# Walden University

College of Social and Behavioral Sciences

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#### Abstract

Stress, Social Support, and Mindfulness in Parents of Children with Neurodevelopmental

Deficits: A Quantitative Analysis

by

Branden D. Syrotchen

MS, Walden University, 2012

BS, Spring Arbor University, 2001

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

Walden University

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#### Abstract

Parenting children with neurodevelopmental deficits (NDDs) is very stressful, more so than the parenting of typically developing children. There is considerable research on the topic of chronic stress experienced by caregivers; however, less is understood of parental stress experienced when raising children with NDDs. The purpose of this study was to examine how parental traits and habits, in the forms of mindfulness and social support levels, affect this cohort's general stress levels. The study was guided by Self-Determination Theory, which explored how parental acts could be classified along a continuum of being intrinsically or extrinsically derived. A convenience sample of parents (n = 71) with a child diagnosed with at least one NDD were recruited from online support groups on Facebook. The participants fully completed the Parental Stress Scale to measure parental stress, the Mindful Attention Awareness Scale to measure trait mindfulness, and the Family Support Scale to quantify social support to the family. Correlation analysis and multilinear regression analysis were used to determine that higher levels of social support and mindfulness in the participants predicted lower levels of perceived parental stress; the model was statistically significant,  $R^2$ =.284, F(2,68)=13.504.p<.001. As a set, the two predictors accounted for 28.4% of the variation in stress. This study helps to promote positive social change by providing informing data on population-specific research, which can assist in the development of empirically supported treatments that could be used by professionals and paraprofessionals in treatment planning, therapies, and psychoeducational interventions.

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#### Dedication

I dedicate this work to my Lord Jesus Christ who assisted me around, over, under, and through every barrier that arose during this long and exhaustive endeavor. I also recognize and greatly appreciate the support of my family. To my wife Brandy, who allowed me to take of our precious time and resources for all the years necessary to complete this journey, you are one in a million. Who else would put up with this? To my mother, Diane, who has helped me accomplish this task both financially and with great emotional support. In the mother lottery, with all the winning numbers, I could not have done any better. To my children—Joshua, Ariel, Elizabeth, and Josiah—thank you for being supportive and giving greatly of your time. I had little idea of the commitment I was making when I started this process. In hindsight, I should have talked about it with all of you before I started. Again, thank you for enduring this.

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It is my desire that this thesis will help build on the available knowledge in the area and hopefully ease the load on this overburdened population group.

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#### Chapter 1: Introduction to the Study

#### **Background**

The role of a parent is full of new learning experiences, personal growth, and difficulties. Parenthood universally exposes individuals to additional stress opportunities. Research shows that parenting children with neurodevelopmental deficits (NDD), such as Attention Deficit Hyperactive Disorder (ADHD), Autism Spectrum Disorder (ASD), and Intellectual Developmental Disabilities (IDD) is associated with significantly higher everyday levels of stress than parenting typically developing children (Neff, 2010; Theule, Wiener, Rogers, & Marton, 2011). Social support and mindfulness could be helpful in managing these higher stress levels, since both are generally helpful in decreasing stress, especially in the caregiver population. High stress is suspected in having a detrimental effect in DNA. Blackburn and Epel (2012) and Puterman and Epel (2012) reported on how the mothers of chronically ill children demonstrate statistically shorter telomeres, the protective end caps of DNA, which help to resist against DNA cell degeneration. These researchers observed that along with shorter telomeres, their sample group also produced lower amounts of telomerase, which is the enzyme the body produces to aid in repairing eroding telomeres.

High levels of stress are also correlated with the degrading of the immune system and a plethora of physical ailments in organ systems; Kamal et al. (2010) and Lakshminarasimhan and Chattarji (2012) focused on the negative effects of chronic stress in the hippocampal and amygdala areas of the human brain. Researcher Robert Sapolsky (1996; 2006) found high rates of pathology and disease, isolated to hierarchal systems, brought about by primate cultural practice, which promote long-term chronic stress and disease, especially apparent in lower hierarchy participants. Some studies estimate that up to two-thirds of individuals who provide

family caregiving experience chronically elevated levels of stress (Baker-Ericzen et al., 2005; Tomanik, Harris, & Hawkins, 2004).

Given that high stress is a problem, particularly in the parents of children with NDDs, finding ways to reduce or alleviate stress is an important pursuit. According to Van der Oord, Bögels, and Peijnenburg (2012), Black and Fernando (2014), Burke (2010), and Modesto-Lowe, Chaplin, Godsay, and Soovajian, (2014) mindfulness practices tend to reduce stress in children and adolescents and their parents (Van der Oord et al., 2012). Additionally, Theule et al. (2011) and Neff (2010) have measured the use of social support and found it to be helpful towards decreasing parental stress in the parents of children diagnosed with a NDD such as ADHD.

#### **Problem Statement**

Stress represents a multidimensional construct, which can help people at moderate and infrequent levels. For example, if an individual goes bungee jumping, the stress response is part of what makes the experience enjoyable. In like manner, if an individual goes jogging and an aggressive dog begins to chase them, the stress response helps to better focus all the individual's faculties for immediate action. It is clear that the physiological response from stress is helpful at times; but the schism in this system is that many individuals do not know how to return to baseline once a perceived threat is over (Sapolsky, 2006).

According to a recent survey conducted by the American Psychological Association (APA, 2017), North American culture, in general, does not promote or encourage the deescalation of stress in everyday cultural practice. An existence that contains any measure of responsibility will also have degrees of motivation to strive towards perceived necessities, goals, or actions. As a direct result of daily striving, or indirectly through day-to-day experiences, stress will occur. Research has found that chronic high stress promotes neural cell atrophy (Kamal et

al., 2010; Lakshminarasimhan & Chattarji, 2012), high blood pressure (Wilkinson, 1996), reduced immunity (Sapolsky, 2006), and contributes to a higher mortality rate (Puterman & Epel, 2012). The parents of children with NDDs tend to suffer from higher than average levels of stress in comparison with, parents of average developing children. These parents are negatively impacted in that their chromosome ends (telomeres) appear consistently shorter when compared to the telomeres of parents with typically developing children (Blackburn & Epel, 2012). It must be noted that telomere research is still a relatively new field of study and several researchers question the veracity of telomere studies that connect chronological age with telomere erosion since these findings have not been able to be replicated in other clinical studies. This topic will be expanded upon in Chapter 2.

Social support is commonly understood as an important aspect of an individual's social life; however, it is also an important therapeutic resource and will be addressed as such in this work. Social support is an individual's accumulation of accessible social resources, all of which may foster a family's ability to cope with life difficulties. Researchers have noted that as parents expand their coping mechanisms, they generally do better in coping with their family stressors and tend to handle everyday stressors in a more capable manner (Neff, 2010; Theule et al., 2011). Social support activities can include: going to worship services, family activities that include multiple participants, going out to eat, and verbal or physical interactions with relatives or friends, whether on the phone or in person. Researchers generally view social supports as representing an important outlet for families that have children with neurodevelopmental difficulties, such as ADHD (Neff, 2010; Theule et al., 2011). However, research is particularly sparse outside of the general caregiving area. The population of parents with children who have NDDs would likely benefit from targeted studies in this area; additional data would likely add

attention towards this population and assist toward increased psychoeducational training to this population group.

The concept of mindfulness does not yet have mainstream recognition outside of individuals who practice it. Many people understand that it is a method to help bring about relaxation but probably understand little more. Mindfulness interventions focus on an intentional strategy for decreasing anxiety and stress within applied populations; currently however, there is sparse research available that indicates whether this intervention continues to be effective over time (Black & Fernando, 2014; Burke, 2010; Modesto-Lowe et al., 2014; van de Weijer-Bergsma, Formsma, de Bruin, & Bögels, 2011).

Research on mindfulness interventions with children and adolescents note that there is an initial reduction of symptoms within ADHD populations; however, no long-term studies were found in this area. Also noted was that the symptom reduction in these children had a statistically significant association with symptom reduction in their parents (Burke, 2010; van der Oord, Bögels, & Peijnenburg, 2012). Van Der Oord et al. (2012) completed a quasi-experimental study in which both the child and the parent received structured mindfulness training that lasted for eight weeks. They found that mindfulness training did help decrease symptomology by decreasing general stress and situational parental over-reactivity, as rated by the participating parents. The researchers concluded that future research remains necessary to establish the efficacy of this treatment within varying economic groups in a larger ADHD population. The authors saw a pattern in which individuals with a higher-than-average income tended to utilize this intervention more often; therefore, a general question occurred as to its effectiveness and utilization in the general population.

Researcher Burke (2010) compiled a meta-analysis of 15 studies of mindfulness-based stress reduction and mindfulness-based cognitive therapies, noting their efficacy with child and adolescent populations. It was found that mindfulness-based interventions demonstrated a statistical significance in symptom reduction but there was a consistent lack of standardization with these types of interventions, from one to another. Burke (2010) recommended continued research with a focus towards broader population groups and additional parent participation with their child to increase mindfulness interventions general usefulness.

Modesto-Lowe et al. (2014) focused on the area of effective interventions for the parents of teens with ADHD. They surmised that pharmacotherapy, parenting styles, resiliency factors, and mindfulness training all appeared to positively affect these teens' symptomology. However, they hypothesized that the efficacy of mindfulness training is likely due to increases in parental resilience rather than in the shifting of parental style or children's symptomology. The researchers recommended additional research to better understand why mindfulness is effective.

The consensus is that mindfulness is effective, but not uniformly applied or understood well enough to know how, why, or its range of effectiveness. Continued empirical research remains vital, as it appears clear that mindfulness-based approaches appear to be growing, and mindfulness is gaining more acceptance within mainstream culture. It is now important that the therapeutic mechanisms of mindfulness are broken down and more fully understood.

## **Purpose of the Study**

The purpose of this quantitative study was to compare how level of mindfulness and social support affect perceived stress in parents of children with NDDs. The dependent variable was perceived stress levels in parents. The predictive variables were the levels of mindfulness

and social support. The study examined the degree to which the predictor variables, independently or in combination, explain detected variance in the dependent variable.

#### **Research Questions and Hypotheses**

## **Research Question 1**

Regarding the parents of children with neurocognitive deficits, is their level of social support as measured by the Family Support Scale correlated with their level of perceived stress, as measured by The Parent Stress Scale?

Null hypothesis ( $H_01$ ): Social support, as measured by The Family Support Scale has no significant relationship on the level of perceived stress, as measured by The Parent Stress Scale within the specified population.

Research hypothesis ( $H_a1$ ): Social support, as measured by The Family Support Scale, has a significant relationship on the level of perceived stress, as measured by The Parent Stress Scale within the specified population.

#### **Research Question 2**

Regarding the parents of children with neurocognitive deficits, is their level of mindfulness, as measured by The Mindful Attention Awareness Scale, correlated with their level of perceived stress, as measured by The Parent Stress Scale?

Null hypothesis ( $H_02$ ): The level of mindfulness, as measured by The Mindful Attention Awareness Scale, has no significant relationship on the level of perceived stress, as measured by The Parent Stress Scale within the specified population.

Research hypothesis ( $H_a2$ ): The level of mindfulness, as measured by The Mindful Attention Awareness Scale, has a significant relationship on the level of perceived stress, as measured by The Parent Stress Scale within the specified population.

#### **Research Question 3**

Regarding the parents of children with neurocognitive deficits, do higher levels of social support, as measured by The Family Support Scale, and mindfulness, as measured by The Mindful Attention Awareness Scale, significantly predict less perceived stress, as measured by The Parent Stress Scale?

Null hypothesis (*H*<sub>0</sub>3): Higher levels of social support, as measured by The Family Support Scale, and mindfulness, as measured by The Mindful Attention Awareness Scale, does not predict less perceived stress, as measured by The Parent Stress Scale in the specified population.

Research hypothesis (*H*<sub>a</sub>3): Higher levels of social support, as measured by The Family Support Scale and mindfulness, as measured by The Mindful Attention Awareness Scale does predict less perceived stress, as measured by The Parent Stress Scale in the specified population.

#### Theoretical Framework

The theoretical framework for this study used Richard Ryan and Edward Deci's theory of motivation, amply titled, self-determination theory (SDT) (Deci, Schwartz, Sheinman, & Ryan, 1981; Ryan & Deci, 2000a). The SDT addresses motivations for behaviors which typically result in any given action. This theory distinguishes the motivations for carrying out actions into two categories: intrinsic and extrinsic (Ryan & Deci, 2000a). Intrinsic and extrinsic motivations tend to contrast each other. Ryan and Deci (2000a) posited that intrinsic motivation is the motivation used in carrying out actions that are inherently interesting or enjoyable. Extrinsic motivation includes the type of motivation needed in carrying out actions that are not inherently desirable. Intrinsic motivation remains critical in the domains of cognitive, and social development, because it leads humans to act on their inherent interests. These reactions do not occur for rewards or incentives, but rather for the fulfillment of carrying out the tasks.

The individual is being led by his or her intrinsic motivation, which is the reward that leads to personal growth (Ryan & Deci, 2000a). On the other hand, extrinsic motivation leads humans towards actions that may not be inherently interesting to them. For example, a percentage of the general population works in a vocation they do not necessarily like, so that they can pay their bills. These individuals would not do this type of work if it were not financially important to them. Their extrinsic motivation is the need for money, which is what motivates them, not their natural inherent desire. Extrinsic motivation can also include a task or action that one views as remaining important in the eyes of others they feel significant connections to and or whom they feel the need to please.

Actions represent demonstrations of the type of motivation they initiate from, by the actions relative closeness to the originators perceived self or against their perceived self. An individual's perceived self consists of their ideas, values, and worldview. Self-concept represents an individualistic concept from one person to another. For one person the idea of dwelling on negativistic thoughts remains inconsistent with who they perceive themselves to represent. For other individuals, the freedom of all types of thoughts stand as their individual rights and perceived duties as free people. Simply stated, one's perceived self represents the sum of their idealized ideas, values, and actions. SDT simply categorizes motivations based on the individual's actions in accordance with their perceived self, and how closely those actions align with their self-image (Ryan & Deci, 2000a).

For example, intrinsic and extrinsic motivation can be seen in the United States 2016 primary election. The candidates included Republicans, Independents, Democrats, and other smaller party ideology groups. If you were speaking with people regarding preferred political affiliation, you would likely hear some intense opinions in all three directions. Ideally, most

people consider the facts as they understand them, and then choose the candidate they think can accomplish their vision for the county. However, there is not one universally accepted vision. This act of supporting a candidate, as though they stand for a specific representation of the individual, represents an act of intrinsic motivation. However, an individual might vote for a candidate or party system that they do not approve of because they think it will serve the greatest good, even though they do not care for it on a personal level. An individual may even feel that the electoral college annuls their suffrage, so they may decide to just not vote.

An analogy between these three types of voters can be made in the three types of motivational regulatory styles. Many voters pick the candidate that best suits their personal views, like intrinsic motivation. Other voters pick a candidate that they see to have both good and bad qualities, lesser of two evils. If there was another viable candidate the voter might vote that way instead; this is like extrinsic motivation and it exists on a continuum. Other individuals could vote but choose not to, for one reason or another, like ambivalent motivation, where no real control or autonomy is perceived as being gained, so there is no point in acting. These examples represent an oversimplification of these concepts. Everyday actions consist of complex motivational demands, things people inherently like and many things they do not like. It may be that many people simply ignore how they really feel, conform to their perceived sociocultural worldview, and conform particularly to their present situation to function more effectively. Chapter 2 will contain a detailed explanation of the theoretical framework.

Additionally, Researchers have suggested that mindfulness training helps individuals focus on the current and help avoid outside interests or behaviors (Brown, Kasser, Ryan, Linley, & Orzech, 2009; Brown & Ryan, 2004; Brown, Ryan, & Creswell, 2007). It remains likely that mindfulness training may help the parent lean further towards their perceived culturally

influenced self. In other words, use fewer behaviors that are oriented to gaining personal control of the situation, and move towards a more relational authoritative parental style, which is considered a healthier parental style.

### Nature of the Study

The design of this research study was quantitative and comparative in design, to best suit the examination of relationships between variables, and it was cross-sectional to accommodate for data procured at only one distinct time (Creswell, 2013). An online survey format method was used for three reasons: (a) the convenience to the participants, (b) better representation of the population in the selected sample, and (c) the added ability to access young and harder to reach demographics (Whitaker, Stevelink, & Fear, 2017).

A quantitative study is an effective design, because it can reveal the independent variable of stress levels and how that variable is influenced by the dependent variables of social support and mindfulness, along with any possible interaction effect between the variables. This study included online assessment measures that target the population via Facebook and other online support groups, such as Autism Speaks. The participants were told that research on their population group could be helpful in providing more data, better understanding, and eventually more effective services. The survey participants' stress levels were measured with the Parent Stress Scale, their level of social support was assessed with the Family Support Scale, and their degree of trait mindfulness, was measured with the Mindfulness Attention Awareness Scale. To determine how separately or in unison, the variables have a relationship on the perceived stress levels of this population.

This study provided data about how these variables interact with each other, and possibly helped to explain specific interactions between stress in the parental population, social support,

mindfulness, and the effectiveness of higher levels of the independent variables in the population. Chapter 3 will discuss sample selection, size, and data analysis to address the research questions that contain the study's objective.

#### **Definition of Terms**

The following words are defined according to the purposes of this study:

Awareness: The state of being conscious of what is happening around you, with the use of the five physiological senses (Siegel, Germer, & Olendzki, 2009).

Attention: The state of focusing one's awareness on one's current environment (Siegel et al., 2009).

*Mindfulness:* Synonymous with mindfulness meditation. Using the Sati portion of Pali religious text, which covers three states of: Awareness, Attention, and Remembrance (Siegel et al., 2009).

Remembrance: The state of practicing one's refocusing towards attention in the current moment (Langer, & Moldoveanu, 2000; Siegel et al., 2009).

Social Support: A social system's provision of psychological and physical resources, given to assist the recipient with the coping of assorted stressors, which manifest in the form of emotional, or instrumental action (Shavitt et al., 2016)

Stress: An action and resulting casual reaction of a pressure applied towards an individual or object, identifying a set capacity. It is also a physiological reaction to unpleasant or harmful environments (Cooper, & Dewe, 2008). The main definition used in this study is the combination of physical and psychological responses precipitated from the interaction between the individual and their environment, which is appraised as a threat or potential threat (Lazarus & Folkman, 1984).

Variations of mindfulness: Include but are not limited to: Using non-judgmental attitudes towards one's thought life (Williams, & Kabat-Zinn, 2013), or just assessing ones' awareness, and attention (Brown, & Ryan, 2003).

### **Assumptions and Limitations**

The participants in this study were recruited from Facebook via their parental support group forums. The MAAS (Brown & Ryan, 2003) is a reliable and valid instrument used in the measure of mindfulness. The FSS (Dunst, Jenkins, & Trivette, 1984) is both a reliable and valid instrument used in clinical and research settings. The PSS (Berry & Jones, 1995) is a reliable and valid instrument used in clinical and research settings. The participants in the study were asked to complete the entire survey in the form of general demographic questions, three small test measures, and then instructed that only completed surveys would be accepted for research purposes. The scales used to assess support and stress used the emotionality of perceived support and perceived stress to direct the respondents away from acquiescence bias (Berry, & Jones, 1995; Dunst et al., 1984), while the MAAS (Brown, & Ryan, 2003) avoided questions that include emotional or motivational intent to assist in that area. All three measures used questions that reflected actual experience rather than expectations to assist in avoiding social desirability responses. All three test measures included original instructions in accordance with administration and scoring as to maintain reliability and validity.

It was assumed the person answering the survey was the same individual recruited and that she or he would complete the survey accurately and honestly. It was also assumed that by following established guidelines for conducting online data collection, participant confidentiality would be maintained. Since respondent accessibility was a foreseeable issue, a convenience sample was used, which introduced an additional population generalization weakness. Using an

online survey approach added the weaknesses of not being able to control the administration of the survey and would limit the survey respondents to individuals with internet access.

Behavioral research data collection, such as the type used in this study, can be susceptible to several possible biases. Recall bias is difficulty recalling the past events the way they occurred and is primarily due to degrading of memory. There is also the respondent's mood state, or transient mood state bias, which is the respondent's propensity or current situational likelihood to respond in an excessively positive or negative manner (Podsakoff, Mackenzie, Lee, & Podsakoff, 2003). One method suggested to help with mood state and transient mood state bias is the counterbalancing of question order from the predictor and criterion variables (Podsakoff et al., 2003). This study presented the criterion variable of perceived stress in the context of the PSS (Berry & Jones, 1995) as the first order of measures, to aid with this potential bias.

This researcher recruited and collected the sample entirely in the online environment. In doing so, there were three difficulties with generalizing the study results to the populations other than similar populations. Firstly, as a direct result of research design via the use of a convenience sample. Secondly, the problem was that 95.8% of the sample were females. According to the NAC, roughly 75% of all caregivers are female (National Alliance for Caregiving, 2009), so even with this statistic considered, the sample did not represent the general population. Thirdly, the disorders that the parents reported their children having in the demographic area of the survey, were not representative of the general population in frequency rates (i.e., more children identified with ASD than ADHD).

#### **Scope and Delimitations**

This study used a quantitative approach to measure differences in the perceived stress of parents of children with NDDs, as affected by their level of trait mindfulness and social support.

The study centered on the high levels of stress that this population regularly endures (Neff, 2010; Theule et al., 2011). The population of parents with NDDs was selected to include a wide array of parents that experience these difficulties (Neff, 2010; Theule et al., 2011); however, to narrow the scope, caregivers were not included unless they were the primary caregiver for a child with NDDs. Including all caregivers that experience high stress would have broadened the population, but also would have expanded the topic area.

The variables of mindfulness (Black & Fernando, 2014; Burke, 2010; Modesto-Lowe et al., 2014; van de Weijer-Bergsma et al., 2011) and social support (Neff, 2010; Theule et al., 2011) were selected because they are both constructs currently being utilized to decrease stress and both were accessible. Many other relevant variables—such as the parents' SES level, parental personality, level of symptoms occurring with the child, the child's level of functioning, and level of behavioral problems—could have been included; however, several of these topics have been extensively studied such as SES level of the parent and level of the child's behavioral problems. Other variables such as parental personality types in parenting and degree of symptomology of the child, would have narrowed the scope and distracted from the study's secondary focus of easily assessable ways to decrease stress within this population.

One assessment measure was used for each of the three variables, along with the qualifying demographic data questionnaire. A non-randomized convenience sample was used in this study since the targeted population was particularly narrow and not foreseeably assessable. This, however, limited the ability for generalization of the data to the entire population. A convenience sample would introduce the possibility of self-selection bias, caused by the very act of the respondent choosing to participate, instead of randomly being picked (Xu et al., 2017). The selection of online support groups was used because of the very limited clinical access to

local populations, and to add convenience for a participant population that already has high levels of demand on their available time (parents of children with NDDs).

### Significance

This study was unique because it examined stress within the context of the interaction of the levels of social support and of mindfulness. Researchers have strongly suggested that stress includes a host of detrimental effects (Kamal et al., 2010; Lakshminarasimhan & Chattarji, 2012; Puterman & Epel, 2012; Sapolsky, 2006; Wilkinson, 1996). Discovering new ways to decrease stress or to even moderate it represents a worthwhile pursuit. Because stress remains indirectly correlated with many health problems, researchers do not typically give it the mainstream attention that an entirely causal disease might receive. Additionally, the theme of the shortening of telomeres is likely not well understood or interpreted as equally important as a visibly diagnosable disease.

When considering this information, along with a strong indication that the problems this parent population incur, the importance of this study is clear. The research-focused studies in this area help to expose the less visible areas of associated health problems within this parent population. This information directs attention towards the health and safety of these parents as they are more likely to focus on the needs of their own child, to the neglect their own self-care. Commonly understood, prolonged levels of stress in this population, are neither healthy nor helpful. If parents focus exclusively on the child and disregard their own health, the likely consequences will be significantly poorer health as they age. However, there is a secondary result. It could also increase the severity of their children's symptomology due to the hypothesized association; the parent and child's symptomology increase or decrease together. In other words, the parent and child symptoms tend to equalize with the other. When one member is

responding appropriately or poorly, the counterpart tends to follow suit in that direction.

Research theorizes that the parent and child's symptoms align with each other (Modesto-Lowe et al., 2014).

It remains noteworthy in the literature that because these parents can become entangled within negative symptomology, they will more likely focus on the *reactive* management of behaviors rather than the *proactive* continuation of care. This approach clearly does not represent the most effective approach. Researchers have demonstrated that increased stress levels correlate with increased symptomology within this child and adolescent population (Healey, Flory, Miller & Halperin, 2011; Moghaddam, Assareh, Heidaripoor, Rad, & Pishjoo, 2013; van der Oord et al., 2012). With increased symptomology also comes a greater likelihood of the use of negative parental styles, which include behaviors such as yelling, shaming, and ignoring the child/adolescent. These adult reactions have consequences in that the focus remains on negative behaviors. Notably, these issues complicate the parent-child dynamic and strain general rapport. It remains clear within the mental health field that both good rapport and a strength-based approach typically is the most effective way of seeking positive change.

As data emerges within this area, society becomes more familiar with the detrimental effects of stress, the stressors unique towards this population, and the positive aspects of mindfulness, and social support. It is expected that, this information challenges the way our society views the multidimensional aspect of stress, and the perceived need to cope with daily stressors appropriately. It is expected that dissemination of this data and feedback will have a gradual effect on positive social change, in the form of how these issues are handled. The use and dissemination of new and innovative implemented interventions, such as mindfulness, are envisioned to as helping to decrease negative parental dynamics and general symptomology

among families with children that have ADHD (Bögels, Lehtonen & Restifo, 2010; van der Oord et al., 2012; van de Weijer-Bergsma et al., 2012).

Given current practice, it seems clear that this population of parents is underserved.

Given the gravity of symptomology of children with NDDs, it is clear why much of public attention and public policy focus on the welfare of the child, in ignorance of the toll that these types of circumstances can take on the parents' associated health. However, given this information, it is not responsible, sustainable policy to continue to be ignorant of the full dynamics of this problem. Rather, treatment of both the child and the parent is more likely to meet the holistic needs of this issue from a family systems perspective (Johnston & Mash, 2001).

#### Summary

Although stress is a general problem in North American culture, it is an even larger problem for the parents of children with NDDs (Neff, 2010; Theule et al., 2011). Prolonged stress is a problem because of the many emotional, physical, and health detriments that accompany it (Kamal et al., 2010; Lakshminarasimhan & Chattarji, 2012; Puterman & Epel, 2012; Sapolsky, 2006; Wilkinson, 1996). Two methods being used to help diverse populations decrease their stress levels in general, and to a lesser extent the target population, are mindfulness/meditation (Van der Oord et al., 2012) and social support (Neff, 2010; Theule et al., 2011). This study examined how the populations' excessive stress may encourage extrinsically motivated (non-desirable) responses, through the lens of SDT (Ryan & Deci, 2000b), and how mindfulness and social support may encourage intrinsically motivated (self-desirable) responses. The focus of this study was to observe how meeting various levels of internal needs by means of mindfulness and social support, affect individual levels of perceived stress.

With a better understanding of how stress affects this population, and with added vigor to current practices, program development researchers can more effectively institute efficacious interventions, to limit the environmental factors that affect this problem.

Chapter 2 covers the empirical literature on self-determination theory (Ryan & Deci, 2000), the history of stress research, a current understanding of the physically and emotionally destructive nature of chronic stress, an understanding of stress within the population, the origins of mindfulness, contemporary mindfulness its variations and use as an aid in stress relief, social support and its use in the assistance of stress relief, and an overview of the guiding theory- how actions that encourage intrinsic motivation may encourage less perceived stress. Chapter 3 includes the details of the study, its methodology, and design. Chapter 4 presents results from the analysis of the data in relation to the research questions and hypothesis. Chapter 5 presents interpretations, limitations, recommendations, implications and a conclusion of the study.

#### Chapter 2: Literature Review

#### Introduction

Stress, as the term is popularly used, represents a multidimensional construct that can be helpful at moderate levels; however, at sustained high levels, stress contributes to many health problems (Kunz-Ebrecht, Mohamed-Ali, Feldman, Kirschbaum & Steptoe, 2003; Gouin, Scarcello, da Estrela, Paquin, & Barker, 2016). The parents of children with NDDs experience stress at a higher rate and frequency than parents of typically developing children (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005; Neff, 2010; Theule et al., 2011; Tomanik et al., 2004). These higher rates of stress pose an increased risk to health. This research was focusing on mindfulness (Sedlmeier et al., 2012) and social support (Lindo, Kliemann, Combes, & Frank, 2016) because they both have a moderating effect on health risks by reducing perceived stress. The present study sought to address how inherent mindfulness and the level of social support affect the perceived stress levels in the population of parents of children with NDDs.

The literature review will include literature search strategies and the theoretical framework that informs the study. It will also cover the following topics: (a) an overview of the history of stress research, (b) the effect of chronic stress in the population, (c) the current applications of stress research, (d) the current research on the effect of social support on stress reduction, (e) a history of mindfulness with an elementary understanding of its origin, (f) definitions of the construct of mindfulness, and the (g) application of trait mindfulness towards this study. This literature review establishes a need for continued research and dissemination of outcomes in the areas of mindfulness and social support as they affect the perceived stress levels of adults, specifically the parents of children with NDDs.

#### **Literature Search Strategy**

A search of literature was conducted digitally through the following electronic databases: PsycINFO, PscyARTICLES, SocINDEX, PsycBOOKS, MEDLINE, Mental Measurements Yearbook, Health and Psychosocial Instruments, Sage, EBSCOhost, and Medscape. The list of search keyword strings used to conduct this literature search were as follows: history of stress research, stress research, stress and stressors, chronic stress, parental stress and NDDs, parental stress and developmental deficits, stress and neurobiological disease, Self-Determination Theory, SDT, self-determination theory interventions, self-determination theory and mindfulness, origins of mindfulness, mindfulness and types, history of mindfulness, mindfulness and mindlessness, social support and parental stress, social support and disabilities, social support and culture, and stress. The books and peer-reviewed articles were reviewed from the early 1960s to 2017.

#### **Theoretical Framework**

The primary theoretical framework for this study is Self-Determination Theory (SDT), developed by Deci and Ryan (1981). The secondary theoretical framework is the Theory of Cognitive Appraisal (Lazarus & Folkman, 1984), which proposes appraisals of stressors and resultant coping. This secondary framework provides the structure between the outcome variable of stress and SDT (Ryan & Deci, 2000a). SDT was formally introduced in the year 2000 but has been informally in development since the mid-1980s (Deci et al., 1981; Deci, Eghrari, Patrick, & Leone, 1994; Deci & Ryan, 2000; Ryan & Deci, 2000a; 2000b). Self-Determination Theory (Ryan & Deci, 2000) proposes that six meta-theories impact individuals through cultural and social forces that interact with the individual's personal autonomy and ability to freely act on their will.

For the purpose of this study, the first three meta-theories of SDT will be thoroughly covered. In SDT theory, the fuel for healthy development is the fulfillment of three basic psychological needs—personal autonomy, competence, and relatedness. These human needs are purported to have the largest positive effect on the promotion of personal will and initiative. As interactions in these three areas are met, an individual will experience better psychological wellbeing and functionality in his or her social-ecological system. As these three individual needs are encouraged, SDT theory implies that the individual will experience more volition and be encouraged into a higher quality of motivational engagement in their environment. However, if these three areas are stifled, it is believed the individual will experience lower levels of motivation and well-being. Intrinsic motivation represents the individual's motivation that most closely aligns with his or her perceived self—their internalized values, goals, and belief systems. Intrinsic motivation is best represented as personal will as directed by internalized belief systems. Extrinsic motivation is represented by the contrasting range of motivations that one must pick from for practical reasons; these motivations are thought to discourage personal autonomy, competence, and relatedness.

As six meta-theories are integrated together, they form SDT theory. SDT theory generally seeks to explain human action in the context of motivation. SDT is an organismic meta-theory because of its focus on the specific development of the individual via the integration of key needs, such as autonomy, relatedness, and competence. As these needs are met, they assist in the whole development of the individual. The first of SDT's meta-theories is Cognitive Evaluation Theory (CET), which helps explain the differences from one person to another regarding intrinsic motives.

CET refers specifically to environmental and social factors and how they either encourage or discourage intrinsic motivation. The theory states that if individuals get these needs met, they inherently respond with intrinsic motivations (Deci et al., 1994; Deci & Ryan, 2000; Moller & Deci, 2010; Ryan & Deci, 2000a). The CET theory purports that feedback, communication, and rewards all help to increase the individuals' competence during participation of intrinsic actions. As a sense of competence is also combined with autonomy, the combination encourages intrinsic motivation. According to SDT theory, autonomy needs to be encouraged or previously developed within the individual; otherwise, it will not naturally occur. In other words, SDT states that humans need encouragement in the direction of these needs for motivational maturity to happen. In the opposing direction of self-directed behavior are threats, imposed deadlines, goals, directives, and pressuring evaluations, which are all thought to diminish autonomy. In reference to this study's target population, as the parent feels a sense of mastery/competence and self-will/autonomy in parenting their child, they are more likely to enjoy doing so. According to SDT, along with their basic needs being met more fully, additional intrinsic motivation to initiate parental roles/responsibilities will arise because they feel like they can.

The second micro-theory of SDT is Organismic Integration Theory (OIT). This micro-theory is focused on the degree of internalization of extrinsic motivations. Internalization refers to the degree in which a person could take an idea or concept as their own. In other words, some actions, ideas, rules, and instructions are more difficult to go along with than others. An individual accepts an idea or concept on how closely it aligns with his or her perceived self. These concepts are close to moral judgments and most likely would align with one's morals. However, individuals may experience variance in moral temperance, yet still move towards a

direction that aligns with how they really feel. Intrinsic motivations are acted on because they are enjoyable or desirable; however, extrinsic motivations are more complex.

Extrinsic motivations take place on a continuum, with high control/less autonomy on one end of the continuum and high autonomy on the opposing end. On the high autonomy end of the continuum, one might only be able to distinguish motivation from being extrinsic versus intrinsic by whether it was initiated by the individual or by an external source. The OIT meta-theory reports of extrinsic motivation in terms of a continuum; as if a line was drawn, moving from external control on one side to autonomy on the other, control begins to decrease as autonomy begins to increase, see figure 1. The continuum of extrinsic motivations consists of a high degree of control with external regulation (ER). Introjected regulation (INR) is the next phase of the continuum, then Identified regulation (IDR), and finally integrated regulation (ITR).

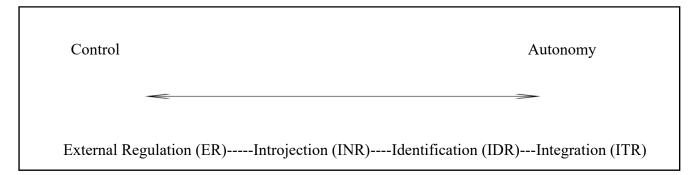


Figure 1. The continuum of extrinsic motivation: in terms of Control Vs Autonomy. An adaption from the OIT theory model. (Deci & Ryan, 2000a).

The ER area consists of completely external forces, which both push the source and the individual to be motivated. This could consist of rule compliance, financial incentives, and perceived consequences. The INR area of the continuum is more autonomous; it is theorized to involve the individual's personal will via ego-involved activities. Ego-involved activities of this area include anything that the individual did because it helps relieve stress in areas such as

anxiety, fear, or guilt. This area could also include demonstrations of ability, power, or control to show skill or to impress others. The next area of the continuum (IDR) moves even further towards personal autonomy, via the individual consciously valuing the regulation; thus it is an identified regulation because the individual personally identifies with the idea/concept. The final phase in the extrinsic motivation continuum is the ITR area, which entails a congruence with the actor's personal view of himself or herself (Deci & Ryan, 2000; Ryan & Deci, 2000). Even though the individual does not self-initiate the motivation, he or she is still pleased to do it because it is consistent with the autonomous desires and views.

As this relates to the stated population, many acts of parenting are not black or white, rather they are on a continuum. Choices are made because they are weighed as being more beneficial, but not necessarily more desirable. For example, there are not many parents who want their child to be consistently taking prescription antidepressants or antipsychotics; however, when the situational risks become too high, they may decide it is the best current direction. If the prescription ends up helping their child better maintain their symptoms, the parent may begin to integrate the idea of these types of medications as being very helpful in certain circumstances. As demonstrated by the OIT meta-theory of SDT, as the extrinsic act is deemed to be helpful or hurtful, it will likely move on the continuum towards integration or external control.

The third micro-theory that makes up SDT is causality orientation theory (COT). This part of the meta-theory addresses the three types of regulatory styles of motivation, which are ambivalent, autonomous, and external exertion of control. Ambivalent regulation is demonstrated by individuals who are undecided in a situation; they are thought to not care about the results or not believe they can exert control/autonomy over an issue or situation. This could be compared to the individual who thinks that there is no reason to vote for a preferred political

candidate because he or she will personally have no effect on the outcome. Likewise, a parent who feels they are expending all their mental resources towards their child with a neurodevelopmental deficit with no beneficial results will feel neither competence nor personal autonomy within the situation.

According to SDT, if this continues, they are likely to lean towards ambivalence, in the areas most lacking in these needs. The second regulatory style of motivation is autonomous/intrinsic, which, as previously described, includes decisions initiated and controlled by individual choice. As noted, these often correlate with values, beliefs, and morals.

The third type of regulatory style of motivation is extrinsic. It is best understood as choices made that are always externally pressured to some degree. This concept is better understood when combined with the second meta-theory of (OIT), which states that these types of choices are typically made based on a continuum of outside pressure that is mixed with varying degrees of autonomy. In other words, when using the analogy of voting, this same individual may have voted for a political candidate, not because it was the best choice, but rather because it appeared as the least destructive choice. If the decision was completely autonomous, the individual may have been tempted to pick none of the above; however, a balance was sought instead (Deci & Ryan, 2000; Ryan & Deci, 2000a).

For the purposes of this study, the researcher used the cognitive appraisal of stress, based on the Transactional theory of stress and coping (Lazarus & Folkman, 1984). The view of stress, as described by this theory, is individualistic, psychological in nature, and experienced via one's perception of environmental demands that exceed one's capacity. As taxing environmental situations happen, the individual psychologically accesses the stressor as a determined injury, a threat, a challenge, or a neutral event. Lazarus and Folkman (1984) refer to this process as the

primary cognitive appraisal. As this appraisal happens, the individual is classifying the stressor via a level of personal relevance and significance. If the event is relevant and significant, the individual evaluates his or her level of autonomy and external control of the situation; this process is referred to as a secondary appraisal. As SDT (Ryan & Deci, 2000b) and Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984) are applied in conjunction with one another, a pattern emerges that is used to visualize stress and autonomy.

In the application of the CET meta-theory of SDT (Ryan & Deci, 2000a), the three basic psychological needs of autonomy, relatedness, and competence are used in the primary and secondary appraisals of stressors (Lazarus & Folkman, 1984); individuals then use past experiences to envision the stressor as an injury, threat, challenge, or benign situation. As the individual appraises the autonomy and competence on a primary level as being associated with the stressor, he or she is more likely to perceive it as a challenge. On a secondary appraisal level, the individual is also more likely to perceive external control over stressors that he or she feels autonomous over and competent to handle. However, where stressors, autonomy, and competence are low, the individual is more likely to experience primary and secondary appraisals of injury or threat because of a lower degree of personal proprietorship and control (autonomy and competence).

In the application of the OIT meta-theory of SDT (Ryan & Deci, 2000a), the image of a range scale is appropriate, with full autonomy on one side and full external control on the opposite end. The primary and secondary stress appraisals (Lazarus & Folkman, 1984) form as the individual categorizes the stressor and the ability to control it. Applied to the parents of children with NDDs, the appraised goals of these stressors in question can range from everyday difficulties in managing their children to their children becoming autonomous over their own

lives (Theule et al., 2011; Tomanik et al., 2004). As stressors arise daily, if they are perceived as an injury or a threat, it is more likely the parent is appraising the stressor from a position of external control. This perceived situational control is thought to derive from the social environment, as it either provides or denies the individual's basic psychological needs.

As the levels of perceived autonomy, competence, and relatedness increase in the perceived social environment in which the stressor is derived from, the individual is more likely to see challenges rather than injuries or threats. In the application of the COT meta-theory of SDT (Ryan & Deci, 2000b), the issue is the causality orientation of the stressor. The individual disposition of any parent is also going to affect the direction in which he or she perceives injury, threats, challenges, or neutrality (Lazarus & Folkman, 1984) in each stressor. For example, a parent who has more anxiety than average is more likely to also experience increased physiological effects from perceived injury, threats, and low control. Additionally, a negative emotional response is co-occurring with an appraisal of injury or threat in the above case. The degree to which the parents of children with NDDs respond to these appraisals of stress as a challenge rather than an injury or threat results in their ability to respond with effective coping skills. Ultimately, effective coping skills are associated with better physical, psychological, and well-being outcomes (Aldwin, 2000; Lazarus, 1991).

Self-Determination Theory (Ryan & Deci, 2000) in its current form has been applied in areas too numerous for the scope of this study; however, of interest is its use in child development and parenting. In the convergence of applying SDT (Ryan & Deci, 2000b) and Transactional Theory of Stress and Coping (Lazarus & Folkman, 1984), a tentative model has been established that is demonstrative of the connections between these theories; the connections are found in how individuals cope with stressors in conjunction with their motivational goals

(Ntoumanis, Edmunds & Duda, 2009). SDT (Ryan & Deci, 2000b) has been applied in the autonomy-supportive parenting of toddlers to encourage autonomy and in the internalization of parental rules. As the parents consistently support their child's psychological age-appropriate needs, they are more likely to go along with age-appropriate parental demands (Laurin & Joussemet, 2017).

Two other studies also reinforced autonomous-supported parenting in adolescents and college-aged students as encouraging autonomous-motivated practices (Roth, Kanat-Maymon & Assor, 2016). Within the population of individuals with NDDs, specifically mild intellectual disabilities, autonomy-supported parenting has demonstrated benefits in the areas of autonomy and activity satisfaction, decreased anxiety, and increased levels of personal engagement (Pelletier & Joussernet, 2016). SDT research has been applied cross-culturally in the study of 457 South African adolescents that measured the degree to which their psychological needs were met via the makeup of their family structure. However, in that study, the adolescents who had higher levels of met psychological needs tended to have higher levels of extrinsic goal pursuits rather than intrinsic (Davids, Ryan, Yassin, Hendrickes, & Roman, 2016).

In parenting adolescents, while concerned about their ideological and social development, mothers who promoted extrinsic goal seeking, as they parented, were more likely to form an attachment of their personal self-worth associated with their adolescents' achievements (Soenens, Wuyts, Vansteenkiste, Mageau & Brenning, 2015). The mothers of adolescents with high social dominance orientation in the for mentioned study, tended to associate their personal self-worth with their child's achievement, which is also associated with an extrinsic motivation external control style. Self-Determination Theory (Ryan & Deci, 2000a) is used for this study because of the volitional effects that accompany it. In other words, SDT assists with informing

the researcher to the beneficial connections between SDT theory and improved well-being, seen when the three basic psychological needs are sufficiently met, and theorized as lacking in situations where these needs are not met. As individual parents are getting their own psychological needs met, they will be more likely to encourage these same practices in their children.

The central focus of this study is the perceived level of stress, as the outcome variable, of the parents of children with NDDs. Lazarus and Folkman's theory of stress and coping (1984) and its associations (Ntoumanis et al., 2009) with SDT inform the study of how the theory may work and form a reasonable theoretical framework. All three of the research questions to be asked in this study are centrally focused on perceived stress and modifiers of stress within the target population. Higher levels of mindfulness have direct connections with SDT in the area of personal well-being and are generally associated with lower levels of stress (Brown, Ryan, Creswell & Niemiec, 2008). Higher levels of social support appear to act as a stress modifier within the population researched. A high level of social support is theorized to bolster two of the three basic psychological needs of SDT in the forms of relatedness, and competence (Kazak & Wilcox, 1984; Ryan & Solky, 1996). The degree to which levels of social support, mindfulness, and possibly an interaction effect decrease, increase, or have no effect on the stress levels of the participant in the study and will help build upon the associated link (Ntoumanis et al., 2009) between the two theories of stress and coping and SDT.

#### Stress

### **History of the Construct of Stress**

In defining stress, the Latin word *stringere* is thought to be the origin of the word stress, which means to draw tight. To understand current stress research, it is necessary to have an

overview of what is meant by the word and how the meaning has changed as the research in this area has developed. Even before scientific research demonstrated empirical evidence of this phenomenon, many physicians in the 1700s believed that nervous stress or exhaustion, so-called neurasthenia, was indeed a medical reason for the sudden acute decrease of mental capacity. One early stress pioneer, Robert Hooke, viewed stress as an overly simplified external demand placed on the human system. Hooke perceived that this demand appeared to take a physical toll over time. He comparatively viewed humans much like the law of elasticity, in which they appeared to also show the effects of both time and energy expended (Cooper & Dewe, 2008).

Rene Descartes came afterward and noted a mind and body connection, where they appeared to have a definitive effect on each other. A commonly held notion of the time by many practicing researchers/physicians was that one-third of disease was caused by nervous orientation in various forms of stress disorder. Later in stress research, stress was a word used to describe the biomechanical cut-point of stress, as the point at which a material or person could withstand pressure until it succumbed to distortion. World War II veterans, and the poor psychological state in which many came home, encouraged more scientific interest and research in the area.

Researchers began exploring stress, much along the lines of mechanistic views. As people were psychologically and/or biologically pushed beyond their capacity, they too would break down and succumb to diseases. This type of thinking veered towards an evolutionary worldview, that humankind was also not immune from degradation (Cooper & Dewe, 2008).

The professional work of one early researcher, George Beard, focused on Neurasthenia, meaning an individual experiencing a dysfunctional nervous system. A common diagnosis of the day was nervous exhaustion. The research was helpful during this time in that it changed these issues from being flaws of character towards being a legitimate medical issue. Yet many other

researchers at that time viewed stress as a byproduct of the progress of the new age. Claude Bernard revigorated the mechanistic viewpoint of humankind. Much like machines, humans would break down from wear and tear over time. In the field of psychology, a mechanistic view was proposed with William James theory of functionalism, which is concerned with how the body and mind interact together as a system.

In the research of the time, stress was beginning to separate into two different areas—fatigue and mental hygiene. Fatigue was primarily researched for vocational and military applications, such as finding ways to help minimize work fatigue. Mental hygiene was used in clinical applications such as diagnostics and treatment. During this period, Walter Cannon expanded on Bernard's theory of homeostasis, with a new aim towards psychosomatic medicine. Cannon's focus was on the relationship between emotions and disease. Cannon is commonly recognized as the researcher who coined the phrase "the fight or flight response." He defined homeostasis as a condition of stability that may fluctuate but eventually drifts back to baseline. His focus was on the efficiency of the regulatory mechanisms at maintaining this stability. What he came across was the autonomic nervous system, which consists of the sympathetic and parasympathetic systems. These two systems work in conjunction with each other in such a way that the sympathetic system kicks into emergency action, while the parasympathetic imposes the calming down cycle (Cooper & Dewe, 2008).

Cannon's theory was that evolution produced emotions such as fear and anger to trigger the sympathetic system. However, the theory appeared to come up short due to numerous other human emotional expressions. Cannon was on track with the idea that this system appeared to perceive all threats as serious and potent, regardless of actual endangerment. Later, physician-researcher Hans Selye presented his General Adaption Syndrome (GAS) theory, which describes

the cycle of stress, rather than just the stressor. Since he was still developing his theory, the word stress was not used; rather he described the stress process and its prolonged effect on the human body. The GAS theory consisted of three parts: Alarm, the body's call to alertness; resistance, the body's opposing forces; and exhaustion, the depletion of energy, which, he theorized, eventually led to disease and then death (Cooper & Dewe, 2008).

However, Selye's definition of stress was a bit vague; it could mean the stimulus, the response, or the interaction between the two. Selye did identify four types of stress in his expanded GAS theory: eustress, good stress; distress, harmful stress; hyper-stress/over-stressed; and hypo-stress/ under-stressed. This expanded GAS theory appeared to be the first written observation where stress was both helpful and/or harmful, depending upon type and duration. Selye noted that because this system responded to both specific and non-specific threats, disease could be the result of hyper-stress of non-specific threats when there was no actual threat potential. He discovered that the system used to assist the body with fighting off threats could also cause disease by targeting non-existent threats and thereby continue to focus physiological resources to the point of exhaustion (Cooper & Dewe, 2008).

Researcher Jean M. Charcot pursued stress research in hysteria, via psychosomatic medicine and careful observation. Sigmund Freud, also a physician, found the psychosomatic medical approach to be lacking, so he began the development of psychoanalytic theory. Freud thought that individuals who were stressed to the point of having profound life problems needed a guided exploration of their unconscious thoughts, to understand the root of their stress problem. Researcher Franz Alexander, a proponent of the psychoanalytic approach, also recognized organic issues and automatic physiological mechanisms but identified that they were generally out of the area of human willful manipulation.

Researcher Harold Wolf expanded on Selye's work, emphasizing how individuals tended to over-respond to threats, to the extent that they reacted both mentally and physically to a perceived threat. Wolf termed this process "protective reaction response." It differed from Selye's work because of his view of the chain reaction of response, and the view that this response was typically over-reactive in both the quality of an appropriate response and useful intensity (Cooper & Dewe, 2008). As the cognitive movement began to gain ground in psychology, it expanded the idea that individually experienced pressures, would impact individual actors differently, depending upon their past experiences, personality, fears, and pressing issues. The added component was that the stimulus had a varying effect depending upon the unique person, thus the stimulus-organism-response model.

The focus on the theory of coping and the appraisal of stress was being developed in the late sixties in the research of Richard Lazarus. One focus area of his research was the interaction between the individual and his or her environment, which at times taxed the individual to the point he or she was not able to manage at a baseline level or otherwise respond in a typical way. In other words, the issue lay in the judgment of the stimulus, rather than the originator of the stress. Lazarus' original theory of stress and coping (Lazarus, 1966) has been modified somewhat to reflect a relational transaction between the individual and the environment in the form of cognitive appraisals (Lazarus & Folkman, 1986). The cognitive appraisal of stress is foundational in viewing this study from an SDT perspective.

## Effects of Stress in Primates, the General Population, and Target Population

The parents of children with disabilities statistically demonstrate higher levels of stress than their peers, the parents of children without disabilities (Neff, 2010; Theule et al., 2011). Some studies have found that up to two-thirds of this population have significantly elevated

stress levels (Baker-Ericzen et al., 2005; Tomanik et al., 2004). This population is more likely to engage in poorer health habits, which result in poorer health. These poorer health habits take the form of inadequate sleep, increased likeliness to smoke tobacco, higher blood pressure, as well as impaired cognitive and thyroid functions (Gouin et al., 2016). These individuals have higher inflammatory cortisol and C-reactive protein, which is associated with various negative effects in the body (Kunz-Ebrecht et al., 2003).

Another one of the many difficulties of this added stress as it applies to a generalized population of parents of children with disabilities is that their subjective appraisal of their situation determines their degree of well-being. Research in the field is demonstrating that mindfulness and social support help to buffer the effects of chronic stress in these parents. It is hypothesized that these positive effects decrease the overall stress burden, due to increases in the individuals' capacity to cope, strengthening of resources, and training to slow down impulse responses. Of interest in the negative aspects of higher-than-average stress is the topic of how stress affects the individual physiologically, and the crossover between species.

Neuroendocrinologist Sapolsky (2004) has been studying stress via baboons in Kenya. His research has centered on the social standing of baboons in their colony and their associated health benefits or deficiencies. His findings show that when these primates are larger, they also tend to be healthier. These benefits include availability of food, mating choices, greater capacity of choice, and fewer hassles from other baboons. On the other end of the scale, the smaller baboons are more likely to access the leftover food, have fewer mating options, have less control in the colony, and are more likely to be physically abused by other baboons. Although stress is undesirable, it is needed in the right amounts, to help motivate both baboons and humans to go about their daily lives and get their general needs met.

The stress response, also called the "fight or flight response," keeps both humans and animals at the appropriate physiological level for demanding situations. However, it is noted through blood samples in baboons and general stress research in humans, that chronic stress via this long-term exposure to excessive glucocorticoids has many damaging effects on the body (Sapolsky, 2004). This research is noted in the baboon population because the baboons that are not alpha males are noted to statistically have more health problems. Their arteries have more plaque build-up, a higher mortality rate, and higher blood pressure. The overall climate of the typical baboon troop, as observed by the researcher, was more likely to be riddled with physical hostilities towards smaller baboons. In other words, the picture was likened to a few kings that rule their group, and every other baboon was subservient to their rule. The consequence for not going along with this system ends with escalated physical violence perpetrated towards weaker peers. Although this is an overly simplified picture, the result is that adversity rolls downhill, and the smaller one is, the farther downhill one is living. Sapolsky (2004) reports that the complications of being chronically stressed include a less effective immune system, increased chances of stroke, heart attack, cardiovascular disease, ulcers, mental health disorders, permanent health and brain dysfunction in prenatal mammals, and learning and memory difficulties.

Another area of research (Shively et al., 2008) has noted similarities that Cynomolgus monkeys share in comparison with humans and how stress changes psychological body processes. Humans, as well as monkeys, receive a large amount of stress from interactions with their associates; this is particularly seen in macaque monkeys and their peer group. The weaker ones are more likely to be stressed by their peers, which results in measurably higher level of plaque build-up in their arteries, reduced blood flow, higher blood pressure, higher risk of heart attack, heart damage, and a larger proportion of calories stored in the abdominal region. Fat

stored in the abdominal region has consistently been shown to be unhealthier than if it were located within other areas of the body.

A newer area in stress research is the measurement of an individual's telomeres. Telomers are theoretically being used as biological markers of an individual's degree of stress. Several researchers in this area have noted that in several environments of chronic stress, there also appears to be an associated increase in the rate of cellular aging. This is notable through several different mechanisms, which ultimately speed the erosion of the chromosome. This erosion process is aimed at the end of the chromosome, where the telomeres protect. These telomeres are a type of protective cap, which rudimentarily protects the chromosome from fraying. It is hypothesized that this process happens in three separate ways associated with chronic stress: first, by weakening of the cell's immune functions, then by oxidative stress damage caused by the chronic excessive production of glucocorticoids, and lastly, by an abnormally lower production of telomerase.

All three of these pathways have demonstrated distinctive problems in populations of individuals experiencing various forms of chronic stress, as seen via their shorter than average telomere lengths. Telomere length is thought to be a good biological marker of age because telomer lengths progressively become shorter as individuals age, and measurements of these lengths are consistent in average samples of the population. As humans age, their chromosomes replicate and a small amount of the telomere ends are not replaced. Therefore, they shrink very minimally with age until replication problems occur, as naturally happens in the aging process. Average physiological functioning in the human body produces an enzyme, telomerase, which helps aid the process of telomere replication. When this enzyme is being produced at a normal rate, the individual's cells also age at a normal rate. However, when an individual experiences

prolonged stress, their telomerase production is also believed to reduce the average rate of chromosome replication. As telomeres shorten in length, from any of the three possible pathways, it shortens the DNA sequence. This eroding affects the efficiency of how these cells repair and replicate, which eventually affects the DNA sequence and quality of the data.

Ultimately, the data becomes corrupted to the point at which the cell does not have enough information to function in the way it was made to function. Chronic stress thus effectively accelerates the decompensation of genetic materials, as though the host were aging quicker than he or she biologically should (Chan & Blackburn, 2003; Epel, 2009; Epel et al., 2004; Epel, Burke & Wolkowitz, 2007). Some researchers state the direct connection between chronic stress and numerous states of disease. Other researchers (Jodcyzk, Fergusson, Horwood, Pearson& Kennedy, 2014) do not find significant associations between stress and individual telomere length in phenotypic data analysis. The association between stress and telomere length is a relatively newer approach and the research that suggests this connection is limited and conflicts with other research. This may just be an area of promise in the future. If this body of work continues to demonstrate causal evidence of this process in the future, it would add vigor to the already mounting body of evidence related to the consequences of chronic stress.

### The Psychological and Physiological Effects of Stress in the Population

Research demonstrates that the parents of children with NDDs have additional family life challenges, which are associated with typified increases of stress. These additional stressors lead to further psychologic struggles in various forms, such as the additional financial pressures of needing extra professional services, adaptive equipment, and medications for their child's needs. Financial pressures are likely to increase as the parent acts as a caregiver and has less available time for monetary pursuits (Parish, Rose, Swaine, Dababnah, & Mayra, 2012).

There is the additional strain in marital relationships, which accompanies extra stressors and family challenges. There also appears to be an increase in the rate of divorce among this population. Research studies do not support media reports that the divorce rate among families with children with autism was extremely high. However, rates of separation in these situations are almost double (23.5%) to that of families with average developing children (13.8%) (Freedman, Kalb, Zablotsky & Stuart, 2012; Hartley et al., 2010). One study conducted in a Bedouin culture found that siblings of children with developmental disabilities experienced higher levels of perceived stress, which compounded overall family stress levels (Manor-Binyamini & Abu-Ajaj, 2012).

Research supports general decreases in parenting self-efficacy and general well-being in the population. These problems are associated with additional mental and physical difficulties that accompany raising a child with NDDs. Behavioral problems that the child may have added to psychological strain in the form of caregiver burden that largely varies depending upon the level of severity (Karst & Van Hecke, 2012). One study that focused primarily on the parents of children with developmental deficits, parental stress, and child behavioral problems demonstrated support for an association between this population and poor sleep quality. Over half of the control group of that study (Gallagher, Phillips, & Carroll, 2010) were classifiable as parents of children with a neurodevelopmental deficit. The researchers reported that their finding was consistent with caregiver literature and poorer sleep quality, suggesting a likely association between highly stressed caregivers and poorer sleep quality.

There is also support in the literature that this population is more likely to experience depression than parents of average developing children (Al-Oran & Al-Sagarat, 2016). Al-Oran and Al-Sagarat's (2016) meta-analysis of predictors of high stress in the parents of children with

autism found the following life situations to incur high stress: mothers younger than 30, having children younger than 6, recent diagnosis of their child, low education level, lower socioeconomic status, and being a single parent.

The parents of children with NDDs experience sustained higher than average levels of stress. In association with chronic stress, research suggests that these individuals are more likely to have poorer health routines, such as cigarette smoking or routinely getting inadequate sleep (Lindo et al., 2016). The physiological effects of chronic stress include inflammation in the form of overproduction of cortisol and C-reactive protein (Gouin et al., 2016), and specific impairments affecting many of the main systems in the human body, such as the respiratory, cardiovascular, endocrine, gastrointestinal, and nervous system (Sapolsky, 2004).

As these findings are viewed through an SDT (Deci & Ryan, 1985) lens, there is a theme of lower levels of well-being and higher levels of stress. According to SDT, when autonomy, relatedness, and competence are not being sufficiently met, the individual's well-being will be negatively affected (Deci & Ryan, 1985). An important factor of chronic stress is that it is primarily experienced as a psychological perception. Given this information, it appears that any intervention that helps individuals re-access stressful stimuli in a less threatening way would be helpful. The review of the literature suggests that interventions that focus on decreasing stress appear to increase an individual's capacity to deal with stress in multiple ways. Social support has demonstrated limited support within the target population.

### **Social Support**

The definition of social support has a lot of variances, depending upon the source of support, the quality, and type of implied support. Social support can be support given by family, friends, or any one of many community entities. The support aspect of this could be emotional or

instrumental, or a combination of the two. For example, a grandparent could provide emotional support to the parent by nurturance as he or she goes through tough times. Instrumental support could be helping parents by watching their child, providing respite care, helping with expenses, or offering supplemental physical assistance as needed. Social support can be providing informational assistance, such as ideas, methods, and actions that the supporter has learned. In line with the direction of this study, and with a focus of stress reduction, social support is defined as a social system's provision of psychological and physical resources, given to assist the recipient with the coping of assorted stressors (Shavitt et al., 2016). Social support has been used as an assistive and protective aid against stress in the population of parents with children having various developmental deficits (Lindo et al., 2016). Research for increasing social support, generally targeted toward caregivers, and specifically aimed at the parents of children with disabilities, is demonstrating statistical power in several areas.

Social support provided by an individual's family is generally associated with higher degrees of experienced support, whereas multiple avenues of social support typically seem to be associated with higher levels of well-being (Hill & Rose, 2009). Higher levels of parental well-being also appear to be associated with higher levels of child well-being. The general thinking is that family support is more effective because families provide a higher level of unconditional support. For example, when adolescents are behaviorally difficult and the parents' community resources and friends have conceded to their difficult behaviors, their immediate family is more likely to continue to support them (Trute, Worthington & Hiebert-Murphy, 2008; White & Hastings, 2004; Yagmurlu, Yavuz, & Sen, 2015).

The parents of this population also demonstrate that perceived higher levels of social support benefit more from specific needs being met over general social support. There are also

the social benefits of group therapy, which seem to be consistently reported as helping decrease perceived stress. Social support has also been found to be inversely related to a decrease in reported depression and anxiety (Gray & Holden, 1992; Weiss, 2002). The general thinking is that increased levels of stress result in more mental health symptoms; therefore, appropriately applied social support helps to decrease stress and is ultimately associated with fewer mental health symptoms in the above areas. Social support not only decreases stress and influences psychological well-being in parents of children with NDDs, but also does so in the parents of children with sudden acute disabilities, such as TBI. Because of the sudden and sometimes severe nature of these incidents, social support is reported as being very helpful for these parents (Kirk, Fallon, Fraser, Robinson, & Vassallo, 2015). Social support is viewed as a buffer against stress for this parent population. In other words, when these parents have appropriate avenues of support, it appears to ease the burden of their self-reported stress levels.

In this parent population, social support is viewed as a type of scaffolding, which extends their ability to cope with chronic parental stress. This is demonstrated by reports of their stressors still occurring as frequently, but an overall feeling of fewer perceived stress symptoms in their environment. Additionally, it appears that the quality of the social support may be more important to this sub-population than the quantity. This is demonstrated in sub-populations of parents who are experiencing frequent behavioral symptoms with their children; they are more likely to not feel supported at a level that is satisfactory (Cuzzocrea, Murdaca, Costa, Filippello & Larcan, 2016). It is not suggested that this parental population has developed the incapacity to respond adequately; instead, it is proposed that their capacity to respond to their situations becomes depleted quicker because of the additional life difficulties that come with their child's difficulties.

Much like a vicious cycle, as the child experiences more difficulties with daily functions, so do their parents. As the parents' stress levels go up, it is more likely that their children will sense their distress and feel more distress also. Most likely, if this is the first child the caregiver has with these difficulties, he or she will have little experience in navigating these difficulties. Unless they are already acquainted with the complexity of helping a child with these types of additional needs, it is likely to be a "learn as you go" process. Many of these parents, who require high levels of professional support for their children, communicate concerns that they will lose this needed support when their child ages out of services. This anticipation of eventually losing services creates the additional stress of having too many difficulties all at once. Understandably, when the job of parenting gets overwhelming, these parents are not just able to hang on until the eighth hour, clock out and go home, and recharge for the next day. It is obviously a different experience for a parent to manage a behaviorally challenged child than it is for a practicing professional or for a facility that staffs at a 1-to-3 ratio, in three eight-hour shifts per day.

In association with the current understanding of the benefits of early interventions in many different areas, Guralnick, Hammond, Neville, and Connor (2008) have found that higher levels of social support during the elementary years appeared to be associated with generally lower levels of maternal stress in the population several years past elementary. There also appears to be a general dynamic in which parental stress levels appear to decrease as children age past middle and high school years. Related to this area, researchers have found that parents of children with additional adaptive functioning deficits are more likely to have high stress levels. This also appears to be the case in families with children that have poor maladaptive behaviors too, which compounds the stress in these families. The general trend is, as more difficulties are

added to the family's environment, parental stress levels increase. In criticism, there does not appear to be any casual effects between any one of the many different NDDs a child may have and parental stress; yet there are distinct trends towards variable levels of stress, depending upon the number of difficulties within these environments.

A common theme emerges in social support that it is usually helpful if the support was perceived as being quality or functional support rather than just the quantity of support. There is a body of support with the findings between higher levels of perceived social support and maternal well-being. One study within this area finds that in women of a mature age who have grown children diagnosed with intellectual disabilities, the population benefited from an increase of emotional support (Hill & Rose, 2009; Hong, Seltzer & Krauss, 2004). This population did not report a benefit from a larger support network, but from a select group in which they felt more supported. Again, this points towards the importance of quality over quantity of social support.

In diverse cultural differences of social support, one study (Al-Gamal & Long, 2013) implies that collectivist cultures may help buffer the high-stress environments of raising children with NDDs more than individualistic cultures because of the emphasis of the whole group above the individual. There is a basis for criticism in this general area of research because of the lack of positively reported perceptions. This criticism stems from perceptions of only deficiency, as though a child with these difficulties has no good qualities, and that the current research is almost always centrally focused on the areas of deficit. One cross-sectional study cited additional studies where various pan-cultural population groups of parents do find social support of sorts from their own children. These parents are reported as experiencing positive perceptions in their

children's disability, which encouraged effective coping strategies, which encouraged additional positive feelings and perceptions.

These parents are engaging in a positive feedback system (Al-Gamal & Long, 2013). Another study (Duvdevany & Abboud, 2003) found that in specific collectivist cultures, not all kinds of social support are viewed as having a positive effect. For example, one study that focused on Arab mothers found that asking for or receiving social support was more likely to be a source of shame and conflict for the parents of this population. The cultural values of Arab society focus on the family as the main source of comfort, security, self-esteem, and identity. Seeking help outside the family in the community, government, or professionally was not generally perceived as a stress buffer. The general reasoning was that there was a cultural apprehension towards support systems outside of the family. Thus, the general bias was that social support outside of one's family was more of a negative attribute than a source of strength, and not generally viewed as being beneficial to their well-being (Duvdevany & Abboud, 2003).

A possible limitation of this study is that in the half of the sample of mothers receiving governmental support, who neither reported a significant decrease in stress or improved wellbeing, they may have just sought services for instrumental reasons, whereas the group that was only receiving informal social support demonstrated signs of both decreased stress and improved well-being. It is hypothesized that the mothers in the study who felt marginalized were not seeking any other support than financial. This would be consistent with previous findings that only perceived support is viewed as adequate. In other words, these mothers may have only desired the type of support which they were seeking. Factors such as socioeconomic status could explain why one individual is pleased with information support while another is concerned with just meeting the basic needs.

A relevant sub-topic of social support of this parental population is the increased risk factor of parents tending to violent statements and actions towards their children. This type of abuse is more common in this parent population because of elevated levels of parental stress as well as inadequate professional and social support. Research findings (Svensson, Eriksson & Janson, 2013) show that some of these parents find themselves in difficult situations with their children. They are more likely to become emotionally overwhelmed, thus more likely to respond poorly or aggressively. Several of the parental study participants reported having thoughts towards their child that were violent in nature, where they felt as though they were out of control. One of the difficulties of bringing up these issues in a professional context is the topic of professional mandatory reporting. As a parent is experiencing extreme levels of frustration and stress, they may fear communicating this with the professional, because of possible repercussions. The same study (Svensson et al., 2013) commented on the importance of the professional working with these families to introduce potential risk factors of excessive stress, and to encourage forthright communication in families where this is identified.

When these types of issues were not explored, it appeared reminiscent of the past United States military program "don't ask don't tell." Many professionals are mandated within their license or credentialing body as mandatory reporters of abuse. Given the legal, social, and cultural repercussions of abuse or neglect such as mandatory involvement of child protective services, the police, and the court system, it is a naturally uncomfortable topic. Thus, most professionals who are not mandated to ask questions in these areas are less likely to focus in that direction without any leading statements. However, given the data in this area and the general taboo nature of the topic, it would be beneficial for professionals to encourage these types of conversations with this high-risk population. If difficulties are identified, professionals or family

members could provide aspects of support. Research in social support specifically in the target population supports that early interventions that encourage the use of multiple forms of usefully perceived support, helps to decrease stress through each development period (Guralnick, Hammond, et al., 2008). A general conclusion was that successful coping helped parental confidence, with variations of strength, within the different types of social support, with intimate/family support having the strongest statistical strength. This was consistent with the competence component of SDT (Ryan & Deci, 2000b) three basic psychological needs that encourage personal well-being. In association with SDT (Ryan, and Deci, 2000b) relatedness, most closely associated with attachment, did not measure any increased effect with social support. However, measures of decreased stress were not orientated towards measuring an effect in that area, but rather how social support effected perceived stress levels.

#### Mindfulness

The history of mindfulness is rich in content and diverse in practice and its current collective practice originates from differing sources. Mindfulness is commonly and accurately associated with the far eastern religious practice of Buddhism (Kirmayer, 2015; Williams & Kabat-Zinn, 2013). Although the practice of mindfulness varies in forms and application, its clinical use is relatively new within the North American culture. Mindfulness, when viewed as a type of meditation, shares associated components with the big three religions of the world: Christianity (Frederick & White, 2015), Judaism (Pinson, 2004), and Islam (Pirani, Papadopoulos, Foster & Leavey, 2008).

Mindfulness-Based Stress Reduction (MBSR) (Kabat-Zinn, 1982) was one of the first mindfulness interventions implemented in North America; it was first started in 1979 and pioneered by Jon Kabat-Zinn. This MBSR program was implemented at the University of

Massachusetts Medical Center at the Stress Reduction Clinic. The intervention was found to be consistently helpful in enabling the participants to significantly decrease their stress levels. From the introduction of mindfulness in North America in the late seventies to current day research, the clinical applications have grown significantly. This growth has expanded from one program to the point at which the National Institute of Health is funding hundreds of research projects in the area of mindfulness. This scientific rigor is demonstrative of the seriousness that mindfulness is receiving as a legitimate mental health approach (Williams & Kabat-Zinn, 2013). The background and origins of mindfulness are important in identifying the need for mindfulness and helpful in starting a discussion of its uses.

To acquaint the reader with mindfulness' historical application, a brief background section will be covered. This overview will seek to explain definitions and simplistic origins, while not delving into the depth and breadth of Hindu or Buddhist religious text. A complete examination of Buddhism practice, from which mindfulness derives, would also require extensive religious texts, which is beyond the scope of this study. Mindfulness is identified as a type of meditation useful in various forms of therapy, lifestyle, and outlook. Mindfulness as both religion and discipline proceeds predominantly from the Pali. The Pali language has its origins in northern India and is the language in which much of Buddha's teachings were recorded within the Pali Canon. The Sati is a part of this text, which is predominantly identified with the construct of mindfulness. In this construct of mindfulness, the Sati contains three states: awareness, attention, and remembrance (Siegel et al., 2009). With the goal of understanding these concepts, as identified by the Pali, each will be identified.

Awareness is the state of being conscious of what is happening around one, with the use of the five physiological senses. Attention is a state of focusing one's awareness on one's current

environment. Remembrance is the state of practicing one's refocusing on attention towards the current moment (Langer & Moldoveanu, 2000; Siegel et al., 2009; Williams & Kabat-Zinn, 2013). Another component of mindfulness is the practice of being non-judgmental towards the thoughts passing through one's consciousness. This practice of non-judgment refers to both positive and negative thoughts, with the target goal of eventually identifying which thoughts lead to happiness, and which thoughts lead to misery. It is the last aspect of Sati, which begins to separate the religious worldviews of mindfulness from Western secularized forms (Brown & Ryan, 2003; Sharf, 2015; Williams & Kabat-Zinn, 2013). Although there are various applications and adherence to traditional Buddhist mindfulness, these definitions can be used to model its general construct. Mindfulness is just one component of Buddhist practice, used towards the goal of achieving enlightenment.

In Buddhism, mindfulness is used in conjunction with other techniques and includes a worldview that hope, desire, and life mastery are futile and will always disappoint. Traditional applications of this Pali text make claims that being free from attachment is enabled by being free from basic human desires. Although this is an oversimplified version, it identifies why remembering to be aware is a key component, because failing to do so is more likely to result in nonproductive/suffering induced thinking (Nyanaponika, 1972).

In the practice of mindfulness, it is thought that the discipline of present moment awareness keeps one from getting lost in the endless introspections of one's life. On the other end of the mindfulness spectrum is a westernized version of mindfulness, which centers one's thoughts as a calming/relaxing pursuit with little to no worldview shifts (Brown & Ryan, 2003). It appears more common in the westernized version of mindfulness for the users to seek the benefits of relaxation and peace without the radical worldview change (Carmody, 2014). The

descriptions of mindfulness are quite varied, depending upon the source of the definition and the constructs of mindfulness that are being identified. Early pioneers in North American mindfulness research, Williams and Kabat-Zinn (2013) describe their philosophical roots of mindfulness meditational practice to be derived from Buddhist meditational practice. This practice consists of being actively aware as well as having clarity of mind, balanced emotional regulation, and compassion. These qualities are reported to be developed by intentionally directing attention, meditative practice, and Buddhist worldview thinking. Another researcher (Sharf, 2015) perceives westernized mindfulness as a made-to-order construct, which has slight overtones of Buddhist mindfulness, so altered from its structural foundations that it has lost its original intention and effectiveness.

Sharf (2015) contends that alternative versions of mindfulness result from practitioners of westernized mindfulness who are not familiar with Buddhist practices. This points to an understanding that mindfulness within its variant forms is just a component of Buddhist enlightenment practice. Accordingly, westernized mindfulness would come up short within the orthodox practice of Buddhism. The premise of this practice of mindfulness is a basic understanding of Sati, which is also known as a present-centered awareness that consists of the absence of judgment regarding the thoughts that come into and flee from one's consciousness.

The basics of Buddhist understanding is that a Buddhist renounces anything of fleshly human value or attachment. The Buddhist practitioner generally finds ways to seek happiness in this world, via the re-orientation of values and enlightenment. One of the foundations of this re-orientation is the refusal of hope that life will work out as one desires it to. However, other schools of Buddhist scholars (Nyanaponika, 1972) think that westernized mindfulness should be considered Buddhist modernism and note the lack of a complete framework of Buddhism. Sati,

as it relates to Buddhist practice, is the examination of one's thoughts and the relative value of those thoughts within a Buddhist moral valance. In this system, for example, negative emotions are noted to be of no value; only positive emotions, which bring happiness and peace, are of value.

The practitioner is instructed via Buddha's teachings to give up his or her positive expectations of this world because they only disappoint. However, the remembrance of the virtuous dharma's, which are Buddha's religious teachings, are worthy of remembering.

Mindfulness specialist Nyanaponika (1972) comments that mindfulness is an awareness of events, one's perception of events, and the effect the events have on us. He elaborates that mindfulness allows the participant unencumbered freedom to clearly see associated negative and unhelpful thoughts, which accompany many everyday interactions. In other words, mindfulness helps one climb out of the ditch of a negative thought cycle pattern, to see a clearer view of what is impeding one's daily life.

Other researchers (Brown & Ryan, 2003) view human consciousness as being composed of both awareness and attention, which work together in unison. Awareness is comparable to the heating unit that produces heat when directed. Attention is comparable to the thermostat that directs heating to start when needed. In this analogy, mindfulness enhances one's thermostat and maximizes the energy capacity of one's heater to encourage maximum heating efficiency. These authors view mindfulness as a component of the individual's consciousness, with the acknowledgment that some individuals operate with higher levels of awareness and attention than others.

With this orientation of mindfulness, the religious overtones of Sati are not needed to benefit from being more present. One example of an orthodox style of Buddhist practice that is typically in conflict with western European culture is the encouragement to sustain from sex because it ultimately leads to more suffering, although only the most spiritual Buddist, in the form of a monastic follower, is expected to do this (Jones & Hostler, 2005). In rebuttal to a purely westernized version of mindfulness that solely involves a focus on attention and awareness, Williams and Kabat-Zinn (2013) comment that the alleviation of pain and suffering, which mindfulness meditation can help develop, overrides the concern of the initiation of religious practices in secular settings. The authors refer to the use of mindfulness and cognitive behavioral therapy within these intervention programs.

The authors comment that MBSR and MBCT are portals into Buddhist practice, which many consumers would not choose if they were unambiguously stated as such. This is notable since not all interventions promote Buddhist religious practice. Given that this Buddhist worldview is identifiably countercultural to mainstream western European worldviews, it appears reasonable to pose that this rift of worldviews may hold part of the responsibility, of a religious system presented as secular helping tools, with some practitioners.

# **Applications of Mindfulness Used for Decreasing Stress**

The earliest North American program that specifically addressed stress management is Mindfulness-Based Stress Reduction (MBSR) intervention (Kabat-Zinn, 1982), where mindfulness meditation and associated techniques were taught in two- to three-hour sessions, over a ten-week period. The initial study demonstrated that over half of the sample had significant improvements in their stress symptoms, which assisted in decreasing their self-reported pain levels. The success of this initial intervention using MBSR has resulted in many other similar programs based on stress reduction. A smaller study of 22 participants reported that MBSR is an effective intervention for decreasing stress symptoms. In that study, MBSR

aided in decreases of anxiety in individuals with anxiety disorders, up to three years post-intervention (Miller, Fletcher & Kabat-Zinn, 1995).

Another study (Hou et al., 2013) with 141 participants reported that MBRS was effective in the treatment group at decreasing the stress of caregivers of relatives with chronic illnesses or conditions. There are multiple different applications of mindfulness that are utilized towards various problem areas for the purpose of decreasing physical, and emotional distress (Carmody, 2014). The forementioned study was interested in meditation research study results that were similar in form to mindfulness, such as Transcendental Meditation (TM). Additionally, there were studies that focused on mindfulness but did not include direct results that were oriented towards decreasing stress. A meta-analysis overview of meditation studies, which included several types of meditations, such as TM and mindfulness, noted a consistent medium effect size (r=.28) in 125 of the 163 studies, sourced from peer-reviewed journals (Sedlmeier et al., 2012). Interestingly, the type of meditation used did not seem to differ significantly in the global analysis results, although TM's effect sizes were slightly stronger. Of the 125 peer-reviewed studies, 16 had a dependent variable of stress, with an effect size of (r = .27) and total sample number of 855. As mindfulness is examined in studies with the goal of decreasing stress, the results appear to demonstrate a degree of effectiveness.

# **Mindfulness in Comparison to Mindlessness**

In the literature, one of the stark contrasts of mindfulness is mindlessness. This term is used commonly (Brown & Ryan, 2003; Langer & Moldoveanu, 2000; Siegel et al., 2009) to help the reader clearly understand the other end of the spectrum, where little to no mindfulness is being used. Generally, mindfulness describes a deliberate focus on attention and awareness.

Depending upon the orientation of the practitioner, it includes remembrance and intentional non-

judgment of one's present moment environment. Mindlessness is quite different from mindfulness in its characteristics since there is a lack of intentional action. Mindlessness is not the exact opposite but is representative of a lack of practice of these choices. People in society at large, specifically the Western European culture, spend much of their awake time processing thoughts and possible difficulties. Much of this thinking regards issues that are not in-the-moment events.

For example, much of one's natural daily life routine may operate like a plane that is on autopilot yet not really in the present moment cognitively. These actions may typically serve individuals well, in circumstances such as not actively having to think about directions on the drive back home. However, the drawback to routinely functioning like this is that even though it is physically living in the moment, one's conscious thinking patterns are partially living in some other moment. As individuals cognitively operating from past or future intent, they are likely was not fully engaged in current-moment attention, as defined via mindfulness. The reasoning for this being that individuals have limited cognitive capacity, and if they are participating in mental multitasking, they are more likely to be responding to stimuli that is not present-moment complete and thus not fully present-moment current.

Using a cognitive behavioral lens, cognitive behavioral therapy (CBT) instructs that these types of non-productive thoughts are thinking errors, also known as cognitive distortions (Lee, 2004). Cognitive distortions are like the state of mindlessness, in form, as routine implicit memory that is procedural in nature lends towards over-generalizations in events or behaviors. Mindlessness may also take the form of fully conscious memory bias and worldviews, such as an individual with a negative self-concept who filters daily stimuli through past experiences and future expectations and desires. Mindlessness is the state of not demonstrating full mental

engagement in the current moment. Another example of mindlessness is when two people are engaging in conversation, and the listener is thinking about what he or she wants to say next instead of fully listening to the talker. In these situations, it is commonly recognized that the listener is not fully hearing all the information that is being communicated. The general mindfulness teaching on this is that an individual must be in the current moment to be fully engaged in that moment. Sharf (2015) also comments on mindlessness of a different type, which is a technique/mindset used to disassociate oneself from human cognitive ownership.

## **Constructs used in Measuring Mindfulness**

In viewing utilizations of mindfulness in a Western European cultural context, it is supportive to find an operational definition of this kind of meditation. One unifying definition of mindfulness has yet to find consensus among scholars; however, several groups of researchers have attempted it (Bishop et al., 2004; Brown & Ryan, 2003; Walach, Buchheld, Buttenmuller, Kleinknecht, & Schmidt, 2006). Contributing to the murkiness of operationalizing mindfulness is the ambiguity of whether mindfulness is a state (Bishop et al., 2004) or both a state and a trait/disposition (Brown & Ryan, 2004; Friese & Hofmann, 2016; Garland, Hanley, Farb & Froeliger, 2016; Kiken, Garland, Bluth, Palsson, & Gaylord, 2015). A variety of measures of mindfulness have been developed such as: The Mindful Attention Awareness Scale (MAAS) (Brown & Ryan, 2003), The Revised 12-item Cognitive and Affective Mindfulness Scale (CAMS-R) (Feldman, Hayes, Kumar, Greeson & Laurenceau, 2007), The 30-item Freiburg Mindfulness Inventory (FMI; Walach et al., 2006), and the Kentucky Inventory of Mindfulness Skills (KIMS) (Baer, Smith & Allen, 2004).

The instruments that measure levels of mindfulness vary greatly from instrument to instrument. The FMI (Walach et al., 2006) is reported as a single factor assessment; however, the

intention of the FMI is to measure mindfulness as an attentional observation that is experienced in fully unbiased ways. The assessment target respondents were intended to be individuals who have some familiarity with meditational practice. The MAAS (Brown & Ryan, 2004) reports one factor, in the forms of awareness and attention, to describe individual mindfulness levels, whereas the KIMS (Baer et al., 2004) accesses the construct of mindfulness with four separate factors in the forms of observation, description of experiencing, acting with awareness, and non-judgmental acceptance.

The CAMS-R (Feldman et al., 2007) conceptualizes mindfulness in the four components of attention, awareness, present focus, and acceptance. The instrument designers reported that their initial design was based on researcher Kabat-Zinn's definition of mindfulness as purposeful attention that manifests present-moment awareness, while simultaneously being non-judgmental towards internal and external events.

As the literature of mindfulness is examined, it is apparent that mindfulness is both a current state of being, which can be taught and encouraged, as evidenced by the many various types of mindfulness-based programs, and a trait, which some individuals appear to just demonstrate more than others (Friese & Hofmann, 2016; Garland et al., 2016; Kiken et al., 2015; Brown & Ryan, 2004). Many individuals naturally tend to ruminate, ponder, and live actively in the past and future, more so than others, which appears to be universally accepted by mindfulness scholars. Likely, that is part of the reason why Buddhist teaching includes remembering as part of mindfulness because one must remember to be in this state, because a general inclination is not directed towards mindfulness (Siegel et al., 2009). This helps one to understand mindfulness as a trait, in the degree of mindfulness that can be measured in individuals at any time.

Mindfulness as a state occurs when activities that promote attention, awareness, and non-judgmental thoughts are primed or practiced; for example, after individuals attend a mindfulness session, they will likely be practicing more mindfulness in their daily lives; however, how much more and for how long? One group of researchers (Kiken et al., 2015) contend that as their participants practiced mindfulness meditation over an eight-week period, their state levels of mindfulness increased post-intervention. However, most of the literature suggests that increases in long-term trait mindfulness require long-term lifestyle changes, of the magnitude of changes in one's worldview (Sharf, 1995; 2015; Siegel et al., 2009; Williams & Kabat-Zinn, 2013). As with many other interventions, the generalization of state and trait mindfulness levels in the literature are that they initially increase during and after mindfulness interventions.

However, these higher levels tend to move back towards baseline levels over time. There would appear to be a benefit in increasing mindfulness on a trait level. Considering the literature, it appears that measuring state mindfulness only explains the current state of the individual, rather than the individual's baseline level of mindfulness. Brown and Cordon (2009) comment that as measures of mindfulness have been developed, state mindfulness is difficult to measure unless it is primed first. This aspect of trait mindfulness allows a more accurate anytime measure of mindfulness to assess the degree to which an individual lean toward these traits. Measures of trait mindfulness appear to be more useful for this study since measures of trait mindfulness access predisposition or lifestyle choices towards mindfulness. Additionally, to successfully prime state mindfulness in individuals, these individuals need to be trained and the typical program consists of eight to twelve weeks of training for several hours per session. Given that mindfulness is not sought to be raised, but rather measured in this study, a measure of trait mindfulness was picked as being the most appropriate.

## **Summary**

The general population of parents of children with neurodevelopmental disabilities experiences stress at higher than average levels (Neff, 2010; Theule et al., 2011). What is experienced as overly stressful to one individual is experienced as minor stress to another. Important themes are: stress is a perceived experience and individual stress thresholds determine an individual's capacity and ability to cope. Additionally, as the stressors increase or are continuous within the environment, parents tend to respond poorly (Svensson et al., 2013). Methods such as mindfulness and social support appear to increase the population's ability to manage their environment. It is the management of stress that is the problem, not the stressors. The population is also more likely to engage in poor health habits in association with sustained high stress; the result is generally poorer health outcomes in a variety of areas (Kunz-Ebrecht et al., 2003; Lindo et al., 2016). Social support appears to buffer the effects of stress for this population. Although an adequate quantity of support levels is helpful, the quality of social support is reported as being paramount. Individual levels of adequate social support appear to lighten the burden of stress in this population (Cuzzocrea et al., 2016). Mindfulness as a practice demonstrates helpfulness within the literature, as a method used to decrease the emotional distress of stressor (Carmody, 2014). Mindfulness is reported as both a state and a trait. Since mindfulness as a state needs to be primed first in individuals, with the design of this study it appeared efficacious to measure mindfulness as a trait, which then can be randomly measured at any time (Friese & Hofmann, 2016; Garland et al., 2016; Kiken et al., 2015; Brown & Ryan, 2004).

Since there is a variety of defining characteristics of mindfulness specifically and meditation in general, there are no current unifying operational definitions of mindfulness

(Bishop et al., 2004; Brown & Ryan, 2003; Walach et al., 2006). Current research appears to conclude that mindfulness is helpful in reducing the stress response via helping individuals build resiliency towards the effects of chronic stress. This is viewed in many of the study respondents reporting no less stress in their lives, but rather more ability to cope with their current stress more easily (Carmody, 2014). The sustainability of mindfulness is an appropriate question since it is not a common state, trait, or lifestyle choice in Western European culture (Kirmayer, 2015; Sharf, 2015). However, if a portion of the target sample demonstrates both higher degrees of trait mindfulness and lower levels of stress, this will suggest an association, which suggests that mindfulness has a mediating role in the reduction of the stress response in this population group.

In the scope of this study, the three topic areas of stress, mindfulness, and social support have been researched before but not collectively. The aim of this research is to seek reasonable and readily available tools, which might benefit the high-stress population of parents with children with NDDs, in thus, the researcher addresses a gap within the literature. Few studies have been done in social support and the target population, though most have focused on caregivers in general. Even fewer studies have been done with mindfulness and the target population, and no peer-reviewed articles were found that address both topic areas with a similar population group. Given this population's higher incidence of stress, further understanding of stress mediators and effective interventions for this group will extend the knowledge base within this specified area of research.

Chapter 3 provides a comprehensive description of the research methods used for this study, which include a detailed discussion of the research design, the sample population, data collection measures, data analysis, and ethical considerations. The three identified variables of inquiry are social support (IV), as measured by the Family Support Scale (FSS) (Dunst et al.,

1984), Mindfulness (IV) levels, as measured by The Mindful Attention Awareness Scale (MAAS) (Brown & Ryan, 2003), and stress (DV), as measured by the Parental Stress Scale (PSS) (Berry & Jones, 1995). These three research questions are quantitatively addressed with an analysis of descriptive statistics and multiple linear regression.

### Chapter 3: Research Method

### Introduction

The purpose of this quantitative study was to determine how individual levels of mindfulness and social support affect perceived stress in the parents of children with NDDs. The dependent variable was perceived stress levels. The predictive variables were the levels of mindfulness and social support. The study included an examination of the degree to which the predictor variables, independently or in combination, explain detected variance with the dependent variable.

This chapter presents a summary of the participants, research setting, data collection, analysis, research methods, rationale, and ethical protections for the participants. The method of conducting online surveys, sources, and rationale are all discussed, along with the statistical power needed to collect this data at levels that conveyed significance. The collection of current resources includes research on stress, stresses detrimental effect on the parents of children with NDDs, the effectiveness of mindfulness, and social support. Currently lacking empirical rigorthis population's level of social support and trait mindfulness has been understudied and generalized with similar sub-population groups such as general caregivers, effectively underserving this overly stressed population.

### Research Design and Rationale

In this quantitative cross-sectional study, perceived stress was the dependent variable; mindfulness and social support were the independent variables. Both the dependent and independent variables were measured with an interval scale. The statistical tests used to measure the data were correlational analyses and multiple linear regression.

This study was conducted with an online survey method. The participants who met the target population requirements were given information about the study. Those who agreed to participate were also encouraged to complete the survey, which included all three test measures, and anonymous demographic information. The survey compiled demographics and responses, which were retrieved via online access for scoring and analysis, after a sufficient number of participants had responded.

The theoretical lens of this study was aligned with the scientific method, with its theoretical and objective stance. This worldview is compatible with a quantitative design in the use of both determinism and reductionism as the means for testing theories with objective relationships among variables. A degree of determinism was embraced because of the cause-and-effect relationship that results from all interactions, as one act affects another. Aspects of reductionism are used in that general concepts such as stress, support, and mindfulness, which function as a system, can be broken down into smaller pieces and analyzed.

As a system is broken down and understood better, pertinent variables are then measured on validated assessment instruments and data is gathered and scored using statistical procedures (Creswell, 2013). The most efficient method to do this type of analysis is a quantitative one because of the generalization of results to a larger population. A cross-sectional data draw would be appropriate for this study because of the benefit in sampling a pertinent number of participants from the population at one particular point in time so that the data could then be viewed as representing that particular population. This type of sample draw would work well because it is an effective method for evaluating this type of study, and consequently would provide flexibility for participants and aid in the generalization of data results towards a larger population (Creswell, 2013).

An internet survey design was selected for this study because it allows for the gathering of essential information regarding the population from a representative sample. The use of surveys is both effective and appropriate for quantitative studies because the data supplied can then be used to generalize towards the larger sample population. In this study, the parents of children with any type of NDD were invited to fill out several data measures via an anonymous online survey. The primary caregiver of the child was sought and given the study's inclusion and exclusionary requirements, in order to proceed they had to agree that they meet the requirements of the study, and then agree to the informed consent of the study. Since the researcher requested personal information of the participants, it was necessary to provide anonymity to participants. In understanding that parents answering questions associated to the disabilities of their children, likely considered this information both private and intrusive, and anonymity has also been used in association with previous research of this nature (Wright, 2005). Given the inconspicuousness of an online survey form, there was an expectation that parental privacy associated with discussing these types of disorders and resulting difficulties would be minimized a considerable extent.

The surveys targeted users of support websites and population support groups that were based in the online environment. With a high rate of the target population using these types of online communities, along with anonymity during participation, there was minimal parental reluctance towards participation. While there was likely natural apprehensiveness about sharing family information with unknown researchers, having a third-party survey site distributing the surveys added another level of anonymity, thus reducing concerns for loss of anonymity (Wright, 2005). It was assumed that participants answered survey questions accurately because they had

an inherent level of personal investment in the subject, and because the anonymity of the survey allowed for a non-direct way for them to communicate their answers.

There are both positives and negatives aspects to online surveys. One positive reasoning for an online survey is that the individual taking the survey appears to be less concern with social desirability because of the added anonymity (Joinson, 1999). Online surveys do have some inherent difficulties, but no less than surveys completed via mail, facilities, laboratories, or universities. Wright (2005) notes that online survey participants have greater freedom maintaining their autonomy, while the quality of measurement was equal to more conventional methods, and even higher in quality at times. The reduction of costs associated with online surveys is another benefit, which allows researchers a wider utilization of limited resources to reach the target population and achieve a representative sample.

## **Setting and Sample Size**

The aim of this study was to survey the parents of children with NDDs between the ages of 3-17. This study quantitatively measured how the parents' levels of trait mindfulness and social support affected their level of perceived stress. The age range was selected because of statistics stated by the Center for Disease Control and Prevention, that one in six children in the United States, between the age of 3 and 17, are diagnosed as having a developmental disability or delay (United States Environmental Protection Agency, 2013). It is generally accepted that these group of conditions appear before the child enters grade school, around the age of 6.

The recruitment of participants centrally focused on Facebook, which has multiple neurodevelopmental support groups, such as ADHD Kids Care-Support group for Parents and Autism Moms Support group. Online server sites that focus on the dissemination of information towards the target population, such as ADDitude Magazine, which focuses on ADD articles, and

has online support forums, was also sought but proved to not be a viable source for participant recruitment. An ad was initially planned to run on Facebook that would appears on the home page of interested users, however, because of how Facebook advertising in manually operated, and the degree of success to which the online support groups offered, the advertising component of using Facebook was declined. Facebook has reported web traffic of 1.28 billion daily users and up to 1.8 billion per month. Kapp, Peter, and Oliver (2013) commented that Facebook could specifically funnel interested Facebook users towards the recruitment of their sample via the users' profile page.

The target demographics were parents who are at least 18 years old, expressed interest in information about any NDD and/or parenting support for ADHD, Autism, ASD, learning disorders. The recruitment advertisement used include the eligibility, exclusionary criteria, and details of the study's purpose, along with a web-link to a dedicated Facebook home page. The eligibility and exclusion criteria for the study were as follows:

- Eligibility: Pparents who reported their children have been diagnosed with one or more of the following disorders: attention deficit hyperactivity disorder, autism spectrum disorder, communication disorders, intellectual development disorder, motor disorders, and learning disorders. The parent also must be at least 18 years old.
- Exclusion criteria: parents who report current mental health difficulties causing significant problems, a recent death in the family, homelessness, or extreme financial difficulties.

The study's Facebook page contained more information regarding the survey. Facebook support group administrators and moderators were the only parties responsible for deciding to

allow the recruitment advertisements to be posted on the support site board, which added another layer of anonymity for the participants.

By example, a few of the online Facebook support group sites where ads were placed on included: Dyslexia, Dyscalculia, LD Parent Support Group, ADHD Parent Support, The Nemechek Protocol Autism and Developmental Disorders Support Group, and Autism and Special Needs Action Group. All the online forums sites were connected to Facebooks main site, but group content varied from information, resources, protocols, and general peer support. Groups varied in support sites from parents only to family group members. The group area of Facebook also contained groups that were specific to a particular population such as: ADHD, Autism, intellectual disabilities, and other individual NDDs. An email was sent to the moderator/administrator of each forum used, in seeking permission to post the recruitment ad. As permission was granted, an ad was then placed on the forum that invited eligible parents to participate in the survey. There was a link for these individuals to click on, which would then take them to a secure web host, and/or the dedicated Facebook page if they desired more information about the study. All participant ads posted include eligibility, exclusionary criteria, and details of the study's purpose.

The parents who were interested in participating in the study followed the link to an encrypted website where they filled out eligibility questions. Eligible participants were then able to fill out the consent form, agree to the study, and gain access to the survey. The survey did not capture any identifying information such as the name of the parent, name of the child/children, address, or the internet protocol address.

Calculating the sample size required four main considerations: the statistical test being used, the power used for the study, the alpha used, and effect size. To determine an adequate

sample size to generate a medium effect, the researcher used a power analysis for linear multiple regression with an effect size of 0.15 f²,a power of 0.80, and an alpha of .05. (see Figure 2). A medium estimated effect size was derived from effect sizes reported in previous research in the population (Al-Gamal & Long, 2012; Guralnick, Neville, Hammond, & Connor, 2008). In calculating the power analysis, it was determined that a sample of 68 participants would be needed to achieve a medium effect size. Hence 68 participants were needed to allow the study to have adequate statistical power to infer the results to a larger population.

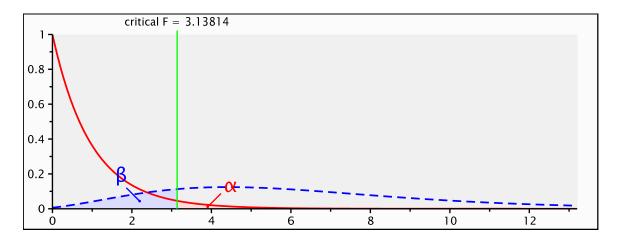


Figure 2. Power plot from G\*power 3.1.9.2. (Faul, Erdfedler, Lang, & Buchner, 2009).

The power analysis was conducted via the statistical software program G\*Power 3.1.9.2, (Faul, Erdfelder, Buchner, & Lang, 2009). Three additional participants were gathered for a total of 71 participants since only completed surveys were able to be submitted. Survey attrition is not anticipated; however, three extra participants were included in case of small-scale data corruption. Additional parameter commands were embedded in the survey so that only allow completed surveys were able to be submitted. This added parameter was implemented to assist in the data sets maintaining adequate statistical power.

#### **Instrumentation and Materials**

## **Demographics**

Relevant demographic data were collected from all participants in the following forms: if the parent has current live-in support, age of parent and child with neurodevelopmental deficit, marital status, which professional mental health diagnosis the parents child received, the parents perception of the others bioparents level of involvement, the number of hours spent weekly acting as a caregiver to the child, and how many professional services were being used monthly.

# **Family Support Scale (FSS)**

The Family Support Scale (Dunst et al., 1984) is a 19-item self-report that includes two additional voluntary participant-initiated items. Respondents are asked to answer all items on a 5-point Likert scale system. Respondents are asked to rate, with the Likert scale, how helpful the item/questioned individual or groups have been to their family. The qualifiers are the specific listed item group or person, and that the help-support has been ongoing for 3-6 months, as of the time of the survey. The FSS can be completed in 2-4 minutes. The FSS is reported to measure the perceived helpfulness of the sources of support to families with children. The FSS is used to find the level to which families with children, feel supported by those they interact with on a continuing basis. This measure has been used to examine the effect of social supports, in several areas of research such as: parent health, and well-being, family systems, parental perceptions of child functionality, and parent-child interaction styles (Dunst et al., 1984).

The FSS (Dunst, Trivette, & Jenkins, 2007) is a commonly used instrument when measuring parental social support, demonstrating acceptable reliability and validity. The FSS reliability and validity were observed in the study of 224 parents of children, that had a diagnosed disability, or were at-risk for poor developmental outcomes. The FSS demonstrated

acceptable internal consistency with a coefficient alpha of .77, from correlation among the 18 scale items. The split-half reliability was .77, when the Spear-Brown formula was used to correct for the short length (Dunst & Trivette, 1988). The Test-retest reliability coefficient was .50; however, this was over the course of 1-2 years between T1 & T2. Construct validity was assessed via factor analysis using varimax rotation; the analysis showed 5-orthogonal factors that accounted for 55% of the variance, which is demonstrative that the FSS is measuring five independent types of social support. Factors included: kinship, spouse/partner support, social organizational support, informal support, and professional support.

Concurrent predictive validity found a correlation between the FSS total helpfulness scores, and the questionnaire on Resources and Stress (QRS), in the correlational analysis the coefficient sizes were not large; however, the values were consistent, directional, and predictive. The more support these groups had, the less personal and family problems they reported. An ANOVA was used to analyze the two measures using orthogonal comparisons, the groups that scored low, medium, and high in support. Poor Health/Mood, F(1, 218) = 11.82, p < .0001, Excessive Time Demand, F(1, 183) = 6.28, p < .01, and Family Integrity, F(1, 183) = 6.47, p < .01 subscales. The low and median support groups differed from each other on the Poor Health/Mood, F(1, 183) = 10.19, p < .002, subscales. All the results predicted a direction, which higher levels of reported social support were associated with lower perceived personal, and family difficulties (Dunst et al., 2007).

#### **Scoring**

Item questions are all scored as recorded; items marked as non-available (NA) are scored as zero. A Likert scale is used with a general application of each item, asking "how helpful the people and groups have been to your family during the past 3 to 6 months" (Dunst, Trivette &

Deal, 1994). The Likert scale is recorded and scored: 0 (not available), 1 (not at all helpful), 2 (sometimes helpful), 3 (generally helpful), 4 (very helpful), 5 (extremely helpful). The responses are totaled in each one of the 5-subscale sources of support: Kinship, Spouse/partner Support, Informal Support, Program/Organizational Support, and Professional Services. Each of the subscales is divided by the number of items within that subscale for an adjusted score; this step is utilized so the assessor may compare mean scores between subscales.

Non-adjusted scores are then totaled in the first four subscales to render the informal social support score. The formal support score is the non-adjusted score of the professional services subscale. The FSS total scale score is the non-adjusted sum of all 19 items. Lower scores in both the subscales and total scales scores are indicative of low levels of perceived support, inversely higher range scores indicate higher levels of perceived support (Dunst et al., 2007). On the FSS (Dunst et al., 1984), specifically defining cut scores are not indicated in the validity and reliability write up on the measure (Dunst et al., 1984) or with an applicable manual. The range of scoring for the FSS is from 0 to 76.

# The Mindful Attention Awareness Scale (MAAS)

The MAAS is a self-report scale that contains 15 items using a six-point Likert scale system. The MAAS is designed to assess an individuals' trait mindfulness via their typical degree of awareness and attention. The MAAS's instructions ask the respondent to rate item statements regarding their day-to-day life, according to how frequently they engage in associated themes of mindfulness. The survey is easy to understand and takes between 5 -10 minutes to complete. The MAAS was developed on research in mindfulness, attention, and other measures of varying conscious state. However, the MAAS is reported to only measure the variable of dispositional/trait mindfulness. The developers of the scale comment, that although mindfulness

appears to be both awareness and attention, however, the two are intertwined. A comparison used is the picture of seeing both the figure and the ground while viewing something. The ground is awareness of what is around and in front of you. Attention is representative of the figure that you are focusing on. Mindfulness is purposely doing both, with the priority being on attention, which is commonly referred to as focusing (Brown & Ryan, 2003).

Reliability and validity of the MAAS make it one of the most commonly used instruments when data regarding trait mindfulness is needed. The MAAS was developed for use with a general sample of US citizens, 18 to 77 years old, and university students. Confirmatory factor analysis supported the instruments one-factor structure in both the general and university samples. The MAAS demonstrates satisfactory internal consistency with an alpha of .82. The test-retest reliability was sufficient with an intraclass correlation coefficient of .81. Correlation data was numerous, and reported as: P < .0001 = strongly related, P < .001 = moderate, P < .01 = modest, and P < .05. = unrelated. Since 18 other measures were used, half of which focused on well-being, the authors were expecting to see both convergent and discriminant correlations.

There were demonstrated modest correlations with attention to emotion, and openness to experience. There were moderate correlations with emotional intelligence, and strongly related to clarity of emotional states, and mood repair. As expected, the MAAS correlated with measures such as the Mindfulness/Mindlessness Scale, strongly in measuring similar constructs, such as mindful engagement, moderately with Novelty seeking, Producing, and unrelated in cognitive flexibility. In incremental validity, the well-being scales demonstrated significant correlations when controlling for each covariate examined. The Measure of mindfulness scale (MMS) demonstrated the strongest direction of effect with the MAAS, in assessing criterion validity with well-being scales. The MAAS demonstrated sufficient correlations in similar measures of

mindfulness; the MAAS was able to discriminate between measured groups expected to differ in their reported level of mindfulness. The MAAS demonstrated both convergent and discriminant validity in measures that were similar, predictive, and inversely associated. (Brown & Ryan, 2003).

## **Scoring**

Item questions are scored with a numerical value of 1 to 6 points as recorded. A Likert-type scale is used to ask respondents to rate their day-to-day experience of the items asked. The theme is how frequently the respondent engages in each item experience. Indirect questions are purposefully asked to encourage an answer of experience rather than intent. The Likert scale is recorded and scored for each item as: 1 (almost always), 2 (very frequently), 3 (somewhat frequently), 4 (somewhat infrequently), 5 (very infrequently), 6 (almost never). The responses are then sum totaled. Lower scores are indicative of low levels of trait mindfulness and higher range scores are indicative of higher levels of trait mindfulness (Brown & Ryan, 2003). On the MAAS, a definition of the specificity of scores was not constructed, other than low scores being indicative of low levels of trait mindfulness, and high scores are indicative of high levels of trait mindfulness. The range of scores for the MAAS start at 15 and extend to the highest possible score of 90.

### **Parental Stress Scale (PSS)**

The Parental Stress Scale (Berry & Jones, 1995) is a self-report scale, which contains 18 items that are used via a Likert scale system to measure the testers parental stress score. Since the PPS consist of 18 items and simplistic instructions, it can be completed in 5-10 minutes. The PSS was developed for both mothers and fathers and was normed for both clinical and non-clinical populations. The respondents are instructed to identify the test items with their usual relationship

with their child. Item questions are representative of positive perceptions of parenthood, while others are more negatively themed perceptions. Positive perceptions included positive feelings, self-enrichment, and personal development. Perceived negative items included deficiencies of resources, loss of potential opportunities, and situational limitations. The PSS addresses the parent-child relationship and the family as a whole system.

The reliability and validity of the Parental Stress Scale have contributed to this measure being a commonly used item in research in this population. A total of 1276 participants were used in the development of the PSS. The PSS demonstrated to have an appropriate level of internal reliability, with an internal consistency coefficient of .83. The PSS demonstrated test-retest reliability of .81, with a 6-week span between assessments. The PSS also demonstrated satisfactory convergent validity towards other comparable parent stress measures, in the areas of stress, emotion, and role satisfaction. Compliable measures included: the Parenting Stress Index (PSI), Revised UCLA, Loneliness Scale (R-UCLA), The State Anxiety Scale (STAI), and the Social Support Scale (MOS-SSS). The PSS demonstrates no significant mean differences between parent genders, and the ability to discriminate between parental stress in parents with children of typical development, and parent stress levels with children that have behavioral and developmental difficulties (Berry & Jones, 1995).

### **Scoring**

Item questions 1, 2, 5, 6, 7, 8, 17, and 18 are reverse scored via the Likert scale, with a 1 scored as a 5, a 2 scoring as a 4, a 3 is 3, and so on. Each item is presented in the Likert scale as: 1 (strongly disagree), 2 (disagree), 3 (undecided), 4 (agree), and 5 (strongly agree). Once scored, the total parental stress score ranges from 18-90. Lower scores indicate low parental stress, whereas higher range scores indicate higher levels of parental stress (Berry & Jones, 1995).

## **Research Questions and Hypotheses**

### **Research Question 1**

Regarding the parents of children with neurocognitive deficits, is their level of social support, as measured by The Family Support Scale (FSS), correlated with their level of perceived stress, as measured by The Parent Stress Scale (PSS).

Null Hypothesis ( $H_01$ ): Social support, as measured by The Family Support Scale (FSS) has no significant relationship on the level of perceived stress, as measured by The Parent Stress Scale (PSS) within the specified population.

Research Hypothesis ( $H_a1$ ): Social support, as measured by The Family Support Scale (FSS), has a significant relationship on the level of perceived stress, as measured by The Parent Stress Scale (PSS) within the specified population.

## **Research Question 2**

Regarding the parents of children with neurocognitive deficits, is their level of mindfulness, as measured by The Mindful Attention Awareness Scale (MAAS) correlated with their level of perceived stress, as measured by The Parent Stress Scale (PSS).

Null Hypothesis ( $H_02$ ): The level of mindfulness, as measured by The Mindful Attention Awareness Scale (MAAS), has no significant relationship on the level of perceived stress, as measured by The Parent Stress Scale (PSS) within the specified population.

Research Hypothesis ( $H_a2$ ): The level of mindfulness, as measured by The Mindful Attention Awareness Scale (MAAS) has a significant relationship on the level of perceived stress, as measured by The Parent Stress Scale (PSS) within the specified population.

### **Research Question 3**

Regarding the parents of children with neurocognitive deficits, do higher levels of social support, as measured by The Family Support Scale (FSS) and mindfulness, as measured by The Mindful Attention Awareness Scale (MAAS) significantly predict less perceived stress, as measured by The Parent Stress Scale (PSS)

Null Hypothesis ( $H_0$ 3): Higher levels of Social support, as measured by The Family Support Scale (FSS) and mindfulness, as measured by The Mindful Attention Awareness Scale (MAAS) does not predict less perceived stress, as measured by The Parent Stress Scale (PSS) in the specified population.

Research Hypothesis ( $H_a3$ ): Higher levels of Social support, as measured by The Family Support Scale (FSS) and mindfulness, as measured by The Mindful Attention Awareness Scale (MAAS) does predict less perceived stress, as measured by The Parent Stress Scale (PSS) in the specified population.

### **Procedures**

Prior to data collection, the Institutional Review Board (IRB) of Walden University approved data collection from August 6, 2018 to August 6, 2019. The IRB approval number is 08-07-18-0200656. Data collection began on August 10, 2018 and the survey was closed on September 17, 2018, after which analysis commenced.

Respondents were allowed access to the secure online site via a hyperlink, which then brought them to the survey host. Upon clicking on the hyperlink, the host site (https://app.surveygizmo.com) brought them to the informed consent page (included in Appendix A). This page included statements of the anonymous nature of the survey and study, the participants right to quit the survey at any time, an acknowledgement that participation is completely voluntary and will not result in any compensation, the estimated time needed to take

the survey, and how to contact the researcher. Respondents had the opportunity to read the informed consent, agree to the terms, and then proceed to the survey as a participant. Once the participant agreed to the informed consent, they are then brought to the beginning on the survey, which starts with the three separate measures, and then concludes after nine demographic questions (Appendix B). The survey is constructed on the host site so that all the participant must do is hover over the answer, click it, and occasionally push next after several questions have been completed. The design of the host site, and survey, only allows completed surveys to be submitted when all of the questions have been answered. Participant are alerted if they attempt to submit an incomplete survey. In addition, participants were only able to submit one survey. However, If the participant began a survey and was unable to complete it at that particular time, or it was disrupted; their past responses were saved, and they were able to resume where they had left off by pressing the hyperlink again.

# **Data Collection and Analysis**

Before any analysis of data was done, instrument items scores were checked to establish that they are within the five to six-point range. The screening was conducted to assure the integrity of the data, with a focus in the following areas: Missing data, out of range data, duplicate data, and outliers. This was done to guard against data corruption, inaccuracies, and non-measured variance. No problems were discovered, and all of the completed surveys were utilized for data. Data screening and analysis was completed using the statistical software program SPSS 21. This quantitative study used a numeric description of the data, which provided a descriptive of the sample that was used to generalize the data to a larger population.

Univariate and bivariate statistical analysis were used with the demographic questionnaire (Appendix B). Among demographic data, central tendency in the forms of mean, and standard

deviation were used. In choosing a statistical analysis technique for this type of data, multiple linear regression (MR) was chosen. MR is the appropriate type of statistical analysis with the goal, of this type of analysis being to determine the strength, direction, and significance of two continuous predictor variables on the continuous criterion variable. A factorial Analysis of Variance (ANOVA) was initially considered; however, it was ruled out as being unsuitable because it would require dichotomizing the two predictor variables, which leads to problems in power, and potential false positive issues in hypothesis testing. Descriptive statistics were used with the demographic questions, the two predictor variables, and outcome variable, the purpose being to find distributions in the interval and ordinal level of measurement. Trait mindfulness (IV) was measured by the MAAS, using an interval scale. Social support (IV) was measured by the FSS, using an interval scale. Perceived Stress (DV) was measured by the (PSS), with an interval scale.

The completed survey contains the following components: informed consent, demographic questions, and online versions of the MAAS, FSS, and PSS. The survey data is maintained on a secure website account controlled by the researcher on the survey-site, (https://app.surveygizmo.com). This survey site is a website that allows the user to create and disseminate data collections instruments via online surveys. This site also allows the user an option to transfer all the completed survey data into SPSS for screening and analysis.

## Threats to Validity

Several participant biases are viewed as being possible threats to internal validity with this study: social desirability, Halo effect, and acquiescence. On a self-report having to do with parents and their children, social desirability could be a factor. This is because the issue of their children having a NDD, and their resulting stress, is most likely a sensitive topic. The study guarded against

this threat by picking assessments and demographic questions that focused on matter-of-fact statements and questions of the situation, and a reminder in the survey to the participant of their anonymity in participation. A halo effect was also perceived as a potential threat to validity in self-report surveys of this type since a likely reason for their participation is their child's deficit and a hope for better treatments. The study used instruments and demographic questions that contained no negatively contrived statements regarding their children other than to be identified as having a diagnosis. Additionally, the instructions to the survey are short and were carefully worded as not to prime the participants' answers in one direction or another. The last threat seen as being a possible threat to validity was acquiescence. This is a possible threat because it is a self-report survey and because of its length of up to 25 minutes. This study guarded against this threat by putting few yes or no questions into the survey, giving the participant a time estimate before they started the survey, and choosing relatively short instruments in the three separate areas.

# **Ethical Protection of Participant Rights**

This research proposal was submitted to the IRB board of Walden University for approval before any participants were recruited or sought. Multiple precautions were followed to ensure ethical protection of the participants in this study. The researcher, upon IRB approval, set up a website that post information regarding the purpose of the study, informed consent, a statement of the volunteer nature of the study, and instructions for how to participate.

There are no foreseeable complications or distress, for participants that engaged in this study. All participation in the study were informed that it was voluntary, with the intended value being for research purposes. The participants were only allowed access to the study's criteria, instructions, and survey site through the site's moderators. The administrators/moderator were the only party to give permission for the recruitment of participants on each individual support group

site. Participants were solely recruited from the social media outlet Facebook. After viewing a recruitment ad potential participant, clicked on the hyperlink, and were then brought to the informed consent form, which re-inform them of criteria information, right to participate, right to terminate, risk and benefits, how the survey could only be submitted if it is complete, and how to contact the researcher if they have questions. Collected data are being maintained on a password-protected site for a period of 5 years, after which time it will be destroyed. Access to this data has been limited to the researcher and dissertation committee members.

### Summary

Chapter 3 described the research methodology for this cross-sectional study, which is both quantitative and comparative. This design permitted the formation of numerical relationships between the independent variables of mindfulness and social support, and the dependent variable of perceived stress, along with any interaction effects. The population group are parents 18 years and older with children between the ages of 3 to 17 years old, having at least one type of neurodevelopmental deficit. Chapter 3 reported on the setting of the research on social media and online based support groups, along with a sample size of 71 participants. It included the instruments (MAAS, PSS, and FSS) along with specifically established validity, reliability, and scoring of each instrument. The research questions, procedures, data collection, and analysis were presented. Multiple linear regression was the statistical technique, which best fits this type of study. Finally, threats to validity were covered along with ethical protections of the participants. Chapter 4 will present descriptive statistics of the sample population and the main analysis of the predictor, and outcome variables.

### Chapter 4: Results

#### Introduction

This chapter reports on the analytical operations conducted to determine how parental levels of mindfulness and social support relationally affect perceived stress in the parents of children with NDDs. These analyses were conducted with the underlying assumption that participants' level of mindfulness and social support would demonstrate a directional relationship to their levels of perceived stress.

### **Research Questions and Hypotheses**

## **Research Question 1**

Regarding the parents of children with neurocognitive deficits, is their level of social support as measured by the Family Support Scale correlated with their level of perceived stress, as measured by the Parent Stress Scale?

Null hypothesis ( $H_01$ ): Social support, as measured by the Family Support Scale has no significant relationship on the level of perceived stress, as measured by the Parent Stress Scale within the specified population.

Research hypothesis ( $H_a1$ ): Social support, as measured by the Family Support Scale, has a significant relationship on the level of perceived stress, as measured by the Parent Stress Scale within the specified population.

# **Research Question 2**

Regarding the parents of children with neurocognitive deficits, is their level of mindfulness, as measured by the Mindful Attention Awareness Scale, correlated with their level of perceived stress, as measured by the Parent Stress Scale?

Null hypothesis ( $H_02$ ): The level of mindfulness, as measured by the Mindful Attention Awareness Scale, has no significant relationship on the level of perceived stress, as measured by the Parent Stress Scale within the specified population.

Research hypothesis ( $H_a2$ ): The level of mindfulness, as measured by the Mindful Attention Awareness Scale, has a significant relationship on the level of perceived stress, as measured by the Parent Stress Scale within the specified population.

### **Research Question 3**

Regarding the parents of children with neurocognitive deficits, do higher levels of social support, as measured by the Family Support Scale, and mindfulness, as measured by the Mindful Attention Awareness Scale, significantly predict less perceived stress, as measured by the Parent Stress Scale?

Null hypothesis ( $H_03$ ): Higher levels of social support, as measured by the Family Support Scale, and mindfulness, as measured by the Mindful Attention Awareness Scale, does not predict less perceived stress, as measured by the Parent Stress Scale in the specified population.

Research hypothesis ( $H_a3$ ): Higher levels of social support, as measured by the Family Support Scale and mindfulness, as measured by the Mindful Attention Awareness Scale does predict less perceived stress, as measured by the Parent Stress Scale in the specified population.

This chapter will cover the following topics: (a) review the results of the data analysis of the research questions and hypotheses used to direct this study, (b) the time frame of the data collected, (c) recruitment, (d) response rate and report of no discrepancies, (e) characteristics of the sample and how well it represented the population, (f) discussion of the results via descriptive statistics, assumptions, analytical findings, and (g) a summary of the chapter.

#### **Data Collection**

This study used a convenience sample to survey a sample of self-selected participants, which were recruited from online support groups located on Facebook. The survey data were collected from the period of August 10, 2018 through September 17, 2018. There were no discrepancies in the data collection from the plan described in the design. The site (surveygizmo.com) that hosted the survey recorded a total of 115 respondents. Of those respondents, 71 qualified and fully completed the survey, 16 participants were disqualified, and 28 withdrew. All 115 of the respondents both gave consent to participate and identified that they were 18-years-old or older. However, 7 individuals (6.1%) answered that they were experiencing moderate to severe mental health difficulties, 2 individuals (1.7%) answered that they have had a recent death in the family, and 6 individuals (5.2%) answered that they were experiencing extreme financial difficulties. Logic built into the survey removed these participants from the survey and offered an explanation that these situations were viewed as being too stressful to accurately measure parental stress.

Completed surveys were the most observed response, the second most observed response was partially completed surveys where 28 (24%) of respondents withdrew from the study. There are five possible factors that may have contributed to withdrawing from the survey, even though it was stated in the informed consent section before the start of the survey that only completed surveys could be submitted. It is possible that respondents may have overlooked this. Since the survey was longer than some participants may have expected, this factor may have contributed to a response burden, deterring some participants from completing the entire survey. Also, it was not projected that participants might use their smartphones to complete the survey. Of the 28 participants who withdrew from the survey, 15 of them (53.6%) were identified as using an

iPhone to access the survey site with a smartphone within the data export file. In test runs of the survey, a smartphone was initially used; however, it was found to make survey navigation more difficult to complete; it is possible that this factor increased user difficulty and resulted in added response burden. Additionally, on one of the many support group sites on Facebook, one site user identified that the survey must be based out of the United States, because the question being asked (demographic) was based on an educational grade system that does not exist in the UK, thus the user reported that a best-guess equivalent was used.

After the survey data were collected, the export file revealed that the survey was being answered by English speakers in seven different countries: United States, New Zealand, United Kingdom, Ireland, Australia, Canada, and the Philippines. It was not surprising that there were participants from other countries since Facebook is a global site. However, differences in demographic norms between nations was not foreseen, possibly adding a degree of difficulty and adding to the response burden for a few of the participants. Lastly, the way the site designed their survey progress meter does not represent actual progress, but rather block percentage chunks of time, which may have impressed on some respondents that the survey was longer than it really was.

# **Description of the Sample**

The participants included parents or primary caregivers who were at least 18 years old who had a child between 3 and 17 years of age living in their home and diagnosed with any type of NDD. Online versions were used for the test measures of the PSS, FSS, and the MAAS. Since some of the measures included limited self-scoring procedures, these were omitted in the online version to discourage participants from scoring and possibly being influenced by their results. To help maintain accuracy of the data set, raw scores were entered into the database and then scored.

Since the online versions did not vary in content from the print form, there was no variance in the interpretation of results. The survey consisted of eight demographic questions, the PSS, the FSS, and the MAAS. To ensure the survey had sufficient statistical power to generalize inferences towards this population group, 71 completed surveys were used.

The following tables describe baseline descriptive, demographic characteristics of the sample, and how well the sample represented the general population group. The degree to which the sample represented the actual population will be discussed, along with reasoning as to why the sample did not fully represent the general population. As seen in Table 1, an overwhelming majority of participants who completed the survey were females (95.8%), while males accounted for only 4.2% of respondents. According to current statistics, this sample was not representative of the general population. According to the NAC, roughly 75% of all caregivers are female (National Alliance for Caregiving, 2009). Within the specific population of parents with children that have NDDs, many males fill the parental role towards their children, but more females end up providing most of the direct care with these children (Al-Farsi, Al-Farsi & Al-Adawi, 2016).

One plausible reason for this is that the sample group did not accurately represent the general population of parents with children that have NDDs. Another plausible reason for this could be gender stereotypical roles that females within the family tend to be more concerned with their maternal role, whereas males veered towards a provider role, which has a degree of support with family systems research (Katz-Wise, Priess & Hyde, 2010). Additionally, it is plausible that the individuals that participated in this study had strong opinions of the stress associated with the parenting of children with NDDs, and thus wanted to participate as a way of

being acknowledged. This could point towards participants who are more likely to take time out of their day and express their views on a topic area that has a large effect on their life.

Table 1

Frequency Table of Gender (N = 71)

	Female	Male	Total
Frequency	68	3	71
Percent	95.8	4.2	100.0
Cumulative Percent	95.8	100.0	

A great majority of the participants (87.3%) were in the age range of 31 to 50 years of age. Most participants fell between the age range of 41 and 50 years of age (47.9%), as seen in Table 2. The age range of 51 to 60 years of age had the least number of participants (4.2%). A plausible reason for an uneven distribution of the sample is a higher reported rate of children being diagnosed with one or multiple NDDs. Although only a couple of these disorders such as ADHD and autism are observed to be occurring at higher rates than they were two decades ago, it is also thought that the general symptoms and understanding of these disorders are more recognizable. In line with NDDs being more recognizable, within the areas of education and pediatric care, professionals in these areas have noted an increase in the reporting of behavioral and learning problems in children (Environmental Protection Agency, 2013).

Table 2

Frequency Table for Age Range of Parent (N = 71)

			Cumulative
	Frequency	Percent	Percent
21 to 30 years old	6	8.5	8.5
31 to 40 years old	28	39.4	47.9
41 to 50 years old	34	47.9	95.8
51 to 60 years old	3	4.2	100.0
Total	71	100.0	

A majority of the participants reported in the category of being married to their child's biological parent (54.9%), while (12.7%) of the participants indicated that they were in a relationship with their child's biological parent. About 15.5% indicated that they were divorced from the child's other biological parent, 5.6% reported that they were separated, and 11.3% were not inclined to answer the question, as viewed in Table 3. The sample appeared to represent the general population within this area.

Table 3

Frequency Table for Relationship Status (N = 71)

	•	•	Cumulative
	Frequency	Percent	Percent
In Relationship	9	12.7	12.7
Married	39	54.9	67.6
Separated	4	5.6	73.2
Divorced	11	15.5	88.7
N/A	8	11.3	100.0
Total	71	100.0	

The survey asked the participates their view on how involved the other parent is. A majority (54.9%) of the participants perceived the other parent as being very involved, 23.9% reported that the other parent was not involved, while 21.1% perceived that the other parent had satisfactory involvement (see Table 4). According to the US Census Bureau (2013), 23.6% of children under the age of 18 live in a home where their father does not live. According to research collected by the U. S. Census Bureau (2013), single-parent households were roughly five times more likely to have a single mother than father, so the demographics were not uncharacteristically homogenous in containing more females than males. It was thought that more of the sample would perceive an unsatisfactory level of parental involvement; however, with so many other mediating variables in this situation, it is hard to speculate why.

Table 4

Frequency Table for Perception of other Bioparent Involvement (N = 71)

Cumulative

	Frequency	Percent	Percent
Not Involved	17	23.9	23.9
Satisfactory Involvement	15	21.1	45.1
Very Involved	39	54.9	100.0
Total	71	100.0	

A majority of the participants (31%) indicated that they did not know how many NDDs their child has, whereas the second most common answer was two co-occurring NDDs (28.2%), and the third most common answer was one neurodevelopmental deficit (23.9%), as indicated in Table 5. The statistic that the most common response to this question was "I am not sure", is not too surprising since, at times, a quick assessment by a Primary Care Physician is used to just to qualify children for services and may require a more thorough battery of tests to understand areas of deficit comprehensively. It is estimated that around 4% of all US children have both ADHD and a learning disorder (Pastor & Reuben, 2008). Within a climate where multiple disorders are initially discovered and changed at times, it is not untypical to continue to seek the best services, but not always be knowledgeable about what those are, especially with co-occurring disorders, and confounding symptom sets.

Table 5

Frequency Table for the Number of NDDs Their Child has (N = 71)

	•	•	Cumulative	•
	Frequency	Percent	Percent	
I am not Sure	22	31.0	31.0	,
One	17	23.9	54.9	
Two	20	28.2	83.1	
Three	6	8.5	91.5	
Four or More	6	8.5	100.0	
Total	71	100.0		

The most common level of education for respondents was a bachelor's degree (35.2%), and the second most common answer was those reporting to have an associate's degree or Tech/Trade school (28.2%), as seen in Table 6. The sample is reasonably representative of individual education levels of the actual population in the United States. The United States census taken in 2015 reported that 41.2% of the population reported having at least an associate's degree, and 1 in 3 adults (33%) held at least a bachelor's degree (U.S. Census Bureau, 2015).

Frequency Table for Level of Education (N = 71)

	Frequency	Percent
Less than 9th Grade	1	1.4
9th to 11th Grade	3	4.2
High School Diploma/GED	10	14.1
Associate Degree/Tech/Trade	20	28.2
School		
Bachelor's Degree	25	35.2
Master's Degree	10	14.1
Doctoral Degree	2	2.8
Total	71	100.0

The participants responded overwhelmingly that they were spending large amounts of time on a weekly basis acting in a caregiver role for their child with a neurodevelopmental deficit, as observed in Table 7. In that regard, a majority (64.8%) answered that they spend 70 plus hours per week giving care to their child. Only 4 participants (5.6%) answered that they spent less than 30 hours per week providing caregiving to their child with a neurodevelopmental deficit. This sample is fairly representative of the general population of parents in these types of circumstances, which are spending very large amounts of time caring for their child (Dudley & Emery, 2014).

Table 7

Frequency Table for Weekly Hours Spent as Caregiver to your Child (N = 71)

		Cumulative
Frequency	Percent	Percent
2	2.8	2.8
2	2.8	5.6
4	5.6	11.3
5	7.0	18.3
6	8.5	26.8
6	8.5	35.2
46	64.8	100.0
71	100.0	
	2 2 4 5 6 6 46	2 2.8 2 2.8 4 5.6 5 7.0 6 8.5 6 8.5 46 64.8

Regarding the question of how many professional services they utilized for their child, the three highest reported answers were: 26.8% answered N/A, 21.1% answered one, and 21.1% answered two, as seen in Table 8. The range of responses is likely due to unknown factors, such as: their level of knowledge regarding their disorder, and their child's deficit areas that could improve, severity of their child's disorder, whether behavioral problems accompany the disorder, whether the diagnosing professional recommended seeking out additional services.

Table 8

Frequency Table for Number of Professional Services Used Monthly (N = 71)

		•	Cumulative	
	Frequency	Percent	Percent	
N/A	19	26.8	26.8	
1 Service	15	21.1	47.1	
2 Services	15	21.1	69.0	
3 Services	8	11.3	80.3	
4 Services	6	8.5	88.7	
5 or More Services	8	11.3	100.0	
Total	71	100.0		

In response to the item, titled the diagnosis of your child, the three most common responses, in order, were Autism Spectrum Disorder at 33.8%, more than one co-occurring NDD at 25.4%, and various communication disorders at 14.1% (see Table 9). As a representative sample of the general population of parents that have a child with one or more neurodevelopmental deficit, the sample is not representative of this general population. One possible reason for this might be because it was a convenience sample, where individuals self-selected participation, likely because it caught their attention; parental stress was the main topic of the study, so it may have attracted more participants that could relate with the high stress levels of parenting a child with these issues, so parents that were not experiencing as much stress in intensity or frequency may not have opted to participate.

Table 9

Frequency Table for Diagnosis of Participants Child (N = 71)

	Frequency	Percent	Cumulative Percent
ADHD	9	12.7	12.7
ASD	24	33.8	46.5
Communication Disorders	10	14.1	60.6
Motor Disorders	2	2.8	63.4
Learning Disorders	6	8.5	71.8
Not Sure	2	2.8	74.6
More than One	18	25.4	100.0
Total	71	100.0	

## **Research Questions and Results**

All the ranges of the variables were inspected through frequency analysis and found to be within the corresponding range for all variables. Univariate outliers were inspected by examining the z scores for both independent variables. There were no problems with univariate outliers in the data. The means standard deviations and internal consistencies for the variables are seen in Table 10. The internal consistencies for the mindfulness and stress scales were very good, whereas they were lower for the social support scale, but still in an acceptable range. As seen in Table 10, the variables used were reasonably normal in shape, with skewness and kurtosis values being within an acceptable range, +2 to -2 (Lomax & Hahs-Vaughn, 2012).

Table 10

Descriptive Statistics and Internal Consistencies of the Variables (N=71)

Variable	Mean	Standard deviation	Skewness statistic	Kurtosis statistic	Cronbach's alpha
Mindfulness	3.585	.900	.002	770	.937
Social support	1.688	.548	.593	114	.720
Perceived stress	2.445	.637	.458	.156	.908

*Note.* \*\*p<.001; \*p<.05

## **Interpretation of Bivariate Correlation Analysis**

**Research Question 1.** Regarding the parents of children with neurocognitive deficits, is their level of social support as measured by the Family Support Scale correlated with their level of perceived stress, as measured by the Parent Stress Scale?

Null hypothesis ( $H_01$ ): Social support, as measured by the Family Support Scale has no significant relationship on the level of perceived stress, as measured by the Parent Stress Scale within the specified population.

Research hypothesis ( $H_a1$ ): Social support, as measured by the Family Support Scale, has a significant relationship on the level of perceived stress, as measured by the Parent Stress Scale within the specified population.

Pearson's correlation was used to examine whether there is a relationship between family support and stress. As seen in Table 1, social support was negatively and significantly correlated with perceived stress, r(69)=-.262, p=.028. r<sup>2</sup>=.0686. An |r|=.10 indicates a small correlation, and according to Cohen, the correlation coefficient is an indicator of effect size (1988, p. 79-80) the effect size of this relationship is considered small. Therefore, this result supports the rejection of the null hypothesis.

Pearson's Correlation of Variables (N=71)

Variable	1.	2.	3.	
1. Mindfulness	-	.136	496**	
2. Social support		-	262*	
3. Stress			-	

*Note.* \*\*p<.001; \*p<.05

**Research Question 2.** Regarding the parents of children with neurocognitive deficits, is their level of mindfulness, as measured by the Mindful Attention Awareness Scale, correlated with their level of perceived stress, as measured by the Parent Stress Scale?

Null hypothesis ( $H_02$ ): The level of mindfulness, as measured by the Mindful Attention Awareness Scale, has no significant relationship on the level of perceived stress, as measured by the Parent Stress Scale within the specified population.

Research hypothesis ( $H_a2$ ): The level of mindfulness, as measured by the Mindful Attention Awareness Scale, has a significant relationship on the level of perceived stress, as measured by the Parent Stress Scale within the specified population.

Pearson's correlation was used to examine the relationship between mindfulness and stress. Mindfulness was negatively and significantly correlated with perceived stress, r(69)=-.496, p<.001, r=.496, r<sup>2</sup>=.25. An |r|=.50 indicates a large relationship, and according to Cohen (1988), the correlation coefficient is an indicator of effect size (p. 79-80) the effect size of this relationship is considered large. This result supports the rejection of the null hypothesis.

**Research Question 3.** Regarding the parents of children with neurocognitive deficits, do higher levels of social support, as measured by the Family Support Scale, and mindfulness, as measured by the Mindful Attention Awareness Scale, significantly predict less perceived stress, as measured by the Parent Stress Scale?

Null hypothesis ( $H_03$ ): Higher levels of social support, as measured by the Family Support Scale, and mindfulness, as measured by the Mindful Attention Awareness Scale, does not predict less perceived stress, as measured by the Parent Stress Scale in the specified population.

Research hypothesis ( $H_a3$ ): Higher levels of social support, as measured by the Family Support Scale and mindfulness, as measured by the Mindful Attention Awareness Scale does predict less perceived stress, as measured by the Parent Stress Scale in the specified population.

According to Osborne and Waters (2002), assumptions for multiple linear regression analysis are normality, independence of observations, linearity, reliability of measurement, and homoscedasticity. A power analysis reported that at least 68 participants were needed for the study to have adequate power; 115 participants responded, some participants were disqualified, and others did not fully complete the survey, leaving 71 full surveys to be analyzed.

An analysis was performed to evaluate whether the assumptions for multivariate regression were met. By examining standardized residuals, there was no evidence of univariate outliers within the data set, and the residuals demonstrated acceptable normal distribution. The Mahalanobis distances were examined for possible multivariate outliers. There was no evidence in the data that any case(s) were multivariate outliers. The assumption of constant variance of the residuals was assessed using the Breusch-Pagan test, and the test showed non-significance (BP=3.172, p=.205), suggesting the assumption of constant variances was met. The Cook's d method was used to examine any cases in the data, which may have a substantial impact on the regression model. All Cook's d values were less than 1, which indicated that there were no problems with influential cases causing undue influence on the model. Multicollinearity was not a problem either among the predictors, as they were correlated at r=.136, p=.257.

Multiple linear regression was performed to predict the influence of social support and mindfulness on perceived stress levels. The model contains two independent variable scores obtained from the social support and mindfulness instruments. As seen in Table 12, and 13, the model was found to be statistically significant, R-square=.284, F(2,68)=13.504.p<.001. As a set, the two predictors accounted for 28.4% of the variation in stress.

Table 12

Model Summary

Wiouci Su	immar y			
Model	R	R Square	Adjusted R	Std. Error of
			Square	the Estimate
1	.533ª	.284	.263	.54714

Note. Predictors: (constant), social support, mindfulness.

Table 13

ANOVA Table

Model	Sum of		<del>-</del>	<u> </u>	
	Squares	df	Mean Square	F	Sig.
Regression	8.085	2	4.043	13.504	.000 <sup>b</sup>
Residual	20.356	68	.299		
Total	28.441	70			

*Note.* b. Predictors (constant), social support, mindfulness.

As seen in Table 14, in interpreting the regression slope, mindfulness was a statistically significant negative predictor of stress (b=-.332, s.e.=.073,p<.001), as also was social support (b=-.230, s.e.=.12, p=.031, one-tailed).

Table 14

Coefficients Matrix for Study Variables

		Unstandardized Coefficients			
		Coefficients		•	
Model	В	Std. Error	Beta	t	Sig.
(Constants)	4.024	.316		12.718	.000
Mindfulness	332	.073	469	-4.528	.000
Social Support	230	.120	198	-1.909	.061

Note. (constant) stress.

Based on an evaluation of the standardized regression coefficients, it appears that mindfulness was the stronger of the two predictors. Indeed, the standardized regression slope for mindfulness was approximately 2.369 times greater than the standardized slope for social support. Thus, although both predictors were statistically significant in the model, the standardized effect of mindfulness appeared considerably greater than the effect of social support.

#### **Summary**

In summary, using a Pearson's correlation analysis for (RQ1), which queried if the target population's level of social support correlated with their level of stress, data analysis suggested that for the sample, social support was negatively and significantly correlated with stress, thereby leading to the null hypothesis being rejected. For (RQ2), a Pearson's correlation was also used; RQ2 asked if the target populations level of mindfulness correlated with their level of stress. Data analysis suggested that for the sample, mindfulness was negatively and significantly correlated with stress, and unrelated to social support. The results again lead to the null hypothesis being rejected.

Multivariate linear regression was used for (RQ3) it queried if higher levels of social support and mindfulness significantly predict less stress in the target population. Data analysis suggested that in the sample, the complete model and both predictor variables were statistically

significant. Thereby the research hypothesis was supported that there is a predictive relationship between higher levels of social support and trait mindfulness and perceived stress. Nonetheless, I found that the standardized effect for mindfulness was about 2.369 times greater than the effect of social support within the model. This highlights the differential contributions of the two predictors when accounting for variation in stress.

The current chapter reported on and discussed the raw and transformed data in depth.

Chapter 5 will cover an interpretation of these findings, the limitations to this study,
recommendations, and implications towards the target population.

## Chapter 5: Interpretations, Limitations, Recommendation, and Implications

#### Introduction

The parents of children with NDDs experience stress at a higher and more frequent rate than parents with typically developing children (Baker-Ericzen et al., 2005; Neff, 2010; Theule et al., 2011; Tomanik et al., 2004). It is commonly understood that chronic stress is bad for health and is generally associated with a higher disease risk. This population group are at a higher risk. Physiologically, chronic stress promotes high blood pressure, reduced immunity (Sapolsky, 2006), poorer health routines (Lindo et al., 2016), and an increased mortality rate (Puterman & Epel, 2012). Chronic stress also has negative affects the respiratory, cardiovascular, endocrine, gastrointestinal, and nervous systems (Sapolsky, 2004). Psychologically, this population is affected by stress in direct and indirect ways. Directly, they are affected in areas such as caregiver burden, less time for self-care, less time for sleep and poorer quality of sleep (Gallagher et al., 2010). Indirectly, the population is affected by a higher risk of anxiety, depression (Al-Oran & Al-Sagarat, 2016), increased financial pressures (Parish et al., 2012), and increased divorce rates (Freedman et al., 2012; Hartley et al., 2010).

There are many professional services that a child with a diagnosed neurodevelopmental disorder may qualify for, which is where most of the professional attention goes for these families, and rightly so. Yet, research suggests that when the parents of these children have higher levels of well-being, their children also have higher levels of well-being (Hill & Rose, 2009). The benefit of identifying the risk factors of high stress for this population is that it helps maintain a healthy family system to preserve positive parenting practices (Svensson et al., 2013).

Both social support and mindfulness are identified in the research as valid management strategies for stress. Social support can be defined as: an individual's accumulation of accessible

social resources, which generally helps families better cope with everyday stressors (Neff, 2010; Theule et al., 2011). The caregiving research clearly shows that higher levels of social support are beneficial. Two factors are particularly salient regarding the issues of support: quality and quantity: however, quality of support appears to be the more important to the consumer. Mindfulness is also showing much promise toward managing stress in this population group, along with that of their children (Burke, 2010; van der Oord, Bögels & Peijnenburg, 2012). Mindfulness as an intervention is being used as a component of interventions, as with Dialectic Behavioral Therapy (Lineham, 1993), and as the main intervention such as with MBRS (Kabat-Zinn, 1982).

The purpose of this quantitative study was to examine how the participants' levels of mindfulness and social support affect perceived stress in the parents of children with NDDs. The dependent variable was perceived stress levels in parents. The predictive variables were level of mindfulness and social support. I examined the degree to which the predictor variables, independently or in combination, explained detected variance with the dependent variable. Mindfulness and social support and were used in this study because they both demonstrate properties that assist towards the decrease of perceived stress. Additionally, both of these constructs (mindfulness and social support) have been successfully used or utilized within the social helping fields.

For this study, I used an online survey design to garner participants from online support groups that focused on parents of children with various NDDs. The survey was comprised of online versions of the Family Support Scale, the Parent Stress Scale, the Mindful Attention Awareness Scale, informed consent, and demographic questionnaire. The key findings of the study suggest that there is an association between mindfulness and social support (on the one

hand) and stress (on the other). Higher level of mindfulness was predictive of lower levels of perceived stress. Similarly, higher level social support was predictive of lower levels of stress. Even so, mindfulness appeared to be the stronger of the two predictors in the regression model.

### **Interpretation of the Findings**

Regarding RQ1, previous studies have suggested that social support does serve as an assistive and protective aid against stress for populations of parents who have children with developmental deficits (Gouin et al., 2016; Guralnick, Hammond, et al., 2008; Lindo et al., 2016). There is less empirical support specifically targeted towards the neurodevelopmental parent population, with much of the literature, focusing on the general caregiving population. The study results confirmed previous research findings that social support is assistive in reducing the effects of perceived stress (Gouin et al., 2016; Guralnick, Hammond, et al., 2008; Lindo et al., 2016), and, to a lesser degree extent, the knowledge base in that higher levels of perceived social support tend to decrease the negative aspects of stress in parents of children with NDDs.

Concerning RQ2, there is mounting evidence that mindfulness is both an effective and specifically efficacious intervention when used for stress reduction. Mindfulness techniques are professionally used in many differing intervention programs, some that focus primarily on mindfulness, and others that use it as a piece of a multicomponent intervention. A few of the uses for mindfulness include: the reduction of stress incurred from physical pain via one type of MBRS (Kabat-Zinn, 1982), assisting in the ease of psychological stress as incurred with anxiety (Miller et al., 1995), to reducing the stresses of caregiving burden (Hou et al., 2013).

When specifically focusing on a population of parents with children with developmental deficits, mindfulness has been effectively used in collaboration with other assistive interventions, such as with behavioral parent training (Lindo et al., 2016). Notwithstanding, most of the

intervention programs, are targeted towards specific problem areas rather than the population group. where stress reduction is needed. The results of this study both confirmed previous research and, to a lesser degree, extended the knowledge base that higher levels of trait mindfulness tend to decrease the negative aspects of stress among parents of children with NDDs.

Since mindfulness as a clinical intervention is still novel in comparison to more established interventions, and although it is generally viewed as being effective, the etiology and duration of its effects are not yet fully grasped (Carmody, 2014). Since there is a lack of specificity as to the duration of increased mindfulness, even after an intervention program is completed, this researcher measured trait mindfulness, so that the participants' levels of everyday mindfulness could be measured, rather than needing to be primed prior to participation.

In addressing RQ3, mindfulness as previously discussed in Chapter 2 has diversely defined features that include a range of practices that extend from: being cognitively in the present moment, to major shifts in cultural worldview, and religious doctrines. For this study, the scope of mindfulness was an individual's present moment attention and awareness. I chose this scope because it was culturally relevant to a Western European audience, predominantly void of Buddhist religious commitment and any need for worldview changes, so that the study would be accessible to as wide an audience as possible. Additionally, using both attention and awareness as the chief identifiers of mindfulness was consistent with the definitions used by the MAAS scale.

The findings of this study agree with the literature that mindfulness and social support both tend to ease the stress burden on individuals who experience chronic stress. More particularly this study agrees with research in the area that higher levels of these individual

variables tend to be effective at decreasing perceived stress in parents who have a child diagnosed with a neurodevelopmental deficit. Still, to a lesser degree, the study extends knowledge in that both high levels of trait mindfulness and social support appear to generally predict a lower degree of perceived parental stress. Notwithstanding, the results of this study must be interpreted with caution because the sample failed to generalize to the target population due to limitations in participant recruitment and using a non-representative sample (over-representation of female parents).

## **Self-Determination Theory Application**

The study was guided by SDT (Ryan & Deci, 2000a,) and used in conjunction with Lazarus and Folkman's (1984) stress appraisal and coping theory, which afforded a conceptual lens from which positive and negative cycles of parenting could be viewed. When viewed through an SDT lens, components of the family dynamic of this population were insightful: increased stressors, appraisal of stress, and coping skills within cycles of incurred chronic stress, relational difficulties, varying degrees of parental competence, and autonomy concerns (Theule et al., 2011; Tomanik et al., 2004).

Research suggests that as stressors reach an individual's personal threshold or are unresolved in the environment, that individual is more likely to use poorer parenting practices (Svensson et al., 2013). Yet, some researchers advocate that, as parents consistently practice parenting that meets their child's needs and encourage their child's own autonomy, their child is more likely to maintain parental demands (Laurin & Joussemet, 2017; Roth et al., 2016).

The theoretical approach in this study is that as primary and secondary appraisals of stressors occur, individuals use past experiences to envision stressors as an injury, threat, challenge, or benign situation. However, as the individual appraises stressors associated with acts

of self-will or past successes on a primary level, he or she is more likely to perceive it as a challenge, because of the perceived additional resources. On a secondary appraisal level, the same individual is also more likely to perceive control and or competence over stressors (Lazarus & Folkman, 1984). In other words, if competence, control, and autonomy are perceived, the individual is more likely to sense additional resources. However, when stressors signal low degrees of autonomy and competence, the individual is more likely to experience primary and secondary appraisals of injury or threat because of a lower degree of personal proprietorship and control (Nyoumanis, Edmunds, & Duda, 2009).

Looking at parental stressors from an SDT perspective may provide insight as to how this population responds to appraisals of stress, assist with interventions to promote autonomy, competence, and relatedness to promote appraisals as a challenge rather than injury or threat and strengthen individual ability to respond with effective coping skills. The research suggests that effective coping skills are associated with better physical, psychological, and well-being outcomes (Aldwin, 2000; Lazarus, 1991). The predictor variables used in this study are viewed as contributing positive influence towards factors in this construct model. Mindfulness is associated with SDT (Ryan & Deci, 2000) by promoting personal well-being, lessening stress burden, and by association promoting more autonomy in the form of expanding response choices (Brown et al., 2008). Higher levels of social support appear to act as a stress modifier within the population researched, and high degrees of social support are theorized to bolster two of the three basic psychological needs of SDT (Ryan & Deci, 2000a) in the forms of relatedness and competence (Kazak & Wilcox, 1984; Ryan & Solky, 1996). As for this study, there was a demonstrated tendency in the population group sampled, that higher levels of mindfulness and social support predict lower levels of perceived stress. In the merging of the theoretical

frameworks, the study appears to generally agree with the constructs and workings of these theories.

## **Limitations of the Study**

This study had numerous limitations. The study was correlational in nature, based on cross-sectional data obtained from a set of parents with children with NDDs. This necessarily limits inferences concerning possible causal relations between the predictor variables (mindfulness & social support) and perceived stress. While the fit of my model may support my proposed causal model, it is also possible that other models of proposed associations would fit the same or better. Given the convenience sampling approach taken in this study, it seems reasonable to question the degree to which the findings obtained in this study may generalize to the broader population of parents with children with NDDs. Indeed, my sample was comprised almost exclusively of mothers, raising questions as to whether my results would generalize to a broader population containing both mothers and fathers of children with NDDs. Given my sample limitations, I would suggest that efforts be made to cross-validate the results from this study in samples that are more heterogenous with respect to role as mother and father. Another limitation of my study is that my data were obtained based on self-reports in response to survey questions. Although the measures used in my study have evidence within the literature of good reliability and construct validity, there remains the question of whether factors external to the testing procedure may have impacted results. For example, being able to report greater levels of "mindfulness" might be viewed as more socially desirable. Similarly, reporting greater levels of "stress" might be viewed by respondents as less socially desirable. Although it is impossible to address the effects of socially desirable responding with my data, this is a consideration worth raising when carrying out future studies on this topic. Failure to account for this possibility and

others when using self-report data may result in biased estimates of relationships among variables. There were other difficulties in the area of external validity, in that the sample was not representative of the general population of parents who have a child with a neurodevelopmental deficit by an over-representation of children diagnosed with ASD (33.8%), and an underrepresentation of children diagnosed with ADHD (12.7%), which is more common in the general population.

In terms of internal validity, the study had several issues of potential biases. In addition to possible sampling self-selection bias, the survey was susceptible to response bias in that it was a longer survey and one particular demographic question (highest grade level achieved-potential ranges) was identified as not being as relevant to some participants outside the United States. Also, female participants were overrepresented parents in the study. It is a possible internal validity problem because some research in the area suggests that there are some differences between how females and males tend to experience and respond to parental stress, which may have skewed the data (Beck, Daley, Hastings & Stevenson, 2004; Reynolds, Bendixen, Lawrence & Lane, 2011; MacDonald, Hastings & Fitzsimons, 2010).

Other limitations centered around the use of an online social media environment. A flaw on one demographic question (the highest grade achieved, in ranges) was detected when two support group site members were discussing -how the study must be based in the US, since the UK did not have grade levels equivalent to the question. Also, although it was not observed, participants may have urged fellow group members to participate in the study or shared their responses with peers on the site. Since the survey was located on a survey centered website, only participants with internet access could have participated, which would have limited the sample group to individuals with that type of access.

It was noted during data analysis that over half (53.6%) of the individuals that withdrew from the study were using an iPhone, whereas other phone systems were not able to be identified, but, it appears likely that smartphone users may have been impeded by the length and technical difficulties of navigating the survey site with their smartphone, which may have also limited the population of parents that participated in the study. Another limitation of the study was that it was not possible to determine truthfulness, specifically whether participants child had actually received a diagnosis, and generally within the accuracy of the survey responses.

Nevertheless, there was no evidence that participants recruited from social media platforms answer less truthfully than ones recruited from more traditional sources. The study was also limited in its cross-sectional design and lack of an intervention, which did not allow any causation to be shown, but rather limited it to inferences regarding relationships between variables.

#### Recommendations

There are several recommendations for future research associated with the topic areas of this study. Mindfulness appears to be helpful in numerous areas of stress reduction, yet the mechanisms of mindfulness are not operationally understood; continued research as to what components of mindfulness are assistive, and how they are assistive, would be in a universal definition of mindfulness, and in operationalizing it. As mentioned previously, the model of mindfulness that I used in this study might be compared to very basic components of mindfulness, which are attention and awareness. Whereas, other frameworks of mindfulness such as what is used with MBSR (Kabat-Zinn, 1982 & 2011) attention, awareness, non-judgement, clarity of mind, emotional regulation, compassion, are summed up as dharma or Buddhist cosmic law and order. Obviously, there is a large difference between these two versions of the same

construct of mindfulness, and since research appears to suggest that mindfulness in general appears to be helpful with stress; the question remains, how and why is that so? Additionally, within the sample group, if individuals had higher levels of trait mindfulness and social support, they were likely to have less stress. However, it should be emphasized that these findings to not equate to (more mindfulness and social support less stress) or the other way around. The analysis from this study just supports and fills a gap within the current literature that these constructs (mindfulness and social support) both tend to be useful towards decreasing the problem of chronic stress; in the parents of children with NDDs, as they were represented within my sample group.

A longitudinal study of mindfulness that included varying lengths (10, 16, 20, 30-weeks) of the intervention, control groups, and several repeated measures during and after the study would all help to partly answer some of these questions. This would be helpful since it is not clear how much mindfulness training individual's needs to make a difference, how long mindfulness training is retained, or even what types are more effective than others. One meta-analysis studying several mindfulness methodological intervention types concluded that the majority of mindfulness-based interventions were helpful in the area of stress reduction (Sedlmeier et al., 2012). From the review of multiple mindfulness intervention types, it was still not clear as to how practical they are for the average consumer, or if users must convert their cultural, belief, or worldview systems in order to fully utilize these interventions; research in this area could lead to an expansion of benefit to more population groups. Another study of 22 participants that received eight weeks of mindfulness training found that even after three years, the participants continued in their initial decreases in anxiety and related symptom (Miller et al., 1995), although this provided little supporting evidence.

A research study that expanded on this current study with an aim to investigate if interventions of mindfulness and social support may decrease perceived stress in the target population, would be warranted given the results of this study. Given the study's sample group did respond as predicted, the parents that had higher levels of trait mindfulness, and social support, also had significantly lower levels of perceived stress. An experimental study conducted with an equal number of females and males from the target population would help answer questions that are still unknown such as: is mindfulness and social support effective as an intervention for the target population and does equal representation of both parent genders have any effect on the predicted relationship between variables?

This study did not conduct any research with SDT, but rather used it as a lens from which to view the dynamics of this parental group, stress, and possible relationships with SDT. It was viewable in the patterns of this population group that high levels of stress would likely lead to lower levels of SDT's three psychological needs of autonomy, competence, and relatedness; in theory, it appears viable. A study in which this theory could be tested, for example, if when the three basic psychological needs are at higher levels, does this predict higher levels of well-being or lower levels of perceived stress. If this theory is accurate and parental motivation could be intentionally fortified and reinvigorated it would be a real agent of positive social change in this area

#### **Recommendations for Action**

It was noted during the data analysis phase of this study that only 11.3% of participants reported spending less than 40 hours a week being a caregiver to their child, whereas 64.8% reported spending more than 70 hours a week, which is similar to working two full-time jobs that do not compensate with any monetary wages, sick time, benefits, vacation days. Additionally,

this role does not end after the shift is over, this population is on call 24 hours a day, 7 days a week. How do these individuals get a break? This topic was briefly touched upon in the literature review section and highlighted after the data from this study was analyzed. This factor alone appears worthy of additional research inquiry.

## **Implications**

Additional research with the focus of parental stress associated with parenting a child(ren) with NDDs is needed, as that it is limited in quantity and is more likely to focus on populations, such as parents that have a child with an intellectual disability or ASD (Bazzano et al., 2015; Reynolds et al, 2011; Lindo et al., 2016; Woodman, Mawdsley & Hauser-Cram, 2015). Although these groups are within the range of NDDs, there does not appear to be many differences between the issues that are associated with high stress with these parents. The stressors that appeared across the spectrum could be categorized in themes of time, physical, and psychological concerns. In the area of time concerns, issues arise that tax these parents in areas of social isolation (Baker-Ericzen et al., 2005), relational (Freedman et al., 2012), and finances (Parish et al., 2012).

As was identified in Table 7, the majority of the participants in this study were working the equivalent of two full-time jobs in the caregiving of their child. Clearly, this has an effect in other areas of the parents' lives that require an investment of one's time to maintain and thrive in quality. In the area of physical health, as previously covered in chapter two, this population are more likely to practice poorer health habits, experience poorer quality and quantity of sleep, (Lindo et al., 2016). They are more likely to experience chronic inflammation (Gouin et al., 2016) and are at higher risk for diseases in the respiratory, cardiovascular, endocrine, gastrointestinal, and nervous systems (Sapolsky, 2004).

In the area of psychological health, this population is at an increased risk of anxiety, and depression (Al-Oran & Al-Sagarat, 2016; Bevans & Sternberg, 2012; Karst & Van Hecke, 2012) and have poorer well-being outcomes (Aldwin, 2000). The severity of the child's diagnosis and symptoms is a paramount factor, which affects the parents in all the other areas. The challenges in caring for a child with a mild learning disorder are distinctly different from those associated with caring for a child with ASD cooccurring with a communication disorder. Although the degree of obstacles associated with caring for a child with a neurodevelopmental deficit may vary with severity and symptoms, this still does not address all of the other stressors within a family system. Therefore, it was advantageous for this study to look at these stressors from a wide scope of disorders and view unifying stress themes that are commonplace for these families, yet still very debilitating and destructive.

## **Implications for Positive Social Change**

It became evident in the process of this study that the parents of children with NDDs are underserved. If they have no prior experience in this area, they will likely have a long road of self-education to discover practical, impractical, and dangerous treatments for their child and family. For example, while negotiating recruitment posts with social media support group administrators, it was noted that some of these groups encouraged no medications at all, but rather the use of supplements. Another encouraged the sole use of only essential oils; one reported that ASD could be completely reversed through a specially regimented dietary-supplement routine.

In viewing some of the personal advice given from one parent to another, some of it was inaccurate and troubling. For instance, there was guidance that if your child responds poorly to the regimen, you really need to wait it out and it will eventually work its magic; a few of these

groups had thousands of registered users, while the majority of them were just functioning as support groups. There were a few that aggressively marketed their chosen non-medical treatment. There are many different views outside of evidence-based treatments and some make claims that have shown no evidence to validate them. Additionally, others appear to be peddling specific supplements, such as companies that effectively sell cures for ADHD and ASD; it is noteworthy that these companies have little oversight. The FDA does not regulate them. Because of the erratic and unpredictable nature of parent support groups, it is likely that unless a professional brings up the subject of parental self-care while seeing their child, it may never occur to the parent that they might need to address these issues.

Among different types of insurance coverages, children with NDDs are typically allocated some type of services once they are diagnosed. Many schools also have a mental health professional either embedded or assigned to the district because of disability legislation such as the IDEA law (U. S. Department of Education, 2015). These measures typically add another tier of protection besides parental initiative, which helps identify and address these deficits. However, for the parents, it is likely that they would either have to seek help from there PCP or from a professional counselor if they have the resources.

It is unlikely that this situation will change anytime soon unless it is addressed individually by health and mental health professionals with a familiarity with the unique challenges this population faces. Additionally, treatment facilities that serve clientele with these types of disorders could start implementing holistic integrative mental health services for the whole family. This could be very similar to the current services provided but might also include relevant topical information on how these disorders can also affect family life, psychoeducational classes could be conducted that focused on the especially stressful areas (just

diagnosed-what do I do now, behavioral difficulties, aging out of services), and also implement parent support groups that provide childcare (Catalano, Holloway, & Mpofu, 2018).

#### Conclusion

As most individuals with children could attest, parenting is an inherently stressful role that asks much from the individual and, at times, requires more than can be given. Yet, being a parent of a child with a neurodevelopmental disorder presents potentially escalating difficulties, which are over and above those experienced by individuals parenting a typically developing child. This population has life limitations in the areas of earning potential, autonomy of time, additional challenges to their parental competency, and threats to parent-child relatedness, which is closely associated to attachment (van IJzendoorn et al., 2007). These limitations expose this population to a greater stress potential, which then may extend past the individual's stress threshold. As the circumstances and stress become unmanageable for the parent, they end up being exposed to a greater risk for chronic stress and associated risks factors in the forms of physical, social, and mental health problems. This study looked at this problem from a Self-Determination Theory perspective in an attempt to view how motivation may interact with these parents, their environment, and the stress dynamics. There were no instrumental applications of this theory in this study; however, it did provide an insightful lens from which to view positive and negative aspects within these relationships.

The resolve of this study was to identify readily available psychoeducational and intervention tools that have been used to help with stress reduction and determine if individuals from the population that practice higher degrees of these would also have lower degrees of perceived parental stress. Seventy-one parents of children diagnosed with at least one neurodevelopmental deficit were recruited from seventeen online social media support groups.

These participants were then given an online version of the MAAS, FSS, and PSS along with a short demographic questionnaire. Analysis of the data led the researcher to reject the null hypothesis in all three of the research questions used and indicated that both mindfulness and social support had a significant linear relationship with stress and that higher levels of mindfulness and social support were predictive of lower levels of parental stress.

Considering the review of the literature in the area and the analyzed data, the study produced several valuable insights that have important implications. Mindfulness and social support would most likely be a helpful tool in decreasing the stress burden of this population. This population experiences an excessive amount of potential high-risk factors, which equates to higher rates of health and mental health difficulties. Insurance companies and managed care should take note, as the cost-effectiveness of this issue proves to be more complicated than the traditional preventive care vs an acute care and treatment model. There are also considerations that if the child is responding poorly, the parent is more likely to also respond poorly, contributing to this negative cycle, in that the parent-child dyad tends to follow one another's symptomology (Modesto-Lowe et al., 2014). It is likely easier to integrate family services as a package to reduce and possibly prevent some of these difficulties, rather than to remedy them afterward. Additionally, since many of these families are already seeking help from professionals for their children (73.2% of the studies participants, as seen in Table 8), many of these holistic integrative changes would be relatively small in nature, and most likely be cost-effective in the long term. It was also promising to see the potential insights that Self-Determination theory could bring when applied with the theory of Stress and Coping towards the population.

The study concurred with the previous finding as to the sheer workload that many of the caregivers in the population experience; however, when contemplated within the context of all

the other stressors these individuals face, it hardly appears sustainable in the long term. Further research is needed; nevertheless, mindfulness and social support appear to show great promise in the pursuit of easing the dis-ease of this population group.

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# APPENDIX A: DEMOGRAPHIC FORM

1. parental involvement status of your child's biological parent?
○ Not Involved, ○ Satisfactory Involved, ○ Very involved, ○ More involved than m
2. Relationship & parental involvement status with your child's biological parent?
○ In relationship, ○ Married, ○ Separated, ○ Divorced, ○ NA
3. Your age range group?
○ 18-20 years old, ○ 21-30 years old, ○ 31-40 years old, ○ 41-50 years old, ○ 51-
60 years old, $\bigcirc$ 61 years old plus
<b>OThe Number of Neurodevelopmental deficits your child Has</b>
$\bigcirc$ = 1, $\bigcirc$ = 2, $\bigcirc$ = 3, $\bigcirc$ = 4, $\bigcirc$ = 5 or more, $\bigcirc$ = I am not sure
4. Highest level of education you have completed?
○ Less than 9 <sup>th</sup> grade, ○ 9 <sup>th</sup> - 11 <sup>th</sup> grade, ○ High School Diploma/GED
OAssociate Degree/Technical/Trade School
○ Bachelor's Degree, ○ Master's Degree, ○ Doctoral Degree
5. Weekly hours spent as a caregiver to your child/children in question?
$\bigcirc$ Less than 5 hours, $\bigcirc$ 6-10 hours, $\bigcirc$ 11-15 hours, $\bigcirc$ 16-20 hours, $\bigcirc$ 21-25 hours
○ 26-30 hours, ○ 31-35 hours, ○ 36-40 hours, ○ 41-45 hours, ○ 46+ hours

6.	How many professional services are being used monthly, for your child? Example			
	of professional services such as: case-management, therapies, day programs,			
	individual or group skills training, and informational classes.			
$\bigcirc$	None, $\bigcirc =1$ , $\bigcirc =2$ , $\bigcirc =3$ , $\bigcirc =4$ , $\bigcirc =5$ , $\bigcirc =6$ or more			
7. With which of the following disorders has your child been diagnosed?				
C	=ADHD,			
$\subset$	= Intellectual Development Disorder,			
C	) = Any type of Learning Disorder, $\bigcirc$ = Not sure, $\bigcirc$ = Multiple			
8.	Your gender. O Female, O Male, O Other, O NA			

## APPENDIX B: PERMISSION TO USE FAMILY SUPPORT SCALE

Permissions: Test content may be reproduced and used for non-commercial research and educational purposes without seeking written permission. Distribution must be controlled, meaning only to the participants engaged in the research or enrolled in the educational activity.

RE: Using FSS measure

CD

Carl Dunst <cjd@puckett.org>

## Reply all

Mon 7/9, 8:04 AM

Branden Syrotchen

Inbox

**Action Items** 

I provide permission for students to use the scale. Therefore you can go ahead and use it for your research. all the best.

# APPENDIX C: PERMISSION TO USE THE MINDFUL ATTENTION AWARENESS SCALE IN ONLINE FORMAT

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Using MAAS measure

KB

Kirk Warren Brown <a href="mailto:kwbrown@vcu.edu">kwbrown@vcu.edu</a>

## Reply all

Mon 7/9, 8:27 AM

Branden Syrotchen

Yes you are welcome to use the MAAS for your study. You can find the scale, along with background normative and other information, on the 'Resources' page of my Lab website, the link for which is below. The 'Publications by topic' page has papers related to the validation of the MAAS. See especially Brown and Ryan (2003).

All the best with your research,

Kirk			

Kirk Warren Brown, PhD

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# APPENDIX D: PERMISSION TO USE PARENTAL STRESS SCALE IN ONLINE FORMAT

Permission to use PSS in research study

Berry, Judy <judy-berry@utulsa.edu>

# Reply all

Yesterday, 7:02 AM

Branden Syrotchen;

Louie, Ashley <adl667@utulsa.edu>

You have my permission to use the Parental Stress Scale for your research.

Judy Berry