The Influence of Daily Stressors, Severity of Behavior Problems, Uncertainty, and Coping Strategies on Family Adaptation in Families of Adolescents with Autism Spectrum Disorders

A DISSERTATION

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School of Nursing
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By
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The prevalence of autism spectrum disorder (ASD) is rising exponentially. U.S. public health authorities report a 78% increase in ASD prevalence rate during the period (2002-2008), effecting 1 child in 50. Families of adolescents with ASD face the complex task of managing their children’s transition into adulthood. Complicating this task is the limited information available to guide families of adolescents with ASD and to guide supportive resource personnel, including nurses.

Utilizing McCubbin’s (2003) Resiliency Model of Family Adjustment and Adaptation, this study investigated the influence of four independent variables: a) daily stressors, b) severity of behavior problems, c) uncertainty, and d) coping on the dependent variable of family adaptation. Participants (103) were recruited from the web-based Interactive Autism Network and met the criteria: a biological or adoptive parent, stepparent, partner of a parent, or custodial grandparent of an adolescent, aged 13 to 22, diagnosed with ASD.
This study employed a prospective, descriptive, correlational design. Parents completed five research instruments and a background information questionnaire, using an on-line methodology. Multiple regression analysis was conducted and the appropriate statistics were reported.

The study found that three of the four independent variables had a statistically significant independent relationship with the dependent variable of family adaptation when each variable entered the model: a) daily stressors \[F (3,99) = 7.3, p = .008\] accounted for 6.8% of the variance in family adaptation, b) the severity of behavior problems \[F (4, 98)= 6.5, p = .012\] contributed 5.8% to the variance in family adaptation, c) and parent’s perception of their adolescent with ASD’s disability \[F (5, 97) = 7.6, p = .007\] contributed 6.3% to the variance in family adaptation when it entered the model. The full model was statistically significant \[F (6, 96) = 4.2, p = .001\] and the combination of independent variables explained 20.8% of the variance in family adaptation.

This study supports qualitative research with parents of adolescents with ASD, who report concerns of uncertainty regarding their adolescents with ASD’s future and unpredictability of behavioral symptoms. Because this is the first quantitative study with such findings, additional research is recommended.
This dissertation by Sandra O’Brien fulfills the dissertation requirements for the doctoral degree in Nursing approved by Jean Toth, PhD, RN, APN, BCCC, as Director, and by Janice Agazio, PhD, RN, CRNP, and Elizabeth Hawkins-Walsh, PhD, RN, CPNP, MCHN, as Readers.

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Elizabeth Hawkins-Walsh, PhD, RN, CPNP, Reader
Dedication

This dissertation is dedicated to family members who provide care to adolescents with autism spectrum disorders. I am especially appreciative to those who participated in this research study. In sharing their “voices,” they have assisted me to contribute to the body of knowledge regarding the less researched field of parenting adolescents with ASD.

This dissertation is also dedicated to my family. I thank my husband, Rich for his constant support and belief in the importance of this research. I also thank my children, Bill, Neil, and Brigid, and those special near-daughters Gen and Erin. Their loving support, many prayers, sacrifices, and extra chores have made this work possible. Many thanks also to my extended family. I treasured their prayers and appreciated their support of Rich and the “kids.”
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CHAPTER I: THE PROBLEM

Background

Autism Spectrum Disorder (ASD) is one of the most difficult disorders with which a family must cope and is particularly difficult for families of adolescents with ASD (Fong, 1992; Gray, 1993). Even so, little research has been conducted to assist parents of adolescents with ASD, the focus of this study, during this challenging family life cycle stage (Orsmond, Seltzer, Greenberg, & Krauss, 2006). While family adaptation is positively influenced by informational support, the lack of such support, conversely, may increase the family’s burden (Patterson, 1988).

ASD is defined as a life-long, pervasive, developmental disability that affects an individual’s neurological and biological systems. Individuals are affected to varying degrees by ASD; hence it is referred to as a spectrum disorder (Centers for Disease Control and Prevention, [CDC], 2009). ASD affects males four times more often than females but affects all races equally (CDC, 2007). The prevalence of autism spectrum disorder (ASD) is rising exponentially. U.S. public report a 78% increase in ASD prevalence rate during the period (2002-2008), reflecting a prevalence rate of 1 in 50 (Blumberg et al., 2013). In the last 20 years, there has been a 600% increase in the number of diagnosed cases of ASD (Autism Speaks, 2009a). This rate significantly exceeds the 25% that is accounted for solely by increased surveillance (Autism Speaks, 2009b). Not restricted to the United States, increasing prevalence of ASD has been observed worldwide with nearly 67 million individuals affected by the disorder (Autism Speaks, 2009b; McDonald & Paul, 2010).
An individual is diagnosed with ASD if he/she demonstrates abnormalities in each of three domains prior to age three: a) impaired communication, b) restrictive interests or repetitive behaviors, and c) restricted reciprocal social interactions (CDC, 2008). While these impairments may improve as the child ages, longitudinal studies demonstrate significant impairments in the three domains persist throughout the individual’s lifespan (Billstedt, Gilsberg, & Gilsberg, 2010; Howlin, Goode, Hutton, & Rutter, 2004; Jennes-Coussens, Magill, & Konig, 2006). Gray (1993), who conducted several longitudinal qualitative studies with families of children with ASD stated,

The prognosis for autism is very limited. There is no cure, and few…individuals [with ASD] are ever likely to work or live independently of their families other than in an institution….Even if the disruptive symptoms of the disease are reduced by treatment, families of autistic individuals care permanently for a disabled person. (p. 103).

Other researchers have reached similar conclusions regarding the long-term prognosis. They found that even adults with the mildest form of ASD rarely gained independent living status, were chronically un- or underemployed, and infrequently formed deep interpersonal relationships (Billstedt et al., 2010; Howlin et al., 2004; Jennes-Coussens et al., 2006). Although millions of dollars have funded ASD research (Singh, Illes, Lazzeoni, & Hallmayer, 2009), these intensive research efforts have focused primarily on younger, newly diagnosed children, and have been conducted primarily with mothers, thus leaving a void of information pertaining to the parenting of older children (Lutz, 2008; Orsmond et al., 2006).
A Description of Parenting an Adolescent with ASD

With the exception of recent team-led research at the University of Wisconsin-Madison, research that includes parents of older children with ASD in the previous three decades has been published by only a handful of researchers, including several articles by Gray (1993; Gray, 2002; Gray, 2003; Gray, 2006), and individual efforts by Cashin (2003), Fong (1992), Lutz (2008) Swanepoel, (2003), and Vliem (2009). Collectively, the parents in these studies identified difficult parenting tasks related to raising their adolescents with ASD. These difficulties involved a) supervision during an extended period of dependency, b) managing increasing behavior problems including aggression, tantrums and inappropriate public social behavior, and c) persistent impairments in social interactions (discussed below). Additionally parents reported the impact of these difficulties, including a) stigma and social isolation, b) physical and emotional fatigue, and c) family and marital strains. In spite of these challenges, most parents viewed their childrearing experience as a positive one (Cashin, 2003; Fong, 1992; Gray, 1993; Lutz, 2008; Swanepoel, 2003). These themes will be further discussed in this chapter.

Supervision during a Prolonged Period of Dependency

On the whole, parents reported their adolescents with ASD needed more assistance and supervision than is required for normally-developing peers. Vliem (2009) concluded parents faced “challenges in teaching basic life skills… protecting them from danger and preparing them for adult life” (p. 6-7). In Lutz’ (2008) study, mothers described continued dependency as caring for a “teenager acting…like a toddler” (p. 125) and for a “child who now resides in an adult body” (p. 69). Regarding basic skills, a mother explained “[You] have to make sure his hands are washed and that he’s got on clean underwear” (Fong, 1992, p. 125). Also parents reported
the continuing need to protect their adolescent from danger. In addition, outside the home without supervision, adolescents are especially vulnerable, because adolescents with ASD may have little sense of danger (Vliem, 2009). For example, adolescents with ASD reportedly have difficulty identifying and negotiating traffic hazards and consequently, have been struck or nearly struck by a car (Fong, 1992; Lutz, 2008). In another example, a mother recounted her son ‘snuck away’ from home during the winter. Exposed to the elements without hat, coat or gloves, his fingers became frostbitten (Fong, 1992).

Parents may not be able to let their guard down inside the home, either. Parents have reported they must be alert to deter the destructiveness of the adolescent with ASD (Swanepoel, 2003). For example, a mother described her home as a “fortress…with locks on every door, cabinet, refrigerator, and gates across entrances” (Swanepoel, 2003, p. 154). Another mother described her cautious efforts, “[if] I haven’t seen him for 10 or 15 minutes, you just sort of quietly do check what he’s doing…you’ve sort of gotta watch him” (Gray, 2006, p. 974). Finally, a mother remarked such vigilance prohibited her from indulging in a ten-minute shower, fearing to leave her adolescent unattended (Fong, 1992), clearly a stressor for family adaptation.

Managing Increasing Behavior Problems

Gray (1993) observed “the adolescent period usually marks…[a] difficult stage when the child develops sexually and…become[s] more aggressive. These problems are complicated by the increasing physical size and strength of the autistic adolescent” (p. 117). Furthermore, Konstantareas (1991) remarked “older…children become management problems because of their increased strength and [they also] have older parents, with flagging energy levels and years of providing unremitting care” (p. 366). Providing an example of her son’s increased
aggressiveness, a mother stated “He has a one-to-one aide, but often he requires two or three people to manage his aggression” (Lutz, 2008, p. 109) She added, “He is unpredictable in his behavior and...his siblings avoid him because of his aggression” (Lutz, 2008, p. 106). Similarly a mother reported her son with ASD “fought with his father and threatened to hurt family members with a knife or a gun” (Fong, 1992, p. 103). This represents a serious family stressor.

As a consequence of the increased aggression and behavioral management difficulties, parents may consider institutionalization of their adolescent children with ASD (Gray, 1993; Gray, 2002). In addition to aggression, parents reported an increased number of tantrums and problems managing inappropriate public behavior (Fong, 1992; Konstantareas, 1991). This behavior is discussed below.

**Tantrums.** Many parents, in the reviewed qualitative studies, reported difficulties in managing the tantrums of their adolescents with ASD (Fong, 1992; Gray, 2002). Tantrums, common in early childhood, decrease during the school-aged years, and re-intensify during adolescence (Cashin, 2003). They occur most frequently during transition periods or when the adolescent is stressed or frustrated (Cashin, 2003; Fong, 1992). To counter this tension, adolescents with ASD often employ routines and rituals to cope with the unpredictability of their world (Cashin, 2003). When the inevitable disruption arises, adolescents with ASD may feel overwhelmed and release tension through a tantrum (Cashin, 2003; Fong, 1992).

A mother in Lutz’ (2008) study gave an example of a tantrum-triggering event. Her son tried to bang the car windows when the car stopped somewhere other than at McDonald’s or home. She stated her son “tantrums when unfamiliar activities are out of his comfort zone” (p. 106). Adolescents with ASD, often larger and stronger, may cause damage during the tantrums.
Accordingly, when tantruming they have been known to strike parents, teachers or classmates and throw tables and chairs across the classroom (Fong, 1992). While controlling the tantrum is challenging to the parent; also challenging is the unpredictability of the tantrums’ occurrence. Parents have described this experience as “feeling on guard...always anticipating…and not knowing how they will cope and how others…will react” (Fong, 1992, p. 106).

**Inappropriate public behavior.** Parents described feelings of stigma related to the adolescent with ASD’s inappropriate behavior in public that includes more than the tantrum itself. Parents reported coping with the experience by withdrawing socially and eventually become socially isolated (Cashin, 2003; Fong, 1992; Gray, 1993; Lutz, 2008; Swanepoel, 2003). The inappropriate behaviors of the person with ASD have been reported as talking excessively, communicating intrusively with strangers, invading strangers’ personal space, and performing odd gestures such as exploring their hands, twirling their fingers, flapping their arms and banging their head (Fong, 1992; Konstantareas, 1991). Other adolescents with ASD have reportedly performed more serious behaviors, such as disrobing, urinating (Fong, 1992), or touching genitals in public (Gray, 1993) and peering in strangers’ windows (Fong, 1992; Lutz, 2008).

Such behavior in the small child may be overlooked; however such inappropriate behavior by an adolescent is usually not tolerated by society (Gray, 1993).

**Impairments in Social Interactions**

**The stigma associated with ASD.** Parents report the public seems confused by their adolescent with ASD’s behavior. Gray (1993) stated “the normal physical appearance of autistic children and the relative lack of public knowledge of the disorder mean that parents with autistic children may be more likely to experience hostile public reaction” (p. 113). Similarly, Lutz
(2008) referred to ASD as an “invisible disability” (p. 110). This situation may explain why strangers occasionally misattribute the adolescent’s inappropriate behavior to result from poor parenting skills (Lutz, 2008). One mother reported being told, “Don’t use autism as an excuse” (p. 112). This situation elevates stressors for the family.

**Social isolation in response to stigma.** Swanpoel (2003) remarked that parents of children with ASD respond to stigma by curtailing public outings since they may be “venue[s] for confrontation and sources of embarrassment due to the children’s challenging behaviors” (p. 50) eliminating the possibility of the development of public outings into a familiar family event. This response on the part of parents of children with ASD may place them “at risk for social isolation” (p. 50). Accordingly, a mother explained it was easier to remain at home than to “try to get others to understand” (Lutz, 2008, p. 123). However, Gray (2006) did not see social isolation as an entirely negative occurrence, but instead viewed it as a coping strategy. Gray (2006) reasoned that avoiding uncomfortable and demanding situations reduces family stress. This strategy was employed most often by younger parents during their initial adjustment to the child’s disability. In follow-up studies, Gray (2006) found older parents, while still reclusive, were less distressed by the self-imposed isolation.

**Impaired Social Relationships**

The third criterion for the diagnosis of ASD, also includes difficulty in reciprocal social interactions. Seltzer et al. (2003) found this impairment persists in varying degrees into adulthood. Researchers assert that ASD disrupts the affected individual’s ability to understand others’ thinking processes and consequently hinders the establishment of relationships (Frith & Happe, 1999). Fong (1992) wrote of adolescents with ASD, “They lack the requisite social skills
and appropriate social judgments” (p. 117). As an example, a mother commented, “He talks to everyone, wherever he goes, and he just has no idea whether something is appropriate or not or to whom he should speak” (Fong, 1992, p. 117). Consequently developing peer relationships is challenging for the adolescent with ASD. Parents have observed that their adolescents’ awkward social skills interfere with forming friendships, lead to rejection, and often to teasing and bullying (Fong, 1992; Gray 1993). A parent stated, “Although he is more or less accepted in the classroom, most of the kids do not accept him as a friend” (Fong, 1992, p. 123). The adolescents’ poor social skills have other long-term consequences, such as obtaining or maintaining employment or forming a relationship with a life-long partner. These tasks, fundamental to transitioning into greater independence, are impacted by ASD.

**Impact of ASD on families of adolescents with ASD**

**Physical and emotional fatigue.** Vliem (2009) commented that the “burden of caring for the child [exacts a] physical toll” (p. 6) on parents. As an example, a mother stated, “After that battle [assisting her uncooperative adolescent] I literally am worn out” (Lutz, 2008, p. 109). Parents in Cashin’s (2003) and Gray’s (1993) studies reported emotional fatigue, as well. Cashin (2003) commented the fatigue stems from “the act of care and ongoing anxiety” (p. 103) and the inability of parents to rest and restore themselves (Cashin, 2003).

**Marital and family strain.** Vleim (2008) stated “parenting a child with autism is a demanding task and can strain family ties, including the marital relationship” (p. 135). On this theme, a mother in Swanepoel’s (2003) study related, “So we never had time alone, and we could not leave them with anyone else. And, what used to happen is that we used to argue….So, it put a lot of strain on our marriage” (p. 36).
The data support the parental observations regarding marital strain. A recent study found during the adolescent life cycle stage, the divorce rate was significantly higher (23.5%) for parents of adolescents with ASD than for parents of normally-developing adolescents (13.8%) (Hartley et al., 2010). Also in contrast to families of normally-developing children, the divorce rate steadily increased with the age of the child with ASD (Hartley et al., 2010). The factors found to be predictive of marriage dissolution in families of adolescents with ASD were a) the unpredictability and lack of improvement of ASD symptoms and b) the persistence of behavior problems, such as aggression (Hartley et al., 2010). Thus all fields of nursing encounter individuals with ASD and their families who experience considerable health and psychological outcomes related to ASD.

Adaptation

A description of parenting an adolescent with ASD would be incomplete without a discussion of the adaptation of families of adolescents with ASD to their unique challenges. Patterson (1988), a family theorist, stated of family adaptation, “The concept of family adaptation is used to describe a continuum of outcomes that reflect family efforts to achieve a balance” (p. 231) after a significantly large stressor or stressors. The pattern of family adaptation “usually evolves over a long period of time and has longterm [sic] consequences” (p. 230). Patterson further explained family adaptation is a “balance between the needs, tasks, and demands of the individual family-member and the family system’s capabilities to bring the necessary resources, coping behaviors, and perceptions into play” (p. 229).

Families of adolescents with ASD endeavor to achieve long-term balance to raising a child with a disability. On the one hand, the families may adapt to parenting a child with ASD,
now an adolescent, by developing a more negative long-term response. Gray (1993) reported parents appeared to reach a point where they became less sensitive to the reactions of outsiders…[and] often experience[d] a degree of emotional exhaustion…develop[ing] a certain degree of emotional detachment over time” (p. 117). Also, Gray (1993) observed “the stress of living with such an individual [with ASD] can affect the psychological well-being of family members as well as generate conflicts among them” (p. 103).

On the other hand, many parents developed a more positive long-term response to parenting an adolescent with ASD. For example, parents reported that by parenting their own child with ASD, they “[have] grown in compassion for children with and without ASD” and had developed an appreciation for “those with disabilities or who face stigma” (Lutz, 2008, p. 133). One mother expressed she was able to take comfort in her belief that God had a reason for allowing her son to have ASD (Lutz, 2008). Finally, some parents expressed their pleasure in their children with ASD, reflecting in the child’s positive traits. For example, a mother stated, “Even though autism stole the child of my dreams…my child is beautiful…I love her” (Lutz, 2008, p. 134).

Taken together, in spite of the challenges of raising an adolescent with ASD, most families are not necessarily shattered by the experience. This fact is evidenced by the majority (76.5%) of families raising adolescents with ASD remaining intact (Hartley et al., 2010). Therefore it is important to understand the combination of factors that predict the effective coping and optimal family functioning in families of adolescents with ASD.

The following section will discuss some relevant factors and to present the need for this study. McCubbin’s Resiliency Model of Adjustment and Adaptation (RMF) (McCubbin,
Thompson, & McCubbin, 2003) will serve as the theoretical framework for this study. The purpose, hypotheses and variables will flow from the RMF model and will be discussed further. The specific variables of daily stressors, severity of behavior problems, uncertainty, and coping are derived from the RMF and will be presented in order to further explicate their relationships to family adaptation.

**Variables under Study**

**Daily Stressors**

A daily stressor is a minor, daily inconvenience, such as misplacing a personal item, sitting in traffic gridlock, or experiencing conflict with a partner or colleague (Lazaus & Folkman, 1984). Daily stressors are even more influential on an individual’s mental and physical health than are major life events, such as divorce or birth of a child with disabilities (Lazarus & Folkman; Konstantareas & Homatidis, 1989; Stoneman & Gavidia-Payne, 2006), because daily stressors, or hassles, weigh heavily because they occur frequently and often unpredictably (Lazarus & Folkman). Stressors of daily life have a negative influence on all individuals and families, including families of children with disabilities (Seltzer et al., 2009). However, Smith et al. (2010) found daily stressors disproportionately impact mothers of adolescents with ASD. In addition, the long-term effect of daily stressors is cumulative and appears to translate into more generalized chronic stress (Seltzer et al., 2010). Furthermore, research has established a link between daily stressors and negative health outcomes (Lazarus & Folkman, 1984; Konstantareas, 1991).

Accordingly, studies have demonstrated the negative role of daily stressors for parents of children with disabilities including ASD (Stoneman & Gavidia-Payne, 2006). Studies have
shown that daily stressors are predictive of individual and family functioning in families of children with disabilities (Crnic & Greenberg, 1990; DeLongis, Folkman, & Lazarus, 1988). Smith et al.’s (2010) study of the influence of daily stressors on mothers of adolescents and adults with ASD found the mothers had higher levels of daily stressors and greater levels of chronic stress than other mothers with normally-developing adolescents and adults. The mothers of adolescents with ASD encountered daily stressors which included: a) extra time needed to care for their child, b) child-related concerns interrupting their work day, and c) arguments, and avoided arguments both at work and at home. Mothers of adolescents with ASD were nearly three times more likely to report a daily stressful event than the mothers of normally-developing adolescents. However, the studies regarding daily stressors were limited to mothers (Smith et al., 2010).

**Severity of Behavior Problems**

Research has shown parents of children with disabilities, including ASD experience as a significant negative stressor, the management of their child’s behavior when heavily impacted by the severity of the child’s behavior problems. Numerous studies have demonstrated that the severity of behavior problems is directly related to parental stress in children with disabilities. These studies involved a wide variety of disabilities including attention deficit hyperactivity disorder (Cronin, 2004; Kendall, 1998), cystic fibrosis, (Cronin, 2004), and intellectual disability (Baker, Blacher, Crnic, & Edlebrock, 2002; Eisenhower, Baker, & Blacher, 2005; Hastings & Brown, 2002; Neece & Baker, 2008). The resulting parental stress may negatively influence a couple’s relationship. Consistent with this observation, Stoneman and Gavidia-Payne (2006)
reported a strong correlation between child behavior difficulties in families of children with disabilities and marital adjustment problems.

Studies also have validated similar concerns in parents of younger children with ASD (Benson & Karloff, 2008; Herring et al., 2006; Osborne & Reed, 2009a; Osborne & Reed, 2009b). The studies have indicated the parental stress related to behavior problems significantly exceeds that of parents of children of other types of disabilities (Epstein, Saltzman-Benaiah, O’Hare, Goll, & Tuck, 2008; Griffith, Hastings, Nash, & Hill, 2010; Osborne & Reed, 2009a; Osborne & Reed, 2009b). Other studies have established an association between severity of behavior problems and negative parental outcomes, such as depression, anger or stress in families of younger children with ASD (Benson, 2006; Hastings et al. 2005; Herring et al. 2006; Phetrasuwan, & Miles, 2008; Pottie, Cohen, & Ingram, 2009). For example, Lecavalier, Leone, & Wiltz (2006) studied the effect of behavior problems on parental stress in families of younger children (mean age 9 years) with ASD. The researchers found a direct correlation between the severity of the child’s behavior problems and parental stress scores. However, the relationship between the severity of behavior problems in older children with ASD and parental stress has been investigated less frequently (Orsmond et al., 2006).

Only relatively recently have researchers explored the severity of behavior problems in mothers of adolescents and adults with ASD and then, only as a part of a secondary analysis (Lounds, Seltzer, Greenberg, & Shattuck, 2007; Smith, Greenberg, Seltzer, & Hong, 2008). Among the numerous variables explored, the researchers found a strong correlation between behavior problems and negative maternal outcomes, including negative maternal affect,
depression and anger. Yet no study has measured the relationship between severity of behavior problems and paternal or family outcomes including family adaptation.

**Uncertainty**

Uncertainty is a stressor that negatively impacts families of children with serious illnesses, such as cancer, and disabilities (Stewart & Mishel, 2000). Mishel (1988) conducted a series of research studies aimed to better understand the relationship between uncertainty and negative stress. From this work, Mishel developed the Uncertainty in Illness (UIT) theory. The researcher determined four sources may contribute to the perception of uncertainty in patients with serious illness and uncertainty in parents of children with serious illness: a) ambiguity associated with the condition, b) complexity associated with the treatment and health care delivery system, c) lack of information regarding the diagnosis or severity of the condition and d) unpredictability of symptom manifestations over the long-term course of the disorder (Mishel, 1988). Mishel’s original research was conducted with persons with cancer and other serious life-threatening illnesses. Subsequent research expanded the application of the UIT to include chronic illnesses and disabilities (Garwick, Patterson, Meschke, Bennet, & Blum, 2002; Holm, Patterson, Rueter, & Wamboldt, 2008; Santacroce, 2001; Santacroce, 2003).

Stewart and Mishel (2000) found uncertainty was a predominant theme in their systematic review of literature exploring family adjustment to serious childhood illnesses. The literature revealed that over the course of a serious illness or disorder, the parent’s uncertainty fails to abate. The uncertainty first emerges when parents detect abnormal health or behavioral symptoms and intensifies during the parents’ pursuit of a definitive diagnosis (Stewart & Mishel, 2000). The average length of time between parental initial concerns and actual diagnosis of ASD
ranges from 18 to 48 months (Wiggins, Baio, & Rice, 2006). Accordingly, parents in Stewart and Mishel’s (2000) review described the stress related to the uncertainty during this waiting period as nearly intolerable. Even after a diagnosis is made, Stewart and Mishel found the stress of uncertainty may persist if healthcare providers fail to communicate effectively about the condition. Also they noted parental uncertainty may be heightened by complex, overwhelming or unclear information related to the child’s disease process (Stewart & Mishel, 2000).

The review also found that another source of uncertainty for parents is the lack of clarity regarding the disorder’s etiology of the disorder (Stewart & Mishel, 2000). Stewart and Mishel found parents reported their worries over their potential responsibility for the disorder and these worries re-emerged periodically. Consistent with this finding, the mothers of a child diagnosed with ASD have reported worries that they may have harmed the fetus during pregnancy or permitted their infant to receive vaccinations, resulting in ASD (Freed, Clark, Butchart, Singer, & Davis, 2010; Retzlaff, 2007). Stewart and Mishel (2000) noted a final source of uncertainty, the unpredictability of worsening symptoms of an illness or the unpredictability of the disorder’s trajectory.

Skaggs & Barron (2006) theorized that uncertainty hinders the family’s adjustment to chronic illness or disability, blocking the family’s appraisal process. Along these lines, in qualitative studies, parents of children with ASD have reported difficulty finding quiet time for reflection due to the busyness of life and the demands of caring for their child with ASD (Cashin, 2003; Fong, 1992). Several studies provide support that the hindered appraisal process may result in poor adaptation to illnesses and disabilities (Stewart & Mishel, 2000). Consistent with this, Garwick et al., (2002) and Holm et al. (2008) found an association between uncertainty and
deterioration in parental physical and mental health. In the case of ASD, Warter (2009) utilized a descriptive multivariate design and similarly found uncertainty to be a predictor of parental distress in families of children with ASD.

Finally, Stewart and Mishel’s (2000) review of research literature found parents experienced increased periods of uncertainty during normal transitions such as during adolescence or surrounding the time of high school graduation. Along these lines, Holm et al. (2008) found parents of adolescents with disabilities worry about the unclear path of their child’s future. Similarly, in several qualitative studies, parents of adolescents with ASD have reported concerns about their adolescents’ future (Fong, 1992; King et al., 2006; Krajewski, 2005; Lutz, 2008). However, no quantitative studies have measured the influence of uncertainty on parental stress or family adaptation in families of adolescents with ASD.

Coping Strategies

Family theorists have proposed that coping strategies counterbalance the stressors and demands experienced by the family. Studies show that although mothers of adolescents with ASD utilized coping strategies commonly used by other mothers, they did so with less efficacy Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008. However, the research literature provides no explanation into this phenomenon.

Patterson defined coping strategies as the efforts individuals or families employ to reduce or manage the demands of their situations. Patterson stated “family coping could be viewed as coordinated problem-solving behavior of the whole system… [and] involve efforts of individual family members that fit together as a… whole”(p. 218). Patterson (1988) further described five patterns of family coping behaviors, including a) taking specific action to reduce the number of
stressors faced by the family; b) allocating existing family resources more effectively; c) seeking additional resources to augment the family’s existing resources; d) reducing tension associated with the continuous strain of a chronic situation; and e) utilizing cognitive appraisal, or assigning a meaning to the family’s situation. Folkman, Lazarus, Dunkel-Shetter, DeLongis, and Gruen (1986) categorized coping strategies by different method: problem-focused and emotion-focused coping behaviors. According to Folkman et al., problem-focused coping was considered to be the most adaptive because the coping responses directly addressed the problems. Conversely, Folkman and colleagues considered emotion-focused coping less adaptive because the coping responses were primarily focused on regulation of the emotions and not aimed directly at addressing the problem itself. Contemporary coping research often describes the used of both methods to illustrate the effectiveness of a family’s coping.

**Coping and family life cycle stage.** Family theorists assert that situational demands and the types and effectiveness of coping responses may differ according to family life cycle stage. Patterson (1988) posited all families:

> go through repeated cycles of adjustment-crisis-adaptation [upheaval and response to upheaval]. Some cycles are triggered by normal developmental changes (eg., birth of first child, a child becoming an adolescent), which produce normative crises or transitions, followed by periods of relative stability (p. 226).

However, Patterson observed these cycles are more stress-producing in families of children with chronic conditions “because the ongoing care and management of the condition rests primarily on the family” (p. 233).
Coping research with families of younger children with ASD. A review of coping research literature shows that the most widely used coping behaviors utilized by families of children with chronic illnesses and disabilities including ASD are a) cognitive appraisal/assigning meaning and b) utilizing additional supports, especially social support and spiritual resources (Luther, Canham, & Cureton, 2005; Twoy, Connolly, & Novak, 2007). Of note, mothers of younger children with ASD more frequently used the emotion-focused coping responses of withdrawal and escape and greater utilization of cognitive reappraisal and social/emotional support than did mothers of normally-developing children (Orsmond et al., 2006; Pakenham Samios, & Sofronoff, 2005; Sivberg, 2002).

Coping research with families of adolescents with ASD. Similar to parents of younger children with ASD, qualitative studies conducted with families of adolescents with ASD found parents most often reported using the coping strategies of cognitive reappraisal and social support (Fong, 1992; Gray, 2002; Gray, 2006). However, in a longitudinal study conducted by Gray (2006), parents also reported they coped by had developing greater reliance on internal family support, less reliance on community support resources, and greater utilization of spiritual practices.

Quantitative studies seem to suggest the coping strategies employed by mothers of adolescents with ASD may not be sufficient to counterbalance the stressors they are encountering. When compared to mothers of toddlers with ASD, mothers of adolescents with ASD had greater levels of anger and depression and more frequently utilized social withdrawal (Orsmond et al., 2006; Smith, Seltzer, et al., 2008). Also studies have shown mothers of adolescents and adults with ASD have more negative maternal outcomes including anger and
depression than similar mothers of normally-developing adolescents and adults (Seltzer et al., 2009). Lounds et al. (2007) reported mothers of adolescents and adults with ASD’s level of pessimism about their child’s future increased over time. When pessimism about their child’s future was used as a variable, it was found to be directly related to an increased use of psychotropic medications (Lounds, et al., 2007). Although parents of children with ASD use similar coping strategies, these strategies do not appear to sufficiently address maternal adaptation or adjustment of older mothers. However, no studies could be located that measured the variable of coping on paternal or family adaptation for families of adolescents with ASD.

**Family Adaptation**

Family adaptation is an outcome measurement, reflecting the state of family functioning (McCubbin et al., 2003) which encompasses the family’s ability to meet each member’s biological, psychological and emotional needs (Epstein et al., 2008). It measures the net change in the system’s functioning after a solitary event of great magnitude or a compilation of several smaller stressors; a summation of all of the stresses and counterbalancing coping responses (Patterson, 1988). The effectiveness of family adaptation is especially apparent during the family’s response to crises or management of excessive demands (Epstein et al., 2008) and is described as effective or ineffective adjustment and effective or ineffective adaptation (Patterson, 1988).

Research has shown family adaptation is influenced by several factors, including severity of symptoms or degree of impairment in families of children with asthma (Svavarsdottir, Rayens, & McCubbin, 2005), families of adolescents and young adults with bipolar disorder (Sullivan & Miklowiski, 2010) and mothers of boys with Asperger Syndrome (AS), a form of ASD in which
affected individuals have normal or above IQ (Pakenham et al., 2005). Family adaptation was also predicted by other factors including socioeconomic resources (Sullivan & Miklowski, 2010; Wade et al., 2006), family hardiness and family sense of coherence (Svavarsdottir et al., 2005), pile-up of demands that pre-dated the crisis, level of stress (Leske, 2003; Pakenham et al., 2005), positive appraisal of the stressor (Pakenham et al., 2005) and use of coping strategies, including social support and emotional coping (Leske, 2003; Pakenham et al., 2005).

Family life cycle stage has also been found to impact family adaptation. Lin’s (2000) study of family adaptation in families of children with cerebral palsy found families of adolescents had less effective adaptation compared to other family life cycle stages. Despite the importance of understanding factors that predict the family’s optimal functioning, family adaptation has not been measured as a dependent variable in families of adolescents with ASD.

**Summary**

Despite the use of similar coping strategies, mothers of adolescents with ASD have increased negative outcomes such as anger, depression, pessimism, and increased reports of daily stressors when compared to peers or mothers of younger children with ASD. It is unknown to what degree the stressors of daily stressors, severity of behavior symptoms, and counterbalancing and problem-solving and coping strategies affect family adaptation. There is a lack of research evidence to explain the factors or processes underlying this phenomenon.

Current research literature has been conducted nearly exclusively with mothers of adolescents with ASD. It would be helpful to understand the functioning of the entire family system during the family life cycle stage of adolescence. It is unknown if other family members are providing compensatory support during a time when mothers of adolescence are experiencing
increasing challenges. However, no studies have been reported on paternal outcomes or family adaptation in families of adolescents with ASD. Important gaps in the literature exist and should be addressed.

The specific variables of daily stressors, severity of behavior problems, uncertainty and coping and family adaptation were drawn from the RMF. Their relationships to the RMF will be presented in order to provide additional clarification of the problem.

**Statement of Problem**

The relationships among several variables, daily stressors, the severity of behavior problems, uncertainty, coping and family adaptation in families of adolescents with ASD has received limited investigation. Also the combined effect of these variables in families of adolescents with ASD on family adaptation has received limited investigation. There is a gap in the literature that must be addressed.

**Theoretical Framework**

The Resiliency Model of Family Adjustment and Adaptation, or RMF, was the theoretical framework for this study. Resiliency according to McCubbin, Mc Cubbin, Thompson, Han, & Allen (1997) is the ability of the family to recover quickly from adversity. The model has provided a theoretical framework for nurses and social scientists in order to promote resiliency, or the ability of families to rebound for difficulties or crises (McCubbin et al., 2003). The thrust of the RMF is family adaptation or the re-establishment of harmony and balance (bonadaptation) after one catastrophic crisis or after a pile-up of demands, stressors, strains and life transitions (McCubbin et al., 2003). The model’s theorists extended Hill’s (1949) ABCX model, which focused on a family adjustment phase, whereas by augmenting the ABCX model,
the RMF focused on adaptation phase (McCubbin et al., 2003). According to McCubbin and colleagues, the two phases, family adjustment and family adaptation, differ in the degree of change in family functioning required by the family to respond to difficulties. The family is in the adaptation phase if the family must make major changes in its current functioning to address the difficulties.

Family adaptation is influenced by four categories of model components: a) pileup of demands, stressors, strains and family life transitions, b) situational appraisal resources, c) family recovery, and d) problem solving and coping (McCubbin et al., 2003). Family recovery resources include couple problem-solving communication, strength of the couple’s relationship, and the availability of family and community supports (McCubbin et al., 2003). The degree of severity to which the family ascribes to the problem(s) is situational appraisal. The family may appraise the problem as catastrophic, moderate or little consequence. Situational appraisal is influenced by ethnicity, culture and previous experience with surmounting difficulties (McCubbin et al., 2003). According to McCubbin and colleagues, problem-solving and coping is the component of the model which describes the family’s capacity to utilize family recovery resources and the situational appraisal system to address difficulties. The RMF defined five types of problem-solving and coping: a) acquiring social support, b) passively appraising, c) seeking spiritual support, d) cognitive reframing and e) mobilizing family resources to acquire help (2003).

**Application of the RMF**

The following vignette illustrates the components of the RMF. A family of an adolescent with ASD experiences an escalation of the adolescent’s physical aggression at home and school.
According to the RMF, the family may appraise their problem (situational appraisal), the escalating aggression (pileup of demands, strains, stressors or family life transitions), as a crisis or as a serious problem but within their capacity to manage. To address the problem, the family might engage their problem-solving and coping skills to mobilize family recovery resources. One potential family recovery resource would be to seek assistance from their adolescent’s medical care provider and behavioral/mental health care provider. Another potential solution (mobilizing family recovery resources), might be to seek the counsel of their clergy person and receive prayer and support. If these measures (problem-solving and coping) successfully address their situation and re-establish harmony at home, they have adapted well, or have achieved bonadaptation.

The RMF has been widely used in predicting family adaptation in families facing moderate and exceptional difficulties. The model has been utilized in studies of family, maternal or paternal adaptation in families of children with disabilities (McCubbin et al., 1997; Salvoitta, Italinna, & Leinonen, 2003; Svavarsdottir et al., 2005; Van Riper, 2007). Using the RMF as a framework in study of mothers of pre-adolescent boys with ASD, the components of the model explained 61% of the variance in maternal adaptation (Pakenham et al., 2005).

The RMF proposes the outcome of family adaptation is influenced by four categories of factors (pile up of demands, stresses, strains, and life transitions, situational appraisal, family recovery resources, and problem-solving and coping); each were addressed in the study. Family recovery resources were not directly measured in this study, but were measured as a function of coping. This approach reduced the burden to study participants. Empirical indicators for each variable were drawn from the model and are presented in Figure 1.
**Pile up of demands, stresses, strains, and life transitions.** The RMF proposes that family functioning must change when the family experiences a large number of stressors or one substantially large stressor, or crisis. The magnitude of stressor(s) surpasses the family’s usual coping patterns. In this study, the variables of daily stressors and the severity of the adolescent’s behavior problems served as stressors to which the family must respond or adapt. If the number or magnitude of stressors is large, this would be expected to negatively influence family adaptation.

**Situational appraisal.** The RMF posits that how the family perceives their situation strongly influences family adaptation in conjunction with the other components. A large body of research has validated this proposition with families of children with disabilities including ASD. However there is only limited literature of this component with families of adolescents with ASD. This model component was evaluated by exploring the influence of uncertainty on family adaptation. The UIT proposes that uncertainty hinders the appraisal process, particularly if the level of uncertainty is high. Therefore, it can be anticipated that if the level of uncertainty is high, it would influence the family’s situational appraisal, and thus negatively influence family adaptation.

**Family recovery resources.** Researchers investigating family recovery resources have operationalized this component as social support. Numerous studies with families of children and adolescents with disabilities and ASD have explored the role of social support on family
Resiliency Model of Family Stress, Adjustment and Adaptation

Figure 1. Theoretical-Empirical Structure of the Study’s Variables
outcomes. The beneficial role of social support is well established. The instrument that measured coping strategies also assessed the use of coping strategies. Therefore the discussion of this component of the model will fall under problem solving and coping.

**Problem-solving and coping.** Problem-solving and coping is the component of the RMF that counterbalances the stressors by drawing on the recovery resources and situational appraisal. Research has demonstrated that families are empowered to deal with difficult challenges through the use of coping strategies. A large body of literature demonstrates the powerfulness of this component. If the family is utilizing a number of coping strategies, then one would expect family adaptation to also be positively influenced. However, few studies have investigated the number and types of coping strategies employed by families of adolescents with ASD and the influence of these coping strategies on family adaptation in families of adolescents with ASD. Therefore this study measured the number and types of coping strategies used by families of adolescents with ASD and the influence these coping strategies had on families of adolescents with ASD.

**Family adaptation.** Family adaptation is the outcome of the adaptation process and is the combined effects of the component of a) stressors, strains pile up of demands and life transitions, b) the situational appraisal and c) the utilization of problem-solving and coping strategies. It is a point on the continuum between bonadaptation and maladaptation. Effectiveness of adaptation is a reflection of the combined changes made at both the individual and the family level. If the family has been adept at rallying their problem-solving and coping skills to confront their difficulties, then the level of family adaptation is high (McCubbin et al., 2003). However, if the family fails to achieve bonadaptation, it will cycle again through the
adaptation process, until it regains harmony and balance or devolves into dysfunction (McCubbin et al., 2003). This study measured the level of family adaptation and explored the influence of multiple variables on this outcome measure.

Statement of Purpose

The purpose of this study was to measure the effect of: a) daily stressors, b) severity of behavior problems, c) uncertainty, and d) coping strategies on family adaptation in families of adolescents with ASD.

Definitions

Daily Stressors

**Theoretical definition.** Daily stressors were theoretically defined as “experiences or conditions of daily living that have been appraised as salient and harmful to the endorser’s well-being” (Lazarus, 1984, p. 376).

**Operational definition.** Daily stressors were operationally defined as the score on the Weekly Stressor Inventory-Short Form (WSI-SF) (Brantley et al., 2007). (See Appendix A).

Severity of Behavior Problems

**Theoretical definition.** The severity of behavior problems was theoretically defined as the degree to which problem behaviors, exhibited by the child with ASD, affects parental demands or stress (Clark, 2008).

**Operational definition.** The severity of behavior problems was operationally defined as the mark made by the study participant on a Visual Analog Scale. The mark indicated the degree to which the family member perceived being impacted by the behavior problems (See Appendix B).
Uncertainty

**Theoretical definition.** Uncertainty was theoretically defined as “the inability to determine the meaning of illness-related events and occurs in situations where the decision maker is unable to or is unable to accurately predict outcomes because sufficient cues are lacking” (Mishel, 1990, p. 256).

**Operational definition.** Uncertainty was operationally defined as the score on the Parents’ Perception of Uncertainty in Illness Scale (PPUS) (Mishel, 1997) (See Appendix C).

Coping Strategies

**Theoretical definition.** Coping was theoretically defined as the use of strategies designed “to deal with and attempt to overcome problems and difficulties” (“Coping”, 2009, para. 1).

**Operational definition.** Coping was defined operationally as the score for the participants’ responses to the F-COPES (McCubbin et al., 2003) (See Appendix D).

Family Adaptation

**Theoretical definition.** The theoretical definition of family adaptation was net change in the system’s functioning after a solitary event of great magnitude or a compilation of several smaller stressors; a summation of all of the stresses and counterbalancing coping responses (Patterson, 1988).

**Operational definition.** The operational definition was the participant’s score on the General Function (GF) scale of the Family Adaptation Device (Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990) (See Appendix E).
Family

**Theoretical definition.** Family was theoretically defined as “two or more people… related by birth, marriage, or adoption and residing together in the same housing unit” (U.S. Census Bureau, 2010).

**Operational definition.** Family was operationally defined as biological parents, adoptive parents, stepparent, a partner of a parent or custodial grandparent who lives with the child at least 50% of the time (Garwick et al., 2002).

Adolescent

**Theoretical definition.** Adolescent was theoretically defined as an individual who is in the “psychosocial and emotional transition from childhood to adulthood” (Burns, Dunn, Brady, Starr, & Blosser, 2004, p. 151).

**Operational definition.** An adolescent was operationally defined as an individual between the ages of 13 to 22 (Carter & McGoldrick, 1999).

Autism

**Theoretical definition.** Autism was theoretically defined as a pervasive, developmental disability. The affected individual must manifest deficits in each of three domains prior to age three: a) impaired communication, b) restrictive interests or repetitive behaviors, and c) restricted reciprocal social interactions (CDC, 2007).

**Operational definition.** Autism was operationally defined as a formal diagnosis of ASD made by a health care professional.
Research Questions

Q1a: What is the effect of daily stressors on family adaptation in families of adolescents with ASD?

Q1b: What is the effect of the perception of the severity of behavior problems on family adaptation in families of adolescents with ASD?

Q1c: What is the effect of uncertainty on family adaptation in families of adolescents with ASD?

Q1d: What is the effect of coping on family adaptation in families of adolescents with ASD?

Q2: What is the combined effect of daily stressors, the severity of behavior problems, uncertainty, and coping on family adaptation in families of adolescents with ASD?

Research Hypotheses

H1a: Family members reporting greater impact of daily stressors will have a lower level of family adaptation in families of adolescents with ASD.

H1b: Family members reporting greater severity of behavior problems in their adolescent with ASD will have a lower level of family adaptation in families of adolescents with ASD.

H1c: Family members with greater levels of uncertainty will have lower levels of family adaptation in families of adolescents with ASD.

H1d: Family members reporting greater use of coping strategies will have higher levels of family adaptation in families of adolescents with ASD.

H2: The combined effect of daily stressors, severity of behavior problems, uncertainty and coping strategies will contribute significantly to explain the variance in family adaptation in families of adolescents with ASD.
Significance of the Study

Although federal health authorities have identified autism research as a national priority, limited research has been conducted with families of adolescents with ASD and no studies have explored family adaptation with this population. Previous studies of ASD have focused on families of younger children or on families of those newly diagnosed with ASD. Earlier studies conducted with families of adolescents with ASD, were either exploratory, qualitative studies, or have investigated aspects of maternal well-being. Also no studies investigated the number and types of coping strategies employed by families of adolescents with ASD and the influence of these coping strategies on family adaptation in families of adolescents with ASD. Therefore, this study expanded the limited body of knowledge regarding family adaptation in families of adolescents with ASD.

Findings regarding the relationship of daily stressors, severity of behavior problems, uncertainty, coping strategies, and family adaptation have implications for health professionals including nurses. A more complete understanding of factors influencing family adaptation in families of adolescents with ASD, will guide nurses and other healthcare providers in the design of effective interventions. Identifying and addressing stressors and enhancing coping strategies are within the domain of nursing, especially psychiatric/mental health clinical nurse specialists and psychiatric/mental health nurse practitioners. However, psychologists, social workers, licensed marriage and family therapists, can all use the findings in counseling and therapy. Knowledge of factors that positively influence family adaptation can serve as a foundation for interventions to strengthen the family. The findings might also undergird therapeutic modalities
addressing stressor reductions for families who face increased demands related to the transition of their children from adolescence to adulthood.

School nurses and nurses in primary care settings are well-positioned to identify signs that a family of an adolescent with ASD is making ineffective adaptation or is in crisis and, thus, make intervention. The needs of adolescents with ASD require greater amount of parental attention over those of the normally-developing adolescent (Smith et al., 2010). Availability for counseling or support might be challenging for these families. However, the advent of teleconferencing and skyping can greatly expand the nurses’ reach. Interventions that respect the parents’ needs without increasing their burden are important.

This study hoped to improve the application of the RMF (McCubbin et al., 2003) and better address parental needs of children with disabilities, and more specifically in families of adolescents with ASD during this important family life cycle stage transition. This increased understanding will assist nursing and educators to teach the implications of the RMF model of family adaptation.

**Assumptions**

1. Family members of adolescents with ASD experience stress.
2. Family members of adolescents with ASD will answer survey tools honestly and to the best of their ability.
3. IAN members have an adequate level of competency regarding computer technology to answer on-line survey tools.
Limitations

This study was limited by the use of only one sample, members of the IAN community, who were self-selected and provided self-reported data. However, the sample was randomly selected from 3,500 members who reside in all 50 of the United States and are likely to be very representative of the wider United States. Therefore the results of the study should only be generalized beyond the study’s sample of interest with caution.

Summary

The problem of ineffective family adaptation in families of adolescents with ASD is significant for nurses and other health care professionals, especially in psychiatric and mental health support roles. The stressors of daily stressors, uncertainty, and behavior problems may impact the effectiveness of the family adaptation in families of adolescents with ASD, but these relationships heretofore had not been studied. Coping strategies have been found to counterbalance the effects of stressors. However no studies of coping strategies had been conducted in families of adolescents with ASD. The combined effects of the variables on family adaptation had not been investigated in families of adolescents with ASD. These variables are amenable to nursing interventions, especially in the primary care setting. Therefore these factors were selected for this study and the RMF model was chosen as the theoretical framework.

This chapter introduced factors faced by families of adolescents with ASD that might result in less effective family adaptation. The purpose of the study has been stated. The significance of the study has been presented. The variables of daily stressors, uncertainty, severity of behavior problems, and coping have been identified and defined. The assumptions
and limitations have been stated. The RMF which served as a framework for the relationships between the variables and as a foundation for the hypotheses, also, were tested.
CHAPTER II

This chapter, a targeted review of the literature, presents evidence that family functioning, or family adaptation of families of adolescents with autism spectrum disorder (ASD), is influenced by multiple factors including demands unique to this family life cycle stage. The family life cycle stage is based on the age of the child with ASD. For the purposes of this study, families of adolescents will have children ages 13 to 22. The Resiliency Model of Family Adjustment and Adaption (RMF), a family theory which serves as this study’s framework, conceptualizes the family’s adaptive process in response to a solitary crisis or a pile-up of lesser stressors. According to the RMF proposes the four influential components of family adaptation are: a) pile-up of stressors, strains, and family life transitions, b) family resources, c) situational appraisal, and d) problem-solving and coping (McCubbin et al., 2003). This study will investigate the effect each variable, a) daily stressors, b) severity of behavior problems, c) uncertainty, d) coping strategies, has on the adaptation of families of adolescents with ASD. Each variable is drawn from the RFM’s four components and are represented in Figure 1.

Introduction

Although raising an adolescent with ASD involves many challenges, the majority of families remain intact and functional (Gray, 2006; Hartley, 2010). Therefore, it is important to understand which combination of factors contributes to effective family adaptation in families of adolescents with ASD. This chapter will review research literature on each variable in relationship to family adaptation. Except for foundational works, the included research literature was conducted in the last fifteen years. During this timeframe, ASD became a subject of intense research interest and a national funding priority. The NIH, alone, increased its funding for ASD
research five-fold during this transformational period, starting with the late 1990’s (Singh et al., 2009). The reviewed research literature includes work conducted by nurses or other social scientists, with families of adolescents with ASD or conducted with families of children with comparable disabilities. The literature for each variable will be organized by family life cycle stage, in order to contrast differences according to the family life cycle stage, when such differences exist. The reviewed literature will not include basic scientific research.

**Family Adaptation**

Family adaptation is one indicator of family functioning. It is a reflection of the family’s ability to re-establish balance and harmony after upheavals or significant challenges (McCubbin et al., 2003). The majority of research studies reviewed demonstrates statistically significant relationships between the dependent variable of this study, family adaptation, and multiple influences. The influences included: a) the severity of symptoms (Lounds et al., 2007; Magana & Smith, 2006; Smith, Seltzer, et al., 2008; Svavarsdottir et al., 2005), b) socioeconomic resources (Wade et al., 2006), c) family hardiness (Svavarsdottir et al., 2005), d) mental health outcomes (Lounds et al., 2007; Magana & Smith, 2006; Orsmond et al., 2006; Pakenham et al., 2005), e) uncertainty (Warter, 2009), f) pile up of demands (Pakenham et al., 2005; Svavarsdottir et al., 2005; Wade et al., 2006), and g) coping strategies (Lin, 2000; Twoy et al., 2007). The RMF or similar family theories provided the theoretical underpinning of the reviewed studies.

Evidence indicates family adaptation may differ according to family life cycle stage and reflects that parents of adolescents are less effective in achieving or reestablishing balance related to the increased family demands. Lin (2000) found differences in family adaptation according to family life cycle stages. The investigator studied the effects of various coping
strategies and family life cycle stage on family adaptation in 278 families of children with cerebral palsy (CP) in a descriptive, correlational study. For comparison, the families were grouped into family life cycle stages according to the age of the child with CP.

The researcher utilized a modified Family Crisis Oriented Personal Evaluation Scales (F-COPES; McCubbin et al., 2003) to measure coping strategies and the General Functioning subscale of the Family Adaptation Device (FAD) (Epstein, Baldwin, & Bishop, 1983) to measure family adaptation (Lin, 2000). Among the findings, the researcher noted families of school-aged children with CP had higher, or more effective, family adaptation scores than families of adolescents with CP. The researcher explained these findings by stating families of adolescents with CP have increased demands occurring during this family life cycle stage (Lin, 2000).

**Literature on Family Adaption with Parents of Younger Children with Disabilities**

One study has been conducted regarding adjustment or adaptation in families of younger children with disabilities using a general qualitative design. King et al. (2006) collected data from three focus groups, comprised of 15 parents and four service providers of younger children with Down syndrome (DS) or ASD. The themes emerging from the data revealed parents adapted to raising a child with a disability by changing their perspective. They gradually adapted and became stronger because of their experiences. A service provider said of family members of children with disabilities, “They are some of the healthiest and strongest families that I’ve known… [the experience] strengthens the values that were there before” (p. 361).

Two quantitative studies have investigated family adaptation in families of younger children with disabilities or chronic illnesses. They disagreed regarding what factors, if any, influenced family adaptation.
An international, descriptive comparative study investigated factors that influence family adaptation in 129 American and 123 Icelandic parents of children (mean age 3.0 years American and 3.6 years Icelandic) with the chronic illness of asthma (Svavarsdottir et al., 2005). The researchers hypothesized the effects of disease severity and family demands on family adaptation would be moderated by family sense of coherence and family hardiness.

The study found direct relationships between (1) family sense of coherence and family adaptation and (2) family sense of coherence and family hardiness in both samples. Also, there was an indirect relationship between family demands and family adaptation. However, disease severity was not predictive of family adaptation in this sample. The researchers interpreted the findings to indicate family demands associated even with mild asthma prove challenging enough to disrupt family balance and harmony (Svavarsdottir et al., 2005).

In contrast, LoBiondo, Williams, and McGhee, (2004) did not find any factors that influenced family adaptation in a descriptive study that compared two rounds of data collected six years apart with mothers whose children had undergone liver transplantation. The current study explored the variables of uncertainty, stress severity, coping, and family adaptation nearly six years after the original study. In the intervening years, nearly half the children had died. The mean age of the remaining seven children at follow-up was nine and one-half years. The researchers compared the Time 1 and Time 2 data collected with five tools including the Parent Perception of Uncertainty Scales (PPUS) created by Mishel & Epstein (1990), the Family Adaptation Device (FAD) created by Epstein et al. (1983), and three other instruments.

No statistically significant relationships between the variables were observed. The researchers found mothers experienced less mood disturbance and confusion than in the first
study and their coping scores improved. However, changes in family adaptation scores were not found to be statistically significant. This study was limited by small sample size and involved multiple t-tests which increased the chance of a Type 1 error (LoBiondo et al., 2004).

**Literature on Family Adaptation in Younger Children with ASD**

Similarly, quantitative studies of families of school-aged children with ASD conflicted regarding the factors that influence the adaptation process. Pakenham et al. (2005) found several variables predicted family adaptation in 47 families of boys (ages 10 to 12) with Asperger Syndrome (AS). AS is a milder form of ASD, by which the affected individual has normal or above IQ. The researchers used a descriptive, correlational design to test the applicability of the Double ABCX model of family adjustment, a precursor of the RMF (Pakenham et al., 2005). The resulting model was reported as significant ($F_{8, 38} = 7.3, p < .001$) and predicted 61% of the variance in maternal adjustment or adaptation. Maternal adaptation was predicted by increased social support, increased emotional coping, less severe child behavior problems, lower pile-up of demands, more positive appraisal of stress, and passive stress avoidance.

By contrast, nurse researchers Twoy et al. (2007) explored family adaptation and coping. They found no statistically significant differences in family functioning between a sample of 55 parents of children (ages 12 and under) with ASD and norm-referenced adult values published in the F-COPES research instrument’s manual. The researchers attributed this finding to the strength the families of younger children with ASD had acquired as a result of addressing their challenges. Consequently the researchers concluded the parents had a greater ability to face adversity than families of normally-developing children.
Research of the adaptation process in younger children with disabilities including ASD lacks definitive conclusions. By contrast, studies of families of adolescents with disabilities identify the severity of the disorder among several factors that influence family adaptation.

**Literature on Family Adaptation in Parents of Adolescents with Disabilities**

Wade et al. (2006) found severity of injury strongly influenced family adaptation. Their longitudinal, descriptive, multivariate study explored the effects of severity of injury, injury-related burden, psychological distress, life stressors, background, and environmental factors on family adaptation in families of adolescents (mean age 14) who had severe traumatic brain injury (TBI), mild TBI, or orthopedic injuries. The researchers collected data annually and this study reflected the sixth round of data collection. Family adaptation was measured utilizing the General Functioning (GF) scale of the Family Adaptation Device (FAD) created by Miller, Bishop, Epstein, & Keitner (1985).

The results showed at least one-quarter of the parents, regardless of diagnostic group, had family adaptation scores sufficiently elevated that mental health intervention would be appropriate (Wade et al., 2006). Family adaptation was found to be an interaction between diagnostic group, time since injury, and socioeconomic resources. The researchers were surprised to learn that of three diagnostic groups with higher socioeconomic resources, parents of children with moderate TBI had the lowest level of family adaptation. Wade et al. (2006) explained, “The sequelae of injury may be more ‘unexpected’ in children with moderate TBI…and that the child’s difficulties meeting expectations may contribute to … parental adjustment problems” (p. 1080).
Because all diagnostic groups experienced increased levels of distress and dysfunction from previous five rounds of data collection, the researchers speculated that parents might be facing increasing challenges related to raising an adolescent with a long-term disability (Wade et al., 2006). This echoes Lin’s (2000) observations regarding unmet demands associated with the family life cycle stage of adolescence.

Sullivan and Miklowitz (2010), similarly found severity of a disorder strongly influenced family adaptation. They conducted a descriptive, multivariate study investigating the combined effects of family conflict, family cohesiveness, expressed emotions, and severity of the disorder on family adaptation in 58 parents of adolescents (mean age 14.5) with bipolar disorder (BD).

The results showed parents of adolescents with BD had less effective family adaptation than families of children without mental health challenges. Additionally, there was a curvilinear relationship between the severity of the disorder and family adaptation. The most effective family adaptation was reported with families of adolescent with the mildest and the most severe BD. The researchers explained the families of adolescents with moderate BD may misattribute the behavioral manifestations of BD as the adolescent being a defiant or oppositional teenager, rather than to the disorder of BD. The study recommended further study to understand this finding (Sullivan & Miklowitz, 2010).

**Literature on Family Adaptation with Parents of Adolescents with ASD**

No studies have explored family adaptation in families of adolescents with ASD quantitatively. Therefore qualitative studies exploring family adaptation (Fong, 1992; Gray, 2002; Gray, 2003; Gray, 2006), and several quantitative studies investigating maternal well-being in mothers of adolescents and adults with ASD will be reviewed (Baker et al., 2011;
Several qualitative studies focused on parenting adolescents with ASD. Their findings demonstrate family adaptation is a non-linear process (Gray 2002; Lutz, 2008; King et al., 2006; Krajewski, 2005). Lutz (2008) conducted a narrative analysis study, a nursing dissertation, with 16 mothers of adolescent and adult children, in order to understand the process by which they adapted to having a child with ASD. The mothers reported they experienced periods of ups and downs and described the adjustment as falling along a dynamic hope-despair continuum which varied daily. Similarly Krajewski (2005), through his narrative, or auto-ethnography, likened his adaptation to parenting his 29 year old son with ASD to a “rollercoaster ride” (p. 338).

Gray (2002; Gray, 2003; Gray, 2006) also found parents’ hopes that their children would lead nearly normal lives faded over time. Gray’s three articles were all derived from one round of data collection, conducted ten years after an original qualitative study. Parents explained their initial expectations, particularly regarding the child’s communication diminished. As parents gradually came to terms with the permanence of their child’s disability, they developed a deeper appreciation of the child’s positive attributes. One parent stated, “She still brings a lot of joy….that’s the side I focus on… and that helps me get through” (Gray, 2006, p. 975).

**Maternal Functioning in Mothers of Adolescents with ASD**

The findings of four descriptive, longitudinal, correlational studies (Lounds et al., 2007; Magana & Smith, 2006; Orsmond et al., 2006; Smith, Seltzer, et al., 2008) shared common themes with the qualitative studies and reflected that the ASD-demands associated with the transition through adolescence complicates the adaptation process. The studies explored
maternal well-being in families of adolescents with ASD. The data were drawn from the Adolescent and Adult with Autism (AAA) dataset (Seltzer et al., 2003; Shattuck et al., 2007).

The initial AAA dataset included a sample of 450 mothers of individuals with ASD who resided either in Wisconsin or Massachusetts. Data collection commenced in 1998 and continued with three additional rounds of data collection (waves) at eighteen month intervals, ending in 2003. An additional wave of data was collected in 2008. The initial sampling inclusion criteria were: a) mothers of children ages 10 years or older, b) the children were diagnosed with ASD, AS, or pervasive developmental disorder, and c) the children had their diagnosis of ASD confirmed with the Autism Diagnostic Interview-Revised, (ADI-R; Rutter, LeCouteur, & Lord, 2003). At the first wave of data collection, two-thirds of the individuals with ASD were teenagers and lived with their mothers. The majority (92.6%) of the mothers were White, married (78.4%), and worked (66.7%) outside the home (Magana & Smith, 2006; Ormond et al., 2006; Smith, Seltzer, et al., 2008). Each wave collected data regarding numerous variables including individual with ASD’s characteristics, maternal characteristics, and maternal functioning, such as well-being, caregiver burden, and maternal mood (Baker et al., 2011; Seltzer et al., 2003; Shattuck et al., 2007).

**Maternal Mental Health Indicators during the Adolescent Family Life Cycle Phase**

Several indicators of maternal functioning improved during the transition through adolescence. Lounds et al. (2007) compared multiple variables during the four and one-half year interval which represented the individuals with ASD’s transition through adolescence. While maternal depression and pessimism remained stable, maternal anxiety decreased in a statistically significant manner. The warmth of the maternal-child relationship increased significantly. The
individuals with ASD’s behavior problems and physical health remained relatively stable. Although there was a significant decrease in ASD symptoms, there was also a corresponding statistically significant increase in the use of psychotropic medications by the individuals with ASD. Finally, mothers whose adolescents were on the most medications had the greatest pessimism regarding their adolescent’s future (Lounds et al., 2007).

The researchers noted, contrary to their hypothesis, transitioning from high school (completing their formal education), was not associated with an increase in maternal depression. However, the AAA dataset did not measure other stressors and coping strategies. Therefore it is not possible to determine whether the transition from high school resulted in other types of increased demands or how the mothers were able to address the demands (Lounds et al., 2007).

**Comparisons of maternal mental health outcomes.** AAA consortium studies measuring several mental health outcomes of mothers of adolescents and adults with ASD found the mothers compared less favorably to mothers of normally-developing adolescents. Using the AAA dataset, Magana and Smith (2006) compared whether the effects of selected variables differed according to ethnicity between White and Latina mothers of adolescents with ASD. The findings showed White mothers had greater levels of maternal pessimism regarding their adolescent’s future than Latina mothers. Although both ethnic groups expressed satisfaction with having their adolescent child with ASD living at home, 40% of the total group of mothers had clinically significant levels of depression, anxiety, and anger (Magana & Smith, 2006). The researchers, also, compared the data to matched mothers with normally-developing children in the National Survey of Midlife in the United States (MIDUS II) database (Ryff & Davidson, 2010). By comparison, the mothers of adolescents and adults with ASD had statistically higher
levels of anxiety and depression. Researchers concluded that mothers of older children with ASD experience more upheaval and demands than mothers of normally-developing children (Magana & Smith, 2006).

Smith, Seltzer, et al. (2008) found mothers of adolescents with ASD were more impacted by parenting a child with ASD than mothers of toddlers with ASD. The researchers compared several variables including maternal well-being between mothers of 153 toddlers and 201 adolescents with ASD. Data regarding mothers of adolescents with ASD were drawn from the AAA dataset and data regarding mothers of toddlers with ASD from a longitudinal study (Carter et al., 2007).

The researchers found mothers from both family life cycle stages faced difficulties. Toddlers with ASD had greater challenges with social impairments and adolescents with ASD had greater challenges with repetitive behaviors and restricted interests. Although both groups of mothers demonstrated an increased risk of depression, mothers of adolescents with ASD had an elevated level of psychological stress and lower level of maternal well-being when compared to mothers of toddlers with ASD (Smith, Seltzer, et al., 2008). The researchers explained these findings reflect mothers of adolescents with ASD were experiencing increased difficulties associated with the transition of the adolescents into puberty (Smith, Seltzer, et al., 2008).

**Influences on maternal adaptation.** AAA consortium researchers studied the effects of selected variables on maternal adaptation, using proxies of maternal well-being and maternal caregiving strain. Magana and Smith (2006) studied the effects of selected variables on maternal
well-being on White and Latina mothers. They determined ethnicity had little influence on maternal well-being.

By contrast, Ormond et al. (2006) found caregiver strain was influenced by three characteristics of the individual with ASD: age, the severity of behavior problems, and the physical health of the individual with ASD. Caregiver strain was lowest in mothers whose adult children with ASD were in good health, and had the fewest behavior problems. These variables predicted 70% of the variance in caregiving strain. Ormond et al. also found maternal pessimism regarding their child’s future had a direct relationship with maternal caregiving strain.

All the AAA consortium studies noted as a limitation, a lack of diversity regarding gender, socioeconomic, or ethnicity in their samples. As a consequence they encouraged replications with samples more representative of the broader population of families of children with ASD.

**Summary of Family Adaptation Literature**

The majority of literature supported the conclusion that family adaptation is influenced by a variety of factors and its effectiveness may differ based on the family life cycle stage and the severity of child’s ASD or behavioral symptoms. Inconsistent conclusions regarding family adaptation in studies of families of younger children with disabilities, including ASD underscore the need to conduct additional studies to understand the phenomenon of family adaptation. Because studies of adolescents with disabilities including ASD reflect that family adaptation is a challenge related to increased demands, it is important to identify and address these influential factors.
Taken collectively, the extant literature on family adaptation may indicate that parents of adolescents are less effective in achieving balance than parents of other family life cycle stages. However, no studies have been conducted to explore the adaptation of the family system during the family life cycle stage of adolescence. Especially, given the lack of diversity of the included samples, including gender disparities, it is important to conduct additional studies, such as this study, to better understand family adaptation in families of adolescents with ASD.

**Daily Stressors**

The influence of daily stressors on family adaptation has received limited study. However, research of daily stressors has been conducted in both families of normally-developing children and families of children of all ages with disabilities, including ASD and demonstrates their negative influence on mental health and family functioning (Kohn & Macdonald, 1992; Wallander, Pitts, & Mellins, 1990). Kohn and Macdonald (1992) conducted a review of literature on daily hassles or daily stressors. They concluded there was a strong association between daily hassles and an individual’s diminished physical and mental well-being. Similarly, although Wallander et al. (1990) found that major life events did not significantly predict maternal mental health, they noted daily hassles and the impact of a child’s disability-related problems did exert a significant negative influence on maternal mental health. The investigators proposed the mechanism by which daily hassles influenced maternal mental health was to create a pile up of demands (Wallander et al., 1990).

Because families are composed of individual members, daily stressors also influence mental health outcomes of couples and families. Crnic and Greenberg (1990) found that daily stressors in typically-developing children predicted less positive family well-being. Also,
Stoneman and Gavidia-Payne (2006) observed an indirect relationship between daily stressors and marital adjustment. Florian and Findler (2001) similarly found an association between daily stressors and decreased marital adaptation.

**Daily Stressors Literature with Parents of Younger Children with Disabilities**

Only one study was found that included themes related to daily stressors and family adaptation in families of younger children with disabilities. Leyser and Dekel (1990) found daily stressors negatively affected parents of children with disabilities. Using mixed methods, the researchers investigated the adjustment of 82 families of children (mean age 6.2 years) with disabilities in the religious Jewish families in Israel. The children’s disabilities included learning disabilities, intellectual disability (ID), neurological disorders, and ASD.

Parents who reported the greatest impact related to parenting a child with disabilities also reported the greatest number of daily hassles. Impact of parenting a child with a disability was influenced by several factors: increased age of parent, fewer children in the household, and having a male child with a disability. Regarding their adaptation to having a child with a disability, the majority of parents (50%) stated they and the family had good or very good adaptation. Many expressed their belief that God had allowed the situation to happen or God had chosen them for a special purpose: To raise a child with a disability. However, the parents identified challenges such as financial strain, lack of support services, feeling stigmatized, and burden of caring for the affected family member. Also, child’s behavioral difficulties were also mentioned by half of the families as problematic (Leyser & Dekel, 1990).

Similarly, Stoneman and Gavidia-Payne (2006) found that an increased frequency of daily stressors was associated with less positive family accord. These researchers compared
mental health measures with both families of normally-developing children and children (mean age 45 months) with mixed types of disabilities (n = 67) to understand the influence of daily stressors on marital adjustment. The types of disabilities of the children included developmental delay, physical disorders, CP, DS, visual impairment, and ASD.

All families in the study, regardless of the child’s diagnostic category, were negatively impacted by daily stressors. Daily stressors were related to lower daily mood and reduced marital adjustment (Stoneman & Gavidia-Payne, 2006) in parents of children with disabilities, including ASD. Gender-based differences were noted as well. Mothers of children with disabilities reported statistically significantly more daily hassles than fathers. While fathers’ adjustment was influenced only by the number of daily hassles, mothers’ adjustment was predicted by both the number of daily hassles and the fathers’ problem-focused coping. This study demonstrated that the daily stressors in families of children with disabilities served as family stressors. Stoneman and Gavidia-Payne (2006) explained that “the irritation and annoying demands of everyday life…seem small in isolation but are cumulative in their impact” (p. 2).

**Daily Stressors Literature with Parents of Toddlers with ASD**

Rutgers et al. (2007) investigated several variables, including the impact of daily parenting hassles on parental attachment in 89 Dutch parents of toddlers (mean age 26.5 months) with and without disabilities. The researchers compared these variables between five groups of toddlers based on disability category, which were a) high functioning ASD group, b) low functioning ASD, c) intellectually impaired group, d) learning disabled group, and e) the comparison group of normally-developing toddlers.
The study found parents of toddlers with ASD had significantly higher scores of parental daily hassles than parents of normally-developing toddlers. Data analyses also demonstrated an inverse relationship between parental daily hassles and parental efficacy and a direct relationship between parental daily hassles and social support in parents of toddlers with ASD. Because parents of toddlers with ASD faced significant strains and reduced parental efficacy in the early stages of their family’s life, the researchers considered the parents to be at risk for additional future parenting difficulties. Therefore they recommended further research to guide intervention services for parents of children with ASD and other disabilities (Rutgers et al., 2007).

Pottie and Ingram (2008; Pottie et al., 2009) similarly found a statistically significant relationship between daily stressors and mental health outcomes. The researchers investigated the daily stress, coping, and daily mood of 93 parents of children (mean age 7.3 years) with ASD while taking into account personal and situational factors (Pottie & Ingram, 2008). The data were collected over 12 weeks and analyzed by means of multi-level modeling. The three levels were a) within-person, b) between-person, and c) between-families levels. The within-person data analysis reflected the daily variation of coping, stress and mood for each participant. The between-person data analysis calculated the variation between the parental responses in the initial surveys. Finally, the combination of the between-person and between-families data represented the situational factors (Pottie & Ingram, 2008; Pottie et al., 2009).

The researchers utilized a participant-intensive data collection method which resulted in a large amount of missing data. The daily stressors were measured according to Stone and Neale’s (1984) methodology which directs participants to record daily data in a diary format. Participants were instructed to complete and return eight research instruments, including
measurements of daily stressors using a diary twice weekly for three months. The missing data (25%) was accounted for through data modeling.

The majority of the sample were White (87%), married or in a committed relationship (53%), and most parents were employed (all fathers and 53% of mothers). Amongst the findings, the researchers noted an indirect relationship between daily stressors and daily positive mood. Social support was found not to play any positive or negative influential role (Pottie & Ingram, 2008; Pottie et al., 2009).

Studies of parents of younger children with ASD demonstrate that daily stressors have a negative impact on parental mental health outcomes. Two studies of daily stressors were conducted with parents of older children with disabilities and reached similar conclusions (Seltzer, et al., 2009; Smith et al., 2010).

**Daily Stressors Literature with Parents of Adolescents and Adults with Disabilities**

Seltzer et al. (2009) learned daily stressors were associated with physiological stress in 82 parents of adolescents and adults with disabilities. The researchers studied the influence of several variables including daily stressors on physiological stress in middle-aged parents, comparing the data between parents of children (mean age 29) with and without disabilities. Physiological stress was measured as the diurnal (daily) pattern of salivary cortisol. The normal diurnal pattern of cortisol is: (1) rising within 30 minutes of awakening, (2) steadily decreasing throughout the day, and (3) dropping off at bedtime. Failure for the cortisol to decline may indicate the individual continues to engage in external demands (Seltzer et al., 2009). The authors suggested that chronic exposure to stress, such as grieving or psychological trauma, may lead to persistently elevated levels of cortisol (Seltzer et al., 2009).
Both parents of adult children with disabilities and matched parents of adult children without disabilities were initially drawn from the second wave of data collection of the National Survey of Midlife in the United States (MIDUS II) (Ryff & Davidson, 2010). The adult children had disabilities including: attention deficit hyperactivity disorder (ADHD), BD, schizophrenia, depression, DS, and others (48.7%). Both groups of parents were asked to collect daily samples of saliva at four distinct points during the day for eight days. During the same eight day period, they also participated in daily telephone interviews to measure their time use, exposure to daily stressors, exposure to daily positive and negative events, their affect, and their physical symptoms (Seltzer et al., 2009).

The results showed parents of children with disabilities had statistically significantly greater number of daily arguments, a greater number of daily avoided arguments, more numerous reports of negative affect, and more numerous reports of daily stressors than the comparison parents. Although both groups had a morning rise in cortisol, the parents of children with disabilities had a less sharp, or more flat, decline in the cortisol level throughout the day. Also, the parents of adult children with disabilities had statistically significantly less drop off, or less deactivation, of the cortisol at the end of the day (Seltzer et al., 2009).

Seltzer et al. (2009) concluded both mothers and fathers of adult children with disabilities have increased exposure to daily stressors, which exerted negative physiological impact. Because both samples were 59% female, 96% White, and 79% married, and had a reported annual income of $75,000 or above, the researchers called for additional research due to the homogeneity of the sample. They also encouraged additional study to learn what may buffer
parents from daily stressors and whether the daily stressors vary according to diagnostic category of disability.

**Daily Stressors Literature with Parents of Adolescents and Adults with ASD**

Research conducted with mothers of adolescents and adults with ASD similarly demonstrated the mothers had higher levels of daily stressors, and were more impacted by daily stressors than other mothers of adult children without ASD. For example, using the same methodology as Seltzer et al. (2009), Smith et al. (2010) found mothers of adolescents and adults with ASD were more affected by daily stressors than mothers of normally-developing adolescents and adults. The researchers compared several variables including daily stressors between the groups of mothers. The sample of mothers of adolescents and adults with ASD (n = 98) was selected from the fifth wave of data collection of the AAA dataset (Seltzer et al., 2003; Shattuck et al., 2007). Comparison mothers were selected from the MIDUS II dataset (Ryff & Davidson). The data were analyzed using multilevel modeling (Smith et al., 2010).

The analysis demonstrated mothers of adolescents and adults with ASD were nearly three times more likely to report a daily stressful event than their comparison counterparts. The stressful events included arguments, avoided arguments, work-related stressors, home-related stressors, and stressors related to their support network. Also, mothers of adolescents and adults with ASD reported spending significantly more time caring for their child with ASD and experiencing more child-related intrusions during their work day than their counterparts. Additionally, mothers of adolescents and adults with ASD reported fewer negative and positive emotions and generally were less reactive to the number of daily stressors. The researchers interpreted the mothers’ blunted emotional responses were similar to persons experiencing post-
traumatic stress disorder (PTSD). PTSD is a condition that occurs in response to an overwhelming event. The symptoms may include anxiety, repetitive reliving of the event, nightmares, and recurrent thoughts related to the event (United States Department of Veterans Affairs, 2013). The researchers concluded that two decades or more of daily life stressors, associated with caring for a child with ASD, had a cumulative negative effect on maternal well-being (Smith et al., 2010).

**Summary of Research Literature on Daily Stressors**

A limited number of studies have been conducted on daily stressors. They demonstrated that daily stressors have negative influence on maternal and family mental health outcomes in parents of younger children with disabilities including ASD. Similarly, daily stressors negatively influenced the well-being and affect of parents of adolescents and adults with disabilities including ASD (Seltzer et al., 2009; Smith et al., 2010). However no studies reviewed have measured the impact of daily stressors on family adaptation in families of adolescents with ASD. Therefore additional studies are needed to address this gap in the literature.

**Severity of Behavior Problems**

**Patterns of Behavior Problems in Children with ASD**

Research findings regarding patterns of behavior problems in families of children with ASD are inconclusive regarding whether behavior problems worsen (Lecavalier et al., 2006), improve (Bopp 2006; Osborne & Reed, 2009a; Osborne & Reed, 2009b), or remain relatively unchanged (Benson, 2006; Benson & Karloff, 2008). Nevertheless, the literature demonstrates individuals with ASD have behavior problems that persist throughout the lifespan (Baker et al., 2011; Seltzer et al., 2003; Turner, 1999). For example, Seltzer et al. (2003) investigated long-
term patterns of behavior problems in individuals with ASD by comparing AAA data. Of the data, they formed an adolescent cohort (mean age 15.7 years) and an adult cohort (mean age 31.6 years).

The adult cohort performed better than the adolescent cohort in all the studied behaviors. However, only a third of the adults had significant and meaningful improvements in their behavior problems. The remainder continued to have difficulties with the ability to interact appropriately in social situations. Three-quarters of the adult cohort had persistent challenges with offering comfort to others and three-quarters of all adults experienced discomfort in another individual’s company (Seltzer et al., 2003).

Also, in the reviewed studies, individuals with ASD had more behavior problems than normally-developing individuals (Osborne & Reed, 2009a; Osborne & Reed, 2009b). Correspondingly, parents of children with ASD had a higher level of anger and depressed mood related to the individual’s behavior problems than parents of normally-developing children (Benson, 2006; Benson & Karloff, 2008; Lecavalier et al., 2006).

**Severity of Behavioral Problems as a Negative Influence on Parental Outcomes**

Whether or not ASD-related behavior problems improve over a lifespan, extant literature demonstrates that behavior problems exert a negative influence on mental health outcomes in families of children with ASD, including marital adjustment, parental mood, parental or caregiver stress. Although no studies have reported the influence of the severity of behavior problems on family adaptation, research literature demonstrated there was a relationship between the increased severity of behavior problems in adolescents and adults with ASD and lower levels of maternal well-being (Seltzer et al., 2010).
**Marital adjustment.** In addition to daily stressors, Stoneman and Gavidia-Payne (2006) measured the impact of child behavior problems on the dependent variable of marital adjustment. Comparisons were made between families of normally-developing children (mean age 45 months) and those of children with several types of disabilities (n = 67 each). The researchers found behavior problems were more prevalent in children with disabilities, including ASD. These behavior problems were a strong predictor of less effective marital adjustment (Stoneman & Gavidia-Payne, 2006).

**Parental mood.** Three studies found severity of behavior problems is related to increased levels of negative parental mood. Benson (2006) and Benson and Karloff (2008) investigated the impact of child symptom severity on parental depressed mood and stress proliferation (pile up of stressors) in parents of 68 children (mean age 7.2) with ASD. The study found the level of parental depression and stress proliferation was directly related to child symptom severity. Although the majority of participants experienced no change in level of anger or depressed mood, there was a marked decrease in stress proliferation (pile-up of stressors) over the course of the study (Benson, 2006; Benson & Karloff, 2008).

Similarly in a study of 93 parents of school-aged children with ASD (mean age 7.3 years), Pottie et al. (2009) found children’s disruptive behaviors predicted parental daily negative mood. Amongst the many variables including behavior problems and parental mental health indicators Pottie et al. investigated, unexpectedly social support was found not to predict daily parental mood.

Hastings and Brown (2002) also found an indirect relationship between children’s behavioral problems, parental efficacy, and parental mood in 46 parents of older school-aged
children with ID and ASD (mean age 12.15). The total score on the Daily Behavior Checklist (DBC), a measure of challenging behavioral problems, explained 47% of the mother’s depression and 54% of the mother’s anxiety.

**Parental stress.** Several studies demonstrated the relationship between the behavior problems of children with ASD and parental stress. Clark (2008) observed an association between increased severity of behavior problems and increased parental stress in families of children with ASD. The researcher conducted a web-based, dissertation study that explored the influences of several variables including behavioral difficulties on parental stress in 225 parents of children with ASD and 34 parents of normally-developing children (mean age of 9.5 years for both groups). Severity of behavior difficulties was measured by a seven-point scale that was included on the background information form. The study was posted on Survey Monkey, an internet survey website, and participants were recruited by emailed requests to chapters of Autism Society of America and other informal recruiting efforts.

The results showed parents of children with ASD had statistically significantly more parental stress than parents of normally-developing children. Also the increased behavioral difficulties were directly related to parental stress in parents of children with ASD (Clark, 2008). The results did not demonstrate any gender-based differences in either group of parents. Because there was a disproportionately large number (95%) of mother participants, the results were limited in their ability to be generalized to a broader population (Clark, 2008).

Bopp’s (2006) dissertation study investigated the interrelationships between child behavior problems, coping, life events, and parental stress and was a secondary analysis of a database of parents of 70 children (mean age at baseline 4.2 years) with ASD in British
There was a statistically significant decrease in children’s acting-out behaviors and stereotypical behaviors over the study’s two year timeframe. These were related to a statistically significant decrease in maternal stress. Also the researcher noted parents of children with the greatest level of acting-out behavior had the highest level of stress (Bopp).

Osborne and Reed’s (2009a and 2009b) study had similar findings in two rounds of data collections with two different samples. The first sample included 65 children (mean age of 3.4 years) and the second sample included 83 children (mean age of 8.8 years). Over a nine to ten-month period, there was a statistically significant reduction in behavior problems in children with ASD. These reductions were related to a statistically significant decrease in parental stress (Osborne & Reed, 2009a; Osborne & Reed, 2009b).

In contrast with the three preceding studies (Bopp, 2006; Clark, 2008; Osborne & Reed, 2009a; 2009b), Lecavalier et al. (2006) observed increased severity of behavior problems and increased caregiver stress over the course of a school year. The researchers investigated the variables of behavior problems and social competence in 293 school-aged children, ranging from three to eighteen (mean age 9 years) with ASD, to determine their influence on caregiver stress in teachers (n = 98) and in parents (n = 253). Similar to the three preceding studies (Bopp, 2006; Clark, 2008; Osborne & Reed, 2009a; Osborne & Reed, 2009b), the researchers found an association between the behavior problems of children with ASD and caregiver stress. Also parents and teachers of children with the highest levels of behavioral problems, including disruptive behavior and rule-breaking behavior, had the highest level of caregiver stress. The researchers encouraged replication studies to better understand their conclusions, which were at odds with other similar research (Lecavalier et al., 2006).
Maternal Outcomes related to Behavior Problems in Mothers of Adolescents with ASD

A limited number of studies regarding the severity of behavior problems and their effects on mental health outcomes have been conducted with mothers of adolescents with ASD. The studies demonstrated the well-being of mothers of adolescents and adults with ASD is negatively influenced by the severity of behavioral problems (Baker et al., 2011; Greenberg et al., 2006; Lounds et al., 2007; Seltzer et al., 2010; Smith, Greenberg, et al., 2008). For example, drawn from wave two and three of the AAA dataset, Smith, Greenberg, et al. (2008) observed a relationship between the variables of maternal warmth and behavior problems in adolescent and adults with ASD. The warmth of the mother-child relationship was measured utilizing expressed emotion as obtained from a mother’s five-minute speech sample. The analysis showed an association between greater warmth of the maternal-child relationship and reduction in behavioral problems.

Using a similar longitudinal, cross-lagged design and similar sample (Smith, Greenberg, et al., 2008), Greenberg et al.’s (2006) study found an inverse relationship between warmth of maternal-child relationship and severity of behavioral problems in adolescents and adults with ASD. Mothers with the highest level of negative expressed emotion reported the greatest number of behavior problems in their adolescent and adult children with ASD.

In 2010, Seltzer et al. investigated the relationships between behavior problems, ASD symptoms in adolescents and adults with ASD, and maternal well-being, as reflected by the diurnal pattern of cortisol levels. As an extension of their 2009 study of parents of adolescent and adult children with disabilities, Seltzer and colleagues (2010) investigated these variables exclusively with mothers of adolescents and adults with ASD. Similar to the broader study,
Seltzer et al. (2010) found that mothers of adolescents and adults with ASD have altered diurnal patterns of physiological stress responses. The mothers of adolescents and adults with ASD had a normal morning rise of cortisol but a significantly more flat decrease in the level of cortisol throughout the day. However, neither mother’s reports of daily stressors or reported child behavioral problems alone predicted the daily cortisol level. Instead it was predicted by an interaction of the two variables. Mothers of adolescents and adults with ASD, whose children manifested an aberrant behavior problem, had a higher stress response than mothers who reported chronic behavior problems in their adolescent and adult children with ASD. The researchers explained after a lifetime exposure to stressors such as behavior problems, mothers of adolescents and adults with ASD have an altered physiological response to stress, similar in nature to PTSD (Seltzer et al., 2010).

Lounds et al. (2007), using data drawn from wave three and wave four of the AAA dataset, measured the changes in behavior problems over the eighteen month period and the influence of these changes on maternal well-being. The researchers reported, in general, behavior problems decreased over time. However, over a third of the parents reported worsening behavior problems, and nearly a quarter reported no improvements in behavior problems. During the study’s timeframe, there was no statistically significant change in maternal well-being. Additionally, the level of maternal well-being was significantly lower than comparison mothers of normally-developing adolescents and adults with ASD (Lounds et al., 2007).

Baker et al. (2011) similarly found in spite of improvement in behavior problems in individuals with ASD, mental health indicators in mothers of adolescents and adults with ASD did not improve in corresponding manner. By examining the complete ten-year AAA dataset
spanning from 1998 to 2008, researchers compared the trajectories of several variables, including behavior problems, ASD symptoms, and maternal well-being. Consistent with other AAA studies (Greenberg et al., 2006; Lounds et al., 2007; Smith, Greenberg, et al., 2008), Baker and colleagues’ results demonstrated that over time ASD symptoms improved and the severity of behavioral problems in individuals with ASD remained unchanged. Also, although mothers’ anxiety improved over the study period, mothers’ depressive symptoms remained unchanged, even though the majority of the adult children’ moved away from the families’ residences (Baker et al., 2011). Although anxiety decreased after the adolescent moved outside the home, mothers’ level of stress remained significantly elevated especially in comparison to mothers of normally-developing children. The researchers concluded there may be a long-lasting effect of stressful parenting which may result in reduced maternal well-being (Baker et al., 2011).

**Summary of Research Literature on Behavioral Problems**

Whether the pattern of behavioral problems in individuals with ASD improves over the lifespan, extant literature demonstrates behavioral problems persist into adulthood. Maternal mental health issues likewise persist, even after the individual with ASD has left the home (Baker et al., 2011). Also research literature demonstrates the severity of behavior problems is a stressor and is associated with negative parental mental health outcomes. However the generalizability of these studies is limited by the sample’s lack of diversity (Baker et al., 2011; Greenberg et al., 2006; Seltzer et al., 2010; Smith, Greenberg, et al., 2008). For example, no studies have investigated the relationship between the severity of behavior problems in adolescents with ASD and mental health outcomes of fathers of adolescents with ASD. Also because no studies have examined the severity of behavior problems in relationship with family
adaptation in families of adolescents with ASD, additional research should be undertaken to address these gaps in the literature.

**Uncertainty**

Research literature demonstrates uncertainty is associated with negative mental health outcomes, such as depression and anxiety (Holm et al., 2008; McCormick, 2002; Santacroce, 2003; Santacroce, 2001). Yet limited research has been conducted regarding the influence of uncertainty in families of children with chronic illnesses or disabilities, including ASD (Dodgson et al., 2000). For example, Skaggs and Barron (2006) proposed the mechanism by which uncertainty exerts its negative influence is by hindering an individual’s appraisal, or the meaning-making process. According to the RMF, individual or situational appraisal is crucial to effective adaptation to a challenging situation. In several qualitative studies, parents of adolescents with ASD reported difficulties with appraisal or reported sources of uncertainty that serve as stressors (Fong, 1992; Gray, 2006).

**Studies regarding Uncertainty in Parents of Younger Children with Disabilities**

Parents of children with disabilities of DS and ASD in King et al.’s (2006) study discussed their experiences with uncertainty. Parents reported experiencing feelings of ambiguity and a lack of control when initially learning their child’s diagnosis. This sense of lost control prompted parents to reexamine their beliefs. Eventually their transformed spiritual beliefs and hope empowered the parents to address their difficulties.

Cronin (2004) found similar themes related to uncertainty in interviews with 22 mothers of children with ADHD (mean age 9) and 22 mothers of children with CF (mean age 11). Mothers of children with both disorders reported the unpredictability of the child’s symptoms
disrupted family routines and hindered family communication. This triggered feelings of chaos and uncertainty. Mothers discussed another source of uncertainty was their worries about their children’s ability to establish future independent living.

Garwick et al. (2002) found uncertainty was a stressor for parents of children with chronic illness and disabilities. The researchers investigated the relationship between perceived severity of illness and family distress in 99 families of children (mean age 9 years) with chronic health care needs, including cancer, cardiac problems, and developmental disabilities. The analysis showed the more unpredictable the child’s symptoms, the greater degree of distress the parents experienced. There was also a direct relationship between the unpredictability of the child’s future and family disruptions and a direction relationship between the unpredictability of the child’s future and mothers’ emotional burden (Garwick et al., 2002).

Building on these results, Holm et al. (2008) found uncertainty impacted the physical health of 228 parents of children with chronic health care needs, including ASD. They investigated the effects of uncertainty in several child-related variables negatively influenced several co-dependent variables including the a) parents’ psychological symptoms, b) the parents’ energy level, and c) the parents’ physical symptoms. While there was a direct relationship between the degree of mothers’ uncertainty and increased level of negative physical symptoms, such a relationship was not evident for fathers. Researchers recommended replication studies with a more diverse sample (Holm et al., 2008).

**Qualitative Studies of Uncertainty in Families with ASD**

Similar to King et al. (2006) and Cronin (2004, themes related to uncertainty emerged in Cashin’s (2003) study regarding the experience of parenting a child with ASD. Cashin
conducted a hermeneutical phenomenological qualitative exploration guided by Van Manen’s (1990) methodology. Van Manen’s approach directs the researcher to explore a phenomenon as a lived experience utilizing six interrelated research activities (Creswell, 2007). From interviews with nine parents of younger children (ages 4 to 10 years) with ASD, the researcher constructed a framework to serve as a launching point for four focus groups.

Parents reported their child’s insistence on sameness of routine was fueled by the child’s attempt to reduce uncertainty and unpredictability. Cashin (2003) also found because their children find the world bewildering, or feel they are “drowning in the world” (p. 94), the children “grasp a control afforded by predictability” (p. 196). In response, parents of children with ASD strove to eliminate uncertainty for the child through careful planning. However, this resulted in narrowing or “shrink[ing]” (p. 196) their world. Parents also reported concern about the future, especially the impact of the parent’s death, was an additional stressor.

Several qualitative studies involving families of adolescents with ASD also found uncertainty an emergent theme in the data analysis. Similar to Cashin’s study, parents of adolescents with ASD reported several sources of uncertainty (Fong, 1992; Krajewski, 2005; Lutz, 2008). For example, Fong (1992) explored the experience of parenting an adolescent with ASD, utilizing Colaizzi’s (1978) empirical, transcendental phenomenology. The aim of this technique is to perceive the phenomenon of interest, as through the participant’s eyes (Creswell, 2007). Accordingly, Fong interviewed eight parents and amongst the findings the researcher learned parents’ daily lives were impacted by uncertainty. The unpredictable behavioral manifestations of the participants’ adolescents required hyper-vigilance and even impeded the
simple act of taking a daily shower. Parents’ worries about their adolescent’s ability to function independently in the future, also served as a sources of stress (Fong, 1992).

Similarly, Lutz (2008) found themes related to uncertainty while exploring the journey toward adaptation in mothers of adult children with ASD. Lutz (2008) stated, “Unremitting uncertainty maintained a constant presence in the families’ lives as the individual with autism aged” (p. 151). Mothers expressed their initial experiences of uncertainty occurred when they first suspected their children had ASD, and again at the time of their children’s initial diagnosis. They also experienced uncertainty when deciding the best method of treatment for their children, and when contemplating the children’s future as an adult.

Furthermore, Krajewski (2005) discussed his experience with uncertainty as a father of an adult child with ASD (age 29 years). He similarly voiced his concerns regarding his son’s future and how the son would function without him. He stated, “It has been difficult for me to face the possible future reality” (p. 344). “It’s all fearful. What will happen to our son when I die?” (p. 342).

**Quantitative Studies of Uncertainty in Parents of Children with ASD**

Several quantitative studies found uncertainty negatively impacted parents of children with ASD. Wong and Heriot (2007) found parents of children with ASD and other neurological disorders experienced uncertainty and lacked hopefulness regarding their child’s future. The researchers conducted a descriptive correlational study to compare the concept of vicarious futurity (VF) between 22 parents of children with ASD (mean age 7 years) and seven parents of children with childhood dementia (CD). They also compared these variables between all the parents of children with neurological disabilities and 296 parents of normally-developing
children. Parents of all children with neurological disabilities experienced less hopefulness and greater despair regarding their children’s future than did the parents of normally-developing children. Wong and Heriot (2007) recommended additional studies to confirm these results, especially because the study was limited by small sample size (n= 22 and n = 7).

Smith, Seltzer, et al. (2008) viewed uncertainty as a stressor in a study comparing maternal well-being between mothers of toddlers and mothers of adolescents. Researchers noted that mothers of adolescents with ASD more often used emotion-focused coping than mothers of toddlers with ASD. The researchers concluded the findings represent a sense of lost control and uncertainty which stemmed from the child’s increased physical size. This increased size, associated with the pubertal growth spurt, diminished the effectiveness of managing the child’s behavioral problems in a physical manner. Smith, Seltzer, et al. (2008) stated, “Emotion-focused coping is often employed when there is uncertainty associated with a stressor” (p. 886) and when a person senses a loss of situational control (Smith et al.).

Finally, Warter’s (2009) nursing dissertation study determined uncertainty had a strong influence on family adaptation in families of children with ASD. The investigator conducted a descriptive correlational, cross-sectional study with 207 parents of children with ASD (mean age 10 years). The purpose was to investigate the combined effects of a) selected family demand variables: perceived severity of the child’s ASD and uncertainty, and b) family protective variables: optimism, mastery beliefs, and control beliefs on family adaptation. The researcher selected family quality of life as a measure of family adaptation.

The findings demonstrated an indirect relationship between uncertainty and family quality of life. Uncertainty predicted 22.8% of the variance in family adaptation. While
optimism and sense of coherence each served as partial mediators for the variables of uncertainty and family adaptation, control beliefs had no mediating effect (Warter, 2009).

**Summary of Uncertainty Literature**

Limited attention has been given to the influence of uncertainty on mental health outcome in families of children with disabilities including ASD. Extant literature demonstrates uncertainty has a negative influence on parental outcomes including diminished physical health, parental stress, distress, and less effective family adaptation.

Although Smith, Greenberg, et al. (2008) found mothers of adolescents and adults with ASD experience uncertainty related to the “unpredictable behavior problems associated with autism” (p. 877), no quantitative studies were found that investigated the variable of uncertainty on maternal or family outcomes in families of adolescents with ASD. Warter (2009) found an indirect relationship between uncertainty and family functioning in families of school-aged children with ASD. However, no studies were reviewed that studied the influence of uncertainty on family adaptation in adolescents with ASD. Additional research is needed to address this gap in the literature.

**Coping Strategies**

Few quantitative studies have been conducted with the singular purpose of investigating the effectiveness of coping strategies utilized by parents of children with ASD (Hastings et al., 2005; Luther et al., 2005; Pisula & Kossakowska, 2010; Twoy et al., 2007). However, several quantitative studies of parents of children with ASD have included coping strategies as one of several investigated variables (Altieri & von Kluge, 2009; Bopp, 2006; Lee, 2009; Pakenham et al., 2005; Pottie et al., 2009; Pottie & Ingram, 2008).
No empirical studies have investigated the utilization of coping strategies on family outcomes in families of adolescents with ASD. Therefore, what has been published regarding the use of coping strategies in families of adolescents with ASD builds on the coping literature from families of younger children with ASD and from several qualitative studies on the parenting experiences of parents of adolescents with ASD (Lutz, 2008; Fong, 1992; Gray, 2002; Gray, 2003; Gray, 2006; Krajewski, 2005).

**Coping Differences by Family Life Cycle Stage**

Study findings disagree about whether coping differs according to family life cycle stage in families of children with disabilities including ASD. Two studies found such differences and (Lin, 2000; Smith, Seltzer, et al., 2008) and one study did not (Hastings et al., 2005).

Lin’s (2000) study found statistically significant differences in the use of coping strategies between families of children with CP according to family life cycle stages. The researcher found families of preschool children with CP used positive appraisal more often than families of school-aged children and more often than families of young adults with CP. Also, families of pre-schoolers with CP coped more often by positive social support than families of young adults with CP. Additionally, while families of younger children with CP managed their stress more often by drawing on outside-the-family support, families of adolescents with CP less often used such external support and were more self-reliant. Finally, families of school-aged children with CP had better coping scores than families with adolescents with CP. Lin reasoned, although parents of adolescents with CP had learned to manage their situation over the course of time, they were facing new challenges associated with the onset of puberty. Lin further reasoned these challenges strained the effectiveness of past learned coping behavior.
Smith, Seltzer, et al. (2008) similarly detected statistically significant differences in coping when comparing the coping of mothers of toddlers with ASD and mothers of adolescents and adults with ASD. Mothers of adolescents and adults with ASD more often used emotional-coping strategies, especially behavioral disengagement and emotional venting, than did mothers of toddlers with ASD. The researchers concluded this may reflect a period of increased stress related to the transition from childhood to adulthood in families of adolescents with ASD.

By contrast, Hastings et al.’s (2005) study of coping strategies found no differences according to family life cycle stage. The researchers studied coping strategies according to the age of the child and by gender of the parent in two samples of parents of children with ASD. Sample 1 included 26 mothers and 20 fathers of school-aged children and Sample 2 included 48 mothers and 41 fathers of pre-school children. The mean age of the children of Sample 1 parents was 12.15 years and of the children of Sample 2 parents was 37 months. There were no statistically significant differences between coping strategies between the parents of preschool and school aged children. However, nearly than half of the school-aged children lived away at boarding school, lessening the impact of caring for a child with ASD and parental stress (Hastings et al., 2005).

Hastings et al. (2005) also found parents of children with ASD most often coped by cognitive reframing. The researchers explained cognitive reframing, a type of emotion-focused coping, “may be one of the only effective coping strategies under extreme conditions [such as ASD] where it is very difficult to act directly to reduce the impact of a stressor” (p. 386).
Qualitative Literature of Coping Strategies used by Parents of Younger Children with ASD

Cashin (2003) and King et al. (2006) found themes related to parental coping in parents of children with disabilities, including ASD. Cashin (2003) found parents cope with the challenges of raising a child with ASD by becoming overly rigid and overly structured. As previously discussed, in regards to adapting to a child with ASD, the more complex the child perceived their world, the more the parent coped by “retreat[ing] to sameness and routine” (p. 185). The researcher viewed this approach as problematic because it perpetuates the children’s exposure to an ever narrowing range of experiences.

In King et al.’s (2006) qualitative study, parents coped by reappraising their beliefs. They expressed that initially they experienced feelings of sadness “due to lost dreams” after learning of their child’s disability (p. 364). One parent stated, “It [the disability] completely turns your life upside down. I had plans, I wanted my child… to be happy but I wanted … [my child] to be accomplished” (p. 358). Eventually, parents reported they stopped “trying to fix the child” (p. 364) and gradually accepted their child’s situation.

Quantitative Literature of Coping used by Parents of Younger Children with ASD

Similar to King et al. (2006) the parents of children with neurological disabilities in Wong and Heriot’s (2007) experienced less hopefulness, or increased despair regarding the child’s future than parents of typically-developing children. The researchers stated parents had difficulty maintaining hope for their child. This was “due to the loss of expectations they originally had…due to conditions that have no cure and as the result of setbacks in their child’s progress” (Wong & Heriot, 2007, p. 1838).
Several studies (Altieri & von Kluge, 2008; Bopp, 2006; Lee, 2009; Pakenham et al., 2005; Pisula & Kossakowska, 2010; Pottie & Ingram, 2008) compared the use of coping strategies between diagnostic groups or according to gender. In general, the use of coping strategies reduced parenting stress in parents of younger children with ASD. Researchers found some strategies were more effective than others in reducing stress or improving mental health outcomes (Altieri & von Kluge, 2008; Bopp, 2006; Pakenham et al., 2005; Pottie & Ingram, 2008). Conversely, some types of coping strategies were associated with negative mental health outcomes (Lee, 2009; Pakenham et al., 2005; Pisula & Kossakowska, 2010). Also, several studies also investigated the effectiveness of problem- and emotion-focused coping strategies (Pakenham et al., 2005; Pisula & Kossakowska, 2010; Pottie & Ingram, 2008).

Bopp’s (2006) dissertation study of mothers of young children with ASD (mean age 4.2 years) found that greater use of problem solving strategies was associated with a greater decrease in parental stress over the course of two years. Conversely, mothers with the greatest number of negative life stressors had less reduction in parenting stress over two years.

Pisula and Kossakowska (2010) investigated the use of coping strategies and their influence on Polish parents’ sense of coherence (SOC). They also compared these variables between 24 parents of children (mean age 4.2 years) with ASD and 34 parents of normally-developing children (mean age 4.2 years). The analyses showed parents of children with ASD more often used escape-avoidance strategies and emotion-focused coping than parents of normally-developing children. However, these emotion-focused strategies were found to be beneficial in addressing stress. Emotion-focused coping and escape-avoidance coping strategies were related to an increased SOC in parents of children with ASD. Similar to Hastings et al.
(2005), Pisula and Kossakowska (2010) interpreted these findings to show the emotion-focused coping may be an effective strategy when there is no way to modify the situation.

Pottie and Ingram’s (2008) study also compared the efficacy of problem versus emotion-focused coping. They measured the influence of several variables including coping strategies on the daily mood of parents of children (mean age 7.3 years) with ASD. The study found no gender-based differences in coping strategies, but did find several specific coping strategies were more effective than others. The following coping strategies were associated with improved daily mood: a) seeking support, b) positive reframing, c) problem-focused coping, d) emotional regulation, and e) compromise. By contrast, several coping strategies predicted decreased daily positive mood: a) escape, b) withdrawal, c) worrying, d) blaming, and e) helplessness. The study also provided a corollary to the findings of Hasting and Brown (2002) and Pisula and Kossakowska (2010). Problem-focused coping, long thought to be a superior type of coping (Lazarus & Folkman, 1984), was not effective in addressing daily negative parental mood.

Using a family systems’ orientation, Altieri and von Kluge (2009) also compared coping strategies, family cohesion and adaptability, and satisfaction with family functioning between mothers and fathers of children with ASD (mean age 7.5 years). The study found only one statistically significant gender-based difference in coping: Mothers more often coped by acquiring social support in times of crisis more often than fathers did. Small sample size (n = 26) may explain the lack of many statistically significant findings.

Similarly Lee (2009) compared coping and family adaptation between 48 parents (24 couples) of children with high functioning ASD (HFASD) and 26 parents (13 couples) of normally-developing children (ages 6 to 13). The results showed two statistically significant
gender differences between the coping of mothers and fathers of children with HFASD. First, mothers of children with HFASD had higher levels of anxiety than did fathers of children with HFASD. Second, mothers of children with HFASD coped most often by seeking social support, accepting social support, and utilizing spiritual resources than fathers did.

Finally Pakenham et al. (2005) similarly studied the effects of multiple variables, including coping strategies, on maternal adjustment in mothers of older school-aged boys with AS (mean age 12 years). The researchers found significant relationships between several variables. First, coping strategies had a counterbalancing influence on maternal depression and maternal anxiety. The use of coping strategies accounted for nearly 25% of the variance in maternal adjustment. Secondly, some coping strategies were not beneficial. Mothers who coped most often by using behavioral disengagement had higher levels of emotional distress. Those mothers who most often coped by seeking emotional support had lower levels, or less effective, maternal adjustment. Finally, similar to Pottie and Ingram (2008), the researchers observed no association between problem-focused coping and improved maternal adjustment. The researchers called for additional research to better understand the findings.

**Comparisons of Coping Strategies with Parents of Normally-developing Children**

Several studies compared the use of coping strategies between parents of children with ASD and parents of normally-developing children. The results were inconclusive regarding which group has more effective use of coping strategies. For example, Lee (2009) additionally compared coping strategies used by parents of children with HFASD and parents of normally-developing children. Parents of children with HFASD had lower levels of optimism and self-esteem. They also (a) made less use of cognitive reframing and social supports, (b) made greater
use of spiritual coping, and (c) made increased use of formal supports than did the comparison parents. However, these results are at odds with studies conducted by nurses Luther et al. (2005) and Twoy et al. (2007).

Twoy et al.’s (2007) study of parents of school-aged children with ASD (mean age 10 years) found the parent participants had better coping and family adaptation scores than the norm-referenced values. Parents of children with ASD more often used cognitive reframing and spiritual coping than did the norm-referenced adult values as published in the F-COPES instrument’s manual. Also fathers of children with ASD had higher total coping scores than mothers of children with ASD.

Similarly Luther et al.’s (2005) study found no significant difference between coping in families of school-aged children with ASD (mean age 10 years) and the norm-referenced families. The results showed parents of children with ASD utilized cognitive reframing and sought out community support more often and less often coped by spiritual support than the norm-referenced adult values as published in the F-COPES instrument’s manual.

The research by Twoy et al. (2007) and Luther et al. (2005) may not adequately explain the coping and family adaptation in families of school-aged children with ASD. These two quantitative studies were severely limited by small sample size (n = 55 and n = 18, respectively). Also both studies utilized the norm-referenced group data published with the F-COPES instrument’s manual that was originally studied 30 years ago. With the dynamic changes in family composition and family demands in the last several decades, the norm-referenced group may no longer serve as an ideal comparison group (Luther et al., 2005).
Coping Strategy Literature with Parents of Adolescent and Older Children with ASD

Several qualitative studies have explored the experiences of parenting adolescents or older individuals with ASD and found they utilize a variety of coping strategies. Similarly to King et al.’s (2006) findings with younger children with ASD, cognitive reframing or appraisal was a frequently reported strategy for families of older children.

The mothers in Lutz’ (2008) study described the use of cognitive reframing in their “journey towards adaptation” (p. vi). Mothers reported over time they experienced a loss of dreams. One mother stated, “We’ve gotten more realistic…all those hopes and dreams…they’ve fallen by the wayside… [you try] …to let go of your hopes” (p. 150). Mothers coped with their loss by “[re]defining and appreciating their lives …and [they] ultimately changed their expectations and revised their goals and their dreams” (p. 153).

Krajewski’s (2005) autoethnography had a similar theme of coping by letting go of dreams and eventual acceptance. He stated at a certain point his focus shifted from sadness for lost dreams to developing a positive outlook regarding his son, “I replace[d] my initial dreams for him into new ones” (p. 341).

The parents in Fong’s (1992) study described additional methods of coping including cognitive reframing. “We’ve widened our vision…being more tolerant. Things I used to worry about are irrelevant…. [now we are] better people, better citizens, better human beings” (p. 133).

Coping through mutual support. Two qualitative researchers provided unique insights regarding the coping of parents of adolescents with ASD (Fong, 1992; Gray, 2002; Gray, 2003; Gray 2006). The parents of adolescents with ASD in Fong’s (1992) study stated that their coping had changed over time. By the time their children with ASD reached adolescence, the
couple relied less on external supports, because “somehow that support goes away a bit more as you get older” (p. 135). Similar to Lin’s (2000) findings, the parents of adolescents with ASD expressed that they, instead, relied more on each other. One parent stated, “We both needed each other’s support and agreement…It’s got to be both parents pulling the same way” (p. 134).

Similar to Fong (1992) the parents in Gray’s (2006) study explained that they shared “surveillance” (p. 171) duties over the adolescent with ASD, and routinely provided the other parent with a respite from caregiving.

**Spiritual coping.** Fong (1992) and Gray (2006) observed parents coped by deepening their involvement in spiritual practices over time. One parent stated, “I guess what God did in my life was help me to become stronger spiritually, so that I would be better able to deal with things” (Fong, 1992, p. 171).

**Other strategies used by parents of adolescents with ASD.** Parents also identified other methods of coping. Parents in Fong’s (1992) study described engaging support from other parents of children with ASD, particularly by sharing stories and laughing together. Parents also reported coping by finding an outlet, such as engaging in a hobby or working outside the home (Fong, 1992). Similar to Cashin’s (2003) findings, the parents in Gray’s (2006) study coped with having an adolescent with ASD by carefully planning daily activities and contrastingly, by taking things one day at a time.

**Gender differences in coping.** Gray (2003) observed gender-based differences in coping patterns between mothers and fathers of adolescents with ASD. The researcher noted mothers more often vented their frustrations, through tears and talking about their situation; whereas fathers suppressed their feelings (Gray, 2003). On the one hand, fathers stated they
were not affected directly by the child’s condition. On the other hand, they were indirectly affected by their wives’ stress. One father stated, “I don’t like seeing my wife upset” (p. 635).

Fathers attributed their wives’ increased impact to raising a child with ASD to their role differences, especially because their wives were more involved in the daily care of the adolescent with ASD. One father stated, “A lot of burden…tends to be put on the mother because the father is working…The father essentially has…respite care five days a week” (p. 635).

**Summary of Coping Literature**

No studies have explored the influence of coping strategies on family adaptation in families of adolescents with ASD. What literature exists demonstrates that parents of adolescents incorporate several coping strategies. Also there are differences according to gender (Gray, 2002; Gray, 2003; Hastings et al., 2005; Holm et al., 2008; Lee, 2009) and family life cycle stage in families of children with disabilities including ASD (Gray 2006; Lin, 2000; Smith, Seltzer, et al., 2008). However, the findings have limited generalizability, because nearly all the studies of coping had limitations regarding the lack of diversity of the included samples. The samples were predominately White, married, well-educated, and had an annual income above $70,000 (Gray, 2006; Pakenham et al., 2005; Smith, Seltzer, et al., 2008). No researchers have published studies regarding the most effective coping strategies for families of adolescents with ASD and no studies have investigated the effect of coping strategies on family adaptation. Therefore additional studies should be undertaken to fill this gap in the literature.

**Chapter II Summary**

The studies presented in this chapter explored the variables of family adaptation, daily stressors, the severity of behavior problems, uncertainty, and coping. A review of literature
demonstrated there was a need for this research because no previous study had measured the combined effects of the variables in relationship with family adaptation in families of adolescents with ASD. The major limitations of the extant literature include the narrow focus on mothers in the research, the narrowness of the ethnic background of the samples, and the use of secondary analysis with the same population in the AAA dataset. It would be helpful to understand family adaptation during the family life cycle stage of adolescents if a broader, more diverse sample were included. Researchers in foundational studies of families of adolescents with ASD uniformly called for additional research with larger and more diverse samples, more inclusive of gender, and cultural differences (Gray, 2006; Krajewski, 2005; Magana & Smith, 2008; Lecavalier et al., 2006).

The majority of studies of adolescents with ASD was conducted with mothers and indicated the mothers experienced levels of depression, anger, and anxiety well above mothers of normally-developing adolescents. Additional research, that includes other adult family members, will help to identify which, if any, other adult family members provide compensatory support in the family adaptation process. No studies had investigated the variable of family adaptation exclusively with families of adolescents with ASD. A review of current literature supports the need to investigate the combined effects of daily stressors, severity of behavior problems, uncertainty, and coping on family adaptation in families with adolescents with ASD.
Chapter III

Methodology

This chapter presents the methodology used in the study. The purpose, research questions, variables, hypotheses, design, setting, sample, instrumentation and procedure will be discussed.

Purpose

The purpose of this study was to measure the effect of the independent variables: a) daily stressors, b) severity of behavior problems, c) uncertainty, and d) coping strategies on the dependent variable of family adaptation in families of adolescents with ASD. The variables of this study are found in Table 1.

This chapter describes the design of the study and the process that was followed to test the hypotheses. A description of the setting and participants, the research tools, the procedure, data analysis methods and the limitations will be discussed. The research tools that were used in this study include: a) Weekly Stressor Inventory-Short Form (WSI-SF) (Appendix A), b) a Visual Analog Scale (VAS) to rate the severity of the adolescent’s behavior problems (Appendix B), c) Parents’ Perception of Uncertainty in Illness (PPUS) (Appendix C), d) Family Crisis Personal Evaluation Scale (F-COPES) (Appendix D), e) the General Functioning subscale (GF) of the Family Assessment Device (FAD) (Appendix E) and f) a Background Information Form (Appendix F).

Research Hypotheses

The following hypotheses guided the study to measure the relationship between the selected variables and the dependent variable of family adaptation.
H1a: Family members reporting greater impact by daily stressors will have a lower level of family adaptation in families of adolescents with ASD.

H1b: Family members reporting greater severity of behavior problems in their adolescent with ASD will have a lower level of family adaptation in families of adolescents with ASD.

H1c: Family members with greater levels of uncertainty will have lower levels of family adaptation in families of adolescents with ASD.

H1d: Family members reporting greater use of coping strategies will have higher levels of family adaptation in families of adolescents with ASD.

H2: The combined effect of daily stressors, severity of behavior problems, uncertainty, and coping strategies will explain a significant amount of the variance in family adaptation in families of adolescents with ASD.

**Statistical Hypotheses**

Statistical hypotheses of no relationship for each of the research hypotheses were tested at an alpha level of .05. Rejection of the statistical hypothesis provided support for the research hypothesis.

**Study Variables**

Table 1 Representation of the Study’s Variables

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Dependent Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Stressors (WSI-SF)</td>
<td>Family adaptation (GF)</td>
</tr>
<tr>
<td>Severity of Behavior Problems (Visual analog scale)</td>
<td></td>
</tr>
<tr>
<td>Uncertainty (PPUS)</td>
<td></td>
</tr>
<tr>
<td>Coping strategies (F-COPES)</td>
<td></td>
</tr>
</tbody>
</table>
Design

Salvoiita et al. (2003), a family researcher, stated “family outcomes following the impact of a stressor event...are the result of multiple factors interacting with each other” (p. 301). Therefore, hierarchical multiple regression was used for this study (see Table 1).

Setting

The study was conducted in a naturalistic setting of the participant’s home. Families of adolescents with ASD might have found it difficult to manage their adolescent’s special needs while completing several survey tools in a public space. Therefore, participants completed the on-line surveys at a time and location of their convenience, and thus ease the burden of participation.

Sample and Inclusion Criteria

Inclusion Criteria

This randomly selected sample consisted of one or both biological parent(s), one or both adoptive parent(s), one or both stepparent(s), a partner of a parent, or one or both custodial grandparent(s) of an adolescent with ASD. If two members of the household completed the study, their responses would have been evaluated independently. The adolescent, between ages thirteen and twenty-two, had been diagnosed with ASD. Participants needed to be able to read English. A diverse sample of subjects, in terms of gender and cultural/ethnicity that would reflect the larger population of families, was sought.

Participants were not be eligible (1) if their child is older than twenty-two, (2) younger than thirteen year of age, or (3) if the child has never received a formal diagnosis of ASD. Also,
caregivers who received pay or remuneration to oversee the adolescent with ASD’s care were not eligible for the study.

**Sample Size**

A sample of 85 participants was determined to be needed for the study. The sample size was determined through a priori power analysis for multiple regression using the formula: \( N = \frac{L}{f^2} + 1 \) (Polit & Beck, 2004). The sample size was calculated using an alpha level of .05, four predictors, a medium population effect size \((f^2)\) of .15 and a power of .80 (Polit & Beck, 2004; Soper, 2010), or there will be an 80% chance of finding a difference, if a difference does exist. \( L \) value = 11.94; \( N = \frac{L}{f^2} + k + 1; N = 84.6 \) (Polit & Beck, 2004; Soper, 2010).

**Procedure**

The sample was a randomly selected sample of 500 of the 3,500 Interactive Autism Network (IAN) families that met the study’s criteria. All were members of the larger database of 40,000 families of children with ASD (Interactive Autism Network [IAN], 2011). The IAN is a web-based virtual support community comprised of individuals with ASD, their families and friends, researchers, and professionals in the field of ASD research and intervention. The community’s stated goal is “to better understand this complex disorder through research and collaboration, and to develop effective strategies that will improve the lives of people on the spectrum” (IAN, 2011). The IAN family members reside in all fifty states of the United States of America.

**University Approval**

Approval was given by The Catholic University of America’s School of Nursing and The Catholic University of America’s Committee for the Protection of Human Subjects to conduct
the study. Next the researcher contacted The Catholic University of America’s Center for Planning and Information Technology (CPIT) for assistance with the planning and implementation of the internet–based research. The CPIT staff translated the researcher’s model study from Survey Monkey and posted the approved study onto the researcher’s dedicated space in the university’s system. They also created a direct link for access to the study by potential study participants.

**Role of Interactive Autism Network**

Next, the researcher applied for IAN’s approval to recruit participants from the IAN database. The IAN research team assists researchers in several ways. First the IAN research team emails the researcher’s recruitment letter (Appendix H) to IAN community members who meet the study’s criteria. Second, the IAN research team posts an announcement of the study on the IAN’s website. Finally, the IAN research team announces the study on IAN’s community web-based bulletin board (IAN, 2011). However, only the emailed recruitment letter with embedded link was utilized for this study. The embedded link enabled IAN’s families to enter the study with only a mouse-click.

The IAN research team generated a random sample of 500 by using Stata 9.x using UNIFORM() command and emailed the researcher’s recruitment letter to each of the 500. The recruitment letter contained a two paragraph introduction mandated and composed by the IAN research team. The introduction informed the family that one or more members of the family may qualify for the study and reassured the family that participation was voluntary. It also

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1 There is a one-time only $2,000 fee for the recruitment services of the IAN research team.
informed them there would be no reprisal for non-participation and reminded them that IAN did not endorse the study (IAN, 2011). The second portion of the recruitment letter was the researcher’s invitation to participate in the study and provided information regarding the study, including: the name of the study, the eligibility criteria, the name and contact information of the researcher, the web-based nature of the study, the number of research instruments to be completed, the approximate length of time involved in completing the study, and an optional $15 gift card as an incentive. The informed consent process is further described in the Protection of Human Subjects section.

**Incentives**

Participants were offered their choice of a $15 redeemable coupon from a national coffee franchise (i.e., Starbucks) or a national book and merchandise-selling franchise (i.e., Amazon.com). After completion of the survey, participants could elect to register for their incentive. The participants were informed that by providing their email address to receive their coupon, they retained their confidentiality. The addresses were used solely to facilitate the receipt of the incentive. The email addresses were retained until the analysis of data is completed. Then all email addresses were deleted and any paper records were destroyed (see Appendix G).

**Data Collection**

The researcher reviewed the surveys for completeness and validated they met eligibility criteria. Once at least 85 completed surveys that meet criteria were obtained, data collection was suspended. The researcher notified IAN that data collection was completed. IAN, in turn, placed a notice on the web-based community bulletin board announcing recruitment for the study.
is closed. Also, The CUA computer department replaced the greeting page with a notice that data collection had been completed and the study was closed.

When potential participants learned of the study, they linked directly to the study by 1) typing the URL address into their web browser or 2) clicking on the link embedded in the recruitment letter. The link connected participants directly to the study instruments housed in the secure server of The Catholic University of America. The interactive survey was designed so that after connecting to the URL address, potential participants first viewed a greeting page (Appendix I) that described the study, its purpose, and the eligibility criteria. Potential participants indicated their continued interest and eligibility for the study by clicking on the “Continue” button. On the next page potential participants viewed the informed consent information and determined if they wished to participate in the study. More information on the informed consent will be discussed in the Protection of Human Subjects section. If potential participants were not interested in completing the study or did not meet the three criteria, they clicked on the “Exit” button. The computer recorded approximately 38 visits to the study’s welcoming page did not result in participation in the study.

**Instruments**

Six instruments will be used in this study (Refer to Table 1). The instruments used to measure the independent variables were: (a) the Weekly Stressor Inventory-Short Form (WSI-SF) (see Appendix A), (b) a VAS to measure the parent’s perceptions of the severity of their adolescent’s behavior problems (see Appendix B), (c) the Parents’ Perception of Uncertainty in Illness (PPUS) (see Appendix C), (d) the Family Crisis Personal Evaluation Scale Evaluation Scales (F-COPES) (see Appendix D). The instrument used to measure the dependent variable
was the General Functioning (GF) subscale of the Family Assessment Device (FAD) (see Appendix E). Background information was collected with the Background Information Form (see Appendix F). All the tools except for the Background Data Form have supported validity and reliability and have been used in with similar populations, of families with chronic illnesses or disabilities, including ASD. These are discussed below.

**Weekly Stressors Inventory-Short Form (WSI-SF)**

Daily stressors for this study were measured by the Weekly Stressors Inventory-Short Form (WSI-SF) (see Appendix A). This instrument is a 25-item self-report scale that measures low-level daily stressors that occur over the course of a week. The Weekly Stressors Inventory was derived from Brantley’s (1997) original Daily Stressors Inventory. Brantley concluded that reviewing the impact of daily stressors over the course of a week provided greater stability in reports of daily stressors rather than logging the daily stressors at the end of each day. Use of a weekly form decreased the participant’s burden, as well.

The participants were first asked to indicate whether the events happened during the last week. Then they were instructed to rate the impact of each item on an eight-point Likert scale. The lowest value on the scale is 0 (did not happen) to 7 (extremely stressful). From this, two scores are derived: a) an event score (WSI-SFE) and b) an impact score (WSI-SFI). The event score reflects the total number of items from the 22 questions that occurred during the last week. A separate score, the impact score, is a summation of the stress caused by the events. Total scores range from 0 to 175 points. A high score represents the greater impact of daily stressors and a low score represents less impact of daily stressors.
Validity. The WSI-SF demonstrates convergent validity through comparison with the original Weekly Stressor Inventory. The original instrument was validated initially in 1997 and used for research purposes for ten years. When administered together, the shortened form of the tool (WSI-SF) showed a positive relationship between the two subscales of both the original and the shortened form, event scales ($r = .79$, $p < .01$) and impact scales ($r = .24$, $p < .01$). The validity of the WSI-SF was demonstrated with intercorrelations between the WSI-SFE and WSI-SFI using a Pearson Product-movement correlation. The two scales were found to be related ($r = .69$, $p < .01$) (Brantley et al., 2007). The researchers reported the literacy level of the tool according the Flesch-Kincaid scale as a 2.8 grade level. The researchers reported individuals needed two to three minutes to complete the tool (Brantley et al., 2007).

Reliability. The WSI-SF demonstrated an internal consistency (Cronbach’s alpha) for the total instrument of .91 (Ames, Jones, & Brantley, 2001). The internal consistency for the subscale WSF-SFE was .92 and for the subscale WSI-SFI was .91 (Brantley et al., 2007).

Web format. In order to accommodate a web-based format, with permission, the researchers’ original instructions were modified slightly. The original instructions stated that if an event did not happen, the participant should fill in a circle labeled “X” to the right of the item. In the web-based format, the item “did not happen” is a choice placed beside the remaining scale of impact items.

Severity of Behavior Problems

The families’ perception of the severity of behavior problems exhibited in their adolescent with ASD was measured using a visual analog scale (VAS). By convention, a VAS is a continuous scale, represented by a horizontal line and anchored on each end with verbal labels
of opposite extremes. An example of such anchor points would be “very poor” and “very good.” Study participants place a mark on the scale which best represents their perceptions of the phenomenon under investigation. Studies have supported the VAS is a valuable instrument for measuring psychosocial phenomena (Hollen et al, 2005; Reips & Funke, 2008; Steiner, Steiner, & Ba, 2005) and was effectively utilized to measure parental perceptions of the severity of behavioral problems in children, including those with ASD (Clark, 2008; Findling, Aman, Eerdekens, Derivan, & Lyons, 2004; Shea et al., 2004).

Validity. Parallel validity. Svennson (2000) established the VAS’s validity using parallel validity, or the degree of agreement between several VAS formats. Svennson administered an unspecified questionnaire using one of three of VAS formats: a) a traditional VAS, b) a graphical response scale (GRS), and c) a five-point verbal descriptor (VDR-5). The researcher calculated the intra-rater agreement and evaluated the rank-invariant properties of the VAS’s. The degree of agreement, or monotonic agreement (MA), for the VAS’s was as follows: a) between the GRS and the VDS-5 was .94, b) between the traditional VAS and the VDS-5 was .87, and c) between the traditional VAS and the VDR-5 was .67. Svennson stated that this agreement indicated that all formats performed acceptably well in representing the questionnaire’s underlying constructs.

Construct validity. In Steiner et al.’s (2005) study of premenstrual symptoms, single-item VAS’s were utilized to measure four mood symptoms and seven physical symptoms, including feeling out of control and lack of energy. The scales were based on the DSM-IV criteria for premenstrual dysphoric disorder. Each VAS was a horizontal line with anchors points of 0 representing “not at all,” to 100 representing “extreme symptoms.” To evaluate
construct validity, the four VAS mood items were compared to scores based on an established research instrument, the Premenstrual Tension Syndrome-Observer (PMTS-O). The correlation coefficients between the VAS and the PMTS-O scores ranged from .42 to 0.5 (p < .01), representing a moderately strong correlation between the instruments (Steiner et al, 2005).

**Convergent validity.** Hollen et al. (2005) compared the use of two versions of VAS’s, a traditional VAS and a numerical rating scale (NRS) for the administration of a lung cancer symptom scale (LCSS). Both versions performed well and participants rated both the traditional VAS and the NRS easy to navigate. The NRS was an eleven-point numeric scale with box-enclosed numbers; 0 representing the lowest rating of a symptom and 10 representing the highest or worst rating of a symptom. The traditional VAS was a 100 mm horizontal line with the same bipolar verbal anchors as the NRS. Participants used both VAS formats to rate each of nine symptoms, which comprise the LCSS. Convergent validity was established by the level of agreement between the two forms of the VAS’s. This agreement was calculated by both the intraclass correlation coefficient (ICC) and Lin’s concordance coefficient (CCC). The ICC is a gauge of within-person agreement and measures how much an individual observation deviates from the line of best-fit for all the observations. The CCC is a measure of precision and accuracy and also accounts for inter-rater bias. The ICC was >.90 and the CCC was also > .90, representing a high level of agreement between the two formats.

**Reliability.** Cooper, Tongangeau, and Conrad (2006) compared three formats of VAS, a) a scale with a virtual adjustable slide, b) a numeric entry scale, and c) a row of unnumbered radio buttons, and found no statistically significant differences in their performance. Cooper et al. reported the inter-item correlations were moderately high for each VAS format. The Cronbach’s
alpha was: .651 for the virtual slide VAS, (b) .682 for the numeric entry VAS, (c) and .664 for the radio button VAS. Similarly Hollen et al.’s (2005) lung cancer symptom study found the Cronbach’s alpha of the traditional VAS was .90 and for the NRS was .89. Steiner et al. (2005) also reported good internal consistency with Cronbach’s alpha for the single-item VAS’s of the four mood symptoms. Across three different trials, the internal consistency ranged from .88 to .91, and as anticipated, varied according to the menstrual cycle phase.

Studies have utilized a VAS to measure the severity of behavior problems in children with ASD. Using a web-based design Clark (2008) measured the effect of several independent variables, including the severity of behavior problems, on parental stress. The researcher employed a seven-point scale which ranged from “never difficult” to “always difficult.” Data analysis demonstrated parental perceptions of the children’s behavioral difficulties were highly correlated with parental stress.

Similarly, a VAS was used in an open trial of medication (risperdone) versus placebo in children with severe behavior problems, including ASD. At several intervals over the course of the study, parents were asked to rate their child’s “most troublesome behavior problem” using a VAS. Following the cross-over from administration of the placebo to administration of the medication, there was a statistically significant decrease in the parental rating of the severity of their child’s behavior problems (F (1, 56) =26.11, p < .001) (Findling et al., 2004).

**Scoring.** For this study, the severity of behavior problems was measured by a digitalized 100 mm scale linear visual analog scale (VAS), designed by The Catholic University of America’s computer department. The selection of this design was utilized for this study because this design performed well in Steiner et al. (2005)’s study of severity of pre-menstrual dysphoria.
The verbal bipolar anchor points were labeled “not at all difficult” and “extremely difficult.” (See Appendix B). Participants were asked to click on a point on the scale that represented the severity of their adolescent with ASD’s behavior problems. The left-hand anchor point of the VAS, associated with 1, was “not at all difficult” and the right-hand anchor point, associated with 100 was “extremely difficult.” The participants viewed a line on their computer screens that was composed of 100 images. Each image was 5 pixels wide and 20 pixels high. The image carried a value equal to its location in the sequence from 1 to 100. When one of the images was clicked, the computer interpreted the clicked image into scores ranging from 1 to 100 percent. The higher the score, the greater the severity of behavior problems the respondent perceived their adolescent with ASD was experiencing.

**Uncertainty**

The Parents’ Perception of Uncertainty in Illness Scale (PPUS) (see Appendix C) measures parental uncertainty regarding their child’s illness and cancer treatment, and other chronic illnesses and disabilities, such as ASD (Mishel, 1990). The instrument was developed to measure the concepts explicated in Mishel’s Theory of Uncertainty in Illness. Mishel (1990) postulated uncertainty arises from a) ambiguity, b) lack of clarity, c) lack of information, and d) unpredictability related to an illness. The PPUS is a 31 item self-administered survey tool with four subscales reflecting each of the elements that contribute to uncertainty.

The instrument instructs participants to select a response that most closely reflects how the participants are feeling about their child today. Responses to each item are rated on a five-point Likert scale, that ranges from (1) strongly agree to (5) strongly disagree. The subscale scores may be tallied for each individual subscale or be summed to provide a total score for the
entire tool. The total scores range from range from 31 to 155. Eleven items (6, 9, 11, 19, 23, 25, 27-31) are reversed within the instrument so recoding prior to analysis is not needed: items. A higher score indicates greater uncertainty experienced by the participant related to their child’s disorder (Mishel, 1997).

The guidelines for the PPUS manual indicate that word substitutions in the instrument are permitted to better address the condition being researched. For example the word “pain” may be modified to the word “symptoms”. The word “illness” may be changed to “autism spectrum disorder” and “doctor” may be changed to “professional” (Mishel, 1997; Warter, 2009). Additionally, item 17 which read, “It’s vague to me how I will manage the care of my child after he/she leaves the hospital” was modified to read, “It’s vague to me how I will manage the care of my child.”

**Validity.** Face validity of Mishel’s scales was established with a panel of experts composed of physicians, nurses, and patients (Mishel, 1983). Confirmatory factor analysis demonstrated the construct validity of the PPUS (Mishel, 1983; Mishel, 1997; Santacroce, 2003). The subscales and the total instrument have demonstrated validity of known group differences due to their ability to distinguish between clinical and non-clinical, or between families facing challenging illnesses and disabilities and those without such issues (Mishel, 1997; Santacroce, 2003; Warter, 2009).

**Reliability.** The PPUS has an overall Cronbach’s reliability coefficient was .81-.93 (Mishel, 1997). The alpha’s for the subscales ranged from .72 to .87 (Lipinski et al., 2006). In Warter’s (2009) study of factors influencing family adaptation in families of younger children with ASD, the PPUS had an internal consistency alpha of .88.
**Web format.** Permission was obtained from the researcher to administer the PPUS in a web-based format. The paper and pencil form instructs participants to place an “X” under the column of choices. However, in order to accommodate a web-based format, instead participants were instructed to “click” on their choice of responses.

The PPUS was an appropriate measure for the target population. Although the PPUS was originally tested with children with cancer and life-threatening illnesses, its use has been employed more broadly in studies of parents of children with long-term disabilities such as spina bifida, chronic orthopedic problems, and genetic chromosomal conditions (Lipinski et al., 2006; Neville, 2003; Santacroce, 2001; Stewart & Mishel, 2000). It was employed recently to study uncertainty and family adaptation in families of children with ASD (Warter, 2009).

**Coping Strategies**

The Family Crisis Oriented Personal Evaluation Scales (F-COPES) (Appendix D) was used to measure the use of coping strategies. The authors hypothesized families respond to crises be adapting at two levels: (1) on the individual family member level and (2) on the larger community level. The survey explores five subscales, reflecting the various coping strategies a family may utilize to address difficulties at both levels, including: a) acquiring social support, b) reframing, c) seeking spiritual support, d) mobilizing family to acquire and accept help, and e) passive appraisal (McCubbin et al., 2003). The F-COPES tool is a self-administered survey with 30 items that are rated on a five-point Likert scale that ranges from (1) strongly disagree to (5) strongly agree. Items 12, 17, 26 and 28 were recoded prior to analysis. Total scores range from 30 to 150. A higher score reflects the greater use of coping strategies (McCubbin et al., 2003).
Validity. The instrument was first tested with a sample of 119 undergraduate and graduate students. The construct validity of the instrument was established by confirmatory factor analysis. A confirmatory factor analysis was conducted with a second sample of 2,740 adults, graduate students and high school students. Because most of the participants were married and parents, the researchers separated the data from the married couples into two subgroups, Sample 1 and 2. The factor analysis was repeated and the subscales were established in their present form. The data from two samples served as a normed reference group and the data published in a manual for assist with the interpretation the F-COPES (McCubbin et al., 2003).

Reliability. The reliability of the tool was established with test-retest methodology at a four to five week interval with a test-retest reliability for the subscales ranging from .61 to .95 and for the entire tool .81. The overall Cronbach’s alpha of the entire tool was reported to be .77-.86. The internal consistency of the individual subscales ranged from .61-.95 (McCubbin et al., 2003).

Web format. Permission was obtained from the researchers to administer the F-COPES in a web-based format. Participants were instructed to read the list of response choices and then determine how well each statement describes their family copes in response to problems. The researchers’ original instructions were slightly modified. The paper and pencil instructions directed participants to circle a number that matches their response to the statement. These instructions were modified for the web-based version and directed participants to “select” and not circle the desired response.
Family Adaptation

Family adaptation was measured by the General Functioning subscale (GF) of the McMaster Family Assessment Device (FAD). The FAD was developed for clinical practice by marriage and family counselors at McMaster University in Ontario, Canada. The tool’s purpose was to identify families with less effective adaptation and in need of intervention (Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990). The FAD is a 60 item self-administered survey tool with four-point Likert scale with six subscales that measures dimensions of family functioning, including: a) problem solving, b) communication, c) roles, d) affective responsiveness, e) affective involvement, and f) behavior control. Participants are instructed to answer according to how they see their family. Responses range from 1 representing “strongly agree” to 4 representing “strongly disagree.” Through a multi-step scoring process, the total score for the FAD ranges from “1” to “4.” The higher the score, the less effectively is the family functioning.

Validity of the FAD. The FAD demonstrated discriminant validity as it was able to distinguish between families whose functioning is at-risk and in need of intervention and those without such difficulties (Epstein, Baldwin, & Bishop, 1983).

Reliability of the FAD. The reliability of the FAD was established by the test-retest method, given at a two week interval. The Cronbach’s alpha of internal consistency for the entire tool was between .72 and .92. The internal consistency of the subscales ranged .66 to .76 (Epstein, Baldwin, & Bishop, 1983).

The GF subscale validity. The 12 item General Functioning (GF) subscale of the FAD has been validated for administration independent of the entire FAD and is the dependent variable of this study. The GF subscale is useful for as a global assessment of family functioning.
and adaption. Each item is scored on a four-point Likert scale. Items 1, 3, 5, 7, 9, and 11 are recoded prior to data analysis. Concurrent validity of the GF subscale was established by administering the GF subscale and two other similar, validated tools, the Family Unit Inventory (FUI) (Van der Veen, 1969) and the FACES-II (Miller et al., 1985; Olson, Portner, & Bell, 1982). The GF subscale compared favorably with the other tools with statistically significant correlations (-.75 and -.61) (The correlations have negative values due to differences in the directionality of the scales). The subscale’s construct validity was tested with all the subscales by confirmatory factor analysis (Kabacoff et al., 1990). The GF subscale was found to be highly correlated to the six other subscales. When the GF subscale was used independently, it too, was found to have discriminant validity in distinguishing between well-functioning families and those families at-risk due to ineffective functioning (Byles, Byrne, Boyle, & Offord, 1988).

**Reliability.** The GF subscale’s Cronbach’s alpha ranged from .83 to .86 (Kabacoff et al., 1990), .92 (Epstein et al., 1983), and .86 (Byles, Byrne, Boyle, & Offord, 1988). A test-retest reliability at a one week interval was .71 (Miller et al., 1985).

**Scoring the GF.** The scoring of the GF subscale involves several steps. The initial step is to transform the scores of the recoded items by subtracting each score from 5. Next, the scores for all twelve items are totaled. Finally, the total score is divided by 12. A score of “1” is considered to be a “healthy” family; whereas a score of “4” is considered “unhealthy.” A score greater than “2” indicates the family would benefit from supportive mental health assistance (Ryan, Epstein, Keitner, Miller, & Bishop, 2005).

Two studies utilized the FAD of the GF subscale to investigate family functioning in families with disabilities including ASD. Lin (2000) used the GF subscale of the FAD to
evaluate family adaptation in families of children with CP. Vliem (2009) used the entire FAD including the GF subscale to measure the adaptation of adolescent siblings of children with ASD.

**Web format.** The researchers’ original instructions were modified slightly. In the paper and pencil version, participants were instructed to “mark all your answers in the space provided to the left of each statement.” In the web-based format, the participants are instructed to “mark all your answers in the space provided for each statement.” The instrument authors have agreed that the researcher may utilize the FAD or the GF subscale in web-based research, requesting the researcher purchase an “institutional copy” of the instrument.²

**Background Information Form**

The Background Information Form (See Appendix F) is a self-report form developed by the researcher to collect demographic data. There were 15 items on the form including: a) the participant’s gender, b) age, c) race, d) marital status, e) level of education, f) family income, g) age of adolescent, h) participant’s relationship with the adolescent with ASD, i) by whom the adolescent’s diagnosis was made, j) any co-morbid condition the adolescent had, k) past treatments the family utilized to address the adolescent’s ASD, and l) gender and age of other children in the household with ASD. There was also an open “comments” box for participants to share any reflections regarding raising an adolescent with ASD.

**Protection of Human Subjects**

Approval for this study was obtained from The Catholic University of America (CUA)’s School of Nursing and Committee for the Protection of Human Subjects. Approval was also

² The current price is $150.
sought from IAN’s Subject Recruitment Services. IAN contacted potential participants, members of their database who met the study’s criteria, with a written description of the study and the recruitment letter (Appendix H).

Potential participants who elected to participate in the study linked directly to the secure server of CUA data management system. The greeting page (Appendix I) provided a written description of the study and the inclusion criteria. The second page provided the terms of the informed consent (Appendix J). The informed consent included: 1) the name of the investigator, 2) contact information of the researcher, 3) the purpose of the study, 4) the benefits of participation, 5) any risks for participation, 6) the voluntary nature of their participation and the right to withdraw from the study without reprisal, 7) the instruments to be completed, 8) the approximate length of time needed to complete the survey tools, 9) the maintenance of confidentiality by the researcher, 10) the manner in which the collected data would be stored, and 11) the manner in which the participant could request a summary of the results of the research.

Any potential risks were presented, including potential emotional upset. In the event of emotional upset, potential participants were informed they could contact the researcher by phone or email to obtain a referral to a mental health resource. This referral would have been located through SAMHSA Mental Health Facility Locator, based on the participant’s zip code. The SAMHSA locator provides a directory of mental health services and resources, and can be found at http://findtreatment.samhsa.gov (Substance Abuse and Mental Health Services Administration, 2013). No participants contacted the researcher for mental health services.
The informed consent was also present information regarding the confidentiality of the data. Potential participants were informed that it would not be possible to identify an individual participant’s data and the participant’s data would be stored in the university’s secure server. When downloaded for data analysis purposes, printed hard-copies of the data would have been kept in a secure, locked location and the code books that link their identity to the data would have been destroyed at the conclusion of the study. No identifying or individual results from this study were to be shared with anyone in any form. The potential participants were informed that their research records, like hospital records, could be subpoenaed by court order or be inspected by federal regulatory authorities.

The investigator’s phone and email information was on the form. Potential participants had the opportunity to ask questions about the research and their participation in the research. The potential participants were informed that they could delay participation until their questions were answered. One participant contacted the researcher to ask for clarification regarding the definition of family.

If the potential participants agreed to the terms and wished to provide their consent, they were instructed to click “I accept the terms and volunteer to participate” and enter the study. If they did not agree to the terms, they were instructed to click on “I do not accept the terms and do not wish to participate” and they were thanked and exited from the system. If a potential participant wished to obtain a printed copy of the consent form, they were instructed to contact the researcher, who would mail it to an address provided by the potential participant. No participant or potential participant requested the printed consent form. After a participant
completed the study, they were thanked for their interest in autism research and assistance with the research.

**Data Analysis**

Descriptive statistics including means, median, frequency distributions, correlation coefficients, and standard deviations were analyzed to describe the sample and the demographic data. A hierarchical multiple regression analysis with family adaptation as the dependent variable was computed with all the independent variables. Age and level of education of study participants served as blocking variables and were entered into the model first. Then the following variables were entered sequentially: daily stressors, severity of behavior problems, uncertainty, and coping. The order of entry into the hierarchical multiple regression were based on the theoretical sequencing of components in the RMF model. After controlling for the age and level of education of the study participant, the analysis determined to what extent the independent variables of daily stressors, the severity of behavior problems, uncertainty, and coping explained the variance in family adaptation (Polit & Beck, 2004).

The total score for the daily stressors using the WSI-SF to measure the impact of daily stressor, the percentage of the VAS selected by participants to reflect the severity of their adolescents’ behavior problems, the total score on the Parents’ Perception of Uncertainty in Illness Scale (PPUS) (Mishel, 1990) to measure uncertainty, the total score of the F-COPES (McCubbin et al., 2003) to measure coping strategies, and the transformed score of the GF subscale of the FAD (Epstein, 1983) was used to measure family adaptation. Reliabilities for the WSI-SF, the PPUS, the F-COPES, and the GF scale were also calculated.
Limitations

This study was limited by the use of only one sample, members of the IAN community, who were self-selected and provided self-reported data. However, the sample was randomly selected from 3,500 members who reside in all 50 of the United States and are likely to be very representative of the wider United States. Therefore the results of the study should only generalized beyond the study’s population of interest with caution.

Summary

This chapter described the methodology for this study. It included the elements of: a) study design, b) research questions, c) hypotheses, d) setting, e) sample, f) procedure, g) instrumentation, h) protection of human subjects, i) data analysis, and j) limitations. Each element was described sufficiently to allow replication of the study.
CHAPTER IV

Findings

The purpose of this study was to measure the effect of several independent variables, a) daily stressors, b) severity of behavior problems, c) uncertainty, and d) coping strategies, on the dependent variable of family adaptation in families of adolescents with ASD. The variables of this study are found in Table 1.

Table 1

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Dependent Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Stressors (WSI-SF)</td>
<td>Family Adaptation (GF)</td>
</tr>
<tr>
<td>Severity of Behavior Problems (Visual Analog scale)</td>
<td></td>
</tr>
<tr>
<td>Uncertainty (PPUS)</td>
<td></td>
</tr>
<tr>
<td>Coping Strategies (F-COPES)</td>
<td></td>
</tr>
</tbody>
</table>

Data for this study were collected over a one month period using a randomly selected sample of 500 of the 3,500 IAN families that met the study’s criteria. The IAN research team generated a random sample by using Stata 9.x using UNFORM() command and emailed the researcher’s recruitment letter (A. Marvin, personal communication, April 9, 2013). All participants were members of the Interactive Autism Network (IAN), a web-based virtual support community associated with the Kennedy-Krieger Institution in Baltimore. The IAN community members reside in all fifty states of the United States of America (Interactive Autism Network, 2011). The recruitment letter contained an embedded link to the study, which was
posted on The Catholic University of America’s (CUA) computer server. The potential participants were able to link directly to the study with one mouse-click.

The CUA computer server system recorded approximately 156 potential participants viewed the greeting page that described the study, its purpose, and the eligibility criteria. Eligibility for the study allowed inclusion of one or both biological parent(s), one or both adoptive parent(s), a stepparent, a partner of a parent, or one or both custodial grandparents of an adolescent with autism; an adolescent for this study is a child ages 13 to 22. One hundred eighteen participants completed all or most part of the study. Data from 15 participants was unusable due to a) excessively missing entries, b) failure to indicate the age of their child with autism, or c) multiple identical submissions by the same participants. As a result, 103 participants had usable data.

This chapter provides descriptive information regarding the sample and the data collection instruments. Following this is the hypotheses testing and a summary of the findings.

Description of the Sample

Data which describes the sample were obtained from the 15-item Background Data Form (see Appendix F). This form requested data about a) the participant’s gender, b) age, c) race, d) marital status, e) level of education, f) range of family income, g) age of adolescent with ASD, h) participant’s relationship with the adolescent with ASD, i) the type of professional by whom the adolescent’s diagnosis of ASD was made, j) any co-morbid condition the adolescent has, k) past treatments the family utilized to address the adolescent’s ASD, and l) gender and age of other children in the household diagnosed with ASD.
Table 2
Selected Individual Characteristics of Participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
<th>Frequency&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Percentage&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age&lt;sup&gt;c,d&lt;/sup&gt;</td>
<td>39-45</td>
<td>30</td>
<td>29.4</td>
</tr>
<tr>
<td></td>
<td>46-52</td>
<td>40</td>
<td>39.2</td>
</tr>
<tr>
<td></td>
<td>53-59</td>
<td>29</td>
<td>28.5</td>
</tr>
<tr>
<td></td>
<td>60-67</td>
<td>3</td>
<td>2.9</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>94</td>
<td>91.3</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>9</td>
<td>8.7</td>
</tr>
<tr>
<td>Ethnicity&lt;sup&gt;d&lt;/sup&gt;</td>
<td>White</td>
<td>92</td>
<td>91.2</td>
</tr>
<tr>
<td></td>
<td>Latino</td>
<td>5</td>
<td>4.9</td>
</tr>
<tr>
<td></td>
<td>Asian</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>African American</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Mixed ethnicity</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>South Asian</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married</td>
<td>80</td>
<td>77.7</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>13</td>
<td>12.6</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td>4</td>
<td>3.9</td>
</tr>
<tr>
<td></td>
<td>Committed relationship</td>
<td>3</td>
<td>2.9</td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>3</td>
<td>2.9</td>
</tr>
<tr>
<td>Type of relationship&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Biological parent</td>
<td>94</td>
<td>93.1</td>
</tr>
<tr>
<td></td>
<td>Adoptive parent</td>
<td>6</td>
<td>5.9</td>
</tr>
<tr>
<td></td>
<td>Custodial grandparent</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

<sup>a</sup>N=103,  <sup>b</sup>all variables = 100%,  <sup>c</sup>in years,  <sup>d</sup>missing value = 1,  <sup>e</sup>missing value = 2

**Participants’ characteristics.** The majority (91.3%) of the participants were female.

The mean age of the participants was 49.3 years old; the youngest participant was 39 and the oldest was 67. The majority of participants (99%) were biological parents or adoptive parents.
and 1% were custodial grandparents. The participants identified their ethnicity, listed in order of percentages, as White (90.2%), Latino (4.9%), Asian (2.0%), African American (1.0%), mixed ethnicity (1.0%), and South Asian (1.0%). Most participants were married (77.7%) or in a committed relationship (3.9%), or were divorced or separated (15.5%). See Table 2 for details.

Table 3

Education and Income Participants’ Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
<th>Frequency a</th>
<th>Percent of Participants b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>Level completed</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Less than 8th grade</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>8th grade</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>High school diploma or GED</td>
<td>19</td>
<td>18.6</td>
</tr>
<tr>
<td></td>
<td>Associate’s degree</td>
<td>17</td>
<td>16.7</td>
</tr>
<tr>
<td></td>
<td>Bachelor’s degree</td>
<td>27</td>
<td>26.5</td>
</tr>
<tr>
<td></td>
<td>Master’s degree</td>
<td>29</td>
<td>28.4</td>
</tr>
<tr>
<td></td>
<td>Doctorate or terminal degree</td>
<td>8</td>
<td>7.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Income</th>
<th>Annual $ earned</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt; 20,000</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>20,000-49,000</td>
<td>24</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>50,000-79,000</td>
<td>24</td>
<td>24</td>
</tr>
<tr>
<td></td>
<td>80,000-119,000</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>120,000-149,000</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>&gt; 150,000</td>
<td>13</td>
<td>13</td>
</tr>
</tbody>
</table>

a N=103, b all variables = 100% c missing value = 1, d missing value = 3
Many levels of education were represented by the participants. On one end, 18.6% completed high school or a GED and on the other 7.8% completed a doctorate or other terminal degree. Nearly two-thirds of the participants had a bachelor’s or more advanced degree. Additionally, there was a wide range of incomes represented by the participants. Half the participants earned less than $79,000 annually and 13% earned more than $150,000 annually. See Table 3 for details.

Table 4

<table>
<thead>
<tr>
<th>Selected Individual Characteristics of Adolescents with ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable</td>
</tr>
<tr>
<td>Age c</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Children in household with ASD</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

\( ^a N = 103, ^b \text{ all variables} = 100\%, ^c \text{ in years} \)

Adolescents’ characteristics. The majority of the adolescents with ASD (84.5%) were male. The mean age of the adolescent with ASD was 16.2 years (SD 2.70) and their ages ranged from 13 to 22 years old. The majority (64.1%) of adolescents had other medical conditions in addition to ASD. The majority (63.8%) of the adolescents had been diagnosed by medical doctors or medical specialists. Other diagnosing practitioners were identified as psychologists
(19.6%), or members of an interdisciplinary team (7.8%). None were diagnosed by a doctor of osteopathy or naturopathy or a nurse practitioner. A small percentage (14.6%) of the adolescents with ASD had other siblings with ASD in the same household. In 11.7% of adolescents household’s there were a total of two children diagnosed with ASD and in 2.9% of the households there were a total of three children diagnosed with ASD. See Table 4 for details.

**Evaluation of Instruments**

The following research tools were used in this study on family adaptation in families of adolescents with ASD: a) Weekly Stressor Inventory-Short Form (WSI-SF) (Appendix A), b) a Visual Analog Scale (VAS) to rate the severity of the adolescent’s behavior problems (Appendix B), c) Parents’ Perception of Uncertainty in Illness (PPUS) (Appendix C), d) Family Crisis Personal Evaluation Scale (F-COPES) (Appendix D), e) the General Functioning subscale (GF) of the Family Assessment Device (FAD) (Appendix E) and f) a Background Information Form (Appendix F). Findings from the instruments are discussed below. Data from the Background Information Form were previously discussed in this chapter.

**General Functioning subscale**

Family adaptation was measured by the General Functioning (GF) subscale of the Family Assessment Device (FAD). The 12-item subscale of the FAD has been validated for administration independently of the entire FAD. Each item is scored on a four-point Likert scale. Six items were recoded prior to data analysis. The subscale has been utilized by mental health professionals to evaluate which families might be in need of mental health services. After reversals, the total scores of the GF subscale are divided by 12 with total scores ranging from 1 to 4. The higher the score, the less effectively is the family functioning. A score greater than 2
indicates the family would benefit from assistance (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). Descriptive statistics for the General Functioning subscale are presented in Table 5.

Table 5

Descriptive Statistics for the General Functioning subscale *a*

<table>
<thead>
<tr>
<th>Range</th>
<th>M</th>
<th>SD</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – 3</td>
<td>2.03</td>
<td>.477</td>
<td>.87</td>
</tr>
</tbody>
</table>

* N= 98

The mean for this sample is 2.03, slightly above the instrument’s “cut off” value. This would suggest the family adaptation for some participants may be less than optimal and whose family could benefit from mental health support.

The reliability coefficient for this scale was .87, which compared well with the reliability coefficients of .66 to .76 provided by the instrument’s designers (Epstein, Baldwin, & Bishop, 1983). Table 6 presents the responses to individual questions on the GF subscale. Item to total correlations in this scale with this sample ranged from .323 to .595.

The item with the lowest mean score was item 2, which asked the degree to which participants agreed with item 2 regarding mutual support within the family. This is supported by the raw data that indicated 85.4% of participants agreed or strongly agreed with this statement. The item with the highest mean score, reflecting less effective family adaptation, was item 9, regarding whether there were problems with decision making for the family. This item is a reverse coded item. The raw data shows 61.2% of participants disagreed with this item, indicating making decisions was not a problem for them.
The item with the lowest mean score was item 2, which asked the degree to which participants agreed with item 2 regarding mutual support within the family. This is supported by the raw data that indicated 85.4% of participants agreed or strongly agreed with this statement. The item with the highest mean score, reflecting less effective family adaptation, was item 9, regarding whether there were problems with decision making for the family. This item is a reverse coded item. The raw data shows 61.2% of participants disagreed with this item, indicating making decisions was not a problem for them.
Overall, the raw data indicates that the majority of participants view their family functioning or adaptation positively. However, as previously discussed, the mean score for this sample is slightly above the “cut off” score indicating suboptimal family adaptation.

**Weekly Stressors Inventory-Short Form**

Daily stressors were measured by the Weekly Stressors Inventory-Short Form (WSI-SF) (see Appendix A). This instrument is a self-report scale that measures low-level daily stressors that occur over the course of a week (Brantley et al., 2007). Brantley et al, the instrument’s designers, after testing both a daily and weekly measurement of daily stressors concluded that reviewing the impact of daily stressors over the course of a week provided greater measurement stability. The WSI-SF is a 25-item instrument with a possible range of scores from 0 (stressor did not happen) to 7 (extremely stressful). Total possible scores range from 0 to 175. Higher overall mean scores indicate greater impact of daily stressors experienced by the participant. Reliability of the scale for this sample was a coefficient alpha of .92. This compares well to the reliability coefficient reported by the instrument’s authors of .91 (Brantley et al., 2007).

Descriptive statistics on the WSI-SF are presented in Table 7.

**Table 7**

<table>
<thead>
<tr>
<th>Range</th>
<th>M</th>
<th>SD</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 – 140</td>
<td>43.67</td>
<td>28.51</td>
<td>.92</td>
</tr>
</tbody>
</table>

*a* N= 97

Table 8 presents the responses to individual questions on the Weekly Stressors Inventory-Short Form (WSI-SF) which had the overall highest and lowest mean scores, indicating the most
and least impacting daily stressors experienced over the course of a week. Item to total correlations in this scale and sample ranged from .184 to .686. Polit & Becker (2008) recommend retaining items in a scale with item-total correlations greater than .30; otherwise the item may be incongruous with the scale’s construct.

Table 8

<table>
<thead>
<tr>
<th>Item #</th>
<th>Content area</th>
<th>M</th>
<th>SD</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>Forgot something</td>
<td>2.87</td>
<td>2.03</td>
<td>.582</td>
</tr>
<tr>
<td>15</td>
<td>Not enough time for fun…or recreation</td>
<td>2.79</td>
<td>2.30</td>
<td>.599</td>
</tr>
<tr>
<td>16</td>
<td>Had someone disagree with you</td>
<td>2.75</td>
<td>2.16</td>
<td>.608</td>
</tr>
<tr>
<td>13</td>
<td>Was interrupted while talking</td>
<td>2.54</td>
<td>1.99</td>
<td>.686</td>
</tr>
<tr>
<td>21</td>
<td>Was told what to do</td>
<td>2.38</td>
<td>2.13</td>
<td>.619</td>
</tr>
<tr>
<td>22</td>
<td>Lost or misplaced something (wallet, keys)</td>
<td>2.11</td>
<td>2.19</td>
<td>.598</td>
</tr>
<tr>
<td>23</td>
<td>Spoke or performed in public</td>
<td>.64</td>
<td>1.19</td>
<td>.184</td>
</tr>
<tr>
<td>7</td>
<td>Competed with someone</td>
<td>.73</td>
<td>1.31</td>
<td>.322</td>
</tr>
<tr>
<td>18</td>
<td>Argued with a friend</td>
<td>.79</td>
<td>1.77</td>
<td>.448</td>
</tr>
<tr>
<td>8</td>
<td>Had a minor injury (stubbed toe, sprained ankle)</td>
<td>.88</td>
<td>1.74</td>
<td>.521</td>
</tr>
<tr>
<td>17</td>
<td>Did poorly because of others</td>
<td>.93</td>
<td>1.89</td>
<td>.679</td>
</tr>
<tr>
<td>25</td>
<td>Had someone cut in front of you in line</td>
<td>.97</td>
<td>1.85</td>
<td>.488</td>
</tr>
</tbody>
</table>

Daily stressors with the greatest impact over the last week

Daily stressors with the least impact over the last week

The item with the lowest mean score, item 23, asked about public speaking or performance. The raw data indicated 65% of the participants gave a “0” as their response, meaning this stressor has not happened during the last week. The item with the highest mean
score, item 20, asked about forgetting something. The raw data showed 87.4% of participants had experienced this stressor over the last week. Of this group, 54.4% experienced moderate impact from this stressor (slightly stressful, mildly stressful, or moderately stressful), while 22.4% experienced much higher impact from this stressor (stressful, very stressful, or extremely stressful).

Most parents were strongly impacted by arguments or having too little time to decompress after a taxing day. They appear to remain unperturbed when they experienced a minor inconvenience such as being “cut off” in line or traffic. The mean for the total sample was 43.67 out of a possible 175. Overall, the participants reported experiencing very low levels of impact by daily stressors.

Severity of Behavior Problems

The severity of behavior problems was measured by a digitalized visual analog scale (VAS), designed by The Catholic University of America’s computer support team. Participants were asked to click on a point on the scale that represented the severity of their adolescent with ASD’s behavior problems. The left-hand anchor point of the VAS, associated with 1, was “not at all difficult” and the right-hand anchor point, associated with 100 was “extremely difficult.” The participants viewed a line on their computer screens that was composed of 100 images. Each image was 5 pixels wide and 20 pixels high. The image carried a value equal to its location in the sequence from 1 to 100. When one of the images was clicked, the computer interpreted the clicked image into scores ranging from 1 to 100 percent. The higher the score, the greater the severity of behavior problems the respondent perceived their adolescent with ASD was experiencing. Table 9 provides descriptive statistics for the VAS.
Table 9
Descriptive Statistics for the Severity of Behavior Problems Visual Analog Scale $^a$

<table>
<thead>
<tr>
<th>Range</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – 100</td>
<td>52.25</td>
<td>27.20</td>
</tr>
</tbody>
</table>

$^a$ N= 103

The examination of the data reveals a very even distribution of scores. There were 26 participants who rated the severity of their adolescent’s behavior problems in the bottom quartile, reflecting a very low level of severity. Also there were 27 participants who rated the severity of their adolescent’s behavior problems in the top quartile of the VAS, or the highest level of severity. Similarly, 27 rated the severity to be in the lower middle quartile and 23 in the upper middle quartile. Parents in the study faced severity of behavior problems across an entire spectrum.

The Severity of Behavior Problems, measured by a digitalized visual analog scale, was able to distinguish between groups of participants in this sample. In order to test this function, the total scores of the General Functioning Subscale were dichotomized. The GF subscale designers have associated participant’s scores over 2 to indicate a potential need for mental health resources. Participants who scored between a 1 and 2 on the GF scale were assigned a “1” and all those who scored above a 2 were assigned a “2”. This divided the total group into Group 1, those who did not need mental health support and Group 2, those who may require such assistance.

**Discriminant function.** An independent t-test was conducted to compare the severity of behavior scores between the two groups based on the participants’ GF scores. The Levene’s test for equal groups indicated the variances of the means were not the same. The t-test for Equality
of the means demonstrated there was a significant difference between the means of the two groups. The mean for Group 1 was 46.29 (SD 26.19) and the mean for Group 2 with scores was 58.06 (SD 27.85); t(96) = -2.156, p < .05. The magnitude of the differences in the means (mean difference = 11.78, 95% CI; -22.62 to -.936) was a moderate effect (eta squared = .05). This suggests the Severity of Behavior Problems VAS had some discriminant ability with this sample.

Data obtained from a VAS is accepted as interval-level data (Reips & Funke, 2008). It is often treated as non-parametric data when utilized for data analyses purposes (Ahearn, 1997). However, given the even distribution of the data from this sample, parametric procedures were utilized.

Other better recognized tools are available to assess the severity of behavior problems, including the Nisonger Child Behavior Rating from (Aman, Tasse´, Rojahn & Hammer, 1996) or the Child Behavior Checklist (Achenbach & Rescorla, 2011). However, they are lengthy, 66 and 120 questions respectively. Shorter instruments, such as the Childhood Autism Rating Scale, Second Edition (Schopler, Van Bourgondien, Wellman & Love, 2010), require specialized training prior to administration. The VAS performed adequately to determine the impact of this variable in this sample, without overburdening study participants.

The total mean for this sample was 52.25. This indicates, overall, most parents reported the severity of behavior problems their adolescents with ASD were experiencing was at the medium level, near the mid-point between the two extremes of “not at all difficult” and “extremely difficult.”
Parent’s Perception of Uncertainty in Illness (PPUS)

Parental uncertainty related to the adolescent with ASD’s disability was measured using the Parents’ Perception of Uncertainty in Illness Scale (PPUS) (see Appendix C). The instrument has 31 items which participants rated on a five-point Likert scale, (5) strongly agree to (1) strongly disagree. A total score may be calculated for the entire tool and scores range from 31 to 155. Also scores may be tallied for each of four subscales, ambiguity, lack of clarity, lack of information, and unpredictability. A higher score indicates greater uncertainty experienced by the participant regarding their child’s disability. The reliability of the entire instrument with this sample was a coefficient alpha of .86. This compares well to the Cronbach’s alpha given by the instrument’s designer of alpha of .81-.93 (Mishel, 1997). Descriptive statistics of the PPUS are presented in Table 10.

Table 10
Descriptive Statistics for the Parent’s Perception of Uncertainty in Illness (PPUS) a

<table>
<thead>
<tr>
<th>Range</th>
<th>M</th>
<th>SD</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>50 – 119</td>
<td>85.83</td>
<td>15.21</td>
<td>.86</td>
</tr>
</tbody>
</table>

a N= 89

Table 11 presents the responses to individual questions on the Parent’s Perception of Uncertainty in Illness (PPUS) which had the overall highest and lowest mean scores, indicating the highest and lowest sources of uncertainty regarding their adolescent’s disability. Item to total correlations in this scale and sample ranged from .021 to .661.

The item with the lowest mean score, item 26, asked the participant how strongly they agree/disagree to the statement regarding whether the child has been given a definite diagnosis. A review of the raw data for this item shows that 93% of the participants either disagreed or
strongly disagreed with the statement, or perhaps did not understand the diagnosis was definitive. The item with the highest mean score, item 18 asks how strongly the participant agrees/disagrees with the statement regarding how certain the participants is regarding what will happen to the child. The raw data indicates that 73.5% of participants agree or strongly agree with the statement.

Although they understand their adolescent’s diagnosis, they have uncertainty about the adolescent’s future. Several of the items had low item-total correlations, .021 for item 29, .068 for item 25, and .117 for item 31, suggesting they are not congruent with the underlying construct of uncertainty with this sample.

Table 11
Item Analysis for the Parent’s Perception of Uncertainty in Illness Survey (PPUS) \(^a\)

<table>
<thead>
<tr>
<th>Item #</th>
<th>Content area</th>
<th>M</th>
<th>SD</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>Ambiguity about child’s future</td>
<td>3.74</td>
<td>1.09</td>
<td>.593</td>
</tr>
<tr>
<td>27</td>
<td>Unpredictability regarding the course of the condition</td>
<td>3.72</td>
<td>1.07</td>
<td>.391</td>
</tr>
<tr>
<td>16</td>
<td>Ambiguity regarding changeability of symptoms</td>
<td>3.62</td>
<td>1.24</td>
<td>.531</td>
</tr>
<tr>
<td>17</td>
<td>It’s vague… how I will manage the care of my child</td>
<td>3.36</td>
<td>1.21</td>
<td>.483</td>
</tr>
<tr>
<td>15</td>
<td>Condition unpredictable, cannot plan for the future.</td>
<td>3.45</td>
<td>1.12</td>
<td>.591</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Least sources of uncertainty</th>
</tr>
</thead>
<tbody>
<tr>
<td>26</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>22</td>
</tr>
<tr>
<td>12</td>
</tr>
<tr>
<td>9</td>
</tr>
</tbody>
</table>

\(^a\) N = 89, \(^b\) 1-5 points, \(^c\) Corrected item to total correlation, \(^d\) reverse scored
**PPUS subscales reliability.** The PPUS measures four categories of uncertainty.

Therefore, the responses were further analyzed by subscales corresponding to each category: a) ambiguity, lack of clarity, lack of information, and unpredictability (See Table 12).

**Table 12**

<table>
<thead>
<tr>
<th>Sources</th>
<th># of items</th>
<th>Range</th>
<th>M</th>
<th>SD</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambiguity ^a</td>
<td>13</td>
<td>17-57</td>
<td>38.89</td>
<td>8.6</td>
<td>.83</td>
</tr>
<tr>
<td>Lack of Clarity ^b</td>
<td>9</td>
<td>10-38</td>
<td>23.36</td>
<td>5.29</td>
<td>.716</td>
</tr>
<tr>
<td>Lack of Information ^c</td>
<td>5</td>
<td>5-18</td>
<td>10.88</td>
<td>3.02</td>
<td>.525</td>
</tr>
<tr>
<td>Unpredictability ^d</td>
<td>4</td>
<td>4-20</td>
<td>12.64</td>
<td>3.05</td>
<td>.537</td>
</tr>
</tbody>
</table>

^aN= 95, ^bN = 99, ^cN = 100, ^dN = 102

Two of the four subscales, Ambiguity and Lack of Clarity had acceptable reliability coefficients ≥ .70. The other two subscales, Lack of Information and Unpredictability are composed of relatively few items. Scales with a low number of items may struggle with lower reliabilities (Pallant, 2007). Also the subscales are comprised of items that may not fit well together. For example, the Lack of Information subscale is composed of items 1, 12, 26, 28, and 30. By examining the raw data, four of these items make statements with which the majority (70-90%) of participants disagreed or strongly disagreed. Item 1 regarding lack of information about condition, item 12 regarding lack of information regarding treatments, and item 26 regarding lack of information regarding definite diagnosis. However there was no clear majority in participants’ responses to item 28 regarding the definitiveness of child’s diagnosis and item 30 regarding the seriousness of the condition. The raw data showed roughly 50% agreed, 25% undecided, and the remaining 25% disagreed. The frequencies of responses suggest the items on
this scale do not seem to measure the same underlying concept, lack of information, for this sample.

The same issue is true of the Unpredictability subscale. The scale is composed of items 11, 19, 23, and 27. For three items in this scale, participants were split in their responses. Roughly 45% agreed, 15% undecided, and 40% disagreed with the following items: item 11 regarding the predictability of the course of the condition, item 19 regarding of the predictability of symptoms, item 23 regarding the predictability of the condition. However, a strong majority (70.6%) disagreed with item 27 the predictability regarding the long term course of the child’s condition. This reflects the fact that the long term course of the condition is unpredictable. Seemingly with this sample, these items, collectively, do not measure the same element of unpredictability.

If any of the items were deleted from the underperforming subscales, the reliability would have only been enhanced slightly or would have worsened. While the total PPUS instrument has good reliability, the subscales work less well if used independently.

The overall mean score for this sample of the PPUS was 85.83 out of a possible 175, which is nearly at the midpoint of the possible range of scores. The participants were experiencing average amounts of uncertainty. The chief sources of uncertainty were related to daily changes in symptoms of the adolescent with ASD and concerns about the adolescent’s future.

Family Crisis Oriented Personal Evaluation Scales

The Family Crisis Oriented Personal Evaluation Scales (F-COPES) (Appendix D) was used to measure coping strategies. The F-COPES tool has 30 items rated on a five-point Likert
scale that ranges from (1) strongly disagree to (5) strongly agree. Items 12, 17, 26 and 28 were recoded prior to analysis. Total scores can range from 30 to 150. A higher score reflects the greater use of coping strategies and a better level of coping (McCubbin et al., 2003). Descriptive statistics on the F-COPES are presented in Table 13.

Table 13

Descriptive Statistics for the Family Crisis Oriented Personal Evaluation Scales (F-COPES) a

<table>
<thead>
<tr>
<th>Range</th>
<th>M</th>
<th>SD</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>64 – 128</td>
<td>89.34</td>
<td>12.29</td>
<td>.772</td>
</tr>
</tbody>
</table>

\(^a\) N= 91

Table 14 presents the responses to individual questions on the F-COPES which had the overall highest and lowest mean scores, indicating the most frequently and least frequently used coping strategies. Item to total correlation in this scale and sample ranged from -.092 to .538.

Table 14

Item Analysis for the Family Crisis Oriented Personal Evaluation Scales (F-COPES) a

<table>
<thead>
<tr>
<th>Item #</th>
<th>Content area</th>
<th>M</th>
<th>SD</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most frequently used coping strategies</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Facing problems “head on”</td>
<td>4.08</td>
<td>.833</td>
<td>.221</td>
</tr>
<tr>
<td>19</td>
<td>Accepting that difficulties occur unexpectedly</td>
<td>4.07</td>
<td>.772</td>
<td>.212</td>
</tr>
<tr>
<td>15</td>
<td>Accepting stressful events as a fact of life</td>
<td>4.00</td>
<td>.843</td>
<td>.316</td>
</tr>
<tr>
<td>30</td>
<td>Having faith in God</td>
<td>3.64</td>
<td>1.41</td>
<td>.342</td>
</tr>
<tr>
<td>7</td>
<td>We have the strength to solve our problems</td>
<td>3.63</td>
<td>1.02</td>
<td>.392</td>
</tr>
</tbody>
</table>
The F-COPES further explores dimensions of coping strategies by categorizing them into five subscales a) acquiring Social Support, b) Reframing, c) seeking Spiritual Support, d) mobilizing family to acquire and accept help (Family Support), and e) Passive Appraisal. Table 15 is a summary of the F-COPES subscales.

**F-COPES subscale reliabilities.** Three of the subscales, the Social Support, the Reframing strategies, and the Spiritual Support scales, had acceptable reliability coefficients ≥ .7. Two scales, Family Support and the Passive Appraisal had very low reliabilities. Both scales would have performed more poorly if any of the items were deleted.

Examining the frequencies of the raw data for the Family Support subscale suggests the questions may not be appropriate as a subscale for this sample. The subscale is composed of Items 4, 6, 9, and 21. Item 4 suggests coping by “seeking information and advice from persons in other families who have the same or similar problems.” The majority (61.8%) of participants, who are members of an on-line support network, agreed with this statement. However the three

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<table>
<thead>
<tr>
<th>Item #</th>
<th>Content area</th>
<th>M</th>
<th>SD</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>29</td>
<td>Sharing problems with neighbors</td>
<td>1.67</td>
<td>.883</td>
<td>.322</td>
</tr>
<tr>
<td>25</td>
<td>Asking relatives about problems we face</td>
<td>1.97</td>
<td>1.09</td>
<td>.400</td>
</tr>
<tr>
<td>27</td>
<td>Seeking advice from a minister</td>
<td>1.97</td>
<td>1.16</td>
<td>.538</td>
</tr>
<tr>
<td>10</td>
<td>Asking neighbors for favors and assistance</td>
<td>1.98</td>
<td>1.15</td>
<td>.232</td>
</tr>
<tr>
<td>8</td>
<td>Receiving gifts and favors from neighbors</td>
<td>2.34</td>
<td>1.25</td>
<td>.320</td>
</tr>
</tbody>
</table>

*a N = 91, b 1-5 points, c Corrected item to total correlation, d reverse scored*
remaining items, item 6, 9 and 21, suggest coping by seeking formal resources outside the family, for example, community agencies, professional counseling, and the family doctor. Item responses to these items were split for this sample. While nearly three-fifths of participants agreed they coped by using those resources, slightly more than a fifth disagreed with the statement, and the remainder were undecided. The items collectively in the Family Support subscale may not measure the same construct with this sample.

Similarly, the Passive Appraisal subscale does not function well with this sample. It is comprised of items 12, 17, 26, and 28. This subscale suggests participants cope by more internal methods of handling stress: item 12 by watching television, item 17 by trusting in luck, item 26 by feeling helpless against fate, and item 28 by waiting for the problem to resolve itself. A strong majority of participants (63 – 87%) disagreed strongly with coping by trusting in luck or wishing the problem away. However there were widely divided responses with no clear majority related to coping by watching television and feeling helpless.

Similarly, the Passive Appraisal subscale does not function well with this sample. It is comprised of items 12, 17, 26, and 28. This subscale suggests participants cope by more internal methods of handling stress: item 12 by watching television, item 17 by trusting in luck, item 26 by feeling helpless against fate, and item 28 by waiting for the problem to resolve itself. A strong majority of participants (63 – 87%) disagreed strongly with coping by trusting in luck or wishing the problem away. However there were widely divided responses with no clear majority related to coping by watching television and feeling helpless.
Table 15
Descriptive Statistics for the F-COPES Subscales

<table>
<thead>
<tr>
<th>Sources</th>
<th># of items</th>
<th>Range</th>
<th>M</th>
<th>SD</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support 🅛</td>
<td>9</td>
<td>9-35</td>
<td>22.87</td>
<td>6.73</td>
<td>.81</td>
</tr>
<tr>
<td>Reframing 🅜</td>
<td>8</td>
<td>18-40</td>
<td>30.33</td>
<td>4.44</td>
<td>.75</td>
</tr>
<tr>
<td>Spiritual Support 🅝</td>
<td>4</td>
<td>4-20</td>
<td>11.40</td>
<td>4.83</td>
<td>.88</td>
</tr>
<tr>
<td>Family Support 🅞</td>
<td>4</td>
<td>4-19</td>
<td>13.19</td>
<td>3.37</td>
<td>.64</td>
</tr>
<tr>
<td>Passive Appraisal 🅟</td>
<td>4</td>
<td>4-17</td>
<td>9.30</td>
<td>2.87</td>
<td>.47</td>
</tr>
</tbody>
</table>

* N= 99, b N = 101, c N = 101, d N= 101, e N = 102

The total mean score for the F-COPES with this sample was 89.34, out of a possible 150. Overall, the participants were utilizing slightly above the average amount of coping strategies.

Accompanying the F-COPES instrument, McCubbin, Thompson & McCubbin, (2003) provided comparative data from a normative sample. The overall means for the total F-COPES for the normative sample was 95.91 (SD 12.17). By comparison, the normative sample had higher use of coping strategies (better coping) than the participants in this sample.

Summary of Instrument Data

Reliability analyses of the General Functioning subscale, the Weekly Stressors Inventory-SF, the Parents’ Perception of Uncertainty in Illness Scale, and the Family Crisis Oriented Personality Evaluation Scales demonstrated excellent internal consistency in this sample. The VAS to measure severity of behavior problems demonstrated a discriminant function.

Hypothesis Testing

The following research hypotheses were investigated in this study:

H1a Family members reporting greater impact of daily stressors will have a lower level of family adaptation in families of adolescents with ASD.
H1b. Family members reporting greater severity of behavior problems in their adolescent with ASD will have a lower level of family adaptation in families of adolescents with ASD.

H1c. Family members with greater levels of uncertainty will have lower levels of family adaptation in families of adolescents with ASD.

H1d. Family members reporting greater use of coping strategies will have higher levels of family adaptation in families of adolescents with ASD.

H2. The combined effect of daily stressors, severity of behavior problems, uncertainty and coping strategies will contribute significantly to explain the variance in family adaptation in families of adolescents with ASD.

**Missing Data Addressed**

For the purposes of hypothesis testing, the means for missed items on the research instruments, were imputed. See Table 16 for the details.

**Table 16**

<table>
<thead>
<tr>
<th>ID</th>
<th>GF a</th>
<th>Age</th>
<th>Edu</th>
<th>WS b</th>
<th>PPUS c</th>
<th>FCOPEd</th>
<th>ID</th>
<th>GF a</th>
<th>Age</th>
<th>Edu</th>
<th>WS b</th>
<th>PPUS c</th>
<th>FCOPEd</th>
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<tbody>
<tr>
<td>3</td>
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<td>18</td>
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<td>74</td>
<td>2</td>
<td></td>
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<td>1</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
Correlation Analysis

Relationships among the variables were determined using Pearson Product-moment correlation analysis. Table 17 presents a correlation matrix of the study’s variables.

There were several significant relationships. Logically, there was a statistically significant direct relationship between increased age and increased level of education ($r = .286$, $p \leq .01$). Also, there was an inverse relationship between the level of education and the severity of behavior problems ($r = .215$, $p \leq .05$) or as education increased, the severity of behavior problems decreased. Perhaps imbedded in the advanced education were additional skills to address the child with ASD’s behavior problems, thus leading to fewer behavioral issues. Less clear is an explanation for the inverse relationship between increased level of education and decreased use of coping strategies ($r = -.221$, $p \leq .05$).
Table 17

Zero Order Correlation Among the Study Variables $^a$

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Age $^b$</td>
<td>1</td>
<td>.286**</td>
<td>.072</td>
<td>-.005</td>
<td>-.011</td>
<td>-.071</td>
<td>-.067</td>
</tr>
<tr>
<td>2 Education $^c$</td>
<td>1</td>
<td>.047</td>
<td>-.215*</td>
<td>.040</td>
<td>-.113</td>
<td>-.221*</td>
<td></td>
</tr>
<tr>
<td>3 Family adaptation</td>
<td>1</td>
<td>.303**</td>
<td>.261**</td>
<td>.351**</td>
<td>-.260**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Severity of behavior problems</td>
<td>1</td>
<td>.338**</td>
<td>.303**</td>
<td>-.124</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Daily stressors</td>
<td>1</td>
<td>.314**</td>
<td>-.130</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Uncertainty</td>
<td>1</td>
<td>-.333**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Use of coping strategies</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

$^a$ N= 103, $^b$ in years, $^c$ grade level completed,**significant at the .01 level, * significant at the .05 level

There were several significant relationships. Logically, there was a statistically significant direct relationship between increased age and increased level of education ($r = .286$, $p \leq .01$). Also, there was an inverse relationship between the level of education and the severity of behavior problems ($r = .215$, $p \leq .05$) or as education increased, the severity of behavior problems decreased. Perhaps imbedded in the advanced education were additional skills to address the child with ASD’s behavior problems, thus leading to fewer behavioral issues. Less clear is an explanation for the inverse relationship between increased level of education and decreased use of coping strategies ($r = -.221$, $p \leq .05$).
There were several statistically significant relationships that appear interconnected and were related to less effective family adaptation. First, as the severity of behavior problems increased, the scores for family adaptation scores increased, reflecting less effective adaptation \((r = .303, p \leq .01)\). The relationship between the variables of daily stressors and family adaptation and for uncertainty and family adaptation is similar. As the impact of daily stressors increased, so did the family adaptation scores, reflecting less effective family adaptation \((r = .261, p \leq .01)\). Also as uncertainty regarding the adolescent with ASD’s disability increased, family adaptation scores increased, again reflecting less effective family adaptation \((r = .351, p \leq .01)\). One variable, use of coping strategies, was related to more effective family adaptation. As the use of coping strategies decreased, the family adaptation scores increased, reflecting less effective family adaptation \((r = -.260, p \leq .01)\).

Two variables were related to increased impact of daily stressors, a) increasing severity of behavior problems and b) increasing uncertainty regarding the adolescent with ASD’s disability. The relationship between the severity of behavior problems and the impact of daily stressors was determined to be \(r = .338, (p \leq .01)\) and the relationship between impact of daily stressors and uncertainty regarding the adolescent with ASD’s disability was determined to be \(r = .314 (p \leq .01)\). Also there was a statistically significant relationship between the impact of the severity of behavior problems and increased level of uncertainty regarding the adolescent with ASD’s disability \((r = .303, p \leq .01)\).

Finally, there was an indirect relationship between participant’s perception of uncertainty regarding the adolescent with ASD’s disability and the use of coping strategies \((r = -.333, p<.01)\). Participants who perceived their adolescents to have more severe behavior problems
reported using fewer coping strategies than parents who perceived their adolescents with ASD to have less severe behavior problems.

Although there were several statistically significant relationships among the variables, there was no evidence of multicollinearity. First, none of the correlations were significantly above .3 and well below the accepted .85 “cut off” indicating issues with multicollinearity (Munro, 2005). Second, Tolerance and Variable Inflation Factor (VIF) were acceptable and will be discussed further in the chapter.

Multiple Regression Analysis

Hierarchical multiple regression analysis was utilized to investigate the relationship between family adaptation in families of adolescents with ASD and the study’s variables using SPSS version 20.0 (2011) statistical software. Family adaptation was the dependent variable. Age of the participant and level of education were used as controlling variables and were entered into the model first. The independent variables were then entered into the model in the following sequence: a) daily stressors, b) severity of behavior problems, c) uncertainty, and d) use of coping strategies. The order of entry into the hierarchical multiple regression was based on the theoretical sequencing of components in the RMF model. The level of statistical significance was set at an alpha of .05 when the variable was entered into the equation.

Examination of assumptions for multiple regression. Prior to conducting the hierarchical regression analysis, an examination of all the underlying assumptions for multiple regression was performed. There were no significant violations of normality, linearity, homoscedasticity, multicollinearity, or evidence of significant outliers.
**Multicollinearity.** The correlations between the study’s variables were all well below the .7 “cut off” value conventionally accepted as indications of multicollinearity (Munro, 2005; Meyers, Gamst & Guarino, 2006). Additionally, the collinearity diagnostics, output of the SPSS program, support the lack of multicollinearity among the variables. The Tolerances were larger than the minimum acceptable level of .1 (Pallant, 2007; Meyers et al., 2006) and the VIF were smaller than the largest acceptable value of 10 (Pallant; Meyers et al.).

Table 18

<table>
<thead>
<tr>
<th>Variable</th>
<th>Tolerance</th>
<th>VIF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of Participant</td>
<td>.910</td>
<td>1.099</td>
</tr>
<tr>
<td>Education</td>
<td>.791</td>
<td>1.264</td>
</tr>
<tr>
<td>Daily Stressors</td>
<td>.819</td>
<td>1.221</td>
</tr>
<tr>
<td>Severity of Behavior Problems</td>
<td>.790</td>
<td>1.265</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>.756</td>
<td>1.323</td>
</tr>
<tr>
<td>Use of coping Strategies</td>
<td>.814</td>
<td>1.226</td>
</tr>
</tbody>
</table>

*Statistics from the final regression model, **VIF = Variable Inflation Factor*

**Normality.** The Kolmogorov-Smirnov Test of Normality for General Function was non-significant, indicating normal distribution. Also the histograms of all the study’s variables showed relatively normal distribution. Additionally, the Normal Q-Q Plot for all variables showed a relatively straight line suggesting normal distribution. The Detrended Normal Q-Q Plots revealed an absence of clustering around the zero line. Finally, a boxplot of the distribution of scores revealed relatively little skewing of data.
**Outliers.** There were no significant outliers. The Normal P-P Plot of Regression standardized residuals demonstrated a reasonably straight line from bottom left hand corner to upper right hand corner. The Mahalanobis distance value can be calculated on the regression z-scored regression residuals to indicate potential presence of significant outliers. For this study the Mahalanobis value was 19.128 and did not exceed the critical value for 6 independent variables of 22.46 (Pallant, 2007).

**Linearity.** A scatterplot of the residuals for each variable against those of the dependent variable of family adaptation revealed a positive linear pattern. The direction of the linear pattern for the independent variable, use of coping strategies, was a negative pattern. There was no evidence of curvilinear relationship or other unusual pattern.

**Homoscedasticity.** A scatterplot of the data showed acceptal evidence of a “rectangularity” of distribution in the residuals scatterplot output (Meyers, Gamst & Guarino, 2006).

**Discussion of Hypothesis 1a through 1d Testing**

Table 19 summarizes the results of the multiple regression using the hierarchical model as each independent variable was entered into the model with the scores on the General Functioning subscale as the dependent variable.
Hypothesis 1a: daily stressors. Family members reporting greater impact by daily stressors will have a lower level of family adaptation in families of adolescents with ASD. Step two of the regression analysis demonstrated a significant relationship between daily stressors and family adaptation [F (3, 99) = 7.3, p = .008, sign]. Daily stressors accounted for 6.8% of the variance (R^2 change = .068) of family adaptation. The statistical hypothesis that there would be no difference in the family adaptation in families of adolescents with ASD who had greater impact of daily stressors and those with less impact of daily stressors was therefore rejected and the research hypothesis was supported.

Hypothesis 1b: Severity of behavior problems. H1b: Family members reporting greater severity of behavior problems in their adolescent with ASD will have a lower level of family
adaptation in families of adolescents with ASD. When severity of behavior problems was entered into the regression equation, there was also a statistically significant relationship between this independent variable and family adaptation \[F(4, 98) = 6.5, p = .012, \text{sign}\]. Severity of behavior problems contributed 5.8\% (\(R^2\) change = .058) to the variance in family adaptation. The statistical hypothesis that there would be no difference in the family adaptation in families of adolescents with ASD who perceived their adolescents to have a greater severity of behavior problems and those who perceived their adolescents to have a lower severity of behavior problems was therefore rejected and the research hypothesis was supported.

**Hypothesis 1c: Uncertainty regarding the adolescent with ASD’s disability.** Family members with greater levels of uncertainty will have lower levels of family adaptation in families of adolescents with ASD. With the addition of the independent variable, parent’s uncertainty regarding their adolescent’s disability into the regression, there was a statistically significant relationship with family adaptation \[F(5, 97) = 7.6, p = .007, \text{sign}\]. Uncertainty contributed 6.3\% (\(R^2\) change = .063) to the variance in family adaptation. The statistical hypothesis that there would be no difference in the family adaptation in families with a greater level of uncertainty regarding their adolescent’s disability and those with lower levels of uncertainty regarding their adolescent’s disability was therefore rejected and the research hypothesis was supported.

**Hypothesis 1d: Coping strategies.** H1d: Family members reporting greater use of coping strategies will have higher levels of family adaptation in families of adolescents with ASD. Step five of the regression, which was the addition of the variable, use of coping strategies, did not show a statistically significant relationship between this independent variable and family
adaptation \[F(6, 96) = 1.6, p = .209, \text{NS}\]. The statistical hypothesis that there would be no
difference in the family adaptation in families with a greater use of coping strategies and those
with less use of coping strategies was supported and therefore the research hypothesis was
rejected.

**Discussion of Hypothesis 2 Testing: Combined Effects**

H2: The combined effect of daily stressors, severity of behavior problems, uncertainty,
and coping strategies will explain a significant amount of the variance in family adaptation in
families of adolescents with ASD. When all the independent variables were entered into the
regression analysis, a statistically significant amount of the variance in family adaptation was
explained \[F (6, 96) = 4.197, p \leq .001\]. See Table 20. The full model explained 20.8% of the
variance in family adaptation.

Table 20

<table>
<thead>
<tr>
<th>Variable</th>
<th>Sum of Squares</th>
<th>df of F</th>
<th>Cumulative F (^b)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age and Education</td>
<td>.133</td>
<td>2, 100</td>
<td>.297</td>
<td>.744</td>
</tr>
<tr>
<td>Daily Stressors</td>
<td>1.670</td>
<td>3, 99</td>
<td>2.643</td>
<td>.053*</td>
</tr>
<tr>
<td>Severity of Behavior Problems</td>
<td>2.970</td>
<td>4, 98</td>
<td>3.721</td>
<td>.007**</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>4.383</td>
<td>5, 97</td>
<td>4.687</td>
<td>.001***</td>
</tr>
<tr>
<td>Use of coping strategies</td>
<td>4.681</td>
<td>6, 96</td>
<td>4.197</td>
<td>.001***</td>
</tr>
</tbody>
</table>

\(^a\) N = 103, \(^b\) Cumulative F values for when all variables entered into the equation * p < .05,
** p = .007, *** p < .001
The statistical hypothesis that the combined effects of daily stressors, severity of behavior problems, parent’s uncertainty regarding the adolescent with ASD’s disability, and use of coping strategies will not explain a significant amount of variance in family adaptation in families of adolescents with ASD was rejected. The research hypothesis that the combined effect of daily stressors, severity of behavior problems, uncertainty, and coping strategies will explain a significant amount of the variance in family adaptation in families of adolescents with ASD is supported.

**Summary of the Findings**

This chapter presented the findings of the study. The characteristics of the participant and their adolescent with ASD were discussed. The data collection instruments were evaluated. The Severity of Behavior Problems VAS provided normally distributed data and demonstrated a discriminant function. The other research instruments showed good internal consistency when used for total scores.

Five research hypotheses were tested using hierarchical multiple regression. Four of the hypotheses were supported. There was no statistically significant difference in family adaptation in families of adolescents with ASD based on the use of coping strategies. The following model was used for the analysis: a) first the controlling variables of age and education were entered into the model, b) daily stressors, c) severity of behavior problems, d) uncertainty regarding the adolescent’s disability, and e) use of coping strategies. The combination of the independent variables explained 20.8% of the variance of family adaptation, with parent’s perception of uncertainty regarding their adolescent with ASD’s disability making a unique contribution.
The next chapter will provide a discussion of the research findings. It will also present implications for nursing and other health professionals.
Chapter V
Discussion, Conclusions, Implications, and Recommendations

Purpose and Hypotheses

This study investigated the relationships among several variables: a) daily stressors, b) the severity of behavior problems, c) parents’ perceptions of uncertainty regarding their adolescent with ASD’s disability, d) use of coping strategies, and d) family adaptation in families of adolescents with ASD. Also the independent effect and combined effect of the independent variables on the dependent variable of family adaptation was investigated. The research hypotheses were:

H1a: Family members reporting greater impact of daily stressors will have a lower level of family adaptation in families of adolescents with ASD.

H1b: Family members reporting greater severity of behavior problems in their adolescent with ASD will have a lower level of family adaptation in families of adolescents with ASD.

H1c: Family members with greater levels of uncertainty will have lower levels of family adaptation in families of adolescents with ASD.

H1d: Family members reporting greater use of coping strategies will have higher levels of family adaptation in families of adolescents with ASD.

H2: The combined effect of daily stressors, severity of behavior problems, uncertainty, and coping strategies will contribute significantly to explain the variance in family adaptation in families of adolescents with ASD.
Problem

This study addressed an identified lack of evidence related to families of adolescents with ASD. Studies of parents of younger children with ASD demonstrated the parents have increased levels of parental stress, marital discord, and less effective family adaptation (Altieri & von Kluge, 2009; Pakenham et al., 2005; Stoneman & Gavidia-Payne, 2006). Qualitative studies conducted with parents of adolescents with ASD have described similar findings (Fong 1992; Gray, 2006; Lutz, 2008). Also, a quantitative study comparing mental health outcomes in mothers of children with ASD found mothers of adolescents with ASD had increased levels of distress and lower levels of maternal well-being compared to mothers of younger children (Smith, Seltzer, et al., 2008). However, quantitative studies related to adolescents with ASD have been limited to mothers. Therefore this study aimed to provide a more inclusive sample by expanding the eligibility criteria and utilizing a nationwide selection pool to address this gap in the literature. Finally, no previous research was located through a review of literature on family adaptation in families of adolescents with ASD. Also no study was located that investigated the effects of the combination of variables, selected for this study, on family adaptation. Consequently, this study was conducted to address this gap in the literature.

Conceptual Framework

The Resilience Model of Family Adjustment and Adaptation (RMF) served as the conceptual framework for this study. The RMF proposes that family adaptation is the net outcome of the interaction of several components in the model: a) stressors, strains, or a pile up of demands, b) situational appraisal, c) family recovery resources, and d) the utilization of problem-solving and coping strategies. In other words, family adaptation is considered to be a
point on the continuum between bonadaptation (effective adaptation) and maladaptation (ineffective adaptation). The effectiveness of adaptation takes into account changes at both the individual and the family level. If the family is proficient at balancing demands on the one hand, and resources on the other, then the level of family adaptation will likely be effective (McCubbin et al., 2003).

**Methodology**

The influence of each component in the model was investigated in part, to test the validity of the RMF in predicting family adaptation in families of adolescents with ASD. Family adaptation, the dependent variable in this study, was measured by the total scores on the General Functioning subscale (Ryan, Keitner, Miller, & Bishop, 2005). In order to investigate the influence of a pile up of demands, daily stressors were measured by the Weekly Stressors Index-SF (Brantley et al., 2008). The severity of behavior problems, also, was measured as a type of stressor. This variable was measured by a visual analog scale. Situational appraisal can be influenced by uncertainty. The Parent’s Perception of Uncertainty in Illness (Mishel, 1997) was utilized to measure the variable of uncertainty. The use of coping strategies, which may counterbalance negative stressors, was measured by the F-COPES instrument (McCubbin et al., 2003).

Participants completed five research instruments and a background information form by means of a web-based, computer-administered design. Each instrument measured one of the variables in the study.

Descriptive statistics and correlational analyses were conducted to describe the sample and the relationships among the variables. Hierarchical multiple regression analysis was utilized
to determine the influence of each independent variable on the dependent variable of family adaptation and also to determine the combined effect of all the independent variables in explaining the variance in the dependent variable of family adaptation. The order of entry into the hierarchical multiple regression was based on the theoretical sequencing of components in the RMF model.

Data for the study were collected over a one-month period using a randomly selected sample of 500 families of adolescents with ASD recruited from the Interactive Autism Network (IAN). One hundred eighteen participants completed the study. However, 103 participants had sufficient usable data to be included in the study. The remaining fifteen were eliminated for the following reasons: a) too much missing data (more than two items missed on any instrument), b) did not provide the age of the adolescent with ASD, or c) failed to complete the single-item severity of behavior problems visual analog scale (VAS).

Findings

Demographic characteristics. The mean age of the participants was 49.3 years of age and 91.3% were mothers. The majority of the adolescents were male (84.5%) and their mean age was 16.2 years. The sample, although randomly selected, lacked diversity. Few fathers, few members of ethnically diverse background, and few members of alternative household arrangements were represented, in spite of broad eligibility criteria. The eligibility criteria were one or both biological parent(s), one or both adoptive parent(s), a stepparent, a partner of a parent, or one or both custodial grandparents of an adolescent with autism; an adolescent for this study is a child ages 13 to 22. While there was a wide range of economic and educational background represented in this sample, the sample was comprised of largely White (90.2%)
mothers (91.3%). Other ethnicity/races were represented; Latino (4.9%), Asian (2%), African American, South Asian, and mixed ethnicity, one percent each. Nine fathers and one grandmother participated as well. With the exception of one custodial grandmother, all families of the adolescents with ASD were biological or adoptive parents.

**Demographic characteristics comparison.** This sample is similar to the other studies conducted with families of children with ASD and those with families of adolescents with ASD. For example, the largest collection of studies investigating families of adolescents and adults with ASD is the longitudinal Adolescents and Adults with Autism (AAA) dataset (Seltzer et al., 2003; Shattuck et al., 2007). The initial sample of the AAA dataset was comprised of White (91%) mothers (100%) who were 44.36 years old. The majority was married (86%), and worked outside the home (66.7%). They had a college degree (58%) or graduate degree (23%) and had an annual income between $45,000 and $60,000. The majority of the adolescents were male (74%) and aged 14.77 years of age (Barker, Seltzer & Greenberg, 2011).

By comparison, this study’s sample was comprised of fewer married participants (77.7% versus 86%) and had a greater diversity in education and income represented. However, in this sample, adult male participation was 9%, whereas Seltzer et al.’s (2003) sample was entirely female. Also more male adolescents with ASD were represented in this sample (84.5% versus 74%), and the adolescents in the sample were slightly older (16.24 versus 14.77 years) than in Seltzer et al.’s. On the whole, this study’s sample, while lacking somewhat in diversity, is similar to other studies with families of adolescents with ASD.

**Findings of multiple regression.** Hierarchical regression analysis was used to test each of the hypotheses for the study and statistically significant relationships among the variables
were noted as well. Each of the independent variables of a) daily stressors, b) severity of behavior problems, and c) uncertainty regarding the adolescent with ASD’s disability were statistically significant when entered into the regression model. Utilizing this hierarchical regression model, the variable of the use of coping strategies was not statistically significant when added to the equation. The full regression model was also statistically significant and explained 20.8% of the variance in family adaptation. Using this regression model, parent’s uncertainty regarding the adolescent’s disability was the most impactful variable.

Similar to this study, Warter (2009) found uncertainty played a role in family adaptation in families of younger children with ASD. However, other than this current study, no other study could be located that investigated the role of uncertainty upon family adaptation in families of adolescents with ASD. It demonstrated that parents’ perceptions of uncertainty regarding their adolescent with ASD’s disability have an important influence on the family’s adaptation during the transitional years of adolescence.

**Discussion of the Research Hypotheses**

Five research hypotheses were tested and all except one were supported. Using hierarchical multiple regression analysis, the full regression model explained 20.8% of the variance in family adaptation. The blocking variables of age and education as well as coping strategies were not statistically significantly related to family adaptation. Interpretation of findings of the hypotheses testing is presented.

**Hypothesis 1a: Daily Stressors**

The first hypothesis stated that family members who report greater impact of daily stressors will have a lower level of family adaptation in families of adolescents with ASD.
When entered into the multiple regression equation, a significant relationship was identified between the variable of daily stressors and family adaptation \([F (3,99) = 7.3, p = .008]\). As the scores for daily stressors increased, the scores measuring family adaptation increased as well, reflecting less effective family adaptation. Based on these findings, research H1a, was supported. The total mean score for this sample was 43.67 out of a possible range of 0 to 175, reflecting a relatively low level of impact from the stressors. Even so, the regression model data demonstrated the variable of daily stressors exerted a measurable impact on the families of adolescents with ASD’s ability to adapt and maintain equilibrium.

This finding is similar to research conducted by Smith et al. (2010) who investigated the types and impact of daily stressors on mothers of adolescents and adults with ASD using the Adolescent and Adult with Autism (AAA) dataset (Seltzer et al., 2003; Shattuck et al., 2007). The researchers compared daily stressors with mothers of normally-developing adolescents and adults and of the two groups found the mothers of adolescents with ASD had a greater number of and higher impact of daily stressors. The study, also, found mothers of adolescents and adults with ASD reported a daily stressful event nearly three times more often than their comparison counterparts. The stressful events included: a) extra time needed to care for their child, b) child-related issues interrupting their work day, and c) arguments and avoided arguments, both at work and at home. However, the study regarding daily stressors was limited to mothers (Smith et al., 2010).

Furthering this work, Wong et al. (2012) studied the interrelationships of several variables in mothers of adolescents and adults with ASD and found that daily stressors were especially influential in conjunction with the negative life events the mother was experiencing.
The morning cortisol level was utilized as an indicator of effectiveness of stress response. The data were drawn from the AAA dataset (Seltzer et al., 2003; Shattuck et al., 2007) from Time 4 (2004) and Time 5 (2006-2007). The mean age of the mothers of adolescents and adults with ASD was 51.4 years, and the mean age of the individual with ASD was 22.1 years and Time 4.

The study revealed mothers who experienced a greater number of both daily stressors and negative life stressors had a flatter morning cortisol level, reflecting an abnormal, inadequate stress response. This effect was heightened in mothers who reported a greater impact of daily stressors during the previous day. Analyzing the trajectories of these variables between Time 4 and Time 5, the relationship was expressed by the equation “(stressor slope estimated at zero negative life events; $\beta = 0.097$, SE = .0048, p < .05)” (p. 947). The researchers also found a statistically significant interaction between participants’ daily stressor severity and the number of negative life events on awakening cortisol level ($\beta = 0.025$, SE = 0.010, p < .05)” (p. 947).

The researchers concluded while daily stressors exert a negative influence on the mothers with adolescents with ASD, the total life experience of the mother also must be considered. Further research to better understand these interrelationships would be valuable for mothers and by extension, families of adolescents with ASD.

**H1b: Severity of Behavior Problems**

H1b stated family members reporting greater severity of behavior problems in their adolescent with ASD will have a lower level of family adaptation in families of adolescents with ASD. When entered into the multiple regression equation, a significant relationship was identified between the variable of the severity of behavior problems and family adaptation [$F (4, 98) = 6.5$, $p = .012$]. As the parents perceived greater severity of behavior problems (higher
scores) of their adolescents with ASD the family adaptation scores increased as well, reflecting less effective family adaptation. Based on these findings, the H1b research hypothesis was supported. The total mean score for this sample was 52.25 out of a possible 100 and reflected moderate severity of behavior problems. However, this variable had a negative influence on family adaptation.

Other research has reported similar findings in younger children with ASD. Warter (2009) investigated the relationships among several variables and explored which have moderating effects on family adaptation with families of children with ASD (mean age 8.8 years). The researcher measured family adaptation with the Family Quality of Life Survey (FQOL; Beach Center on Disability, 2003) and measured severity of behavior problems with the Parental Concerns Questionnaire (PCQ; McGrew, 2007). The PCQ is a 13-item self-report instrument with strong internal consistency reported as .93 and convergent validity with two other behavior problem evaluating instruments. In Warter’s correlational analysis, a statistically significant indirect relationship was observed between the severity of behavior problems and family adaptation, or as the parents perceived their children’s behavior problems to be more severe, family functioning was less effective. The strength of the relationship was expressed as (r = -.478, p < .01).

Manning, Wainwright, and Bennett (2011) also observed a statistically significant inverse relationship between the severity of behavior problems and family adaptation in families of children with ASD (mean age 8.8 years) in their investigation of the effects of four variables on family adaptation. They found as the severity of behavior problems increased, the effectiveness of family functioning decreased. The researchers measured the severity of behavior problems
with the Social Communication Questionnaire (SCQ; Berument, 1999), a 40-item instrument and
the outcome measurement of family adaptation was measured by the Family Environment Scale
(Moos & Moos, 1981). The sample for Manning et al.’s study was notably more diverse
compared to most studies of families of children with ASD. Whites represented 59% of the
sample and five other races/ethnicity represented between 5 and 25% of the remaining
participants. The researchers found the severity of behavior problems had a moderately strong
negative impact on family functioning \(r = -0.34, p < .01\), or parents who perceived their
children’s behavior problems to be more severe, also reported less effective family functioning.

This current study appears to be the first to measure the effect of severity of behavior
problems on families of adaptation in families of adolescents with ASD. In the full regression
model, the severity of behavior problems trended towards statistical significance at \(p = .056\) and
in the zero-order correlation analysis, the relationship between the two variables was \(r = 0.303, p
\leq .01\). Greater severity of behavior problems was related to less effective family adaptation.

**H1c. Parent’s Perception of Uncertainty in Illness**

H1c stated family members who reported greater levels of uncertainty will have lower
levels of family adaptation in families of adolescents with ASD. When entered into the
hierarchical multiple regression equation, a significant relationship was identified between the
variable of the parent’s perception of uncertainty of the adolescent with ASD’s disability and
family adaptation \([F (5, 97) = 7.6, p = .007]\). Parents, who reported greater uncertainty regarding
their adolescent’s disability (higher scores), also had higher family adaptation scores, reflecting
less effective family adaptation. Based on these findings, the H1c research hypothesis was
supported.
The total mean score for this sample was 85.83 out of a possible 175 and reflected average levels of parental uncertainty. Nonetheless, this variable had a measurable, negative effect on family adaptation.

**Comparison with other studies using the PPUS instrument.** Families of adolescents with ASD in this sample had similar levels of uncertainty for the total PPUS instrument as did the PPUS comparison sample. The PPUS instrument manual provides pooled data deposited by a number of researchers utilizing the instrument, and the deposited data may serve as a comparison sample \(N = 899\) (Mishel & Epstein, 1990). The types of medical issues represented in the PPUS comparison sample included children hospitalized for acute infections, surgery, or trauma, and non-acute, non-hospitalized children with mental health issues and cystic fibrosis. The mean score for the total PPUS instrument for the PPUS comparison group was 80.1 (Mishel & Epstein). Since the possible scores for the total PPUS range from 1 to 175, the PPUS comparison group overall experienced slightly lower than average levels of uncertainty regarding their child’s condition (Mishel & Epstein, 1990).

The levels of parental uncertainty differed for the total PPUS and its subscales between this sample in this current study, the pooled data for the PPUS comparison group (Mishel & Epstein), and two other studies that utilized the PPUS. Warter (2009) utilized the PPUS to determine the role uncertainty played in the process of family adaptation in families of children with ASD (mean age 10.4 years). LoBiondo-Wood, Williams, and McGhee (2004) administered the PPUS when investigating uncertainty, family stress, severity of stressor, coping, and family adaptation in mothers of young children awaiting a liver transplantation (mean age 3.6 years). Table 21 presents comparison data between this current study, the PPUS comparison group
The sample in this current study, LoBiondo et al.’s, and Warter’s samples had similar total PPUS scores, reflecting similar levels of uncertainty as that of the PPUS comparison group. However there were differences in the mean scores of the PPUS subscales.

**Comparison of PPUS subscale scores.** A comparison of the mean scores on the PPUS subscales reveal differing sources of uncertainty between the various studies’ samples. Warter’s study with younger children with ASD did not report on the PPUS subscales and therefore could not be utilized for comparison.

<table>
<thead>
<tr>
<th>Mean Score of Instrument</th>
<th>This study</th>
<th>LoBiondo-Wood et al.</th>
<th>Warter</th>
<th>PPUS comparison sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>85.53</td>
<td>87.9</td>
<td>85.81</td>
<td>80.1</td>
</tr>
<tr>
<td>Lack of Information</td>
<td>10.88</td>
<td>10.5</td>
<td>N/A</td>
<td>11.8</td>
</tr>
<tr>
<td>Ambiguity</td>
<td>38.89</td>
<td>36.2</td>
<td>N/A</td>
<td>33.80</td>
</tr>
<tr>
<td>Unpredictability</td>
<td>12.64</td>
<td>29.0</td>
<td>N/A</td>
<td>12.7</td>
</tr>
<tr>
<td>Lack of Clarity</td>
<td>23.36</td>
<td>12.1</td>
<td>N/A</td>
<td>21.8</td>
</tr>
</tbody>
</table>

This current study’s sample of families of adolescents with ASD and mothers of young children awaiting liver transplantation (LoBiondo et al., 2004) had similar scores on the Lack of Information and the Ambiguity subscales as the PPUS comparison group (Mishel & Epstein, 1990).
However, mothers of children awaiting liver transplantation (LoBiondo et al.) had scores on the Unpredictability subscale that were nearly double that of the other groups of parents. The Unpredictability subscale asks parents about the long term predictability of the condition, the predictability of the child’s symptoms, and predictability of improvement in the child’s condition. An item analysis of responses to the PPUS questionnaire revealed this type of unpredictability was the greatest cause of uncertainty for mothers of children awaiting liver transplantation.

By contrast, families of adolescents with ASD and the PPUS comparison group (Mishel & Epstein) had scores in the Lack of Clarity subscale that were nearly double that of mothers of children awaiting liver transplantation (LoBiondo et al.). (Refer to Table 21). The Lack of Clarity subscale asks parents whether they have unanswered questions, whether explanations about their child’s condition are hazy, and whether the roles of the staff are clear to them. Mothers of children awaiting liver transplantation (LoBiondo et al.) appeared to have a solid understanding of the management of their child’s conditions, whereas parents of adolescents with ASD appeared to be less certain about management issues. One explanation for this may be the lack of clear guidance regarding best treatment approaches for children with ASD.

Lack of clarity and unpredictability of autism symptoms, including behavior problems were an important source of uncertainty for families of adolescents with ASD. This current study is the first study that could be located that measured uncertainty in parents of adolescents with ASD utilizing quantitative methodology.

Qualitative studies support the current findings of this study which highlight the uncertainty in families of adolescents with ASD and other disability. For example, Fong (1992)
and Gray (2002; Gray, 2003; Gray, 2006) reported parental concerns about the unpredictability of their adolescent with ASD’s symptoms, including aggression. The parents also reported uncertainty regarding their future and the future of their adolescent with ASD. Mothers of adolescents with cerebral palsy in Burkhard’s (2011) qualitative study similarly reported concerns about their adolescents’ future. Taken together, the data suggest the need for additional research with parents of children with ASD and other disabilities to better understand the impact and sources of uncertainty. This additional information would provide a basis for interventions.

**H1d: Use of Coping Strategies**

Hypothesis H1d stated family members reporting greater use of coping strategies would have higher levels of family adaptation in families of adolescents with ASD. Step five of the regression, which was the addition of the variable, use of coping strategies, demonstrated there was no statistically significant independent relationship between the use of coping strategies and family adaptation \([F (6, 96) = 1.6, p = .209, NS]\). This means there was no statistically significant difference in the level of family adaptation based on the degree to which families of adolescents with ASD used coping strategies. Therefore, the research hypothesis was rejected and the statistical hypothesis was supported.

However, the zero-order correlations in this current study revealed a direct relationship between the use of coping strategies and family adaptation \((r = -.260, P < .01)\). The participants who reported higher utilization of coping strategies also reported lower scores on the General Functioning subscale, reflecting more effective family adaptation. Therefore it is likely, had this independent variable been entered into the regression equation first, it would have reached statistical significance.
Comparison with other studies using the F-COPES. Two similar studies reported on the use of coping strategies in families of younger children with ASD. Twoy, Connolly, and Novak (2007) administered the F-COPES (McCubbin, Thompson, McCubbin, 2003) to a sample of 55 parents of children with ASD under 12 years of age and Luther, Canham, and Connor (2005) did the same with 18 parents of children with ASD with a mean age of 8 years. Both studies found the parents made greater use of coping strategies than the normative group which serves as a reference group for the F-COPES instrument (McCubbin et. al.).

A comparison of the mean scores of the F-COPES demonstrated a different level of overall coping ability between families of children with ASD. The families of adolescents with ASD in this current study made less use of coping strategies, with a mean score for the total F-COPES instrument of 89.34 when compared to Luther et al.'s sample, with a total F-COPES mean score of 103.8. (Refer to Table 22).

Table 22
F-COPES Total and Subscales Comparisons

<table>
<thead>
<tr>
<th>Mean Score of Instrument</th>
<th>This study</th>
<th>Luther et al. g</th>
<th>Twoy et al. h</th>
<th>Normative sample i</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>89.34 a</td>
<td>103.8</td>
<td>95.64 male</td>
<td>95.91</td>
</tr>
<tr>
<td></td>
<td></td>
<td>95.45 female</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td>22.87 b</td>
<td>27.50</td>
<td>25.06</td>
<td>27.77</td>
</tr>
<tr>
<td>Reframing</td>
<td>30.33 c</td>
<td>31.3</td>
<td>29.65</td>
<td>32.23</td>
</tr>
<tr>
<td>Spiritual Support</td>
<td>11.40 d</td>
<td>14.3</td>
<td>10.46</td>
<td>13.77</td>
</tr>
<tr>
<td>Family Support</td>
<td>13.19 e</td>
<td>15.6</td>
<td>15.06</td>
<td>13.63</td>
</tr>
<tr>
<td>Passive Appraisal</td>
<td>9.30 f</td>
<td>14.6</td>
<td>15.37</td>
<td>8.91</td>
</tr>
</tbody>
</table>

a N = 91, b N = 99, c N = 101, d N = 101, e N = 101, f N = 102, g N = 18, h N = 55, i N = 65
Similarly, a comparison of mean scores for the F-COPES subscales revealed similarities and differences in the types of coping utilized by families of children with ASD. On the one hand, the parents of all three samples used the coping strategies of social support and reframing to a similar degree. The families of adolescents with ASD in this sample had a mean score on the Social Support subscale of 27.87, the parents of younger children in Twoy et al.’s mean score was 25.06 and for Luther et al.’s sample was 27.50. Scores for the use of reframing were similar as well (this study 30.33, Twoy et al. 29.65, and Luther et al. 31.30). On the other hand, parents of adolescents with ASD appeared to use the coping strategies of family support and passive appraisal to a lesser degree than the parents of younger children with ASD. (See Table 22).

These findings support the qualitative research of Fong (1992) and Gray (2002; Gray, 2003; Gray, 2006) with parents of adolescents with ASD. Parents of adolescents with ASD reported coping through spiritual practices, such as dependence on God and prayer. However, church attendance as a coping strategy was used to a lesser degree. Twoy et al. and Luther et al. had similar findings. They explained church attendance is likely difficult for families of children with ASD, given the demands of addressing the child with ASD’s behavioral challenges, especially in group settings.

In addition to spiritual practices, parents in Fong (1992) and Gray’s (2002; Gray, 2006) samples reported coping by methods infrequently reported in coping literature. They utilized coping by internal methods of self-reliance and dependence on the other spouse. The parents reported less reliance on formal external supports such as community programs, mental health counseling, and agencies or informal supports of reliance on extended family or neighbors. Parents reported the formal supports they had utilized in the past were no longer available,
especially as the children “aged out” of specialized programs. Instead, in the absence of these programs, parents reported coping by means of teamwork and self-reliance. Fong reported parents took turns or “shifts” to provide the necessary oversight of their adolescents, taking leave from work when the adolescent had an unanticipated crisis. Similarly, the mothers of adolescents with cerebral palsy (CP) in Burkhard’s (2011) sample discussed “teamwork” between the parents to address the adolescent’s needs.

Lin’s (2000) study of coping and family adaptation in families of children with CP had findings consistent with the aforementioned qualitative studies. The researcher compared coping and family adaptation and found differences in coping according to family life cycle stage. Families of younger children with CP coped more often by reaching out to extended family and neighbors. By contrast, families of adolescents with CP less often coped using external supports and were more self-reliant. However, the teamwork approach to coping is not specifically measured by the F-COPES instrument (McCubbin et al.). Additional research would be recommended to further investigate this aspect of coping with families of adolescents with ASD.

**Hypothesis H2: Combined Effects of All Variables**

Hypothesis H2 stated the combined effect of the variables of daily stressors, severity of behavior problems, uncertainty, and coping strategies will contribute significantly to explain the variance in family adaptation in families of adolescents with ASD. The results of the multiple regression analysis showed this hypothesis was supported and the statistical hypothesis was rejected. When all the independent variables were entered into the multiple regression analysis, the combined effect of daily stressors, severity of behavior problems, uncertainty, and coping strategies was found to be statistically significant [F (6, 96) = 4.197, p ≤ .001]. Therefore, based
on these findings, H2 was supported. The combination of all the independent variables explained 20.8% of the variance in family adaptation.

Previous research with families of children with ASD or other disabilities has demonstrated family adaptation was influenced by a number of variables. Pakenham et al. (2005) employed the Double ABCX, a predecessor of the RMF, as a framework to study the ability of eight variables to predict maternal adjustment in 47 mothers of older school-aged boys (ages 10 to 12) with Asperger’s Syndrome (AS) (Pakenham et al., 2005). AS is a milder form of ASD. The variables included in the analysis were selected maternal demographics, severity of the stressor (AS symptoms), pile-up of demands, quality of social support, parenting stress, coping, and maternal behavior disengagement. The entire model was statistically significant with 61% of the variance in maternal adjustment explained by the variables \[F(8, 38) = 7.30, p < .001\]. The variables that made a statistically significant contribution to the model were: a) maternal age (beta = -.19, p < .05), b) severity of stressor (beta = .34, p < .05), and c) social support (beta=.42, p <.001).

Similarly, Lin (200) found coping strategies also predicted family adaptation in families of children with cerebral palsy (CP). The researcher utilized a modified F-COPES (McCubbin, Thompson, & McCubbin, 2003) to investigate use of coping strategies. Three coping strategies, a) support from concerned others, b) personal growth and advocacy, and c) positive social interaction, had no statistically significant correlation with family adaptation and were not entered into the multiple regression analysis. The full regression model, which included the two remaining coping strategies, a) positive family appraisal and b) spiritual coping, was statistically significant \[F (2, 270) = 176.27, p < .001\]. Positive family appraisal explained 56% of the
variance in family adaptation and spiritual coping made a unique contribution of 1% to the variance in family adaptation.

Extending these findings, Baker, Seltzer, and Greenberg (2011) found family adaptation exerts influence on individual family member’s well-being. The researchers measured the characteristic of family adaptability influenced mental health outcomes in mothers of adolescents and adults with ASD and the behavior problems of adolescents and adults with ASD over time. As part of a secondary analysis of the Adolescents and Adults with Autism (AAA) dataset (Seltzer et al., 2003; Shattuck et al., 2007), several variables, including family adaptability, were measured at two different time intervals, five years apart. Family adaptability data were only collected in the first wave of data collection (1998-2000) and measured with a modified FACES II, a well-recognized measure of family adaptation (Olson, Portner, & Bell, 1982). The instrument had an alpha of .63, well within the expected range for the tool. All other variables, including selected maternal demographics and child demographics, child behavior problems, and maternal depression were measured again at the wave 3 of the dataset (2002-2003). The data analysis included descriptive, correlational, and path analysis.

The results showed family adaptability predicted changes in maternal depression and child behavior problems. Several statistically significant relationships were observed in the correlation analysis. There was a significant association between family adaptability at Time 1 and child problems at Time 3 (r = .20, p < .10), meaning the less adaptable the mother initially reported being, the greater levels of child behavior problems she reported five years later. Also, there was an association between family adaptability and maternal depression at both Time 1 (r = .19, p < .1) and at Time 3 (r = .28, p < .05), meaning the less adaptable the mother reported
being, the greater problems with depression the mother reported both at the initial data collection period and five years later.

The path analysis validated and extended the correlational analysis findings, showing family adaptability at Time 1 was predictive of both adolescent with ASD’s behavior problems and maternal depression at Time 3 (depression est. = -3.210, SE = 1.203; behavior problems est. -3.241, SE 1.253) (Baker et al., 2011, p. 605). The researchers interpreted these findings to indicate adolescents with ASD respond to and interact with their family’s environment. Consequently, a mother’s adaptability appears to impact on the adolescent with ASD’s behavior problems, either to improve or exacerbate them.

This current study highlights the important role family adaptation plays in families of adolescents with ASD. Also the findings of this study are consistent with the RMF model. Families of adolescents with ASD who experience life challenges, such as severity of the adolescent with ASD’s behavior problems or uncertainty regarding the adolescent with ASD’s disability, as overly burdensome, may struggle to counterbalance these challenges. This may result in less effective family adaptation. Baker et al.’s (2011) study suggest that struggling to maintain family functioning and balance may have a cyclical impact on individual family member’s mental health outcomes, and ultimately exacerbate child behavior problems.

Because only a fifth of the variance in family adaptation was explained by this current study’s variables, it is possible other factors exist that would explain additional variation in the dependent variable of family adaptation. Therefore, additional study would be recommended to determine the unidentified factors.
Additional Findings

Functioning of F-COPES subscales

This current study demonstrated low internal consistency in several of the F-COPES subscales (McCubbin et al., 2003). Other researchers reported similar experiences with the F-COPES subscales. Greeff, Vansteenwegen, and Gillard (2012) administered the F-COPES in their study of coping skills of Dutch parents of children with disabilities and the coping skills of their children with disabilities. The researchers found low internal consistency in two subscales, Spiritual Support (alpha of .69) and the Passive Appraisal subscale (alpha of .63). See Table 23 for the details.

Manning, Wainwright and Bennett (2011) reported similar low internal consistencies with the F-COPES subscales. Initially the researchers had planned to use three of the F-COPES subscales in their study of family adaptation in families of children with ASD (mean age 8.8 years). However, the Family Support subscale was not utilized for the study because the researchers stated the internal consistency was too low. However they did not elaborate on this or provide the Cronbach’s alphas. See Table 23 for the details.

Similarly, two of the F-COPES subscales in this current study had low internal consistency. The Family Support subscale had a Cronbach’s alpha of .64 and the Passive Appraisal subscale had a Cronbach’s alpha of .47. As discussed in the previous chapter, each of these subscales contained one item that did not seem to fit well together with the subscales other items, based on the raw item frequencies.
For comparison, the internal consistency scores for the F-COPES subscales for the three studies appear in Table 23. Included in the table are the original internal consistencies as published by McCubbin et al. (2003), in the instrument’s manual.

Comparing the three studies and the instrument’s references figures, the two subscales with the lowest internal consistency were the Family Support and Passive Appraisal subscales. This may indicate a need to reevaluate and perhaps re-align the F-COPES subscales to improve their internal consistency.

**Testing of Resilience Model of Family Adjustment and Adaptation (RMF)**

McCubbin et al., (2003) view family adaptation as a dynamic process of rebalancing after the family experiences an overwhelming number of stressors, strains, or pile-up of demands, or a solitary overwhelming crisis. In order to achieve bonadaptation, or a favorable adaptation, the stressors must be counterbalanced by three other components, a) situational appraisal, or the meaning the family assigns to their situation, b) family resources, both formal and informal, and c) their ability to solve problems and cope. Research has investigated the stress and coping
response in families of children with disabilities. As a result, this body of knowledge explains
that most families of children with chronic illnesses and disabilities including ASD have a
greater degree of stress and cope less well than families of children without such challenges
(Pisula & Kossakowska, 2010; Tunali & Power, 2002). However, little research has investigated
the long-term experience of families of children with chronic illnesses and disabilities or
investigated the coping process according to the family life cycle stage of adolescence. What
research that exists, suggests families of adolescents face stressors unique to this family life
cycle stage (Baker, Seltzer, & Greenberg, 2011; Lin, 2000).

The findings of this study, on the whole, were consistent with the RMF model
(McCubbin et al., 2003). Participants in the study were affected by the stressors of daily
stressors and severity of behavior problems of adolescents with ASD. Daily stressors exerted a
measurable influence in the adaptation process of families of adolescents with ASD. The same is
true of the severity of behavior problems as perceived by the families of adolescents with ASD.
Those participants who reported a greater number of daily stressors also reported less effective
family adaptation. Those participants, who reported a greater severity of their adolescent with
ASD’s behavior problems, also had less effective family adaptation.

The situational appraisal process may have been hindered by the element of uncertainty
as was proposed by Skaggs and Barron (2006). In this study, uncertainty was the single most
impactful component on the family adaptation process. Families reporting higher levels of
uncertainty also had less effective family adaptation.
Finally, using the hierarchical regression model proposed for this study, the use of coping strategies did not have a strong independent influence on the family adaptation process for families of adolescents with ASD once the other variables had entered the regression equation.

The RMF model functioned adequately as the framework for this study. However, the combined independent variables only explained 20.8% of the variance in the outcome variable, family adaptation (F (6, 96) = 4.2, p <.001). The RMF model had a better fit in two other studies with different samples of parents of children with ASD or other disabilities.

Pakenham et al. (2005) found the eight combined variables in their study explained 61% of the variance in maternal adjustment in mothers of boys with Asperger Syndrome (a milder form of ASD), ages 10-12 years (F8, 38 = 7.0, p < .001). The researchers used the Double ABCX model, a precursor to the RMF. The three variables that made a statistically significant unique contribution to the full regression model were maternal age, severity of autism symptoms, and social support.

Similarly, Lin (2000) found the use of two types of coping strategies explained 60% of the variance in family adaptation in families of children of all ages with cerebral palsy (F 2, 257 = 176, p < .001). The two types of coping strategies were situational appraisal and spiritual coping.

However, using the Double ABCX model as a framework, Manning et al. (2011) found the nine combined variables in their research only explained 28% of the variance in family functioning in families of younger children with ASD, mean age 8.8 years (F (9, 157) = 6.88, p < .001). The three variables that made a statistically significant unique contribution to the full
regression model were severity of behavior problems, situational appraisal, and subjective social status.

It may be the RMF model was not the best model for this sample. Two other family systems models have been proposed that address the adjustment of families of children with disabilities; the Family Systems-Illness (Rolland & Walsh, 2006) and Family Stress and Family Resilience Model (Patterson, 1988). However, little research has been conducted to test the models. Additional research is recommended to determine if other family systems models would better explain the family functioning of this sample.

**Significance and Nursing Implications**

Nursing practice is grounded in research evidence. Based on the findings of this study, the nurse has many opportunities to assist families of adolescents with ASD to achieve optimal family functioning.

**Screening for Negative Mental Health Outcomes**

The findings of this study suggest the participants’ perceptions of the severity of their adolescent with ASD’s behavior problems and the participants’ perceptions of uncertainty regarding their adolescent with ASD’s future exerts a negative influence on their family adaptation, or ability to maintain effective balance in the family. Therefore, there may be great utility in the nurse proactively addressing the mental health needs of family members of adolescents with ASD. The primary care setting or school health suite may be particularly well suited for this purpose. As family members and their adolescents with ASD are in the waiting room, in the examination room, or visiting the school health suite, the nurse or nurse practitioner may administer an anxiety or depression screening instrument. The Patient Health Questionnaire
-9 (PHQ9) (Kroneke, Spitzer, & Williams, 2001) is one such brief, well-recognized, no-cost, depression screening instrument. Based on the results of the screening, the nurse clinician may make appropriate referrals to address any identified mental health needs.

**Addressing Uncertainty**

Based on this study’s results, the factors most influential on families of adolescents with ASD were uncertainty regarding the behavioral manifestations or symptoms of ASD and uncertainty regarding the adolescent with ASD’s future. Families of adolescents with ASD experienced uncertainty regarding how they will manage their adolescent in the future. They have reason for their concerns. The findings of three separate research studies indicated even high functioning individuals with ASD have poor long-term outcomes. Individuals with ASD have persistent ASD behaviors and symptoms, rarely gain competitive employment opportunities, infrequently obtain independent living situations, or seldom engage in deep romantic relationships (Billstedt, Gilsberg & Gilsberg, 2010; Howlin, Goode, Hutton, & Rutter, 2004; Jennes-Coussens, Magill & Konig, 2006). Nurses are well-positioned to assist families of adolescents with ASD, by connecting them with appropriate informational content, to reduce their uncertainty by connecting them with experienced mentors, and by connecting them with resources.

**Connecting with content.** Nurses may assist families of adolescents with ASD to reduce their uncertainty regarding their adolescent’s transition into adulthood by connecting them with existing informational content. This sample is united by their participation in an on-line support community. This current study’s data indicated the participants coped most often by utilizing resources inside the family rather than relying on external resources. At present, there are
several experts in the field of transitioning the adolescent with ASD into adulthood and they present periodically at regional autism seminars. Nurses partnering with these experts could utilize current technology to record the presentations and post them to sponsoring autism websites. This would provide family members of adolescents with ASD access to the information in a convenient on-line manner.

Additionally, nurses could also translate available informational resources on transitioning adolescents into adulthood into web-based presentations and post to sponsoring autism websites. Suggested content for these presentations would include a) respite care, b) group homes and assisted living situations, c) supported college programs, d) job search skills and supported employment opportunities, e) health, safety, and sexuality courses, f) mobility and transportation services, and g) wills and trusts.

Connecting with experience. Second, nurses may assist families of adolescents with ASD by connecting them with a supportive network of experienced parents of older individuals with ASD. An on-line support community may serve this purpose. Nurses could recruit the participation of parents of older adults with ASD willing to serve as mentors. The mentors would share their experiences of successfully navigating the uncharted waters of the transition of the adolescent with ASD into adulthood. Nurses could broker these connections through existing on-line autism websites in a Google-group type forum. Uncertainty would be reduced as families of adolescents with ASD gain insight from experienced parents who have faced similar challenges.

Connecting with resources. Third, nurses are in a position to assist families of adolescents with ASD by connecting them with resources as they plan for their adolescent’s
transition from formal educational services. At one time, such resources were scarce. Now the resources exist but are fragmented and poorly coordinated (Lawrence, Alleckson, & Bjorklund, 2009). Also, parents of older children with disabilities including ASD have reported the limited availability of resources including respite care and supported recreational activities once the individual with a disability leaves the formal education system (Burkhard, 2011; Gray, 2006). Nurses are in a position to link families of adolescents with ASD with existing resources by creating and maintaining a comprehensive, organized listing of resources with internet links. With appropriate promotion, it could become the prime internet destination for transition resources for families of adolescents with ASD. Finally, after identifying gaps in existing support services, nurses may undertake initiatives and design programs to better assist parents of adolescents with ASD with this transition process.

**Increasing effectiveness of family adaptation**

The RMF model theorizes that families achieve greater effectiveness in their adaptation if they are able to balance their family’s demands and resources. Based on the results of this study, the nurse may intervene with the family of adolescents with ASD to achieve this balance by assisting families to minimize the impact of daily stressors, to reduce their uncertainty, to assist them to find meaning regarding their situation, and to expand the utilization of supportive resources. Posting content pertaining to these issues to a sponsoring autism organization’s website would expand the nurse’s reach. Collectively these measures may assist the families of adolescents with ASD to regain or maintain their equilibrium.
Limitations

This study was limited by the use of only one sample, members of the IAN community, who were self-selected and provided self-reported data. However, the sample was randomly selected from 3,500 members who reside in all 50 of the United States and are likely to be very representative of the wider United States. The study was also limited by the lack of diversity as it was largely comprised of married, White mothers of adolescents with ASD with few fathers, members of alternative household arrangements, or custodial grandparents. Therefore the results of the study should only generalized beyond the study’s population of interest with caution.

Research Recommendations

Based on the results of this study, further research in the following areas is recommended:

1. The study lacked ethnic and gender diversity and diversity of family composition. Further study would be recommended to broaden participation and address this limitation.

2. In full regression model, daily stressors were not found to be statistically significantly related to family adaptation in families of adolescents with ASD. However, there was a statistically significant relationship between the variables of daily stressors and family adaptation in the zero-order correlations ($r = .261, p < .01$). Therefore, further research is recommended to better understand the impact of daily stressors on family adaptation for families of adolescents with ASD.

3. In the full regression model, the severity of behavior problems trended towards statistical significance at $p = .056$. Also there was a statically significant relationship between the variables, severity of behavior problems and family adaptation in the zero-order correlations ($r =$
Therefore, additional research to better understand the impact of the severity of behavior problems on family adaptation is recommended.

4. The data from some participants were eliminated because participants failed to complete the single-time visual analog scale that measured the severity of behavior problems. Therefore additional study would be recommended utilizing a longer instrument so as to avoid the loss of data. Utilization of both the single-item VAS and the longer instrument for comparison purposes would be recommended.

5. Because this was the first study, that could be located, that measured uncertainty in families of adolescents with ASD, additional research with parents of adolescents with ASD would be recommended to better understand the impact and sources of uncertainty on family adaptation.

6. A comparison of the mean scores for the PPUS for the entire instrument and its subscales, suggest families of adolescents with ASD have different levels and sources of uncertainty than families of younger children with ASD. Additional research is recommended to determine if there are differences in parent’s perception of uncertainty regarding their child with ADS’s disability according to family life cycle stage.

7. Several of the F-COPES subscales had low internal consistency with this study’s sample. Additional research utilizing a different coping instrument for this sample is recommended.

8. Participants in this sample and in several qualitative studies coped using more self-reliant coping and less often utilized the external coping strategies listed in the F-COPES. Additional research to further investigate coping with families of adolescents with ASD is recommended, using a different coping instrument.
9. The variable of the use of coping strategies did not have a statistically significant independent relationship with family adaptation using this study’s hierarchical regression model. However, there was a statistically significant relationship between the use of coping strategies and family adaptation in the zero-order correlations ($r = -.26, p < .01$), indicating that when the participant used more coping strategies, the participant had more effective family adaptation. This suggests that if another regression model were utilized, for example, entering the variable of the use of coping strategies into the model first, coping strategies would likely have contributed to the full regression model in a statistically significant manner. Therefore, conducting additional analyses with different regression models is recommended.

10. A comparison of mean scores of the F-COPES for the entire instrument and its subscales, suggests families of adolescents with ASD have different levels and usage of coping strategies than families of younger children with ASD. Therefore additional study to compare the use of coping strategies according to family life cycle stage would be recommended.

11. Only 20.8% of the variance in family adaptation is explained by this study’s independent variables. Other studies investigating family adaptation in families of children with ASD or other disabilities using the RMF model explained a greater amount of the variance in family adaptation than this current study. Additional study would be recommended to determine a) if there are other variables that would help explain a greater amount of variance in family adaptation, and b) if another family model of resilience would better explain family functioning in families of adolescents with ASD.

12. This sample was all members of an on-line support community. It would be informative to conduct a study of similar design using the same research instruments with families of
adolescents with ASD recruited in a face-to-face approach to determine if there are any differences according to recruitment approach.

**Conclusion**

Barker, Seltzer, and Greenberg (2011) described the period leading up to the adolescent transition to adulthood as a particularly stressful time for parents of adolescents with ASD. “As adolescents become more independent and the desire for individuation becomes more pronounced, the family system must be flexible enough to adjust to related role changes and novel issues that arise (p. 3).” RMF model guided this current study and the findings of the study have contributed to the body of knowledge regarding family adaptation. The goal of the RMF is to predict and promote optimal family functioning within all families, especially when challenged by a pile-up of demands or by one overwhelming crisis. This current study found family adaptation is influenced by multiple factors including daily stressors, the severity of behavior problems, uncertainty and the use of coping strategies. This knowledge can equip nurses and other health professionals to assist families of adolescents with ASD to be flexible and more easily adjust during the stressful period of their adolescents with ASD’s transition to adulthood.
### Appendix A: Weekly Stressors Index- Short Form (Brantley et al., 2007)

<table>
<thead>
<tr>
<th></th>
<th>X</th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Had pet peeve violated (someone fails to knock, etc.)</td>
<td></td>
<td>Did not</td>
<td>Happened</td>
<td>Slightly</td>
<td>Mildly</td>
<td>Moderately</td>
<td>Stressful</td>
<td>Very</td>
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<tr>
<td></td>
<td></td>
<td>happen</td>
<td>not</td>
<td>stressful</td>
<td>stressful</td>
<td>stressful</td>
<td>stressful</td>
<td>stressful</td>
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<tr>
<td>2. Was excluded or left out</td>
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<td>3. Was without privacy</td>
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<td>4. Was ignored by others</td>
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<td>5. Was stared at</td>
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<td></td>
</tr>
<tr>
<td>6. Was lied to, fooled, or tricked</td>
<td></td>
<td></td>
<td></td>
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<td>7. Competed with someone</td>
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<td>8. Had minor injury (stubbed toe, sprained ankle, etc.)</td>
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<td>9. Had too many responsibilities</td>
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<td>10. Was forced to socialize</td>
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<td>11. Did something you were not good at</td>
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<tr>
<td>12. Dealt with rude waiter, waitress, or salesperson</td>
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<td>13. Was interrupted while talking</td>
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<td>14. Was clumsy (spilled or knocked something over)</td>
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<tr>
<td>15. Not enough time for fun (movie, eating out) or recreation</td>
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<tr>
<td>16. Had someone disagree with you</td>
<td></td>
<td></td>
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<tr>
<td>17. Did poorly because of others</td>
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</tbody>
</table>
Appendix A: Weekly Stressors Index- Short Form (Brantley et al., 2007) continued

<table>
<thead>
<tr>
<th></th>
<th>X</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Did not happen</td>
<td>Happened not stressful</td>
<td>Slightly stressful</td>
<td>Mildly stressful</td>
<td>Moderately stressful</td>
<td>Stressful</td>
<td>Very stressful</td>
<td>Extremely stressful</td>
</tr>
<tr>
<td>18.</td>
<td>Argued with a friend</td>
<td></td>
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<tr>
<td>19.</td>
<td>Not enough time to socialize</td>
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<tr>
<td>20.</td>
<td>Forgot something</td>
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<tr>
<td>21.</td>
<td>Was told what to do</td>
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<tr>
<td>22.</td>
<td>Lost or misplaced something (wallet, keys)</td>
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<td>23.</td>
<td>Spoke or performed in public</td>
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<tr>
<td>24.</td>
<td>Did not hear from someone you expected to</td>
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<tr>
<td>25.</td>
<td>Had someone cut in front of you in line</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
WSI Short-From
4 messages

Phillip Brantley <Phil.Brantley@pbrc.edu>        Wed, Oct 6, 2010 at 12:47 PM
To: 24obrien@cardinalmail.cua.edu

Ms O'Brien

You have permission to use/reproduce my WSI Short form for use in your research. Please send me a report of your results so I can include your work in future reviews.

Phil Brantley

Phillip J. Brantley, PhD
Professor and Chief
Behavioral Medicine
Pennington Biomedical Research Center
6400 Perkins Road
Baton Rouge, Louisiana 70808-4124
(225) 763-3046
phil.brantley@pbrc.edu

---

Sandra O'Brien <24obrien@cardinalmail.cua.edu>        Wed, Oct 6, 2010 at 1:39 PM
To: Philip Brantley <Phil.Brantley@pbrc.edu>

Thank you.
May I place it in an electronic form on the secure server at The Catholic University of America as part of my data collection for my participants? They will be given a link to the server. Then they will access the survey tools for data collection.

Sincerely,
Sandra

---

Phillip Brantley <Phil.Brantley@pbrc.edu>        Wed, Oct 6, 2010 at 1:40 PM
To: Sandra O'Brien <24obrien@cardinalmail.cua.edu>

Yes
Appendix B: Severity of Behavioral Problems

Please click the line below to indicate how severe are your adolescent with Autism Spectrum Disorder (autism)’s behavior difficulties.

<table>
<thead>
<tr>
<th>My adolescent with Autism Spectrum Disorders (autism)’s behavior difficulties are</th>
<th>Not at all difficult</th>
<th>Extremely difficult</th>
</tr>
</thead>
</table>

[Click line to indicate severity]
INSTRUCTIONS:
Please read each statement. Take your time and think about what each statement says. Then place an “X” under the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would mark under either “Strongly Agree” or “Agree.” If you disagree with a statement, then mark under either “Strongly Disagree” or “Disagree.” If you are undecided about how you feel, then mark under “Undecided” for that statement. Please respond to every statement.

1. It is unclear how bad my child’s pain will be.

   | Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
   | (5)            | (4)   | (3)       | (2)      | (1)               |
   |                |       |           |          |                   |

2. I can predict how long my child’s illness will last.

   | Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
   | (5)            | (4)   | (3)       | (2)      | (1)               |
   |                |       |           |          |                   |

3. Because of the unpredictability of my child’s illness, I cannot plan for the future.

   | Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
   | (5)            | (4)   | (3)       | (2)      | (1)               |
   |                |       |           |          |                   |
4. It’s vague to me how I will manage the care of my child after he/she leaves the hospital.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. I’m certain they will not find anything else wrong with my child.

<table>
<thead>
<tr>
<th>Strongly Agree (5)</th>
<th>Agree (4)</th>
<th>Undecided (3)</th>
<th>Disagree (2)</th>
<th>Strongly Disagree (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
On Wed, Sep 22, 2010 at 6:56 AM, sandy staley <sstaley@email.unc.edu> wrote:

She [Dr. Merle Mishel] does give you permission to use her research [electronically, in the context of the email, author’s note]. I will try to locate the request that she signed giving you permission. However, we are in the process of moving between two offices, so putting my hands on this quickly may be a challenge. If this email is [not] sufficient, please let me know.
Appendix D: Family Crisis Oriented Personal Evaluation Scales

F-COPES
Family Crisis Oriented Personal Evaluation Scales©
Hamilton I. McCubbin David H. Olson Andrea S. Larsen

Purpose
The Family Crisis Oriented Person Evaluation Scales is designed to record problem-solving attitudes and behaviors which families develop to respond to problems or difficulties.

Directions
First read the list of “Response Choices” one at a time. Second, decide how week each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you strongly agree; if the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1, 2, 3, 4, or 5) to match your response to each statement. Thank you.

When we face problems or difficulties in our family, we respond by:

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Strongly Disagree</th>
<th>Moderately Disagree</th>
<th>Neither Agree</th>
<th>Moderately Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Sharing our difficulties with relatives</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2.</td>
<td>Seeking encouragement and support from friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3.</td>
<td>Knowing we have the power to solve major problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4.</td>
<td>Seeking information and advice from persons in other families who have faced the same or similar problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5.</td>
<td>Seeking advice from relatives (grandparents, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6.</td>
<td>Seeking assistance from community agencies and programs designed to help families in our situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7.</td>
<td>Knowing that we have the strength within our family to solve our problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8.</td>
<td>Receiving gifts and favors from neighbors (e.g. food, taking in mail, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9.</td>
<td>Seeking information and advice from the family doctor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
## Appendix D: Family Crisis Oriented Personal Evaluation Scales continued

<p>| | | | | |</p>
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</thead>
<tbody>
<tr>
<td>10.</td>
<td>Asking neighbors for favors and assistance</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11.</td>
<td>Facing the problems “head on” and trying to get solution right away</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12.</td>
<td>Watching television</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13.</td>
<td>Showing that we are strong</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14.</td>
<td>Attending church services</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15.</td>
<td>Accepting stressful events as a fact of life</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16.</td>
<td>Sharing concerns with close friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17.</td>
<td>Knowing luck plays a big part in how well we are able to solve family problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18.</td>
<td>Exercising with friends to stay fit and reduce tension.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19.</td>
<td>Accepting that difficulties occur unexpectedly</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20.</td>
<td>Doing things with relatives (get-togethers, dinner, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21.</td>
<td>Seeking professional counseling and help for family difficulties</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22.</td>
<td>Believing we can handle our own problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23.</td>
<td>Participating in church activities</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24.</td>
<td>Defining the family problem in a more positive way so we do not become too discouraged</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25.</td>
<td>Asking relatives how they feel about problems we face</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26.</td>
<td>Feeling no matter what we do to prepare, we will have difficulty handling problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27.</td>
<td>Seeking advice from a minister</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28.</td>
<td>Believing if we wait long enough, the problem will go away.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
## Appendix D: Family Crisis Oriented Personal Evaluation Scales continued

<table>
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<tr>
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<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>29. Sharing problems with neighbors</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>30. Having faith in God</td>
<td></td>
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</tbody>
</table>
use of the F-COPES for on-line research

4 messages

Sandra O'Brien <24obrien@cardinalmail.cua.edu> Sat, Apr 3, 2010 at 1:25 PM

To: familyresistance@earthlink.net

Dear Sir/Ma'am,

Thank you so much for assisting me with information for use of Family Assessment Measures in my dissertation research. Currently I am in the final stages of preparing my dissertation proposal for research on factors influencing family adaptation in families of adolescents with autism spectrum disorders. I am writing to request permission to place the F-COPES on the secure server at The Catholic University of America as part of my data collection.

I believe on-line data collection is an ideal strategy for my research. Families of children with autism, my target population, have many demands for their time including the burden of caregiving. On-line technology will lighten the burden of completing multiple research tools if the families can participate at a convenient time and in an environment of their own choosing.

Additionally on-line survey technology may broaden the representativeness of the participants. I plan to invite the participants of several national support organizations to link directly to the instruments secured on the university’s data management system. Upon completion, their confidential data would be stored in the secure system as well.

I hope you will consider my request favorably.

Sincerely,

Sandra O'Brien, RN, MSN, CRNP-F, PHCNS, PhD student
The Catholic University of America

Sandra O'Brien <24obrien@cardinalmail.cua.edu> Thu, Apr 8, 2010 at 10:00 PM

To: familyresistance@earthlink.net

Dear Sir/Ma'am,

I am responding this in the event the message arrived during break.

Sandra

[Signature]

hamil mossadin <hamil.mossadin@earthlink.net> Thu, Apr 8, 2010 at 11:11 PM

To: Sandra O'Brien <24obrien@cardinalmail.cua.edu>

Permission granted for this project. Best to you and this fine project.

[Signature]

hamil mossadin <hamil.mossadin@earthlink.net> Fri, Apr 9, 2010 at 7:04 AM

To: Sandra O'Brien <24obrien@cardinalmail.cua.edu>

Please note, given this measure will be on-line, the copyright symbol and list of copyright holder is required. Permission granted for this project. Best to you and this fine project.

[Signature]
Appendix E: General Functioning Subscale of the Family Assessment Device

(Ryan, Epstein, Keitner, Miller, & Bishop, 2005). This instrument is only available by purchase from the instruments’ designers. Therefore only a representation of the content areas is presented below.

Instructions
Following are a number of statements about families. Please read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family.
For each statement there are four (4) possible responses:

1 = Strongly Agree
Select 1 if you feel that the statement describes your family accurately.

2 = Agree
Select 2 if you feel that the statement describes your family for the most part.

3 = Disagree
Select 3 if you feel that the statement does not describe your family for the most part.

4 = Strongly Disagree
Select 4 if you feel that the statement does not describe your family at all

Representation of content

1. Misunderstandings within the family.
   ___SA   ___A   ___ D   ___SD    ________________

2. Mutual support.
   ___SA   ___A   ___ D   ___SD    ________________

3. Unable to communicate well.
   ___SA   ___A   ___ D   ___SD    ________________

4. Acceptance of family members.
   ___SA   ___A   ___ D   ___SD    ________________
5. Avoidance of discussing challenging topics.

_____SA  ____A  ____D  ____SD  ________________


_____SA  ____A  ____D  ____SD  ________________

7. Tension within family.

_____SA  ____A  ____D  ____SD  ________________

8. Acceptance of each other.

_____SA  ____A  ____D  ____SD  ________________

9. Problems with decision making.

_____SA  ____A  ____D  ____SD  ________________

10. Ability to solve problems together.

_____SA  ____A  ____D  ____SD  ________________

11. Unable to get along.

_____SA  ____A  ____D  ____SD  ________________

12. Sharing intimate thoughts and feelings.

_____SA  ____A  ____D  ____SD  ________________
Hi Ms. O'Brien,

We discussed your request at our team meeting this afternoon and agreed that if you would be willing to purchase the institutional license for the computer-based FAD and scoring system, it would be fine for you to upload the computer-based FAD to the CUA server.

I am attaching the order form for the computer-based FAD and scoring system. Please be in touch with any questions or concerns.

Warmly,
Abigail
Appendix F: Background Information Form

1. Do you have an adolescent with an Autism Spectrum Disorder (autism) between the ages of 13 and 22?  (   ) Yes  (   ) No

2. Age of person completing this form:     ________ (fill in)

3. Gender of person completing this form:
   (   ) Male  (   ) Female

4. Marital Status:
   (   ) Single
   (   ) Married
   (   ) Committed Relationship
   (   ) Widowed
   (   ) Divorced
   (   ) Separated

5. Race/Ethnicity:
   (   ) African American/Black
   (   ) White
   (   ) Latino
   (   ) Asian
   (   ) Native American/Alaskan
   (   ) Other: ________________________

6. Highest grade complete:
   (   ) Did not complete 8th grade
   (   ) Completed 8th grade
   (   ) Completed high school or obtained GED
   (   ) Completed Associate’s degree
   (   ) Completed Bachelor’s degree
   (   ) Completed Master’s degree
   (   ) Completed Doctorate degree
   (   ) Other: ________________________
Appendix F: Background Information Form continued

7. Family Income:
   ( ) Less than $20,000 annual income
   ( ) Annual income between $20,000-49,000
   ( ) Annual income between $50,000-79,000
   ( ) Annual income between $80,000-119,000
   ( ) Annual income between $120,000-149,000
   ( ) Annual income greater than $150,000

8. How old is the adolescent with Autism Spectrum Disorder (autism)? _____

9. What is the gender of the adolescent with Autism Spectrum Disorder (autism)?
   ( ) Male    ( ) Female

10. What is your relationship to the adolescent with Autism Spectrum Disorder (autism)?
    ( ) Biological Parent
     ( ) Adoptive Parent
     ( ) Stepparent
     ( ) Partner of Parent
     ( ) Custodial Grandparent
     ( ) Other______________

11. By whom was the adolescent diagnosed with Autism Spectrum Disorder:
    ( ) Medical Doctor
     ( ) Doctor of Osteopathy or Naturopathy
     ( ) Psychiatrist
     ( ) Psychologist
     ( ) Nurse Practitioner
     ( ) Developmental Pediatrician
     ( ) Pediatric Neurologist
     ( ) Other

12. If the adolescent with Autism Spectrum Disorder has other medical conditions, please list:
Appendix F: Background Information Form continued

13. Please list treatments your adolescent has received for his/her Autism Spectrum Disorder (autism) disorder.

14. Are there children in the household other than the adolescent with Autism Spectrum Disorder? If so, please complete the following:

   a. Gender   b. Age   c. Has Autism Spectrum Syndrome?
      Yes   No

   _____   _____   _________________________
   _____   _____   _________________________
   _____   _____   _________________________
   _____   _____   _________________________
   _____   _____   _________________________
   _____   _____   _________________________
   _____   _____   _________________________
   _____   _____   _________________________

15. Comments about raising an adolescent with autism
Appendix G: Exit Page

Thank you for your interest and your assistance with my research!

Sandra O’Brien, PhD candidate, MSN, RN, CRNP-F, PHCNS-BC

You may select between a $15Starbuck’s or a $15 Amazon card as a “thank you” for participating in my research study. In order to send your card it will be necessary to provide your email address. Your email address will be used solely to assist me to send your “thank you” card. Your email address will be retained until the data analyses of the study are completed. Then your email will be deleted and any paper records will be destroyed.

Choose your “thank you” card
( ) Starbuck’s
( ) Amazon
( ) I do not wish to receive a “thank you” card

If you would like to receive a “thank you” card, please provide your email address where you would like your “thank you” card sent.

________________________________________
Appendix H: Recruitment Letter with link

Dear IAN Research participant,

Based on your family profile, one or more members of your family may qualify for the study below. If you are interested in participating, please click on the link below or contact the research team directly, using the information provided below. You do not have to participate in this study and your non-participation will neither affect the care you receive from any health provider nor your standing as a participant in IAN Research.

Please note that IAN Research is serving as a resource linking the autism community and researchers. This study is not endorsed by or performed under the auspices of the IAN Research project at Kennedy Kreiger Institute/ Johns Hopkins.

Name of Study: Your Future, Your Adolescent’s Future: Experiences of Families of Adolescents with Autism Spectrum Disorder

Location: web-based survey. No geographic location limitation.

Eligibility Criteria: One or both biological parent(s), one or both adoptive parent(s), a stepparent, a partner of a parent, or one or both custodial grandparents of an adolescent with autism; an adolescent for this study is a child ages 13 to 22.

Principal Investigator: Sandra O’Brien, MSN, RN, CRNP-F, PHCNS-BC

Institution: The Catholic University of America

Contact Information: 24obrien@cardinalmail.cua.edu or phone 301-213-8896

Study link: https://surveys.cua.edu/autism

Dear Parent,

I am inviting you to participate in a research study which will learn more about factors that influence family adaptation, such as daily stressors, behavior problems, uncertainty, and coping strategies. This research is needed because currently very little is published about families of adolescents with autism.

The study is web-based and would involve completing six online questionnaires regarding your adjustment to raising an adolescent with autism. The study would take approximately 45 minutes
to complete. You will need to complete the study in one session. However, if you are interrupted, you may leave your browser open and return to complete the study later.

You will not be asked for any personally identifying information and your information will be stored on a secure server at The Catholic University of America.

To thank you after completing the study, you may elect to receive a $15 Starbuck’s or Amazon e-gift code. You will need to provide your email address in order for me to send your e-gift code. The email address will not be used in any other manner.

If you are interested in participating, please click on this link: https://surveys.cua.edu/autism

Thanks in advance for your time and assistance,
Sandra O’Brien, MSN, RN, CRNP-F, PHCNS-BC
Appendix I: Greeting Page

An Invitation

As a nurse, I am interested in understanding factors that influence a family’s adjustment to raising an adolescent with Autism Spectrum Disorder (autism). Please consider Participating in this research because your information is important and because I believe there is little information available for families on this topic.

To review, I am conducting an on-line study to investigate several factors that might influence a family's adjustment to raising an adolescent with autism. The study will take about 45 minutes to complete and includes 99 survey questions and 15 background questions. All the information will be kept confidential. It will not be possible for me or anyone else to identify you or connect you with your responses. If you are interrupted during the survey, the system is able to save your answers and allow you to resume the study later.

In appreciation for completing the study, you are invited to select a $15 value coupon for either Starbucks or Amazon. You will be given instructions on how to receive this coupon after completion of the study. However, you will be asked for your email address, which will be used solely for the purposes of providing your redeemable coupon.

You are eligible to participate if you meet the following criteria:
1. If you are a biological or adoptive parent, stepparent, partner of a parent, or custodial grandparent of an adolescent with an Autism Spectrum Disorder (autism),
2. If the adolescent has a formal diagnosis of an Autism Spectrum Disorder (autism), and
3. If the adolescent is between ages 13 and 22 years of age.

Sandra O'Brien, PhD candidate, MSN, RN, CRNP-F, PHCNS-BC

If you are interested in completing the study and meet the three criteria, please click on the "Continue" button now.

If you are not interested in completing the study and/or do not meet the three criteria, please click on the "Exit" button now.
Appendix J: Approved Informed Consent

THE CATHOLIC UNIVERSITY OF AMERICA
School of Nursing
Washington, D.C. 20064
202-319-5400
Fax: 202-319-6485

Name of Study: The Influence of Daily Stressors, Severity of Behavior Problems, Uncertainty and Coping Strategies on Family Adaptation in Families of Adolescents with Autism Spectrum Disorder

Investigator: Sandra O’Brien, PhD candidate, MSN, RN, CRNP-F, PHCNS-BC
Phone: 301-213-8896
Supervisor: Jean Toth, PhD, RN, AHN
Phone: 202-319-6555

Description and Purpose of the Study: I understand that I am being asked to participate in a research study exploring daily stressors, severity of behavior problems, uncertainty, coping strategies, and family adaptation in families of adolescents with Autism Spectrum Disorders (autism). The completion of the research is in partial fulfillment of the requirements for Doctor of Philosophy degree at The Catholic University of America.

Procedures: I understand that I will complete an on-line survey composed of five questionnaires and one background information form. It will take approximately 45 minutes to complete the survey.

I understand that the research study consists of: (a) The General Functioning Scale of the Family Assessment Device, a 12 item questionnaire to measure family functioning (b) Weekly Stress Inventory, a 25 item questionnaire to evaluate daily stressors, (c) a Visual Analog Scale to evaluate the severity of the adolescent with autism’s behavior problems, (d) Parent’s Perception of Uncertainty in Illness Scale, a 31 item questionnaire to measure uncertainty in the family with an ill or disabled child, (e) F-COPES, a 30 item questionnaire to measure coping, and (f) a 14 item background information form.

Benefits that may occur: I understand that the research study will not benefit me personally, but my contribution may provide information that is helpful to other parents, nurses and social scientists, who care for families of children with Autism Spectrum Disorders.
Risks, inconveniences, and/or discomforts that may arise: I understand that participation in this survey is voluntary. I also understand that completing the questionnaires may cause me to have upset feelings. If this happens, I understand that I may stop filling in the forms and contact the researcher to ask for a referral to a health provider to help me with my upset feelings. I understand that I may also be inconvenienced by the amount of time it takes to fill in the questionnaires.

Right to Withdraw: I also understand I may withdraw at any time from the study without penalty.

Confidentiality of research records: I understand that all of the information that I may give will be kept confidential. My answers to the questionnaires will be coded and contain no information that would identify me. The research study results will be stored on a secure computer-server at The Catholic University of America. When downloaded for data analyses, printed hard-copies of the data will be kept in a secure, locked location. All code books will be destroyed following data analyses. I further understand that no identifying or individual results from this study will be shared with anyone in any form. I understand that my research records, like hospital records, may be subpoenaed by court order or may be inspected by federal regulatory authorities.

Because the researcher has provided contact information, I have had the opportunity to ask questions about the research and my participation in the research. I either chose not to contact the researcher prior to my participation in the survey or I have contacted the researcher, and these questions have been answered to my satisfaction.

(For on-line survey) I volunteer to participate in this study. I may contact the researcher at 24obrien@cardinalmail.cua.edu to obtain a printed copy of this consent form.

Participant’s Signature_________________________Researcher’s Signature_________________________

Date_________________________Date_________________________

Any complaints or comments about your participation in this research project should be directed to the Secretary, Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Services, The Catholic University of America, Washington, DC 20064; Telephone: (202) 319-5218.
May 30, 2012

Ms. Sandra O’Brien
2805 Advent Court North
Bowie, MD 20716

Dear Ms. O’Brien:

Your research project titled “The Influence of Daily Stressors, Severity of Behavior Problems, Uncertainty, and Coping Strategies on Family Adaptation in Families of Adolescents with Autism Spectrum Disorder”, protocol number 12-047, was certified by the Committee for the Protection of Human Subjects (CPHS) as meeting the requirements of the Federal regulations governing protection of human subjects.

CPHS will maintain a copy of your submission on file. You are obligated to follow the research protocol and procedures for obtaining informed consent as you have specified. If you wish to initiate any changes in the research protocol or the informed consent procedure, you should submit this request to CPHS in writing. You must use the stamped consent forms that accompany this letter.

This approval will expire on April 24, 2013. If the project continues beyond this period, please resubmit your materials for renewal in a timely fashion so that your research may continue uninterrupted.

Good luck with your research.

Sincerely,

[Signature]

Ralph Albano
Secretary
Committee for the Protection of Human Subjects

cc: Dr. Jean Toth
September 21, 2011

Ms. Sandra O’Brien
2805 Advent Court N
Bowie, MD 20716

Dear Ms. O’Brien,

re: IAN (Interactive Autism Network) Project Subject Recruitment Support for
_The Influence of Daily Stressors, Severity of Behavior Problems, Uncertainty and Coping on Family Adaptation in Families of Adolescents with Autism Spectrum Disorders_ (IAN Application SR00449)

The IAN Project would like to offer its support for the above study. The IAN Project is an innovative online project designed to accelerate the pace of autism research by linking researchers and families. The IAN Project consists of two primary areas:

- **IAN Research** is an autism-focused longitudinal database and research registry designed to facilitate research efforts. Families impacted by an Autism Spectrum Disorder (ASD) share their information via the internet from the comfort of home, while researchers apply to access data or to recruit research participants. IAN Research is governed by the Johns Hopkins Medicine IRB (NA_00002750; PI Dr. Paul Law).
- **IAN Community** is a website and meeting place where all concerned with ASDs can gather to learn about autism research, view up-to-date IAN Research findings, and provide input into the research process.

IAN helps researchers with recruitment in two ways: by informing our participants about studies for which they qualify via email and by posting information about such studies on the IAN Community Research Opportunities Bulletin Board. To date IAN has provided recruitment and/or data services for over 300 research studies.

Since the launch of the project in April 2007, IAN Research has consented nearly 40,000 participants, including nearly 15,000 children with ASD. This includes more than 3,500 high-functioning affected children aged between 13 and 22 years of age. This represents the anticipated size of the eligible pool of participants for your study.

IAN services will include: assistance with the development of the IAN subject recruitment letter for your study; selection of potentially eligible IAN participants for your study; emailing the IAN subject recruitment letter to the parents of potentially eligible IAN research participants, including a follow-up reminder email; and general assistance with IAN Subject Recruitment application. **For these services, IAN’s estimated subject recruitment cost recovery fee will be $2,000.**

We at the IAN Project look forward to working with you on this study.

J. Kiely Law, MD, MPH
Research Director, IAN Project
lawk@kennedykrieger.org
443-923-4142

Alison R. Marvin, PhD
Research Coordinator/Data Manager, IAN Project
marvin@kennedykrieger.org
443-923-4143

A web project of Kennedy Krieger Institute ∙ Sponsored by Autism Speaks and the Simons Foundation

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