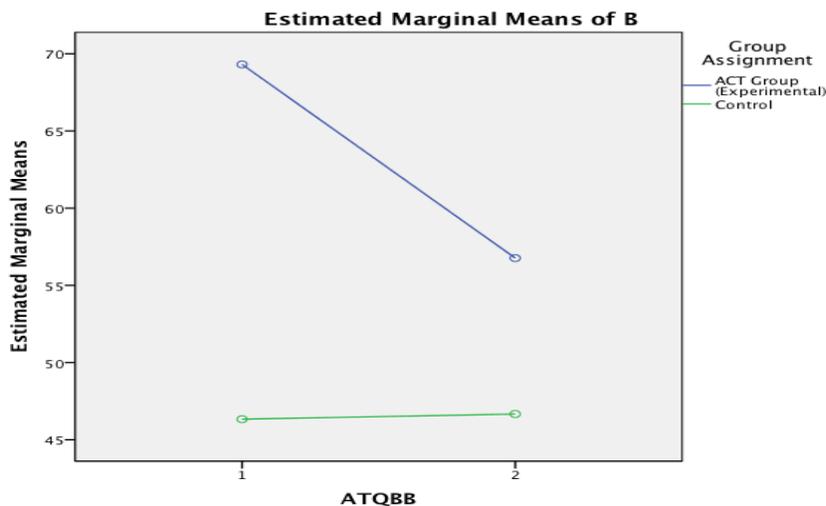


Figure 19. Means for Time X Group Interaction on ATQ-B

### Correlations: Exploratory Analyses

The final step in data analysis was to 1) examine the relationship between subscales on the BRIEF-A and the AAQ-II, and 2) explore the relationship between measures of externalizing, internalizing, and adaptability on the BASC-2 with the total score from the PSI-SF. First, the results for determining convergent validity of the AAQ-II will be discussed. Table 5 shows Pearson correlations between AAQ-II and the various BRIEF-A scores at each time point. There are several significant results, especially at the first and follow-up measurements. In the case of the Inhibit scale, it is the post-intervention measurement where the two correlate ( $r = .503, p = .047$ ). The Shift scale correlates highly and significantly at pre-intervention ( $r = .615, p = .009$ ) and follow-up ( $r = .732, p = .004$ ). The Emotional Control scale does not have any significant correlations with AAQ-II, but Self Monitor does at pre-intervention ( $r = .541, p = .025$ ) and post-intervention ( $r = .576, p = .020$ ). Initiate correlates with AAQ-II significantly at pre-intervention ( $r = .711, p = .001$ ) and follow-up ( $r = .630, p = .021$ ).

Likewise, Working Memory correlates significantly at pre-intervention ( $r = .550, p = .022$ ) and follow-up ( $r = .806, p = .001$ ). Plan/Organize correlates at  $.622 (p = .008)$  and  $.735 (p = .001)$ .

= .004) at times 1 and 3, respectively. Task Monitor follows the same pattern, correlating at .697 ( $p = .002$ ) at pre-intervention and .646 ( $p = .017$ ) at follow-up. Organization of Materials only has a significant correlation with AAQ-II at follow-up ( $r = .588, p = .025$ ). The correlation for the Metacognition Index is significant at both pre-intervention ( $r = .696, p = .002$ ) and follow-up ( $r = .690, p = .009$ ). The correlation for the Global Executive Composite is also significant at pre-intervention ( $r = .734, p = .001$ ) and follow-up ( $r = .786, p = .001$ ).

Table 5

*Correlations between AAQ-II and BRIEF-A Scales*

BRIEF	Pre-intervention	Post	Follow-up
INHIB	.349	.503*	.516
SHIF	.615**	.304	.732**
EC	.46	.255	.377
SM	.541*	.576*	-.131
INIT	.711**	.277	.630*
WM	.550*	.238	.806**
PO	.622**	.493	.735**
TM	.697**	.434	.646**
OOM	.346	.446	.588*
MI	.696**	.358	.690**
GEC	.734**	.485	.786**

Note. \*  $p < .05$ . \*\*  $p < .01$ .

Table 6 displays correlations between PSI-SF total scores and three of the BASC-2 scales. The only correlation that is significant is between EXP and PSI at the pre-intervention-measurement ( $r = .483, p = .049$ ). The rest of the  $p$ -values are all greater than .05.

Table 6

*Correlations between PSI-SF Total Score and BASC-2 Scores*

BRIEF-A	Pre-intervention	Post	Follow-up
INP	.333	.113	.475
EXP	.483*	.159	.401
ADAP	-.271	-.469	-.512

Note. \*  $p < .05$ .

Table 7 shows the same, but for the Parental Distress scale of the PSI-SF. In this case, none of the correlations are significant.

Table 7

*Correlations between PSI-PD and BASC-2 Scores*

BRIEF-A	Pre-intervention	Post	Follow-up
INP	0.131	-0.037	0.249
EXP	0.278	0.153	0.133
ADAP	0.022	-0.092	-0.110

Note. \*  $p < .05$ .

### Post-Treatment Questionnaire Results

The results of a post-treatment questionnaire generated by the first author to assess participants' satisfaction with the treatment groups reflect that overall, mothers were pleased with the interventions; however, very limited data ( $n = 2$ ) were obtained from the mothers in the TAU condition. Ratings were obtained on a rating scale of 1 to 5, with behavior anchors of 5-very much; 4-a good amount; 3-somewhat; 2-a little bit; 1-not at all. When asked about the usefulness of the group, mothers in the ACT and TAU reported similar feedback (ACT,  $M = 4.33$ , TAU,  $M = 4$ ). Some variation between groups was seen in their ratings of how helpful the group leader was, which supports some of the comments received from mothers in the support group, like "I would like the group leader to facilitate more" (ACT,  $M = 4.83$ , TAU,  $M = 3.5$ ). Overall, ACT participants found their group more helpful than did TAU group members (ACT,  $M = 4.17$ , TAU,  $M = 2.5$ ). It followed that ACT group members were more likely to report that they would recommend their group to a friend (ACT,  $M = 4.83$ , TAU,  $M = 4$ ).

Some of the anecdotal comments offered by participants prove very useful for guiding future applications of the intervention. A few ACT mothers commented that they would have liked to have had less of an introduction of the ACT background/view on language: "It took too

long to get to the ‘meat’ of the intervention.” Most commonly, ACT participants cited the fact that the group had to end as the “least liked” aspect, solidifying the ACT group’s satisfaction with the treatment. One mother noted that “sometimes it seemed ACT was directed to people who have a negative stream of thoughts running through their head, and that is not my case, so that didn’t speak to me.” Some mothers in both groups commented on the make-up of the group and how it certainly may affect the way a person responds to the intervention (e.g., “sometimes got annoyed by a group member or two, at times,” “would liked to have more sharing among group members,” “I felt an instant connection to these ladies since the first meeting”). This point is likely one addressed by most group-based interventions but, nevertheless, something to keep in mind. One mother liked that the ACT group’s focus “wasn’t just about autism but more so about how we deal with life in general,” while another enjoyed “learning that it was ok not to ‘get over’ something, but to not let it take over my life.”

## **Chapter 5: Discussion**

The results of hypothesis testing are discussed in greater detail below, as are general implications of these findings when compared to previous research, limitations to the current study, and directions for future research. Overall, the outcomes of this study indicate that a group-based ACT intervention is effective in reducing levels of parental distress and psychological dysfunction in a non-clinical sample of mothers who have children with an ASD. Mothers who completed this study also demonstrated significant increases in their ratings of positive aspects of caregiving. Additionally, mothers who reported significantly greater levels of externalizing problem behaviors for their children also tended to endorse higher parental distress. Finally, exploratory analysis revealed that experiential avoidance was positively correlated with multiple aspects of the neurobiological construct of executive functioning, suggesting construct validity for the newer concepts of experiential avoidance and psychological inflexibility.

### **Between-Group Comparisons**

The original aims of this study included hypotheses related to both within-and-between-subjects, as the initial experimental design included a TAU group as well as repeated measures. Unfortunately, the TAU group was only implemented for the initial wave of treatment and only included pre-intervention and post-intervention treatment (not follow-up) data; thus, statistical analyses were completed to examine the comparison using a limited dataset. The results indicated that only the ATQ frequency scale demonstrated a significant difference between groups. Mothers in the TAU group demonstrated faster gains from pre-intervention to post-intervention in their frequency scale of the ATQ; thus the mothers in TAU reported a higher frequency of negative automatic thoughts.

While this was not a hypothesized finding, it does support findings related to thought suppression and its effects on cognition. It might be that mothers in TAU condition experienced significant emotional reactions to their interactions with other mothers (e.g., it is very sad to hear how much a mother is struggling financial to pay for ABA services for their child). In an attempt to eliminate these feelings, participants may have deliberately tried to stop thinking about these emotions. The thought suppression literature (Wenzlaff & Wegner, 2000) would suggest that this attempt to stop thinking might have actually produced an increase in thoughts related to sadness and financial stressors. In a support group with few strategies to address ways to cope with such strong emotional reactions, the mother's dissatisfaction and ultimate termination is not necessarily a surprise.

This finding also suggests a lack of treatment efficacy for TAU peer-to-peer support groups that are regularly used in the community. It may be reasoned that mothers who may not have experienced significant negative thoughts about themselves and their situation may have become more likely to endorse these symptoms following discussions with other mothers. These results were very different from the believability scale, which changed by roughly only one point from baseline to post-intervention. If future research explores the role of a TAU, it would be interesting to evaluate the follow-up results in the frequency scale ratings to see if these gains remain.

### **Within-Group Comparisons**

The following discussion of the tested hypotheses will focus on the comparisons between repeated measures within-subject for the ACT group. I will review the findings that examine pre-intervention-, post-intervention-, and follow-up changes on major outcome and process measures: the PSI-SF, BSI-18, AAQ-II, PAC, ATQ, and FFMQ.

**General psychological distress.** It was predicted that mothers in the ACT group would have a statistically lower report of psychological distress, as measured by the total score on the Global Severity Index of the BSI-18 at follow-up as compared to the baseline. There was significant evidence to partially reject the null hypothesis, as the significant finding was seen from Time 1 to Time 2, but not for Time 3. The fact that the GSI results were not statistically significant from baseline to post-intervention assessment was not necessarily consistent with preliminary findings from Hayes and colleagues (2006), who find that oftentimes treatment gains are seen more so from post-intervention to follow-up rather than baseline to post-intervention. However, the trend toward lowered global distress overall was clear, and this is an important finding in a relatively nonclinical sample.

The specific scales of depression and anxiety did not show significant changes from baseline to follow-up, although some trends emerged. These results may be a result of limited sample size and subclinical levels of psychopathology in this sample. The BSI-18 has been used in other studies (e.g., Kreutzer, Rapport, Marwitz, Harrison-Felix, Hart, Glenn, & Hammond, 2009) but not specifically with ACT interventions. Using the guidelines suggested in the BSI-18 manual, a *t*-score of 63 was selected as a cut point to represent caseness on each subscale (Derogatis, 2000). At baseline, 7% ( $n = 1$ ) of the mothers in the ACT group were in the clinical range for somatization, 15% ( $n = 2$ ) for clinically significant depression, and 23% for clinically significant anxiety ( $n = 3$ ). Overall, these are relatively low rates of baseline psychopathology and thus may affect our overall findings. In contrast, in Blackledge and Hayes's (2006) study, depression was measured using the BDI-2, and 25% of their sample met criterion for clinical depression.

**Parental distress.** It was also predicted that those in the ACT group would report less subjective parental distress (as measured by the Parental Distress Index on the PSI-SF) at follow-up than at baseline. The results indicate that when comparing baseline results to follow-up data, there is sufficient evidence to reject the null hypothesis. While there was not a significant reduction in parental distress from baseline and post-intervention measure, the results at follow-up are statistically significant. It is important to note that the results for parental stress were not statistically significant from baseline to post-intervention assessment, a finding that has been noted in other outcome measures in the ACT literature (Luoma, Kohlenberg, Hayes, & Fletcher, 2012). This is consistent with preliminary findings from Hayes and colleagues (2006) who suggest “effect sizes generally seem somewhat larger with more severe problems, and larger at follow up than immediately post intervention, although the literature is too young to say for sure” (p. 21). One might hypothesize that this occurs because producing change in values-based actions requires time and long-standing effort best seen over multiple encounters.

Zaidman-Zait and colleagues (2010) suggested that the parental distress subscale items are useful in assessing the distress in parents of children with ASD because the changes in a parent’s overall parental distress are reflected in changes in item scores at the entire range of distress scores. In their sample of similar parents of children with ASD, the mean score on the PD scale at baseline was 31.5 ( $SD=9.6$ , range 13-56), which falls in the nonclinical range. Scores at or above 33 are considered at the 85<sup>th</sup> percentile and enter the clinically significant range (Abidin, 1995). Although the mothers in this study did not, as a whole, evidence significant psychopathology, they did experience considerable parental distress. At baseline, the PD mean was 34.46, just above the 85% clinical cutoff, and more than half (53.8%) of mothers in our study scored above the clinical cutoff score.

**Positive aspects of caregiving.** The next hypothesis stated that mothers in the ACT group would endorse significantly greater amounts of positive aspects of caregiving (as measured by a PAC total score) at follow-up as compared to baseline. The results suggest that there was a failure to reject the null hypothesis for this specific result; however, similar to the delayed treatment effect of parental distress, significance ( $p = .034$ ) was found from post-intervention measurement to follow-up. Upon visual analysis of the data, a clear increasing trend occurred for PAC across the intervention measurements. These gains may best be explained as a result of the mindfulness training that is incorporated into the ACT intervention. Fredrickson and colleagues (2008) have previously demonstrated that specific mindfulness exercises can result in increased experience of positive emotions and related psychosocial benefits. Future research might wish to explore this finding further by evaluating the extent to which participants felt they utilized aspects of the ACT treatment during the post-intervention time. For instance, if participants who report utilizing mindfulness experiences also report more PAC, this may further support this correlation and afford insight into possible mediators or moderators for this mechanism of action.

These findings are the first to directly report PAC levels for mothers of children with ASD, as this measure is relatively new and utilized largely in the caregiving literature. The parental experience for children with special needs is not traditionally examined as a caregiving experience, much the same way it is for individuals caring for loved ones with a dementing illness or chronic medical conditions. However, the same literature base could be very applicable to these parents, especially when considering the amount of effort and energy their parenting experience entails. In the Alzheimer's caregiving literature, levels of PAC were found to moderate the treatment response (Hilgeman, Allen, DeCoster, & Burgio, 2007). The role of PAC

as a possible moderator, or at the least a protective factor, for parents who experience significant amounts of caregiving stress is important for future researchers to investigate. In this study, baseline levels of PAC for all participants ( $M = 31.62$ ) were slightly less than the mean ( $M = 34.0$ ) for the overall sample of adult caregivers in Tarlow and colleagues' (2004) original study. However, the results were more similar at follow-up measurement ( $M = 35.54$ ).

**Psychological flexibility.** A secondary aim of this intervention was to examine the role of specific ACT processes, such as psychological flexibility and mindfulness. It was predicted that mothers in the ACT group would demonstrate a greater change in experiential avoidance (as measured by AAQ-II total score) at follow-up than their baseline levels. The results indicate that there was no statistical difference across the three time points, failing to reject the null hypothesis. This finding is not consistent with the treatment literature using ACT with a variety of populations, as many of these interventions demonstrated change in the psychological flexibility/experiential avoidance concept.

There are multiple considerations to be made when interpreting this finding. First, it is important to consider that the ACT group's baseline rates of experiential avoidance ( $M = 18.38$ ;  $SD = 6.117$ ) were similar to the non-clinical rates reported in previous studies (Bond et al., 2011). This suggests that these mothers did not experience a significant degree of EA and/or psychological inflexibility. This is important to recognize because while reductions in EA are typical in ACT intervention studies, researchers have noted that in non-clinical samples (such as employees or community workshops) the most change may be produced in concepts such as behavioral effectiveness, values clarification, and committed action (Bond et al., 2011). It would have been fruitful to include additional ACT process measures for values clarification and committed action to examine the effects in these areas.

It is also plausible that the lack of demonstrated change is partially related to the version of the AAQ-II that was used for this study. Most of the previous literature, including Blackledge and Hayes's (2006) study with this same population, used the 9-item version of the AAQ. In order to address these variations in versions of the AAQ, some researchers elect to include multiple versions of the measures (e.g., Hinton & Gaynor, 2010). One consideration when using this approach is the additional effort asked by already stressed participants in completion time of the measures, especially when multiple measures appear similar. If participants are receiving some type of compensation, they might be more willing to engage with these requests. Until consensus is acquired within in the field as to the "gold standard" for measurement of experiential avoidance and psychological flexibility, it might be useful to weigh the costs of time against gaining the necessary data.

To avoid some of the pitfalls previously discussed with the current AAQ options, there are a few options for measuring experiential avoidance that are worth consideration. Researchers could consider use of The Avoidance and Fusion Questionnaire (AFQ-Y). The AFQ-Y, previously used with children and adolescents, was recently (see Schmalz & Murrell, 2010) validated with an adult population and showed adequate reliability ( $\alpha = .92$ ). The authors note that while the AAQ-II and AFQ-Y were significantly correlated, results did not necessarily suggest that the two were measuring the exact same construct. They recommend that future researchers utilize both measures to examine how they might differ or share similarities in different capacities. Alternatively, some researchers elect to establish or use a previously established version of the AAQ validated for a specific population or circumstance. For instance, the Parental Acceptance and Action (PAAQ; Cheron, Ehrenreich, & Pinus, 2009) was created to measure both a parent's unwillingness to witness their children experience negative emotion and

their inability to effectively manage parental reactions to their children's affect and predicts a significant amount of variance in parent- and clinician-rated levels of psychopathology. This 15-item measure was considered for use in this study but was not deemed to be as relevant for this group due to specificity of the questions that relate to parental tolerating of children's affect, rather than emphasizing toleration of their own emotions, such as guilt and shame.

***Convergent validity.*** Through more exploratory analysis, we were able to determine a clear positive correlation between the total score on a measure of psychological flexibility (AAQ-II) and multiple subscales on the neurocognitive measure of executive functioning (BRIEF-A). These significant correlations can be seen more at baseline and follow-up, and the TAU group did not have follow-up data. Therefore, it is important to identify what might have been different at Time 2 to result in these discrepancies, as one would expect more stability on this measure over time. The rationale for this discrepancy may be the inclusion of the TAU group in these analyses and the trend for a number of scales to decrease from Time 1 to Time 2. These results indicate that mothers who report more difficulty in aspects of executive functioning also tend to report greater degrees of psychological inflexibility. Thus, this research demonstrates the first relationship between these concepts. Although construct validity has been demonstrated on this measure, the link between a newer construct of psychological flexibility and well-established neurocognitive process has not previously been examined. Visual analysis of the means for the subscales reveal that the majority of scales remained stable across the three time points, whereas Working Memory and Initiation post-treatment scores increased (i.e., mothers reported greater difficulties in these areas).

The scales that reflect the most significant correlations were those that would have been expected, including the Global Executive Composite, Metacognition, Initiation, and Shift. Taken

at face value, these aspects of executive functioning appear most related to the concept of psychological flexibility. Executive functioning has been defined as one's ability to "re-focus or rapidly shift cognitive sets and thereby shift attention" (Goldberg, 2001). Kashdan and Rottenberg (2010) recently hypothesized that executive functioning is one of three basic building blocks of psychological flexibility. Although this concept has, to our knowledge, not been investigated in prior work, this study established an initial association and should be followed up by additional investigation in this area. Establishing further links between the treatment outcome and cognitive sciences literature bases can really only benefit all researchers interested in these concepts.

**Automatic thoughts.** It was also predicted that individuals in the ACT group would experience significant reductions in the total score of believability of their thoughts (as measured by the B scale on the ATQ) at follow-up as compared to baseline. After post-hoc analysis, the results only show statistically significant change ( $p = .020$ ) using the total score of the ATQ; thus we partially reject the null hypothesis. It was expected that the believability scale alone would produce significant results, but likely due to sample size, this result was not found.

The means of the ATQ-B changed from 69.31 at baseline, to 56.77 at post-intervention, to 51.23 at follow-up, suggesting a clear trend in decreasing believability, but this did not remain significant following post-hoc analysis. These results vary from other findings (Bach & Hayes, 2002) that suggest ACT interventions are most successful in producing change to the believability of one's automatic thoughts versus overall symptom reduction, but sample size might be the best explanation. These results can be compared to changes in means for the ATQ-F scale, which in previous research has not demonstrated as significant a change: 56.77 at baseline, 54.92 at post-intervention, and 51.46 at follow-up. The more extreme change in the believability

scale was expected, given ACT's primary focus on helping people changing their relationship to thoughts rather than changing or eliminating the thoughts themselves. Anecdotally, some of these automatic thoughts made by mothers in our group included "the autism is my fault," "my family will never be what I expected," and "I am a bad mother." These results, coupled with findings from the between-group comparison, indicate that this intervention was successful in reducing the believability, but not necessarily the frequency. The mechanism by which this typically occurs in ACT incorporates the techniques used to facilitate cognitive defusion, which help to change one's relationship to thoughts and language.

**Mindfulness.** The final hypothesis predicted that participants would endorse more indicators of mindfulness (as measured by the total score of the FFMQ) at follow-up than at baseline levels. The results indicated that means from baseline to follow-up increased slightly (128.15 and 131.85, respectively) but did not obtain statistical significance for the total score measurement. When comparing this baseline average to norms in the published literature (Bear et al., 2008), these mothers did possess greater degrees of mindfulness than a community sample with an average educational level of 12.9 years ( $M = 116.9$ ), particularly in the subscales of nonjudging of inner experience and describing. However, the overall mean ( $M = 137.32$ ) was below a norm obtained from a highly educated sample, 18.2 years on average, a factor that has been demonstrated to be modestly correlated with mindfulness facets (Baer et al., 2008). Based on subjective comments from those who participated in the intervention, many of the mothers had participated in formal or informal mindfulness training at some time prior to the intervention. The assessment of formal mindfulness training would be an important addition in future research seeking to measure change on this measure.

The use of more informal mindfulness exercises versus more formal exercises of specific mindfulness training in the ACT treatment manual utilized for this study may help explain this finding. Sheets (2010) found variable changes in mindfulness using the FFMQ in her study using ACT to address delusional beliefs in psychotic patients. Future researchers may want to evaluate the level of meditation experience for the participants to examine what, if any, effects prior experience has on changes in the FFMQ scores. Additionally, consideration should be given to the particular mindfulness measure that is used. The FFMQ is a newly established measure and still undocumented in terms of use of measuring process outcomes in ACT interventions.

**Parental distress and behavioral problems.** An additional focus of the current project evaluated the link between participants' subjective ratings of their child's behavioral problems and their measurement of parental distress across the three time points. The findings from this study suggest that mothers at baseline who report higher levels of parental distress also report greater clinically significant externalizing behavioral problems ( $r = .483$ ). These same results were not seen when analyzing just the Parental Distress subscale of the PSI-SF. As these results were purely correlation and a subjective rating, it is not possible to discern whether parents who are experiencing significant parental distress tend to view their children as more problematic or whether the distress is a true result of significant behavioral problems.

This finding supports a notion that many of the mothers in this study express anecdotally, which is that when their child creates a disturbance with a tantrum or other noticeable behavior, this may result in feelings of embarrassment, shame, or anger for the parents. This might be compared to a child who is socially withdrawn or depressed but who does not create the same difficult emotional affect in the parents. Further understanding of the link between experience of varying types of emotions and the related impact of parental distress is an

important for future research. This finding adds to the literature on the correlation between maternal stress levels and behavioral difficulties. Previous research has found that three subscales—emotionally reactive behavior, withdrawn behavior, and attention problems—on a measure of children’s behavior and emotional problems explained a third of the variance in maternal stress (Peters-Scheffer, Didden, & Korzilius, 2012). The significant result found for externalizing behavior problems encompasses two of three aspects found in their research (emotional reactivity and attentional issues) but does not support evidence for withdrawn behavior, which would be an internalizing problem. Shine and Perry (2010) found a modest negative correlation between maternal stress levels and their children’s adaptive skills, a finding that was not replicated in our study.

### **Findings Related to Population Sample**

It is important to note that the current sample of participants represent a group who, on average, have children who were diagnosed approximately 3 years ago. Therefore, the emotional reactions to diagnosis, engagement in the treatment process, and general distress might look significantly different than in a group of women with children who were more recently diagnosed and thus younger in age. It can be hypothesized that parents of children who have received treatment/education services for 2-4 years might have children who experience fewer behavioral difficulties. Additionally, these parents may have developed functional coping skills for issues related to an ASD diagnosis (e.g., ways of dealing with embarrassing situations or managing the stress of facilitating treatment goals), perhaps more so than parents of newly diagnosed children. Alternatively, parents of older children might face unique issues, such as having a more realistic picture of the achievement trajectory for their children, which might be less than they have expected when they were newly diagnosed. Some mothers in this study

discussed feelings of disappointment and resentment related to their child's outcomes, as well as a sense of worry about their children's future needs.

Another factor that is worth discussion is the demographic makeup of the mothers who participated. Although the sample was racially diverse, it is apparent that the participants in this study were generally more educated than the general population, and more than half of the women had previously sought some form of counseling services. These factors, as well as the inherent self-selection bias, might have made these women more interested in this particular intervention. Anecdotally, the fact that several mothers had some personal experience with mindfulness meditation might have been related to the fact that these women elected to self-select to a treatment intervention study in the first place. Further assessment of the use of this intervention for parents with less educational background and varying experience/interest in Eastern philosophy issues would be important.

### **Strengths and Clinical Implications of the Present Study**

The present study contributed to the understanding of how a manualized ACT intervention can be used to decrease parental distress and general psychopathology in mothers who have children who have received a diagnosis of ASD. To this author's knowledge, this is the first study to examine the use of an 8-week group-based ACT intervention with this nonclinical situation-specific population. Even though the TAU condition could not be carried out throughout the intervention, preliminary information about subjective reactions to this format of intervention will be useful when generating treatment options for these families. Overall, the population sample used was a racially diverse group of individuals and delivered across time, which allowed for incorporation of follow-up on adherence to committed values-based action over time in the intervention.

In addition to the findings on outcome and ACT process measures, we were able to obtain additional convergent validity data on the AAQ-II, a widely utilized tool in ACT research. Additionally, correlational data regarding the mothers' experience of parental distress and their children's externalizing behavioral problems expanded the knowledge base in this area of maternal stress research. Also, despite stressors in the mothers' lives during the time of the study, there was a 100% data completion rate for mothers who were treatment completers and thus used in the data analysis. Some of the mothers discussed assessment package completion as a goal during the section on values-based committed action, offering that contributing to the literature of maternal stress in this population was very important to them.

Given the brevity of these workshops and likely cost-efficiency of some group-based interventions (Tucker & Oei, 2007), this workshop would be an ideal compliment to any center- or community-based early intervention program for children with ASD who wish to incorporate an empirically supported therapeutic intervention for families who desire additional support adjusting and coping with this disorder. A potential advantage of continuing to present this intervention as a therapeutic workshop, rather than traditional psychotherapy, would be to break through historical stereotypes against receiving mental health services. Therapists and parents should view this intervention as a complement to their children's therapy and something that is open to individuals based on their situational need (having a child with ASD) rather than a clinical one (e.g., meeting criterion for a depressive disorder). The current study directly demonstrates the effectiveness of this intervention with nonclinical participants; however, future researchers would be wise to explore the use of this intervention with a more clinical sample.

Additionally, many intensive behavioral intervention programs may already have a staff member who has some experience using ACT interventions, given the strong behavioral

paradigm roots of this intervention. A possible consideration to address this challenge might be to incorporate these workshops into a treatment facility where the children are already receiving services. Thus, parents could receive support and connect with other families during a convenient time. Providing transportation and or childcare would also address some barriers that were witnessed in the current study.

### **Limitations and Future Directions**

As with any research project, this study has several limitations that warrant discussion. The sample size was small (ACT  $n = 13$ ; TAU  $n = 4$ ), which is a clear limitation of the current intervention, particularly when examining the between-groups effects. In general, most of the sample received a similar amount of treatment, although the average of one missed session per mother might have resulted in significant differences in information obtained and possibly affected the results (e.g., missing the night dedicated to mindfulness could affect post-intervention scores on the FFMQ). The loss of a formal control group mid-study hindered the amount of power for this sample, as the methodology then relied upon participants to serve as their own controls. This study was originally conceptualized as a randomized mixed-group design, which would have provided additional control and increased the power of the statistical analyses. However, the format for which the TAU group was offered to participants was not well tolerated. Participants made comments to the group facilitator that they did not like the fact that they were largely providing peer-to-peer support rather than receiving skills training on ways of coping with stress. Some also found difficulties with the group dynamics, stating that some mothers were further along in the “treatment process” than they were, and that resulted in some negative projections of progress for them.

Additionally, there are some general issues with recruitment. Mothers of children with ASD are typically busy women, as they often are juggling school, work, treatments, family, and possibly siblings. The mothers who did self-select for participation were clearly highly motivated, making generalization of the results to less-motivated mothers more difficult. Another limitation of the study is the lack of treatment integrity data. Failure to obtain data on how the treatment has been implemented makes it difficult to draw conclusions about possible threats to validity of the intervention (e.g., therapist provides intervention differently in different waves, or TAU conditions were implemented differently than the manual indicated). Another factor to consider for this study is generalizability of the findings. It is clear that this workshop-style format is effective in reducing levels of parental distress in non-clinical populations, but the result of generalizing these findings to a population of mothers who already experience significant depression or anxiety difficulties is unclear. Given ACT's empirical evidence for treatment of these disorders, one might expect generalization; however, this is not yet validated.

Another issue to consider with generalizability is the application of this intervention to fathers of children with ASD as well. While the ACT literature has traditionally treated both genders using the same intervention, it would be important to explore whether fathers experience their adjustment to this diagnosis in a significantly different way than mothers. Blackledge and Hayes (2006) successfully included mothers, fathers, and couples in their workshop-based group intervention, but further examination of this issue would shed additional light onto how to best generate programs to support these families. Possible extension of these treatments to grandparents, siblings, and other caregivers might be warranted, as the stress associated with characteristics of autism taxes the entire family unit (Anderson, 2010; Harris & Glasberg, 2003).

Investigation of the degree to which to the timing (in terms of time since diagnosis) affects participation and outcome would also be very important to research.

The assessments used were all of a self-report nature. Ideally, incorporation of some direct observations of behaviors such as values-based committed actions or interactions with spouses/children would have provided a nice complement to the self-report assessment data. Given the practical and financial limitations of the current study, these were not feasible but should be considered in further research. Another limitation to this study is the limited reliability and validity of information on some of the measures used for assessment. The ATQ has been utilized as a measure of ACT's process variable for nearly 20 years with limited validity information (Zettle & Hayes, 1986). The previously discussed challenges in examining the fundamental characteristics of the ACT intervention, experiential avoidance/psychological flexibility, also serve as a significant drawback in this study. Given that our study was not able to demonstrate significant change on this concept, further exploration of ways to evaluate changes in concepts such as psychological flexibility and experiential avoidance are needed.

## **Conclusions**

In spite of the limitations noted, the current study serves as a significant addition to the treatment literature addressing parental distress in mothers of children with ASD. The present study expanded a previous demonstration of ACT effectiveness in this population and incorporated both a between-subject and within-subject repeated measures design. Mothers in both the ACT and TAU condition were assessed at three time points to test the effects of an 8-week intervention.

Results indicated significant differences between groups on the frequency scale of the ATQ, with mothers in the TAU condition representing a faster change rate on the frequency of

their automatic thought reduction than ACT participants. For mothers in the ACT condition only, repeated measures ANOVAs were used to determine significant findings from pre-intervention to post-intervention on the PSI-SF Parental Distress scale, with some regression to baseline at follow-up but overall reductions maintained. Baseline to follow-up intervention changes were seen for the GSI of the BSI-18, as well as for the PAC, ATQ total score, and the believability scale.

No significant improvements were observed on the measure of experiential avoidance (AAQ-II) or the mindfulness measure (FFMQ). The results also suggest that a cost-efficient ACT-based treatment is effective in reducing stress related to the difficulties in raising children diagnosed with an ASD. Exploratory analysis also revealed that experiential avoidance, as measured by the AAQ-II, was positively correlated with multiple scales of a self-administered measure of executive functioning. This finding serves as convergent validity of experiential avoidance (or psychological inflexibility) with well-known neurocognitive constructs of cognitive flexibility suggestive of the prefrontal cortex. Results also indicated that mothers who reported significantly greater levels of externalizing problem behaviors, as measured on the BASC-2, also reported of higher degrees of parental distress, as measured by the total score on the PSI-SF. Overall, these results provide further information on the effectiveness of an ACT intervention with parents of children with ASD, as well contributing to the literature about the concept of experiential avoidance.

This intervention has the potential to be an integral part of the treatment process for children who are diagnosed with ASD and involved in various therapeutic techniques. Incorporating the treatment into that of their child's might address some of the stigma that is commonly associated with using mental health services. This stigma will also be addressed by

relying more on the workshop format, rather than more traditional psychology. Continued research in this area will provide these parents with the time and attention their situations truly deserve.

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**APPENDICES**

## Appendix A: ACT Treatment Manual

Adapted from Hayes, Strosahl, & Wilson (1999) and Blackledge & Hayes (1998)

Throughout the workshop, exercises and metaphors will be kept as interactive as possible, using client material as their subject matter.

### WEEK 1

**\*\*Consent forms. Make sure everyone individually signs and agrees.**

#### **Introduction**

- I. Introduce myself, who I am, what brought me to want to work with parents of developmentally delayed/disabled children.
  - A. Early work as a behavioral tutor followed by work at a center-based clinic, then as a behavioral consultant, then applications with other populations. When I first began to learn how demanding the teaching process is for these children, I was floored by the notion of what it must take to parent a child with ASD 24 hours a day, 7 days a week.
  - B. Over the years, I have been fortunate to share the lives of many families, in their home and in the clinics. I have seen firsthand what kind of stress this disorder, and intensive ABA treatment, brings upon a family.
  - C. When I began to talk to some parents and checked the research literature, I found out what all of you already know intimately—that raising a child with autism poses some difficult and often very demanding challenges.
  - D. It struck me that, given how stressed out by life the rest of us are.....
  - E. I applaud each of you for taking the time for yourself to do this workshop. Oxygen mask on plane metaphor.
  
- II. The specific approach to life and its roadblocks that we'll be experiencing in depth for the next 8 weeks is a rather unique one, and represents a way of approaching life's challenges that I honestly think everyone could benefit from. I want to tell you a little about this approach before we dive into the approach itself.
  - A. It has a solid scientific basis, in fact more so than many of the approaches being used in psychology today.
  - B. It's been found to be helpful for a wide variety of people, starting with professionals who have taken weekend workshops similar to this one in order to learn how to use this approach with clients who found out that it was just as applicable to their own lives (in fact, I've heard many of them have said things like "this was a mindblowing experience for me" or "this changed my life"), to people with severe anxiety, depression, trauma histories, hallucinations and delusions, drug and alcohol problems, people who just want to stop smoking, and people that are lucky enough to have relatively smooth lives (if there is such a thing as a relatively smooth life) but just feel like there's something lacking at the end of the day. It's kind of an equal opportunity approach—it's been applied to a

lot of different challenges and a lot of different people, and I strongly suspect that it will turn out to be applicable to a lot more.

- C. This approach makes some very atypical assumptions about human beings and about the challenges we face. It assumes that:
1. We're all essentially in the same boat. Those teaching this approach (people like me) are not immune from the difficulties and sometimes the struggles of being human—in fact, we're all very much steeped in it. This may differ from some of the encounters with “mental health professionals” that some of you may have had in the past—where you may have felt patronized, like you lacked something, like there's something wrong with you that the professional is there to fix because there's nothing “wrong” with the professional. The only reason I'm sitting up here and doing most of the talking is because I've studied and practiced this approach for about 7 years.
  2. It assumes that pain and suffering—what some people refer to as psychological problems or disorders—are a normal part of being human. Pain and suffering is not a sign that there is something wrong with us, but rather is a sign that we are human and that bad things that happen to us can take their toll.
  3. Moreover, it assumes that virtually anyone thrown in to the same circumstances as you—the same life, the same history, the same present circumstances—would be doing exactly what you are doing. So there's no assumption of “brokenness”—only an assumption that there's something about being human that leads all of us to be at least occasionally dissatisfied—and sometimes even distraught—with ourselves and with our lives. We are going to explore in great detail what that “something” might be in the next 7 weeks, from the inside out.
  4. I stress these points because I want to contrast this approach with how our culture in general—and correspondingly, many “mental health professionals”—views psychological pain and suffering because I have the suspicion that many of us have unnecessarily encountered some pain because of the prevailing cultural view that psychological struggles indicate that there is something wrong with us. I don't want to debate this point or try to convince you of it, I just want to orient you toward what we'll be doing in the next 7 weeks. This approach is something like the old Monty Python catch-phrase, “And now for something completely different.”
- D. A few points regarding how you can get the most out of this workshop
1. Stay open to what we'll be discussing and the exercises I'll be taking your through. Really try to make room for something big to happen here for you. In some ways this experience is like any other experience. If you expect that nothing will happen, that's likely what you'll get.
  2. Participate fully in the workshop—particularly in the experiential exercises we'll be doing. It's the nature of this approach that you only really learn it by doing it. Listening to what I have to say is a good start, but taking a good honest stab at the exercises is essential for getting

something out of this. The best way to understand this approach is to do it. I'd encourage you to share some of the things that come up for you when I ask for volunteers during the workshop, as well. There is no pressure on you to do so, and no judgments made about you if you don't—you'll simply get more out of it if you do.

3. Approach what you learn in this workshop as skills that must be practiced and regularly applied. It's as if we were all in the middle of the forest and my job is to show you a route through the forest that you hadn't considered before. It's my job to help you draw a map and learn how to use the compass, and to help you take some important first steps. But it's up to you to keep using that compass and map. Toward the end of the workshop, I'll be giving you some handouts about some ways you can keep practicing this approach.
4. Stay in the room (physically) except when we are on breaks. Sometimes during some of the experiential exercises we'll be doing, you may have some potent emotional stuff come up for you. Sometimes people get the urge to leave the room, so that they can compose themselves or distract themselves. I'm going to ask that you do not do that for the simple reason that if you do, you will miss out not only on what we do next in here, but also miss out on a golden opportunity to practice exactly what we're doing here in the midst of that potent emotional stuff. If potent emotional stuff shows up for you, stay with it in the manner that we'll be discussing, and you'll get far more out of the experience. The good news is that, in over 20 years of these workshops being conducted, no one's head has ever exploded from potent emotions—so have faith that yours won't either, even if your mind convinces you otherwise in the moment.
5. Make room for other people's pains and struggles. This is a unique gathering of people. Everyone here is human, and everyone here has a child diagnosed with autism, and you therefore have some insights into each other's lives that no other people have. So there's a very real and unique bond between you already, a special understanding and acceptance of a significant portion of what the person sitting next to you experiences in his or her life. Extend that understanding and acceptance to the rest of them and their lives during the workshop. If at some point you find an urge to criticize or evaluate people for what they share during the workshop, or for the emotions that they reveal, please don't follow through on the urge. Because all of us do many things every day that can be criticized and negatively evaluated regardless of our circumstances. Let's just make an agreement not to do that here, to make this a safe, supportive, constructive environment.
6. Don't "rescue" people that communicate distress during the workshop. The natural urge for many of us when someone is upset is to say things like "Now, now—it'll be okay <pat on the shoulder>", or "But you're such a good person—those bad things you think about yourself just aren't true", or "Buck up, 'lil camper", or anything designed to "make them feel better". I'm going to ask that you give people room to feel

what is there to be felt, without trying to change their minds or their perspectives. Interestingly, usually what we're really intending when we act on this kind of "Now, now—it'll be okay" approach is not just trying to make them feel better. We do it because we don't like how we feel when they feel upset. So, in essence, we're saying "Stop feeling that, because I don't like how I feel when you feel that." So when you get the urge to console, instead focus on what feelings you are trying to push off of.

7. Come back each week. The approach you'll be learning and practicing over the next 7 weeks requires a good amount of time to understand. You can't get it in just one day. It can be exhausting and stressful to sit through 12 hours of this, especially when your mind gives you thoughts like "I'm giving up a Saturday morning for this", or "Well, I haven't got a lot out of it yet, so I don't think I'll come back next week", or "I think I get it, so I don't need to come back next week," or "This is too heavy—I don't think I can take any more of this." But you have the potential to make a big difference in your life if you really stick with this for both days, and I think you'll find that that outweighs the difficulties in giving up a few Saturday mornings.

- III. Ask participants to introduce themselves and what they hope to gain from this workshop. Summarize, and address that this approach should address those issues.
  - A. Tentatively put all client responses into one of two categories: Feeling better/Thinking better, and Living what I value more often/more effectively. By "values" I'm referring to those ways of living that give your life meaning and richness. So (use client examples of values)
  - B. Use good examples of client issues to show how issues fit into these 2 boxes. Ask clients if anyone feels their concerns don't fit into these two categories. Gently re-frame if so.
  - C. Say, "So, it looks like there are two main issues that are showing up in your lives—feeling worse than you'd like to at times, and not being able to do the things you want or need to do. We're going to cover both of these things in detail, starting with the "feeling bad" part.
    1. But first, I'd like to spend about 15 minutes giving you all a chance to think specifically about what it is in your lives that you value. The reason we're doing this is: Sometimes we get so caught up in living our lives on autopilot and just trying to keep our heads above water, that we forget a little bit about what it is we want our lives to stand for. I'd like to have you thinking about some of these things today, so that you'll have a clearer picture of what you want your life to stand for when we deal with this stuff more directly tomorrow.
    2. I have a sheet that I'm passing out to you now. It talks about different parts of your lives that you might choose to find meaning in, that you might choose to value—intimate relationships, social relationships, employment, education, & career issues, spirituality, citizenship, and physical health issues. I'd like you to think for a minute about which of

these areas are the most important to you, individually, and focus on your “top three”. Then, write down the kind of person you most value being (REFER TO OVERHEAD DESCRIBING HOW TO CLARIFY AND CAST VALUES) in these three areas, under “Describe your personal values below.” Once you’ve done this, write down a few things that get in the way of you acting in those ways more often under “Reasons that values are not being lived.”

## WEEK 2

### IV. Feeling better and not feeling bad.

- A. One of my goals here today is to give you some tools that will help you deal more effectively with the emotional reactions that show up with respect to your autistic children. But this workshop is largely intended to address much larger issues in your life than that. Essentially, each one of you will become more clear on what you value most in your life, and how to deal with the thoughts, anxieties, frustrations, fears, and other emotions that make it more difficult to live those values.
- B. I want to spend the rest of the session on the first part of this equation—in other words, how do you deal with overwhelming thoughts and feelings when they show up, especially when they keep you from living your values more often and more fully?
- C. Take a moment to think about the biggest feelings that you struggle with—some of your biggest “demons”, so to speak. How have you tried to deal with them? How has that worked? (To group in general—take a few examples). Distinguish between emotion/cognition focused coping and active coping PUT CATEGORIES ON BOARD AND FILL IN EXAMPLES.

Regarding emotion/cognition focused coping: ‘It sounds as though in some ways this worked, at least in the short run. But I’m wondering, what is your sense about how it worked at a really basic level? Did it really change things in a basic way, in the way you had been hoping for?’

Regarding emotions that used to be struggled with but no longer: Sometimes things change, and issues that we used to struggle with heavily either become less important or we find a way around them.

- D. Everyone take a few minutes to write down the things they have tried to “get better” when they have felt overwhelmed, frustrated, angry, sad, anxious, ashamed, guilty (use client words when possible).
  - E. Ask for volunteer(s) to read off items from their list (or have me read them off), and their workability.
1. How have things worked?
    - a. Note strategies that the clients describe as not having worked.
    - b. Note strategies that the clients say do work. Validate active coping strategies. Regarding emotion/cognition focused coping, assess to see for how long. Validate that they work short-term, and see if they really work long term.

1. e.g., do the same kinds of feelings and thoughts come back eventually?
  2. Do these strategies work when they matter the most? (when the feelings and thoughts are really intense, and it's critical that you get rid of them?)
  3. One of the most consistent findings in psychology is that short term pay-offs usually push us around more than long-term pay-offs. It's not surprising that we continue to do things that may often work for a while, but don't work over the long haul.
2. How about strategies that actually make things worse over the long run?
- a. See if any clients are aware of things they do that make things worse.
  - b. Stay in psychological domain (vs. active coping domain)
  - c. Give example of drinking to deal with stress.
    1. Seems to work for a while—most people here have probably had the successful experience of getting drunk and “blowing off steam”.
    2. What about the next morning? How well do you do things then?
    3. What about getting into arguments with your spouse while you were drunk (or about your drinking)? Anyone know anybody like that?
    4. You can imagine how drinking as a long-term strategy causes problems (e.g., missed work, decreased ability to do things well when you're drunk or hung over, problems with loved ones and others as a result, etc.)
3. What about less extreme ways of coping—like trying not to think about what's bothering you, or distracting yourself with work or other things so you don't think or feel anything bad?
- a. There's been some very consistent findings in psychology about how things like this work.
    1. Suppression rebounds.
    2. Does this ring a bell with anyone? Has anyone here noticed anything like this happening?
    3. Have the “bad” thoughts and feelings that you have run into lately felt familiar? Were they brand new, or have you had them before? In other words, are the thoughts and feelings you struggle with new, or do the same tough thoughts and feelings keep showing up? Think about how well your coping strategies have worked for you—especially the ones that seem to work really well. If it feels like they work well, does it seem a little fishy that the same kinds of “bad” thoughts and feelings keep showing up? If they really, really worked—would that happen?

4. Again, I want to make it clear again that you shouldn't believe anything I'm telling you. I just want you to take a good, honest look at your experience and ask yourself, honestly, "Have the things I've tried to feel better, to 'think better thoughts', worked—especially over the long haul?" "Have they ultimately gotten rid of what I struggle with?"
  5. If anyone answers "Yes—there are some things that I use to struggle with that I don't struggle with anymore," ask them if it's possible that something other than the struggling could have been responsible for it going away. E.g, time, things happening that solve the problem, etc.
4. Ask non-volunteers if they are willing to read off one or two things.

F. Deliver "man in the hole" metaphor interactively.

*Clients are asked to imagine that they are a person who has been placed in an open field blindfolded with a tool bag to carry and who is told that living a life means running around that field. Unfortunately the field is filled with a variety of large holes. Inevitably, they fall into one of the holes, and are stuck at the bottom, much like they are stuck in the current predicament. After a while they feel inside the tool bag to see if there is something that that would help. It contains nothing but a shovel. So they dig, with big scoop or little, fast scoop or slow. But the hole is not getting smaller, it's getting bigger. And here they are, seeing a therapist, in the secret hope that therapy is a really huge shovel. But shovels aren't for getting out of holes – shovels make holes.*

1. What if all the things you have tried to get out of your "holes" are just different ways of digging?
2. You've tried everything you could think of to get out—to *feel* better—and nothing has worked. You've tried every logical thing that you could think of—you've tried every logical thing I could think of as well.
3. You know it hasn't worked; consider the possibility that it can't. Consider the possibility that, despite what everyone has told you, you can't just make yourself feel better—by thinking positively, by counting your blessings, by trying only to focus on the positives, by working your fingers to the bone, [add client strategies]. I'm asking you to check back with your experience here, not to believe me. In your experience, have you been able to make yourself "feel better"—feel not guilty or ashamed when....., not embarrassed when....., not frustrated or angry, not sad or miserable—especially when it mattered most? Maybe there were times when it worked for a while, but for how long? Did those feelings eventually come back?

Did the things you did to get rid of them cause other problems? So, what if the solution is actually part of the problem—what if all the efforts you've made to dig yourself out not only haven't worked, but have actually made the hole deeper?

- b. It's not just you—it's every single one of us. Inside this room, and outside.

4. (check in) Where is everybody at with all this? How does this strike you? Following sequence delivered in an interactive manner, using client material.
  - a. “What do we do, then?”—What I want you to do right now is just notice whether or not you’re stuck. Just check back with your experience to find if your efforts to dig your way out of the hole have gotten you out. Have they? Do the same kinds of struggles, the same kind of feelings keep showing up, almost regardless of what you try?
  - b. Gold plated steam shovel. I can’t give you that. I don’t know how to dig out of that hole either. I don’t know of any psychologist in the history of mankind who knows either.
  - c. Let’s sit with that for a minute.....Nothing any one of us has thought of can get rid of those feelings, those thoughts—especially when it matters most. And now I’m telling you, as a psychologist, that nobody knows how to do that. What’s all this feel like? How do you all feel right now?
    1. Allow time for reports and sitting with emotions.
    2. If no one brings it up first: Does anyone feel let off the hook? I mean, what does it feel like to notice that it isn’t just you—it’s everybody?
    3. What other feelings show up in response to this idea?
  - d. Putting the shovel down is the first step. Noticing that nothing has worked.
5. Weave in to client material: The importance and yet the irrelevance of history. We all found our own specific ways to fall in holes, and all of us have some unique ways of digging. But here we are. All in holes.
6. Weave in to client material: Responsibility versus blame. Maybe it’s not your fault you fell in that hole. Maybe that’s what human beings do. Walk around blindfolded in a field for a while until...

### WEEK 3

Now, we’re going to be doing a lot of experiential exercises and using a lot of metaphors to get at things during the next couple of days, because the points I’m trying to make are pretty hard to put into words—it really only works if you experience this stuff first hand—Just talking about it doesn’t cut it. So, here’s an experiential thing that will help you understand a little more what we’ve been talking about. **HAND OUT CHINESE HANDCUFFS TO PARTICIPANTS.** So, I want you to put these on, and as you play around with them for a minute, think about this: Struggling against your own pain is like struggling against being in these handcuffs.

After: So, what if the problem isn’t necessarily that we feel bad and don’t know how to avoid that? What if the problem is that we create a lot of additional suffering when we struggle against the pain we already have?

- II. Emotional control as the problem.
  - A. In the word outside the skin the usual rule is “if you don’t want something, figure out how to get rid of it and get rid of it” (This rule consistently works well when

you are trying to change things “out there” (examples, including behavior of autistic child).

B. Given that this rule works so well “out there” (If you don’t want something, figure out how to get rid of it and get rid of it), it seems like it should work well with feelings and thoughts—and from early on in our lives, we’re taught that this is the case:

1. Important people in our lives have told us that this is the case
  - a. “stop crying or I’ll give you something to cry about”
  - b. “have fun, damnit”
  - c. you’re a good boy or girl if your happy all the time, but not if you’re “difficult”—as if it were your fault that you felt bad.
2. People in our lives have apparently shown us that they can successfully control how they feel
  - a. parents who look like they have it together—but down a few drinks every day after work, etc.
  - b. Everyone else looks like they’re always o.k., always in control—but you don’t feel that way. One thing I’ve experienced is that everyone feels that way.
3. Sometimes it really seems like it does work. If you distract yourself, or have a few beers, or work harder, sometimes it keeps the “bad” stuff at bay. But my guess is that the things you were struggling with when you walked in that door aren’t new. You’ve felt those feelings before and thought those thoughts. If your attempts to get rid of those things really worked, doesn’t it seem a little bit fishy that they keep showing up? Is it possibly more accurate, in your experience, that some of those things work in the short term, but not over the long haul?
4. No one has ever taught us an alternative.
5. Polygraph metaphor. (Example of anxiety—being anxious about being anxious):
 

*“Suppose I had you hooked up to the best polygraph machine that’s ever been built. This is a perfect machine, the most sensitive ever made. When you are all wired up to it, there is no way you can be aroused or anxious without the machine knowing it. So I tell you that you have a very simple task here: all you have to do is stay relaxed. If you get the least bit anxious, however, I will know it. I know you want to try hard, but I want to give you an extra incentive, so I also have a .44 Magnum which I’ll hold to your head. If you just stay relaxed, I won’t blow your brains out, but if you get nervous (and I’ll know it because you’re wired up to this perfect machine), I’m going to have to kill you. Your brains will be all over the walls. So, just relax! ... What do you think would happen? Guess what you’d get? Bamm! How could it work otherwise? The tiniest bit of anxiety would be terrifying. You’d be going “Oh, my God! I’m getting anxious! Here it comes!” BAMM! You’re dead meat. How could it work otherwise?”*

Panic attack example.

6. \$10 million to fall in love.
7. Can you think of any times where you thought you should feel differently about something, but you just couldn’t get yourself there? (e.g., spouse comes home and tells you about something they found really exciting...)
  - C. It’s not just feelings, its thoughts too....

Chocolate cake:

*“Suppose I tell you right now, I don’t want you to think about something. I’m going to tell you real soon. And when I do don’t think it even for a second. Here it comes. Remember, don’t think of it. Don’t think of.... Warm chocolate cake! You know how it smells when it first comes out of the oven... Don’t think of it! The taste of the chocolate icing when you bite into the first warm piece ... Don’t think of it! As the warm, moist piece crumbles and crumbs fall to the plate... Don’t think of it! It’s very important, don’t think about any of this!”*

Don’t salivate when I tell you to think about biting into a juicy, yellow, lemon...

Its human nature to continue to do what you’ve been told to do a thousand times—even if it doesn’t make sense.

- a. What are the numbers? (“Suppose I said I was going to give you three numbers to remember. It is very important that you remember them, because several years from now I’m going to tap you on the shoulder and ask, “What are the numbers?” If you can answer, then I’ll give you a million dollars. So remember, this is really important. You can’t forget these things. They’re worth a million bucks. OK. Here are the numbers, ready? One... two... three...”) Instead of \$\$, tell them that all their uncomfortable thoughts and feelings will go away forever; now forget numbers, and 4, 5, 6 instead. Can you do it? How do you know? You’ve just added something to 1, 2, 3, not gotten rid of it. nervous system works only by addition. You’ve been programmed, so to speak, with 1, 2, 3—and even though it’s silly, even though its not true that remembering 1, 2, 3 will get rid of your uncomfortable feelings, you still remember them—just because some idiot psychologist told you something.
- b. It’s not just numbers—it’s all kinds of things. Our minds have been programmed by all kinds of experiences. Do you ever notice, after you say or do something that you just did the same kind of thing that your mom or dad does?

When someone asks for your opinion on politics, or what just happened in the news, do you find sometimes that you just repeat what you heard someone else say about it, or give an opinion like your mom or dad would?

**COMPUTER PROGRAMMING METAPHOR** (add in, you remember the old saying, “Don’t believe everything you read”? That applies to this programming—to these programmed thoughts that pop up on your ‘computer screens’, so to speak.

No one has ever taught us an alternative.

- c. So, your mind might spit out a thought like “I don’t fit in”, or “The fact that my child is autistic is my fault, or my wife’s fault”, or **ADD CLIENT THOUGHTS**. But how do you know that remembering thoughts like this isn’t as ridiculous as remembering 1, 2, 3 because I told you to?
- d. We forget that our ideas our programmed—and it’s very easy for anyone to come along and program a new one in our minds. Once they’re there, they stay there.

D. In the world inside the skin and in some external situations as well, the rule is” if you are not willing to have it, you’ve got it.” Does this feel accurate?

But we still try desperately to get rid of these feelings, these thoughts, that are so hard to bear. It’s kind of like:

2. Tug of war with a monster:

*“The situation is like being in a tug-of-war with a monster. It is big, ugly, and very strong. In between you and the monster is a pit, and so far as you can tell it is bottomless. If you lose this tug-of-war you will fall into this pit and will be destroyed. So you pull and pull, but the harder you pull it seems the harder the monster pulls, and it seems you edge closer and closer to the pit. The hardest thing to see is that our job here is not to win the tug-of-war. .... Our job is to drop the rope.”*

**Emotional Willingness.**

A. The alternative to trying to control your thoughts and feelings—trying to get rid of the uncomfortable ones get the “good” ones—is called willingness. There really aren’t any really good words to describe what I mean by willingness—it has to be experienced directly, rather than talked about directly. So I’m going to use a lot of metaphors and exercises to teach you what willingness is.

1. Two scales metaphor (133-135):

*“Imagine there are two scales, like the volume and balance knobs on a stereo. One is right out here in front of us and it is called “Anxiety” [Use labels that fit the client’s situation, if anxiety does not, such as “Anger, guilt, disturbing thoughts, anger,” etc. It may also help to move ones hand as if it is moving up and down a numerical scale]. It can go from 0 to 10. In the posture you’re in, what brought you in here, was this: “This anxiety is too high.” It’s way up here and I want it down here and I want you, the therapist, to help me do that, please. In other words you have been trying to pull the pointer down on this scale [the therapist can use the other hand to pull down unsuccessfully on the anxiety hand]. But now there’s also another scale. It’s been hidden. It is hard to see. This other scale can also go from 0 to 10. [move the other hand up and down behind your head so you can’t see it] What we have been doing is gradually preparing the way so that we can see this other scale. We’ve been bringing it around to look at it. [move the other hand around in front] It is really the more important of the two, because it is this one that makes the difference and it is the only one that you can control. This second scale is called “Willingness.” It refers to how open you are to experiencing your own experience when you experience it—without trying to manipulate it, avoid it, escape it, change it, and so on. When Anxiety [or discomfort, depression, unpleasant memories, obsessive thoughts, etc.—use a name that fits the client’s struggle] is up here at 10, and you’re trying hard to control this anxiety, make it go down, make it go away, then you’re unwilling to feel this anxiety. In other words, the Willingness scale is down at 0. But that is a terrible combination. It’s like a ratchet or something. You know how a ratchet wrench works? When you have a ratchet set one way no matter how you turn the handle on the wrench it can only tighten the bolt. It’s like that. When Anxiety is high and Willingness is low, the ratchet is in and Anxiety can’t go down. That’s because if you are really, really unwilling to have Anxiety then anxiety is something to be anxious about. It’s as if when Anxiety is high, and Willingness drops down, the anxiety kind of locks into place. You turn the ratchet and no matter what you do with that tool, it drives it in tighter. So, what we need to do in this therapy is shift our focus from the Anxiety scale to the Willingness scale.*

*You've been trying to control Mr. Anxiety for a long time, and it just doesn't work. It's not that you weren't clever enough; it simply doesn't work. Instead of doing that we will turn our focus to the Willingness scale. Unlike the anxiety scale, which you can't move around at will, the Willingness scale is something you can set anywhere. It is not a reaction—not a feeling or a thought—it is a choice. You've had it set low. You came in here with in set low—in fact coming in here at all may initially have been a reflection of its low setting. What we need to do is get it set high. If you do this, if you set Willingness high, I can guarantee you what will happen to anxiety. I'll tell you exactly what will happen and you can hold me to this as a solemn promise. If you stop trying to control anxiety, your anxiety will be low ... or ... it will be high. I promise you! Swear. Hold me to it. And when it is low, it will be low, until it's not low and then it will be high. And when it is high it will be high until it isn't high anymore. Then it will be low again. ... I'm not teasing you. There just aren't good words for what it is like to have the Willingness scale set high—these strange words are as close as I can get. I can say one thing for sure though and your experience says the same thing—if you want to know for sure where the anxiety scale will be then there is something you can do. Just set Willingness very, very low and sooner or later when anxiety starts up the ratchet will lock in and you will have plenty of anxiety. It will be very predictable. All in the name of getting it low. If you move the Willingness scale up then anxiety is free to move. Sometimes it will be low, and sometimes it will be high, and in both cases you will keep out of a useless and traumatic struggle that can only lead in one direction.”*

#### Week 4

What if the only way out is to drop the rope?

#### II. Cognitive Defusion

- A. Maybe the biggest reason we keep struggling against our feelings and thoughts is because of the war our minds works. Our minds claim to be the ultimate authority—they claim to know what's true—SCIENCE METAPHOR.
- B. Ideas [thoughts] are interpretations of experience. We tend to mistake our ideas for the real thing—we mistake our thought for facts.” Words claim to describe our experience very well, to capture reality. Let's do a few little experiments here to see how well our minds can describe what's going on:

Sports metaphor for experiencing rather than rule-governance:

1. Notion that the direct experience of hitting the ball (etc.) is something different from talking about hitting the ball.
2. Notion that talking about how to hit the ball can't adequately capture what the experience is actually like.
3. Tell me how to walk.
4. Has anyone ever had other experiences that they just couldn't put into words? Or you put it into words, and realize that you still can't capture what it was like? Who here has been to Europe? What was it like? Those of you that haven't been to Europe—do you know now what it is *really* like to be there? Those of you who just described going to Europe—did your description capture what it was *really* like to be there?
5. Has anyone ever had the experience of being anxious about doing something, or not wanting to do it, or thinking you wouldn't enjoy it---and then you did it and it was very different from what you expected?

6. One of the things I want all of you to try on for size today is the possibility that words don't describe experiences well—that experiencing something is different from talking about the experience, and that we very often mistake the way we talk about an experience for the experience itself.

Finding the descriptions and the evaluations.

Words cause a lot of problems for us, because when we think something, we automatically assume that what we are thinking is real—that our thoughts perfectly fit our experience, that they describe what is really happening to us. In other words, we think that our thoughts are as real and as tangible as something we can touch, like this table. We tend to automatically think that our thoughts are solid, tangible facts (pounding table) rather than thoughts. This may be at the core of the struggle we have with our emotions and experiences, at the core of this very serious, very lethal tug of war with our monsters. Because our minds can tell us. When we assume our thoughts are true, we're pretty much forced to believe the bad things they say about us and do the things our thoughts say we should do—do the things that our minds tell us to do. Now, I don't want you to believe any of what I'm saying. We're going to be talking a lot more about this now, and doing some exercises. What matters is not what I'm saying, and not whether or not your mind believes what I'm saying. We'll just keep checking back in with your experience to see if this stuff rings true at a deeper level than what your mind thinks—if this stuff seems to match up to your experience. And will be doing a number of other exercises and things that give you all a chance to view your thoughts from a different perspective and see for yourself if they're fishy or not. We'll start with this one:

Thoughts can be lumped into one of two categories: Descriptions and evaluations.

Descriptions are thoughts that simply describe the factual, directly observable aspects of things

Examples:

*This is a table.* (Tables are hard, solid, have four or more legs, etc.)

*I am feeling anxiety* (Anxiety consists of certain physical sensations, and urges).

*My friend is yelling at me;*. (He/she is speaking loudly and quickly at me gesturing wildly.)

Evaluations are thoughts that compare events and assign an evaluative label (like good or bad, unbearable or bearable, rude or polite, prohibitive or permissive, shameful, embarrassing, and any other way of negatively or positively evaluating feelings, events, people, or experiences ).

Examples:

*This is a good table.*

*This anxiety is unbearable (or bad, or prevents me from giving this speech, etc.)*

*My friend is a jerk for yelling at me (or I can't handle being yelled at, or I need to yell back at him to prove my point, etc.)*

Thus, *descriptions* are solid, tangible, like this table, the chair you are sitting on, and the clothes you are wearing. *Evaluations* seem a little more fishy, a little less solid, a little more “airy”, a little more suspicious. They seem like they don’t describe the kind of solid facts that descriptions do, but rather describe cultural or personal *opinions* or *judgments*.

*Looking at how different events are evaluated in different cultures provides a good example about how evaluations are based on arbitrary cultural conventions (or opinions) rather than fact.*

*Examples:*

“Belching in Burma”

“Waving” in Greece.

“No Thank You, Mr. Swede”

Late night visits in Brazil

In all these examples, you can discriminate between the descriptions and the evaluations. *Descriptions* of these events would include “someone belched”, “someone held his open hand out in front of him”, “Inga said Thank you to Ivar and Ivar said nothing”, and “Paula and Sean came over at 10:30 unannounced on a work night with a six pack to visit.” People from every culture could confirm these descriptions because they are directly observable. They are facts. They are “etched in stone”, so to speak, “Truth with a capital ‘T’”.

Much of our suffering comes from mistaking evaluations from descriptions. We very often believe that our evaluative opinions are just as much based on fact as descriptions. Yet when we examine evaluations more closely, they start to look a little fishy. *Evaluations* of these events differ depending on cultural or personal opinion.

*They exist in the mind, not in reality. They are not etched in stone, and are not Truths with capital T’s.*

*So, descriptions describe events or experiences that are “firm to the touch”, “solid”, real. Evaluations are not solid, and although they are often mistaken for Truths, on much closer inspection, their illusory quality begins to show.*

*When you notice your mind making evaluations, remember: Thoughts are just thoughts, not facts—even the ones that say they are!*

Let’s do this with an example that hits closer to home: Let’s try and tease apart the descriptions and evaluations that show up when we’re feeling anxious. PUT CATEGORIES ON BOARD; USE CLIENT EXAMPLES TO FILL OUT. Note discrepancies in tangibility between descriptions and evaluations.

### ***EXPLAIN ROOT WORD & ORIGINAL MEANING OF ANXIETY.***

PUT UP CONSTELLATION CHARTS AND TIE IN. E.G., “The solid parts of anxiety are like these stars—here’s rapid heart rate, here’s tight shoulders, here’s shallow, rapid breathing, here’s sweating, here’s the urge to run. And when we start adding on all these evaluations, it starts to look like this: put up fleshed out 3-D constellation. The thing is this: Is this thing here really what’s there? Is this lion really what is up in the sky, or are the only

things really etched in stone these stars? What if feelings like anxiety are like this? What if our minds talk us into believing that this (stars) is actually this (constellation)?

Actually, all words seem a little fishy. They all claim to describe your experience, what's really happening to you. Let's try an exercise:

Milk exercise.

Process experiences clients had with the stimulus functions of the word "milk".

7. "When you say things to yourself, in addition to any meaning sustained by the relation between those words and other things, isn't it also true that these words are just words? The words are just smoke. There isn't anything solid in them."

What if the words were "I'm a bad person", or "I can't do this anymore" or [add client statements]. Find common negative self-evaluative short phrase and repeat exercise.

Now, I'm interested in how these descriptions and evaluations show up at times when you are most distressed. So, thinking back toward the beginning of the workshop when I asked you to think about the biggest feelings, the biggest experiences that you struggle with—What kinds of thoughts show up for you in the middle of those struggles that are tough for you? What are the evaluations there? What are the descriptions? (Take a few examples from clients and work through these questions).

Now, I'm definitely not asking you to not believe the evaluations, and I'm definitely not asking you to try to get rid of those evaluations. I'm just asking you to notice what the evaluations are, and what the descriptions are, in the middle of those struggles. Notice how your mind claims to know exactly what your experience is? That those evaluations are True with a capital T? Given what we've talked about so far, does it seem possible that your mind might not know what your experience is? Now, I'm asking your experience, not your mind!

Your mind is not your friend (151):

*"You've probably guessed by now that I'm not a big fan of minds, when it comes to living life in between the ears. Its not that I don't think minds are useful, I just don't think they know what they are doing when they mess with our private experiences. I'm pretty sure minds evolved to give us a more elaborate way of detecting threats to our survival and they probably helped organize packs of ape-men in ways that led to less killing, stealing, incest and so forth. One things minds didn't evolve for was to help apes feel good. You know, its kind of hard to imagine apes sitting around a fire, contemplating their belly buttons, hugging and going through ape bonding. And, if you look at recent studies of natural thought processes, what you consistently see is that a large percentage of all mental contents is negative in some way. So, it looks to me as if we're in this stew together. We both have minds that are built to produce negative content in the name of "warning us" or "keeping us in line with the pack". We will have to address this paradox: Your mind is not your friend, and you can't do without it."*

Let's do another exercise that is helpful in learning how to unhook from our minds—how to use our minds but not get used by them.

Exercise: Say it and don't believe it.

here is the list of sentences:

I can fake my way through this

Children should be seen and not heard  
 The incestuous mating of melons  
 It's not fair how I am treated  
 My Daddy loves me and my Mommy is good looking  
 Do as I say, not as I do  
 My legitimate needs are not being met  
 I want to be a star when I grow up  
 Do unto others as you would have them do unto you  
 I respect you for that  
 Love me tender, love me true  
 I feel stupid, ugly, and alone  
 Do it because I said so  
 But soft? What light through yonder window breaks?  
 I came, I saw, I conquered

The directions for the exercise:

The goal: To willingly speak each thought, fully experience the process of speaking it, and not believe the thought as you are speaking it. By not believing, I mean don't get attached to it, don't get sucked in by it, don't let it define your reality. Say it, fully experience the process of saying it, and don't believe it.

Two people sitting across from each other. One a checker the other a doer.

1. The checker says when the other may begin
2. the doer looks at the list of sentences above, and says what is there  
"cleanly"
3. the checker gives a "pass" or "no pass". No reassurance, no explanation.

Checkers: don't rip off your partners

4. A "no pass" is given if the checker detects such things as: controlling, restraining, withholding, altering, manipulating, adding, subtracting, directing, efforting, stiffening, heightening, flattening, resisting, encouraging, augmenting, diminishing, reacting, or performing
5. No checking the checker. No side communication from doer or checker
6. continue until it is stopped
- 7 partners will shift after one round through.

After exercise: Were there any thoughts that any of you stayed stuck on? If so, try the "say it slow" language convention with client in front of group. Try "having the believed thought that...." with another client.

do basic mindfulness (eyes-closed exercise) focusing on breathing, physical sensations, hearing, etc.

Begin with basic mindfulness (eyes-closed).

Emotional Willingness cont.

8. Clean vs dirty discomfort OR pain vs struggling (where pain = suffering without the struggle):

*“We should try to distinguish between ‘clean’ and ‘dirty’ discomfort. The discomfort that life just dishes up—that comes and goes as a result of just living your life—is clean discomfort. Sometimes it will be high, or it will be low, because of your history, the environmental circumstances in which you find yourself, and so forth. The clean discomfort is what you can’t get rid of by trying to control it. Dirty discomfort, on the other hand, is emotional discomfort and disturbing thoughts actually created by your effort to control your feelings. As a result of running away, whole new sets of bad feelings have shown up. That may be a big part of why you are here. That extra discomfort—discomfort over discomfort—we can call ‘dirty discomfort’, and once willingness is high and control is low, it kind of falls out of the picture and you’re left with only the clean kind. You don’t know how much discomfort you’ll have left in any given situation once only clean discomfort is there. But be very clear, I’m not saying that discomfort will go down. What I am saying is that if you give up on the effort to manipulate your discomfort, then over time it will assume the level that is dictated by your actual history. No more. No less.”*

Another way of saying this is this: If you do this stuff (give up the struggle against the pain in your life) with the agenda of getting rid of pain, you’re still struggling—still trying to control what you think and feel. It’s kind of like giving up on the idea that you’re going to get out of the handcuffs. The handcuffs will come off when they want to come off (your pain will continue as long as circumstances say that there should be pain there). But you’re guaranteed those handcuffs will stay on and get tighter if you struggle against them—that your pain will get more intense if you fight against it. BACK ACHE EXAMPLE.

So, willingness is about giving up the time and effort involved with struggling against the pain that is already there—the pain that you really could say is supposed to be there given what is happening now in your life, and given what’s happened to you in the past—and instead directing that time and effort toward living more of a valued life.

a. Anxiety as an example

1. Getting anxious about being anxious
2. If you were willing to have the initial anxiety—the clean anxiety--, the other stuff wouldn’t be necessary.
3. Possibility that the clean anxiety is perfectly human, perfectly normal—feeling anxious, or sad, or angry, or frustrated, or inferior, or jealous, or embarrassed, etc. is just part of being human.
- 4.

It’s interesting that in our culture, we view psychological struggles as a problem, as an illness that needs to be cured or healed. And by being cured or healed, what we usually mean is getting rid of it. Do you know what the word heal originally meant? It originally meant “to make whole”. Psychological pain is part of our whole experience, and yet we try to compartmentalize it when it shows up, to set it apart from the rest of us and push it away. We’re doing anything but making ourselves whole when we do this. We are actually

fracturing ourselves into pieces. To make ourselves whole, to heal, means to embrace or make room for everything in our experience, to allow the wholeness of you and your experience to exist without fighting against it—not to get rid of uncomfortable parts of our experience. Making an enemy out of entire parts of your experience sets up a war between you and entire parts of yourself. This isn't the way to become whole, to heal. And this fracturing is a very violent, very damaging process. Trying to push your experience away often comes at great cost. Sometimes it involves emotional numbing, where if you fight really, really hard, you can kind of keep the unpleasant stuff at bay, but you also are forced to keep the pleasant stuff at bay. Or you might try to push away those unpleasant experiences by drinking, or drugging. But these things take their toll on your health, your relationships, your job, and everything else that requires a clear head.

9. Pain vs. suffering (or Pain vs. trauma)

- a. Like clean vs. dirty
- b. Pain is a normal part of being alive. Suffering or trauma is what we add to pain in an effort to avoid it.

C. Soldiers in a parade (or leaves in a stream):

I'd like us to do an exercise to show how quickly thoughts pull us away from experience when we buy them. All I'm going to ask you to do is to think whatever thoughts you think and to allow them to flow, one thought after another. The purpose of the exercise is to notice when there's a shift from looking at your thoughts, to looking from your thoughts. You will know that has happened when the parade stops or you are down in the parade or the exercise has disappeared.

*I'm going to ask you to imagine that there are little people, soldiers, marching out of your left ear marching down in front of you in a parade. You are up on the reviewing stand, watching the parade go by. Each soldier is carrying a sign, and each thought you have is a sentence written on one of these signs. Some people have a hard time putting thoughts into words, and they see thoughts as images. If that applies to you, put each image on a sign being carried by the soldiers. Certain people don't like the image of soldiers, and there is an alternative image I have used in that case: leaves floating by in a stream. You can pick the one that seems best.*

*In a minute I am going to ask you to get centered, and begin to let your thoughts go by written on placards carried by the soldiers. Now here is the task. The task is simply to watch the parade go by without having it stop and without you jumping down into the parade. You are just supposed to let it flow. It is very unlikely, however, that you will be able to do this without interruption. And this is the key part of this exercise. At some point you will have the sense that the parade has stopped, or that you have lost the point of the exercise, or that you are down in the parade instead of being on the reviewing stand. When that happens, I would like you to back up a few seconds and see if you can catch what you were doing right before the parade stopped. Then go ahead and put your thoughts on the placards again, until the parade stops a second time, and so on. The main thing is to notice when it stops for any reason and see if you can catch what happened right before it stopped.*

*One more thing. If the parade never gets going at all and you start thinking "it's not working." or "I'm not doing it right" then let that thought be written on a placard and send it*

*down into the parade. OK. Now let's get comfortable, close your eyes, and get centered. [Help the client relax for 1 or 2 minutes]. Now allow the parade to begin. You stay up on the reviewing stand and let the parade flow. If it stops or you find yourself in it, note that, see if you can notice what you were doing right before that happened, get back up on the reviewing stand, and let the parade begin to flow again. OK, let's begin. ... Whatever you think, just put it on the cards. .... [for about two to three minutes, allow the client to work. Don't under do it time-wise, and use very few words. Try to read where the clients are and add a very few comments as needed, like "just let it flow and notice when it stops."]*

#### **D. Passengers on the bus:**

*"It's as if there is a bus and you're the driver. On this bus we've got a bunch of passengers. The passengers are thoughts, feelings, bodily states, memories, and other aspects of experience. Some of them are scary, and they're dressed up in black leather jackets and they've got switchblade knives. What happens is, you're driving along and the passengers start threatening you, telling you what you have to do, where you have to go. "You've got to turn left," "you've got to go right," etc. The threat that they have over you is that, if you don't do what they say, they're going to come up from the back of the bus.*

*It's as if you've made deals with these passengers, and the deal is, "You sit in the back of the bus and scrunch down so that I can't see you very often, and I'll do what you say, pretty much." Now what if one day you get tired of that and say, "I don't like this! I'm going to throw those people off the bus!" You stop the bus, and you go back to deal with the mean-looking passengers. Except you notice that the very first thing you had to do was stop. Notice now, you're not driving anywhere, you're just dealing with these passengers. And plus, they're real strong. They don't intend to leave and you wrestle with them, but it just doesn't turn out very successfully.*

*Eventually you go back to placating the passengers, to try and get them to sit way in the back again where you can't see them. The problem with that deal is that, in exchange, you do what they ask in exchange for getting them out of your life. Pretty soon, they don't even have to tell you, "Turn left"—you know as soon as you get near a left-turn the passengers are going to crawl all over you. Eventually you may get good enough that you can almost pretend that they're not on the bus at all, you just tell yourself that left is the only direction you want to turn. However, when they eventually do show up, it's with the added power of the deals that you've made with them in the past.*

*Now the trick about the whole thing is this: The power that the passengers have over you is 100% based on this: "If you don't do what we say, we're coming up and we're making you look at us." That's it. It's true that when they come up they look like they could do a whole lot more. They've got knives, chains, etc. It looks like you could be destroyed. The deal you make is to do what they say so they won't come up and stand next to you and make you look at them. The driver (you) has control of the bus, but you trade off the control in these secret deals with the passengers. In other words, by trying to get control, you've actually given up control! Now notice that, even though your passengers claim they can destroy you if you don't turn left, it has never actually happened. These passengers can't make you do something against your will.*

### Week 5

Observer perspective exercise (193).

*“We are going to do an exercise now that is a way to begin to try to experience that place where you are not your programming. There is no way anyone can fail at the exercise; we’re just going to be looking at whatever you are feeling or thinking so whatever comes up is just right. Close your eyes, get settled into your chair and follow my voice. If you find yourself wandering, just gently come back to the sound of my voice. For a moment now, turn your attention to yourself in this room. Picture the room. Picture yourself in this room and exactly where you are. Now begin to go inside your skin, and get in touch with your body. Notice how you are sitting in the chair. See if you can notice exactly the shape that is made by the parts of your skin that touch the chair. Notice any bodily sensations that are there. As you see each one, just sort of acknowledge that feeling and allow your conscious to move on. [pause] Now notice any emotions you are having and if you have any just acknowledge them [pause]. Now get in touch with your thoughts and just quietly watch them for a few moments [pause]. Now I want you to notice that as you noticed these things a part of you noticed them. You noticed those sensations ... those emotions ... those thoughts. At that part of you we will call the “observer you.” There is a person in here, behind those eyes, that is aware of what I am saying right now. And it is the same person you’ve been your whole life. In some deep sense this observer you is the you that you call you.*

*I want you to remember something that happened last summer. Raise your finger when you have an image in mind. Good. Now just look around. Remember all the things that were happening then. Remember the sights ... The sounds ... Your feelings ... and as you do that see if you can notice that you were there then noticing what you were noticing. See if you can catch the person behind your eyes who saw, and heard, and felt. You were there then, and you are here now. I’m not asking you to believe this. I’m not making a logic point. I am just asking you to note the experience of being aware and check and see if it isn’t so that in some deep sense the you that is here now was there then. The person aware of what you are aware of is here now and was there then. See if you can notice the essential continuity—in some deep sense, at the level of experience, not of belief, you have been you your whole life.*

*I want you to remember something that happened when you were a teenager. Raise your finger when you have an image in mind. Good. Now just look around. Remember all the things that were happening then. Remember the sights ... The sounds ... Your feelings ... Take your time. And when you are clear about what was there see if you just for a second catch that there was a person behind your eyes then who saw, and heard, and felt all of this. You were there then too, and see if it isn’t true—as an experienced fact, not a belief—that there is an essential continuity between the person aware of what you are aware of now and the person who was aware of what you were aware of as a teenager in that specific situation. You have been you your whole life.*

*Finally, remember something that happened when you were a fairly young child, say around age six or seven. Raise your finger when you have an image in mind. Good. Now just look around again. See what was happening. See the sights ... hear the sounds ... feel your feelings ... and then catch the fact that you were there seeing, hearing, and feeling. Notice that you were there behind your eyes. You were there then, and you are here now. Check and see if in some deep sense the “you” that is here now was there then. The person aware of what you are aware of is here now and was there then.*

*You have been you your whole life. Everywhere you've been, you've been there noticing. This is what I mean by the "observer you." And from that perspective or point of view I want you to look at some areas of living. Let's start with your body. Notice how your body is constantly changing. Sometimes it is sick and sometimes it is well. It may be rested or tired. It may be strong or weak. You were once a tiny baby, but your body grew. You may have even had parts of your body removed, like in an operation. Your cells have died and literally almost every cell in your body was not there as a teenager, or even last summer. Your bodily sensations come and go. Even as we have spoken they have changed. So if all this is changing and yet the you that you call you has been there your whole life that must mean that while you have a body, as a matter of experience and not of belief, you do not experience yourself to be just your body. So just notice your body now for a few moments, and as you do this, every so often notice you are the one noticing. [give the client time to do this]*

*Now let's go to another area: your roles. Notice how many roles you have or have had. Sometimes I'm in the role of a (fit these to client, e.g., "mother... or a friend... or a daughter... or a wife... sometimes I'm a respected worker... other times I'm a leader... or a follower"... etc.). In the world of form I'm in some role all the time. If I were to try not to, then I'd be playing the role of not playing a role. Even now part of me is playing a role... the client role. Yet all the while notice that you are also present. The part of me you call "you"... is watching and aware of what you are aware of. And in some deep sense that "you" does not change. So if your roles are constantly changing, and yet the you that you call you has been there your whole life, it must be that while you have roles, you do not experience yourself to be your roles. Do not believe this. This is not a matter of belief. Just look and notice the distinction between what you are looking at, and the you that is looking.*

*Now let's go to another area: emotions. Notice how your emotions are constantly changing. Sometimes you feel love and sometimes hatred, calm and then tense, joy-sorrowful, happy-sad. Even now you may be experiencing emotions. . .interest, boredom, relaxation. Think of things you have liked, and don't like any longer; of fears that you once had that now are resolved. The only thing you can count on with emotions is that they will change. Though a wave of emotion comes, it will pass in time. And yet while these emotions come and go, notice that in some deep sense that "you" does not change. That must be that while you have emotions, you do not experience yourself to be just your emotions. Allow yourself to realize this as an experienced event, not as a belief. In some very important and deep way you experience yourself as a constant. You are you through it all. So just notice your emotions for a moment and as you do notice also that you are notice them [Leave a brief period of silence]*

*Now let's turn to a most difficult area. Your own thoughts. Thoughts are difficult because they tend to hook us and pull us up to piece level. If that happens, just come back to the sound of my voice. Notice how your thoughts are constantly changing. You used to be ignorant—then you went to school and learned new thought. You have gained new ideas, and new knowledge. Sometimes you think about things one way and sometimes another. Sometimes your thoughts may make little sense. Sometimes they seemingly come up automatically, from out of nowhere. They are constantly changing. Look at your thoughts even since you came in today and notice how many different thoughts you have had. And yet in some deep way the you that knows what you think is not changing. So that must mean that while you have thought, you do not experience yourself to be just your thoughts. Do not*

*believe this. Just notice it. And notice even as you realize this, that your stream of thoughts will continue. And you may get caught up with them. And yet in the instant that you realize that, you also realize that a part of you is standing back, watching it all. So now watch your thoughts for a few moments—and as you do notice also that you are notice them [Leave a brief period of silence]*

*So as a matter of experience and not of belief you are not just your body... your roles ... your emotions ... your thoughts. These things are the content of your life, while you are the arena...the context...the space in which they unfold. As you see that, notice that the things you've been struggling with, and trying to change are not you anyway. No matter how this war goes you will be there, unchanged. See if you can take advantage of this connection to let go just a little bit, secure in the knowledge that you have been you through it all, and that you need not have such an investment in all this psychological content as a measure of your life. Just notice the experiences in all the domains that show up and as you do notice that you are still here, being aware of what you are aware of [Leave a brief period of silence]*

Now again picture yourself in this room. And now picture the room. Picture (describe the room). And when you are ready to come back into the room, open your eyes.

After this exercise, process the clients' experience with the exercise. Be careful to avoid analysis of the experience, but focus on the experience itself. It is useful to see if there were any particular qualities of the experience of connecting with the "you". It is not unusual for clients to report a sense of tranquillity or peace. Life experiences invoked in this exercise, many of which are threatening and anxiety promoting, can be received peacefully and tranquilly (i.e. accepted with a willingness posture) when they are viewed as bits and pieces of self-content, not as defining the self per se. It is usually worth leaving the client with the active implications of this experience. The therapist can link the client back to experiences with the chessboard metaphor: For example, "there is one other thing which the board, as a board can do, other than hold the pieces. It can take a direction, regardless of what the pieces are doing at the time. It can see what is there, feel what is there, and still say, 'Here we go'!

#### **Willingness as all or nothing.**

1. Not the same as wanting—you don't have to want to have these uncomfortable feelings and thoughts.
2. Its kind of like trying to hold your umbrella up against a very hard, very windy rainstorm while you're walking from point A to point B. Your goal is to get to point B, but you start spending more time trying to avoid getting wet than walking forward. And the whole time, you're still getting soaked by the rain! The wind is blowing your umbrella this way and that, the rain is blowing in to you sideways, and so on. And since you are so absorbed in avoiding getting wet, you don't notice that it may be possible to actually get something out of walking in the rain. Walking in that rain is part of the path you can take toward what you value. It is a painful part of the path, and there can be more to it than that. You can still live your values while you are walking in that rainstorm. You can, for example, help shield a family member from the wind, focus on the vitality involved with that wind and rain hitting your skin, get a laugh out of splashing in one of the puddles during the worst part of the downpour, put a quarter in somebody's expired parking meter so they don't get a ticket, and so on. In the middle of that pain, it can be a surprisingly rich experience to open yourself up to that wind and rain coming down on you and to live what you value in the middle of it all. Sometimes

it's not a rich experience, and you still move closer toward what you value. Sometimes you may have gotten sick from walking in the rain, but has it killed you yet?

3. Joe the Bum (240):

*“Imagine that you got a new house and you invited all the neighbors over to a party, a housewarming. Everyone’s invited in the whole neighborhood—you even put up a sign at the supermarket. So all the neighbors show up, the party’s going great, and here comes Joe-the-bum, who lives behind the supermarket in the trash dumpster. He’s stinky and smelly and you think, God, why did he show up? But you did say on the sign, Everyone’s welcome. Can you see that it’s possible for you to welcome him, and really, fully, do that without liking that he’s there? You can welcome him even though you don’t think well of him. You don’t have to like him. You don’t have to like the way he smells, or his life style, or his clothing. You may be embarrassed about the way he’s dipping into the punch or the finger sandwiches. Your opinion of him, your evaluation of him is absolutely distinct from your willingness to have him as a guest in your home. Now you can decide that even though you said everyone was welcome, in reality he’s not welcome. But as soon as you do that, the party changes. Now you have to be at the front of the house, guarding the door so he can’t come back in. Or if you say, OK, you’re welcome, but you don’t really mean it, you only mean that he’s welcome as long as he stays in the kitchen and doesn’t mingle with the other guests, then you’re going to have to be constantly making him do that, and your whole party will be about that. Meanwhile, life’s going on, the party’s going on, and you’re off guarding the bum. It’s just not life-enhancing. It’s not much like a party. It’s a lot of work. What the metaphor is about, of course, is all the feelings and memories and thoughts that show up that you don’t like; they’re just more bums at the door. The issue is the posture you take with regards to your own stuff. Are they welcome? Can you choose to welcome them in, even though you don’t like the fact they came? If not, what’s the party going to be like?”*

4. Physicalizing exercise.

5. Jumping (241):

*“Willingness is like jumping. You can jump off lots of things. [Therapist takes a book and places it on the floor and stands on it, then jumps off]. Notice that the quality of jumping is to put yourself in space and then let gravity do the rest. You don’t jump in two steps. You can put your toe over the edge and touch the floor but that’s not jumping. [Therapist puts one toes on the floor while standing on the book]. So jumping from this little book is still jumping. And it is the same action as jumping from higher places. [Therapist gets up on the chair and jumps off]. Now this is jumping too, right? Same quality? I put myself out into space and gravity does the rest. But notice from here I can’t really put my toe down very well. [Therapist tries awkwardly to touch ground with toe after getting back up on the chair]. Now if I jumped off the top of this building it would be the same thing. The jump would be identical. Only the context would have changed. But from there it would be impossible to try to step down. There is a Zen saying, “You can’t cross a canyon in two steps.” Willingness is like that. You can limit willingness by limiting context or situation. You get to choose the magnitude of your jump. What you can’t do is limit the nature of your action and still have it work.”*

## Week 6

### 6. Eye contact exercise:

*“This exercise is a little like making a small jump. We will look in each other’s eyes for about three minutes. It may seem longer when you actually do it, but that’s all it takes. What the exercise will consist of—if you’re willing to do it—is getting a couple chairs and pulling them close together. The job is to get present with me and maintain eye contact. It is not a stare down. You don’t have to say anything, or do anything, or communicate anything, just be present with me. Now your mind will tell you all sorts of reasons why you can’t do that: it will give you body sensations, or maybe a desire to laugh, or maybe you’ll be worrying about how your breath smells or you’ll be bored or distracted. But the purpose of the exercise is simply to notice these things, to experience all the pieces coming up, and to notice how you sort of come-and-go from being really present, from really experiencing being here with me. As the client does the exercise the therapist says things like “see if you can stay with the simple reality that there’s another person over here, looking at you. See if you can let go of the sense of wanting to do this “right”...if you find yourself talking about this, or evaluating it, just notice that you’re doing that and then come back out into the room and get in touch with the exercise...I want you to notice that the incredible fact that there is another person out here, another human being, looking back at you...see if you can connect with the experience of discomfort in simply being present to another person.”*

Willingness and accomplishing what you want to accomplish.

### 7. Monsters on the bus, revisited.

8. Expanding balloon (Imagine that you are surrounded by a bubble that kind of shields you from the outside world. This bubble can shrink, so that it only just barely surrounds you, or it can expand out very, very far, so that the people and things around you are inside the bubble. In this metaphor, you can only interact with people and things that are inside your bubble—anything that’s outside is off limits. And nothing outside the bubble can hurt you, and nothing outside can help you either. So there is often a payoff for letting people inside your bubble—if you let your wife, or your husband, or your son, or your daughter, inside your bubble, for example, they can sometimes make you feel happy, proud, supported, relieved, etc. And since you have let them inside your bubble now, they can affect you in other ways as well. They can make you angry, sad, anxious, frustrated, angry, embarrassed. They can make you think you’re a bad parent, a bad spouse, a bad person. So you have the choice of shrinking that bubble as tight around you as possible, and having no pain and no pleasure. Or you can expand it so that it fits around people you care about, and have pain and pleasure, depending on when pain and pleasure present themselves.

a. For example, I know everyone in this room desperately wishes that your son or daughter could live as normal a life as possible. You know through being involved in treatment programs that there are many things you can be doing at home—at nights and on the weekends—that make that more possible. If you choose to do those things, it means that you expand your bubble around that child so that he affects you—so that now, you can feel pride, shame, happiness, sadness, guilt, joy, etc., and so that you can think you’re a good parent sometimes, a bad parent sometimes,

you can think you can handle it if he throws another tantrum, or you can think you can't handle it if he throws another tantrum. You invite all of these things inside the bubble because that's how it works.

E. How do you notice barriers to willingness, and how do you get past them?

### 1. FEAR & ACT

- a. FEAR (fusion with your thoughts, evaluation of your experience, avoidance of your experiences, reason giving for your behavior)
- b. ACT (accept your reactions and be present, choose a valued direction, take action toward that direction).

### F. Forgiveness and self-acceptance.

#### 1. Role-Reversal/Forgiveness Exercise

*How hard are each of you on yourselves? When you make a mistake, how much do you beat yourselves up for that? Can people give me some examples? (Process). I want you all to think of a time when you came down hard on yourself for making a mistake. Go ahead and close your eyes and think about it. Remember as many details of that situation as you can, of what it felt like, etc. Once your clear, I want you to think about the person who matters most to you in your life. The person you care about most in your life, that is most accepting of you. If you can't decide on just one, just pick the person that comes to mind first. Imagine that person made the same mistake you did. Take some time and play out that scenario—imagine that person made exactly the same moves you did. Now imagine that person is standing in front of you—feeling exactly the way you did when you made that mistake. Imagine that person is pouring his/her heart out to you, telling you exactly how he/she feels for making that mistake, what they're thinking—that that person is feeling and thinking exactly the way you are about that mistake. Now I want you to think about how you would respond to that person. How do you feel about him or her? Does your heart kind of ache to see them in that much pain? What do you want to tell that person? Imagine that you're telling him or her that. Really imagine yourself saying those things to that person. Is it OK that they made that mistake? Are they a bad person for doing that? Do you love him or her any less? Now I want you to try to respond that exact same way to yourself for making that mistake. Notice that you just forgave that person for the same mistake you made—and that you deserve to give the same forgiveness, the same response to yourself. Really try to let that sink in. Really try to respond to yourself the same way you just responded to that other person. If you can't, I want you to think about how that person would respond to you if he or she knew you were in that much pain over that mistake. Imagine again that he or she is sitting across from you, that you've just poured your heart out—how would he/she respond, what would he/she say? Really let that sink in—really let yourself accept what he or she is saying.*

#### G. Tin can monster (171):

“Facing our problems is like facing a giant monster who is made up of tin cans and string. The 30-foot monster is almost impossible to be willing to face; if we disassemble him, however, into all the cans and string and wire that he's made of, each of those pieces are easier to deal with one at a time. I'd like us to do a little exercise to see if that isn't the way it works. Start by closing your eyes [add the usual patter necessary to get the client centered, focused, and relaxed]. OK. Let's start out by recalling something that happened last summer. Anything that happened is fine. When you have something just let me know.”

“Now I want you to see everything that was happening then. Notice where you are and what is happening. See if you can see, hear, and smell, just like you were back then. Take your time. [the therapist can elicit enough verbal responses to make sure that the client is following and can build on these to encourage the client to get into the memory]. And now I want you to notice that you were there. Notice that there was a person behind those eyes and though many things have happened since last summer notice also that that person is here now. I’m going to call that person the “observer you.” From that perspective of point of view I want you to get in touch with this feeling of panic that can show up at work. Let me know when you have it.”

“Now I want you to watch your body and see what it does. Just stay in touch with the feeling and watch your body until you notice some discomfort somewhere in your body.”

“Now I want you to see if it is possible to drop the rope with that discomfort. The goal here is not that you like the feeling, but that you’re having it just as a specific bodily event. See if you can notice exactly where that feeling of discomfort begins and ends. Imagine that it is a colored patch on our skin. See if you can notice the shape it makes. And as you do that, drop any sense of defense or struggle with this simple bodily sensation. .... If other feelings crowd in, let them know we will get to them later.”

“Now I want you to set that reaction aside. Bring the feeling original feeling back into the center of your consciousness and again watch quietly for what your body does. See if there is another reaction shows itself. As you watch, stay with that observer you—the part of you behind your eyes and watch from there.” [repeat for two or three bodily reactions.]

“Now this time just go back and get in touch with that original feeling.”

“Continue to look for things your body does but this time just look very dispassionately at all the little things that may happen in your body and we will just touch each and move on. So with each reaction just acknowledge it, like you would tip your hat to a person on the street. Sort of pat each on the head and then look for the next one. And each time see if you can welcome that bodily sensation, without struggling with it or trying to make it go away. In a sense see if you can welcome it, like you would welcome a visitor to your home.”

After this sequence is done with bodily sensations, do the same thing with any behavioral domain of interest: things the person feels pulled to do, thoughts, evaluations, emotions, social roles that come to mind, and so on. The more domains that are covered usually the better. Stay with one specific set of reactions at a time. Constantly come back in creative ways to the issue of letting go. Usually the last domain is memories because they can be especially powerful emotionally.

“Now for the last part here, I want you to imagine you have all the memories of your life on little snapshots in a picture album. First I want you to flip back through the album until you reach a memory last summer. And once again, see if you can recall that sense of being a person aware of that scene. Do you have it? Now I want you to reconnect with that original feeling. When you are well connected, start flipping back through the picture album. If you find yourself gazing at a picture, even if it doesn’t make sense that it might be related to panic, stay with it.”

When a memory is contacted, ask questions such as, “Who else is in the picture? How old are you? Where are you? What were you feeling and thinking at the time? What are you doing?”

“Now, I want you to find a place in that memory where something happened that you avoided. See if you did not duck from your own experience in some way. And take this opportunity now to drain out any sense of trauma in that memory by seeing if you go where you would not go psychologically. Whatever your reactions to the memory, just see if you can have that exactly as it is, have exactly what happened to you as it happened. That doesn’t mean you like it, but that you are willing to have it.” [Repeat this with 2 or 3 memories]

Imagine himself or herself as a young child. The age of the child should be that age at which the client remembers first beginning to have trouble in the world. Ask clients to imagine seeing the child standing before him/her. Ask for descriptions: How is the child standing? Notice how small the child’s hands are. What are their mannerisms? What is he or she doing, or saying? Now ask clients to really get into contact with what that child needed and wanted. When that area is fully explored, ask clients to say to the child those things that the child needs to hear; or to imagine giving the child whatever it wants (e.g., taking the child in one’s arms and hugging it, etc.).

“When you’re ready, I want you to close the album, and picture the room as it was here when you shut your eyes and began the exercise. When you can picture it, and are ready come back, just open your eyes and come back to the present.”

### Week 7

#### III. Value driven action.

A. The point of all this willingness stuff is not that you should go around leaning in to all the pain you find. Essentially what I’m asking you today is this:

1. In your experience, has trying to avoid pain (or clean discomfort) ultimately worked for you?
2. In your experience, has trying to avoid pain (or clean discomfort) made it harder to do the things that you really want to do with your life—to live your life the way you really want to live it, deep down?
3. As I said in an earlier session, the purpose of all this talk about words and about willingness is to give you some different tools to make your life—and your children’s lives—more livable. More livable doesn’t mean free from pain. It means more able to do the things that make your life meaningful, that make your life worth living when there’s pain present and when there’s not. So all this willingness stuff involves a set of tools that you can use to move more effectively toward these kinds of goals that give your lives meaning, that matter to you. This is what I mean by values.

B. What are values?

#### 1. **Different from feelings—involves action—argyle socks exercise (211):**

Let’s do a silly little example. Do you care how many people wear argyle socks?

Client: No, why should I?

Therapist: OK. Well, I want you do is really, really develop a strong belief that college boys have to wear argyle socks. Really feel it in your gut. Really get behind it!

Client: I can't.

Therapist: Well, really try. Feel overwhelmingly strongly about this. Is it working?

Client: No

Therapist: OK. Now I want you to imagine that even though you can't make yourself feel strongly about this, you are going to act in ways that make argyle socks important to college students. Let's think of some ways. You could picket the dormitories that have low percentages of argyle sock wearers, say. What else?

Client: I could beat up college students not wearing them.

Therapist: Great! What else.

Client: I could give away free argyle socks to college students.

Therapist: Super. And notice something. Although these things may be silly actions, you could easily do them.

Client: And would be forever remembered as that stupid guy who wasted his time worrying about argyle socks!

Therapist: Yes, and possibly because of your commitment to it, as the person responsible for bringing argyle socks back into fashion. But also notice this, if you behaved in these ways, no one would ever know that you had no strong feeling about argyle socks at all. All they would see is your footprints. . . your actions.

2. Like a compass (e.g., even when you feel lost at sea and don't feel like you can go on, it's a reminder of which way to go).

### 3. Choice vs decision

- a. Decision as selecting among alternatives for reasons (where the reason justifies the selection, directly guided by it, or explained by it). Decisions depend on reasons—when the reasons change, you make a different decision. Decisions can be “right” or “wrong” depending on who you ask to evaluate the decision.
- b. A choice involves selecting between alternatives for no reasons—even when reasons are involved. When I choose this, I do it for no other reason than I choose this—and that's not even a reason. I'm just telling you, I choose this. Period. Even if I have good reasons for not choosing this, I choose it. Even if it doesn't make sense under the circumstances, I choose it.
- c. 7-Up vs. Coke
  1. Choose one (choose without reasons)?
  2. Could you find reasons not to pick that one?
  3. Could you find reasons to pick the other one?
- d. **Values are choices.** You choose the kinds of things you want your life to be about. You don't have to have reasons to choose them. You can choose again to live those values every day, every hour, every second—again for no reasons. Even when you have a lot of good reasons why you can't [use client example]—what good reasons could you think of to not choose to do [things that would

lead to that] in a given moment (to client)? Those are words, and we've kind of exposed words for what they are here today.

**4. Choose what you want you're life to stand for exercise (215):**

*This is what I call the "What do want your life to stand for exercise". I want you to close your eyes and relax for a few minutes and put all the other stuff we've been talking about out of your mind [Therapist assists clients with relaxation for 2-3 minutes]. Now I want you to imagine that through some twist of fate you have died but you are able to attend your funeral in spirit. You are watching and listening to the eulogies offered by your wife, your children, your friends, people you have worked with and so. Imagine just being in that situation and get yourself into the room emotionally. [pause] O.K., now I want you to visualize what you would like these people who were part of your to remember you for. What would you like your wife to say about you, as a husband? Have her say that. Really be bold here. Let her say exactly what you would most want her to say if you had a totally free choice about what that would be. [pause] Now what would you like your children to remember you for, as a father? Again, don't hold back. If you could have them say anything, what would it be? Even if you have not actually lived up to what you would want, let them say it as you would most want it to be [pause]. Now what would you like your friends to say about you, as a friend. What would you like to be remembered for by your friends. Let them say all these things—and don't withhold anything. Have it be said as you would most want it. And just make a mental note of these things as you hear them spoken. [The therapist may continue with this until it is quite clear the clients have entered into the exercise. Then the therapist helps the clients to reorient back to the session, e.g., "just picture what the room will look like when you come back and when you are ready just open your eyes"].*

a. ask clients what the experience was like.

b. Ask clients if any want to share what some of their values are.

**5. Some values take a long time to cultivate—gardening metaphor:**

*"Imagine that you selected a spot to plant a garden. You worked the soil, planted the seeds, and waited for them to sprout. Meanwhile you started noticing a spot just across the road, which also looked like a good spot—maybe even a better spot. So then you pulled up your vegetables, and went across the street and planted another garden there. Then you noticed another spot which looked even better. Values are like where you plant your garden. You can grow some things very quickly, but some things require time and dedication. So the question is "Do you want to live on lettuce, or do you want to live on something more substantial—potatoes, beets, or the like?" You can't find out how things work in gardens when you have than to pull up stakes again and again. Now of course, if you stay in the same spot you'll start to notice it's imperfections. Maybe the ground isn't quite as level as it looked when you started, or the water has to be carried a ways. Some things you plant may seem to take forever to come up. It is times like these that your mind will tell you that "you should have planted elsewhere," "this will probably never work," "it was stupid of you to think you could grow anything here," etc. The choice to garden here allows you to water and weed and hoe, even when these thoughts and feelings show up."*

**Week 8**

You're going to find that there are times—maybe a lot of times—that you get pushed around by reasons, and decide not to walk down a path that you value. That is not only

perfectly o.k., it's perfectly expected. We are all human. There's a couple of things I want you to remember when you fall off the wagon like this.

- a. Remember the place you were in when we did the little child exercise? Or the forgiving the other person exercises? You deserve nothing less than to give that to yourself when you make a mistake, or come down hard on yourself.
  - b. Just because you fell off the wagon with a value doesn't mean you can't get right back on. Unless your choice has changed—unless you don't have whatever value you strayed from anymore—you can still get up, dust yourself off, and start walking down that path again.
    1. Give example of how getting drunk once can throw an alcoholic off track.
    2. Give example of staying committed to autistic child's behavioral program even under specific tough conditions (if and only if that's one of the things you value), and staying committed to your spouse even when things seem very rough (if and only if that's one of the things you value)
    3. Give specific client examples.
6. Homework (values). Go over participants attempts toward committed action, reinforce positive movement forward. Discuss and normalize barriers to values-based action. Generate plans to address barriers moving forward.
  7. Questions from clients.
  8. Review handout packet as a review of treatment strategies utilized.
  9. Summary and goodbyes.

## **Appendix B: TAU Treatment Manual**

### Treatment goals

1. The support group will provide a safe environment, wherein individuals who share a common predicament can offer mutual concern and support to one another.
2. The support group will offer participants the opportunity to learn from one another about effective coping strategies and concrete skills.
3. The support group will offer participants the chance to gain a different perspective through sharing with others, along with helping others to identify and deal with difficult obstacles in their life (e.g., managing the stress associated with raising a child with autism.).

### General Treatment Guidelines

- Unlike a therapy group, support groups are focused more on peer support and deemphasize the role of the group leader.
- The participants are expected to play an active role in the maintenance of the group dynamics and structure (e.g., deciding on group topics, conversation and networking).

### Initial Session Guidelines

- Initial welcome to the group and brief explanation of the research study (e.g., “ a study that will look at comparing two different supportive environments for stress for parents of children with autism- this, a support group and a more focused coping skills group).
- Make sure all participants have either sent in informed consent prior to the first appointment or are able to sign the form at this time. Please make sure participants have any questions or concerns addressed and feel comfortable with the research protocol and informed consent.
- The group leader will begin by introducing her/himself to the group (provide brief educational background, current employment, clinical expertise). The group leader should take caution not to present themselves as the “expert” for the group, rather as someone who is knowledgeable about autism spectrum disorders who will serve as a facilitator for this experience.
- The group leader will ask the group members to introduce themselves. They may share as much or as little about their personal situation as they feel comfortable (e.g., children, diagnosis story, difficulties with stress, journey with autism).
- The group leader should provide the group with some general information about how the group will be run and should include the following in an informal format:

- Group leader will act as facilitator but participants will essentially “lead” the group
- Topics will be selected by the participants based on interest
- Encouragement of peer to peer support (through sharing, advice, information). The therapist should emphasize that although they might have expertise in management of problem behaviors and/or providing therapy for parental stress- neither of these will be explicitly covered during this group.
- General confidentiality statement (“autism community is very small; all information shared within the context of this group is expected to remain within this group).
- A statement about respect within the group (e.g., as many of you know, the diagnosis of autism is a tricky one- and treatment is often trickier. You have probably found that there are many differing opinions out there. It is our goal to have all opinions respected within these sessions. Although it might be difficult at times, please remain respectful of other’s opinions and views)
- The group leader will work with the group to identify topics for the remaining 7 sessions (the last session should include time allotment for wrap-up and review of what has been shared/learned). The generation of topics is to be left up to the discretion of the group; however the leader may need to make some suggestions in order to facilitate the selection process. Possible group topics might include: marital issues, stress related to parenting, management of problematic behaviors in public, involvement of extended family members, dealing with professionals, ins and outs of an Autism diagnosis,

#### Subsequent Sessions

- The group leader should begin with a brief review of what was covered the previous session, including statements about any major consensus the group came to in a previous session (e.g., it seemed like everyone was in agreement last time that it’s important to involve the extended family in supporting you as much as possible).
- The leader should explicitly open up the conversation to the group members after the session’s (predefined) topic has been announced. It might be helpful to start with a query such as “what thoughts come to mind when we say “marital issues”?).
- The leader should allow the conversation to remain amongst group participants as much as possible. However, there will be time when the leader will need to intervene; therefore there are some guidelines for these purposes.

- Disrespect: If the leader feels that a group member is being disrespectful of another group member, he/she should remind everyone of the guidelines and attempt to resolve the conflict.
- Decline in group activity: When the group members engagement in conversation comes to a lull, the leader will facilitate additional conversation by using a number of available prompts (appropriate to the situation). Examples might include: “Does anyone else have anything to share about (\*last topic discussed).” “if someone was struggling with Issue X, how might they go about solving that?,” “has anyone else felt they have been in a similar situation/had a similar experience... what have you done?,” “how was that strategy effective for you?”
- Emotional reactions: inevitably the members will experience emotional reactions over the content of the topics. The leader should use skills such as empathy, supportive listening, validation, warmth, and compassion to serve their facilitative role (e.g., given your situation, I am only imagine how hard that must have been for you/ how you felt”

## Appendix C: Measures

### ATQ

**Instructions:** Listed below are a variety of thoughts that pop into people's heads. Please read each thought and indicate how frequently, if at all, the thought occurred to you *over the last week*.

Please circle a response on the LEFT side of the sheet using the **FREQUENCY** scale:

**1 = not at all    2 = sometimes    3 = moderately often    4 = often    5 = all the time**

Then, please indicate how strongly, if at all, you tend to believe that thought, when it occurs.

Please circle a response on the RIGHT side of the sheet using the **DEGREE OF BELIEF** scale:

**1 = not at all    2 = somewhat    3 = moderately    4 = very much    5 = totally**

Frequency Belief	Item	Degree of Belief
1 2 3 4 5	1.) I feel like I'm up against the world.	1 2 3 4 5
1 2 3 4 5	2.) I'm no good.	1 2 3 4 5
1 2 3 4 5	3.) Why can't I ever succeed?	1 2 3 4 5
1 2 3 4 5	4.) No one understands me.	1 2 3 4 5
1 2 3 4 5	5.) I've let people down.	1 2 3 4 5
1 2 3 4 5	6.) I don't think I can go on.	1 2 3 4 5
1 2 3 4 5	7.) I wish I were a better person.	1 2 3 4 5
1 2 3 4 5	8.) I'm so weak.	1 2 3 4 5
1 2 3 4 5	9.) My life's not going the way I want it to.	1 2 3 4 5
1 2 3 4 5	10.) I'm so disappointed in myself.	1 2 3 4 5
1 2 3 4 5	11.) Nothing feels good anymore.	1 2 3 4 5
1 2 3 4 5	12.) I can't stand this anymore.	1 2 3 4 5
1 2 3 4 5	13.) I can't get started.	1 2 3 4 5
1 2 3 4 5	14.) What's wrong with me?	1 2 3 4 5
1 2 3 4 5	15.) I wish I were somewhere else.	1 2 3 4 5
1 2 3 4 5	16.) I can't get things together.	1 2 3 4 5
1 2 3 4 5	17.) I hate myself.	1 2 3 4 5
1 2 3 4 5	18.) I'm worthless.	1 2 3 4 5
1 2 3 4 5	19.) Wish I could just disappear.	1 2 3 4 5
1 2 3 4 5	20.) What's the matter with me?	1 2 3 4 5
1 2 3 4 5	21.) I'm a loser.	1 2 3 4 5
1 2 3 4 5	22.) My life is a mess.	1 2 3 4 5
1 2 3 4 5	23.) I'm a failure.	1 2 3 4 5
1 2 3 4 5	24.) I'll never make it.	1 2 3 4 5

1 2 3 4 5	25.) I feel so hopeless.	1 2 3 4 5
1 2 3 4 5	26.) Something has to change.	1 2 3 4 5
1 2 3 4 5	27.) There must be something wrong with me.	1 2 3 4 5
1 2 3 4 5	28.) My future is bleak.	1 2 3 4 5
1 2 3 4 5	29.) It's just not worth it.	1 2 3 4 5
1 2 3 4 5	30.) I can't finish anything.	1 2 3 4 5

### Positive Aspects of Caregiving

*Some caregivers say that, in spite of all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. I'm going to go over a few of the good things reported by some caregivers. I would like you to tell me how much you agree or disagree with these statements.*

Providing help to (CR) has...	Disagree a lot	Disagree a little	Neither nor	Agree Disagree	Agree a little	Agree a lot	Refused	Unknown
<b>1. made me feel more useful</b>	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )	
<b>2. made me feel good about myself</b>	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )	
<b>3. made me feel needed</b>	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )	
<b>4. made me feel appreciated</b>	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )	
<b>5. made me feel important</b>	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )	
<b>6. made me feel strong and confident</b>	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )	
<b>7. enabled me to appreciate life more</b>	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )	
<b>8. enabled me to develop a more positive attitude toward life</b>	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )	
<b>9. strengthened my relationships with others</b>	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )	

## AAQ-II

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true
				1	2 3 4	5 6 7

1. My painful experiences and memories make it difficult for me to live a life that I would value.

2. I'm afraid of my feelings.

3. I worry about not being able to control my worries and feelings.

4. My painful memories prevent me from having a fulfilling life.

5. Emotions cause problems in my life.

6. It seems like most people are handling their lives better than I am.

7. Worries get in the way of my success.

## FFMQ

Please rate each of the following statements using the scale provided. Write the number in the blank that best describes your own opinion of what is generally true for you.

1	2	3	4	5
never or very rarely true	rarely true	sometimes true	often true	very often or always true

- \_\_\_\_\_ 1. When I'm walking, I deliberately notice the sensations of my body moving.
- \_\_\_\_\_ 2. I'm good at finding words to describe my feelings.
- \_\_\_\_\_ 3. I criticize myself for having irrational or inappropriate emotions.
- \_\_\_\_\_ 4. I perceive my feelings and emotions without having to react to them.
- \_\_\_\_\_ 5. When I do things, my mind wanders off and I'm easily distracted.
- \_\_\_\_\_ 6. When I take a shower or bath, I stay alert to the sensations of water on my body.
- \_\_\_\_\_ 7. I can easily put my beliefs, opinions, and expectations into words.
- \_\_\_\_\_ 8. I don't pay attention to what I'm doing because I'm daydreaming, worrying, or otherwise distracted.
- \_\_\_\_\_ 9. I watch my feelings without getting lost in them.
- \_\_\_\_\_ 10. I tell myself I shouldn't be feeling the way I'm feeling.
- \_\_\_\_\_ 11. I notice how foods and drinks affect my thoughts, bodily sensations, and emotions.
- \_\_\_\_\_ 12. It's hard for me to find the words to describe what I'm thinking.
- \_\_\_\_\_ 13. I am easily distracted.
- \_\_\_\_\_ 14. I believe some of my thoughts are abnormal or bad and I shouldn't think that way.
- \_\_\_\_\_ 15. I pay attention to sensations, such as the wind in my hair or sun on my face.
- \_\_\_\_\_ 16. I have trouble thinking of the right words to express how I feel about things
- \_\_\_\_\_ 17. I make judgments about whether my thoughts are good or bad.
- \_\_\_\_\_ 18. I find it difficult to stay focused on what's happening in the present.
- \_\_\_\_\_ 19. When I have distressing thoughts or images, I "step back" and am aware of the thought or image without getting taken over by it.
- \_\_\_\_\_ 20. I pay attention to sounds, such as clocks ticking, birds chirping, or cars passing.
- \_\_\_\_\_ 21. In difficult situations, I can pause without immediately reacting.
- \_\_\_\_\_ 22. When I have a sensation in my body, it's difficult for me to describe it because I can't find the right words.

**PLEASE TURN OVER ÷**

1	2	3	4	5
never or very rarely true	rarely true	sometimes true	often true	very often or always true

- \_\_\_\_ 23. It seems I am “running on automatic” without much awareness of what I’m doing.
- \_\_\_\_ 24. When I have distressing thoughts or images, I feel calm soon after.
- \_\_\_\_ 25. I tell myself that I shouldn’t be thinking the way I’m thinking.
- \_\_\_\_ 26. I notice the smells and aromas of things.
- \_\_\_\_ 27. Even when I’m feeling terribly upset, I can find a way to put it into words.
- \_\_\_\_ 28. I rush through activities without being really attentive to them.
- \_\_\_\_ 29. When I have distressing thoughts or images I am able just to notice them without reacting.
- \_\_\_\_ 30. I think some of my emotions are bad or inappropriate and I shouldn’t feel them.
- \_\_\_\_ 31. I notice visual elements in art or nature, such as colors, shapes, textures, or patterns of light and shadow.
- \_\_\_\_ 32. My natural tendency is to put my experiences into words.
- \_\_\_\_ 33. When I have distressing thoughts or images, I just notice them and let them go.
- \_\_\_\_ 34. I do jobs or tasks automatically without being aware of what I’m doing.
- \_\_\_\_ 35. When I have distressing thoughts or images, I judge myself as good or bad, depending what the thought/image is about.
- \_\_\_\_ 36. I pay attention to how my emotions affect my thoughts and behavior.
- \_\_\_\_ 37. I can usually describe how I feel at the moment in considerable detail.
- \_\_\_\_ 38. I find myself doing things without paying attention.
- \_\_\_\_ 39. I disapprove of myself when I have irrational ideas.

### Telephone Screening Form

Name: \_\_\_\_\_

Age: \_\_\_\_\_

Contact Information: \_\_\_\_\_

Are you *the biological or adoptive mother & primary caregiver of a child with a diagnosis of an autism spectrum disorder?* YES NO

Was your child formally diagnosed with Autism Spectrum Disorder?

What is their diagnosis and where/when did you receive it?

Is your child between the ages of 2 and 10? YES NO

How old is your child (with ASD)?

Are you proficient in the English language? YES NO

Do you have access to telephone, either in the home or cellular? YES NO

Do you plan on remaining in the area for at least 6 months? YES NO

Are you currently involved in another clinical trial of psychosocial interventions for parents/caregivers? YES NO

Do you (or your child/spouse) have active major medical issues such as cancer, organ transplant, etc. ? YES NO

AVAILABILITY: Sat Wave? \_\_\_\_\_ Weeknight Wave? \_\_\_\_\_

GROUP ASSIGNMENT \_\_\_\_\_

### Demographic Questionnaire

This questionnaire is intended to gain additional information about you and your child's background. Please answer each question completely by either circling your response or marking an answer.

**Age (Circle number of years) Date of Birth:** \_\_\_\_\_

19 years or less    20-29    30-39    40-49    50-59    >60

**Ethnicity (Circle one)**

Asian

Black

Hispanic

Native Americans

White, Caucasian

Other, please specify \_\_\_\_\_

**Gender (circle one)**

Male      Female

**Marital Status (Circle one)**

Married

Never marries

Divorced/separated

Widowed

Remarried

Living with someone

**What is the highest degree or level of school you have completed? If currently enrolled, mark the previous grade or highest degree received.**

Less than 8th grade

9th, 10th or 11th grade

12th grade, no diploma

High school graduate - high school diploma or the equivalent (for example: GED)

Some college credit, but less than 1 year

1 or more years of college, no degree

Associate degree (for example: AA, AS)

Bachelor's degree (for example: BA, AB, BS)

Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)

Professional degree (for example: MD, DDS, DVM, LLB, JD)

Doctorate degree (for example: PhD, EdD)

**Are you currently....?**

Employed for wages

Self-employed

Out of work and looking for work

Out of work but not currently looking for work

A homemaker

A student

Retired

Unable to work

**How many children, with diagnosis of autism, are you caring for?**

(Please write your answer) \_\_\_\_\_

**What are the birthdates and gender of your children with the diagnosis of autism?**

(Please write your answer) \_\_\_\_\_

**Are you the ...?**

Biological mother

Adoptive mother

Other, please specify

**Are you also caring for children that do not have autism?**

(please circle your answer) Yes / No

**If yes, what are their birthdates and gender?**

(Please write in your answer) \_\_\_\_\_

**When did your child receive his/her diagnosis of autism?**

(Please write in your answer; either age or year) \_\_\_\_\_

**What diagnosis did your child receive?**

Autism Spectrum Disorder

Pervasive Developmental Disorder

Asperger's Disorder

Other, please specify \_\_\_\_\_

**Who provided your child's diagnosis?**

Pediatrician

Neurologist

School professional team

Psychologist

Other, please specify \_\_\_\_\_

**Where on the autism spectrum do you feel your child falls?**

Mild \_\_\_\_\_ Severe

1      2      3      4      5

**What type of treatments have or do you currently utilize to treat your child's autism symptoms?**

(Please circle all applicable)

Intensive behavioral intervention

Dietary modifications (e.g., GF/CF diet)

Dietary supplements

Occupational Therapy

Physical Therapy

Speech and Language Pathology

Play therapy

Chelation

Drug Therapy

Sensory Integration Therapy

Craniosacral Therapy

Biofeedback Treatment

Other, please specify \_\_\_\_\_

**Is your child currently enrolled in an intensive behavioral treatment program?**

(Please circle your answer) Yes NO

**If yes, how many hours per week of behavioral intervention does he/she receive?**

0-10 hours

11-20

21-30

31-40 +

**Have you ever received counseling or psychotherapy for yourself for parental stress related issues?**

Yes, when? \_\_\_\_\_

No



8. What are some things you would change or do differently?

9. Please provide any additional feedback you would like to share.

## Appendix D: Dissertation Approval Forms

### EASTERN MICHIGAN UNIVERSITY Graduate School Dissertation Committee<sup>1</sup> Approval Form

Student	Jennifer D. Kowalkowski	Date	08/10/2010
Student ID Number	E00840432	Department/College	Psychology/Arts & Sciences
Email address	jenniferk512@gmail.com		
Current position	Doctoral Fellow		
Phone (work)	(248) 974-6737	(home)	
Program/Research Area	Clinical Psychology		
Dissertation Topic/Tentative Title	The impact of a group-based Acceptance and Commitment Therapy Intervention for Parents of Children with Autism Spectrum Disorders		
Committee Chair	James T. Todd		
Proposed Member Appointed by the Graduate School	Lori J. Warner, Ph.D.		



Proposed appointee has agreed to serve



(if left blank) Please appoint a member selected by the Graduate School

## Additional Members:

Name	Renee Lajiness-O'Neill	Title	Professor
Name	Tamara Loverich	Title	Professor
Name	Thomas Schmitt	Title	Professor
Name		Title	

## Approval of Committee Roster:

Department Head or School Director	<i>Carol Koed - D</i>	Date	8/19/10
Graduate School and Research	<i>Shirley Lohr - S</i>	Date	8/19/10

*Original to Graduate School student file. Copies to: committee chair and members; department/college*

<sup>1</sup>Graduate School policy requires that committee chairs be tenured or tenure-track full-time faculty with a completed doctorate in the student's specialty. In addition to the chair, committees must consist of from four to six members (normally faculty from within the degree-granting school). At least half of the committee members must be from the student's home school. At least one member must be from outside the student's home school and serves the committee as the Graduate School representative. One committee member may be from outside the pool of graduate faculty (e.g., faculty from other institutions, alumni, community members, corporate partners, internship supervisor, emeritus faculty). All committee members should be experts in at least some aspect of the student's dissertation topic area. The final committee roster, and any subsequent changes in committee membership, must be formally approved by the Committee Chair, Department Head or School Director and Dean of the Graduate School.

RECEIVED

AUG 19 2010

10/07

Graduate School  
Dean's Office

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v2

E00840432

**EASTERN MICHIGAN UNIVERSITY**  
Graduate School  
Approval of the Dissertation Proposal<sup>1</sup>

Candidate Jennifer D. Kowalkowski Date 09/02/2010  
 Major Clinical Psychology Cognate \_\_\_\_\_  
 Dissertation Committee Chair James T. Todd, Ph.D.

TENTATIVE TITLE OF PROPOSED DISSERTATION

**The Impact of a Group-Based Acceptance and Commitment Therapy Intervention on Parents of Children Diagnosed with an Autism Spectrum Disorder**

COMMITTEE REPORT ON DISSERTATION PROPOSAL

After review of the dissertation proposal, the Doctoral Committee certifies that:

- The proposal is satisfactory and the candidate may proceed.
- The proposed research does not involve the use of human subjects OR
- The proposed research involves human subjects and will be sent to University Human Subjects Review Committee prior to data collection.
- The proposal is not satisfactory and the following deficiencies must be corrected:<sup>2</sup>Office of Records & Registration

**RECEIVED**  
FEB 09 2011

Description of deficiencies \_\_\_\_\_

COMMITTEE SIGNATURES

Chair [Signature]  
 Member Representing the Graduate School [Signature]  
 Member [Signature]  
 Member [Signature]  
 Member [Signature]

GRADUATE SCHOOL APPROVAL

Date 2/9/11 Graduate School [Signature]

*Signed original to Record's student file. Copies to: Graduate School, chair, and department/college file*

<sup>1</sup>To be completed only after student has been officially notified of having passed the qualifying examination.  
<sup>2</sup>After the deficiencies have been corrected a new form must be submitted indicating that the proposal is satisfactory and the candidate may proceed.

## Appendix E: Human Subjects Institutional Review Board Approval Forms

**E**ASTERN MICHIGAN UNIVERSITY

*Education First*

February 4, 2011

UHSRC Initial  
Application Determination  
**EXPEDITED APPROVAL**

To: Jennifer Kowalkowski  
Psychology Department

Re: **UHSRC # 110119**                      Category: Approved Expedited Research Project  
**Approval Date:**                      February 4, 2011

Title: "The Impact of a Group-based Acceptance and Commitment Therapy Intervention for Parents of Children with Autism"

The Eastern Michigan University Human Subjects Review Committee (UHSRC) has completed their review of your project. I am pleased to advise you that **your expedited research has been approved** in accordance with federal regulations.

**Renewals:** Expedited protocols need to be renewed annually. If the project is continuing, please submit the **Human Subjects Continuation Form** prior to the approval expiration. If the project is completed, please submit the **Human Subjects Study Completion Form** (both forms are found on the UHSRC website).

**Revisions:** Expedited protocols do require revisions. If changes are made to a protocol, please submit a **Human Subjects Minor Modification Form** or new **Human Subjects Approval Request Form** (if major changes) for review (see UHSRC website for forms).

**Problems:** If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to human subjects and change the category of review, notify the UHSRC office within 24 hours. Any complaints from participants regarding the risk and benefits of the project must be reported to the UHSRC.

**Follow-up:** If your expedited research project is not completed and closed after three years, the UHSRC office will require a new **Human Subjects Approval Request Form** prior to approving a continuation beyond three years.

Please use the UHSRC number listed above on any forms submitted that relate to this project, or on any correspondence with the UHSRC office.

Good luck in your research. If we can be of further assistance, please contact us at 734-487-0042 or via e-mail at [human.subjects@emich.edu](mailto:human.subjects@emich.edu). Thank you for your cooperation.

Sincerely,



Deb de Laski-Smith, Ph.D.  
Interim Dean  
Graduate School  
Administrative Co-Chair  
University Human Subjects Review Committee

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University Human Subjects Review Committee · Eastern Michigan University · 200 Boone Hall  
Ypsilanti, Michigan 48197  
Phone: 734.487.0042 Fax: 734.487.0050  
E mail: [human.subjects@emich.edu](mailto:human.subjects@emich.edu)  
[www.ord.emich.edu](http://www.ord.emich.edu) (see Federal Compliance)

The EMU UHSRC complies with the Title 45 Code of Federal Regulations part 46 (45 CFR 46) under FWA00000050.

# EASTERN MICHIGAN UNIVERSITY

*Education First*

August 18, 2011

UHSRC Modification  
Application Determination

**EXPEDITED MODIFICATION APPROVAL**

To: Jennifer Kowalkowski  
Psychology Department

Re: **UHSRC #110803M**                      Category: Approved Modification Expedited Research Project  
**Approval Date:**                      August 17, 2011

Title: "The Impact of a Group-based Acceptance and Commitment Therapy Intervention for Parents of Children with Autism"

The Eastern Michigan University Human Subjects Review Committee (UHSRC) has completed their review of your modification for a previously approved expedited project. I am pleased to advise you that **your expedited research modification has been approved** in accordance with federal regulations.

**Renewals:** Expedited protocols need to be renewed annually. If the project is continuing, please submit the **Human Subjects Continuation Form** prior to the approval expiration. If the project is completed, please submit the **Human Subjects Study Completion Form** (both forms are found on the UHSRC website).

**Revisions:** Expedited protocols do require revisions. If changes are made to a protocol, please submit a **Human Subjects Minor Modification Form** or new **Human Subjects Approval Request Form** (if major changes) for review (see UHSRC website for forms).

**Problems:** If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to human subjects and change the category of review, notify the UHSRC office within 24 hours. Any complaints from participants regarding the risk and benefits of the project must be reported to the UHSRC.

**Follow-up:** If your expedited research project is not completed and closed after three years, the UHSRC office will require a new **Human Subjects Approval Request Form** prior to approving a continuation beyond three years.

Please use the UHSRC number listed above on any forms submitted that relate to this project, or on any correspondence with the UHSRC office.

Good luck in your research. If we can be of further assistance, please contact us at 734-487-0042 or via e-mail at [human.subjects@emich.edu](mailto:human.subjects@emich.edu). Thank you for your cooperation.

Sincerely,



Deb de Laski-Smith, Ph.D.  
Interim Dean  
Graduate School  
Administrative Co-Chair  
University Human Subjects Review Committee

University Human Subjects Review Committee · Eastern Michigan University · 200 Boone Hall  
Ypsilanti, Michigan 48197  
Phone: 734.487.0042 Fax: 734.487.0050  
E mail: [human.subjects@emich.edu](mailto:human.subjects@emich.edu)  
[www.ord.emich.edu](http://www.ord.emich.edu) (see Federal Compliance)

The EMU UHSRC complies with the Title 45 Code of Federal Regulations part 46 (45 CFR 46) under FWA00000050.

## Appendix F: Informed Consent

### Informed Consent to participate in:

#### **“The Impact of a Group-based Acceptance and Commitment Therapy Intervention for Parents of Children with Autism”**

To be conducted by Jennifer D. Kowalkowski, MS, LLP, BCBA (Doctoral Candidate) and James Todd (Professor of Psychology)

Eastern Michigan University

1. **Purpose of Research Study:** The purpose is to examine the effects of two different types of group-based interventions for mothers of children with autism on parental stress, coping skills, and psychological functioning. If you agree to participate, you will be randomly assigned to a parent support group (“treatment as usual”) or a group-based skills workshop based on Acceptance and Commitment Therapy (ACT). The purpose of the “treatment as usual” support group is to provide a comparison group (i.e., something typically available to parents in the community) to better evaluate the effects of the ACT-based workshop.
2. **Participation Withdrawal or Refusal to Participate:** Participation in this study is purely voluntary. Refusal to participate will not result in any penalty or a loss of benefits. You may decide to withdraw from the study at any time without consequences to you or your child’s current or future treatment with Beaumont Hospitals and/or any of the professionals involved in the study.
3. **Participation Requirements:** You must be a mother of a child who has been given a diagnosis of pervasive developmental disorder (PDD-NOS) or an autism spectrum disorder (ASD; including Autistic Disorder or Asperger’s Syndrome) by a licensed professional. Your child must be between the ages of 2 and 10 years old at the start of the study. Additionally, you must speak English, have access to a telephone, and have plans to remain in the area for at least 6 months following the start of treatment. Unfortunately, we will not be able to include individuals who are currently involved in another study of psychosocial interventions for parents/caregivers or those (or their child/spouse) who have active major medical issues such as cancer, organ transplant, etc.
4. **Description of Study Procedures:** If you are assigned to the ACT-based workshop, the study will consist of the following:
  - a. *Telephone screening:* the Principal Investigator of this study will conduct a short screening via telephone to make sure you are eligible for the study and understand the consent process for participating in research.
  - b. *Assessments:* In order to adequately measure the effects of the different interventions, you will be asked to complete a number of questionnaires at 3 time points in the study (before treatment, after treatment, and at 3 months post treatment). The assessments will measure various aspects of psychological functioning, including your current levels of anxiety and depression, level of parental stress, coping skills, and child’s level of functioning (based on parental report). Each assessment battery should take no longer than 1.5 hours to complete and is mailed to your home to complete. You will be compensated financially for each assessment battery that is completed.
  - c. *ACT-based workshops:* The workshops will be held in a conference room at the Center for Human Development at Beaumont Hospitals. The treatment will be 8 sessions long, with each session lasting 1.5 hours. The workshops are intended to address the potential distress involved with living and with raising a child diagnosed with autism, as well as to discuss how you might be able to live your life with more vitality and richness. This workshop offers an opportunity to gather with other parents of children diagnosed with autism and to learn new ways of coping with difficult

experiences. The workshop will be led by an advanced doctoral student (Ms. Kowalkowski) in clinical psychology with several years of experience studying and practicing techniques helpful in dealing with distressing experiences and improving quality of life. Over the course of the treatment, participants will hear lectures, apply newly-learned coping strategies to their individual concerns, clarify their individual values and goals, and have the option to share their experiences with one another if they so choose. The workshop itself will be experiential, emotional at times, and supportive. Experience with similar workshops in the past has indicated that many participants become aware of important ways in which their lives are not moving in the directions they intend, and how to change that. We hope to create a sense of alliance, optimism, and an increased ability to meet life's many challenges.

If you are assigned to the parental support group, you will participate in the same telephone screening and assessment batteries as the ACT group. The difference will be in the treatment that you will receive.

*Support group:* Support groups have been utilized for many years to assist individuals undergoing a wide array of life's struggles. In this research project, individuals who participate in this group will be provided with 8 weeks of 1.5 hour support group meetings facilitated by a trained mental health professional. The groups will be largely parent-led, as the topics and primary dialogue will be focused around what the group selects. The facilitator will work to create an environment that is open, honest, free from criticism, and hopefully a place where participants can learn and grow from each other's experiences.

5. **Possible Benefits of Participating:** If you participate in either of the two groups, you may benefit from the experience shared by the investigator, Ms. Kowalkowski, and her mentor, Dr. James Todd, who have worked with children with autism spectrum disorders and their families for many years. All participants will receive free access to a supportive group environment with peers who have experienced similar life circumstances (e.g., parenting a child with autism) regardless of their group assignment. If you are selected to participate in the ACT-based workshops, you may see reductions in any emotional distress experienced as a result of parenting stress, as well as some additional coping skills to manage stress and difficult emotions. There will also be some expected benefits to study of psychology/society in general. Although children with autism are a heavily studied population with significant resources spent on treatment outcome research, their caregivers have not received the same degree of support within the research community. The results of this research will serve to further the nature of treatments offered to families who are having difficulty with the experience of living with and raising a child with autism.
6. **Possible Risks of Participating:** Due to the group-based nature of the treatments, it is possible that some participants may feel embarrassment or discomfort associated with the discussion of private events in front of others; however, all participants will be asked to maintain confidentiality of information shared within the group. There is also a potential risk that participants may react to the interventions with sadness or despair over perceived personal failings, lost opportunities as a parent, and conflictual relationships within the family. However, in the previous research using support groups and ACT-based interventions with this population, participants reported that the activities associated with treatment were generally positive. Even so, the researcher and her supervisors will be prepared for potential adverse issues.
7. **Usage and Storage of Research Results:** The results of the study will become Ms. Kowalkowski's Doctoral Dissertation, and may be published in journals or other academic outlets, discussed as cases in college-level courses, or presented at conferences. Your participation will be kept confidential, and any presentation or publication of the findings will not identify you or your child. When presenting this data, your participation will be de-identified using an alternate name or number. All data will be stored in a locked file cabinet by the Principal Investigator, with all identifying information removed. All testing protocols will be kept at the Center for Human Development in a locked research file and will not leave the building. Data stored on computers will also be de-identified using an alternate name or number.
8. **Alternative Treatments Outside of the Study:** There is currently no "gold standard" treatment for dealing with the stress associated with raising a child with autism, or of raising children with special needs more generally. The "treatment as usual" group represents a version of a typical support group offered to parents

by some community agencies. Another avenue for treatment of parental stress would be more formal individual or group psychotherapy, generally to treat a specific disorder such as anxiety or depression. Participants are asked not to undergo additional skills-based or psychological treatments related to parenting behaviors during the course of this research study, although the use of pharmacological treatments is permissible. Should any new findings regarding the procedures under investigation come up during the course of this study, Ms. Kowalkowski will discuss them with you as appropriate.

9. **Videotape Consent:** The content of each session will be recorded using a video camera. The tapes will be reviewed by the experimenter and a research assistant following the intervention for purposes of assessing the aspects of the intervention delivered (e.g., the therapist's adherence to the treatment manual throughout the course of the workshops). As with all information related to participant's identity in this study, the videotapes will be kept in a locked file cabinet and only reviewed in a confidential setting for the purposes stated here. After the necessary treatment adherence data has been collected, the videotapes will be destroyed. Participation in this study requires the authorization for this videotape consent.
10. **Study Contact Information:** Any questions or comments about the study may be directed to Jennifer Kowalkowski (248-974-6737/ [jdelane3@emich.edu](mailto:jdelane3@emich.edu)) or Professor James Todd (734-487-0376/[jtodd@emich.edu](mailto:jtodd@emich.edu)). Each may be written at: Eastern Michigan University, Department of Psychology, Ypsilanti, Michigan, 48197.

This research protocol and informed consent document has been reviewed and approved by the Eastern Michigan University Human Subjects Review Committee for use from 2/04/2011 to 3/04/2012. If you have questions about the approval process, please contact Dr. Deb de Laski-Smith (734.487.0042, Interim Dean of the Graduate School and Administrative Co-Chair of UHSCR, [human.subjects@emich.edu](mailto:human.subjects@emich.edu)).

If you have read and understood the above and will give your permission to participate, please provide your name, date, and signature below. By doing so, you are giving informed and voluntary consent.

Please check the following:

- I agree to participate in the study.**
- I do not agree to participate in the study.**
- I agree to the required videotape consent during the study.**
- I do not agree to the required videotape consent during the study.**

\_\_\_\_\_  
Name (Please Print)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Principal Investigator/Date

**Appendix G: ACT Group Supplemental Handouts**

**Values Assessment Form**

**Describe your personal values below**

**Reasons that values are not being lived**

## Acceptance and Commitment Therapy (ACT): Take Home Tips & Techniques

### Defusion Techniques

Leaves on a stream  
 Repetition (e.g., milk, milk, milk)  
 “I’m having the thought that…”  
 Hearing thoughts in silly voices or accents  
 Saying thoughts super fast or super slow  
 Thank your mind

### Helpful Questions For Unhelpful Thoughts

Is this thought in any way useful or helpful?  
 Is this an old story? Have I heard this one before?  
 What would I get for buying into this story?  
 Could this be helpful, or is my mind just babbling on?  
 Does this thought help me take effective action?  
 Am I going to trust my mind or my experience?

### Contact With The Present Moment

- Any mindfulness exercise, e.g. breath, stretching, sounds, food
- Notice your feet on the floor; your body; your breathing etc.
- 5-5-5 technique: Notice 5 things you can: hear, see, feel - right now

### Things to Remember About Acceptance

- Acceptance = willingness = mindfulness
- Cultivate willingness to feel unpleasant emotions in order to do something of value
- Discriminate willingness from tolerating/ resignation
- You don’t have to like it, want it, approve of it, in order to accept it.
- Acceptance = making peace, letting go of the struggle
- Demons on the Boat/Passengers on the Bus

### Acceptance of Difficult Content

- Mindfulness of physical sensations
- Observe; Breathe; Expand; Allow
- Pick the strongest sensation; observe it like a scientist – non-judgmentally, without trying to interfere; accept it; repeat with next sensation etc
- Visualize feelings as objects: shape, color, weight, temperature, texture etc.

- I'm having a feeling of ...
- This is a feeling of \_\_\_ and I'm evaluating it as \_\_\_

### Values & Committed Action

- What do you really want?
- What do you want your life to stand for?
- What sort of person do you want to be?
- What sort of relationships do you want to build?
- How do you want to act/ behave in the world/ towards others/ towards yourself?
- What do you want to do with your life?
- Funeral / Tombstone / Obituary
- Values first - then goals/actions

### A Few Additional Words on Acceptance

**“You don't have to like it, want it, or approve of it – simply ...  
The Basic Mindfulness ‘Formula’**

Start with focusing on an ‘anchor’ such as the breath or body. Then shift focus to another aspect of experience, e.g. sounds, or thoughts. Then expand focus to become simultaneously aware of multiple aspects of experience, e.g. sounds, thoughts, sensations, breathing, and body posture.

- Find a comfortable position, feet on the floor, back straight, shoulders loose,
- Close your eyes, or fix them on a non-distracting spot
- Make it your intention for the next few minutes to purely and simply be present, here and now – and to notice what is happening, with an attitude of openness and curiosity.
- Bring your awareness to X.
- Simply notice X without judging it, analyzing it, fighting it or trying to change it.
- Observe X with curiosity. Learn as much about X as you can.
- As you maintain your attention on X, thoughts will come into your awareness.
- Allow them to come & go freely, as they please. Don't try & hold on to them or push them away. Simply acknowledge their presence, let them be, and bring your attention back to X.
- From time to time, urges, feelings and sensations will probably arise. When they do, simply acknowledge them, and let them be. Make room for them. Let them stay, or come & go freely, as they please. Don't try & hold on to them or push them away.
- From time to time your attention will “wander off.” As soon as you realize this has happened, gently acknowledge it, briefly note what distracted you, and bring your attention back to X.
- There is no need to be disappointed or frustrated. Our attention naturally wanders.
- Each time you notice your attention has wandered, simply note what distracted you, and gently bring your attention back to X.
- Remember, you are learning a valuable skill so be gentle with yourself. If your attention wanders 1000 times, your aim is simply to bring it back 1000 times.
- Now bring your attention to Y (Repeat previous instructions as desired.)
- Now bring your attention to Z
- Now notice X and Y and Z, all at the same time.

- Now notice where you are, what you're doing, and everything you're aware of; then open your eyes and connect with the room around you, and hold onto that sense of being present, here and now.

### Accepting Emotions

- When you're feeling an unpleasant emotion, the first step is to take a few slow, deep breaths, and quickly scan your body from head to toe.
- You will probably notice several uncomfortable sensations. Look for the strongest sensation – the one that bothers you the most. For example, it may be a lump in your throat, or a knot in your stomach, or an ache in your chest.
  - Focus your attention on that sensation. Observe it curiously, as if you are a friendly scientist, discovering some interesting new phenomenon.
- Observe the sensation carefully. Notice where it starts and where it ends. Learn as much about it as you can. If you had to draw a line around the sensation, what would the outline look like? Is it on the surface of the body, or inside you, or both? How far inside you does it go? Where is the sensation most intense? Where is it weakest? How is it different in the centre than around the edges? Is there any pulsation, or vibration within it? Is it light or heavy? Moving or still? What is its temperature?
- Take a few more deep breaths, and let go of the struggle with that sensation. Breathe into it. Imagine your breath flowing in and around it.
- Make room for it. Loosen up around it. Allow it to be there. You don't have to like it or want it. Simply let it be. The idea is to observe the sensation – not to think about it. So when your mind starts commenting on what's happening, just say 'Thanks, mind!' and come back to observing.
- You may find this difficult. You may feel a strong urge to fight with it or push it away. If so, just acknowledge this urge, without giving in to it. (Acknowledging is rather like nodding your head in recognition, as if to say 'There you are. I see you.') Once you've acknowledged that urge, bring your attention back to the sensation itself.
- Don't try to get rid of the sensation or alter it. If it changes by itself, that's okay. If it doesn't change, that's okay too. Changing or getting rid of it is not the goal.
- You may need to focus on this sensation for anything from a few seconds to a few minutes, until you completely give up the struggle with it. Be patient. Take as long as you need. You're learning a valuable skill.

\* \* \*

- Once you've done this, scan your body again, and see if there's another strong sensation that's bothering you. If so, repeat the procedure with that one.
- You can do this with as many different sensations as you want to. Keep going until you have a sense of no longer struggling with your feelings.
- As you do this exercise one of two things will happen: either your feelings will change - or they won't. It doesn't matter either way. This exercise is not about changing your feelings. It's about accepting them.

## Informal Mindfulness Exercises

### 1) Mindfulness in Your Morning Routine

- Pick an activity that constitutes part of your daily morning routine, such as brushing your teeth, shaving, or having a shower.
- When you do it, totally focus on what you are doing: the body movements, the taste, the touch, the smell, the sight, the sound etc.

For example, when you're in the shower, notice the sounds of the water as it sprays out of the nozzle, and as it hits your body as it gurgles down the hole. Notice the temperature of the water, and the feel of it in your hair, and on your shoulders, and running down our legs. Notice the smell of the soap and shampoo, and the feel of them against your skin. Notice the sight of the water droplets on the walls or shower screen, the water dripping down your body and the steam rising upwards. Notice the movements of your arms as you wash or scrub or shampoo.

When thoughts arise, acknowledge them, let them be, and bring your attention back to the shower.

Again and again, your attention will wander. As soon as you realize this has happened, gently acknowledge it, note what distracted you, and bring your attention back to the shower.

### 2) Mindfulness of Domestic Chores

Pick an activity such as ironing clothes, washing dishes, vacuuming floors, and do it mindfully. E.g., when ironing clothes: notice the color and shape of the clothing, and the pattern made by the creases, and the new pattern as the creases disappear. Notice the hiss of the steam, the creak of the ironing board, the faint sound of the iron moving over the material. Notice the grip of your hand on the iron, and the movement of your arm and your shoulder. If boredom or frustration arises, simply acknowledge it, and bring your attention back to the task at hand. When thoughts arise, acknowledge them, let them be, and bring your attention back to what you are doing. Again and again, your attention will wander. As soon as you realize this has happened, gently acknowledge it, note what distracted you, and bring your attention back to your current activity.

### 3) Take Ten Breaths

1. Throughout the day, pause for a moment and take ten slow, deep breaths. Focus on breathing out as slowly as possible, until the lungs are completely empty, and breathing in using your diaphragm.
2. Notice the sensations of your lungs emptying and your ribcage falling as you breathe out. Notice the rising and falling of your abdomen.
3. Notice what thoughts are passing through your mind. Notice what feelings are passing through your body.
4. Observe those thoughts and feelings without judging them as good or bad, and without trying to change them, avoid them, or hold onto them. Simply observe them.
5. Notice what it's like to observe those thoughts and feelings with an attitude of acceptance.

### Barriers to Action

**F** fusion with your thoughts  
**E** evaluation of your experience  
**A** avoidance of your experiences  
**R** reason giving for your behavior

**A** accept your reactions and be present  
**C** choose a valued direction  
**T** take action toward that direction

### Mindful Moments

Every moment there is an opportunity to be present, notice, be in the now! We can call it lots of different things but generally what we are talking about is paying attention or connecting with what we are doing. In this way we can increase our awareness and get more out of life.

As Jon Kabat-Zinn defines it, mindfulness is *'paying attention in a particular way: on purpose, in the present moment and non-judgmentally'* (Kabat-Zinn, 1990).

Here are some suggestions that you might like to try:

Pay attention to your **breathing**, nothing else, just breathing in and out.

Notice **sounds** around you. What can you hear right now?

Notice what you can **feel**, e.g. the feeling of your clothes, air on your skin, hair on your forehead, your back against the chair you are sitting in and so on.

Really **listen to your friend** or whoever you are talking to!

**Hear the music** or radio or TV and really connect with the words. Switch off other distractions (do you really need to have the radio and TV on as well as chat to someone?)

**Taste your food** like it is the first time you have eaten. What are the flavors? You can also take in the smells and the colors, textures of the food. Take your time to eat rather than gobble it down quickly!

**Read slowly** and aim to increase your focus when you read. Turn off other sounds and each time your mind wanders away from what you are reading gently bring your attention back to what you are reading. With practice your concentration will improve just like doing exercise makes us fitter.

Pay attention whilst you **brush your teeth or shave or have a shower**. Choose an everyday routine activity that you will be practice doing with greater awareness.

**Walk with purpose** and notice what you see and hear and smell. You can also really connect with your body. How does it feel when you walk? What muscles do you notice? Are they telling you something? (you can also do this with **any form of physical activity**).

Pay attention when you **drive**. Other motorists will thank you for it! Do you often see driving as a waste of time? Just a way to get somewhere? Do you often get impatient or angry when driving? It might be useful to see if you can notice your mind chatting away and stay focused on just driving!

**Wash up or iron** and just focus on this! Household chores such as these we can think of as boring or getting in the way of more fun activities. And yet aren't these activities part of life? Do they go away because we wish they would?!?! When you are washing up, just wash up! Feel the soapy warm water and take care as you wash the dishes!

### **The Willingness-and-Action Plan**

My goal is to

The values underlying my goal are

Thoughts, feelings, sensations, urges I'm willing to have (in order to achieve this goal):-

- Thoughts:
- Feelings:
- Sensations:
- Urges:
- It would be useful to remind myself that
- I can break this goal down into smaller steps, such as
- The smallest, easiest step I can begin with is
- The time, day and date that I will take that first step, is

## Appendix H: Recruitment Documents

Dear Parent,

As you know, raising a child diagnosed with autism can be challenging. Living a rich and vital life is often difficult even for those faced with the everyday responsibilities of raising typically-developing children. Leading such a life with the added responsibility of a child diagnosed with autism may seem unrealistic, but it does not have to be!

We are seeking mothers of children diagnosed with autism to participate in one of two free group-based workshops specifically for parents of children diagnosed with an autism spectrum disorder. After an initial phone call to determine eligibility, mothers will be invited randomly to join one of two different groups. The first is a support group facilitated by a mental health professional. This group will meet for 8 weeks (1.5 hour sessions) with approximately 7-9 other women to share their experiences and learn and grow from one another. The other group will address the potential distress involved with living and with raising a child diagnosed with autism in a slightly different way. This workshop is an opportunity to gather with other parents of children diagnosed with autism and learn new ways of coping with difficult experiences and perhaps more importantly, address how you might be able to live your life with more vitality and richness. This workshop will be led by an advanced doctoral student (Ms. Jennifer Kowalkowski) in clinical psychology with several years of experience studying and practicing techniques helpful in dealing with distressing experiences and improving quality of life. Over the course of the eight weekly sessions, participants will hear lectures, apply newly-learned coping strategies to their individual concerns, clarify their individual values and goals, and have the option to share their experiences with one another if they so choose. This workshop will be experiential, emotional at times, and supportive. Our intention *for both groups* is to create a safe environment, free of criticism and evaluation, and rich with acceptance and willingness to listen.

Both of these workshop series will be held at weekly at Beaumont Hospital's Center for Human Development in Berkley, Michigan. The first set of sessions are scheduled to be held on Saturdays mornings from March 19 to May 7 for both the coping workshop and the support group. This initial offering will be followed by another series of workshops beginning in mid April and offered on a weeknight.

The workshops are being offered as part of a dissertation research project, and as such, are free. Participants will be asked to fill out several questionnaires on three separate occasions (before the group, within a few weeks following the group, and approximately 3 months following the group). These questionnaires should take between 60 minutes and 90 minutes to complete on each occasion. You will be compensated with a **\$10 gift card (\$10 for each completed assessment battery)** for the time you devote to completing this portion of the research project. Your participation has the potential to help you cope more effectively and live a more fulfilling life, and also will provide information that could help psychology better

understand the circumstances faced by parents of children diagnosed with autism--and better understand how to help such parents face these circumstances.

If you would like to know more about the nature of the workshop, about the questionnaires, or about the qualifications of the workshop leaders, please do not hesitate to call, write, or e-mail Jennifer D. Kowalkowski (the workshop leader and the doctoral student conducting the research project). **If you would like to participate in the workshop, please contact Jennifer D. Kowalkowski at 248-974-XXXX as soon as possible to set up a time to determine your eligibility for this exciting project.**

We earnestly hope you take advantage of this opportunity, and look forward to the chance to meet you.

Sincerely,

Dr. James T. Todd  
Professor  
Department of Psychology  
Eastern Michigan University  
Ypsilanti, MI 48197  
(734) 487-XXXX  
email: jtodd@emich.edu

Jennifer D. Kowalkowski  
Doctoral Candidate  
Department of Psychology  
Eastern Michigan University  
(248) 974-XXXX  
e-mail: jdelane3@emich.edu

### Listerv Recruitment Statement

Are you a parent? Do you feel stressed sometimes? Of course you do... Feeling stressed is a normal reaction for any parent, even more so when parenting a child diagnosed with an autism spectrum disorder. You DESERVE to do something for yourself! Call today to find out if one of our FREE group workshops will be a good fit for you.

We are recruiting mothers of children diagnosed with autism to participate in research study investigating parental stress. If you are eligible, you will be assigned to one of two workshop styles; one is a support group with a facilitator and the other is a coping skills workshop which will focus specifically learning new ways to cope with the difficult experience of caring for a child with autism. Participants will also be compensated with a \$10 gift card for each of the 3 assessment batteries they will be asked to complete in order to help the researchers understand the findings. Groups begin March 19<sup>th</sup> and run for 8 weeks at Beaumont Hospitals Center for Human Development. For more details, contact Jennifer Kowalkowski at (248)- 974-XXXX or send an email to [autismstresstudy@gmail.com](mailto:autismstresstudy@gmail.com)



## RESEARCH OPPORTUNITY



**Please pass this information on to anyone who might benefit from this opportunity for FREE therapeutic support.**

We are recruiting mothers of children diagnosed with autism (ages 2-10) to participate in research study investigating parental stress through Eastern Michigan University.

If eligible, participants will be assigned to one of two workshop styles; one is a support group with a facilitator and the other is a coping skills workshop (using Acceptance and Commitment Therapy), which will focus specifically learning new ways to cope with the difficult experience of caring for a child with autism.

Participants will also be compensated with a \$10 gift card for each of the 3 assessment batteries they will be asked to complete in order to help the researchers understand the findings.

*The first wave of groups will begin March 19<sup>th</sup> and run for 8 weeks at Beaumont Hospital's Center for Human Development in Berkley, MI.*

## Initial Participation Contact Letter

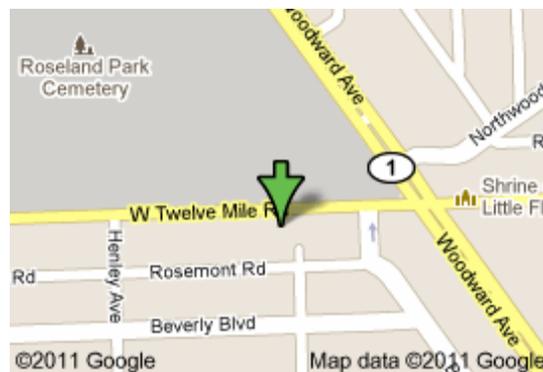
Thank you again for your participation in our study! Enclosed please find additional information on your group assignment, locations and times for meetings, and informed consent form, a number of psychological measures to complete, and a stamped envelope to return the materials. We ask that you complete the assessments at your earliest convenience and return them prior to the beginning of the group sessions. Once your assessment packet has been received, the researchers will mail out your \$10 gift card (one per assessment administration). You can make your selection of where your gift card is purchased from on an enclosed form.

*Informed Consent:* Because these workshops are provided as part of an ongoing research project, included in this packet is an informed consent form. It is important that you read this document thoroughly. If you feel comfortable with the information provided, please sign and return to the researcher. If you have questions or concerns, please contact the researcher (248-974-XXXX).

*Group Assignment:* ACT-based Coping Skills Group

*Group Dates/Times:* Thursdays 6:30-8:00pm

**Apr 14, Apr 21, Apr 28, May 5, May 12, May 19, May 26, Jun 2**



### *Group Location:*

Berkley Medical Center (on 12 Mile Road west of Woodward Ave.)

Center for Human Development 248-691-4744

1695 W. Twelve Mile Road Berkley, MI 48072.

Lower Level, Suite # 120 (enter through West Side of the Building).

Please tell the receptionist you are participating in the Autism Stress Study