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Raising a Child with a Disability: Coping Mechanisms and Support Needs

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Philadelphia College of Osteopathic Medicine

Department of Psychology

RAISING A CHILD WITH A DISABILITY: COPING MECHANISMS AND SUPPORT NEEDS

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Dissertation Approval

This is to certify that the thesis presented to us by ________________________________

on the ______ day of ___________________, 20___, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

Committee Members' Signatures:

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Dedication

This dissertation is first and foremost dedicated to my children, Abigail and Logan, especially Logan, who showed me how to be strong when the unimaginable was happening.

This dissertation is also dedicated to the families who have and will continue to raise a child with a disability. I, and my family, have also walked in those shoes. I encourage and pray for your continued strength when you can no longer find the strength to continue, and the hope that you find the blessing of love in being part of a family who is raising a child with a disability.

I also dedicate this dissertation to my parents who worked tirelessly, lovingly, and courageously to raise a child with a severe disability. They dedicated their lives to ensuring their daughters' health, safety, and happiness was always a priority, never wavering, never quitting. I am so very proud to have been part of this family and to have walked the journey with them.

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Abstract

Raising a child with a disability can affect parents, siblings, and family members in various ways and can be determined by the way in which a parent copes with and appraises the situation. The first goal of this study was to investigate the relationship between a parent's coping mechanism (confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal) on his or her mental health or distress (depression, hopelessness, anxiety, and anger) when raising a child with a disability. The second goal was to investigate whether positive and adaptive coping would result in better mental health outcomes or if additional supports are needed. Two questionnaires were utilized to investigate the relationship between the stress associated with raising a child with a disability and coping mechanisms. Parents rated their coping by completing the Ways of Coping Questionnaire and rated their mental health by completing the Psychological Distress Profile. In addition, six open-ended questions were utilized to add depth to this study by asking parents to discuss their personal journeys. The results indicate parents' coping mechanisms did not have a significant relationship with their distress and that positive adaptive coping did not result in better mental health outcomes. Parents' reports of their own personal experiences yielded consistent results in that they did, in fact, feel socially isolated, financially stressed, and emotionally taxed when raising a child with a disability. Implications regarding parental coping mechanisms and the distress of raising a child with a disability are discussed.

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Chapter 1: Introduction

According to the Centers for Disease Control and Prevention (CDC, 2015), approximately 1 in every 33 babies is born with a birth defect, and about 1 in 6 children is born with a developmental disability. Birth defects are structural changes present at birth that can affect almost any part or parts of the body (e.g., heart, brain, foot). These defects may affect how the body looks, works, or both. Birth defects can vary from mild to severe. The well-being of each child affected with a birth defect depends mostly on which organ or body part is involved and to what extent it is affected. Depending on the severity of the defect and what body part is affected, the expected lifespan of a person with a birth defect may or may not be affected. A *disability* is a physical or mental impairment that substantially limits one or more major life activities, such as caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, learning, reading, concentrating, thinking, communicating, and working (Americans With Disabilities Act, 1990). A disability can be related to conditions present at birth and may affect functions later in life. Such conditions include disorders in single genes, chromosomal disorders, or a mother’s exposure to infections during pregnancy. Additionally, a disability can be associated with developmental conditions that become apparent during childhood or are related to an injury, associated with a long-standing condition, or a progressive illness. The individual must have a record of impairment and be regarded by others as having such impairment (Americans With Disabilities Act, 1990). Overall, children born with birth defects or who are developmentally disabled often need special care and interventions to survive and thrive developmentally.

Raising a child with a disability can be an overwhelming and emotional experience and can pose many difficulties for parents. Benson (2012) explained the long-term care of a child with a chronic disability frequently affects various areas in a parent’s life domains (e.g., marriage, career, relationships), which can lead to stress, and often affects the overall functioning of the family. In addition, parents work to balance their marriages with demands that accompany having a child with special health care needs. Because children with disabilities may require continuous medical support to meet their needs, a parent’s career is then affected because of a high rate of absences and reduced work hours. Equally important, relationships with family and friends can become fragmented by the continuous demands of having a child with a disability, leaving little or no time for fostering such relationships. Moreover, research has shown that parents of children with disabilities experience higher levels of stress and are at higher risk for mental health issues than those with typically developing children (Trute, Hiebert-Murphy, & Levine, 2007).

The theoretical perspective guiding this study was the work of Richard S. Lazarus, PhD, and his belief about an individual’s stress and coping styles. According to Lazarus, stress is a two-way process; it involves the production of stressors by the environment and the response of an individual subjected to these stressors (Lazarus, 1993). His conception of stress led to the theory of cognitive appraisal. Lazarus stated that cognitive appraisal occurs when a person considers whether a particular situation within the environment is relevant to his or her well-being and, if so, in what ways. In the stage of primary appraisal, an individual assesses whether or not he or she has anything to lose. That individual may ask, “What does this stress or situation mean?” and “Is the health or well-being of a loved one at risk?” In secondary appraisal, the individual evaluates if anything can be done to overcome or prevent harm or to improve the potential for benefit (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Secondary appraisals involve those feelings related to dealing with the stressor or the stress it produces. Positive secondary appraisal statements may include, “If this way fails, I can always try another method” and “I can do it if I do my best.” In contrast, statements such as “I can’t do it; I know I will fail” indicate negative secondary appraisal statements. In secondary appraisal, various coping options are evaluated by the individual, including altering a situation, accepting the situation, seeking additional information, or holding back from acting impulsively and in a counterproductive manner. Lazarus proposed primary and secondary appraisal converge simultaneously in an effort for the individual to determine whether the person-environment stressor is regarded as significant for one’s well-being and, if so, what classification it falls under: threat or challenge. In a threat, the person regards the situation as containing the possibility of harm or loss. In contrast, when viewed as a challenge, the person views the situation as holding the possibility of mastery or benefit, leading to the development of a positive stress response (Folkman et al., 1986). Overall, stress appraisals result from perceived situational demands in relation to perceived coping resources; thus, the ability to successfully navigate those stressors is dependent on the person’s coping strategies.

Lazarus emphasized people alter their circumstances to make it appear more favorable in an effort to cope. Coping is an individual’s continuous effort in thoughts and actions to manage specific external or internal demands appraised to be challenging and overwhelming to the individual. In addition, coping is considered highly contextual, in that its effectiveness is determined by the ability to change over time and across different conditions (Folkman & Lazarus, 1985). To expand, coping has two widely recognized major functions: regulating stressful emotions, called *emotional-focused coping*, and changing the troubled person-environment relation that is causing the distress, which is referred to as *problem-focused coping*. Emotional-focused coping is change only in the way in which the individual interprets what is happening, such as using the technique of distancing to remove the cognitive basis of the stress reaction. Problem-focused coping is when an individual's relationship with the environment is changed by the coping action (Folkman & Lazarus, 1985). When examining stress and coping, and whether the change is because of an external condition or from the analysis of it, coping affects psychological stress through appraisal; therefore, appraisal is always considered to be the mediator (Lazarus, 1993). In conclusion, cognitive appraisal and coping are critical mediators of the stressful person-environment relationships for parents as they navigate the immediate and long-term outcomes.

Previous research has shown that with the appropriate support and guidance, parents of children with a disability can cope effectively with the many challenges presented and, in turn, become advocates for their child (Shilling et al., 2013). Therefore, from the individual and societal perspective, identifying and understanding what factors cause parental stress as well as identifying coping strategies that have been beneficial for parents are important for the treatment of the child, the parent or caregiver, the family as a whole, and the community.

Limited research exists regarding the parents' and caregivers' perspectives and their voice in guiding theory and practice regarding family stress and resiliency in families raising children with disabilities. First, because much of the research has pertained to the distinct challenges and lives of families of children with disabilities, taking a strength-based approach to add to the current literature on family coping can have significant implications for theory and practice. Second, this paucity of research means that current theory and practice may lack critical data that can help parents adapt and cope during stressful periods in their lives. Therefore, the major goal of this study was to achieve a more thorough understanding of these families as a fundamental building block for future research and practice.

Statement of the **P**roblem

Although limited research exists pertaining to the stress and coping process of raising a child with a disability, this research has yielded varied results regarding the effects of families caring for a child with a disability. Therefore, this is a significant concern for this understudied but large population. Specifically, some researchers have noted significant stress within families, while others have indicated families have tremendous resilience in helping each other cope with their challenges (Bayat, 2007; Benson, 2006; Benson & Karloff, 2009; Debrowska & Pisula, 2010; Feldman et al., 2007; Myers, Mackintosh, & Goin-Kochel, 2009; Retzlaff, 2007; Van Riper, 2007). Furthermore, the degree of stress and adjustment is dependent on appraisal of the stressors, coping ability, and emotional resources (Folkman et al., 1986).

Parents of children with a disabling condition face various challenges that are often not addressed, as resources tend to be primarily child focused (Woodgate, Ateah, & Secco, 2008). The first challenge faced by parents of children with a disability is social isolation. Family members and friends do not always understand the needs of a child with a disability and may not be able to provide child care support. In addition, activities, such as community outings and recreational activities, are frequently reduced because of caregiver demands. A second challenge reported in the literature is that raising a child with a disability causes significant financial stress. Current research has shown the percentage of families with both parents in the workforce is higher than those with only one parent working (Parish, Seltzer, Greenberg, & Floyd, 2004). Raising a child with a disability may force working parents to reduce their hours or stop working entirely to care for their child, thus reducing family income. This, coupled with the need for specialized services and the out-of-pocket medical expenses, represents a significant financial burden for many parents raising a child with a disability (Reichman, Corman, & Noonan, 2008). A third concern is the well-being of the parents. The increased stress that accompanies raising a child with a disability can negatively affect the emotional, mental, and physical health of the parents trying to balance the needs of their healthy and unhealthy children, work demands, financial demands, and the overall functioning of the family. In addition, the parents may feel guilt and blame, become depressed, or experience reduced self-esteem.

At the same time, living with a child with a disability has also been shown to have significant positive effects on the family and is a unique, potentially enlightening shared experience for families (Williams, Piamjariyakul, Graff, & Stanton, 2010). This situation has broadened horizons, increased family members’ cognizance of their own inner strengths, enhanced the family unity, and encouraged connections to religious affiliations and community groups. In conclusion, all of these potential factors may significantly affect the quality of the relationships between the parents, additional family members, and the family structure (Reichman et al., 2008).

Purpose of the Study

The purpose of this study was to investigate the relationship between a parent's coping mechanisms (confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal) on his or her mental health or distress (depression, hopelessness, anxiety, and anger) when raising a child with a disability. Through this study, the researcher sought to identify particular coping mechanisms that may affect mental health in a positive or negative way, thereby helping counselors encourage positive coping strategies to alleviate parents' psychological distress in raising a child with a birth or developmental disability. In addition, the researcher investigated whether positive and adaptive coping behaviors alone can result in better mental health outcomes or if additional supports are needed. Efforts to understand the coping process of this understudied population can assist researchers in designing interventions that address the key components of the adjustment process, including identification of maladaptive stressor appraisals and coping strategies. Folkman and Lazarus proposed one of the most comprehensive theories of stress and coping in literature; however, their model has received insufficient empirical attention regarding parents' stress and coping when raising child with a disability. In addition, some existing research has yielded conflicting results. The increasing demand for psychologists with knowledge in this specialty area justifies the need for more effective, life-changing approaches. Thus, psychologists will be essential to the stress management of parents of children with disabilities.

Research Questions

Through this study, the researcher sought to answer two research questions: (a) Is there a relationship between the stress associated with raising a child with a disability and parents’ mental health? and (b) Do the coping behaviors in raising a child with a disability affect parents’ mental health outcomes?

It was hypothesized that the stress associated with raising a child with a disability would affect parents’ mental health. Additionally, it was hypothesized that positive coping behaviors when raising a child with a disability would result in better mental health outcomes, but that additional supports are needed to positively influence parents’ mental health.

Chapter 2: Review of Literature

Raising a child with a disability can be an overwhelming experience and may cause an array of emotional implications for the parents and for the entire family unit. The long-term care of a child with a chronic disability frequently affects various areas in parents’ life domains (e.g., marriage, career, relationships), which can lead to stress and affect the functioning of the family as a whole. Research has shown that parents of children with disabilities experience higher levels of stress and are at a higher risk for mental health issues and affected well-being than those with typically developing children (Benson, 2012; Trute et al., 2007).

According to the CDC (2015), approximately 1 in every 33 babies is born with a birth defect and about 1 in 6 children is born with a developmental disability. Developmental disabilities are a group of conditions caused by impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may affect day-to-day functioning, and usually last throughout a person’s lifetime.

Parents face a multitude of changes when raising a child with a disability. The parental roles are often redefined and can become a significant challenge and burden for parents, especially when limited or no supports exist. Parents of children with disabilities encounter new and unfamiliar challenges that redefine the familiar role of parents to advocates, medical caregivers, and organizers of structured activities. Parents also face stressors that can include financial issues, marital discord, and social isolation.

Financial Stress Associated with Raising a Child With a Disability

Increased medical costs. A limited number of studies relating to the economic implications of raising a child with a disability have pertained to the financial expenses associated with caregiving. Children with disabilities require a range of needs associated with their care, including specialized therapies, home modifications, adaptive equipment, medication, and educational services (Parish & Cloud, 2006). These children require a disproportionately large percentage of health care resources and services when compared to children without disabilities. To maintain the optimal level of well-being for the child with a disability, ongoing specialty care and therapies are required. Parents find their private health insurance and social service programs, such as Medicaid, do not cover all of the expenses incurred by the child with a disability. Diapers, over-the-counter medications, special formulas, nursing care, and adaptive equipment are examples of what may not be covered and have been denied as “items of convenience” by insurance carriers. Parish and Cloud (2006) found families of children with disabilities who have special health care needs experience high out-of-pocket expenses that can exceed approximately 5% of the family’s total income. In addition, families can pay an average of 10% of medical costs in deductibles, copays, and coinsurance. Newacheck and Kim (2005) found the total health care expenditures for children with special health care needs were more than three times the average of those for children without special heath care needs. As an example, children with special health care needs had almost four times higher hospital care expenses, more than double the amount of physician visit expenses, and 6 times more nonphysician services expenses than children without disabilities. For prescription medications, costs can exceed 10 times that of children without special health care needs (Newacheck & Kim, 2005). For parents to appropriately provide for the special health care needs of a child with a disability, they often need to pay out of pocket. Therefore, the financial burden of caring for a child with special health care needs leads to additional stress on the family as parents attempt to balance the needs of their child with a disability with the family's needs.

Socioeconomic disparities. Socioeconomic disparities also contribute to the financial burden of families caring for a child with a disability, especially when the child has special health care needs. Families of children with special health care needs were approximately 11 times more likely to be from households below 200% of the federal poverty level (Newacheck & Kim, 2005). In addition, approximately 10% of children with a disability do not have medical insurance (Newacheck & Kim, 2005). For those with insurance, costs associated with health care needs for the child with a disability are reported to be a large barrier to receiving appropriate care for those with lower incomes (Galbraith, Wong, Kim, & Newacheck, 2005).

Galbraith et al. (2005) examined whether income-related disparities existed after the expansions of public insurance for low-income families and if it diminished the families' out-of-pocket health care expenditures. The researchers found although the expansion of Medicaid and the State Children's Health Insurance Program had reduced some of the financial burden and improved access to care for children from low-income families with special health care needs, it is still not enough. Wong, Galbraith, Kim, and Newacheck (2005) also found when measured relative to the families' ability to pay, out-of-pocket health care expenses consumed a large percentage of family income in low-income families compared to more fortunate families.

Because many children with disabilities live at home into their late adult years, the financial implications also exceed parents’ life course trajectories for their child. Whereas many children leave home to begin college or enter the workforce, children with disabilities remain at home and continue to require high cost care of specialized equipment and medication (Parish, Rose, & Swaine, 2010). As parents must continue the role of an active caregiver beyond early childhood into adolescence and adulthood, their financial well-being across the life course also negatively affects their savings and income (Parish et al., 2004; Parish et al., 2010). Parents of children with developmental and health-related disabilities make substantial sacrifices associated with their caregiving roles, which affect their financial well-being.

Negative effect on employment. Given the financial needs that accompany having a child with a disability, the financial well-being of families of children with disabilities is largely dependent on parental employment outside the home. When parents work, they frequently struggle to meet the demands of balancing work and home, which transfers into the home setting. Researchers have indicated that significant time demands are most difficult for mothers (Parish et al., 2004; Warfield, 2005). Caregiving roles and responsibilities can affect paid work time, which results in increased absenteeism, distractions, and an overall negative effect on productivity at work. Mothers of children with disabilities may miss work because of the caregiver demands for children with lower mental, motor, and adaptive functioning or chronic medical concerns and of children who require adaptive equipment. This becomes an increasingly vital concern, as 15.1% of children under 18 years of age in the United States, or approximately 11.2 million children, are estimated to have special health care needs (U.S. Department of Health and

Human Services, 2013). Additionally, 23.0% of U.S. households with children have at least one child with special health care needs. Witt, Gottlieb, Hampton, and Litzelman (2009) found parents of children with new or continuous health care needs had more lost workdays than parents of children with fewer health care issues. In addition, the severity and type of disability also influenced work outcomes and decisions for mothers (Leiter, Krauss, Anderson, & Wells, 2004; Warfield, 2005). For parents of children with developmental disabilities, work outside the home provides not only income, but also a sense of identity and opportunity to develop a social network. However, demands of work and family life can be a significant stressor for parents of children with developmental disabilities (Parish & Cloud, 2006). Although family-friendly policies exist in many work establishments, parents are still limited to part-time jobs for poor wages or are forced to leave their paid employment to care for their child with a developmental disability. These issues are especially challenging for mothers, as they often bear the largest burden of home and child care. This negative effect on employment for mothers affects the financial well-being of the family and can be a significant stressor for both parents as they attempt to balance the needs of their child with a disability with work expectations.

In a national survey, Leiter et al. (2004) found about half of the mothers of children with disabilities were employed. In addition, of these working mothers, more than half needed to reduce their work hours to care for their children with disabilities or ceased full-time employment to care for their children’s needs. Mothers of children with chronic conditions who did not work reported their unemployment was because of their children’s medical care needs, significant time demands, and lack of affordable child care. The long-term effect on part-time employment or loss of one parent's salary can be financially significant. On the whole, parents placed in difficult situations regarding their participation in paid employment find it difficult to balance work and life demands (Leiter et al., 2004).

Need for part-time employment. Daily care for a child with disabilities is different from for a typically developing child, as many dependent on difficult-to-find adequate child care (Sen & Yurtsever, 2007). Mothers of children with disabilities also have fewer resources of reliable child care than mothers of children without disabilities. Many parents are turned away from child care centers and after-school programs because of their child's behavioral, medical, or developmental disability (Warfield, 2005). The barriers parents face in securing appropriate child care for their child with a disability include an inadequate number of trained caregivers who can effectively meet the child's needs, fear about the disability, limited knowledge regarding the nature of the disability, and transportation issues for those with mobility issues (Sen & Yurtsever, 2007). This lack of assistance forces mothers to forgo part-time or full-time employment to become the sole caregiver for their children with disabilities, causing financial hardship.

Mothers of children with disabilities have been viewed as victims of tragic circumstances and have been expected to suffer from emotional distress. Green (2007) conducted a study in which mothers of children with developmental disabilities were interviewed to gain an understanding of the burden associated with raising a child with a disability. The results indicated these mothers were more affected by the financial stresses coupled with the medical, educational, and social needs of their child than by emotional distress. The poorly coordinated and often nonresponsive service delivery system and negative public attitudes were physically exhausting and financially draining (Green, 2007). Moreover, these mothers felt emotionally rewarded by their parenting experiences, not saddened.

In conclusion, various financial stressors are associated with raising a child with a disability. Parents face the burden of balancing the medical needs of their child with a disability and the related expenses with other family needs. In addition, research has shown a large percentage of families of children with special health care needs have incomes below the federal poverty level. Employment status also affects families' financial status, as many parents and caregivers reduce work hours to care for their children with disabilities. The financial hardships of families of children with disabilities can result in emotional distress for parents and the entire family unit.

Family Stress Associated With Raising a Child With a Disability

Effect on marriage. When parents first learn that their child has a disability, their emotional responses vary and have a profound effect on their relationships. Several researchers have examined the interrelationships between marital quality and parenting stress when raising a child with a disability. Kersh, Hedvat, Hauser-Cram, and Warfield (2006) found a better quality of marriage predicted lower parenting stresses and fewer depressive symptoms for both mothers and fathers raising children with developmental disabilities. Paternal involvement with the child with a disability was also a factor in marital quality. In Bragiel and Kaniok's (2011) study of 243 Polish fathers, the researchers found the involvement of fathers in their children's lives, care, rehabilitation, and education was positively correlated with the fathers' report of marital satisfaction. Factors, such as communication and foundational expectations, also contributed to marital success. Parents who openly discussed topics related to their children, other feelings and concerns, and their preparedness for the responsibility of children were identified as helpful to maintaining their marriages (Ramisch, Onaga, & Oh, 2014). Fathers who were involved earlier in parent-child interventions enriched family relations. This paternal support helped alleviate the all-consuming mother-child interaction, which helped maintain marital relations (Mount & Dillon, 2014). In addition, mothers' perceptions of their children with autism spectrum disorder were associated with marital adjustment (Lickenbrock, Ekas, & Whitman, 2011). Mothers who reported higher levels of positive perceptions regarding their children also reported high levels of marital adjustment. Moreover, the marital relationship was also found to relate to the mothers' well-being.

Divorce rates in parents of children with disabilities have been reported higher than those who have do not have children with disabilities (Freedman, Kalb, Zablotsky, & Stuart, 2012; Harper, Dyches, Harper, Roper, & South, 2013; Hartley et al., 2010; Witt, Riley, & Coiro, 2003). In the largest study to date, Witt et al. (2003) compared divorce rates in 5,089 families of children with disabilities and more than 24,000 families of children without disabilities. The prevalence of divorce was higher in the children with disabilies group (14.3%) than the children without disabilities group (11.4%). Additional insight comes from studying marital quality and divorce rates during a longer period of time. In a more recent study, researchers examined the prevalence of divorce in parents of children, adolescents, and young adults with autism spectrum disorder. Parents of children with autism spectrum disorder had a higher rate of divorce (23.5%) than did the comparison group (13.8%) of parents of children without disabilities. The rate of divorce for parents of children with autism spectrum disorder remained high throughout childhood, adolescence, and early adulthood, whereas divorce decreased when children were older than 8 years in the comparison group (Hartley et al., 2010). The vulnerability to divorce can be explained by the high level of parenting demands and stress of having a child with a disability and the subsequent decrease in receptiveness to the needs of one's spouse during these times.

Marital distress is also affected by the characteristics of the child. When comparing fathers to mothers, the fathers' satisfaction with the marriage was unrelated to the child's skills or behaviors, whereas the mothers marital satisfaction was moderately correlated with the child's behavior. The researchers also found marital quality for mothers was associated with efficacy as a parent, while fathers derived their self-perception of parenting ability from sources external to the marriage. However, both parents noted social support correlated with their marital satisfaction, indicating factors outside of the immediate family structure may influence marital quality (Kersh et al., 2006).

Support factors outside the immediate family system, such as external social support through respite care, have been shown to be a significant predictor of marital quality for both husbands and wives. Respite care is an external resource designed to give parents a short break from significant care requirements (Harper et al., 2013). The number of weekly hours of respite care has also been positively associated with marital quality. One additional hour of respite care related to increased scores on the Revised Dyadic Adjustment Scale, at times moving parents from the distressed to nondistressed range. Respite care can provide parents with a break from challenging behaviors and extensive needs, allowing them to spend time together and be temporarily relieved of their caregiver responsibilities. In addition, this can provide parents with the opportunity to spend time with their children without disabilities and engage in typical family outings they may be unable to do without the respite care services (Harper et al., 2013).

Effect on siblings. Being a sibling of a child with developmental disabilities often leads to a range of emotions. Children may resent the amount of parental time and attention their sibling receives and the caregiver responsibilities they may have to undertake to assist in the care of their sibling with a disability. Nonetheless, siblings may also appreciate that the sibling with a disability has special needs. As a result, resentment or even overt hostility is more likely to be directed at the parents than the siblings.

Several researchers have reported adjustment problems in children with siblings with disabilities (Petalas, Hastings, Nash, Lloyd, & Dowey, 2009). Petalas et al. (2009) conducted a study in which they compared siblings of children with intellectual disabilities with and without autism. Siblings described different ways they were affected by having a brother with autism, which included becoming socially isolated, changing their behavior to deal with their brother's odd or aggressive behavior, and decreases in family leisure and recreational time. Siblings of children with both intellectual disabilities and autism had more emotional problems than siblings with intellectual disabilities alone. Thus, the findings of Petalas et al. suggest autism has a more significant effect than intellectual disabilities on the emotional problems of siblings.

As with parents, behavior problems play a considerable role in how children were affected by siblings with intellectual disabilities. Mothers and fathers reported siblings were more negatively affected by having a brother or sister with a mental disability than were siblings of typically developing children. However, when behavior problems were accounted for, a significant relationship no longer existed between child intellectual status and the effect on the sibling (Neece, Blacher, & Baker, 2010).

Some researchers have discussed both the positive and negative reactions to having a sibling with a disability, based on the parents' own perspectives. Mulroy, Robertson, Aiberti, Leonard, and Bower (2008) assessed parents' perceptions of siblings of children with Down syndrome or Rett syndrome. Parents reported positive effects and several disadvantages. The positive effects related to personality characteristics, an understanding of tolerance and awareness of differences, a caring and compassionate nature, an increase in maturity when compared to their peers, and an appreciation of their own health and capabilities. Some disadvantages noted by parents included limited normal recreational activities and family outings, embarrassment and exclusion by their peers, and an increased burden of responsibility to assist with caring for the sibling with a disability (Mulroy et al., 2008).

Williams, Piamjariyakul, Graff, and Stanton (2010) reported similar findings using a similar method to Mulroy et al.'s (2008) study, which reflected parents' perceptions of siblings with a brother or sister with a developmental disability. Parents' descriptions reflected negative effects in 61.1% of siblings of children with developmental disabilities. Positive effects were reflected in 37.2%, and 1.7% reported no effects at all. Williams et al. found negative manifestations of increased risk in siblings, such as feelings of loneliness and isolation, anxiety, depression, vulnerability, anger, worry about the sibling who was sick, school issues, poor peer relations, withdrawal, somatic complaints, low self-esteem, and behavioral issues. Parents also described specific factors that helped foster positive outcomes in siblings, including family closeness, the siblings' increased compassion to caregiving, personal development, and the parental cognizance of their children's individual strengths (Williams et al., 2010).

As parents begin to age, the roles and responsibilities of siblings of children with developmental disabilities change during the life course. Both a stability and a change occur in sibling relationships over time. As adolescents move into adulthood, they maintain close connections with their siblings with disabilities. However, the nature of the relationship shifts as their parents grow older and become less able to care for the children, who are now adults, with disabilities. Siblings thus consider assuming some of these responsibilities. As adults, siblings maintained some type of contact with and provided emotional support for their siblings and had knowledge of their sibling's needs. Moreover, many adult siblings of individuals with disabilities assume a position of advocacy at some point. Early in life, siblings often encounter an array of challenges, such as what to do when others make fun of their brother or sister or when they need to address the disparaging comments of their peers. In adult life, some siblings select careers related to developmental disabilities (Marks, Matson, & Barraza, 2005; Skotko & Levine, 2006). Many choose a career in special education, in part because of their experiences growing up with a brother or sister with a disability. These siblings may feel a sense of responsibility for their brothers or sisters with a disability and thus choose a career related to a desire to improve services for individuals with disabilities, such as the inclusion of students with disabilities into general education classrooms (Marks et al., 2005). Female siblings are had a closer relationship with their siblings with disabilities and were expected to assume caregiving responsibilities in the future (Burke, Taylor, Urbano, & Hodapp, 2012).

Siblings of individuals with developmental disabilities provide a different perspective on the range of concerns they face. Many worry about their ability to live a normal life and whether, given their responsibilities to their brothers and sisters, they should have children. Some are concerned about whether their siblings will ever work or have a satisfying romantic relationship. Others wonder about societal responses if they choose not to maintain a close relationship with their siblings. Siblings of children with developmental disabilities report mixed feelings, in that many report positive emotions, whereas some focus on the negative (Meyer, 2009).

Clear differences exist in the extent to which siblings are involved in the daily lives of their brothers or sisters with disabilities. Some siblings dramatically alter their lives and careers to spend time with their sibling with a disability, whereas others, while acknowledging an attachment to their siblings, choose a more limited relationship. Whatever the differences, these siblings attempt to balance a concern for their brothers or sisters with the need to attend to their own life and family, which can cause stress and affect their well-being.

Effect on grandparents. Just as parents and siblings of children with developmental disabilities must adapt to unexpected roles and changes in family roles, grandparents may find themselves in an unfamiliar and challenging position. The inherent assumption for many grandparents, particularly grandmothers, is that they serve as educational experts for their children, offering advice and information regarding parenting, from toilet training to discipline. As young adults become parents, they often come to value their own mothers more, and their mothers may reciprocate by acknowledging their adult children's status as a parent. Grandparents typically look forward to the time of their lives in which their knowledge is respected and valued while the demands on their time are limited.

When a child has a developmental disability, these expectations are largely put aside, and the primary role of being a grandparent changes to being a supportive figure for their adult child in his or her time of need. However, grandparents may struggle with double grief: they may grieve for the loss of the grandchild that they anticipated, and may experience a deep sadness for their own adult child (Findler, 2014). Common reactions of grandparents when they find out their grandchild has a disability can include distress, sadness, depression, anxiety, shock, denial, disillusionment, and uncertainty (Findler, 2014). After the grandparents have accepted their grandchild's diagnoses, they often respond by becoming more involved and fulfilling a number of supportive functions in the family. In particular, they provide instrumental support, such as grocery shopping and babysitting, as well as emotional support, household responsibilities, or economic and medical support for areas related to school, spiritual, or recreational activities (Gardner, Scherman, Efthimiadis, & Shultz, 2004; Miller, Buys, & Woodbridge, 2012). Findler (2004) found grandparents interpreted the change in their lives as an opportunity for personal growth from the experience of helping to raise a grandchild, watching him or her grow and develop, and the accompanying sense of love, vitality, and joy.

In conclusion, raising a child with a disability affects the parents individually, and affects the relationships of parents and the roles and responsibilities of siblings and grandparents. For all family members, the expectations and roles frequently change when a child with a disability is born. Many families experience grief, sadness, and negative effects of raising a child with a disability. However, researchers have discovered many positive effects, such as a stronger sense of family cohesion, increased compassion, and an overall sense of personal growth.

Mental Health and Well-Being Associated with Raising a Child With a Disability

Social isolation and stigma. Parenting a child with a disability may be a source of significant stress for many parents. In several studies, researchers have compared stress in parents of typically developing children to stress in those parents of children with disabilities. The overwhelming consensus from various authors revealed many characteristics associated with the child’s disability were significant contributing factors to the parents’ stress. One factor related to the level of parenting stress is difficult or disruptive behavioral issues (Estes et al., 2009; Lecavalier, Leone, & Wiltz, 2006; Plant & Sanders, 2007). When children with disabilities have difficulty conforming to expectations, their behaviors arouse various responses from the general public, including shame, laughter, anger, and fear. The children are viewed as social problems when their behaviors do not conform to societal expectations (Green, 2007). As a consequence, some parents may believe their children are not welcome in many situations and therefore reduce their interactions with friends and various social groups. Moreover, limiting such social interactions causes parents to miss opportunities to receive social support as well as to engage in other activities besides parenting (Plant & Sanders, 2007).

Solomon and Chung (2012) found parenting a child with autism can cause parents to feel isolated because of the unpredictable behaviors that the child with autism can exhibit. Parents understandably grow reluctant to venture out into their communities when they encounter repeated situations in which their child with a disability acts out, causing people to stop and stare. The physical appearance of the child with autism, coupled with the lack of understanding of the disorder, can cause parents to encounter hostile public reactions toward their child’s inappropriate behavior (Gill & Liamputtong, 2011). Social isolation is exacerbated by the responses of others in the community. Some parents have commented directly on the stigma related to having a child with a disability. In a qualitative study conducted by Gill and Liamputtong (2011), the authors explored the experiences of stigma among mothers of children with Asperger’s syndrome. The mothers drew a distinction between children with Asperger’s syndrome and other more physically visible disabilities, noting that people are often more understanding and willing to help a child who is deaf, blind, or physically challenged. In contrast, children with Asperger’s syndrome who display behavioral issues evoke a less compassionate reaction.

In light of the typical appearance but unusual behaviors, mothers felt stigmatized in the way that others viewed both them and their children (Gill & Liamputtong, 2011). Social exclusion can cause individuals to withdraw and show contempt. Moreover, the psychological grief associated with social exclusion can serve as an intense form of punishment (Maner, DeWall, Baumeister, & Schaller, 2007). Parents who felt stigmatized had feelings of isolation stemming from society’s lack of understanding and had feeling as though they were in a world of their own (Woodgate et al., 2008). However, Woodgate et al. (2008) found that after parents had educated themselves about their child’s condition, educating others was a means to cope with the stigma.

When individuals are stigmatized, they are excluded from many aspects of society and therefore avoid certain situations (Gill & Liamputtong, 2011). Individuals who feel stigmatized by the community may feel that interactions with members of society are awkward. Stigmatized individuals may feel as though they are being watched and become anxious about the messages they are sending to the community. Feeling socially excluded can lead parents to seek out different interpersonal connections. When the satisfaction of an important drive is thwarted, individuals seek alternative means of satisfying the drive. Therefore, individuals who feel socially excluded may experience an exceptionally strong drive to form positive social bonds. Maner et al. (2007) found socially excluded individuals expressed an increased desire to meet new friends and work on tasks than other people. Moreover, they formed more optimistic impressions of other people and ascribed higher rewards to new interaction partners. Maner et al. suggested individuals who experience social isolation respond to such painful interactions by both withdrawing from certain people who have provoked the uncomfortable encounters and seeking out new social partners.

Children with disabilities are involved in activities less often than children without disabilities. Bedell et al. (2013) found parents of children with disabilities considered environmental factors, including availability or adequacy of programs and services, information, and equipment as barriers more often than did parents with typically developing children. In addition, parents of children with disabilities desired more change in their children’s unstructured physical activities and in getting together with other children in the community. Bedell et al. found parents who desired change in their children’s activities helped to provide some shift in the responsibilities associated with the planning of these activities. This shift in the planning of these responsibilities can provide parents with some respite, enabling them to have time to engage in other activities, thus reducing their stress and feelings of isolation (Bedell et al., 2013).

Plant and Sanders (2007) found some of the variation in parental stress was associated with the caregiving responsibilities related to the heterogeneity of the child's disability, the unique profile of their skills, and the child's behavioral challenges. In addition, parental stress can also be explained by the way parents cope with their caregiving roles, coping process of cognitive appraisal, coping strategies, and coping resources. The way parent interpret, perceive, and appraise their specific caregiving tasks can directly influence their level of stress (Plant & Sanders, 2007).

When parents find themselves in an unexpected and undesirable division of labor as a result of having a child with a disability, roles change and frustration can emerge, which can lead to feeling isolated from others. Parents feel as though they give up things associated with a normal life in addition to facing changes to their sense of self (Woodgate et al., 2008). Solomon and Chung (2012) suggest taking action, such as having couple meetings, which can be beneficial for parents to set aside time to report on their individual spheres, provide them the opportunity to reconnect, and reduce the risk of disconnection and blame. Stay-at-home mothers may feel frustrated by dealing with their child's disability all day and withdraw, in essence isolating themselves. They are burdened by the continuous caregiving responsibilities, affecting their work lives, social lives, and emotional states. Moreover, because mothers are more often responsible for child care in families with a child with a disability, their participation in social activities also decreases (Sen & Yurtsever, 2007). Having an opportunity to talk about their experience with their partner on a daily basis can help moderate this (Solomon & Chung, 2012). Date nights are also considered a form of activity in the action domain and can help parents remember they are a couple in addition to being care takers. Overall, taking actions to reduce parental stress can improve family well-being and resilience and reduce feeling of isolation and social stigma.

Social supports. In the social arena, families are confronted by the attitudes of others and the challenges associated with assimilating their children into peer events. Even when parents are successful at facilitating the peer acceptance of their children with disabilities, these successes require significant effort by the parents, who are already taxed by balancing multiple demands. It is therefore beneficial and undoubtedly necessary for parents to receive social supports from family members, friends, support groups, and other parents of children with disabilities. Family and friends can provide informal, nonprofessional social support by providing information, advice, or more tangible forms of support, such as child care. Support groups can provide information and emotional support. Other parents of children with disabilities can provide support by sharing their stories, which can reduce parental stress and feelings of isolation.

Armstrong, Birnie-Lefcovitch, and Ungar (2005) examined the influence of social support on family well-being and the parents’ capacity to parent. Two models emerged from this study. The main effect model proposed social support facilitated well-being by integrating an individual into a larger social network. The buffering model suggested social supports protected persons from the potentially adverse affects of stressful events. Armstrong et al. proposed the main effect model directly promoted parental well-being, whereas the buffering model promoted both parental well-being and improved the quality of parenting, which provided more favorable outcomes for children.

Parents frequently report that when they were told the diagnosis regarding their child, they were often given little hope and little information pertaining to how to parent of a child with disabilities (Bedell et al., 2013). In a survey conducted by Rhoades, Scarpa, and Salley (2007) of 146 caregivers, only 40% reported the diagnosing physician supplied information and resources about the autism diagnosis, and 15% to 34% provided advice on educational or medical programs. A limited number of professionals (6%) made referrals to specialists in the field of autism, and 18% provided no additional information about autism or related services. Moreover, only 15% to 20% of parents reported they sought the help of other health care or educational specialists, while 71% to 73% looked to social media for information on their child’s diagnosis of autism. Solomon and Chung (2012) suggested parents of children with autism may benefit from accessing support in the form of psychotherapy to help address the multiple chronic and intense stresses experienced by parents raising a child with autism.

Harper et al. (2013) documented the need for respite services in a survey of 101 mother-father dyads raising at least one child with autism. Respite care is an example of an external resource designed to provide parents a break from significant care requirements. Respite care can give a family the opportunity to relax, refocus, and recharge and shifts the focus from the child’s needs to the family members’ needs. Respite can allow the family members to enjoy eating at a restaurant, shopping, and engaging in other typical activities, without being continuously focused on the child who requires continuous care (Doig, McLennan, & Urichuk, 2009). Based on the findings of

Harper et al. (2013), respite care was beneficial in reducing stress perceived by both wives and their husbands. Moreover, the number of hours of respite care was also positively associated with uplifts and improved marital quality.

Strunk (2010) systematically reviewed the literature on respite care for families of children with special needs. The review of 15 quantitative and qualitative studies showed respite care was associated with significant reductions in parental stress and opportunities for enjoy family time with the typically developing siblings. Strunk also observed respite care may be a proactive intervention for the abuse of children with challenging behaviors. The need for respite care transcended many dissimilarities between families, including degree of disability, family income, and living in urban or rural areas. The demand for respite care was higher during the summer months, when the children were not in school. Therefore, respite care for families of children with special needs can alleviate some of the stress associated with raising a child with special needs.

Parental supports. For parents of children with developmental disabilities, social support from groups and other parents can play a special and vital role. Although family members and friends provide invaluable emotional support, they typically do not possess the understanding, personal knowledge, and experiences of parenting a child with special needs. Therefore, seeking support from groups and creating relationships with other parents in a similar situation can help alleviate the sense of social isolation experienced by parents of children with disabilities.

Mobilization of social support is frequently utilized as family members struggle to cope with and understand their children’s disability. Parents seek information on the disorder as an active way to cope. Twoy, Connolly, and Novak (2007) found of their 94 families surveyed, up to 93% sought information and advice from other families that faced similar problems, and 80% sought help from community agencies and programs. These findings indicate a large percentage of families seek out active ways to cope with their child's disability (Twoy et al., 2007).

***Parent support groups*.** Research has shown that two types of parent support groups are effective in mediating parental stress and providing emotional and informational support. Parent support groups provide an opportunity to share common concerns in a group setting. Alternatively, parent-to-parent programs match a trained parent in a one-on-one relationship with a parent who is newly referred to the program.

Support groups have grown in number and have become an important alternative to some parents in supplementing health care. Because most researchers in the health care field have focused on the nature of care and support, the need for psychosocietal support is constantly increasing (Häggman-Laitila & Pietilä, 2009). This finding supports the need to develop preventative and psychosocietal services to increase the quality of the interaction between families and health care providers. By providing group activities and peer support, the bond between parent and health care professionals can be improved. Some lack of parent participation in support groups has been attributed to a lack of self-efficacy in parenting skills (Häggman-Laitila & Pietilä, 2009). Parents also have difficulty attending because of a lack of babysitting help or the belief that they are admitting to being a bad parent. Therefore, the key to increasing parent involvement is to assure them that the group support would help improve skills the parents already possess (Häggman-Laitila & Pietilä, 2009).

Mandell and Salzer (2007) surveyed 1,005 caregivers of children with autism to determine who joined parent support groups. Approximately two-thirds of the parents reported they had participated in an autism-specific support group. The authors found both demographic characteristics of the family and the child’s behavioral characteristics influenced their decision to participate. Parents who participated were more likely to have an annual income higher than $40,000, live in a suburban area, and have college degrees. Additionally, parents of children with self-injurious behaviors, sleep problems, or severe language issues were more like to belong to the support group (Mandell & Salzer, 2007).

Parents who participate in support groups have reported various factors that influence the success of the parent group. Parents have indicated that a good group is informal and includes a professional as an equal group member, in addition to discussing topics that are well-organized and clearly presented. A respectful and reciprocal interaction between parents and professionals is a precursor to an effective and successful collaborative relationship. Additionally, parents have emphasized support is received from two different sources: the professional leader of the group and the other participants. Equality, fairness, confidentiality, and safety, were noted between parents and professionals, whereas mutual recognition, respect, openness, and frankness were noted from the peer interaction. The positive aspects of support groups often encouraged parents to express their own experiences and views (Häggman-Laitila & Pietilä, 2009). Parent support groups with a professional as the leader follow a true family-centered and less specialist-centered approach, in addition to making group work effective without the added costs.

Parent-to-parent support groups. Parent-to-parent support groups are primarily focused on pairing parents of children with disabilities with parents of children with similar disabilities who are approximately the same age. Parent-to-parent support groups are aimed at providing assistance to parents during acute periods of stress and change, such as following a birth, initial diagnosis, or in response to a major medical intervention. Shilling et al. (2013) identified four specific themes in peer support from parents of children with chronic disabling conditions: shared social identity, learning from the experiences of others, personal growth, and supporting others. Of the four themes, the most common related to the benefits of findings a shared social identity with other parents. Parents who felt a shared sense of social identity with other parents had a sense of belonging, support, and empowerment, which enabled them to cope better and reduce their feelings of isolation and loneliness. Learning from the experiences of other parents helped parents to partner and problem solve together, which resulted in increased confidence regarding the future of their child. Additionally, parents who felt a sense of personal growth described feelings of empowerment, confidence, and control, as well as feeling less isolated, which enabled them to develop new skills. Finally, the peer support groups motivated the parents to offer the same support they had received to other parents in need (Shilling et al., 2013).

Results to date suggest parent support groups and parent-to-parent support groups provide a useful complement to the support families receive from family members, friends, and mental health professionals. Data regarding the efficacy of parent support groups are lagging, but the evidence to date is encouraging. Parent support groups provide parents with support and knowledge regarding the ability to deal with their child's disability, which reduces parental distress. Nonetheless, the appeal of parent support programs is consistent with previous findings regarding social isolation, as previously described in this section, indicating socially excluded people have an exceptionally strong drive to form positive social bonds (Manner, DeWall, Baumeister, & Schaller, 2007). Furthermore, social support has been shown to moderate parent stress by reducing feelings of isolation, thus decreasing symptoms of depression and anxiety.

Parental stress and depression. Several scholars have expressed an interest in the relationship between having a child with a disability and parental depression. Findings suggest parents of children with disabilities are at a higher risk for depressive symptoms (Benson, 2006; Benson & Karlof, 2009; Feldman et al., 2007). Depression can adversely affect a child's outcome, as depressed mothers have been found to be less responsive to their children's needs and therefore are less effective in fostering language and psychosocial development in their children (Prakash, Ravichandran, Susan, & Alex, 2013). Children with disabilities may be especially vulnerable to the influence maternal depression, as they are dependent on their mothers for quality caregiving and emotional responsiveness.

Researchers have made progress in to comparing depressive symptoms regarding various disabilities. Bailey, Golden, Roberts, and Ford (2007) critiqued the literature on maternal depression and developmental disability, emphasizing the distinction between depressive symptoms and clinically diagnosed depression. Bailey et al. reviewed 17 studies pertaining to mothers of children without a disability and compared their depressive symptoms with mothers who had a child with a disability. Of the participants, 65% reported a significant difference in depressive symptoms, and that the higher ratings of depressive symptoms were attributed to children with autism or behavior problems. Stress and well-being, maternal coping style, maternal health, family support, and number of other children with a disability consistently related to ratings of depression. Although Bailey et al. acknowledged mothers of children with disabilities exhibited an elevated rate of depressive symptoms relative to mothers of children without disabilities, the researchers concluded the incidence rate may be lower than reported in previous studies because of measurement issues. In particular, many researchers relied on parent input using self-ratings, which were not diagnostic clinical tools, rather than on a diagnosis from a trained psychologist.

Zablotsky, Anderson, and Law (2013) sampled 1,110 mothers to examine the association between child autism symptomatology, the mother's quality of life, and the mothers' risk for depression. The authors found mothers of children who had increased autism symptomatology coupled with co-occurring psychiatric disorders were at a higher risk for treatment of depression and a lower quality of life. In addition, having children with behavioral problems was likely to affect the mothers' or caregivers' depressed mood and decrease life satisfaction (Bailey et al., 2007; Feldman et al., 2007; Zablotsky et al., 2013). Parents' negative perspectives on their quality of life is because of the stresses encountered in personal relationships, caregiving responsibilities, effect on their health, worries about the future, and social support (Murphy, Christian, Caplin, & Young, 2006; Plant & Sanders, 2007; Uskun & Gundogar, 2010; Zablotsky et al., 2013).

Many parents struggle with coordinating their children's numerous and multifaceted medical, educational, and developmental interventions while attempting to balance the needs of the entire family unit. Evidence suggested the caregiving responsibilities associated with continuous needs of the child with disabilitites leaves little time and energy to adequately care for their own emotional and physical health (Murphy et al., 2006). The caregivers revealed their own health care needs ranked lowest when compared to the needs of their child with a disability and the needs of other family members. Most parents reported a lack of sleep and chronic fatigue, and most described at least one chronic physical ailment that they attributed to the long-term effects of caring for their child with a disability. Murphy et al. (2006) also found of the 40 participants surveyed, 32 caregivers reported they suffer from recurrent anxiety, depression, or guilt.

Stress proliferation, which occurs when stressors create additional stressors in various life domains (Benson, 2006; Benson & Karlof, 2009), is a contributing factor to depression among parents. Parents of autistic children reported significantly higher levels of anger and depressed mood. Consistent findings from both studies indicated a relationship between the child’s symptom severity and the parent’s depressed mood. Notably, the child’s symptom severity level increased stress proliferation, which increased depressed mood (Benson, 2006; Benson & Karlof, 2009). Benson and Karlof (2009) also found parents’ anger affected their well-being by having a direct effect on both stress proliferation and parent depression, as well as an indirect effect, because of the mediating role of stress proliferation. Finally, consistent with previous researchers, Benson and Karlof found informal social supports improved the parents’ depressed mood.

Regardless of the cause, depressive symptoms influence parenting quality. For example, depressive symptoms often produce lethargy, which can hinder a person’s willingness to make constructive adaptations to current circumstances. Parents of children with disabilities experience more emotional distress than parents of typically developing children. Parents become fatigued by the multiple demands on their time, and such fatigue may reduce their willingness to contemplate changes in their lives, even changes that would improve their lives. Change requires effort, and an exhausted parent may not be able to muster the energy. Furthermore, consistent evidence has shown that effective coping strategies and information supports can mitigate distress and depressive symptoms. Therefore, from a clinical perspective, these findings strongly suggest the need for services and supports that are differentiated according to the unique needs of the parent, which can help support the needs of the entire family unit.

In conclusion, the mental health and well-being of family members can be affected when raising a child with a disability. When parents feel socially isolated from previous enjoyable experiences of social outings and activities because of their child’s unpredictable behaviors or medical needs, they feel alone and unwelcome. This can lead to parental stress and depression, which can affect the well-being and functioning of the entire family. When parents are provided with supports, such as parent support groups and social supports, they can effectively cope with the stress and demands of raising a child with a disability.

Coping Mechanisms and Interventions When Raising a Child With a Disability

The birth of a child with a developmental disability can impose added stress on parents, including financial, physical, and emotional demands. Research has indicated parents of children with developmental disabilities experience higher levels of stress and depression than other parents, and a disruption to the family unit is like to occur (Benson, 2006; Benson & Karlof, 2009; Debrowska & Pisula, 2010; Feldman et al., 2007).

Although the stress can be overwhelming and exhausting, one should not automatically assume every family has debilitating stress when a child with a disability is born into the family. Some families are able to adapt and cope successfully to keep their stress conditions manageable and their lives in control. A growing body of research indicates that having a child with a disability may contribute to strengthening the family unit, as well as contributing positively to the quality of life of the members of the family (Bayat, 2007; Myers et al., 2009; Retzlaff, 2007; Van Riper, 2007).

Families of children with developmental disabilities utilize various coping techniques to adapt to the changes and stressors in the family unit that occur when a child with a disability enters the family. This understanding of stress and coping is considered to be transactional, in that the person and the environment are viewed as being in a mutually reciprocal, bidirectional relationship. Stress is conceptualized as a relationship between the person and the environment appraised by the individual as challenging, or one that exceeds his or her resources (Folkman et al., 1986).

Behavioral coping strategies. From the perspective of Folkman and Lazarus (1985), two main types of strategies help mediate a person’s stress. Cognitive appraisal refers to the manner in which people interpret an event they experience, which is often related to their emotional reaction. Coping is considered to be the cognitive and behavioral efforts that are continuously changing to master, reduce, or tolerate a specific stressor appraised as exceeding one’s ability and resources (Folkman, Lazarus, Dunkel-Schetter, et al., 1986). This process model of stress and coping has been useful in understanding how families with children with disabilities cope and emphasizes the importance of cognitive appraisal. Parents of children with developmental disabilities may have positive and negative appraisals of the challenge accompanying raising a child with a disability, and they can coexist (Trute et al., 2007). However, positive perceptions can help alleviate the effect of the child's disability on family members, strengthen psychological and physical resources during stress, and protect against clinical depression (Gupta & Singhal, 2004).

Coping strategies aimed at resolving the stressful event are referred to as problem focused, whereas those coping strategies utilized to regulate the unpleasant emotions that arise during the event are emotion focused (Lazarus & Folkman, 1985). Individuals may fluctuate between both types of coping strategies. Emotion-based strategies can include avoidance, questioning, denial, self-blame, and wishful thinking (Abery, 2006). In contrast, problem-focused strategies are efforts directed at solving or managing a problem that causes the distress. This type of strategy can include gathering information, making decisions, performing task-oriented actions, planning, and resolving conflicts (Gupta & Singhal, 2004). Some parents of children with disabilities use problem-solving strategies as a way to alter their response to the stressors that accompany having a child a disability, such as focusing on the positive rather than the negative (Abery, 2006). The use of positive reappraisal, seeking social support, and seeking spiritual and professional support are effective problem-solving strategies that have helped to mediate stress (Bingham, Correa, & Huber, 2012; Gupta & Singhal, 2004; Van Riper, 2007). In addition, effective coping strategies may lead to reappraising a stressor previously thought to be a threat, resulting in further effective coping to deal with the situation (Ntoumanis, Edmunds, & Duda, 2009).

Researchers have explored parental positive and negative appraisals of the effect of raising a child with a disability. Many parents utilize both passive and active coping strategies to cope with their child’s disability. Passive behaviors are often based on parents’ belief that they did not have the ability to alter the outcomes of their child’s disorder. Passive appraisals can include avoidance, whereas active coping strategies are generally those that are considered to be more positive ways of dealing with a stressful event. Active coping strategies are used when a person attempts to change the nature of their stressor or how that person perceives the stressor. An avoidant coping strategy, such as passive appraisal may be stress reducing initially, but avoiding the problem continuously and not addressing the stressor can be detrimental to the individual and can eventually lead to family maladaptation (Twoy et al., 2007). Trute et al. (2007) conducted a longitudinal survey by interviewing mothers and fathers independently to ascertain their appraisal of the influence of a child with a disability on the family. Findings indicated gender differences existed in the early positive appraisal the influence of a child with a disability on the family, but over time, parent appraisal merged. Mothers’ had positive appraisal earlier than fathers, and this early appraisal predicted family adjustment to enhance mothers’ self-esteem (Trute et al., 2007). Overall, both positive appraisal and positive meaning contributed to the parents’ ability to cope with raising a child with a disability. Similarly, Bayat (2007) found positive perceptions and cognitive coping led to the family members possessing the ability to cope with the child with a disability and they were able to positively adjust and adapt to the circumstances.

Pottie, Cohen, and Ingram (2008) identified several coping strategies that significantly affected positive or negative mood. Problem-focused, social support, positive reframing, emotional regulation, and compromise coping were associated with high levels of daily positive mood, while a decrease in daily positive mood was associated with escape, blaming, withdrawal, and helplessness coping styles. In addition, Pottie et al. found when parents engaged in more distracting or pleasurable activities in response to a stressor, they experienced less daily negative moods. Problem-focused coping also predicted both positive and negative mood, which was an unexpected and a concerning discovery by the authors, as problem-focused coping is usually associated with positive outcomes. Conversely, Dardas and Ahmad (2013) stated coping strategies, such as confrontive coping, planful problem solving, self-control, and positive reappraisal, did not show a relationship between mediating stress and the parents' perceived quality of life. Additionally, distancing coping was the least reported parental coping strategy and showed no effect on the relationship between parental stress and quality of life. Dardas and Ahmad postulated that given the research on distancing coping, it may be beneficial to encourage parents to appropriately distance themselves from their stressor to prevent negative outcomes of the parenting experience.

In a study conducted in urban India with mothers of children with intellectual disabilities, John (2011) found negative maternal coping strategies, rather than the child's adaptive functioning, accounted for maternal stress levels and positive maternal coping was associated with lower levels of stress. In addition, when participants used religion to positively reframe their child's disability, it resulted in adaptive coping, whereas when self-destructive behaviors, such as blame and punishment for past sins, were used, the coping became maladaptive (John, 2011). Therefore, use of positive coping methods, such as religion, led to positive adaptations and enhanced one's general health and well-being, as well as the health and needs of the family (John, 2011; Mirsaleh, Rezai, Khabaz, Ardekani, & Abdi, 2011; Norizan & Shamsuddin, 2010).

Resources as coping strategies. A family's ability to adapt to their situation is influenced by the use of personal resources, such as the parents' psychological strengths and family social resources. The significant challenges parents face can lead to personal distress, which can adversely affect the success of the child with a disability and the well-being of the entire family unit. Researchers have proposed several conceptual models to summarize the existing literature with regard to the effects on stress and families and to help guide future areas of exploration. The double ABCX model and adaptation (Lavee, McCubbin, & Patterson, 1985) is an influential model. The model suggests that family stress (X) is influenced by a stressor (A), by the family's resources for dealing with the stressor (B), and by the family's perception of the stressor (C). In application to families of children with disabilities, the stress is a set of changing conditions associated with the child's disability. Resources include personal resources (knowledge and skills), family system resources (cohesion), and social support. Perceptions may include optimism, resilience, and locus of control. Lavee et al. (1985) provided evidence that an accumulation of events leads to family strain, and family system and social support moderated these relationships in different ways. The authors noted family system variables influenced the ability to adapt to the changing demands of raising a child with a developmental disability, whereas social support served as a buffer against stress.

Oelofsen and Richardson (2006) analyzed the relationship between parental stress, sense of coherence, social support, and parental health. Sense of coherence refers to one's global orientation to life (Antonovsky, 1993). Parents of children with developmental disabilities consistently reported higher levels of stress, weaker sense of cohesion, and poorer health than parents of children without developmental disabilities. However, Oelofsen and Richardson found social support did not emerge as a significant differentiating variable in this study. Findings of Olsson and Hwang (2006) concurred with Oelofseon and Richarson (2006), in that parents of children with intellectual disabilities have a lower sense of coherence, which may suggest that the acute stressor of learning one’s child is intellectually disabled may negatively influence one’s sense of coherence. A person with a strong sense of coherence is likely to appraise the stressor in a more positive light and perceive it as a challenge, whereas an individual with a low sense of coherence would more likely perceive the stressor as a threat (Olsson & Hwang, 2006).

In a similar study, Siman-Tov and Kaniel (2011) explored predictors of adjustment in parents of autistic children. In the study, 176 parents of children with autism completed several questionnaires that measured parent stress and personal resources. Congruent with other research, a positive correlation occurred between sense of coherence and mental health, well-being, and adjustment and a negative correction with distress. In addition, locus of control was a predictor of how parents coped with stress in parenting a child with autism. Specifically, a more internal locus of control indicated parents actively dealt with the stressors in the hope of overcoming the stressors, whereas a more external locus of control suggested less activity.

Twoy et al. (2007) found parents effectively coped when they used informal and formal social support networks. Contrary to the findings of Oelofsen and Richardson (2006), social support did decrease stress by increasing parents’ feelings of control and appeared to be a large part of the external coping strategies for the family (Siman-Tov & Kaniel, 2011; Twoy et al., 2007). Moreover, parents who perceived they were helped, understood, and had assistance, experienced less stress (Siman-Tov & Kaniel, 2011). Similarly, the results from McConnell, Savage, and Breitkreuz (2014) suggest families with higher levels of social support coupled with low levels of financial hardship had average to above average family life congruence and that social support emerged as the single strongest variable that predicted family life congruence. Families struggled when they had low levels of social support and high levels of financial hardship.

In summary, although no conclusive findings exist, consistent patterns emerged in relation to a few factors that can enhance family coping and facilitate parental adjustment to the birth of a child with a disability. Positive coping styles, such as positive perceptions and effective problem-solving skills, were associated with successful family adaption and resiliency (John, 2011; Mirsaleh et al., 2011; Norizan & Shamsuddin, 2010; Trute et al., 2007). Overall, effective coping responses can lead to a variety of positive outcomes, such as good physical and psychological health and positive adaptations, and can have a profound influence on the quality of life of the family as a whole, as well as for the child with the disability. Social supports have been effective in reducing stress, and evidence shows a combination of effective coping and social supports are advantageous in mediating stress of parents of children with developmental disabilities. However, further findings indicate some parents have more significant emotional needs, which can be addressed by various clinical interventions with families of children with developmental disorders.

Intervention programs. Parents of children with developmental disabilities typically report high level of stress and are at risk for mental health problems, such as depression. As a consequence, a number of intervention programs have been designed to reduce stress in these parents. For the most part, three types of programs exist. Some program leaders try to reduce psychological stress in parents directly by teaching parents methods for coping with stress. Many of the programs use the well-researched technique of cognitive behavioral therapy. Alternatively, some programs are designed to teach parents how to effectively communicate with their children using appropriate skills, thus indirectly reducing the parents' distress. Finally, some programs involve use of a combination of both approaches.

Parent training programs. Researchers have established parents of children with developmental disabilities on average experience more stress than families with typically developing children. The stress that parents endure can be chronic and persist for an extended period. In addition, parents may feel stress during specific life events that effect the family as a whole, such as marriage and bereavement, as well as during transitional periods the child with developmental disabilities encounters (initial diagnosis, starting school, and aging out of school). These life experiences can cause parenting stress (Hastings & Beck, 2004). Hastings and Beck (2004) reviewed the literature on intervention programs designed to reduce parenting stress. All programs reviewed had positive results. Supports provided for parents who incorporate a model in which one person works closely with the family and professionals can lead to the most positive outcomes. Second, implementing any type of structured intervention program appeared to have a positive result. Third, programs in which a parent acts as a contact for other parents in a similar situation can be effective in reducing parental stress. The fourth and last conclusion of Hastings and Beck was that group interventions only involving use of cognitive behavioral therapy or infusing it within the program were effective in reducing parental stress and improving mental health.

Wong and Poon (2010) tested the efficacy of a culturally attuned cognitive behavioral therapy group for Chinese parents of children with developmental disabilities in Melbourne, Australia. Parents were randomly assigned to cognitive behavioral therapy or list control groups. After 10 weeks of treatment, participants in the therapy groups showed significant improvement in measures of general health, parenting stress, and quality of life. Similarly, Singer, Ethridge, and Aldana (2007) found that when using cognitive behavioral training interventions to teach parents use of self-management skills in reducing parental distress, it was consistently effective.

Researchers have examined programs that teach parents skills for dealing with behavioral issues in their children with developmental disabilities. These programs often involve behavioral techniques, such as interruption of unwanted behaviors and reinforcement of alternative behaviors. Whenever possible, many program leaders sought to integrate these techniques into daily routines, including mealtime, dressing, and bedtime. Research has shown that these programs reduce child misbehavior, thus reducing parental stress. McIntyre (2008) conducted a randomized controlled trial to evaluate a parent training intervention for caregivers of preschool children with developmental disabilities. Families in the experimental group received the usual care, as well as a 12-week program that included group sessions devoted to play, praise, rewards, the setting of limits, and the handling of challenging behaviors. Families in the control group received the usual care only. Parental intervention was superior to usual care in reducing negative parent-child interactions and child behavior problems (McIntyre, 2008). Participants in the experimental group indicated a high degree of satisfaction with the treatment and had high levels of attendance.

In an additional study, Quinn, Carr, Carroll, and O’Sullivan (2007) reported similar results to those of McIntyre (2008). The authors compared pre and posttreatment assessments for parents of preschool children with developmental disabilities and significant behavioral problems. The treatment group was compared with a control group of families on a wait list. The treatment consisted of a group-based parent training package that involved video modeling. The treatment group had better adjustment on posttreatment measures than did the control group, and gains were maintained at a 10-month follow-up (Quinn et al., 2007). However, the strongest evidence for the long-term effects of parent training came from Feldman and Werner (2002), who evaluated collateral effects of parent behavioral training on families with children who have developmental delays as well as behavioral disorders. The intervention consisted of 1- to 2-hour weekly home visits by a behavior consultant and lasted approximately 3- to 6-months. The authors compared 18 behavioral parent training graduates with 18 similar families were waiting for services. Training graduates reported significantly fewer child behavior problems and disruptions to the child and family quality of life, and less stress related to limits on family opportunities (Feldman & Werner, 2002). These results were maintained approximately 5 years after discharge. Graduates also reported higher levels of self-efficacy in extinguishing the child’s behavior problems, preventing new occurrences, and teaching appropriate replacement behaviors.

Several programs have included a mix of stress reduction and parenting techniques proven to be successful. Salt et al. (2002) evaluated the effectiveness of a developmentally based early intervention program for children diagnosed with autism. The program was modeled after a previous successful treatment. Parents were trained to interpret child behavior as potential interaction and to shape the child’s interactions. Parent support groups were also provided. Results indicated children in the treatment group improved significantly more than those in the control group regarding measures of joint attention, social interaction, imitation, daily livings skills, motor skills, and adaptive behaviors. Parents in the treatment group, as compared to those in the control group, had a reduction in total stress (Salt et al., 2002).

In a similar study by Hudson et al. (2003), the researchers evaluated an intervention program for parents of children with developmental delays and challenging behaviors. The program was based on an approach that emphasized child behavior management, as well as stress management for parents. Upon conclusion of the program, parents reported they were less stressed, felt more effective in being able to manage their child’s behavior, and were less troubled about meeting their own needs. Overall, parents reported their child’s behaviors improved and the parents felt an overall satisfaction with the program with regard to its content and delivery. Further researchers found mixed programs are successful. Tonge et al. (2006), for example, combined parent education and behavior management skills in an intervention program for parents of preschool children with autism. The comparison group received parent counseling and parent education, while the treatment group received parent education and behavior management interventions. Both groups had significant improvement in their overall health at follow-up. However, the parent education and behavior management intervention was more effective in alleviating a higher percentage of anxiety, insomnia, somatic symptoms, and family dysfunction than the parent education and counseling at a 6-month follow-up (Tonge et al., 2006).

Overall, regarding balance, these studies indicated programs designed to teach parents effective skills and behavioral strategies help reduce parent stress. Both coping skills and parent training programs have been shown to be effective in reducing parent stress, and evidence shows a combination of the two types of programs is the most effective treatment. Moreover, the gains that the parents achieve can be long lasting.

Psychological interventions. Researchers have established various interventions in an effort to help parents reduce stress associated with raising a child with a disability and become more effective in their parenting skills. Researchers have found positive psychology is effective in helping individuals with depression. Because parents of children with disabilities are at risk for depression, researchers have utilized various positive psychology intervention programs to help parents reduce their depressive symptoms and increase their psychological well-being. Mindfulness interventions may be effective in reducing depression and mental health problems (Grossman, Tiefenthaler-Gilmer, Raysz, & Kesper, 2007; Neece, 2013; Zautra et al., 2008). Grossman et al. (2007) examined the effectiveness of a mindfulness-based stress reduction program on clients with fibromyalgia. The intervention included a variety of mindfulness practices, including yoga and the use of mindfulness in stressful social situations. Relative to a social support condition, participants in the mindfulness groups had increased reductions in pain, anxiety, and depression, and the reductions could be sustained when assessed during the 3-year follow-up analysis. Similarly, Zautra et al. (2008) found evidence supporting the effectiveness of mindfulness interventions in reducing pain and depression in clients with rheumatoid arthritis. Clients who received mindfulness treatments showed an increased reduction in pain than did a group who received education, but reported less reduction in pain than the cognitive-behavioral treatment group. With regard to depression, the mindfulness treatment was most effective. Moreover, the patients who had a history of depression benefited most from the mindfulness treatment.

Given the effectiveness of mindfulness-based interventions to help mediate stress and depression, Neece (2013) evaluated the success of this intervention in parents of children with developmental disabilities. In the study, 46 parents of children with developmental disabilities were randomly assigned to an immediate treatment group or wait list group. Participants completed questionnaires that assessed parental stress and child behavior problems at their initial intake. Both groups completed a second assessment conducted only after the immediate treatment group had received their mindfulness-based stress reduction intervention. Parents who participated in the intervention reported significantly less stress and depression as well as increased life satisfaction when compared to the wait list group that received no mindfulness intervention. Children whose parents participated in the mindfulness-based stress reduction intervention displayed fewer behavior problems following the intervention, especially in the areas of attention problems and attention deficit hyperactivity disorder (ADHD) symptomatology (Neece, 2013).

With regard to well-being, Emmons and McCullouh (2003) explored the effectiveness of gratitude interventions for increasing happiness and well-being in undergraduate students and in individuals with neuromuscular disease. Participants were randomly assigned to one of several conditions. Those in the gratitude condition were asked to identify five things during the past week that they were grateful for. The other participants had to identify hassles or events that were not specifically identified as positive or negative. Participants then recorded their moods, physical symptoms, and overall life satisfaction. The gratitude condition displayed heightened well-being on most measures (Emmons & McCullouh, 2003). Similarly, Lyubomirsky, Sheldon, and Schkade (2005) found participants who counted their blessings or performed acts of kindness improved their well-being during a 6-week intervention period.

Researchers have found positive psychotherapy to be effective in reducing depressive symptoms. Because parents of children with disabilities are at higher risk for depressive symptoms, positive psychology interventions may be beneficial for such parents. In addition, positive psychology interventions, including those related to helping determine personal strengths, promote both happiness and life satisfaction.

In conclusion, raising a child with a disability can be overwhelming and difficult. Many parents have developed successful coping mechanisms to ameliorate their levels of stress associated with raising a child with a disability. In addition, various parent programs help teach parents how work with their child’s behavioral issues in an attempt to reduce parental stress. Parents have also increased their mental health and well-being through psychological interventions, which have improved the overall functioning of the entire family. Research has shown that when parents have well-developed coping mechanisms and supports in place, they are more effective in raising a child with a disability.

In summary, the review of the literature revealed a significant deal of knowledge has been accumulated regarding the experiences of families of children with developmental disabilities. The emergence of a research-based consensus on a number of issues related to raising a child with a disability is encouraging and promising, but still limited. The success of many research programs has opened areas for current and future work, especially in the field of psychology. These emerging lines of study should provide richness and understanding to the depth and multiple ways that children with disabilities influence family functioning.

Chapter 3: Method

The objective of this study was to examine coping strategies used by parents of children with developmental disabilities and how they correlated with their psychological level of distress. In addition, parents had the opportunity to provide their personal experiences by way of completing written responses to a series of researcher-developed questions.

Through this study, the researcher utilized a mixed methods design that consisted of two questionnaires and 10 written responses to questions designed by the researcher. The first questionnaire was the Ways of Coping Questionnaire (WCQ). It consists of 66 questions that comprise eight subscales: Confrontive Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Planful Problem Solving, and Positive Reappraisal. The second questionnaire was entitled the Psychological Distress Profile (PDP). It consists of 20 questions and four subscales: Depression, Hopelessness, Anxiety, and Anger. The 10 written questions were,

1. How did you first find out your child had a birth defect or developmental disability?
2. Do you think it was better to cope with a disability or your own mental health or both?
3. What advice would you give to parents who just found out their child has a disability?
4. What greatest joy has this circumstance brought you?
5. What resources, if any, did you seek out?
6. What resources, if any, were most helpful?

7. How has raising a child with special needs changed your life?
8. With whom, if anyone, did you share your feelings?
9. What do you think was the missing link in helping you navigate this situation?
10. Who provided you with the most support as you navigated through the world of raising a child with a disability?

Participants and Criteria

In the study, 30 parents of children with developmental disabilities diagnosed within the last 10 years participated. The participants were recruited within the local elementary, middle, and high schools, as well as by soliciting colleagues, personal contacts, and referrals with a child who has a developmental disability diagnosis or has been classified as requiring special education and related services. The responsible investigator conducted the screening. The disability could include a medical, physical, or cognitive disability that effects one or more major life activities. Participants were asked to complete the WCQ, the Parent Distress Profile, and the series of researcher-developed questions in writing. A cover letter and return envelope were included in the mailings.

Measures and Materials

Ways of Coping Questionnaire. The WCQ (Folkman & Lazarus, 1985) assesses thoughts and actions individuals use to cope with the stressful encounters of everyday living. It is derived from a cognitive-phenomenological theory of stress and coping that is articulated in *Stress, Appraisal, and Coping* (Folkman & Lazarus, 1985) and elsewhere (e.g., Lazarus, 1981; Lazarus & Launier, 1978). The measure consists of 66 items that comprise eight subscales: Confrontive Coping (6 items), Distancing (6 items), Self-Controlling (7 items), Seeking Social Support (6 items), Accepting Responsibility (4 items), Escape-Avoidance (8 items), Planful Problem Solving (6 items), and Positive Reappraisal (7 items; see Appendix A). The 16 items were not scaled or scored. The respondents were asked to rate the extent to which they used the coping behavior during a stressful situation on a 4-point Likert scale that ranged from 0 (*Does not apply or not used*) to 3 (*Used a great deal*). Raw subscale scores ranged from 0 to 24. High raw scores indicated that person frequently used the behaviors described by that scale in coping with the stressful event. Relative scores described the proportion of effort represented for each type of coping and were expressed as a percentage that ranged from 0 to 100. A high relative score on a scale meant the person used those coping behaviors more than they used other behaviors.

Folkman and Lazarus (1985) considered the traditional test-retest estimates of reliability to be inappropriate, as the WCQ measures coping as a process, which by definition is variable. However, reliability in terms of internal consistency of the coping measure can be evaluated. Lundqvist and Ahlström (2006), using the root mean squared error of approximation (RMSEA), found that the internal consistency yielded an acceptable fit. These findings were consistent with Edwards and O’Neill (1998) and Parker, Endler, and Bagby (1993) and provided support to the 8-factor model of the WCQ. Items at the beginning of the WCQ ask the participants to provide the date, identification number (optional), gender, and marital status.

Psychological Distress Profile. The PDP (Elkins & Johnson, 2015) is a brief measure of four common domains of psychological distress. The PDP consists of 20 items that comprise four subscales: Depression (5 items), Hopelessness (5 items), Anxiety (5 items), and Anger (5 items; see Appendix B). The respondents were asked to rate their belief about their problems on a 5-point Likert scale, ranging from 1 (*Strongly Disagree*) to 5 (*Strongly Agree*). Subscale scores ranged from 5 to 25. A higher subscale score was indicative of a higher level of distress on a particular construct of psychological distress. Elkins and Johnson (2015) found relatively high levels of internal consistency across samples and sexes ranging, from 0.87 to 0.95.

Researcher-designed questions. The researcher designed the written questions, which guided empirical research findings on raising a child with a disability (see Appendix C). The 10 questions were designed to provide parents with the opportunity to express their personal experiences in raising a child with a disability. Answers to the questions provided a richness to the research study in allowing parents' to describe raising a child with a disability.

Research Design

This study followed a quantitative design, as the researcher sought to determine if a relationship existed between two variables by using two questionnaires. To assess the relationships, a series of Pearson's correlations were conducted. The first correlation was conducted to determine if the parents' problem-focused coping influenced their level of psychological distress. A second Pearson's correlation allowed the researcher to compare the subscales of emotional-focused coping with a parent's psychological distress.

Procedure

Participants recruited from within the local elementary, middle, and high schools, as well as by asking colleagues, personal contacts, and referrals with a child who has a diagnosed developmental disability or is classified as requiring special education and related services. Participants were told that the purpose of the study was to investigate their coping behaviors and psychological distress in raising a child with a disability. Each participant was randomly assigned a number. Participants were asked to complete the 66-item questionnaire from the WCQ and the 20-item questionnaire from the PDP, as well as the 10 researcher-developed questions regarding their personal experiences raising a child with a disability.

Chapter 4: Results

The purpose of this study was to examine the relationships between emotional-focused and problem-focused coping strategies and parental psychological distress while raising a child with a disability. This chapter begins with a description of the preanalysis data cleaning, i.e., how outliers and missing data were assessed. Then, the researcher describes the sample characteristics and demographic information. The chapter concludes with a detailed analysis that describes the results for each hypothesis.

Preanalysis Data Cleaning

The starting sample size of this study was 30 participants. Data were screened for accuracy, missing data, and outliers. The researcher tested the presence of outliers by the examination of standardized values. Standardized values were created for each subscale score, and cases were examined for values beyond ± 3.29 standard deviations from the mean (Tabachnick & Fidell, 2013). Three participants had data that contained outliers and were removed from the data set, leaving a final sample of 27.

To test the research hypotheses, the researcher created a series of composite scores. The score representing confrontive coping was comprised of Q6, Q7, Q17, Q28, Q34, and Q46. Distancing was the sum of Q12, Q13, Q15, Q21, Q41, and Q44. Self-controlling was the sum of Q10, Q14, Q35, Q43, Q54, Q62, and Q63. The sum of Q8, Q18, Q22, Q31, Q42, and Q45 represented seeking social support. Accepting responsibility was the sum of Q9, Q25, Q29, and Q51. Escape/avoidance was the sum of Q11, Q16, Q33, Q40, Q47, Q50, Q58, and Q59. Planful problem solving was the sum of Q1, Q26, Q39, Q48, Q49, and Q52. Positive reappraisal was the sum of Q20, Q23, Q30, Q36, Q38, Q56, and Q60. Psychological distress (total) was the scale scores for depression, hopeless, anxiety, and anger.

Descriptive Statistics

The final sample of parents consisted only of women. These women were mostly White (*n* = 26, 96.3%), had an average age of 40.56 (*SD* = 5.54), and an average of 2.44 children at home under the age of 18 (*SD* = 1.01). The average age of the child at the time of diagnosis was 45.85 months (*SD* = 35.65). A slight majority of the women had a household income of $150,000 or more (*n* = 11, 40.7%) and had a master's degree (*n* = 11, 40.7%). Most women were married at the time their child was diagnosed (*n* = 25, 92.6%), although this number decreased slightly at the time of taking the survey (*n* = 23, 85.2%). The most common diagnosis was ADHD/other (*n* = 7, 25.9%), followed by ADHD (*n* = 4, 14.8%), ADHD/autism (*n* = 3, 11.1%), and Down syndrome (*n* = 3, 11.1%). Table 1 presents all frequencies and percentages for the categorical demographic variables. Table 2 presents all means and standard deviations for the continuous demographic variables.

Table 1

Frequencies and Percentages for Demographic Information

Variable	*n*	%
Gender		
Female	27	100.0
Male	0	0.0
Household income		
$30,000–$49,999	4	14.8
$50,000–$69,999	3	11.1
$100,000–$149,999	9	33.3
$150,000 or more	11	40.7
Highest education achieved		
High school diploma/GED	6	22.2
Bachelor’s degree	9	33.3
Master’s degree	11	40.7
Other	1	3.7
Marital status at diagnosis		
Single	1	3.7
Married	25	92.6
Divorced	1	3.7
Current marital status		
Single	2	7.4
Married	23	85.2

Table 1 Continued

Variable	*n*	%
Divorced	2	7.4
Ethnicity		
Anglo/White	26	96.3
Other	1	3.7
Child's diagnosis		
ADHD	4	14.8
Autism	2	7.4
ADHD/autism	3	11.1
ADHD/other	7	25.9
Down syndrome	3	11.1
Other intellectual/learning disability	2	7.4
Heart condition	3	11.1
Other	3	11.1

Table 2

Means and Standard Deviations for Demographic Information

Variable	Min	Max	*M*	*SD*
Age (parent)	33	57	40.56	5.54
Age at diagnosis in months (child)	0	132	45.85	35.65
Number of children in household under 18	1	5	2.44	1.01

The researcher hypothesized that there would be a significant relationship between problem-focused coping (confrontive and planful problem solving) and parents' psychological distress. To test this hypothesis, the researcher performed a Pearson correlation between confrontive coping, planful problem solving, and psychological distress. The results were not significant, indicating that neither confrontive coping, $r(26) = 0.08$, $p = .690$, nor planful problem solving, $r(26) = -0.20$, $p = .511$, had a significant relationship to parents' psychological distress.

The researcher hypothesized that there would be a significant relationship between emotional-focused coping (distancing, self-control, seeking social support, accepting responsibility, escape/avoidance, and positive reappraisal) and parents' psychological distress. To assess this hypothesis, the researcher conducted a second Pearson's correlation to compare the subscales of emotional-focused coping with parents' psychological distress. The results were not significant, which suggests emotional-focused coping did not have a significant relationship with parents' psychological distress (all $p > .05$). Table 3 presents the results of the correlations.

Table 3

Correlations of Parent Psychological Distress and Emotional-Focused Coping

	Parents' psychological distress	
	r	*p*
Distancing	-.05	.793
Self-control	.03	.877
Seeking social support	.04	.856
Accepting responsibility	.03	.880
Escape/avoidance	-.01	.945
Positive reappraisal	-.31	.121

The researcher hypothesized emotional-focused coping mechanisms, when raising a child with a disability, would be associated with more psychological distress factors than problem-focused coping mechanisms. The researcher also hypothesized coping behaviors when raising a child with a disability would be inadequate in decreasing psychological distress. To test these hypotheses, the researcher performed a hierarchical linear regression. In this analysis, the outcome variable corresponded to parents' psychological distress. In Step 1, the predictor variables entered were confrontive coping and planful problem solving (i.e., the problem-focused coping mechanisms). In Step 2, the predictor variables distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, and positive reappraisal were added to the model (i.e., the emotional-focused coping mechanisms). Entering the problem-focused coping variables in Step 1 and the emotional-focused coping variables in Step 2 enabled the researcher to determine if the emotional-focused coping variables predicted parents' psychological distress more than what was accounted for by the problem-focused coping variables. If the emotional-focused coping variables predicted parents' psychological distress more than what was accounted for by the problem-focused coping variables, the hypothesis that emotional-focused coping mechanisms would be associated with more psychological distress factors than problem-focused coping mechanisms would be supported.

Prior to analysis, the researcher assessed the assumptions of normality, homoscedasticity, and multicollinearity. The assumption of normality was assessed through the examination of a normal probability-probability plot of the residuals. The data followed the normality line (see Figure 1), indicating the assumption was met (see Stevens, 2009). The assumption of homoscedasticity was assessed through examination of a scatterplot between the regression standardized residuals and predicted values. The data showed a random pattern (see Figure 2), indicating the assumption was met (Stevens, 2009). Absence of multicollinearity was assured through examination of the variance inflation factor (VIF) scores. No score approached 10, the threshold suggested by Stevens (2009), indicating the assumption was met (see Table 4).

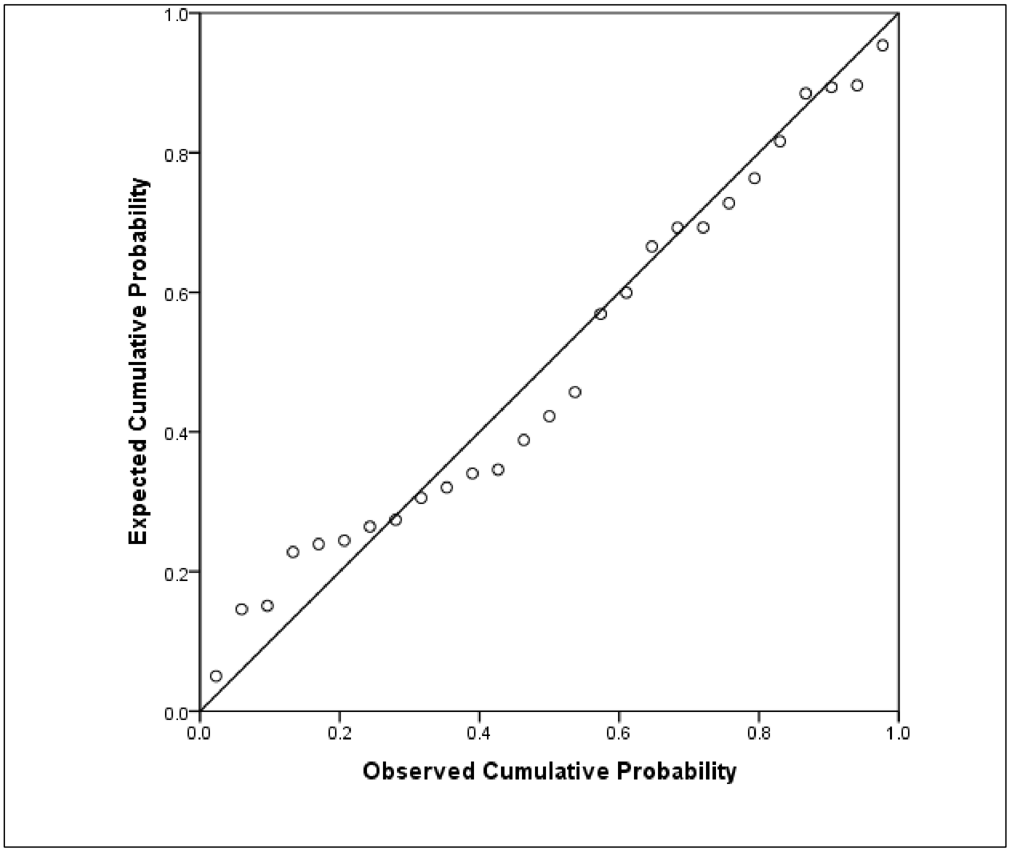

Figure 1. Normal probability-probability plot of the residuals.

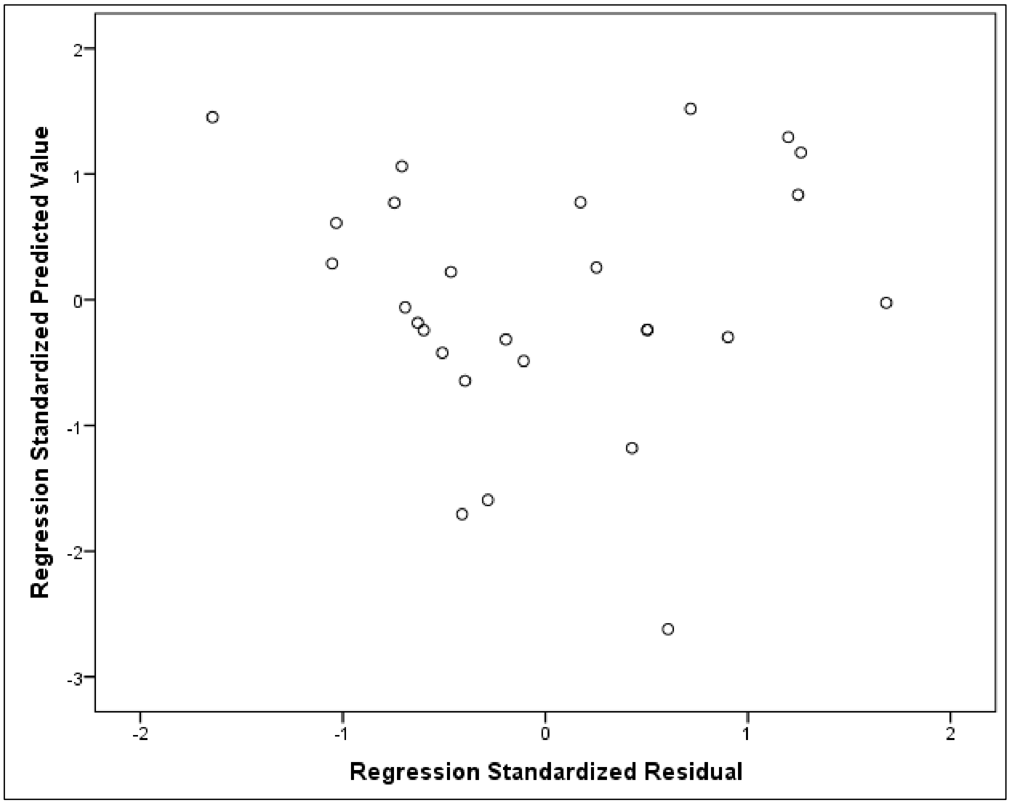

Figure 2. Scatterplot between the standardized residuals and predicted values.

The results for Step 1 of the hierarchical linear regression were not significant, *F*(2, 24) = 0.57, *p* = .572, R^2 = 0.05. This indicates confrontive coping and planful problem solving do not have a significant predictive relationship with parents' psychological distress. As the overall model was not significant, the individual coefficients were not examined. The results for Step 1 of the regression can be found in Table 4.

Table 4

Step 1 of the Regression With Confrontive Coping and Planful Problem Solving Predicting Parents' Psychological Distress

Predictor	*B*	*SE*	β	*t*	*p*	VIF
Confrontive Coping	0.13	0.41	.06	0.31	.759	1.01
Planful problem solving	-0.31	0.30	-.21	-1.04	.307	1.01

Note. $F(2, 24) = 0.57$, $p = .572$, $R^2 = 0.05$.

The results for Step 2 of the hierarchical linear regression were also not significant, $F(8, 18) = 0.84$, $p = .584$, $R^2 = 0.27$. This finding indicates confrontive coping, planful problem solving, and the emotion-focused coping variables do not significantly predict parents' psychological distress. This also demonstrates the emotional-focused coping variables do not significantly predict parents' psychological distress above what is accounted for by the problem-focused coping variables. As the overall model was not significant, the individual coefficients were not examined. Table 5 presents the results for Step 2 of the regression.

Table 5

Step 2 of the Regression With Variables of Interest Predicting Parents' Psychological Distress

Predictor	*B*	*SE*	β	*t*	*p*	VIF
Confrontive Coping	-0.37	0.60	-0.18	-0.62	.544	2.14
Planful problem solving	-0.27	0.33	-0.18	-0.82	.544	1.21
Distancing	-0.19	0.52	-0.09	-0.37	.715	1.42
Self-controlling	0.58	0.46	0.36	1.26	.222	1.98
Seeking social support	0.51	0.32	0.45	1.58	.131	2.03
Accepting responsibility	0.24	0.64	0.09	0.37	.715	1.43
Escape-avoidance	-0.32	0.42	-0.19	-0.75	.461	1.59
Positive reappraisal	-0.68	0.30	-0.67	-2.28	.035	2.11

Note. $F(8, 18) = 0.84$, $p = .584$, $R^2 = 0.27$.

Chapter Summary

To assess the relationship between problem-focused coping, emotional-focused coping, and parental distress, the researcher performed a series of Pearson's correlations. These correlations indicated no significant relationship existed between problem-focused coping and parental distress, nor between emotional-focused coping and parental distress. To assess how these coping mechanisms might affect a parent's distress further, the researcher conducted a hierarchical linear regression. The problem-focused coping variables were entered in Step 1, and the emotional-focused coping variables were entered in Step 2 to determine if the emotional-focused coping variables significantly predicted parents' psychological distress more than what was accounted for by the problem-focused coping variables. The overall models were not significant, indicating that neither problem-focused coping nor emotional-focused coping predicted parental distress. However, this supports the hypothesis that coping behaviors do not decrease parental psychological distress and that a need exists for additional support.

Chapter 5: Discussion

In this study, the researcher examined the relationship between parents' coping mechanisms (confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, and positive reappraisal) on their mental health or distress (depression, hopelessness, anxiety, and anger) when raising a child with a disability. Previous researchers have found parents of children with disabilities often experience higher levels of stress and are at a higher risk for mental health issues than those with typically developing children (Benson, 2012; Trute, Hierbert-Murphy, & Levine, 2007). Family members' ability to adapt to stressful situations that arise from raising a child with a disability depends on a number of variables, including individuals' psychological strengths, resources, and the types of coping strategies they utilize.

The findings of this study indicated no significant relationship existed between problem-focused coping and parental distress, nor between emotional-focused coping and parental distress. In addition, the researcher conducted an analysis to assess how these coping mechanisms might affect a parent's distress further. The overall models were not significant, indicating that neither problem-focused coping nor emotional-focused coping predicts parental distress. However, this supports the hypothesis that coping behaviors do not decrease parental psychological distress and suggest a need for additional support for parents of children with disabilities. These findings are consistent with research that indicates parents can effectively cope with the stress and demands of raising a child with a disability when they are provided with supports (Armstrong et al., 2005; Harper et al., 2013; Shilling et al., 2013; Twoy et al., 2007).

Previous findings have yielded mixed results with regard to problem-focused coping and distress. Pottie et al. (2008) found problem-focused coping predicted both positive and negative mood, which was unexpected, as problem-focused coping was usually associated with positive outcomes. Conversely, Dardas and Ahmad (2013) found coping strategies, such as confrontive coping, planful problem solving, self-control, and positive reappraisal did not have a relationship between stress and parents' perceived quality of life. Additionally, distancing coping was the least reported parental coping strategy and showed no effect on the relationship between parental stress and quality of life (Dardas & Ahmad, 2013). Therefore, the present study adds to these findings and suggests that problem-focused coping may not correlate with parental distress when raising a child with a disability. This finding suggests parents in the current study used problem-focused coping as a positive influence to reduce their stress associated with raising a child with a disability, in contrast to what was hypothesized.

Summary and Interpretation of Findings

Lazarus (1993) explained individuals' psychological stress involves a disparaging person-environment relationship, in which its principle is process and change instead of structure and status. Individuals' ability to cope with stressful situations involves their continuous effort in thought and action to manage specific demands that they consider challenging and overwhelming (Lazarus, 1993). Recently, the American Psychological Association (2012) published guidelines to assist psychologists in conceptualizing and implementing psychological assessment for individuals with disabilities that are fair, ethical, and effective. Through these guidelines, psychologists are encouraged to recognize that families of individuals with disabilities possess strengths and face challenges. Many families are also resilient and regard their experiences related to a disability in terms of meaningful growth. Therefore, the demand for increased knowledge in this specialty area for psychologists and researchers justified the need for this study.

It is possible that no significant relationship was found in the present study between problem-focused and emotional-focused coping when raising a child with a disability and parental distress because of the time lapse between the initial stressor and the completion of the questionnaires. The parents' memory of the significant stressor after a lapse in time may not have been as profound as when the stressor initially occurred. Therefore, it is possible that completion of the questionnaires immediately or shortly after the stressor may have shown a higher level of parental distress. The PDP asked parents to rate their level of distress currently, as opposed to how they felt at the initial diagnosis. Therefore, it is plausible explanation that a parent's level of distress may be higher at the time of the diagnosis.

In addition, the findings also suggest that the prevalence of stress may be lower than reported in previous studies because of measurement issues, as suggested by Bailey et al. (2007). This finding can be further explained because no measurement exists that is designed to specifically address parental coping mechanisms when raising a child with a disability. Various clinical instruments measure adult depression, anxiety, and parental stress, but there is no known measurement specifically for parents of children with disabilities. Therefore, researchers have utilized measurements that have been adjusted or modified for this specific population, possibly resulting in lower rates of stress (Bailey et al., 2007).

In this study, the researcher also sought to determine if coping mechanisms when raising a child with a disability were associated with higher levels of parents' psychological distress. The results are consistent with previous research indicating problem-solving strategies, such as the use of positive reappraisal, seeking social support, and distancing, help to mediate stress (Abery, 2006; Bingham et al., 2012; Gupta & Singhal, 2004; Van Riper, 2007).

The present study's finding of nonsignificance may be attributed to one or more of the coping mechanisms used as positive coping behaviors to help mediate stress, as suggested by Van Riper (2007), Bingham et al. (2012), and Gupta and Singhal (2004). For example, positive perceptions of a stressful situation can help alleviate the effect of the child's disability on family members, which can help strengthen psychological and physical resources during stress (Gupta & Singhal, 2004). A plausible explanation for the current findings is that the participants had positive perceptions that helped with the families' ability to cope with and to positively adjust and adapt to the circumstances of raising a child with a disability, as suggested by Bayat (2007). Another plausible explanation may be that all participants were mothers, as opposed to a population of mother and fathers. Previous research has shown significant differences exist in positive appraisal of the influence of a child with a disability on the family (Trute et al., 2007). Mothers had more positive appraisals than fathers, and mothers' appraisals were found to predict family adjustment and enhance mothers' self-esteem (Trute et al., 2007).

In addition, using emotional-focused coping mechanisms may have led mothers to reappraise a stressor previously or initially thought to be a threat, resulting in effective coping to deal with the situation, as suggested by Ntoumanis, Edmonds, and Duda

(2009). As explained by Trute et al. (2007), mothers were found to appraise their situations when raising a child with a disability as positively when compared to fathers. Because all the participants in the current study were mothers, it may be that the mothers were able to appraise their situations positively, yielding more favorable and appropriate coping strategies, thus mediating their stress associated with raising a child with a disability.

The researcher also hypothesized that coping behaviors, when raising a child with a disability, are inadequate in decreasing psychological distress. Therefore, additional supports would be needed to positively influence a parent's psychological distress. The results of this study partially supported this hypothesis. Specifically, coping behaviors do not decrease parental psychological distress, and a need exists for additional support. As previously discussed, parents' psychological stress can be attributed to feelings of socially isolation, financial stress, and lack of resources. However, parents who perceived that they were helped, understood, and assisted, felt less stress (Siman-Tov & Kaniel, 2011). In addition, parents with higher levels of social support coupled with low levels of financial hardship had better family congruence than those parents who had low levels of support and high levels of financial hardship (McConnell et al., 2014). Social supports have been shown to decrease stress because they increased the parents' feeling of control and appeared to be a large part of the external coping strategies for the family (Siman-Tov & Kaniel, 2011; Twoy et al., 2007).

The findings of the present study could be attributed to participants' economic level (40.7% reported a yearly income above $150,000), as well as to participants' educational levels (74% held a college degree). Children with disabilities require highly coordinated systems of care, including individualized therapies, home modifications, specialized equipment, medications, and educational services (Parish & Cloud, 2006). Parents who are educated and economically stable are able to seek specialty providers, and to afford specialized equipment and services for their children with disabilities. As previously noted, resources and support have been beneficial in reducing parental stress associated with raising a child with a disability. Families with financial strain or of a lower socioeconomic status may have limited access to appropriate health care, thus limiting their support and resources. This situation may cause an increase in distress levels and limit their ability to cope effectively.

The needs of parents raising a child with a disability are often overlooked, as the child and his or her condition become the primary focus. Limited research exists regarding parents' and caregivers' perspectives to guide theory and practice pertaining to family stress and resiliency in families raising children with disabilities. This researcher found that coping behaviors are not sufficient in decreasing parental distress; therefore, additional supports are needed. These findings underscore the lack of knowledge that can help parents adapt and cope with the stress associated in raising a child with a disability. A family's ability to adapt to stressful situations that arise from raising a child with a disability can be affected by the level of resources and supports provided. Consequently, it is imperative that health care providers engage in more effective approaches to support parents' needs. Parents with effective resources and supports may feel empowered to cope with and adapt to their situations, thus lessening their risk for mental health issues and strengthening the family as a whole.

The use of open-ended questions was beneficial in uncovering the perceptions of parents' experiences in raising a child with a disability. The shared stories produced an increased awareness of a time at which they felt isolated or stressed, what resources were sought, and what could have helped them better. Almost all parents reported a situation in which they felt a sense of isolation. Several parents reported feeling socially isolated from family members and friends, as they felt their child's disability was not understood. Many parents also reported they used support groups to help and wished they had more support and services for them and their child with a disability.

Limitations

A number of limitations need to be considered when interpreting the results of this study, some of which were unforeseen, unanticipated, and uncontrollable. The lack of varied demographic data (i.e., gender, age, income, education) and the small sample size (*n* = 27) resulted in the inability to generalize the results to other populations, including fathers. Because of the absence of male participants, it was not possible to conduct data analyses on gender differences. Another limitation was that the participants were of a higher socioeconomic status (74% more than $100,000); therefore, the results may not generalize to lower socioeconomic status or disadvantaged populations. Additionally, more than half of the participants also had college degrees (*n* = 20; 74%); consequently, the results may not generalize well to populations with less education. More than three quarters of the sample consisted of White mothers (*n* = 26; 96.3%). Therefore, it was also not possible to examine the relationship between cultural influences, coping mechanisms, and levels of stress associated with raising children with disabilities.

Another limitation of the study was that a large majority of participants were married at the time the study was completed (*n* = 23, 85.2%). Therefore, the results may not generalize well to single parents, who may have less support than married individuals. Finally, an unforeseen and unpredictable factor was the time between initial diagnosis and current feelings of distress. Because this researcher utilized a maximum of 10 years since initial diagnosis, the extent to which a parent initially felt distress and his or her current feelings might have been significantly different. Differences may exist in perceptions between participants who completed the surveys immediately following the diagnosis and after several years.

Future Directions

One of the most significant problems with research on coping mechanisms and parental distress in raising a child with a disability is the lack of appropriate measures, as found by Bailey et al. (2007). Parents may underreport their symptoms, and the incidence of parental distress may be lower than previously reported. Researchers have examined the relationship between having a child with a disability and parental depression, but have primarily utilized self-rating questionnaires, which are not diagnostic tools, instead of relying on a diagnosis from a trained professional. Future researchers are encouraged to contribute to the literature by developing appropriate measures to accurately determine the level of distress among parents raising a child with a disability.

Given the large number of studies conducted on mothers, future researchers may wish to seek additional input from fathers. A father’s needs, coping behaviors, and level of distress may be vastly different from those of mothers and may require different levels and types of support from professionals. Researchers should also look to expand on the current research to target diverse populations, such as those with lower socioeconomic status and single parents raising a child with a disability. These variables may yield different results with regard to parents' distress levels and coping behaviors. Such studies may elucidate how various populations are affected by raising a child with a disability.

Finally, researchers may wish to investigate parental distress and coping when raising a child with a disability at the time of the diagnosis. This may yield significant information regarding the emotional state of a parent learning the news that their child has a disability. Future researchers should also conduct a longitudinal study to determine parents' coping behaviors and levels of distress at the time of diagnosis and several years later to determine whether a decrease in distress levels exists and to determine what coping behaviors positively influence outcomes. This research would help clinicians to support the needs of parents raising a child with a disability.

Conclusion

Although this study did not yield significant results, the parents provided invaluable information for this researcher's professional growth. As previously discussed, parents of children with disabilities experience higher levels of stress and are at increased risk for mental health issues than those with typically developing children (Benson, 2012; Trute et al., 2007). The family's ability to adapt to stressful situations that arise from raising a child with a disability depends on a number of variables, including parents' psychological strengths, resources, and the types of coping strategies they utilize.

This study provided parents with the opportunity to respond to 10 open-ended questions to allow their feelings to be expressed beyond standardized questionnaires. The answers to these open-ended questions provided evidence that parents do, in fact, feel socially isolated, financially stressed, and emotionally taxed when raising a child with a disability. One of the most frequently stated feelings of raising a child with a disability was social isolation. Several parents responded by writing comments, such as “I felt socially isolated after his initial diagnosis when I would get together with friends and their neurotypical children” and “When old friends no longer wish to be part of our life.” Consistent with previous research, parents also expressed being financially stressed when having to pay for necessary items for their child that insurance did not cover or when they sought private schooling and alternative therapies.

The current findings lend additional support to previous research indicating that raising a child with a disability can bring significant joy. Many parents noted that they learned how to understand and help their child thrive, to cherish the little things and about unconditional love. Additionally, a majority of parents found that supports from friends and family were helpful, as were community resources. The participants strongly urged parents to seek support groups and other resources.

This study underscores the urgent need for medical, phsychological, and educational professionals to provide family-based interventions, especially to help empower parents raising a child with a disability. The predominant messages for professionals from the findings of the study are: (a) the necessity of providing parents with support and resources for their child’s disability, (b) the necessity for ongoing communication between professionals and parents regarding the disability, and (c) the importance of reminding parents also to take time for themselves and their own mental health so they can positively support the needs of their child.

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Appendix A: Perspective Participant Letter

Dear Perspective Participants,

We are conducting a study to obtain information regarding the stress, coping, and personal experiences in parents who are raising a child with a disability. You will be asked to complete two questionnaires and a few open-ended questions. The primary investigator is Noelle A. Cauda- Laufer, a school psychologist, who is a doctoral candidate in the field of school psychology at the Philadelphia College of Osteopathic Medicine. She is under the direct supervision of Dr. Virginia Salzer. We would greatly appreciate your participation in this process.

We are asking a biological parent(s) who have a child with a disability to complete the enclosed packet. Included in the packet are two multiple-choice questionnaires and two short answer surveys. This should take no longer than 20 minutes. In order to ensure that all information remain confidential, no identifying information will be requested. If you choose to participate in this study, please answer all questions as honestly as possible and return the completed questionnaires and personal questions promptly in the enclosed self-addressed stamped envelope. Participation is strictly voluntary and you may refuse to participate at any time. The completed packets will be numbered only and under the care of the primary investigator only.

Thank you for your time and consideration in this study. The data collected will provide useful information for clinicians in how to better serve parents of children with a disability. Completion of this packet will indicate your willingness to participate in this study. If you require additional information or have questions regarding this study, please contact the primary investigator at the email or number listed below.

Sincerely,

Noelle A. Cauda- Laufer

NJ Certified School Psychologist

Doctoral Candidate at P.C.O.M.

(732) 814-5334

noelleca@pcom.edu

Appendix B: Demographics Survey

Demographics Survey

Please circle your answer.

1. Age: ______

2. Gender: Male Female

3. What is your total household income?

    a. Less than $10,000
    b. $10,000 to $29,999
    c. $30,000 to $49,999
    d. $50,000 to $69,999
    e. $70,000 to $99,999
    f. $100,000 to $149,999
    g. $150,000 or more

4. *What is the highest degree or level of school you have completed? If currently enrolled, mark the previous grade or highest degree received.*
    a. High school graduate - high school diploma or the equivalent (for example: GED)
    b. Associate degree (for example: AA, AS)
    c. Bachelor's degree (for example: BA, AB, BS)
    d. Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
    e. Other (specify)________________________________

5. What was the marital status at time of diagnosis?
    a. Single
    b. Married
    c. Separate
    d. Divorced

6. What is your current marital status?
    a. Single
    b. Married
    c. Separate
    d. Divorced

7. How many children reside in your household under the age of 18? _________________

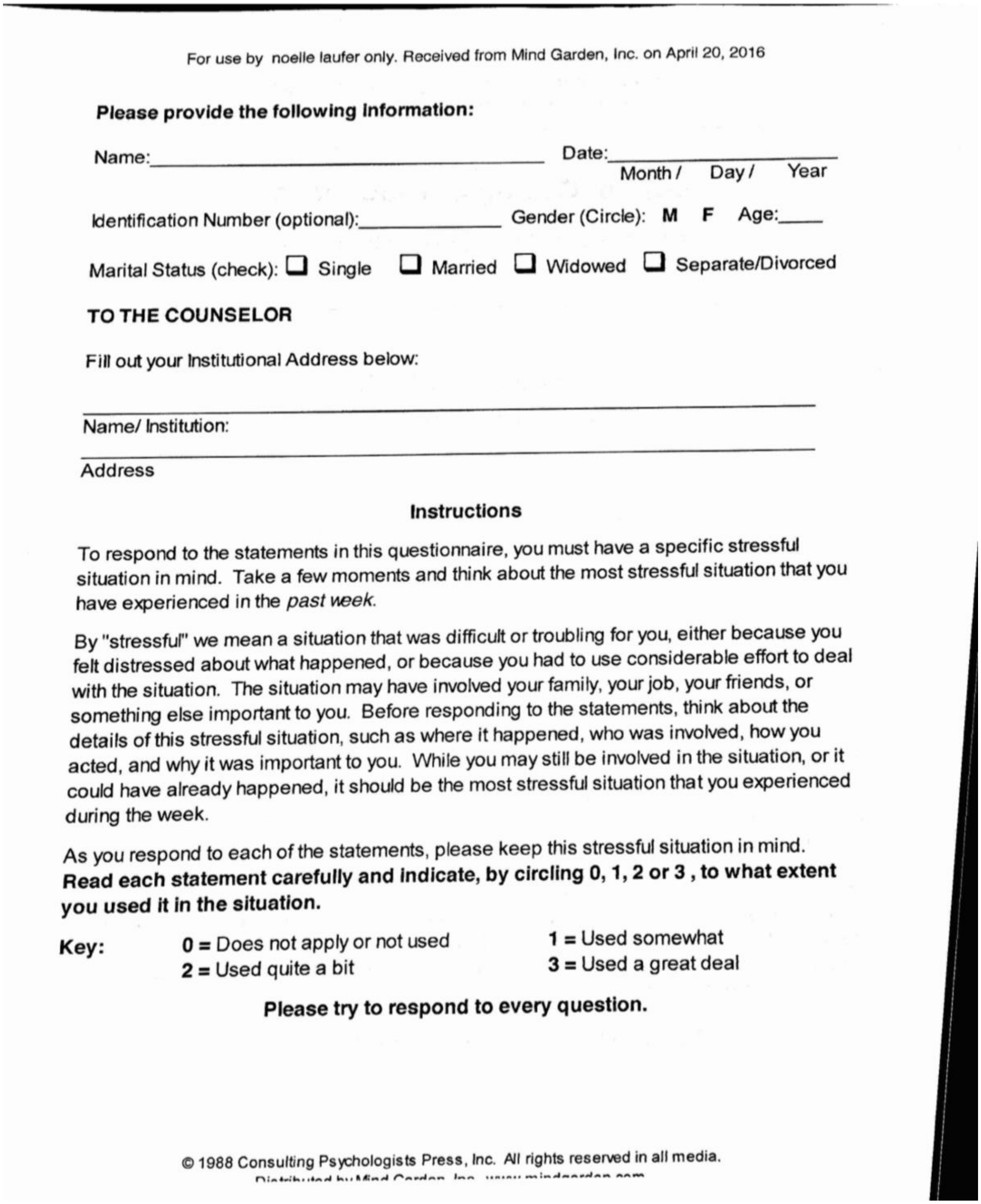
8. Which of the following describes you best?
    a. Anglo/White
    b. African American
    c. Hispanic
    d. Asian American
    e. Native American
    f. Other

9. What is the diagnosis of your child? __________________________________

10. What was the age of your child at initial diagnosis? ______________________

Appendix C: Questionnaires

Ways of Coping Questionnaire



For use by noelle laufer only. Received from Mind Garden, Inc. on April 20, 2016

Please provide the following information:

Name:______________________________ Date:____________________
Month / Day / Year

Identification Number (optional):______________ Gender (Circle): **M** **F** Age:____

Marital Status (check): ☐ Single ☐ Married ☐ Widowed ☐ Separate/Divorced

TO THE COUNSELOR

Fill out your Institutional Address below:

____
Name/ Institution:
____
Address

Instructions

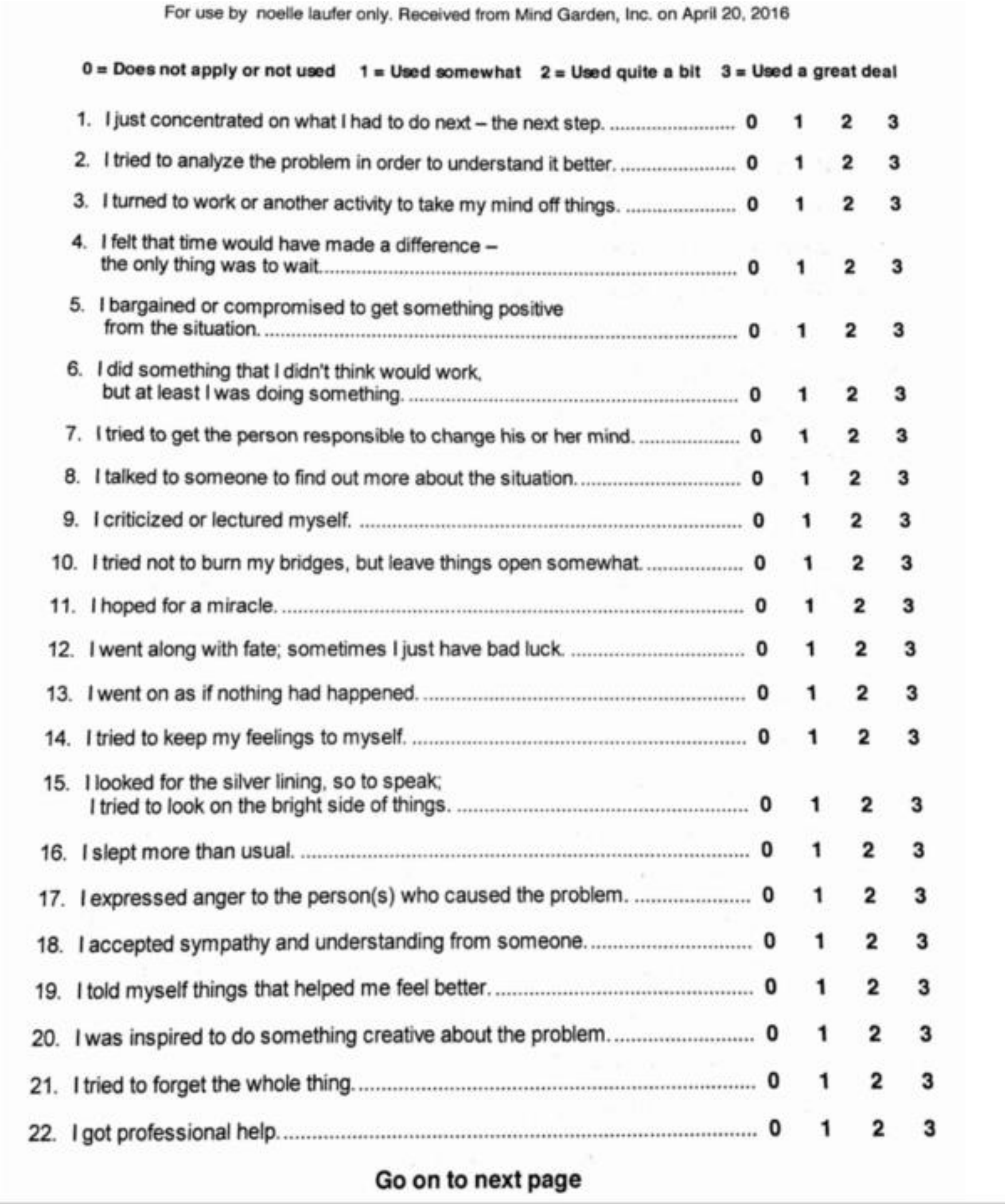
To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few moments and think about the most stressful situation that you have experienced in the *past week*.

By "stressful" we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends, or something else important to you. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind. **Read each statement carefully and indicate, by circling 0, 1, 2 or 3 , to what extent you used it in the situation.**

Key:
0 = Does not apply or not used
1 = Used somewhat
2 = Used quite a bit
3 = Used a great deal

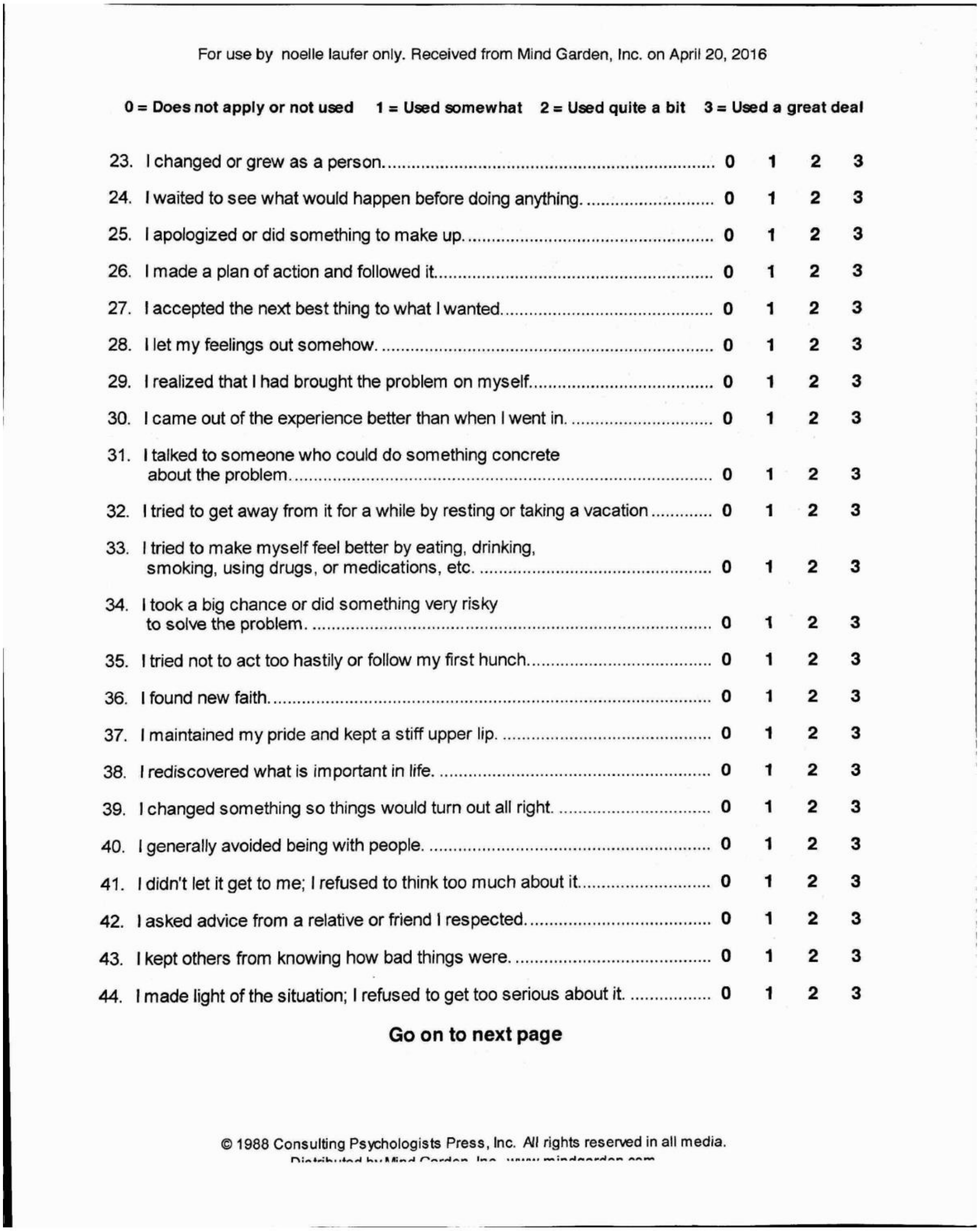
Please try to respond to every question.



0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

1. I just concentrated on what I had to do next – the next step. **0 1 2 3**
2. I tried to analyze the problem in order to understand it better. **0 1 2 3**
3. I turned to work or another activity to take my mind off things. **0 1 2 3**
4. I felt that time would have made a difference – the only thing was to wait. **0 1 2 3**
5. I bargained or compromised to get something positive from the situation. **0 1 2 3**
6. I did something that I didn't think would work, but at least I was doing something. **0 1 2 3**
7. I tried to get the person responsible to change his or her mind. **0 1 2 3**
8. I talked to someone to find out more about the situation. **0 1 2 3**
9. I criticized or lectured myself. **0 1 2 3**
10. I tried not to burn my bridges, but leave things open somewhat. **0 1 2 3**
11. I hoped for a miracle. **0 1 2 3**
12. I went along with fate; sometimes I just have bad luck. **0 1 2 3**
13. I went on as if nothing had happened. **0 1 2 3**
14. I tried to keep my feelings to myself. **0 1 2 3**
15. I looked for the silver lining, so to speak; I tried to look on the bright side of things. **0 1 2 3**
16. I slept more than usual. **0 1 2 3**
17. I expressed anger to the person(s) who caused the problem. **0 1 2 3**
18. I accepted sympathy and understanding from someone. **0 1 2 3**
19. I told myself things that helped me feel better. **0 1 2 3**
20. I was inspired to do something creative about the problem. **0 1 2 3**
21. I tried to forget the whole thing. **0 1 2 3**
22. I got professional help. **0 1 2 3**

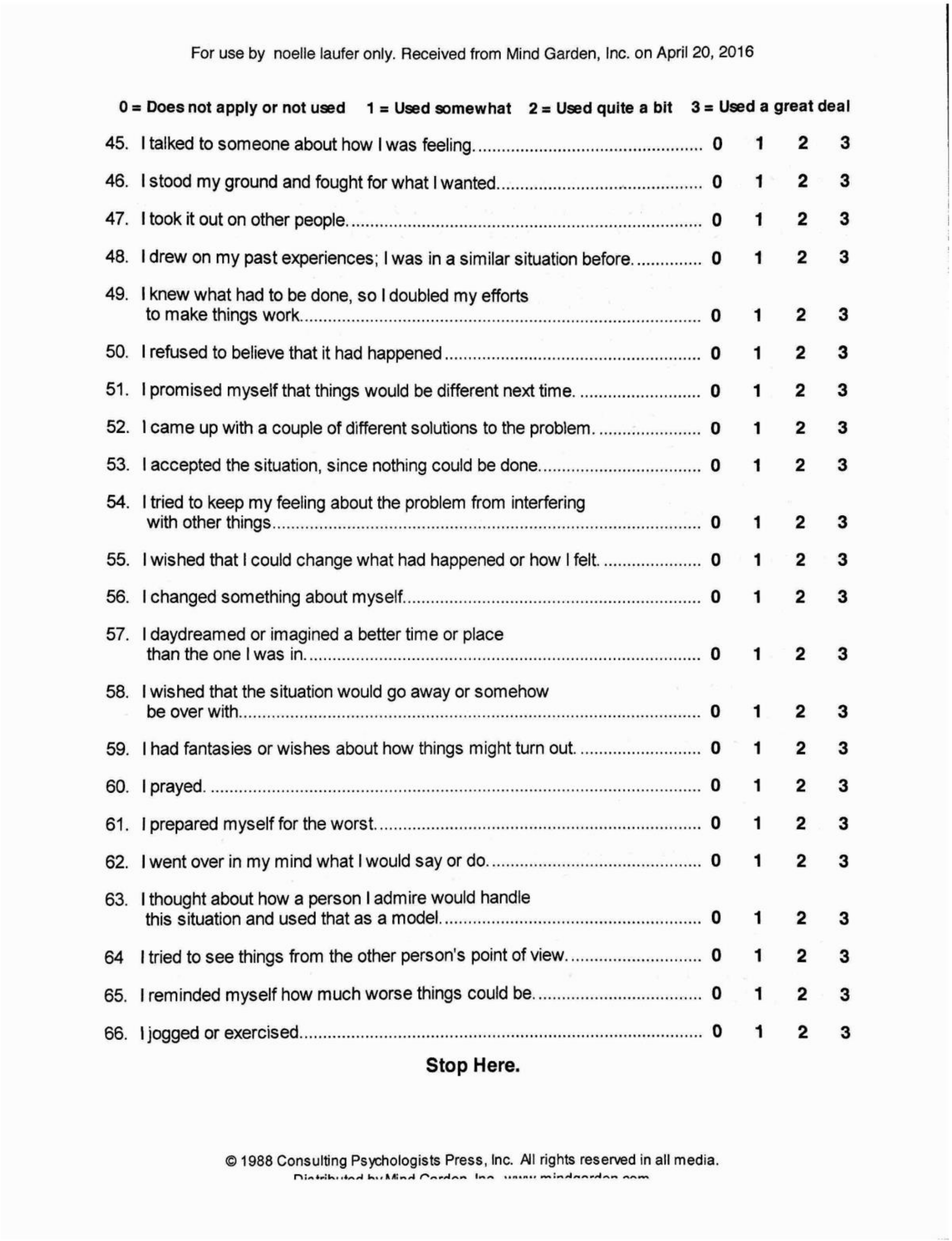
Go on to next page



0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

23. I changed or grew as a person. 0 1 2 3
24. I waited to see what would happen before doing anything. 0 1 2 3
25. I apologized or did something to make up. 0 1 2 3
26. I made a plan of action and followed it. 0 1 2 3
27. I accepted the next best thing to what I wanted. 0 1 2 3
28. I let my feelings out somehow. 0 1 2 3
29. I realized that I had brought the problem on myself. 0 1 2 3
30. I came out of the experience better than when I went in. 0 1 2 3
31. I talked to someone who could do something concrete about the problem. 0 1 2 3
32. I tried to get away from it for a while by resting or taking a vacation 0 1 2 3
33. I tried to make myself feel better by eating, drinking, smoking, using drugs, or medications, etc. 0 1 2 3
34. I took a big chance or did something very risky to solve the problem. 0 1 2 3
35. I tried not to act too hastily or follow my first hunch. 0 1 2 3
36. I found new faith. 0 1 2 3
37. I maintained my pride and kept a stiff upper lip. 0 1 2 3
38. I rediscovered what is important in life. 0 1 2 3
39. I changed something so things would turn out all right. 0 1 2 3
40. I generally avoided being with people. 0 1 2 3
41. I didn't let it get to me; I refused to think too much about it. 0 1 2 3
42. I asked advice from a relative or friend I respected. 0 1 2 3
43. I kept others from knowing how bad things were. 0 1 2 3
44. I made light of the situation; I refused to get too serious about it. 0 1 2 3

Go on to next page



0 = Does not apply or not used 1 = Used somewhat 2 = Used quite a bit 3 = Used a great deal

45. I talked to someone about how I was feeling. **0 1 2 3**

46. I stood my ground and fought for what I wanted. **0 1 2 3**

47. I took it out on other people. **0 1 2 3**

48. I drew on my past experiences; I was in a similar situation before. **0 1 2 3**

49. I knew what had to be done, so I doubled my efforts to make things work. **0 1 2 3**

50. I refused to believe that it had happened **0 1 2 3**

51. I promised myself that things would be different next time. **0 1 2 3**

52. I came up with a couple of different solutions to the problem. **0 1 2 3**

53. I accepted the situation, since nothing could be done. **0 1 2 3**

54. I tried to keep my feeling about the problem from interfering with other things. **0 1 2 3**

55. I wished that I could change what had happened or how I felt. **0 1 2 3**

56. I changed something about myself. **0 1 2 3**

57. I daydreamed or imagined a better time or place than the one I was in. **0 1 2 3**

58. I wished that the situation would go away or somehow be over with. **0 1 2 3**

59. I had fantasies or wishes about how things might turn out. **0 1 2 3**

60. I prayed. **0 1 2 3**

61. I prepared myself for the worst. **0 1 2 3**

62. I went over in my mind what I would say or do. **0 1 2 3**

63. I thought about how a person I admire would handle this situation and used that as a model. **0 1 2 3**

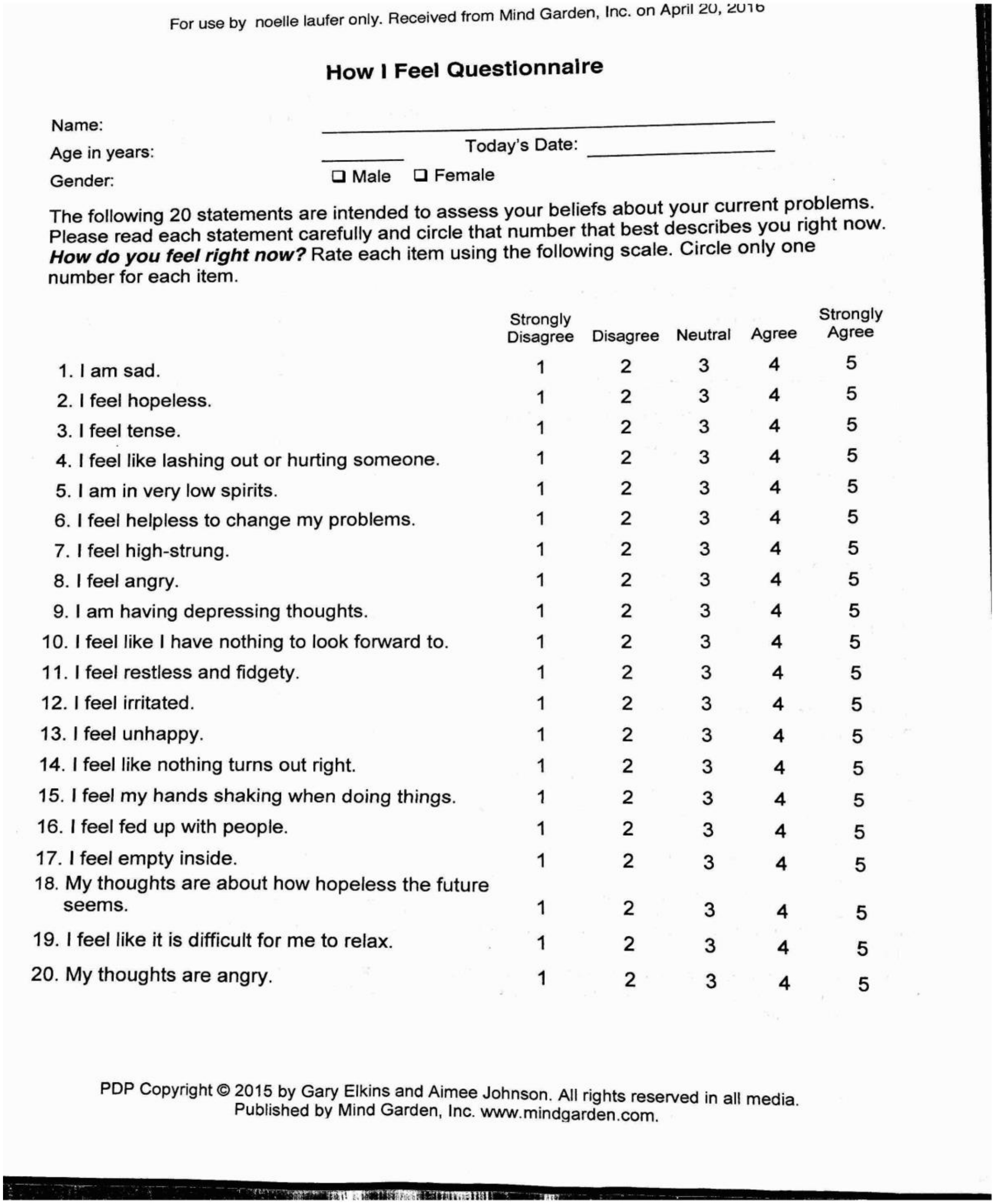
64 I tried to see things from the other person's point of view. **0 1 2 3**

65. I reminded myself how much worse things could be. **0 1 2 3**

66. I jogged or exercised. **0 1 2 3**

Stop Here.

Psychological Distress Profile



How I Feel Questionnaire

Name: ______________________________

Age in years: __________ Today's Date: ______________

Gender: ☐ Male ☐ Female

The following 20 statements are intended to assess your beliefs about your current problems. Please read each statement carefully and circle that number that best describes you right now. ***How do you feel right now?*** Rate each item using the following scale. Circle only one number for each item.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I am sad.	1	2	3	4	5
2. I feel hopeless.	1	2	3	4	5
3. I feel tense.	1	2	3	4	5
4. I feel like lashing out or hurting someone.	1	2	3	4	5
5. I am in very low spirits.	1	2	3	4	5
6. I feel helpless to change my problems.	1	2	3	4	5
7. I feel high-strung.	1	2	3	4	5
8. I feel angry.	1	2	3	4	5
9. I am having depressing thoughts.	1	2	3	4	5
10. I feel like I have nothing to look forward to.	1	2	3	4	5
11. I feel restless and fidgety.	1	2	3	4	5
12. I feel irritated.	1	2	3	4	5
13. I feel unhappy.	1	2	3	4	5
14. I feel like nothing turns out right.	1	2	3	4	5
15. I feel my hands shaking when doing things.	1	2	3	4	5
16. I feel fed up with people.	1	2	3	4	5
17. I feel empty inside.	1	2	3	4	5
18. My thoughts are about how hopeless the future seems.	1	2	3	4	5
19. I feel like it is difficult for me to relax.	1	2	3	4	5
20. My thoughts are angry.	1	2	3	4	5

Appendix D: Open-Ended Questions

Raising a Child With a Disability: Coping Mechanisms and Support Needs

1. How did you first find out your child had a birth defect or disability?

   ____

2. What greatest joy has this circumstance brought you? ____________________

   ____

3. Describe a time in which you felt socially isolated, financially stressed or emotionally or physically stressed? ___________________________________

   ____

4. What resources (e.g. DDD, Community, etc.) did you seek out and can you explain how they were or were not helpful? ___________________________

   ____

5. What advice would you give to parents who just found out their child had a disability? ____

   ____

6. What would have helped you better navigate this new situation? ___________

   ____

Additional comments: ____

____