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Trauma-Informed Mindfulness-Based Stress Reduction to Increase

Family Quality of Life for Mothers of Children with Autism:

A Pilot Study

Carol May Vaughn

A thesis submitted to the faculty of Brigham Young University in partial fulfillment of the requirements for the degree of

**Educational Specialist** 

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Department of Counseling Psychology and Special Education

Brigham Young University

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# ABSTRACT

# Trauma-Informed Mindfulness-Based Stress Reduction to Increase Family Quality of Life for Mothers of Children with Autism: A Pilot Study

# Carol May Vaughn Department of Counseling Psychology and Special Education, BYU Educational Specialist

Mothers of children with autism have a higher rate of stress than mothers of neurotypical children and mothers of children with other disabilities. This impacts their family quality of life. This study aimed to show that by teaching mothers trauma-informed mindfulness-based stress reduction techniques they were able to switch their perspectives and feel that they had increased the relationships with their child with autism and increased the rating they give their family quality of life. The participants were recruited using word of mouth and through distribution of posters to autism communities following approval of the experiment through the institutional review board (IRB). The participants selected were mothers of children with autism. They interacted with the researcher through Zoom. They completed multiple measures to assess their levels of stress, well-being, mindfulness, and family quality of life. Measures included daily stress self-report, Freiburg Mindfulness Inventory-14 (FMI-14), Beach Center Family Quality of Life (FQOL), and a semi-structured interview. This was a multiple baseline study. Data analysis included visual analysis and changepoint analysis.

Mothers of children with autism who utilized mindfulness, defusion, and traumainformed problem-solving resulted in consistently decreasing levels of stress throughout the intervention. Family quality of life increased, especially in the areas of financial well-being and parenting. The mothers reported the most benefit in the practice of defusion and the least benefit from trauma-informed problem-solving.

The research done in this experiment merits further study, especially in the areas of mindfulness and defusion. A larger sample size should be used to identify the benefits more closely from each phase and to identify the impact of a less homogeneous group of people. It can then be generalized to other parents of children with special needs.

Keywords: trauma-informed, mindfulness-based stress reduction, autism, family quality of life

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#### CHAPTER 1

#### Introduction

Parenting a child with a developmental disorder increases the difficulty of raising children. Mothers of children with autism often feel more stressed than parents of children with other developmental disorders (Hayes & Watson, 2012). The increase in stress for the mother invariably increases the stress felt by the child, which often leads to increased maladaptive behavioral displays (Davis, 2015). The prevalence of autism is currently 1 in 36 (Maenner et al., 2023) With this rise in the number of children diagnosed with autism, we can expect an increase in the prevalence of parental stress.

Increased stress affects the perceived family quality of life (FQOL). FQOL is the orientation of the individual's well-being interacting with the orientation of the family well-being (Poston et al., 2003). Goodman and Glenwick (2012) pointed out that a large body of research regarding child–parent attachment has occurred, but relatively little parent–child research has been conducted. A study by Sakaguchi and Beppu (2007) showed that mothers of preschool-aged children with autism reported a greater lack of attachment behaviors than mothers of preschool-aged children with other disabilities. Goodman and Glenwick (2012) studied the factors affecting the affective attachment of parent to child and found that their perceptions of child functional impairment, and if they felt the child was attached to them, significantly impacted their parenting stress and sense of parenting competence. An intervention that comes to mind for decreasing parent stress is mindfulness-based meditation.

Mindfulness-based stress reduction (MBSR) has been shown to be an effective tool in dealing with anxiety and chronic pain (Hoge et al., 2013; Morone et al., 2008). A key component of this treatment is mindfulness-based meditation. Meditation is the act of focusing on the breath

and letting thoughts come and go. It strives to bring the person into present-moment awareness and can be done sitting, standing, or walking (Morone et al., 2008). This flexibility of utility allows meditation to be a tool that can be used by anyone, anywhere.

The approach for mindfulness used in this study was to mingle trauma-informed interventions with mindfulness. A trauma-informed intervention has three primary components: regulate, relate, and reason (Donnelly et al., 2021). These three concepts were expanded within each individual phase of the experiment. *Regulate* means the regulation of the body, which was accomplished through mindfulness. *Relate* is examining one's relationship with the emotion which was done through defusion. *Reason* is the use of problem-solving to either reinforce or avoid different situations (Donnelly et al., 2021).

Mindfulness focuses the mind on one thought—typically the breath. This is one method of regulation. The use of mindfulness helps the body by regulating the autonomic nervous system response (Kox et al., 2012). When engaged, cortisol levels (the "stress" hormone) have been shown to be lower, which indicates that a person is no longer in "fight or flight" mode or feeling high stress (Turakitwanakan et al., 2013). Once the body is out of fight-or-flight, the brain is better able to act rather than to react and to examine the mind's state-of-being. This examination can be done through defusion.

The second component, relate, encompasses how the mother relates with her concept of self and the words she uses to describe herself. Defusion, which is based in relational frame theory (RFT; Hayes & Watson, 2012), was used as part of the relate portion of the study. Practicing defusion helps mothers examine the relationship they have with their emotions and to create separation between what they feel and how they identify themselves. When the mothers can separate identity from emotion, this can assist them to better problem-solve because they are

able to let go of ideas of "bad mother" or "bad child" and instead view themselves or their children as "mother with a bad moment" or "child with a bad moment."

While mindfulness focuses on present-moment awareness and defusion focuses on a person's relationship to their emotions, reason focuses on problem-solving for the future. Decision-making theory (Kording, 2007) indicates that the primary function of the central nervous system is to make optimal decisions based on the environment, known outcomes for specific decisions, and resources available. A related sub-theory of Kording (2007) is the inverse decision-making model. Basically, this decision-making model focuses on exceptions to previous outcomes for specific decisions.

These theories are significant because of the impact trauma has on our decision-making process. One study indicated that mothers of children with autism experience trauma due to physical assaults by their children including being bitten, having ribs broken, and being beaten (Stewart et al., 2017). Carmassi et al. (2020) discuss the psychological impact on long-term caregivers of children and young adults with a severe, disabling, or life-threatening disease. Diseases and conditions include, but are not limited to, cancer, diabetes, seizures, and autism. Their findings indicate an increased incidence of post-traumatic stress disorder (PTSD) in parents of children with chronic, long-term, or terminal conditions (Carmassi et al., 2020). In addition to PTSD, Carmassi noted post-traumatic stress symptoms (PTSS) which include "intrusion symptoms, persistent avoidance, negative alterations in cognitions and mood, alterations in arousal and activity" (Carmassi et al., 2020).

In addition to the physical trauma some parents of children with autism experience, there is the incidence of emotional trauma that can be just as difficult to manage. Stewart et al. (2017) surveyed several parents to ascertain their perceived level of trauma. Of those surveyed, 40%

indicated that they experienced trauma while the other 60% indicated that they did not. However, those 60% who say they did not experience trauma still exhibited trauma-related symptomology (Stewart et al., 2017). Even if the mothers do not recognize traumatic events, they are still exhibiting trauma responses which indicates to the researcher the need for using a trauma-informed approach to the experiment. By using a trauma-informed method of decision-making, mothers of children with autism can gain greater control and perspective on their decision-making efforts.

#### **Statement of the Problem**

Studies have shown that parents of children with disabilities experience lower family quality of life satisfaction. Families with children whose specific disability is autism experience even lower satisfaction rates than those with children with other disabilities. As noted in the literature review, mothers of children with autism tend to experience higher levels of stress than mothers of children with other disabilities (Carmassi et al., 2020; Stewart et al., 2017). Children with autism can experience difficulties with communication and emotional regulation. In addition, supports for families with children with autism can be either difficult to find or expensive to implement. These are both contributing factors to increased parental stress (Dykens et al., 2014).

Despite knowing that raising a child with a disability increases stress (Carmassi et al., 2020), little has been researched to show effective tools for coping with that stress. Meditation is a tool that has been shown to help reduce general stress (Oman et al., 2008). The primary goal of this current study is to determine if meditation can decrease parental stress and increase perceived FQOL. A secondary question is whether increasing perceived FQOL also increases the parent's sense of attachment to the child with autism. And, finally, the tertiary question is

whether using trauma-informed interventions will allow the mother to feel a sense of control as she navigates parenthood.

# **Statement of the Purpose**

The purpose of this pilot study was to examine the effects of trauma-informed mindfulness-based stress reduction on the family quality of life for mothers of children with autism. A pilot study helps determine if an experiment would be feasible and how it should be conducted. Pilot studies are typically conducted with significantly smaller sample sizes (In, 2017).

# **Research Questions or Research Hypotheses**

This study addressed the following research questions:

- Does meditation decrease parental stress and thereby increase perceived family quality of life (FQOL)?
- 2. Does increasing perceived FQOL also increase the parent's sense of attachment to the child with autism?
- 3. Does using trauma-informed interventions allow the mother to feel a sense of control as she navigates parenthood?

#### **CHAPTER 2**

### **Review of Literature**

Parenting is hard. Parenting a child with a developmental disorder increases that difficulty. Mothers of children with autism often struggle with feeling more stressed than parents of children with other developmental disorders (Dumas et al., 1991). Sadly, the increase in stress for the mother invariably increases the stress felt by the child, which often leads to increased maladaptive behavioral displays (Davis, 2015). It is a vicious cycle in which no one wins. Added to this stress is the increase in autism diagnoses. In the 1970s, 1 in 2,500 people were diagnosed with autism. By the 1990s, that number had risen to 1 in 250 (DeFrancesco, 2001). More recently, that number has increased to 1 in 36 (Maenner et al., 2023) With this rise in diagnosis, we can expect an increase in the prevalence of parental stress.

Increased stress affects the perceived family quality of life (FQOL). FQOL is the orientation of the individual's well-being interacting with the orientation of the family well-being (Poston et al., 2003). It can be observed in four domains: daily family life, parenting, family interaction, and financial well-being (Poston et al., 2003). Because the orientation of the individual's perception of personal quality of life influences the perception of FQOL, families with members who have disabilities often score lower on FQOL than those without family members with a disability. For example, Brown et al. (2006) conducted a study measuring FQOL for families with children with autism and families with children with Down syndrome using nine measures for FQOL. On all but two measures (support from disability-related services and spiritual and cultural beliefs), parents of children with autism reported the lowest levels of FQOL. This study found that concerns of health, financial well-being, family relations, support from other people, careers and preparation for careers, leisure and enjoyment of life, and

community and civic involvement are worsened and stress increased due to the increased difficulties of navigating different social systems (such as school or healthcare) and preparing a child with autism for the future (Brown et al., 2006).

Goodman and Glenwick (2012) pointed out that quite a bit of research regarding child– parent attachment has occurred, but relatively little parent–child research has been conducted. A study by Sakaguchi and Beppu (2007) showed that mothers of preschool-aged children with autism reported a greater lack of attachment behavior than mothers of preschool-aged children with other disabilities. Goodman and Glenwick (2012) studied the factors affecting the affective attachment of parent to child and found that their perceptions of child functional impairment, and if they felt the child was attached to them, significantly impacted their parenting stress and sense of parenting competence. An intervention that may help in decreasing parent stress is mindfulness-based meditation.

Mindfulness-based stress reduction (MBSR) has been shown to be an effective tool in dealing with anxiety and chronic pain (Hoge et al., 2013; Morone et al., 2008). A key component of this treatment is mindfulness-based meditation. Meditation is the act of focusing on the breath and letting thoughts come and go. It strives to bring the person into present-moment awareness and can be done sitting, standing, or walking (Morone et al., 2008). This flexibility of utility allows meditation to be a tool that can be used by anyone, anywhere.

There are many ways to conduct mindfulness interventions. One method is to use traumainformed interventions mingled with mindfulness. A trauma-informed intervention has three primary components: regulate, relate, and reason (Donnelly et al., 2021). In this paper, *regulate* refers to the ability to regulate the body and includes a stable, at-rest breathing and heart rate. *Relate* refers to the ability to identify the dominant emotion after an intense emotional episode. *Reason* refers to the ability to problem-solve and make decisions for another, similar emotional episode.

Mindfulness focuses the mind on one thought—typically the breath. This is one method of regulation. The use of mindfulness helps the body by regulating the autonomic nervous system response (Kox et al., 2012). When engaged, cortisol levels—the "stress" hormone—have been shown to be lower, which indicates that a person is no longer in "fight-or-flight" mode or feeling high stress (Turakitwanakan et al., 2013).

Defusion, which is based in relational frame theory (RFT; Hayes & Watson, 2012), was used as part of the relate portion of the study. Defusion is the ability to recognize that the self and emotions, thoughts, or incidents in a person's life are separate. In a sense, it is the ability to put emotional distance between the self and a judgment. For example, instead of mothers saying that they are bad mothers, they instead said that they are mothers who had a bad moment. Practicing defusion can change the relationship mothers have with their emotions and assists them to better problem-solve if they can recognize that they as mothers and their children as children are not the problem.

While mindfulness is focused on present-moment awareness and defusion is focused on a person's relationship to their emotions, reason focused on problem-solving for the future. Decision-making theory (Kording, 2007) indicates that the primary function of the central nervous system is to make optimal decisions based on the environment, known outcomes for specific decisions, and resources available. A related sub-theory of Kording (2007), is the inverse decision-making model. Basically, this decision-making model focused on exceptions to previous outcomes for specific decisions.

These theories are significant because of the impact trauma has on our decision-making process. Mothers of children with autism undergo trauma. Stewart et al., had 12 mothers of children with autism report trauma-related symptoms (2017) including reports of the need to physically restrain a child for the safety of self, others, and the child. During restraint, multiple mothers reported being bitten, having ribs broken, and being beaten (Stewart et al., 2017). Carmassi et al. (2020) discuss the psychological impact on long-term caregivers of children and young adults with a severe, disabling, or life-threatening disease. Diseases and conditions include, but are not limited to, cancer, diabetes, seizures, and autism. Their findings indicate an increased incidence of post-traumatic stress disorder (PTSD) in parents of children with chronic, long-term, or terminal conditions (Carmassi et al., 2020). In addition to PTSD, Carmassi noted post-traumatic stress symptoms (PTSS) which include "intrusion symptoms, persistent avoidance, negative alterations in cognitions and mood, and alterations in arousal and activity" (2020, para 2). By using a trauma-informed method of decision-making, mothers of children with autism can gain greater control and perspective on their decision-making efforts.

#### **Autism Spectrum Disorders**

Autism spectrum disorders (autism) are neurodevelopmental disorders that affect social communication and behavioral routines. Some studies place prevalence of autism diagnosis at about 2% of the population (Maenner et al., 2023; Taylor et al., 2020). The *Diagnostic and Statistical Manual of Mental Disorders* (5<sup>th</sup> ed., Text Revision [DSM-5-TR]; American Psychiatric Association [APA], 2022) lists five major areas indicating possible autism in a client: (a) persistent deficits in social communication and social interaction across multiple contexts, (b) restricted, repetitive patterns of behavior, interests, or activities, (c) symptoms must be present in the early developmental period, (d) symptoms cause clinically significant impairment in social,

occupational, or other important areas of function, and (e) these disturbances are not better explained by an intellectual disability or global developmental delay. Intellectual disability and autism often co-occur (APA, 2022).

Because each person is unique, each case of autism may not present the same way or with the same level of severity, which is why autism is considered a spectrum disorder. Some children may only present mild impairment in social situations while maintaining severe repetitive behaviors, or they may have only minor impairments in each of these areas. In addition, current studies suggest that biological sex may play a role in presentation of autism (Wilson et al., 2016). Currently, boys are four times more likely to be diagnosed than girls, but girls' delays may be unrecognized due to subtler manifestations of their traits (APA, 2022).

Some might wonder why so much time and resources are spent researching a disorder affecting 2% of the population. Two primary reasons are that the rate of diagnosis of autism is increasing (Maenner et al., 2023; Taylor et al., 2020) and that families of children with autism experience more stress than families with children who develop typically (Gunty, 2020). Research in this area has been two-pronged: discover what causes autism and discover how to mitigate the stressors caused by family members with autism. This study focused on the latter.

# **Mindfulness-Based Stress Reduction Interventions**

Many religions have used some form of meditation as part of their practice (e.g., Buddhism, Hinduism, Taoism, Stoicism). Even those that do not formally call it meditation have injunctions to "be still," as can be found in religious texts for Christianity and Judaism. Mindfulness (another name for meditation) did not become used as a scientific tool until the late 1970s, when Dr. Jon Kabat-Zinn created his stress reduction intervention called mindfulnessbased stress reduction ([MBSR] Kabat-Zinn; 2003). Since then, many cognitive behavioral forms of therapy have included some form of mindfulness.

Fletcher and Hayes (2005) have noted that "there is no agreed-upon definition of mindfulness in psychology" (p. 91). Definitions range from regulating attention to orienting oneself to the present moment to having a flexible state of mind. For this paper, the researcher used the acceptance and commitment therapy (ACT) definition of mindfulness, which is "the psychological processes of contact with the present moment, acceptance, defusion, and self as context that result in increased flexibility to behave according to values" (Fletcher & Hayes, 2005, para 25).

Another way of describing the psychological processes of contact to the present moment would be to call it paying attention to the now. Skinner (1965) defined attention as a controlling relation—the relation between a response and a discriminative stimulus. The old saying "making mountains out of molehills" points out that when we give our attention to something, we inevitably make it larger or more serious than it really is. MBSR and ACT focus on changing attention from the stimuli to the present moment. This allows a person to step out of the problemsolving section of their brain and focus on the existing part of the brain.

Acceptance in ACT is accepting that we have emotions and that they are present in every circumstance and being willing to give room and observe those inner events with curiosity (Fletcher & Hayes, 2005). By moving into acceptance, mothers of children with autism can move to the next step, which is defusion.

Defusion is the act of unlinking our person from our thoughts and feelings. It allows us to let go of unwanted or distressing private events and to view them as facts or events that have happened and not as judgment on our character or choices (Fletcher & Hayes, 2005). In theory, mothers of children with autism can let go of judgements that cause division or stress and allow them to move into areas of acceptance and connection by practicing defusion. It can also help them to move into self as context.

Self as context is the ability to recognize that the story we tell about ourselves is not necessarily true (Fletcher & Hayes, 2005). We are beings who react to constantly changing environments, and our ability to observe our self allows us to better identify patterns of behavior and make changes where we desire those changes to be made (Fletcher & Hayes, 2005). By utilizing this type of metacognition, mothers of children with autism gained a more holistic and understanding perception of their self and of their children with autism.

#### **Family Quality of Life**

Family quality of life (FQOL) is considered relatively new as a field of research. It came as a natural outgrowth of the research into individual quality of life. Since the mid-to-late 1980s, the recognition of the importance of FQOL has been growing, especially as a predictor of the effectiveness of policy interventions (Poston et al., 2003). Because of how recent the research is, research into FQOL for those with disabilities is limited. In addition, Poston et al. found that families with children with disabilities tended to have more intense and more frequent concerns, impacting their FQOL rating (2003).

The Beach Center on Disability defines FQOL as how a person feels about their life with their family (Hoffman et al., 2006). They describe five major domains: family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support (Hoffman et al., 2006).

Family interaction is the way children and parents interact with one another (Hoffman et al., 2006). This includes how much the family enjoys spending time together, how often family

members talk openly with each other, and whether the family solves problems together. Each member of the same family has a unique experience within that family because each person interacts with the other differently. So, while a neurotypical brother may list the FQOL high in this area, the mother may rate this area lower because of the differences in interaction.

Parenting is how satisfied the parent or child is with the parent(s') role as parents (Hoffman et al., 2006). It includes components such as helping children with homework, helping children to be independent, and teaching children to make good decisions. Again, this area can change from family member to family member based on how valued each member feels in these categories.

Emotional well-being is focused on stress levels and abilities to relieve stress (Hoffman et al., 2006). It includes items about the family having the support they need to relieve stress, family members having friends or others who provide support, and each family member having time to pursue their own interests. This is another area which can be rated differently from person to person. Due to the types of roles that each family member takes upon themselves and to the types of interactions engaged in from person to person, this area may be rated as higher or lower depending on the person and their perception of how well they fell they are managing this aspect of their life.

Physical or material well-being is focused on physical needs and feelings of safety (Hoffman et al., 2006). It includes items about the family members having adequate transportation, feeling safe in their environment (whether at home, work, or school), and the ability to get medical care when needed. This is an area that may impact parents of children with disabilities more than parents of neurotypical children due to the higher need of support that children with disabilities tend to have and the need for parents to either spend more resources to get needs met than families with neurotypical children or the increased vigilance they may feel is required to keep their children safe.

The final domain, disability-related support, is an additional area that a family with neurotypical children would not use (Hoffman et al., 2006). It recognizes that differences in cognitive development can increase the amount of stress felt by a family. It includes items specific to the family member with special needs, such as that family member receiving support at work or at school, support at home, or having a good relationship with service providers who work with the family.

# **Trauma-Informed Care**

Trauma-informed assessment allows us to examine a person's function considering the trauma they may have experienced (Kerig, 2013). In the podcast *School Psyched!*, Dr. Julie Barta (2021) pointed out that all people have experienced trauma—just because the intensity is different does not mean that it is not trauma. Parenting children with autism presents unique stressors that parents of children with other disabilities may not experience and on a broader range because autism is a spectrum disorder (Stewart et al., 2017). These stressors for some parents have combined to shape a physiological profile like soldiers who experience post-traumatic stress disorder (PTSD; Dixon, 2021). This information indicates that mothers of children with autism may require treatment through trauma-informed services.

According to Elliott et al. (2005) trauma-informed services contain ten basic steps. The first step is to recognize the impact of violence and victimization on development and coping strategies. Second, identify recovery from trauma as a primary goal. Third, employ an empowerment model. Fourth, maximize choices and control over recovery. Fifth, delivery of services should be based on relational collaboration. Sixth, the therapist should create an

atmosphere that is respectful of the survivor's need for safety, respect, and acceptance. Seventh, emphasize strengths, highlighting adaptations over symptoms and resilience over pathology. Eighth, minimize the possibilities of re-traumatization. Ninth, strive to be culturally competent and to understand each woman in the context of her life experiences and cultural background. Finally, solicit consumer input and involve consumers in designing and evaluating services. These ten steps were summed up into the previously mentioned three words: regulate, relate, and reason (Barta, 2021).

A trauma-informed mindfulness-based stress reduction model (TIMBSR) showed promise in women who experienced interpersonal violence. In this study, women who had a history of interpersonal violence participated in an 8-week TIMBSR intervention or a waitlist control group. Those in the TIMBSR group experienced statistically and clinically significant decreases in depression and post-traumatic stress disorder (Kelly & Garland, 2016). The study also noted a direct correlation between increased mindfulness minutes and decreased PTSD symptoms (Kelly & Garland, 2016).

In conclusion, the literature indicates a need for parents of children with autism to have an accessible intervention they can engage in to assist them in parenting children who have a unique method of interacting with the world. By utilizing interventions that decreased stress and increased FQOL, parents may be able to experience increased attachment to their child with autism.

# **Definition of Terms**

Autism spectrum disorders (autism): neurodevelopmental disorders that affect social communication and behavioral routines.

Mindfulness-based stress reduction: a type of meditation therapy used to reduce the

experiences of stress, anxiety, depression, and pain.

Defusion: the ability to recognize that the self and emotions, thoughts, or incidents in a person's life are separate.

Family quality of life: how a person feels about their life with their family, subdivided into five main domains: family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support.

Trauma-informed problem-solving: a problem-solving technique that approaches the problem using a trauma-informed lens; regulate the body, relate the emotion, and reason through the problem.

#### **CHAPTER 3**

#### Method

The participants were selected randomly using word of mouth and through distribution of posters to autism communities following approval of the experiment through the institutional review board (IRB). There were no minors involved in this selection. Participants' informed consent was obtained prior to their participation in the experiment. The setting was in the participants' homes with the researcher interacting through Zoom, an online platform that allows for video and audio conferencing. The researcher never received the participants' home address, which allowed for a greater level of anonymity in the experiment, but which may compromise the homogeneity of the researchers used multiple measures to gather data—daily self-report of stress, Freiburg Mindfulness Inventory-14 (FMI-14), Beach Center Family Quality of Life (FQOL), and an informal semi-structured survey. The procedures involved sending daily emails for the participants to utilize the different measures and a link to download a mindfulness app (see Procedures for descriptions). This was a multiple baseline single subject case study. Data analysis includes visual analysis and changepoint analysis.

# **Participants & Setting**

Two pairs of mother-child dyads from Utah were used for this study. The children were between the ages of 2 and 6 years old and could speak a minimum of single word utterances. Children had a documented diagnosis/identification of autism, either medical or educational classification, and an individual education plan. Flyers were posted on social media, at a school specializing in autism and distributed through autism community email lists. Word of mouth was also used as those who heard of the study shared the opportunity with mothers of children with autism. Four participants were recruited with two completing the study. Initially, one was excluded due to use of medication, but this exclusion was later exempted. However, this participant did not continue the study for reasons not disclosed to the researcher. She discontinued contact with the research team. The other participant did not sign the consent form and was excluded as they also discontinued contact with the research team.

The purpose of this study was to work with people in non-clinical situations. Because of this, parents without significant comorbid psychopathology or who had not been under consistent treatment for mental health conditions for at least 6 months and who had access to a smartphone were included. Mothers needed to have at least one child diagnosed with autism. The child needed to be able to speak a minimum of 10 words. Mothers were included in this study if they had never done any mindfulness practices or mental health therapy or were inconsistent in mindfulness practice as defined by weekly or more regular breathing and emotional regulation or use of mindfulness apps to limit the possibility that these practices or treatments were the cause of improved perceived family quality of life. We used a variety of measures to gather data on the effects of TIMBSR on mothers of children with autism.

# Collette

Collette (no real names are used) was a working mother near the age of 30. She had multiple children who were attending school at the time of this study. She was married at the time of the study.

#### Eve

Eve was a stay-at-home mother around the age of 30. Her oldest child was 5 at the time of this study and attended kindergarten. She had other, younger children, but the number was never specified. She was married at the time of the study.

# Measures

Increased family quality of life is defined as a sense of well-being and positive regard for the status of the family, especially between mother and child. To determine if there was an increase in quality of life, mothers completed several measures. They completed the Beach Center FQOL survey (Hoffman et al., 2006), the FMI-14 (Walach et al., 2006), surveys checking on perceived stress levels and if they completed the intervention, and a voluntary informal interview following the intervention.

# **Beach Center Family Quality of Life**

Mothers completed the Beach Center FQOL (Hoffman et al., 2006) survey prior to receiving any interventions and after all interventions were completed. The Beach Center FQOL measures family functioning across five items: family interaction, parenting, emotional wellbeing, physical/material well-being, and disability related support.

In past studies, the Beach Center FQOL survey had a moderate overall satisfaction rating of  $X^2(5) = 9.13$ , p = .10, comparative fit index = .99, root mean square error of approximation = .06, x = .88 (Hoffman et al., 2006). Test–retest reliability was rated for each individual subtest. The correlations were all significant at the .01 level or beyond. The correlations between time points for importance were .54 for family interaction, .66 for parenting, .69 for emotional wellbeing, .41 for physical/material well-being, and .82 for disability-related support. The correlations between time points for satisfaction were .74 for family interaction, .70 for parenting, .75 for emotional well-being, .77 for physical/material well-being, and .60 for disability-related support (Hoffman et al., 2006). Convergent validity between the Beach Center FQOL subscales and the Family APGAR (acronym for adaptability, partnership, growth, affection, and resolve; Hoffman et al., 2006) was moderately correlated with the satisfaction mean for the Family Interaction subscale, r = .68 with a *p value* of .001 (Hoffman et al., 2006). Convergent validity between the Beach Center FQOL subscales and the family resource scale (Hoffman et al., 2006) was moderately correlated with the mean of the five items on the physical/material well-being subscale, which was most similar in content to the family resource scale, r = .60 with a *p value* of .001 (Hoffman et al., 2006).

The FQOL was assessed at pre– and post-intervention time points. To analyze outcomes and due to the small sample size, researchers used a Bayesian effect size estimation to identify the percentage of the control sample that would fall below each participant's score at pre- and post-intervention data points in the present study. The control sample (priors) was derived from a sample of parents of children with autism who previously completed the assessments found in Hsiao (2018) using the FQOL that had a sample size of 236. To do this, researchers used the SingleBayes.exe software described in Crawford et al. (2010). The control sample did not participate in a pre- and post-assessment.

# Freiburg Mindfulness Inventory

The mothers also completed a weekly FMI-14 (Walach et al., 2006) which was provided through Qualtrics for ease of collection and completion. In prior studies, the FMI-14 has been found to have an internal consistency of Cronbach *alpha* = .86 (Walach et al., 2006), which is moderately strong. The correlation between the FMI-14 and the State-Trait-Anxiety-Inventory (STAI; Spielberger, 1983) and the Beck Depression Inventory (BDI-V: Beck et al., 1961) was r= -.59 (p < .01) and r = -.51, respectively (p < .01; Kohls et al., 2009). The negative correlation between mindfulness and anxiety and depression is described as due to the "acceptance" factor of mindfulness (Kohls et al., 2009).

The FMI-14 was assessed at four time points. After completing the first week of gathering stress data, participants were emailed the FMI-14. The survey was sent again at the end of each intervention: after completing the first week of mindfulness, the first week of defusion, and finally at the end of the first week of trauma-informed problem solving.

To analyze the outcomes and due to the small sample size, researchers used a Bayesian effect size estimation to identify the percentage of the control sample that would fall below each participant's score at the four time points in the present study. The control sample (priors) was derived from Walach et al. (2006) using the FMI-14 (short form) for the full sample (N = 246) that had a mean score of 34.52 and a standard deviation of 6.77. To do this, researchers used the SingleBayes.exe software described in Crawford et al. (2010). The control sample did not participate in multiple repeated measures of the FMI-14 assessment.

#### **Daily Stress Reporting Scale**

Finally, both mothers collected data daily on their perceived level of daily stress. They rated their level of stress on a sliding scale from 1–100. There was a separate slider for morning, afternoon, and evening to help the researchers identify the most stressful times for the mothers and to see the level of impact each intervention had. Mothers responded either that night or the next morning, depending on when they saw the survey. This measure was used for analysis within the multiple baseline design. This measure was unique to this study, without published validity results.

# **Procedure(s)**

The training intervention was provided via telehealth sessions and measures were completed using Qualtrics. Researchers asked participants to maintain their regular routines until asked to change to gather reliable data and establish baseline and treatment patterns. If participants felt they needed to change their routine for their mental health prior to the researchers' indication, they were allowed to do so and were discontinued from the study.

Using emails sent via Proton (a secure email service), mothers were asked to mark their current stress level. When the researchers established a minimum of seven points of baseline stress data, they began the first treatment on the multiple baseline design. Once this baseline pattern was established, they were administered the Beach Center FQOL survey. Seven data points were used to help the researcher more easily track when to send emails. A schedule of the intervention procedures is outlined in Table 1.

# Table 1

Outline of the Intervention

Week 1	Take the FQOL survey Gather baseline stress data
Week 2	Introduce UCLA mindfulness app Continue gathering stress data Take FMI-14
Week 3	Introduce defusion Continue using mindfulness app Continue gathering stress data Take FMI-14
Week 4 Introduce trauma-informed problem solving Continue using mindfulness app Continue gathering stress data Take FMI-14	
Week 5	Take final FMI-14 Take final FQOL survey Respond to semi-structured interview questions

The following interventions were based on previously mentioned studies to regulate, relate, and reason. Regulate is the person's ability to lower their heart rate and breathing rate through mindful breathing. For this experiment, reasoning is problem-solving. Mindful breathing, as defined for the purpose of this paper, is breathing that focuses on the breath for 5 minutes. Relate is a person's ability to recognize relationships. In this study, the researchers asked the mothers to focus on their relationship with themselves. They did this by identifying and acknowledging the predominant emotion they feel in times of stress. Then, they thank that emotion for showing up to keep them safe. Finally, the mothers were asked to reason. They identified what triggered the traumatic event or identified what felt traumatic to them. Then they looked at their response to that event. Finally, they decided how they wanted to respond to a similar event in the future. The first intervention strategy administered was regulation. This intervention focused on modifying and regulating breathing to reduce heart rate. Mothers were instructed to download and use the UCLA mindfulness app (UCLA Mindful Awareness Research Center, 2020) for 5 minutes daily. The daily emails asking them to rate their stress levels continued. At the end of the week, mothers answered questions from the FMI-14.

Once a period of 7 days had elapsed for the first intervention, mothers were introduced to the relating step where they were given two strategies to use. The first strategy asked mothers to think of a single, stressful incident and to imagine holding it in their hands. They were asked to notice and name the emotion they were feeling when stressed. They were asked to acknowledge the emotion and to think of it as something separate from themselves. They would then acknowledge the function of the emotion and choose if they would continue to hold it in their hands or if they would open their hands and let it go. The second strategy was to distance themselves from the "I am" statement. For example, instead of thinking "I am angry," mothers were instructed to think "I am having the feeling of anger" or "I feel anger." Both strategies implement defusion, which is the process of separating the self from thoughts and feelings according to the acceptance and commitment therapy model. Daily stress data collection continued through the daily emails. At the end of the week, they were again assessed using the FMI-14.

The final step, reasoning, was introduced 7 days after the previous intervention. For this step, mothers were asked to think of a common scenario they faced and how it affected them. They were then invited to decide on a new response—emotional and physical—to that event. Data were collected through their daily text messages and the FMI-14 at the end of the week. A week following the final intervention, researchers readministered the Beach Center FQOL survey to measure if a change in perceived quality of life had occurred. Mothers were invited to respond to a brief interview to give their feedback on the helpfulness or lack of helpfulness of each intervention and on what they thought could be improved.

# **Baseline for Pre-/Post-Intervention Measures**

No interventions were provided to the mothers during baseline. Prior to intervention, parents participated in the Beach Center FQOL survey. Mothers were asked to continue their routines without variation except to respond to a daily stress measure. Data from each mother were collected using the daily stress measure for a period of 7 days. Once baseline data were collected, parents were ready to begin training.

# Parent Training in Mindfulness, Defusion, and Trauma-Informed Problem-Solving

Mothers were asked to download and begin using the UCLA Mindful app following baseline data. Instructions on using the app were delivered via the app. They were then introduced to the ACT model of defusion. Instruction was delivered by the researcher via Zoom. Finally, they were taught a decision-making process to help them reason their future reaction(s). Instruction was delivered by the researcher via Zoom.

The UCLA Mindful app (UCLA Mindful Awareness Research Center, 2020) was selected to guide participants through the meditation portion of the intervention. This app was developed by UCLA and is part of UCLA's Mindfulness Awareness Research Center (MARC; UCLA, 2020). MARC is an educational and research program created to advance the scientific basis of mindfulness and to increase the use of these practices. UCLA Mindful was easily accessible, free, and helped to limit variables related to minor differences in training.

The ACT skill of defusion included identifying emotion as an emotion and not as a descriptor of the self. This included labeling the emotion felt, followed by a statement such as, "I

had the feeling of anger" (or any other emotion) versus "I am angry" and by using visualization of the incident that brought on the emotion and choosing to keep it or let it go. The ACT skill of defusion was delivered by the researcher and overseen by Dr. Blake Hansen, a doctoral-level Board Certified Behavior Analyst (BCBA-D) who has a PhD in Behavioral Psychology and over 15 years of experience working with children with autism and their parents.

The decision-making process included looking at the action (or reaction) the parent used in a difficult situation. Researchers then used principles of trauma-informed therapy following the regulate, relate, and reason pattern to help parents either agree that their action/reaction was appropriate or to come up with a different plan for acting/reacting in the future. This was also delivered by the researcher and overseen by Dr. Hansen.

# Informal Interview

Mothers were contacted at the end of the intervention after 1 week to discuss: (a) what they thought about the meditation/mindfulness practice; (b) if defusion changed the way they related to themselves as a mother of a child with autism; (c) how useful the problem-solving technique was; (d) how easy or difficult it was to learn and apply the techniques; (e) if they felt unsafe throughout the process (f) personal outcomes from the interventions and if they accomplished what they hoped or if they wished for something different; (g) how likely they are to recommend meditation to friends with similar challenges; (h) how likely they are to recommend defusion to a friend with similar challenges; (i) how likely they are to recommend problem-solving to a friend with a similar challenge; and (j) what they wish researchers knew about them and their experience with the project. The aims were to assess these items to identify participant satisfaction with the goals, procedures, and outcomes.

# **Research Design**

A single-case multiple baseline design was used in this study (Baer et al., 1968). A multiple-baseline single subject case study design is an experimental design that starts by measuring two or more behaviors prior to interventions, followed by the intervention to affect one of the behaviors while baseline conditions for other conditions remain in effect (Martella et al., 2013). After initial baseline data were collected, the participants began the first intervention according to the study protocol. Use of the daily check-in measure continued for a minimum of 1 week to identify stable behaviors and/or trends prior to commencing the next intervention.

Kratochwill, et al. (2012) gave four fundamentals to establish a valid design. First, the use of a basic protocol in which the independent variable or intervention can be systematically manipulated. Second, the variables should be measured over time. Third, there should be at least three attempts that demonstrate the effect of the intervention at different points in time. And fourth, each phase of data should include at least three data points to demonstrate the stability of the effect of the intervention.

The researcher worked with two mothers of children with autism. Since meditation is a skill that cannot be removed after being taught, differences were measured between the baseline data and the post-intervention data. This same process was used for the next two interventions, checking daily stress levels and weekly mindfulness practices using the FMI-14. Prior to beginning any intervention and following completion of all interventions, mothers received the Beach Center FQOL scale. Data were gathered using the FMI-14 and the Beach Center FQOL. Participants also rated their level of stress daily for morning, afternoon, and evening. Finally, participants were asked to give brief responses to the overall process in a semi-structured interview.

### **Data Analysis**

Data were analyzed using visual analysis for the daily stress data. Visual analysis included observing level, trend, and variability within phases, and immediacy of change between phases. Visual analysis also included observing between participant differences. Effect size estimates were calculated using change point analysis and simulating modeling analysis (SMA; Borckardt et al., 2008). Pre- and post-intervention scores on the FQOL were transformed into a *z*-score and compared to normative samples using the scoring manual (Hoffman et al., 2006).

#### Simulation Modeling Analysis

To obtain an effect size estimate for each participant's daily stress level data, simulation modeling analysis (SMA; Borckardt et al., 2008) was used. SMA is a bootstrapping method that calculates an effect size (Pearson r) and simulates 5,000 datasets of the same length with similar autocorrelation as the original dataset. Simulated data was then used to calculate a *p*-value. These datasets were combined using average of weighted Fisher's Z coefficients with weighting determined by the number of days monitored. For combining correlations, averaging Fisher's z is less biased than the average of Pearson r correlations (Corey et al., 1998). The average Fisher z was then converted to a Pearson r yielding the average effect size for the daily monitoring data.

#### Changepoint Analysis

To analyze the immediacy of effects of the TIMBSR intervention, a changepoint analysis was conducted. Changepoint analyzes the timepoint at which the intervention effects become evident, as opposed to the starting point of an intervention phase. Ideally, the changepoint should be as close to the beginning of the intervention phase as possible. To conduct this analysis, researchers used R version 4.3.1 with the Changepoint version 2.2.4 package.

#### CHAPTER 4

#### Results

The following questions were presented at the beginning of this study:

- 1. Does meditation decrease parental stress and thereby increase perceived family quality of life (FQOL)?
- 2. Does increasing perceived FQOL also increase the parent's sense of attachment to the child with autism?
- 3. Does using trauma-informed interventions allow the mother to feel a sense of control as she navigates parenthood?

Initial findings indicate that the overall intervention reduced stress and increased perceived quality of life. Both mothers indicated that the intervention was helpful, which leads to new questions of how helpful the intervention was and if this intervention would be helpful to others. Only one of the mothers indicated that it changed her perspective on herself as a mother and how she related to her child.

Researchers did not find a clear answer to the question of whether or not meditation decreases parental stress. Both parents experienced a general decrease in stress levels, as can be seen on the graphs asking them to monitor their stress for both morning, noon, and evening. Eve mentioned in the interview that she felt she had more peace at home, but not due to meditation. Collette merely stated that, "It was helpful," but did not elaborate. The most dramatic changes for Collette can be seen in the morning and evening, while the most dramatic changes for Eve can be seen in the afternoon and evening. Some factors that may play into this are the age of the child (Collette's child was older than Eve's) and the amount of time the child was at school. Results were also unclear regarding the benefits of the interventions being traumainformed or merely therapeutic. For example, both mothers indicated that they found defusion to be the most helpful tool that they learned; however, trauma-informed problem-solving was lowest on their list of helpful interventions. In terms of social validity, trauma-informed interventions do not appear to increase a parent's sense of control. In the measurements, there is no sharp change in data as each intervention is introduced. This makes it difficult to identify which intervention of the three was the most helpful.

Finally, FQOL data showed an increase in family satisfaction, but only one parent indicated an increased sense of parental attachment to their child. Both parents indicated significant increases in their sense of family interaction, which may indicate that there is a sense of parental attachment to the child. Only one parent indicated that she felt her parenting practices had improved. Additionally, both mothers indicated a significant increase in their emotional wellness which has been linked to increased attachments between parents and children. Using these parameters, it does appear that increasing FQOL could increase parental attachment to the child, which will continue to create a healthy environment for both parent and child moving forward.

#### **Daily Stress Levels**

Results for daily stress levels are found in Table 2 and Figure 1. Visual analysis of Figure 2 indicates that both Collette and Eve experienced a decrease in their overall levels of stress throughout this intervention. Table 2 indicates that Collette experienced the greatest decrease in the mornings, at about 45% and the smallest decrease occurred in the evening at about 21%. Eve, on the other hand, experienced the greatest decrease in stress around noon at 45% and the smallest decrease occurred in the evening at 29%.

Eve experienced an erratic pattern during her noon measurements, frequently dipping higher and lower with an overall decreasing trend in stress. She experienced the least amount of variation during the morning measurements. She experienced illness toward the end of the intervention, which could explain the spike in stress toward the end of data collection. Despite this spike, she still indicated that her perceived stress seemed lower toward the end of the intervention than the beginning.

Collette experienced the least amount of change in stress at noon. Her evening measurements started with a wide level of variability, but quickly reduced in bounce to a smooth downward trend in stress.

Overall, both parents experienced a decrease in stress levels during the intervention. In addition, their mindfulness inventories had a general upward trend from the beginning of the intervention to the end.

# Table 2

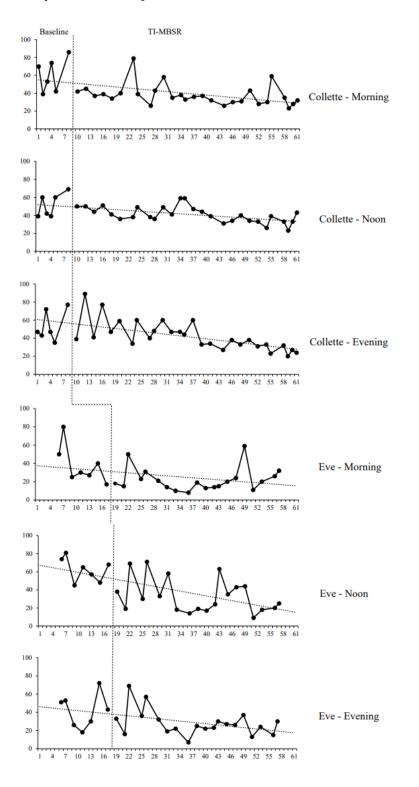
Participant	Time	Baseline M(SD)	TIMBSR M(SD)	Phase Change	Change Point	ES	<i>p</i> -value	CI: +	/- 95%
Collette	Morning	38.4 (21.2)	22.2 (12.9)	6	6	-0.57	< 0.01	-0.69	-0.45
	Noon	62.6 (13.3)	33.4 (19.0)	6	22	-0.40	0.14	-0.48	-0.32
	Evening	41.9 (18.6)	28.2 (14.3)	6	21	-0.26	0.18	-0.31	-0.21
Eve	Morning	56.4 (17.8)	37.3 (12.0)	7	2	-0.44	0.06	-0.54	-0.34
	Noon	51.1 (11.1)	40.0 (8.8)	7	14	-0.60	0.01	-0.75	-0.45
	Evening	56.1 (20.2)	40.7 (13.9)	7	12	-0.37	0.11	-0.45	-0.29
Overall						-0.45		-0.49	-0.41

## Daily Stress Levels for Eve and Collette

*Note.* Daily stress levels were reported on a scale of 1-100, with higher scores indicating higher levels of stress. M = mean, SD = standard deviation, ES = effect size, CI = confidence interval.

## Figure 1

## Daily Stress Levels for Collette and Eve



### FMI-14

Results for the FMI-14 are found on Table 3 and displayed on Figure 2. Visual analysis of Figure 2 indicates that both Collette and Eve experienced an increase in well-being using mindfulness. Eve's level of well-being started close to the control group line and increased more gradually than Collette's did. Collette's sense of well-being started well below the control group and increased to the same level as the control group by the end of the experiment. Looking at the numbers calculated, Collette experienced a 44.58% increase in her sense of well-being and Eve experienced a 50.67% increase in her sense of well-being.

#### Table 3

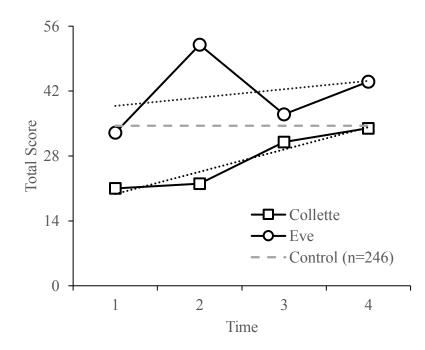
		Time				
	1	2	3	4		
Collette	2.37%	3.31%	30.22%	46.95%		
Eve	41.15%	99.47%	64.25%	91.82%		

Bayesian Effect Size Estimates for the FMI-14 at Times 1–4 for Each Participant

*Note.* Percentages denote the percentage of base rate participants that fall below the participants in the present study.

### Figure 2

Mindfulness Awareness for Collette and Eve, FMI-14 Scores at Times 1–4 with Base Rate



#### **Trauma-Informed Interventions**

According to the mothers' interview question responses, using a trauma-informed intervention neither decreased nor increased her sense of control. These responses may accurately reflect the participants' experiences. It is also possible that their experience with trauma-informed problem-solving was less notable than their experience with defusion, which could lead to a decreased recognition of the efficacy of the intervention.

#### FQOL

Results for the FQOL are found on Table 4 and displayed on Figure 3. Both participants rated an increase in their family quality of life based on the pre- and post-assessment using the

Beach Center FQOL scale. Collette's rating of FQOL increased from 63.34% to 92.80% overall. Eve's rating increased from 59.33% to 90.03% overall.

Mindfulness has been shown to increase the perception of emotional well-being, making the increase in physical/material well-being in both participants a surprise. It is unclear if this increase is a direct result of the experiment or if their financial situation changed throughout the assessment. Family interaction increased about 10–20% with both participants. Disability related support increased only about 5% with Collette, but 30% with Eve. It is unclear if that increase in perception is due to the skills learned or the interaction with the examiner. Visual examination of the bar graph indicates that both parents generally felt at or above the general population using the norm referenced FQOL group.

Collette's responses indicated an increase in family interaction, emotional wellbeing, physical/material wellbeing, and disability related support; but, not in parenting. In contrast, she reported during training that she felt more comfortable being a mom and that she felt better able to allow her child to react to situations however he reacted without placing blame on herself. By taking a step back, she felt better able to predict his meltdowns which led to an increased ability to compensate when his meltdowns occurred.

Eve's responses increased in every category, but she did not report any change in her relationship with her child. This may indicate that she either did not recognize an increase in her relationship or it may indicate that her overall perception of FQOL had improved, but not necessarily a singular relationship within that group.

# FQOL Table 4

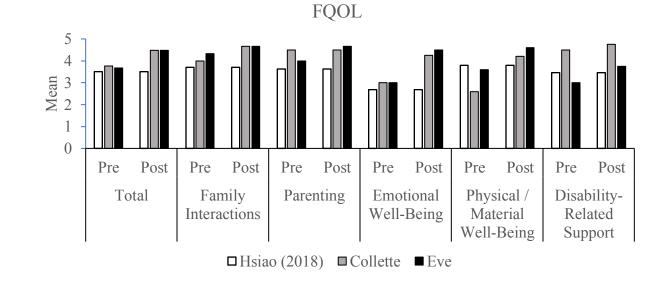
Bayesian Effect Size Estimates for The FQOL at Pre- and Post-Intervention on the Entire

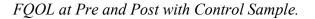
		Pre-Intervention	Post-Intervention
Collette	Total	63.34%	92.80%
	Family Interaction	62.20%	84.79%
	Parenting	84.31%	84.31%
	Emotional Wellbeing	62.27%	93.71%
	Physical / Material Wellbeing	9.17%	67.69%
	Disability Related Support	86.21%	91.16%
Eve	Total	59.33%	90.03%
	Family Interaction	73.63%	84.80%
	Parenting	66.59%	88.56%
	Emotional Wellbeing	62.27%	96.19%
	Physical / Material Wellbeing	41.58%	81.76%
	Disability Related Support	31.47%	61.95%

Questionnaire at Each Subscale for Each Participant.

*Note.* Percentages denote the percentage of control participants that fall below the participants in the present study.

#### Figure 3





### Semi-Structured Survey

Full interview transcripts can be found in Appendix B of the study. The results from both participants indicate that they perceived the greatest increase in change using defusion. Mindfulness had mixed results, while both felt that trauma-informed problem-solving was unhelpful (although they did not indicate that it made their situations worse).

Comparing responses to the semi-structured interview transcript reveals that the mothers had a relatively similar experience with varying degrees of helpfulness. They both indicated that the techniques were easy to learn, but more difficult to apply. Collette's data indicates that the difficulty may lie in remembering the interventions ("I think more examples or something written down would have been helpful.") while Eve's response indicates that it was difficult to concentrate on the intervention (mention was made of meditation specifically). Both mothers used phrases such as "stepping back" or "rephrasing my thinking" in a positive manner, which may indicate that they now have more tools to interact with and help their child and to help themselves as mothers.

Both mothers were considered "detractors" when it came to recommending meditation to another mother of a child with autism. A detractor means that they rated the intervention less than 5 on a scale of 1-10. This may indicate that they did not recognize the benefit of meditating or that they found the time trying to do it more frustrating than helpful.

Eve was considered a promoter of defusion, while Collette was passive on whether she would recommend it. The higher marking for this intervention indicates that it may be the one that provided the most help for the mothers in decreasing their stress and increasing the relationship between them and their children. Eve indicated in her response that she wishes "more focus would have been spent on that."

Both parents were detractors of the problem-solving technique. While comments were generally positive ("... that it helped me engage in new ways of thinking through scenarios"), neither indicated they would recommend this intervention to a friend. This may also indicate that trauma-informed problem solving combined with defusion was more helpful than they consciously recognized.

Eve made more mention of the increased relief she feels in social situations. During training sessions, she made mention of the emotional difficulty she felt going to stores and dealing with others' perceptions of her as a parent and of her child and how the situation (particularly meltdowns) should be handled. She indicated that she feels less stressed to be out in public with her child.

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Overall, both participants indicated that they felt the intervention was helpful. In the final question, Eve mentioned that she wished the researchers had known more about her, her child, and their specific situation. This is likely a common sentiment among parents of children with autism, as autism is on the spectrum and presents so differently with each person.

This study was conducted to identify if reducing parental stress increased FQOL, if increasing FQOL increased the sense of parental attachment to the child with autism, and to see if using trauma-informed interventions allowed the mother to feel a sense of control as she navigates parenthood. Data indicate increases in FQOL and decreases in parental stress but were inconclusive regarding efficacy of trauma-informed practices and increased parental attachment to the child with autism. Some of the inconclusive data may be a result of researcher error in gathering data and it could also be a result of a too small sample size. Further studies should be conducted to either prove or disprove these conclusions.

#### **CHAPTER 5**

#### Discussion

The central purpose of this pilot study was to provide trauma-informed interventions mothers could use unassisted to see if they decreased their daily stress levels, increased their relationship with their children, and increased their family quality of life. This study was important to conduct because of the limited research available on a parent attachment to the child and because the literature shows that parents of children with autism tend to experience decreased FQOL when compared with parents of children with other disabilities.

Current literature typically indicates that using mindfulness and reducing stress increases the perceptions people have of their general well-being but was not specific to parents with autistic children. Our results add to this knowledge as it may apply to families with autism. One surprising finding, however, is that the mothers both indicated that their financial well-being increased over the course of the study. The researcher is unable to determine if this is due to the intervention or if there was an actual change in job status or income level at this time.

The41chooll day is a possible confounding factor when considering the effects of mindfulness. It is difficult to determine if the decrease in stress was due to mindfulness practices or if it was due to their child being at school for much of the day. The researcher believes that mindfulness played a key part because both mothers indicated decreased stress in the evening when their child was home from school. However, their decrease in stress in the evenings could also be attributed to a significant other being home to share the workload.

Whether the interventions needed to be trauma-informed or not is undetermined; however, there was a strong correlation between decreased stress and increased FQOL from the beginning to the end of the study. There is also a small correlation in an increased parent-child relationship.

#### Findings

#### Meditation Decreases Parental Stress

Daily stress levels were measured three times per day (morning, noon, and evening) and the FMI-14 was used weekly when the meditation intervention was taught. Based on the trend in the daily stress graphs, it appears that meditation decreases parental stress. Both parents indicated a relatively significant decrease in stress over the period of the interventions. This would be in accordance with other research done on meditation and stress levels.

#### Trauma-Informed Interventions May Not Show Consistent Benefits

A trauma-informed approach to helping mothers of children with autism was primarily measured through a semi-structured interview. It is unclear if interventions need to be traumainformed or not. Both parents indicated that their sense of well-being increased, which correlates with a sense of control. Based on these assumptions, the researcher would assert that mothers felt a greater sense of control for situations that may arise, but that utilizing a trauma-informed approach may not be benefit all participants equally.

### FQOL Increased in Some Areas, Perhaps not Specifically in Attachment

Both mothers' FQOL ratings increased in certain areas dramatically (particularly financial well-being) but stayed about the same in others. The semi-structured interview was also used to gain the parent's direct perspective of the results of this research.

It is unclear if an increased FQOL also increased the mothers' sense of attachment to their children. Only one mother specifically stated that she felt like a better mother and closer to

her child because of the interventions provided. Given these two participants, that gives us a 50% chance of increasing that relationship through these specific interventions.

### Limitations

This pilot study is limited in scope due to the small sample size used. There were only two participants and both parents seemed to come from a relatively stable relationship and financial background, and both seemed to have access to resources to assist them in learning about their child and how to interact with them. In addition, there were few fidelity controls in place to determine if the participants followed only the protocols offered or if they sought out and used outside resources.

Based on previous research with mindfulness, it would be expected that other parents would experience the same results in decreased levels of stress. Whether that would impact the perceived FQOL for other parents is uncertain. In addition, the number of resources available has been shown to impact the responsiveness of participants to certain interventions (Knifton & Inglis, 2020).

Another limitation for this study is that participants come from a single geographic area. Residents in the area tend to be a relatively homogenous group with 83% reporting as only White according to the United States Census (U.S. Census Bureau, 2021). The study did not consider socio-economic status or familial resources available. There were also few applicants to the study (N = 4) with only two completing the study. Participants received training via Zoom and practiced skills in their homes, so no physical setting was utilized.

Finally, this study may be limited due to the types of data gathered. Most of it relied on participant responses, which may be influenced by the participant's personal bias of what a situation feels like and by their memory of situations.

### **Implications for Future Research**

The next step for this study would be to offer the intervention to a larger sample size of parents to determine generalizability of the process. In addition, the three sections should be split apart to note if merely being asked about mindfulness (the FMI-14) had the same effect as implementing a mindfulness practice, to see what impact trauma-informed problem solving had, and to determine if defusion is the most useful tool to parents as indicated by these mothers.

To improve this study, parents should be asked specifically if they feel that there has been a change in their relationship with their child. There should be a follow-up period to determine the long-term effects of this intervention. And, finally, the researcher would like to know if this is information parents can learn and use on their own or if they need a practitioner to guide them through it (especially the concept of defusion).

### **Implications for Practitioners**

Many parents of children with autism become so focused on their child that they set their self-care to the side, especially in the early days of the diagnosis. Knowing that at least two parents found increased FQOL through these interventions indicates that there is value in sharing these techniques with other parents. These are relatively simple techniques that practitioners can present to their clients upon diagnosis or soon after to help parents maintain a clearer view of themselves as parents and of their children as separate individuals with their own unique needs.

### Conclusion(s)

Results of this pilot study indicate a need for further research. It could be shared with future practitioners of parents of children with special needs to identify if these results are generalizable. If they are, then publication in research articles and in magazines or newspapers that parents of children with disabilities utilize would be warranted. This study shows that some

people found benefit in a daily mindfulness practice, in evaluating their sense of well-being, in learning to separate their identity from the behavior of their children, and in learning to think through problems and plan ahead rather than become overwhelmed in the moment.

#### REFERENCES

- American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders (5<sup>th</sup> ed., Text Revision). Washington, DC: Publisher. https://doi.org/10.1176/appi.books.9780890425787
- Barta, J. (2021, January 3). Trauma-informed care in the schools (No. 119) In *School Psyched!* https://schoolpsychedpodcast.wordpress.com/2021/01/03/spp-119-trauma-informed-carein-the-schools/comment-page-1/
- Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis*, 1(1), 91.
   https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1310980/pdf/jaba00083-0089.pdf
- Beck, A. T., Ward, C. H., Mendelson, M., Mock, J., & Erbauch, J. (1961). Beck Depression Inventory (BDI) [Database record]. APA PsycTests. https://doi.org/10.1037/t00741-000
- Borckardt, J. J., Nash, M. R., Murphy, M. D., Moore, M., Shaw, D., & O'Neil, P. (2008).
  Clinical practice as natural laboratory for psychotherapy research: A guide to case-based time-series analysis. *American Psychologist*, 63(2), 77–95. https://doi.org/10.1037/0003-066X.63.2.77
- Brown, R. I., MacAdam-Crisp, J., Wang, M., & Iaroci, G. (2006). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 238–245. https://doi.org/10.1111/j.1741-1130.2006.00085.x

- Carmassi, C., Dell'Oste, V., Foghi, C., Bertelloni, C. A., Conti, E., Calderoni, S., Battini, R., & Dell'Osso, L. (2020). Post-traumatic stress reactions in caregivers of children and adolescents/young adults with severe diseases: A systematic review of risk and protective factors. *International Journal of Environmental Research and Public Health*, *18*(1), 189. https://doi.org/10.3390/ijerph18010189
- Corey, D. M., Dunlap, W. P., & Burke, M. J. (1998). Averaging Correlations: Expected Values and Bias in Combined Pearson rs and Fisher's z Transformations. *The Journal of General Psychology*, 125(3), 245–261. https://doi.org/10.1080/00221309809595548
- Crawford, J. R., Garthwaite, P. H., & Porter, S. (2010). Point and interval estimates of effect sizes for the case-controls design in neuropsychology: Rationale, methods, implementations, and proposed reporting standards. *Cognitive Neuropsychology*, 27, 245–260. https://doi.org/10.1080/02643294.2010.513967
- Davis, A. (2015). Parental stress and child behavior problems in families of children with autism (Order No. 10112160). https://scholarsrepository.llu.edu/etd/297
- DeFrancesco, L. (2001, May 14). Autism on the rise. *The Scientist*, *15*(10), 16. https://go.gale.com/ps/i.do?p=AONE&u=anon~441a7108&id=GALE|A75466704&v=2.1 &it=r&sid=googleScholar&asid=7959df1b.
- Dixon, E. (2021, September 18). Autism and Maternal Stress. *Psychology Today*. https://www.psychologytoday.com/us/blog/the-flourishing-family/202109/autism-andmaternal-stress?scrlybrkr=1b9fd96e

- Donnelly, R., Comizio, R., & Elias, E. (2021, January 3). *Trauma Informed Care in Schools* (No. 119) [Audio podcast.] In *School Psyched*! https://archive.org/download/spp-119-trauma-informed-care-in-the-schools/SPP%20119\_%20Trauma%20Informed%20Care %20in%20the%20Schools.mp3
- Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, down syndrome, behavior disorders, and normal development, *Exceptionality: A Special Education Journal, 2*:2, 97–110, https://doi.org/10.1080/09362839109524770
- Dykens, E. M., Fisher, M. H., Taylor, J. L., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities: A randomized trial. *Pediatrics*, 134(2), e454–e463. https://doi.org/10.1542/peds.2013-3164
- Elliott, D. E., Bjelajac, P., Fallot, R. D., Markoff, L. S., & Reed, B. G. (2005). Trauma-informed or trauma-denied: Principles and implementation of trauma-informed services for women. *Journal of Community Psychology*, *33*(4), 461–477. https://doi.org/10.1002/jcop.20063
- Fletcher, L., & Hayes, S. C. (2005). Relational frame theory, acceptance and commitment therapy, and a functional analytic definition of mindfulness. *Journal of Rational-Emotive* and Cognitive-Behavior Therapy, 23, 315–336. https://doi.org/10.1007/s10942-005-0017-7
- Goodman, S. J., & Glenwick, D. S. (2012). Correlates of attachment perceptions in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(10), 2056–2066. https://doi.org/10.1007/s10803-012-1453-8

Gunty, A. L. (2020). Rethinking resilience in families of children with autism spectrum

disorders. *Couple and Family Psychology: Research and Practice*. https://doi.org/10.1037/cfp0000155.supp (Supplemental)

- Hayes, S. A., & Watson, S. L. (2012). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43, 629–642. https://doi.org/10.1007/s10803-012-1604-y
- Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Beach Center Family Quality of Life Scale. *Journal of Marriage and Family, 68*(4), 1069–1083.
  http://dx.doi.org/10.13072/midss.327
- Hoge, E. A., Bui, E., Marques, L., Metcalf, C. A., Morris, L. K., Robinaugh, D. J., Worthington, J. J., Pollack, M. H., & Simon, N. M. (2013). Randomized controlled trial of mindfulness meditation for generalized anxiety disorder: effects on anxiety and stress reactivity. *The Journal of Clinical Psychiatry*, 74(8), 786–792. https://doi.org/10.4088/JCP.12m08083
- Hsiao, Y. J. (2018). Autism spectrum disorders: Family demographics, parental stress, and family quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(1), 70–79. https://doi.org/10.1111/jppi.12232
- In, J. (2017). Introduction of a pilot study. *Korean Journal of Anesthesiology*, 70(6):601–605. https://doi.org/10.4097/kjae.2017.70.6.601
- Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: Past, present, and future. *Clinical Psychology: Science and Practice*, 10(2), 144–156. https://doi.org/10.1093/clipsy.bpg016

- Kelly, A., & Garland, E. L. (2016). Trauma-informed mindfulness-based stress reduction for female survivors of interpersonal violence: Results from a stage I RCT. *Journal of Clinical Psychology*, 72(4), 311–328. https://doi.org/10.1002/jclp.22273
- Kerig, P. K. (2013). Trauma-informed assessment and intervention. Los Angeles, CA: National Center for Child Traumatic Stress. https://www.researchgate.net/profile/Patricia-Kerig/publication/304498250\_Trauma-Informed\_Assessment\_and\_Intervention/links/ 57718b0408ae10de639deb03/Trauma-Informed-Assessment-and-Intervention.pdf
- Knifton, L. & Inglis, G. (2020). Poverty and mental health: Policy, practice and research implications. *BJPsych Bulletin*, *44*(5),193–196. http://doi.org/10.1192/bjb.2020.78
- Kohls, N., Sauer, S., & Walach, H. (2009). Facets of mindfulness—Results of an online study investigating the Freiburg mindfulness inventory, *Personality and Individual Differences*, 46(2), 224–230. https://doi.org/10.1016/j.paid.2008.10.009
- Kording, K. (2007). Decision theory: What "should" the nervous system do? *Science*, *318*(5850), 606–610. https://doi.org/10.1126/science.1142998
- Kox, M., Stoffels, M., Smeekens, S. P., Van Alfen, N., Gomes, M., Eijsvogels, T. M., Hopman, M., van der Hoeven, J. D., Matea, M., & Pickkers, P. (2012). The influence of concentration/meditation on autonomic nervous system activity and the innate immune response: A case study. *Psychosomatic Medicine*, *74*(5), 489–494. http://doi.org/10.1097/PSY.0b013e3182583c6d
- Kratochwill, T. R., Hitchcock, J. H., Horner, R. H., Levin, J. R., Odom, S. L., Rindskopf, D. M.,
  & Shadish, W. R. (2012). Single-case intervention research design standards. *Remedial* and Special Education, 34(1), 26–38. https://doi.org/10.1177/0741932512452794

- Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArther, D., Pas, E. T., Salinas, A., Vehorn, S., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J. . . . & Shaw, K. A. (2023). Prevalence and characteristics of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020. *MMWR Surveillance Summaries*, *72*(2), 1–14. http://dx.doi.org/10.15585/mmwr.ss7202a1
- Martella, R. C., Nelson, J. R., Morgan, R. L., & Marchand-Martella, N. E. (2013). Understanding and interpreting educational research. The Guilford Press.
- Morone, N. E., Lynch, C. S., Greco, C. M., Tindle, H. A., & Weiner, D. K. (2008). "I felt like a new person." The effects of mindfulness meditation on older adults with chronic pain: qualitative narrative analysis of diary entries. *The Journal of Pain: Official Journal of the American Pain Society*, 9(9), 841–848. https://doi.org/10.1016/j.jpain.2008.04.003
- Oman, D., Shapiro, S. L., Thoresen, C. E., Plante, T. G., & Flinders, T. (2008). Meditation lowers stress and supports forgiveness among college students: A randomized controlled trial. *Journal of American College Health*, 56(5), 569–578. https://doi.org/10.3200/JACH.56.5.569-578
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation*, 41(5), 313–328. https://doi.org/10.1352/0047-6765(2003)41<313:FQOLAQ>2.0.CO;2
- Sakaguchi, M. & Beppu, S. (2007). Structure of stressors in mothers of preschool children with autism. *Japanese Journal of Special Education*, 45, 127–136. https://doi.org/10.6033/tokkyou.45.127

- Singh, N. N., Singh, A. N., Lancioni, G. E., Singh, J., Winton, A. S. W., & Adkins, A. D. (2009). Mindfulness training for parents and their children with ADHD increases the children's compliance. *Journal of Child and Family Studies*, *19*, 157–166. https://doi.org/10.1007/s10826-009-9272-z
- Skinner, B. F. (1965). *Science and human behavior*. New York: The Free Press. (Originally published 1953.) https://study.sagepub.com/sites/default/files/B.F.%20Skinner.pdf
- Spielberger, C. D. (1983). State-trait anxiety inventory for adults (STAI-AD) [Database record]. APA PsycTests. https://doi.org/10.1037/t06496-000
- Stewart, M., Knight, T., McGillivray, J., Forbes, D., & Austin, D. W. (2017). Through a traumabased lens: A qualitative analysis of the experience of parenting a child with an autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, 42(3), 212–222. https://doi.org/10.3109/13668250.2016.123
- Taylor, M. J., Rosenqvist, M. A., Larsson, H., Gillberg, C., D'Onofrio, B. M., Lichtenstein, P., & Lundström, S. (2020). Etiology of autism spectrum disorders and autistic traits over time. *JAMA Psychiatry*, 77(9), 936–943.

https://doi.org/10.1001/jamapsychiatry.2020.0680

- Turakitwanakan, W., Mekseepralard, C., & Busarakumtragul, P. (2013). Effects of mindfulness meditation on serum cortisol of medical students. *Journal of the Medical Association of Thailand*, 96(Suppl 1), S90-5. https://pubmed.ncbi.nlm.nih.gov/23724462/
- UCLA Mindful Awareness Research Center. (2020). UCLA mindful (Version 1.2). [Mobile application software.] https://www.uclahealth.org/marc/ucla-mindful-app
- U.S. Census Bureau. (2021). QuickFacts. U.S. Census Bureau QuickFacts: United States

- Walach, H., Buchheld, N., Buttenmüller, V., Kleinknecht, N., & Schmidt, S. (2006). Measuring mindfulness—the Freiburg Mindfulness Inventory (FMI). *Personality and Individual Differences*, 40(8), 1543–1555. https://doi.org/10.1016/j.paid.2005.11.025
- Wilson, C. E., Murphy, C. M., McAlonan, G., Robertson, D. M., Spain, D., Hayward, H.,
  Woodhouse, E., Deeley, P. Q., Gillan, N., Ohlsen, J. C., Zinkstok, J., Stoencheva, V.,
  Faulkner, J., Yildiran, H., Bell, V., Hammond, N., Craig, M. C. & Murphy, D. G. (2016).
  Does sex influence the diagnostic evaluation of autism spectrum disorder in
  adults? *Autism*, 20(7), 808–819. https://doi.org/10.1177/1362361315611381

### APPENDIX A

## **Institutional Review Board Approval Letter and Consent**



To: Blake Hansen

Department: BYU - EDUC - Counseling, Psychology, & Special Education From: Sandee Aina, MPA, HRPP Associate Director

Wayne Larsen, MAcc, IRB Administrator Date: May 22, 2023

IRB#: IRB2023-113

Title: Trauma-Informed Mindfulness-Based Stress Reduction to Increase Family Quality of Life for Mothers of Children with Autism

Brigham Young University's IRB has approved the research study referenced in the subject heading as

exempt, categories 2 and 3. This study does not require an annual continuing review. Each year near the anniversary of the approval date, you will receive an email reminding you of your obligations as an investigator and to check on the status of the study. You will receive this email each year until you close the study.

The study is approved as of 05/22/2023. Please reference your assigned IRB identification number in any correspondence with the IRB.

Continued approval is conditional upon your compliance with the following requirements

- 1. A copy of the approved informed consent statement can be found in iRIS. No other consent statement should be used. Each research subject must be provided with a copy or a way to access the consent statement.
- 2. Any modifications to the approved protocol must be submitted, reviewed, and approved by the IRB before modifications are incorporated into the study.
- 3. All recruiting tools must be submitted and approved by the IRB prior to use.
- 4. Instructions to access approved documents, submit modifications, and report adverse events can be found on the IRB website, iRIS guide: https://irb.byu.edu/iris-training-resources
- 5. All non-serious unanticipated problems should be reported to the IRB within 2 weeks of the first awareness of the problem by the PI. Prompt reporting is important, as unanticipated problems often require some modification of study procedures, protocols, and/or informed consent processes. Such modifications require the review and approval of the IRB. Please refer to the <u>IRB website</u> for more information.

### Consent to be a Research Subject

**Title of the Research Study:** Trauma-Informed Mindfulness-Based Stress Reduction to Increase Family Quality of Life in Mothers of Children with Autism **Principal Investigator:** Blake Hansen, PhD BCBA-D LBA **Co-Investigator:** Carol Vaughn

### **Introduction**

.

This research study is being conducted by Dr. Blake Hansen and graduate student Carol Vaughn at Brigham Young University to determine the effect of trauma-informed mindfulness-based stress reduction on the perceived family quality of life for mothers of children with autism. You were invited to participate because you meet the criteria necessary to perform this study.

### **Procedures**

If you agree to participate in this research study, the following will occur:

- You will be asked to complete an online questionnaire before and after interventions. These should require approximately thirty (30) minutes of your time.
- You will be asked to attend via zoom five (5) thirty (30) minute classes on topics including mindfulness, defusion techniques, and trauma-informed problem-solving. The five classes will include a class outlining the procedures of the research and a class that will give you the opportunity to voice how you felt the research went and if it was useful or not. These classes will happen approximately once per week over four weeks.
- You will be asked to download a free app on your smartphone.
- You will be asked to track your progress daily for five (5) minutes per day.
- You will be asked to complete a weekly, ten minute questionnaire sent through your email.

- The researcher may contact you at the end of the study to interview you on perceived effectiveness of interventions for approximately fifteen (15) minutes.
- Total time commitment will be approximately six and one half (6.5) hours to six and three quarters (6.75) hours over the course of five to six weeks (time fluctuation dependent on participating in the final interview).

#### **Risks/Discomforts**

*Psychological*: Meditation often brings up uncomfortable feelings/memories that we have been suppressing. There is no solid research on how long these feelings last because it is dependent on the person and the work they have done previously to resolve these emotions.

*Social*: You may experience discomfort as you begin new mindfulness practices, embarrassment from questions asked, and loss of time within your day. You may decide to do things differently in your life following this intervention. This may result in social stigma/isolation as others do not understand what you are doing and why.

*Privacy*: There is always a potential that a website could be hacked or the laptop with the encrypted information could be stolen and decrypted. This may give information such as birthdates and/or diagnoses to people uninvolved with the study.

We, the researchers, will strive to accommodate class times and potential interviews to your convenience and we have designed the surveys and check-ins to be completed at your convenience each day. All information will be kept on secure electronic devices that are password protected. Files will be stored in BYU's University Box system. Box is a program designed to allow educational facilities to securely share information with the people designated. It is also password protected and those who do not have a Box account and those who have not been given access to the file will not be able to access the information. You may withdraw from the study at any time and without penalty to you.

#### **Benefits**

Benefits of participating in the research may include an increased perceived family quality of life, reduced stress, and increased coping mechanisms with stress.

#### **Confidentiality**

Data will be gathered using the online survey program. Identifying information will be stored separately from the rest of the research data. All data will be password protected. Participants will be given an individual identification number when they complete each questionnaire. Only the researchers named will have access to the data. At the conclusion of the study, all identifying information will be removed and the data will be kept in the University Box with restricted access.

### Data Sharing

We will keep the information we collect about you during this research study for analysis. If the study data contain information that directly identifies subjects: Your name and other information that can directly identify you will be stored securely and separately from the rest of the research information we collect from you.

De-identified data from this study may be shared with the research community, with journals in which study results are published, and with databases and data repositories used for research. We will remove or code any personal information that could directly identify you before the study data are shared. Despite these measures, we cannot guarantee anonymity of your personal data. The results of this study could be shared in articles and presentations, but will not include any information that identifies you unless you give permission for use of information that identifies you in articles and presentations.

## **Compensation**

You will receive a \$20.00 Amazon or Walmart gift card for your participation in this study, unless you choose to withdraw early from the study.

## **Participation**

Participation in this research study is voluntary. You have the right to withdraw at any time or refuse to participate entirely without jeopardy to your reputation or standing in your community.

## **Questions about the Research**

If you have questions, concerns, or complaints, you can contact the Principal Investigator Dr. Blake Hansen at blake hansen@byu.edu and Carol Vaughn at carolmvaughn@gmail.com.

### **Questions about Your Rights as Research Participants**

If you have questions regarding your rights as a research participant contact Human Research Protections

Program by phone at (801) 422-1461; or by email: <u>BYU.HRPP@byu.edu</u>.

## **Statement of Consent**

I have read, understood, and received a copy of the above consent and desire of my own free will to participate in this study.

Name (Printed): Signa	ature Date:
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### APPENDIX B

## **Instruments & Interviews**

# **Beach Center FQOL**

Q1 Respond to each question with how you have felt in general over the last six months.

	Very Dissatisfied (1)	Dissatisfied (2)	Satisfied (3)	Very Satisfied (4)
My family enjoys spending time together. (1)	0	0	0	0
My family members talk openly with each other. (2)	0	$\bigcirc$	$\bigcirc$	$\bigcirc$
My family solves problems together. (3)	0	$\bigcirc$	$\bigcirc$	$\bigcirc$

Q2 Respond to each question with how you have felt in general over the last six months.

	Very Dissatisfied (1)	Dissatisfied (2)	Satisfied (3)	Very Satisfied (4)
My family members support each other to accomplish goals. (1)	0	0	0	0
My family members show that they love and care for each other. (2)	0	$\bigcirc$	$\bigcirc$	$\bigcirc$
My family is able to handle life's ups and downs. (3)	$\bigcirc$	$\bigcirc$	$\bigcirc$	0

	Very Dissatisfied (1)	Dissatisfied (2)	Satisfied (3)	Very Satisfied (4)
Family members help the children learn to be independent. (1)	0	0	0	0
Family members help the children with schoolwork and activities. (2)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Family members teach the children how to get along with others. (3)	0	$\bigcirc$	$\bigcirc$	$\bigcirc$

Q3 Respond to each question with how you have felt in general over the last six months.

Q4 Respond to each question with how you have felt in general over the last six months.

	Very Dissatisfied (1)	Dissatisfied (2)	Satisfied (3)	Very Satisfied (4)
Adults in my family teach the children to make good decisions (1)	0	0	$\bigcirc$	0
Adults in my family know other people in the children's lives (i.e. friends, teachers). (2)	$\bigcirc$	$\bigcirc$	$\bigcirc$	0
Adults in my family have time to take care of the individual needs of every child. (3)	0	$\bigcirc$	$\bigcirc$	0

	Very Dissatisfied (1)	Dissatisfied (2)	Satisfied (3)	Very Satisfied (4)
My family has the support we need to relieve stress. (1)	0	0	$\bigcirc$	0
My family members have friends or others who provide support. (2)	$\bigcirc$	$\bigcirc$	0	$\bigcirc$
My family members have some time to pursue their own interests. (3)	$\bigcirc$	0	0	$\bigcirc$
My family has outside help available to us to take care of special needs of all family members. (4)	0	0	$\bigcirc$	0

Q5 Respond to each question with how you have felt in general over the last six months.

Q6 Respond to each question with how you have felt in general over the last six months.

	Very Dissatisfied (1)	Dissatisfied (2)	Satisfied (3)	Very Satisfied (4)
My family members have transportation to get to the places they need to be. (1)	0	0	0	0
My family gets dental care when needed. (2)	0	$\bigcirc$	$\bigcirc$	$\bigcirc$
My family gets medical care when needed. (3)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

	Very Dissatisfied (1)	Dissatisfied (2)	Satisfied (3)	Very Satisfied (4)
My family has a way to take care of our expenses. (1)	0	0	$\bigcirc$	0
My family feels safe at home, work, school, and in our neighborhood. (2)	0	$\bigcirc$	$\bigcirc$	$\bigcirc$

Q7 Respond to each question with how you have felt in general over the last six months.

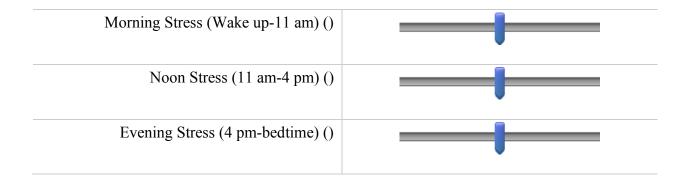
Q8 Respond to each question with how you have felt in general over the last six months.

	Very Dissatisfied (1)	Dissatisfied (2)	Satisfied (3)	Very Satisfied (4)
My family member with special needs has support to make progress at school or workplace. (1)	0	0	0	0
My family member with special needs has support to make progress at home. (2)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
My family member with special needs has support to make friends. (3)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
My family has a good relationship with the service providers who work with our family member with a disability. (4)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

# Daily Check In

Q1 Rate your level of stress from 0 to 100, with 0 being no stress and 100 being complete stress.

0 10 20 30 40 50 60 70 80 90 100



### **FMI-14**

The Freiburg Mindfulness Inventory (FMI) is protected by copyright, owned by Dr. Harald Walach. While the questionnaire is openly available according to Dr. Walach, he asks that studies secure permission for usage.

To obtain a license for the Freiburg Mindfulness Inventory, please message Dr. Walach using this message form: <u>https://harald-walach.info/contact-form/</u>.

### **TI-MBSR Semi-Structured Interview**

Q1

Thank you for participating in this participant satisfaction interview.

What did you think about the meditation?

Q2 How did defusion change the way you relate with yourself as a mother of a child with autism?

Q3 How useful was the problem-solving technique?

Q4 How easy or difficult was it to learn the techniques? What about actually applying the techniques?

Q5 Did you feel safe or unsafe throughout this process?

Q6 Tell me about your personal outcomes with these interventions. Did they accomplish what you hoped they would? Do you wish something would have been different?

Q7 On a scale of 1-10, how likely are you to recommend meditation to friends with similar challenges?

- 0 0 (0)
- 01(1)
- 0 2 (2)
- O 3 (3)
- 0 4 (4)
- 0 5 (5)
- 0 6 (6)
- 07(7)
- $\bigcirc 8$  (8)
- 0 9 (9)
- 0 10 (10)

Q21 On a scale of 1-10, how likely are you to recommend defusion to friends with similar challenges?

- $\bigcirc 0 (0)$  $\bigcirc 1 (1)$  $\bigcirc 2 (2)$
- O 3 (3)
- O 4 (4)

5 (5)
6 (6)
7 (7)
8 (8)
9 (9)
10 (10)

Q20 On a scale of 1-10, how likely are you to recommend the problem-solving techniques to friends with similar challenges?

- 0 0 (0)
- 01(1)
- O 2 (2)
- O 3 (3)
- 0 4 (4)
- 0 5 (5)
- 0 6 (6)
- 07(7)
- 0 8 (8)
- 09 (9)
- 0 10 (10)

Q8 What do you wish the researchers knew about you and/or your experience with this project?

### **Collette Interview**

What did you think about the meditation? It was helpful.

How did defusion change the way you relate with yourself as a mother of a child with autism? *It was good to take a step back sometimes*.

How useful was the problem-solving technique? It was helpful.

How easy/difficult was it to learn the techniques? What about actually applying the techniques? *It was very easy to learn but more difficult to apply*.

Did you feel safe/unsafe throughout this process? Safe.

Tell me about your personal outcomes with these interventions. Did they accomplish what you hoped they would? Do you wish something would have been different? *I think they helped me. I think more examples or something written down would have been helpful.* 

On a scale of 1-10, how likely are you to recommend meditation to friends with similar challenges? *Passive*.

On a scale of 1-10, how likely are you to recommend defusion to friends with similar challenges? *Detractor*.

On a scale of 1-10, how likely are you to recommend problem-solving to friends with similar challenges? *Passive*.

What do you wish the researchers knew about you and/or your experience with this project? *No response.* 

#### **Eve Interview**

What did you think about the meditation? It was difficult to concentrate.

How did defusion change the way you relate with yourself as a mother of a child with autism? It helped me separate my identity and my actions. I didn't see myself as a bad mom when I got upset and began to extend more grace to myself and be able to identify problems and helps I could use in the future. I would say overall it improved my self-image as a mom.

How useful was the problem-solving technique? *The problem-solving technique was useful to me in that it helped me engage in new ways of thinking through scenarios.* 

How easy/difficult was it to learn the techniques? What about actually applying the techniques? It was very easy to learn the techniques. Applying the techniques took more effort on my part because it was different than how I typically operated.

Did you feel safe/unsafe throughout this process? Safe completely.

Tell me about your personal outcomes with these interventions. Did they accomplish what you hoped they would? Do you wish something would have been different? *I feel like I was able to handle social situations and meltdowns better with my child as well as have more peace at home because I was able to defuse things with myself and through my child. I wish more focus would have been on that.* 

On a scale of 1-10, how likely are you to recommend meditation to friends with similar challenges? *Detractor*.

On a scale of 1-10, how likely are you to recommend defusion to friends with similar challenges? *Promoter*.

On a scale of 1-10, how likely are you to recommend problem-solving to friends with similar challenges? *Detractor*.

What do you wish the researchers knew about you and/or your experience with this project? *More about my particular experience and challenges as a mom of a child with autism.*