

AN EXPLORATION OF RESILIENCE IN FAMILIES WITH A CHILD  
DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER

A DISSERTATION

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## DEDICATION

**To Emma K. Eckstein-DuPont (Mom) and Michael R. DuPont II (Mikey), you have been an inspiration to me. Your love, support, and belief in me has guided me.**

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I am grateful to the courageous parents of children with an Autism Spectrum Disorder for telling their stories in an open and honest manner. You are a true inspiration, and my prayer is that others will be inspired by your experiences and triumphs. I want to continue to encourage those who are working with children and families who are impacted by Autism, to please hear them.

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## ABSTRACT

MICHAEL R. DUPONT

### AN EXPLORATION OF RESILIENCE IN FAMILIES WITH A CHILD DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER

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The purpose of this qualitative research study was to explore how families with children with an Autism Spectrum Disorder (ASD) were able to move through the adverse situation that they face while raising a child with significant developmental needs and challenges. The theoretical framework that guided this phenomenological research was family resilience. The research participants included 14 parents of at least one child with an ASD. The age range of the participants ranged from 30 to 65, and they all resided in a large metropolitan area. A face-to-face interview was conducted with each of the participants in their own home or in a private setting. Participants were asked one question: Please tell me about your experience of raising a child with an ASD. The interviews were audiotaped, transcribed verbatim, and analyzed to determine themes.

Eight themes emerged: (a) balancing life around the child with ASD; (b) remaining watchful and alert; (c) reaching a point of acceptance; (d) dealing with judgment; (e) gaining support; (f) relying on spirituality and faith; (g) learning to laugh; and (h) celebrating small successes. Conclusions, implications, and recommendations for future studies were reported in an effort to aid family therapists, school staff, and other

mental health professionals in providing supports and resources to families with children with ASD.

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## CHAPTER I

### INTRODUCTION

Reported cases of Autism in children are on the rise. According to the Centers for Disease Control and Prevention (CDC), the prevalence of children with an Autism Spectrum Disorder (ASD) has increased from 4 to 5 in 10,000 children to 2 to 6 per 1,000 children (CDC, 2007). To further note the significance of this increase, the CDC has reported that the numbers of children with an Autism Spectrum Disorder being served by public schools has increased from 22,664 in 1994 to 211,610 in 2006. The CDC indicates that up to 560,000 individuals from birth to the age of 21 are identified as having an Autism Spectrum Disorder.

Some research concluded that there is a significantly higher level of child related stress in parents with a developmentally delayed child than in parents with a child without delays (Baker, Blacher, Crnic, & Edelbrock, 2002; Peterson & Mathieson, 2000). There is a significantly higher level of child-related stress and lower quality of life reported in parents with an ASD child than in parents with a child without delays (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006). These stressors may revolve around the care-taking, behavioral, and physical demands associated with rearing a child with an Autism Spectrum Disorder. Families' concerns include such elements as demanding supervision requirements, the constant need for care, treatment and health care related costs, specialized educational and treatment programming, and finding well-informed care-

givers, educators, and therapists. According to Schieve, Blumberg, Rice, Visser & Boyle (2007), parenting a child with autism may pose additional stressors related to the child's challenges in communicating, difficult behaviors, social isolation, difficulties in self-care, and lack of community understanding. According to Walsh (2006), "how a family confronts and manages a disruptive experience, buffers stress, effectively reorganizes, and moves forward with life will influence immediate and long-term adaptation for every member and for the very survival and well-being of the family unit" (p. 15).

Due to the rising numbers of individuals identified with ASD and the stressful impact of raising a child with ASD, there is an increased need in providing families with effective services and supports. Support for families and individuals often include behavioral interventions, counseling, educational training, social skills training, specialized therapies (i.e. speech, occupational, and physical), and medical services (Bennett & DeLuca, 1996; Becker-Cottrill, McFarland, & Anderson, 2003; Lozzi-Toscano, 2004; Bailey, Nelson, Hebbeler, & Spiker, 2007). According to Walsh (2006), "families that present multiple, complex, and severe problems, more than one symptom bearer, and recurrent crises make up a disproportionately large segment of the human services caseload" (p. 254). Effective services and supports will include therapists who are skilled and well trained with regard to ASD, empathic to the needs of the family, and capable of providing evidenced-based and strength-based treatment approaches. Therapists and families with newly identified children with an ASD can benefit from gaining information from families who have been able to overcome and move through the adversity of raising a child with ASD. Experienced families can offer ideas to other

families in similar situations and help identify the characteristics that helped them cope and adapt while raising and loving a child with ASD.

### Statement of the Problem

According to Singer, Irvin, Hawkins, Hegreness, and Jackson (1993), there is evidence to suggest that about one-third of families with children with disabilities experience daily stressors related to having a child with a disability, and other research suggest that the majority of families adapt in a positive manner (Summers, Behr, & Turnball, 1988). Brown et al. (2006) compared families with children without disabilities to families with children with either Down syndrome or Autism. They noted that families with a child with Autism reported significantly lower quality of life than the other two groups. Family financial earnings, community and neighbor support, and a higher number of negative quotes that were consistent with the parents' expectations appear to be more pervasive in families that have a child with an Autism Spectrum Disorder. According to Fallon and Russo (2003), families with unmet needs that continue to be unmet over time are at greatest risk for maladaptation in their process of adjustment. Often in the midst of a crisis the focus appears to be on the problems, unmet needs, and stressors. Walsh (2006) noted, "a family resilience framework builds on these developments, shifting our view from seeing distressed families as damaged to understanding how they are challenged by adversity" (p. 17). Instead of looking at what is not working or the lack of resources, more attention is placed on the family's strengths and how a family has succeeded. Often families can become overwhelmed with the diagnosis and the daily stressors in raising a child with an ASD. Therapists can play a

key role in providing resources and supports to families with children with ASD.

According to Walsh (2006), “rather than giving up on troubled families and salvaging individual survivors, we can draw out the best in families, building on key processes to encourage both individual and family growth” (p. 4). Therapists, educators, and family support providers can help focus on the strengths that the family possesses rather on their weakness. Professionals can help identify family strengths, past successes and resources that support the family and then help those families apply these same resources to moving through this adversity.

#### Purpose of the Study

The purpose of this study was to explore how families with children with an Autism Spectrum Disorder are able to move through the adverse situation that they face while raising a child with significant developmental needs and challenges. Using a phenomenological approach, this study applied Walsh’s (2006) family-resilience framework as a lens in focusing on three core issues: the family’s belief system, organization structure, and communication patterns.

#### Research Questions

The following questions guided this study:

1. What meaning does the family place on raising a child with an Autism Spectrum Disorder?
2. What supports have been helpful in strengthening the family?
3. What communication processes are helpful in problem solving in families with children with an Autism Spectrum Disorder?

## Research Approach

Due to the nature of this research, in attempting to better understand the lived experience of parents who are living with a child with an Autism Spectrum Disorder, qualitative face-to-face interviews with parents using a phenomenological research approach were used. According to Creswell (2003), “a phenomenological study describes the meaning of several individuals of their lived experiences of a concept or a phenomenon” (p. 57). By using a phenomenological approach this study attempted to identify some of the commonalities that are shared by these families as they experience living and raising a child with ASD. A goal in using a phenomenological approach was to further bring out individual experiences, in this case, raising a child with an Autism Spectrum Disorder, to provide a description of the nature or essence of that phenomenon (Creswell).

## Conceptual Framework

The theoretical framework that guided this research was family resilience. According to Walsh (2006), “a resilience-based stance in family therapy is founded on a set of convictions about family potential that shapes all interventions” (p. 25). This approach uses a strength-based position in working with families that encourages collaboration, communication, mutual support, and shared beliefs. Walsh identified three keys to family resilience: family belief system, organizational patterns, and communication processes. Walsh stated, “belief systems are at the core of all family functioning and are powerful forces in resilience” (p. 49). This conceptual framework suggests that how a family makes meaning of their adversity, what they see the future

being, and their spiritual and transcendent beliefs are core concepts of the family belief system. Walsh noted that organizational patterns in family functioning point to flexibility in the family structure, how connected family members are to others, and how the family uses the resources of extended family and the community. Lastly, with regards to communication process, Walsh noted, “good communication is vital to family functioning and resilience” (p. 106). This concept refers to the clarity of the family’s communication, the openness and willingness to share emotionally, as well as how the family engages in collaborative problem solving.

#### Definition of Terms

**Resilience:** “the capacity to rebound from adversity strengthened and more resourceful” (Walsh, 2006, p. 4).

**Family Resilience:** “coping and adaptational processes in the family as a functional unit” (Walsh, 2006, p. 4).

**Autism Spectrum Disorders (ASD):** term used for this research to mean the same as Pervasive Developmental Disorder. The DSM-IV-TR indicates that “Pervasive Developmental disorders are characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities” (American Psychiatric Association, 2000, p. 69). ASDs include Autistic Disorder, Asperger’s Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified.

## Delimitations

The following delimitations applied to this study:

1. The participants were biological parents or legal guardians of a child with an ASD.
2. The participants of this study were volunteers who were willing to speak about their experiences as parents of an autistic child.
3. The participants had a child that was at least 6 years old.
4. The children of the participants had a diagnosis of ASD for at least 3 years.

## Assumptions

The following assumptions were made:

1. Families with children with disabilities face challenges and adversity in developing family resilience.
2. Parents of children with disabilities respond in some manner to their child's disability.
3. Participants will respond openly and honestly about their child's disability and their lived experiences.
4. The participants will be willing to share their insights.

## Summary

With an increasing rate of identification of children with an ASD, families may be facing stress and challenges in overcoming this adversity. These stressors and challenges may revolve around the care-taking, behavioral, and physical demands with a child with an ASD. The intent of this study was to identify key resilience characteristics of families

with children with an ASD. This qualitative research looked at how parents made meaning and what they believed about their child, how various supports might have impacted the parents, and how the family communicated in order to facilitate resilience. This chapter provided an introduction to the study's overall focus and identified the research questions, research approach, conceptual framework, definitions, assumptions, and delimitations of the study.

## CHAPTER II

### REVIEW OF THE LITERATURE

This chapter reviews several key areas addressing the research literature with regard to understanding ASD and strengthening family resilience. In order to provide context for the proposed research, this literature review will focus on seven areas. The first section reviews Autism Spectrum Disorders, followed by defining resilience, family resilience framework, the impact of stress on family resilience, family resilience and autism spectrum issues, the role of family supports, and the role of professionals in building resilience. Lastly, a summary addresses the importance of qualitative research to help in strengthening family resilience in families with children on the Autism Spectrum.

#### Autism Spectrum Disorders

Pervasive Developmental Disorders are often referred to as Autism Spectrum Disorders. This group of disorders includes Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified. According to the *Diagnostic and Statistical Manual of Mental Disorders*, 4<sup>th</sup> text revision (APA, 2000), "the disorders on this spectrum typically involves significant and pervasive disruptions in reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interest, and activities" (p. 69). Often ASDs are typically diagnosed in early childhood or

adolescence. Children with an ASD may display a variety of delays early on; however, parents may find it difficult recognizing or understanding these delays. Early detection and intervention appears to be pivotal in addressing the child's needs (Bailey, Nelson, Hebbeler, & Spiker, 2007); however, one source of stress for parents appears to also be getting the right diagnosis, and then other stressors include finding the appropriate treatment and interventions.

The CDC reported that the number of children with an Autism Spectrum Disorder being served by public schools has increased from 22,664 in 1994 to 211,610 in 2006 (CDC, retrieved 10/28/2008). It is also suspected that up to 560,000 individuals from birth to the age of 21 are identified as having an Autism Spectrum Disorder. Given this increase in identification of children with an ASD, it is possible that more families are facing significant challenges in dealing with this adversity.

### Resilience

It has been of great interest in research to try to understand why some people are able to deal with significant adversity and/or loss in their lives, while others may appear trapped or lost in the face of similar adversity. One important concept in reviewing the research on child development and mental health theory is resilience (Walsh, 2006). Werner & Smith (1992) defined resilience as constitutional resources, which help humans survive. Patterson (1991) defined resilience as the ability to recover from adversity, while Fine (1991) suggested that resilience is the ability to meet society's expectations in spite of great odds. According to Walsh (2006), "it is an active process of endurance, self-righting, and growth in response to crisis and challenge" (p. 4).

Early research on resilience focused on individual and personal traits (i.e. hardiness). However, many of the resilience criteria were often based on the view of the dominant culture (Luthar & Ziegler, 1991). Anthony & Cohler (1987) looked at resilience as being an innate quality, something inborn. Masten (2001) stated, “resilience appears to be a common phenomena that results in most cases from the operation of basic human adaptational system” (p. 227). Masten also noted “resilience does not come from rare or special qualities, but from everyday magic of ordinary, normative human resources in the minds, brains, and bodies of children, their families and relationships, and in their communities” (p. 235). Many of the early researchers studied resilience in children at risk for psychopathology and potential problems in their development (Garmezy, 1971, 1974; Rutter, 1979; Werner & Smith, 1992).

In their classic resilience research study, Werner and Smith (1992) followed 700 multicultural children who were living in poverty on the island of Kauai. According to their longitudinal study they found one third of their at-risk subjects had developed into competent and caring adults, while the remainder of the subjects had developed significant needs (i.e., mental health needs, early pregnancy, and trouble with the law). The importance or significance of supportive relationships was found to be a significant variable in the resilience of the children. Additional studies in the development of resilience in children centered on the importance of connectiveness.

Lew (2002), who studied children dealing with the aftermath of the terrorist attacks on September 11, 2001, stressed the importance of connection. “Knowing that we are not alone in life and being in connection with other human beings are vital to

emotional well-being” (Lew, p. 134). In overcoming adversity in an increasingly threatening world, Lew identified four basic cornerstones to emotional well-being, which include developing courage, helping children realize that they count, helping them feel capable, and emphasizing connections. While Lew’s research focused more on the resilience of children, much of the current research in family resilience also identifies the importance of beliefs, connections and supportive resources (Bailey et al., 2007; Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; & Pahi, Manaras, Tuomainen, & Hundt, 2004). While the early definitions focused on individuals’ ability to rebound from adversity, more recent research takes a closer look from a systems perspective and finds that families have similar characteristics.

#### Family Resilience Framework

Rather than looking at the family in distress as broken, a family resilience perspective would see the distressed family as challenged and possessing the capacity to grow through the adversity (Walsh, 2006). This perspective provides a positive view of how families can learn to heal and grow while dealing with adverse situations. The focus is taken away from past failure and instead the focus is on the strengths that families have in helping deal with the current situation.

Walsh (1996) suggests that a family resilience approach to clinical practice may be grounded in family systems theory. Walsh (2002) indicated,

family functioning is assessed in context of the multigenerational system as it moves forward over time, coping with significant events and transitions, including both predictable, normative stresses (e.g., birth of the first child) and

unpredictable, disruptive events (e.g., the untimely death of a young parent). (p. 132).

According to Walsh (2006), “a systems perspective enables us to understand how family processes mediate stress and can enable families and their members to surmount crises and weather prolonged hardships” (p. 15). Walsh identified three key processes involved in the functioning level of the family: the family belief system, the organizational patterns of the family, and the communication patterns of the family. Family resilience is fostered by shared beliefs that help members make meaning of a crisis situation, facilitate a positive outlook, and provide transcendent or spiritual values and purpose (Walsh). This framework suggests that what meaning the family assigns to the adversity and their outlook (i.e. optimism and hope) will play a vital role in the family’s functioning. The family organizational pattern speaks to the importance of flexibility, connectedness, social and an economic resource as the family is faced with a crisis or adversity. Walsh noted, “contemporary families, with diverse forms, must organize in varied ways to meet the challenges they face” (p. 10).

Many families appear to struggle with how to begin addressing their challenges. Research suggests that strengthening family resilience can be enhanced by identifying and developing connection, mutual supports, collaboration, and commitment (Bayat, 2007). Lastly, Walsh (2006) reported, “communication processes foster resilience by bringing clarity to crisis situations, encouraging open emotional expression, and fostering collaborative problem solving” (p. 12). Due to the importance of communication (i.e. transmit beliefs, exchange information, to express emotion, and to solve problems) good

communication is very important to family functioning (Walsh). Good communication consists of clear and consistent messages, allowing for clarification of ambiguous information and/or expectations, and the expression of honest feelings. Walsh also indicated that good communication provides opportunities to share feelings, encourages mutual empathy, tolerances of differences, and encourages self-responsibility for feelings, while also promoting pleasurable interactions and collective problem solving opportunities.

### The Impact of Stress on Family Resilience

Families experience stress due to a variety of factors, which includes numerous family demands, such as discrete events of change, on-going family strains, and daily hassles (Patterson, 2002). Stress appears to become a major factor in family functioning when the family demands far outweigh the family's capabilities. Families that remain in a state of imbalance may remain disorganized, disoriented, and in a crisis mode.

"Families engage in relatively stable patterns of interacting as they try to balance the demands they face with their existing capabilities to achieve a level of family adjustment" (Patterson, 2002, p. 350). Walsh (2002) indicated, "family distress may result from unsuccessful attempts to cope with an overwhelming situation" (p. 132).

Research suggests that a continual accumulation of internal and external stressors and adverse events can overpower a family and serve to elevate the risk of further stress and future problems (Boss, 2001). Families may remain blocked from growth, which may be generated by a crisis event (i.e., a traumatic loss). Other researchers have also

noted that internal and external stressor events can overwhelm the family and heighten the risk of subsequent problems (McCubbin & Patterson, 1983).

According to Judge (1998), coping can be defined as constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person. Fallon and Russo (2003) noted families with unmet needs that continue to be unmet over time are at greatest risk for maladaptation in their process of adjustment.

Another important aspect in fostering resilience is the ability to laugh and communicate through humor. Walsh (2006) stated, "Humor helps families cope with difficult situations, reduce tensions, and accept limitations" (p. 114). Research has suggested that having the ability to see things from a humorous perspective can play an important part in learning to adapt and cope with stressful life situations (Earvolino-Ramirez, 2007; Masten, 1994; Richardson, 2002).

In her extensive research on family resilience, it is Walsh who provides a framework for addressing the strengths of families in crisis. This framework can be applied to families with children on the autism spectrum. These families are challenged with external and internal demands, may experience needs going unmet, demonstrate limited and consistent coping skills, and lack a clear perception for a positive outcome.

#### Family Resilience and Autism Spectrum Issues

According to Singer, Irvin, Hawkins, Hegreness, and Jackson (1993), there is evidence that about one-third of families with children with disabilities experience daily stressors related to having a child with a disability. While other research findings suggest

that the majority of families adapt in a positive manner (Behr, Murphy, & Summers, 1992; Summers et al., 1988).

Brown et al. (2006) compared families with children without disabilities (n = 18) to families with children with either Down's Syndrome (n = 33) or Autism (n = 18). The families completed the Family Quality of Life Survey. They noted that families with a child with Autism reported significantly lower quality of life than the other two groups. The researcher indicated, "the families without a child with a disability showed statistically significant higher levels of satisfaction across all domains (with exception of the disability services domain)" (p. 242). While there is still no full understanding of Autism and its causes, there is a great body of research that increases understanding of pervasive developmental disorders (Attwood, 1998; Dunlap & Fox, 1999; Grandin, 1995; Marcus, Kuncze, & Schopler, 1997; Waltz, 2002). The review of the literature identified limited qualitative research that clearly shared an understanding of the effects of Autism on the family. With more children and young adults being served in public schools and receiving specialized treatments, there appears to be little understanding of how best to help parents and families in coping with the daily stressors that surround raising a child with ASD.

Baker, Blacher, Crnic, and Edelbrock (2002) concluded that there is a significantly higher level of child-related stress in parents with a developmentally delayed child than in parents with a child without delays. These stressors may revolve around the care-taking, behavioral, and physical demands with a child with a pervasive developmental delay.

According to Bailey et al. (2007), “research consistently shows that families with strong support systems are able to handle challenges more effectively than families with few supports” (p. 993). Their research included 2,166 families, who had children participating in an early intervention program, which participated in a 40 minute telephone interview about the quality of child services, quality of family services, family and community support, confidence in parenting, optimism for the future, impact of services, family demographics, and child characteristics. According to Bailey et al., “the majority of families of young children with disabilities report high levels of quality for their early intervention services and generally positive impacts of services on both children and families” (p. 999). Also significant in their findings was the relationship between the perception of quality and the perceived impact. Lastly, they noted informal supports, such as family and community supports, play a vital role in promoting optimism and parenting confidence. Bailey et al. concluded “both formal support (in this case, early intervention services) and informal supports (family and community supports) are important for family adaptation, but likely operate in different ways with differential impacts on families” (p. 1000).

Peterson and Mathieson (2000) reported that families view having a child with a disability as a significant stressor event. Families’ concerns include such things as demanding supervision requirements, the constant need for care, treatment costs, and potential for feelings of anger, sadness, and frustration (DeGrace, 2004). DeGrace used a qualitative approach in studying 5 families’ experiences in living with a child with Autism. Four themes were identified in this small study: 1) the entire family life revolves

around autism; 2) the family feels robbed; 3) the focus seems to be on occupy and pacify; and 4) there are fleeting moments of feeling like a family. According to DeGrace, “these themes suggest a pervasiveness of autism in family experiences” (p. 548).

Other research has found that many families seem to adjust and cope adaptively with life with a developmentally disabled child. Singer, Irvin, Hawkins, Hegreness, and Jackson (1993) reported about one-third of families with children with disabilities experienced daily stressors related to having a child with a disability. Summers, Behr, and Turnball (1988) suggested that the majority of families adapt in a positive manner. However, the one-third of families that experience significant stress on a daily basis deal with a number of issues. Parents of children with an autism spectrum disorder may experience specific and unique sources of stress associated with the child’s disability (Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005; Schieve, Blumberg, Rice, Visser, & Boyle, 2007; Brown et al., 2006). One issue identified is the boundary ambiguity that exists in a family raising a child with an Autism Spectrum Disorder. When Autism is diagnosed, parents have to come to terms with a loss of hopes and dreams (King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006). Boss (2004) has suggested that this type of loss may also be identified as an ambiguous loss. Boss stated, “ambiguous loss is a problem psychologically when there are feelings of hopelessness that lead to depression and passivity, and feelings of ambivalence that lead to guilt, anxiety, and immobilization” (p. 553-554). Families’ beliefs appear to play an important role in how the families move through adversity. King et al. indicated that families reported a reevaluation of their beliefs due to having a child with a disability.

Bayat (2007) studied 175 parents and caregivers of children with an ASD. The participants were asked three open-ended questions: 1) what they thought the effect of autism was on their family; 2) what they thought the effect of autism was on them; and 3) to describe the child with autism in three or four sentences. Bayat noted, “two necessary factors for resilience are the family’s ability to pull resources together, and the family members being connected” (p. 708). Using a qualitative analysis approach, the researcher was able to discover four thematic categories (the family, family resilience, the parent, and the child). Eleven themes were identified and of those, five met the family resilience framework based on the research by Walsh. The positive meaning the families gave their adversity appeared to play a large part in resilient families. “The families studied not only made positive meaning of their child’s disability, they also articulated many contributions and lessons learned as a result of the disability” (p. 710). The families appeared to share some common and/or collective experiences, while also recognizing a more caring and purposeful existence. Lastly, Bayat’s findings also identified the importance of having a spiritual belief system. “While some family members gained a conviction of their faith, others found new spiritual belief” ( p. 711).

### Role of Family Supports

According to Hartshorne (2002) after coping with an event such as a diagnosis of a child with ASD, a second step then includes making decisions about the resources and supports. Trute and Hauch (1988) reported that family members and friends provided emotional support, advice, and social participation. In their study, participants with children with developmental delays identified themselves as having strong and well-

adjusted families. Trute and Hauch also noted that parents identified family members more as a source of material and physical support than friends.

Valentine (1993) concluded that 56% of studied families who had children with disabilities reported having supportive families. Valentine suggested that families benefited from their extended families by gaining child-care, transportation, and financial and emotional support. Much of the family resilience literature appears to stress the importance of providing support to families from families, community providers, religious affiliations, and educational programs (Becker-Cottrill, McFarland, & Anderson, 2003; Gray, 2006; Rahi, Manaras, Tuomainen, & Hundt, 2004). When there is a lack of community and neighborhood support, families with a child with a disability report poor satisfaction and higher rates of isolation (Brown et al, 2006). In their findings Brown et al. (2006) also noted the importance of respite for the family. Their results highlighted the importance and need for the family to engage in activities outside the home, not just in the workplace or family home. However, some of the parents reported that they face challenges during family outings due to some of the difficult behaviors that may be exhibited by their child with an ASD. Respite care provides some families with an opportunity to just catch up on regular family chores, such as cooking, cleaning, and shopping (Brown et al.).

Walsh (1996) noted the crucial influence of significant relationships with caring adults and mentors, who supported the efforts of children. Bennett and Deluca (1996) conducted qualitative research in which they completed in-depth interviews with 12 parents of children with a disability. Family members and friends of the parents were

seen as emotionally supportive during challenging periods. Participants in this study indicated the importance of supports from family and friends. Eight of the parents who participated reported that they participated in self-run parent groups. Bennett and Delucca noted in their review of the literature that research on the effects of parent-run self-help groups is sparse. They indicated that possession of information, emotional support, and effective coping strategies are all partially attainable in self-help groups. These self-help groups can also serve as an opportunity for a safe emotional outlet.

### Role of Professionals in Building Resilience

Bennett and Delucca (1996) found that parents of children with disabilities remain in contact with professional helpers regardless of their child's age. They found that parents in their study wanted to interact with committed professionals who were willing to work in an open and honest collaborative relationship. Interestingly, parents appear to want to work with professionals who are aware and honest about their limitations (Bennett & Delucca).

According to researchers, professional support is often viewed as a formal source of support compared to the informal support of friends and family members. It is the professional helper who provides support to parents by providing resources and expertise (McCallon & Toseland, 1993). Families benefit from efforts that build family resilience by enhancing functioning and well being and reducing pathology and dysfunction (Luthar et al., 2000). Research suggests that family adaptation is facilitated when its available resources balance the demands of the family (Fallon & Russo, 2003). It has also been noted that families benefit from strong supports, which allows them to handle challenges

more effectively than those families with few supports (Bailey et al., 2007). Clinicians and professionals may focus on exploring unmet needs, while providing resources that help mediate stress when working with families with children with disabilities (Judge, 1998). Clinicians, who use a family resilience framework, can help balance the families' needs and help provide a sense of stability (Walsh, 2002). "Especially valuable are strategies that reassure children and other vulnerable family members by coaching behaviors that reflect strong leadership, security, continuity, and dependability" (Walsh, p. 135). By seizing opportunities, Walsh notes, clinicians can help families deal with current and future situations more effectively.

#### Summary

While there is an increase in the identification of Autism and in the treatment of the individual, limited research exists that focuses on working with families with a child with an Autism Spectrum Disorder. Research suggests that families can strengthen their level of resilience in facing future adversity and crisis. Families become more resourceful when interventions shift from a crisis-reaction to a proactive approach, anticipating and preparing for the future. A review of the literature also suggests that resilience should be considered an ordinary phenomenon. Walsh has provided a family strength-based resilience framework that can be applied to working with families with children with an Autism Spectrum Disorder. This approach places an emphasis on a collaborative process while attempting to identify and build strengths and resources.

## CHAPTER III

### METHODOLOGY

This research utilized a qualitative approach. Qualitative research approaches allow for in-depth investigation of a particular problem or issue. This type of research investigation allowed for a richer understanding of the issue and provided an opportunity for a deeper understanding of the lived experience (Creswell, 2007). The purpose was to explore how families with children with an Autism Spectrum Disorder are able to move through adverse situations that they face while raising a child with significant developmental needs and challenges. The findings of this study will aid family therapists and other mental health professionals, as well as school support staff in providing supports and resources to families with children with ASD. Data were collected by using semi-structured, in-depth interviews in order to obtain the participants' lived experiences. The participants were parents of children who had been diagnosed for at least three years with ASD and were at least 6 years of age.

This chapter will explain the research methods utilized in this research, provide an explanation of the conceptual framework that guided this research, describe the research participants, clarify the efforts that were taken to ensure informed consent and protect the research participants, and identify how the research data were collected, stored, treated, and analyzed.

## Conceptual Framework

This research was conducted by using a phenomenological research lens. According to Creswell (2007), “a phenomenological study describes the meaning for several individuals of their lived experiences of a concept or a phenomenon” (p. 57). In this research participants were asked to describe and discuss in-depth their experience of how they have moved through the adversity of raising a child with ASD. Using a phenomenological research approach allowed parents to share in their own words their stories. The parents were able to share what experiences, supports, or resources have been helpful in strengthening their family resilience.

## Researcher as Person

I am a bi-racial, bi-lingual male and a single father of an 18-year old son. This research is part of the requirement for fulfilling a doctorate degree in Family Therapy from Texas Woman’s University. I completed a bachelor’s degree and a master’s degree in Psychology from Angelo State University in 1983 and 1985, respectively.

It is important to note that I have worked for the past 22 years in the mental health and education field working primarily with individuals with developmental disabilities. Over that span of years I have had numerous opportunities to work with individuals and families with ASD. I am currently employed as a Lead Licensed Specialist in School Psychology (LSSP) where I provide psychological services to both general and special education students and staff in a large urban school district. In the role of LSSP, I provide autism assessment services, parent education, family counseling, and staff development to school staff and various Dallas/Fort Worth area school districts and colleges. Because

I have a vast amount of experience in working with children with Autism and their families, it is important to note that I have some ideas on the difficulties and challenges that families face. I do recognize my experiences have motivated me to study this phenomenon and I bracketed my preconceived ideas by recognizing them and setting them aside to allow the voices of the families to be heard.

#### Protection of Human Participants

The participants' rights were protected by providing them with information regarding the study, maintaining confidentiality of data collection forms, protecting voluntary participation and withdrawal in accordance with the policies and procedures of the Texas Woman's University Institutional Review Board (IRB). Prior to any data collection, approval was obtained by the university's IRB and Graduate School.

In order to protect the participants' right to confidentiality, a numeric coding system was used throughout the research process. The coding system began with the number 001 and then proceeded consecutively. The participants' names only appeared on their consent forms, which were stored in a separate file folder labeled Informed Consents locked in the researcher's office at home. To further provide anonymity all transcripts and demographic data remained stored in a separate file. Only the numeric code was be used on the transcripts and demographic information documents. Along with the consent forms, in a separate folder, audiotaped recordings and transcripts were also be stored in a locked cabinet in the researcher's home office. The consent forms, tapes, hard copy transcriptions, and CD-ROM text files will be shredded in two years after the completion of the research.

## Sampling Procedures

Participants for this study were parents of children who had been diagnosed with an Autism Spectrum Disorder. The target population were parents with children who were at least 6 years of age and had been diagnosed with an Autism Spectrum Disorder for at least three years. Participation in this study was announced via mailed flyers (Appendix A) to various local Autism organizations and support groups, local mental health professionals, as well as school districts. The researcher also asked parents to share information and flyers with other families that they knew who had a child with an ASD. The flyers contained the contact information of the researcher.

Upon receiving contact from the family members, the researcher conducted an initial telephone interview using a telephone script (Appendix B) in order to determine if they met eligibility criteria (the child with ASD is at least 6 years old and has had the ASD diagnosis for at least 3 years). The researcher determined, with the assistance of colleagues in the field of Autism assessment, that in order to study family resilience and family strengths, the research should gain information from parents who are not in the initial phase or stage of learning their child has an ASD.

If the parent met the eligibility criteria, the purpose of the research was then explained and any questions from the parent were answered. If the potential participant agreed to participate, an interview appointment was set at a suitable time for the participants and the researcher at a location agreed upon. One interview was conducted in the researcher's university office, while the remainder of the interviews were conducted in the parents' homes.

## Pilot Interviews

In order to help improve the credibility of this qualitative study, two pilot interviews were conducted. The pilot interviews followed the same protocol described in the above section. The first two scheduled parent interviews served as the pilot interviews. The intent of the pilot interviews was to help evaluate the research questions and the interview procedures. Upon completion of the pilot interviews the researcher asked the parents if they would suggest any changes in the interview procedures. Any suggestions were evaluated for possible inclusion in the remaining interviews. In both pilot interviews no significant recommendations were made from parents in the format of the interviews. One father did suggest that the researcher consider more specific questions that might guide the parent; however, due to the intent to obtain a rich narrative in this phenomenological research, the researcher determined that an open-ended question would ensure that each parent's experience is allowed to surface without guidance from the researcher.

## Interview Procedures

Data were collected using semi-structured, in-depth interviews in order to obtain the participants' lived experiences. The participants were asked to respond to one open-ended question along with prompts to speak freely (Appendix C) and a possible follow-up question if needed. The interviews, ranged from 45 minutes – 2 hours in length. They were audiotaped, later transcribed, and analyzed for emerging themes. The results were reported using a narrative format. It is believed that because the parents interviewed varied in age and stage of the family life cycle, their experiences yielded rich narratives.

During the interview appointment, the parent and researcher completed the consent form (Appendix D) and the Demographic data form (Appendix E). The parents were asked to first review the consent form and then the researcher provided an explanation of the material on the consent form. Before consent was obtained, the researcher asked each parent if there were any questions before signing the consent form. Parents were asked to initial all pages and sign the last pages indicating their acknowledgement and consent to participate. A copy of the consent form and counseling references (Appendix G) were given to the parent. Prior to beginning the interview the researcher completed the demographic background questionnaire, reading it aloud to the participant and allowing the participant to respond. After completion of the demographic questionnaire, the researcher asked the participants if they had any questions before the interview began. The researcher answered all questions regarding the research and then turned on the audio tape recorder and began the research interview. The primary interview question was: Please tell me about your experience of raising a child with an Autism Spectrum Disorder.

The audiotaped interview followed the Interview Protocol (Appendix C). The researcher was contacted by 16 parents; however, after several initial contacts two parents indicated that they did not wish to participate. The researcher obtained data from 14 participants. While originally the researcher set out to interview 20 parents, it is believed that the in-depth interviews provided rich and valuable information about this phenomenon. In using a phenomenological research approach focus should be given on interviewing several individuals that have experienced a particular phenomenon, reaching

a level of saturation of data, and it is recommended to interview 5 to 25 participants (Polkinghorne, 1989; Creswell, 2007). Other researchers applying a phenomenological research approach have suggested an acceptable number of participants to be between 3 and 10 (Dukes, 1984; Riemen, 1986). Several studies that were reviewed as part of this research utilized 5 and 12 participants (Bennett & Deluca, 1996; DeGrace, 2004).

Within two weeks after the interview was completed, the researcher contacted the parents via telephone in order to complete a brief follow-up interview. The brief interview followed a brief telephone script (Appendix F). The purpose of the follow-up interview was to allow the parent an opportunity to add any additional information that he or she felt was relevant that may have been omitted during the initial interview.

#### Data Analysis Procedures

Data analysis followed Morrisette's (1999) phenomenological data analysis process. In order for the researcher to remain as familiar as possible with the data, the audiotapes of the interviews were transcribed as soon as possible following each interview. The researcher listened to each interview in its entirety at least once and then transcribed the interview. The researcher further provided participant confidentiality, completed all transcriptions. The researcher included the nonverbal and gestural nuances in the transcript by using brackets to include those expressions (i.e. [laughed] or [long pause]). In order to further include triangulation procedures, two additional researchers (doctoral students with extensive knowledge of qualitative research procedures and who had completed training in protecting research participants) assisted in reviewing the completed transcriptions to help identify emerging themes. In qualitative research this

type of procedure is often employed as a means to enhance reliability of the findings (Creswell, 2007). The researcher placed transcription numbers (ranging 1 – 12) in a bowl and then randomly selected numbers. Five transcript numbers were selected for the first research assistant, and then the numbers were replaced in the bowl and the researcher pulled five more numbers for the second research assistant. Those randomly selected transcripts were then forwarded to each of the research assistants with instructions to read each transcript several times, highlighting any significant statements, and to indicate if there were any emerging themes. After review the research assistants returned their transcripts with significant statements highlighted and themes notated on the transcript. The researcher then compared those themes with the other identified themes.

The researcher reviewed all transcripts, while the additional research assistants reviewed 5 transcripts, each at least twice in their entirety, and identified themes. Data analysis followed several steps that included first order thematic analysis. This allowed each researcher to highlight significant statements. The statements were paraphrased, then assigned a theme, and placed in a tabular format. The research assistants' significant statements and themes were compared to those themes of the researcher. The researcher found that the research assistants found similar statements significant and similar themes. A second order thematic process further synthesized the statements and grouped them together into clusters of the various themes. Lastly, a between-persons analysis was conducted. After the completion of the data analysis, the researcher presented the results using a narrative format that included excerpts from the transcripts (Morrisette, 1999).

## Summary

The purpose of this qualitative research was to explore how families with children with an Autism Spectrum Disorder are able to move through challenges and adverse situations that they face. Data were collected from 14 parents of children with an ASD. The interviews included one open-ended question and follow-up prompting. The audiotaped interviews were transcribed and then analyzed for emerging themes. The themes were reported in a narrative format, which included excerpts of the participants' responses.

## CHAPTER IV

### RESULTS

The results of this qualitative study, which was designed to explore how families with children with an Autism Spectrum Disorder are able to move through the adverse situation that they face while raising a child with significant developmental needs and challenges, will be presented in this chapter. A pilot study was conducted using the first two interviews. The purpose of the pilot study was to help determine if the questions and the interview format allowed the participant to share their experience. A total of 12 interviews were conducted, with 14 parents participating. Two of the interviews included a husband and wife. Participants' confidentiality was protected by assigning a numeric code to each interview and demographic questionnaire. The researcher audiotaped the interviews and transcribed them verbatim, and finally the data were analyzed to identify emerging themes.

#### Description of the Sample

The research sample consisted of 14 adults who were parents of at least one child with an ASD. The participants included parents who had biological children with an ASD (71%). Three parents indicated that they had adopted their child (21%). One parent had served as a foster parent to eleven-year-old twins with an ASD since they were 3 or 4 years of age (7%). Two parents reported having two children with an ASD. Twelve interviews were completed in which two of the interviews included a husband and a wife.

Ten interviews included only the mother as a participant. During one of the interviews the father was present, though only the mother actively participated. Thirteen of the participants resided in the Dallas/Fort Worth metroplex area, while one participant resided in the Houston metroplex area. One participant resided in an urban area, while the remainder of participants resided in suburban communities.

The sample ranged in age from 30 to 69 years with 50% of the parents in the 40-55 year range. Twelve of the participants were women and two were men. Ten of the participants reported their race to be Caucasian, one reported her race as Asian, one participant reported being Nigerian, and one reported being Hispanic/Caucasian. The participants' gender, age, and ethnicity are reported in Table 1. Of the participants, six reported that they were married, two widowed, four were divorced, and one identified as single, never married. One of the divorced participants indicated that she was currently in a stable cohabitating relationship. The participants' relationship status is reported in Table 1. Educational level and religious affiliation is also reported in Table 1. All but two participants indicated a religious/spiritual affiliation and being actively involved in some religious/spiritual activity. The participants varied in educational level. Many of participants had at least a Bachelor's degree (42%), while four participants had a Master's degree, two parents reported some college work, and two parents reported completing high school.

Four participants reported being teachers and four parents described their primary occupation as being homemakers. The occupation statistics are reported in Table 2. The participants' household income level is reported in Table 3.

Table 1

*Demographic Characteristics of Participants (N = 14)*

Variable	Frequency	%
<b>Parenting Status</b>		
Biological Parent	10	71
Adoptive Parent	3	21
Foster Parent	1	7
<b>Gender</b>		
Males	2	14
Females	12	86
<b>Age</b>		
31 – 39	3	21
40 – 55	7	50
56 – 65	4	29
<b>Ethnicity</b>		
African-American	1	7
Caucasian	10	71
Asian	1	7
Hispanic	1	7
Nigerian	1	7

Table 1 (continued)

*Demographic Characteristics of Participants (N = 14)*

Variable	Frequency	%
<b>Current Relationship Status</b>		
Married	7	50
Widowed	2	14
Divorced	4	29
Single	1	7
Cohabiting	1*	7
<b>Highest Level of Education Completed</b>		
High School	2	14
Some College	2	14
Bachelor's Degree	6	42
Master's Degree	4	48

Table 1 (continued)

*Demographic Characteristics of Participants (N = 14)*

Variable	Frequency	%
<b>Religious Affiliation</b>		
Christian	3	21
Anglican	1	7
Pentecostal	1	7
Catholic	2	14
Neo-pagan	1	7
Non-denomational	1	7
Presbyterian	1	7
Baptist	2	14
No affiliation	2	14

\*Parent divorced is in a cohabitating relationship, counted in both categories

Table 2

*Occupation of Participants (N = 14)*

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Variable	Frequency	%
Homemaker	4	29
Sales	1	7
Teacher	4	29
Real Estate	1	7
Nurse	1	7
Librarian	1	7
Accountant	1	7
Custodial staff/Housekeeping	1	7

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Table 3

*Participants' Household Income Level (\*N = 12)*

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Variable	Frequency	%
Below \$ 20,000	1	8
20,000 – 39,999	1	8
40,000 – 59,999	5	42
60,000 – 89,999	1	8
90,000 – 109,999	2	17
110,000 and above	2	17

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\*N represents the number of household that participated. Two of the interviews included a husband and wife, representing one household.

The household income represented 12 families, since two interviews included a husband and wife. Only one participant reported an income level below \$20,000, while four participants reported an income above \$90,000.

Each of the participants reported having at least one child as having been diagnosed with an ASD. Only one of the participants indicated having two children diagnosed with an ASD. Of the participants' children with an ASD, nine were male and 5 were female. The gender, age ranges, specific ASD diagnosis, and educational status varied and are reported in Table 4. Of the 12 families participating, only one reported having only one child. The participants' number of children living in the home and ages is reported in Table 5. Two of the participants indicated that they have grown children who had left home a number of years ago and are not included in the regular home life.

The ethnicity of the children with ASD appears fairly diverse (Table 4). Four of the children with ASD are identified as African-American or Black, six are identified as Caucasian, three as Bi-racial (Hispanic/Caucasian), and one as Asian. Also reported in Table 4 are the children's specific Autism Spectrum Disorder diagnoses. Half of the children in this study were identified as having Autistic Disorder, two were identified as having Asperger's Disorder, and 5 were identified as having Pervasive Developmental Disorder, Not Otherwise Specified (Table 4). Lastly, Table 4 reports the children's educational and vocational status. Eleven of the children with ASD were still receiving public schooling, while three had completed high school. Of the eleven in public school, five children were receiving some type of general education with special education supports. Six children in school were served in a self-contained educational setting.

Table 4

*Demographic Characteristics of Participants' Children with ASD (N = 14)*

Variable	Frequency	%
<b>Gender of Child with ASD</b>		
Males	9	64
Females	5	35
<b>Age of child with ASD</b>		
6 – 9	4	29
10 – 13	4	29
13 – 16	1	7
17 – 20	2	14
21 – 29	3	21
<b>Ethnicity of child with ASD</b>		
African-American	4	29
Caucasian	6	43
Asian	1	7
Hispanic/Caucasian	3	21

Table 4 (continued)

*Demographic Characteristics of Participants' Children with ASD (N = 14)*

Variable	Frequency	%
<b>Specific Diagnosed ASD</b>		
Autistic Disorder	7	50
Asperger's Disorder	2	14
Pervasive Developmental Disorder, NOS	5	36
<b>Current Educational Status</b>		
In private school	0	0
In public school	11	79
- General Education, only	0	0
- Special Education Support	5	45
- Self-Contained Class	6	55
Completed High School	3	21
<b>Vocational Status</b>		
Vocational Setting	1	7
Day Program	1	7
Home-care	1	7
College	0	0

Table 5

*Participants' Number of Children Living in Home and Ages*

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Participants' #	# of children	Ages of children
001	2	10, 8
002	4	18, 18, 15, 10
003	1	7
004	2	27, 17
005	2	21, 19
006	2	7, 6
007	3	11, 11, 8
008	3	16, 14, 11
009	3	10, 8, 6
010	2	12, 6
011	3	29, 24, 15
012	2	13, 9

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Of the three children who had completed high school, one was employed in some type of community job, one was in an adult day program, while one was receiving in-home care.

### Findings

The purpose of this study was to explore how families with children with an Autism Spectrum Disorder are able to move through the adverse situation that they face while raising a child with significant developmental needs and challenges. The researcher was guided by the following three research questions.

1. What meaning does the family place on raising a child with an Autism Spectrum Disorder?
2. What supports have been helpful in strengthening the family?
3. What communication processes are helpful in problem solving in families with children with an Autism Spectrum Disorder?

Each participant was asked one interview question: Please tell me about your experience of raising a child with an Autism Spectrum Disorder. The researcher allowed each parent to speak in their own way and speak openly about their experience. Some prompts and follow up were provided to gain more elaboration on a particular comment made by the participant. The researcher was able to analyze the transcripts and identify various significant statements that were grouped into various categories. Two research assistants also analyzed five transcripts each, and they, too, identified significant statements and categories. Their themes were consistent with those identified by the researcher. From the various categories the following eight themes emerged: (a) balancing life around the

child with ASD; (b) remaining watchful and alert; (c) reaching a point of acceptance; (d) dealing with judgment; (e) gaining support; (f) relying on spirituality and faith; (g) learning to laugh; and (h) celebrating small successes. Each of the themes is illustrated by participant quotations in the following section. A between-person analysis, which identifies the themes and the participants' endorsement, is provided in Table 6 and Appendix H provides a tabular view of this research model.

### *Balancing Life around the Child with ASD*

Each of the participants responded to the interview question by talking about the challenges they faced in raising a child with ASD. These challenges appear to have multiple layers, such as dealing with the significant behavioral issues, the time commitment, the overwhelming amount of responsibility, multiple family roles and responsibilities, and the impact on the rest of the family. Several participants spoke of an up and down feeling, some comparing their life to being like a rollercoaster ride.

Mom: But I will say, we got him at age 2, he was about 5, [Mom references the three year time span between adoption and son being five years old] so about three years, the stress level, even though I am saying this, took a toll. I have had Adrenaline fatigue, ok but I got cured of that. The stress level, you know your body does, I am a doer and a planner, I can do this. Then you are working on it while your body is falling apart.

Dad interjects: It was magnified because we have 2 children with special needs.

Mom: Emotional special needs.

Interviewer: Can you tell me more?

Mom: It does, I guess it has taken a toll on me physically, I never thought it was really that bad, but emotionally, is harder. You say yeah this is it and I know there is a difference between boys and girls. There is drama. There is, this is who I am. (# 001, both parents)

It's been a rollercoaster. We have some really good moments and we had some really, really bad moments, we had craziness, it's been confusing. There is, some, many words that you can use to describe it. It has never been dull. Let me put it that way. [Mom laughs] It's never been dull. (#002, Mom)

Um, having a child with autism, [mom pauses] you need lots and lots and lots of patience. You need to learn more about autism. (#005, Mom)

Oh it's just, that's just what our life is, everything that we do every single day revolves around what they need um, taking care of them, it's easiest for us in a situation like this where they're playing and they're in the house, 'cause they can't play outside by themselves so if they go out the door I have to be with them like hands reach because they have very poor boundaries, no sense of "stranger danger" um, but and they're both very impulsive (#007, Foster Mom)

Exhausting financially, physically, emotionally, ah, makes you feel tattered. I mean it just has been very difficult. (#010, Mom)

All of the participants indicated that over time they were able to manage better and prioritized differently. The families began coordinating together and sharing responsibility.

Mom: We can do a little more today. They say with ABA [Applied Behavior Analysis], ok can move our schedule around him, we check off, Yeap, yeap [Mom demonstrates checking off a list]. That is what we do. He still affects what we do. We can do a little bit more, with his age, his ability to walk, and his, you know.

Dad: For the longest we used to feel secluded or ostracized. You know, I am not going try this. I am not going out in a public setting. It's not , he makes these sounds [child makes loud sounds in background]. (# 001, both parents)

Several of the participants indicated that the family often adjusted based on the needs of the child with ASD, which often times impacted siblings in a negative way. Some of the children with significant behavioral and sensory needs required a great deal more of family adjustment. Several participants spoke about centering family activities (i.e. community outings, leisure activities, or family vacations) on the ASD child's needs. Even those families eventually began taking family vacations and began addressing the challenges with outings.

Some places we'd have to leave, you know, the family you'd go and it was like "no he can't handle it, so we have to leave." You know, I don't suppose it affected [youngest son's name] a lot I know it would affect our daughter who was three years younger than him. So we devised a plan that we were going to Florida,

we're going to Disneyworld, and the plan was that, ok, Daddy you have [son] if the line is too long or whatever, you take him and you go wander around or whatever and I'll stay with the girls to make sure they at least ride some things and you know get some stuff done. (#002, Mom)

Most of the participants spoke about the challenges they faced in balancing all of the additional therapies and services along with family life. The majority of the participants whose child attended public school also received a variety of additional specialized therapies (i.e. Applied Behavior Analysis [ABA] training, speech therapy, riding therapy, in-home training, occupational therapy, etc.), as well as participating in other family activities (e.g., attending church, sibling activities, etc.)

It's basically a 24 hour job. Ah. If you are not working with him you are looking for funds, looking for services. Yes, he goes to ABA three times a week, he was going to OT twice but I had to cut back to one, which I may push back up to two. And then he goes to, ah, swimming, which helps out a lot. He goes swimming every Saturday and then we go to the pool whenever we can. He goes horseback riding. And we keep him in public. (# 012, Mom)

Several of the participants considered themselves as homemakers and managing most of the day-to-day activities of balancing life around a child with ASD. In families with more than one parent, the participants spoke of sharing the responsibility of the family life.

What helps, he [mom points toward dad, smiling] gets up early in the morning. He goes to work-out. He wakes them up, he changes and has the first shift. So

that I can get ready, I can make their breakfast, and ready for school. He sort of started the whole progress. (#001, Mom)

*Remaining Watchful and Alert*

The participants all spoke of having to be extra vigilant and prepared for almost anything. Often they were not sure what to expect from their child, their family, their community, and others, again exposing a number of layers. Many parents reported they always needed to be prepared for the unexpected from their child with ASD. One parent described their son as “Onion Man”.

I call him the “Onion Man” we keep peeling off layers and find something new.  
(#001, Dad)

Well, it’s a trial and error thing; usually the same thing doesn’t work more than twice, because before long they can just figure that out. (#004, Mom)

But all of the boys that are usually around, um, well even my daughter’s husband, when he first started coming around we had to prepare him for some of the things that you know go on because it’s, um, she knows that it’s like, uh, everybody scatters when she comes out of the bathroom and she doesn’t have her clothes on and so [Mom laughs] you know it’s like “I know that’s gonna happen when I open that door.” (#004, Mom)

So, um it’s um, it’s always listening, always being aware of what’s going on with them, and um, it doesn’t change until they are in bed and asleep and then you sleep with kind of one ear open because they’re big enough now to get up and you

know, move around and do things. We haven't gotten to the point where I've had to put alarms on the doors, but I think it's coming pretty quickly. (#007, Foster Mom)

I have, you have to think of everything. You have to anticipate what could happen and we better talk about this. (#008, Mom)

The participants all spoke of having to become experts in understanding their child and in understanding Autism. They also described their experiences in obtaining knowledge to be able to advocate on behalf of their child and make others more aware on how to work with their child. Many of the participants accepted the challenge to advocate and became very active in helping prepare others.

Believe me with 20 years in corporate America, and I never thought this would prep me to do research, from the whole autism spectrum, nutrition, therapies, all of that. I have a degree for a reason, in research for a reason. To be his advocate, to be able to speak to people, to be able to stand up for him. (#001, Mom)

Um, I have definitely become more of a small boys advocate for understanding autism, uh, it's a running joke in my instruction sessions, because if I can't think of a word to search, I just search for autism, millions of hits, and it's a great search for me because I can say, "okay now, how would I narrow that down?" Are we going to look for an autism spectrum disorder? Should we look for Asperger's syndrome? Should we look for PDD-NOS? And students who have

been taught something about autism come along with me but those that don't start realizing "there's more to autism than I realized," um, and you know we have the teaching the exceptional child class here and when I started here I think I ordered 50 children's books on autism because the ones we had were so terrible (#006, Mom)

I done got experience [mom laughs and smiles as she speaks] and I done started asking I don' care questions. It's like you can tell me "yes" or "no", but I don't care I am gonna ask it. What brought that change, is he we fought to get him on SSI and on SSI every three months. My husband gets paid every three weeks, my husband gets paid, whenever he gets paid three times a month he loses disability. So for the longest he was on and off and I just got tired of him not getting services when he really needed them because he would be starting to progress than all of a sudden the services would be stopped and we would be having to start basically start, out luck. (#012)

### *Reaching a Point of Acceptance*

When speaking about their experience of raising a child with an ASD, all of the participants spoke of reaching a point of acceptance regarding their child's developmental differences (Table 6). Acceptance appeared to also have multiple layers, which include first gaining self-acceptance. Parents seemed to identify moving from denial, some hoping their son or daughter was just slow to develop, to a point where they accepted that their child has a significant developmental delay.

Just so that you get a better perspective, this is how I can know that this is who this child is. This child is meant to be for us. Therefore, I have these glasses and know that this child is ours. There is no mistake and whatever, whoever he is, he is mine... OK. So instead saying we made a mistake, especially from an adoption point of view, there is no mistake. (#001, Mom)

You need to accept how he is [Mom pauses] and adjust your schedule [Mom-sighs] (#005, Mom)

I think it is kind of a relief for my mom, for me to know this is why he is the way he is. They are accepting of him. (#008, Mom)

Participants also indicated that it is important to them that others (family members, doctors, schools, and community members) accept their child with ASD. Several shared their challenges in gaining acceptance for their son or daughter. Several participants explained that sharing information to siblings and extended family members was very important in them gaining a level of acceptance for the child with an ASD.

One of the most difficult things about having (daughters) is the fact that both of my sons object strenuously to my having the girls. Um (#007, Foster Mom)

[Mom speaks tearfully about her interaction with her pediatrician] So I started to cry and I asked her why, why she was giving me all these papers? Why aren't you

doing more research on my child? And she said, well if I can't, if I can't find anything wrong with her I can't help you. And I thought that was absurd, because she totally, because she totally ignored .physical symptoms and neurological all the scary stuff started to happen. (#10, Mom)

Umm, I guess I'm more of, umm, before I was more accepting I guess in a way. and now I'm accepting of the disorder and like I said it goes back and forth but um.. It depends a lot on other people's viewpoints and you shouldn't really care about what other people think but you know, just what other people think, as a parent you don't want people thinking "oh my goodness she has a child that doesn't know how to behave" but then you see other people who know, that there's it's not just him having a tantrum, it's he has autism you know, so it's just emotionally heart-wrenching. (003, Mom)

I know that autistic kids are ending up in the neurotypical classes more and more and I want their teachers' to be welcoming of them and not say, "Ugh, God another retarded kid in my class." I want them to see the benefits of having an autistic kid in their class and how they can make it a positive experience for everyone. Um, so, my thing is more, I always want to be seen as the happy woman with the autistic kid because I don't think it's a bad thing that my kid has you know? Obviously it's a label and obviously there are things that we have to

work through with it, but um, I would rather people see um, a happy kid and a happy mom. (#006, Mom)

The youngest is great, she is very accepting very willing to, you know help with [son], the more conflict has been the oldest son. You know they are only two years apart and so sometimes he feels that his space is being invaded. For a while they had to share a room, because we had an older niece that lived with us, but then we made we split them up as soon as we could and give him his space. And that has helped, I don't know if it is just annoying little brother. (#008, Mom).

Yeah, but then there still is the, ah, you know why does he act this way, why does he do the things that he does. You know that is when we have to go back to, hey I told you this is the way he is. He thinks differently, he looks at things differently and you just need to accept that. You know you may not want to accept it, but I am sorry it is not changing. So you just try to be more up front with him. You know and just. (#008, Mom)

### *Dealing with Judgment*

The participants also spoke openly about feeling shame and embarrassment in their journey of raising a child with an ASD. Often many felt judged by others on their parenting skills and their inability to control their child. Typically, these feelings surfaced when their child was engaged in behavior that was atypical or extremely challenging (i.e. the child was difficult to redirect). Several spoke of getting to a point in

which they were comfortable with sharing their experience with those they felt judged by. These feelings of judgment seemed to come from a variety of sources (i.e. from family members, colleagues, and people in the community). Several participants went so far as to approach those people who seemed to misunderstand the situation and provided them with some explanation.

Oh, my gosh. Well it was, here is the thing. In Nigeria, and as well in America. No one wants a child that is different and it a major embarrassment disgrace, what's wrong with that family? Oh, we can't marry in that family because that brother is weird or can't go this because that little weird person in that family. You know. When you get married, I know you marry for love and it's not all arranged marriages. I did not have an arranged marriage. But, when you go to your parents and say you want to marry so-and-so. They are gonna look into that family background. They are not gonna just accept that he is a nice guy. They look into the whole family. Because you marrying the whole family. (#002, Mom)

Yeah, you want the Earth to open up and swallow you because everybody around you is staring and wondering what you're doing because the whole time she's throwing the fit she's saying that "she hit me," or "she's hurting me," "she's" and nobody's touching her [mom laughs], but this is what's coming out of her and so no one fully understands that part. You want to have one of those signs that, you

know, “Excuse me, I’m autistic” [mom laughs] or “I’m a parent of an autistic child” [mom laughs], but that’s about, I think it’s just more um, how people look at it you know. It’s not that I can’t deal with it necessarily, it’s just the way I would have to deal with it may not be what they would want, you know, but you can’t pick somebody that’s 27 years old and weighs what she does, off the floor, so it’s uh, it’s never pretty. (#004, Mom)

Well, it don’t bother me much as it used to, cause I would started telling them, when people ask me questions, when he used to have meltdowns. I am like, if they said, and I knew they would not understand. Cause you learn to figure out who is going to understand and who ain’t going to understand. So I came up with a saying like, if they would ask what was wrong, “Just need a little love and he’ll be alright”. They would look at me like, Yeah! (#012, Mom)

I tell people that. You are lucky you are not like him, but I’m telling you my son won’t hurt you. He has a disease, that’s why he acts like that, but he won’t hurt you. I tell people that. Just for them to stop and be more understanding of others. (#005, Mom)

Even now with my brother, I felt like sometimes there was that whole judgment thing, “Why doesn’t you kid act better?” (#008, Mom)

### *Gaining Support*

All of the participants reflected that gaining support in raising their child was a significant factor in their experience (Table 6). Many of them spoke of a variety of concerns, such as gaining support in the following through with daily life activities; gaining support in accessing the right and best services for their child; gaining financial support to obtain the various therapies and services; and gaining support from school, churches, the work place, and the community. Several participants spoke very positively about their school system, while others shared some real struggles in gaining the support they felt their child needed and deserved. It appeared that schools focused their services based on academic needs, while parents were concerned with social and life planning issues. Some of the participants also noted that gaining support from the insurance providers or medical supplement services was very challenging for them. One parent spoke of losing the support of payment for specialized therapies depending on them making extra monthly income or bonuses. However, the extra money earned was never really enough to cover the regular scheduled therapies. Often they had to find temporary funding sources, pay for the services out of their pocket, or do without the therapy until their insurance picked back up. A number of the parents reported that they were members of an autism support group and that it helped them with learning more about how to access services and to advocate for their child. Those parents that shared feeling supported appeared to have a number of supportive relationships, such as with spouses, family members, support groups, schools, and/or churches.

Mom: But I will say that the school district is very supportive

Dad: The quality of services available, we seem to get it all. School has helped a great deal.

MOM: Yeah, I mean in his class, he's got six kids and a teacher with two aides. I mean so, 3 to 6. I think that is pretty good. Then he gets Speech Therapist in the room.

Dad: They love him.

Mom: That is right, they love him [Mom emphasizes]. I mean, I, I, my ARDs go great. I have no problems with ARDs. [Mom laughs]. You get more with honey, than you know, with, what is the other thing that you don't get with?

Interviewer: Good, Vinegar

Mom: Vinegar, there you go, because I know some parents just come in and "I'm want this, this, this." That does not work so well. So, I feel supported. (#001, Mom and Dad)

Mom: So the church we go to, we called and asked, "Do you have a special needs ministry?" "No, we don't, but he is welcome." Like really, I gave them 3 weeks and asked, "Do you think you can have a buddy to be with him?" And they said, "You pray about it and I'll pray about it." Ok, voila, come there and he is matched up with somebody and then at the end of the services, I go "How did it go?" and the director says, "Well, this is Andrea." You know Andrea, right?

[Mom directs question toward interviewer]

Interviewer: Nods, yes

Mom: It was Andrea. I did not know what her background was [Mom exclaims in amazement]. Hey God, a school psychologist. I burst into tears. Exactly, I am like, "Thank you Lord." Oh, my goodness. Here she was and her friend, Karen, a great teacher. They became his buddies. And so then, from there they had a special needs ministry, that was not there before. You know. He touched a lot of peoples' lives there, and then with those two gals there, they minister to us. I mean, no pay, just minister to us. I mean. (#001, Mom)

At my first school people were very supportive. We're really involved in Autism Speaks. It used to be called Walk For AR and they do a walk every year and we've done it for four years now and the first year it was great at my school. There was just an outpouring of support, not just emotional, but financial and we had a walk team to get people to join your walk team and probably 40% of the student body and the staff joined our team and we had like one of the largest teams in the walk. (#003, Mom)

Her grandfather had a way about him that he could handle her and take her anywhere. You couldn't ask for a better young lady going into a store. (#004, Mom)

My husband did a lot of the raising of her when he was alive because I was working, he couldn't, so he took care of her and they were best buds. [Mom laughs] I mean they were. (#004, Mom)

My family helps me over the years (#005, Mom)

So, it's very difficult to have any sort of a normal life unless you're dealing with people who know something about autism. I have a good friend who um, she and her husband were foster parents for several years at the same agency where I was and um, she has learned by dealing with the girls and so I can take the girls to her house. They can play, they can, you know, like go out in the backyard and stuff (#007, Foster Mom)

I,[pause] fuss at the school [mom laughs] and tell them they have to step up their games or I try to find people to pay for speech for that month or at least a couple of visits while he is off. In the past I done found people to pay for it. (# 012, Mom)

### *Relying on Spirituality and Faith*

Spirituality and practicing their faith in God appears to have been very important to several of the participants. While a few of the participants did not mention anything about faith, God, or spirituality, most of the participants spoke about how important their faith was to them. Several spoke primarily in terms of having faith or belief that things

will get better. They engaged in prayer and/or engaged a thankful attitude toward God. A number of the participants spoke about being more active in practicing their faith, by attending church services, remaining active within their church, and by exercising their religious beliefs.

And the kicker is God's great greatness, this child was named [Mom speaks child's name] and we had chosen that name. [Mom spoke about having selected a name prior to traveling to another country to pick up their son] We got there and we thought we were gonna have this child [mom points in one direction, then points in another direction] and they said no, he had AIDS. We can't let you adopt him, but look, look we find this child. Here is this child he had epilepsy, [Mom explains that a second child was identified instead of the original]. My husband had just had brain surgery, because he had seizures, OK we can handle it. But when they [adoption agency staff] said his name was [Mom said son's name, which was the same name the adoption agency had given the child], Boom, that, that is it. OK, he is our child. From that point on with seizure all the way home on the airplane. God did not make a mistake. He gave us this child and there is a purpose in this child in our lives in our family. Hands open wide [Mom stretched out hands] I am ready, ok what do You [Mom refers to God] want me to learn? (#001, Mom)

Interviewer: What has helped ? Through all this.

Mom: Oh, It's our faith. Our faith, God

Dad: Our faith in Christ. I can't imagine where we would be. Now I understand, not to say this something we would have considered. Our faith in Christ. I am saying this is overwhelming.

Mom: This is different. I have total peace. He isn't a mistake. It was not, this is all part of a plan and as for our marriage and as parents. Individually and in our marriage, I would never be who I am, if he would not be in our lives. It brings out, just like marriage brings out certain things in you. Like, "Ok, I did not want to see that wart." You know, when you have children, they bring out, and then when you have a special needs child on top of that. It just reveals so much for good reason. You changed and it is all changes for the better. I mean, the more Christ blesses me in my life, and I am about a year more ahead than he is.

[pointing to dad] (#001, Mom and Dad)

And I think what helps me a lot is faith in God. Like the way I see it, it's like, ah the way I see how it is, is, it's like a trial for me. (#005, Mom)

Um, for me, for me my religion is a very large part of my life and I draw a great deal of strength and comfort from it (#006, Mom)

### *Learning to Laugh*

The participants all spoke about their experience from a perspective that things were not as bad as they once were. The majority of the participants shared their stories either in a humorous manner (i.e. laughing at various points about the situation or at

themselves) or they specifically indicated that learning to laugh at the really challenging times has been helpful. Though they quickly reminded the researcher that oftentimes the challenges were not funny while they were going through the experience; however, looking back they can appreciate more from a humorous perspective. One parent indicated that sometimes she has to just laugh to keep from crying, when she is faced with a new behavioral challenge from her daughter.

Dad: I remember we called him “Poopypicaso or Fecalangelo”; he used to just paint. The first time we walked in the room, no the first time, he just pooped on himself, we have a picture of it. The next time it was all over the walls, on floors, that was just maddening. [mom and dad laugh]

Interviewer: You used humor therapy [both laugh]

Dad: We laugh about it now; it was not funny then. In fact it was not funny at all.  
(#001, Dad)

It has never been dull. Let me put it that way. [Mom laughs] It’s never been dull  
(#002, Mom)

Mom: You know, it’s a, it’s a little weird, just weird [Mom laughs] but I say as long as she goes from one place to another and she has the turkey baster and will do that I don’t care. [Mom laughs]

Interviewer: You’re laughing?

Mom: Yes, ‘cause it’s, ‘cause it’s, you know it’s kinda funny. (#004, Mom)

It's interesting I have to have a very big sense of humor. (#006, Mom)

Mom: He has an awesome sense of humor.

Interviewer: How does it impact you?

Mom: Ah, it makes you laugh at yourself. (#008, Mom)

### *Celebrating Small Successes*

A number of the participants indicated that they learned that progress for their child's development would be slow and, after having accepted that fact, they were able to begin celebrating small successes. A few parents reported that they would compare their child to other typically developing children and, when they noticed that their child had gained a new skill, no matter how small it had a tremendous emotional impact on them. One mother shared her story of hearing her son call her "Mommy" for the first time. Though no one else was around, she was so overcome with joy, she burst into tears. Her son did not speak for a few more years, but that one moment gave her some comfort. Another mother spoke of her surprise in how her son was able to be responsible for a new family puppy, since the other family members were all very busy. She worried that he might not be able to handle the challenges of a puppy while others were away, but her son was able to care for the puppy. Others reported that when they celebrated those small successes, they began believing that things would get better and life would not always be this way.

He has not spoken since a year plus, when he said like a total of six words and had not spoken again. Other than making sounds or he'd make sounds when he was crying or scream. Oh my gosh, you know that kind of thing. But he clearly said "Mommy" to me twice, and I just stopped. Cause, when he first said it, I thinking I must be dreaming. I was, you know, whatever, we did this and it did not work, whatever. I stopped, did he say what I think he said, and he looked at me and said "Mommy" and then he went on about his business, flopping on the floor and whatever. And it was, there are a couple of moments, this was like the second moment, where I said everything is going to be OK. [Mom laughs].

(#002, Mom)

When I realized at seven that he had a dry diaper all day, he had been going to the bathroom. You know that was another moment. There are all these, little for everyone else, but massive for me. Moments for me, these little moments. Things are going to get better, they're going to be better, and its gonna be ok.

(#002, Mom)

Well umm, as far as successes you know, we try to emphasize the positive so little things like he has two nieces who are his age. They're actually twins, they're just six weeks older than him, so when he learned how to swim before they did, you know, that pride and wow, you know even though he has autism and he has a neurological disorder, he's overcome that and he's doing something before his you know, his peers, his family members, so you know almost, "Oh my child's

gifted, he's gifted physically" [mom laughs] and umm, along the same lines, he learned how to umm.. he reached a physical developmental milestone sooner than his nieces and umm other friends who have children the same age, you know, learned how to, you know, walk sooner. (#003, Mom)

Well, I don't think I feel as overwhelmed as I did the first, um maybe two years, that I had the girls. I certainly know a great deal more about um, you know, therapy and therapists and uh, services and insurance and all of those things. You have to learn about all of that and um, I made the decision to learn as much as I could about autism and so I read books as they come out. I, you know, follow up on studies. I, you know, try to know as much as I can to see if it's anything that might benefit the girls and um, you know, maybe somebody's come up with a plan of action or something new or whatever and so I'm always looking for stuff like that to see if there's anything else we should be doing. (#007, Foster Mom)

They [Mom speaks about deceased husband and their daughter] would work on the computers together. He taught her little games that she could play and, um, she was, you know, more her, his helper. Things that he couldn't go get, she went and got for him. She learned how to make coffee. You know very simple things, but had to go in with steps. (#004, Mom)

I am going to go back to the dog thing, [Mom had shared a story about training the family puppy earlier] it's just really surprised me that he has taken on as much responsibility for the dog. (#008, Mom)

All of the participants spoke freely about their experiences. Several of the participants indicated feeling angry and sad at times; however, these feelings appeared to have been directed at the lack of understanding or acceptance from others, feeling judged, or due to the lack of supports. Many of the participants mentioned that these feelings have lessened with the passage of time. The researcher reviewed these statements; however, anger and sadness did not rise to a level of a theme. All of the participants endorsed the themes of remaining watchful, reaching a point of acceptance, and gaining supports, while a majority of the participants endorsed the remainder of the themes (Table 6).

Table 6

*Between-Persons Analysis - Second Order Themes*

Themes	001	002	003	004	005	006	007	008	009	010	011	012
Balancing life around the child with ASD	X	X	X	X	X	--	X	--	X	X	X	X
Remaining watchful and alert	X	X	X	X	X	X	X	X	X	X	X	X
Reaching point of acceptance	X	X	X	X	X	X	X	X	X	X	X	X
Dealing with judgment	X	X	X	X	X	--	--	X	--	--	X	X
Gaining Support	X	X	X	X	X	X	X	X	X	X	X	X
Relying on spirituality and faith	X	X	--	X	X	X	--	X	--	X	X	X
Learning to laugh	X	X	X	X	--	X	--	X	X	--	X	X
Celebrating small successes	X	X	X	X	--	--	--	--	X	X	X	X

Legend for Table:

X = indicates the presence of a given theme of participant's expressed experience

-- = indicated the absence of a given theme in the participant's expressed experience

## Summary

This chapter presented the results of a phenomenological research study that explored how families with children with an Autism Spectrum Disorder are able to move through the adverse situation that they face while raising a child with significant developmental needs and challenges. The study included 14 participants and represented 12 families. Two research assistants reviewed several transcripts as a means to triangulate and help with credibility of this research. The demographic characteristics of the sample were presented in this chapter. The analysis of the interviews identified eight themes: (a) balancing life around the child with ASD; (b) remaining watchful and alert; (c) reaching a point of acceptance; (d) dealing with judgment; (e) gaining support; (f) relying on spirituality and faith; (g) learning to laugh; and (h) celebrating small successes. Each of the themes, along with several of the participants' comments, are reviewed in this chapter.

## CHAPTER V

### DISCUSSION, CONCLUSIONS, LIMITATIONS, IMPLICATIONS, AND RECOMMENDATIONS

The purpose of this study was to explore how families with children with an Autism Spectrum Disorder are able to move through the adverse situation that they face while raising a child with significant developmental needs and challenges. Using a phenomenological approach, this study applied a family-resilience framework as a lens in focusing on three core issues: the family's belief system, organization structure, and communication patterns. Face-to-face semi-structured interviews were conducted with 14 parents of a child with an ASD. The parents were asked to respond to the following question: Please tell me about your experience of raising a child with an Autism Spectrum Disorder. This chapter reviews the conclusions drawn from this research study, and provides a discussion of the findings and their implications. Also, presented in this chapter are the limitations of this research, recommendations for future research and recommendations for family therapists and other mental health professionals.

#### Discussion

This phenomenological research provided an opportunity for participants to speak openly about their experiences. These findings support previous research findings that suggest families raising a child with an ASD are faced with significant daily stressors and

report a lower quality of life (Brown et al., 2006; Singer et al., 1993; Summers et al., 1988). The eight themes that emerged from the participants' stories will be discussed in this section. Several of the themes identified were also consistent with Walsh's (2006) keys to family resilience. The eight themes that emerged during the data analysis were (a) balancing life around the child with ASD, (b) remaining watchful and alert, (c) reaching a point of acceptance, (d) dealing with judgment, (e) gaining support, (f) relying on spirituality and faith, (g) learning to laugh, and (h) celebrating small successes.

### *Balancing Life around the Child with ASD*

All of the participants discussed the difficulty in balancing day-to-day life while raising a child with an ASD. They spoke of having to deal with fatigue, frustration, managing a number of responsibilities, managing challenging behaviors, learning in detail about ASD, and balancing family life. The participants spoke about how they felt they were on a rollercoaster ride. Many of the participants focused most of their efforts and time providing for the child with ASD. They reported that due to their child's needs or significant behavioral challenges this involvement was demanded of them. DeGrace (2004) also noted, "to families, autism means more than an impairment of the child. For the families, autism is an entity of its own. It, autism, controls their daily lives" (p. 545).

Most of the participants with older children indicated that, overall, things got a little better over the years, as their children matured and they were able to address some of the specific needs. Participants indicated that as they were able to communicate with others about their needs and their child's needs, they noticed a level of improvement. This finding reflects Walsh's (2006) statement that, "good communication is vital to

family functioning and resilience” (p.106). Participants who were willing to speak up and communicate their needs appeared to have more connectedness with others. Several participants spoke about sharing responsibilities with partners and family members, sharing in the day-to-day life, solving problems together, openly expressing their concerns, and communicating clearly. Effective communication helped the participants balance life, a key to family resilience (Walsh, 2006).

### *Remaining Watchful and Alert*

All of the parents reported having 24-hour responsibility in raising their child with ASD. They often had to remain vigilant in addressing their child’s needs, advocating for the child, and expecting the unexpected. DeGrace (2004) indicated, “the anticipation of challenging encounters affected these families’ daily experiences” (p. 546). Parents in this study shared how they often had to prepare for public outings, new social situations, or a new behavioral challenge. Interestingly, several parents also had to learn to prepare for the unexpected from support services. Several parents shared how their insurance coverage might suddenly change and how that impacted their child’s services. This also suggests that parents have to develop flexibility in dealing with problems and new situations. Flexibility is a key component in the resilience research literature (Earvolino-Ramirez, 2007; Masten, 1994; Walsh, 2006).

### *Reaching a Point of Acceptance*

Acceptance appeared to be a theme that had multiple dimensions. One dimension included the parent accepting that their child had an ASD, and that their hopes for the child would take a different path. Several of the participants spoke about having to come

to terms with that and placing a different meaning for their child. According to Bayat (2007), “making meaning out of adversity is known as a key process in family resilience” (p. 710). Making meaning of the adversity is also a key component in Walsh’s (2006) resilience framework.

Acceptance from family and friends was also a valuable dimension. Several parents spoke of how important it was to them that their parents, siblings, and friends accepted their child and recognized their child’s disorder. Research findings have supported how important acceptance, willingness to help, and emotional support from family members is for those families with significant needs and challenges (Bailey et al., 2007; Bennett & DeLucca, 1996; Hartshorne, 2002; Richardson, 2002; Valentine, 1993).

A third dimension of support focused on the support gained from support groups, professionals, school systems, medical staff, and other service providers. This study found that participants benefitted from the supports for information, meaningful connections, obtaining services for their children, and an emotional outlet. Similar findings were reported by Bailey et al. (2007); Becker-Cottrill et al. (2003); Bennett & DeLucca (1996); Gray (2006); and Rahi et al. (2004).

### *Dealing with Judgment*

A number of the participants spoke about feeling judged by others. These feelings appeared to play a significant role in the participants’ experience in raising a child. Some felt ostracized, excluded, or not valued by others. Several mothers shared how they had to learn to speak up and even share information with others about their actions with their child. They felt the need to provide onlookers and others with

information mainly due to their feeling judged as being a bad parent or having an out-of-control child. Research has suggested that some parents with a child with severe autism have to deal with significantly disruptive behaviors that they and others may have difficulty accepting (Brown et al., 2006). Many of the participants felt they would not be included in family celebrations, school, and children's birthday parties, or other events. DeGrace (2004) reported, "it seemed that the families have learned over the years that occasions that bring family together (e.g., family celebrations, birthday parties, and holidays) were not worth the hassle" (p. 548). However, the participants that demonstrated Walsh's key characteristics (e.g., making meaning out of adversity, having a positive outlook, and demonstrating open emotional expression) shared that it no longer mattered what others thought of them. They spoke openly about their feelings and concerns and provided information when they felt it was needed.

### *Gaining Support*

All of the participants in this study emphasized how important gaining the right supports was for them. They indicated that having support from family and close friends was very helpful to them. Several spoke of being able to rely on others to help them out. One mother spoke of a time where she asked a friend to watch her daughter, just so she could rest a bit. Several of the married participants shared how their partners' assistance and support helped them as they dealt with multiple chores and responsibilities. Some parents added that they took turns in shifts, and they recognized when the other needed some relief. Also of help to these families were older siblings of the child with an ASD, grandparents, and siblings of the parents. Many participants indicated that they have

been able to call family members for help. Several families in this study noted that they did not have any immediate family nearby; however, they relied on the supports provided by their church, social support groups, and friends. These findings are consistent with those of Bennett and DeLuca (1996), Brown et al. (2006), Walsh, (2002); and Walsh (2006).

### *Relying on Spirituality and Faith*

Most of the participants interviewed expressed a spiritual faith or belief. They reported that it was this faith or spiritual connection that guided them on this journey. Many prayed and shared their belief in God and some shared how important their religious experiences and practice were to their family life. A review of the research literature on family resilience supports these findings (Bayat, 2007; Bennett & DeLuca, 1996; Walsh, 2006). Walsh (2006) stated, “spirituality can be experienced either within or outside formal religious structures” (p.73). Several of the participants in this study indicated a religious identification, but did not belong to a formal structure.

### *Learning to Laugh*

Many of the participants spoke of how they learned over time to laugh. Several described very challenging behaviors and situations that were not funny at the time they were going through the situation; however, over time they learned to look at those difficulties from a humorous perspective and have applied humor and laughter to their current challenges. During the interviews several of the participants often laughed as they shared stories of significant challenges and accomplishment. Research has suggested that having the ability to see things from a humorous perspective can play an

important part in learning to adapt and cope with stressful life situations (Earvolino-Ramirez, 2007; Masten, 1994; Richardson, 2002).

### *Celebrating Small Successes*

Many of the parents indicated that they had learned to celebrate the small successes, such as a child saying “Mommy” for the first time at age seven or becoming toilet trained at age six, or learning to swim before other children had learned. By celebrating these accomplishments, parents indicated a sense of hope that things would get better for them and their child. Parents who celebrated successes, no matter how large or small, tended to have a positive outlook and not to focus on the weaknesses or challenges so much. Walsh (2006) noted, “hope is a future-oriented belief; no matter how bleak the present, we can envision a better future” (p. 65).

### Conclusions

Participants in this study spoke about their experiences of raising a child with an ASD as a growing process for their child and themselves. Many of them indicated that slowly things got better or of things being better than they used to be. According to Walsh (2007), “family resilience is strengthened through acceptance of the passage of time and the need for change with new developmental challenges” (p. 58).

According to Walsh’s family resilience framework, the meaning one gives to adversity will impact a family’s resilience. The first question, of the three that guided this research, focused on what meaning the family places on raising a child with an Autism Spectrum Disorder. Several of the families described how they had come to view their children as being a gift and the crisis as a challenge. Many of them had

developed a positive outlook on life. Most of the parents spoke of future planning for their child and a hope for normalcy for their child's future.

The participants all shared the importance of supports and connections, answering the second research question regarding what had been helpful in strengthening the family. All of the families appeared to place a great value on obtaining and maintaining appropriate supportive relationships with family, community, spirituality, and professionals. Those participants who had supportive relationships with family members, schools, medical providers, mental health professionals, support agencies for children with special needs, and social support groups were strengthened and displayed a positive outlook.

The third research question about what communication processes were helpful in problem solving in families with children with an Autism Spectrum Disorder was answered as participants indicated the importance of being able to communicate clearly to others about their child's disorder and their needs. The parents spoke of wanting to be heard and valued in the decision making of their child's medical, educational, and treatment planning. Many of the participants also used humor to communicate their feelings and experiences. Over the years the participants developed or relied on their sense of humor in describing their child's needs and concerns. In applying Walsh's (2006) resilience framework, a conclusion that can be drawn from this study is that families and collaborative partners need to focus on building clear channels of communication that allow for open emotional expression and collaborative problem solving.

Other conclusions that were drawn from this research are the following:

1. Resilient families learn to balance family life.
2. Resilient families remain watchful and alert.
3. Resilient families reach a point of acceptance.
4. Resilient families are better able to deal with judgment.
5. Resilient families are able to gain supports from others.
6. Resilient families rely on spirituality and faith.
7. Resilient families learn to laugh.
8. Resilient families celebrate small success.

#### Limitations

The following limitations apply to this research study. The sample participants were individuals who were willing to speak about their experience and may have been more inclined to present their experience in a manner that suggests personal growth. While the participants were somewhat diverse in their ethnic background, the large majority of the participant sample was Caucasian, which may further limit the generalizability across ethnic boundaries. The participants all resided in larger urban or suburban areas, where there may be better access to more information and support services. Families living in rural areas would have added an additional dimension in understanding live of families that might not have access to supports, information, and educational opportunities.

The study included parents with a variety of educational level and socioeconomic level; however, a majority of the participants' educational and socioeconomic levels

appeared to be higher than the majority of the general population. This research did not address any relationship with the participants' educational level or income level and their level of resilience. Although the sample size of this phenomenological study was adequate, a larger sample would add credibility to this study. The majority of participants were mothers, though a small number of fathers did participate. Several participants were married or in relationships; however, their partners did not participate in this study. Gaining the participation of more fathers might have enriched the data that were gathered and provided more understanding of the male experience in raising a child with ASD. Most of the female participants appeared to play the central role in providing day-to-day care, balancing multiple responsibilities, and having to learn as much as possible about autism.

### Implications

The results of this research study highlight several significant implications for professionals including family therapists, counselors, doctors, school and agency staff who work with families with children with an ASD. Many of the families shared their struggle in being heard and gaining acceptance. Professionals benefit from being knowledgeable about the specific disorders, understanding effective treatment options, identifying child and family needs, and working collaboratively. Several participants indicated that they felt that the professionals were not listening to their concerns, ideas, or suggestions. At times schools may focus more on academic needs and concerns, while overlooking the parent's concerns and priorities for their child. Some participants were frustrated with their doctors or their school system, and others were more frustrated at the

lack of acceptance from family members and the community. Also, finding funding sources and financial supports can be very challenging for families that do not have the benefit of great health insurance coverage or medical payment support. Legislators, parents, and mental health providers should consider addressing and reshaping public policy that would focus on helping families with children on the Autism Spectrum with coverage for supports and therapies. Families report significant setbacks when their children lose services due to funding and payment challenges.

This study also reveals the importance of working with these families from a systemic perspective. Most of the participants indicated that life revolved around a number of treatment services, family members, and other supports. Allowing and encouraging family members to tell their stories together will impact each individual and have an overall effect on the family system. Professionals need to address the various dimensions of family life and the supports or lack of supports that the families receive. They may encourage family resilience by becoming and remaining aware of each family's strengths, resources, spiritual values, outlook, communication patterns, and ability to use humor. Professionals can also play an active part in teaching families how to balance their needs with the needs of their children with an ASD.

### Recommendations

This research provides a better understanding to therapists and families with a child with an ASD and in strengthening family resilience. There remains a need for further research in the area of working and helping families with children with an ASD.

The following are recommendations for future research and recommendations for Family Therapists and other mental health professionals.

*Recommendations for Future Research*

Although the research literature includes a great deal of information on diagnosing and working with children with autism, more qualitative research is needed in the area of working with families who are impacted by autism. The following suggestion may be considered for future research.

1. This study may be replicated and include families with other racial/ethnic backgrounds from rural areas, as well as urban and suburban areas.
2. Future studies may include a longitudinal research approach that includes families who have just received their child's diagnosis of an ASD and families who have had diagnosis for several years. These families could be followed up and interviewed over a period of several years.
3. Future research studies on families with ASD children may also include an anonymous questionnaire, since several families indicated being uncomfortable discussing their personal experiences.
4. Replication of this study may specifically target fathers and male partners to gain an understanding of their perspective.
5. Future studies may also compare the families with specific Autism Spectrum Disorders, because the families shared that the degree of the ASD impacted their lives in different ways. Replication of this study might target specifically parents

of children with Autistic Disorder, Asperger's Syndrome, or Pervasive Developmental Disorder, NOS.

*Recommendations for Family Therapists and Other Mental Health Professionals*

Families with children with an ASD might present with unique challenges and a need for understanding their circumstances. This section includes some recommendations for family therapists and other mental health professionals.

1. Family Therapists and other mental health professionals should obtain a good working knowledge of Autism Spectrum Disorders and appropriate treatments for the child and the family.
2. Training programs in Family Therapy, School Psychology, Clinical Psychology, Social Work, and Professional Counseling should include opportunities for training in working with families with children with developmental disorders.
3. Family Therapists, counselors, and school staff working with these families should be open to hearing their stories and concerns, while helping address their needs. Many parents reported that no one really tried to understand what was important to them or what their biggest concerns were.
4. Those providing professional support to families should understand the importance of establishing an empathic collaborative relationship with families with children with an ASD rather than taking on an expert or caregiver role. Parents have indicated that they are looking to partner or work together with the many support services, agencies, and support systems.

## Summary

This study sought to contribute to qualitative research literature on working with families who are impacted by raising a child with an ASD. This chapter contains a discussion of the themes that emerged from the data analysis, conclusions that were made based on the research findings, limitations of this study, and implications of the findings. The researcher also provided recommendations for future research and recommendations for family therapists and other mental health professionals. More research is needed in the area of working with families and children with an Autism Spectrum Disorder.

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## APPENDIX A

### Research Flyer

# Participants Needed For A Dissertation Research Project

**My name is Michael R. DuPont and I am a doctoral candidate conducting a research study for my dissertation at Texas Woman's University.**

**The purpose of this study is to explore how families with children with an Autism Spectrum Disorder are able to move through the adverse situation that they face while raising a child with significant developmental needs and challenges. If you have a child who is at least 6 years of age and has had an Autism Spectrum diagnosis for at least three years, you are invited to participate in this study. The study is open to adult parents or guardians of the child with the Autism Spectrum Disorder. You will be asked to share your experience of raising a child with an ASD.**

**All interviews will be conducted by me in a place we agree on. Your maximum time commitment will be approximately 2 hours. Your confidentiality is important, so your interview will be assigned a code number and no names or identifying personal information will be included in my dissertation or other publication. Your participation is completely voluntary, and you may withdraw from the study at any time without penalty.**

**If you would like to be a part of my study please contact me, Michael DuPont, at 817- 980-7608. If you have additional questions you may also contact my research advisor, Linda Brock, PhD at 940-898-2713 or email at [lbrock@mail.twu.edu](mailto:lbrock@mail.twu.edu)**

## APPENDIX B

### Initial Telephone Call Script

Hello, this is Michael DuPont. How are you doing today? Thank you for responding to my flyer regarding my research. I am a doctoral student in the Family Therapy program at Texas Woman's University where I'm completing this research project as part of my degree.

The purpose of my study is to explore key resilience characteristics of families with children with an Autism Spectrum Disorder. I want to learn about the experiences of families with a child on the autism spectrum.

Before we begin, I want to make sure that you meet the criteria to participate in this study.

- 1) Is your child at least 6 years of age?
- 2) Has your child had an Autism Spectrum Diagnosis for at least three years?

[If the answers are Yes] "If you agree to participate in this study, let's set up an interview at a time and place that works for you and me. The interview will last from 1 to 2 hours. At the time of the interview I will review an informed consent form, complete a demographic questionnaire (that will include child information regarding age and autism diagnosis, parent and family background information, such as age, education level, and a few other things). In the interview portion I will be asking you to share your experiences in raising a child with an Autism Spectrum Disorder. To help me report your experience more accurately, I will record the interview and then transcribe the tape recordings into a written format. I will assign each interview a numerical code in order to help protect your confidentiality."

With your permission I will contact you about one week after the interview to see if you have any additional questions or comments.

Your participation is voluntary and you may withdraw from this research study at any point without penalty. Do you have any questions?

[Participants will be given opportunities to ask questions and will be answered by the researcher.] Would you like to participate in this study? [If the potential participant says “No”, they will be thanked for their time.]

[If the potential participant says, “Yes” to participating, then a time and place will be scheduled for the interview.] [The researcher will confirm the date and time before discontinuing the conversation and thank the potential participant for their time and agreeing to participate.] “I will look forward to meeting with you, Good Bye”.

APPENDIX C  
Interview Protocol

## Interview Protocol

Participant's Code: \_\_\_\_\_

Date of Interview: \_\_\_\_\_

“ I want to thank you for agreeing to participate in this study” (Pause, allow for response). The purpose of this study is to explore how families with children with an Autism Spectrum Disorder are able to move through the adverse situation that they face while raising a child with significant developmental needs and challenges. Do you have any questions regarding the purpose of this study? (Pause)

“I would like to remind you that your participation in this study is completely voluntary and you may withdraw at any point without penalty. If you would like to take a break at any point during the interview process, please feel free to indicate your need. The interview will be audiotaped to help ensure that I represent your information accurately.” (Pause).

“Before we begin with the interview, I would like to go over the consent form. May I read this form to you or would you prefer to read on your own? I will be glad to explain any part that you would like clarification on.” (Pause). If participant will allow me to read the form, then I will read the consent form from start to finish and then ask the participant if they understand their rights and are they willing to participate and sign the form. If they do not wish to sign and participate I will thank them for their time and end the interview.

If they review the form on their own, I will allow them the time they need to review the form and then ask them if they had any questions or concerns. The researcher

will answer all questions from the participant. I will then ask them to initial and sign the bottom of the pages if they wish to participate in the study. I will ask them to write their address at the bottom of the consent form if they want me to mail a copy of the results. I will then ask them, “Do you have any questions before we begin”. The researcher will answer all questions. The participant will sign two copies of the consent form, one for their copy and one copy for the researcher.

“I will now turn on the tape recorder” (Turn the recorder on)

“I am going to begin by asking you questions in order to gather background information. If anything is unclear, please feel free to ask me to clarify my question. If you are uncomfortable answering any of the questions, please feel free to not answer that question. Please just let me know and I will move on to the next question. Do you have any questions?” If the participant has any questions at this point the researcher will answer all questions before moving on. The researcher will then read aloud the questions from the demographic data form. Upon conclusion, the researcher will say, “This concludes this portion of the interview”. We will now proceed with the research questions. I will be asking two questions. There is no right or wrong answer, but I would like for you to speak freely and openly. Please feel free to elaborate as much as you feel comfortable. (Pause)

#### Interview Question

“Please tell me about your experience of raising a child with an Autism Spectrum Disorder.”

Prompts for interview, as needed:

What was that like?

And by \_\_\_\_\_, you mean...?

How so?

Would you say more about that?

Can you tell me more about that?

Nodding

I see

Smiling

Mmhmm

How has that changed over time?

What else comes to mind?

Anything else you think important?

Would you like to add anything else?

Upon completion of the interview I will, thank the participant for their time and participation. I will ask, "Is it OK for me to contact you in about a week for a brief follow-up by phone?" " I will be asking you if you have thought of any additional information that you may want to add to what you have told me today". Also, I will ask them if they know of anyone else who might meet the criteria for participation if they would give them one of my fliers. The researcher will give the participant a flier and a counseling referral list. I will conclude with, "If you think of any other questions, please feel free to call me. Thank you again and enjoy the remainder of your day".

## APPENDIX D

### Consent to Participate in Research

TEXAS WOMAN'S UNIVERSITY  
CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: An Exploration of Resilience in Families with a Child Diagnosed with an Autism Spectrum Disorder

Investigator: Michael R. DuPont, M.S.

817-478-2352, [michaeldup@msn.com](mailto:michaeldup@msn.com)

Advisor: Linda Brock, PhD

940-898-2713, [lbrock@twu.edu](mailto:lbrock@twu.edu)

Purpose:

You are being asked to participate in a research study that is being conducted by Michael R. DuPont, M.S. as a part of the requirement for a Doctor of Philosophy degree in Family Therapy at Texas Woman's University in Denton, TX. The purpose of this study is to explore how families with children with an Autism Spectrum Disorder are able to move through the adverse situation that they face while raising a child with significant developmental needs and challenges.

Research Procedures:

You are being asked to complete a demographic questionnaire and participate in a face-to-face interview. The researcher will conduct all the interviews. The interviews will be conducted in a private setting agreed upon by the participants and the researcher. The interview will be audiotaped. The reason for audiotaping the interviews is to provide an accurate transcription of the information obtained in the interviews. The maximum amount of time you will be asked to spend in this research is two hours. Within one week and after the interview is completed the researcher will contact the parent via telephone in order to complete a brief follow-up interview. The researcher will transcribe the audiotapes and assign a numeric code. The researcher will review all transcripts analyzing them for themes.

Confidentiality:

The risk of loss of confidentiality will be protected to the extent that is allowed by law. Each interview will be assigned a number, rather than using the participant's name, in order to maximize confidentiality. Two research assistants will participate in the transcription analysis; however, they will not have access to the participants' names or demographic information. The two research assistants have knowledge in conducting qualitative research, and each have completed training in protecting research participants. Only the researcher and research advisor will have access to the audiotapes. In order to further safeguard your anonymity, the signed informed consent form will be stored in a separate folder in the researcher's home office in a locked filing cabinet. The tapes, the hard copies of the transcriptions, and the CD-ROMs containing the transcriptions text files will be stored in the researcher's home office in a locked filing cabinet. The consent forms, tapes, hard copy transcriptions, and CD-ROM text files will be shredded in two years after the completion of the research.

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Participant Initials

Page 1 of 3

The results of this study will be published in the researcher's dissertation and possibly in other research publications. However, no names or identifying personal information will be included in any publication.

Risks:

Potential risks related to your participation in the study include physical or emotional discomfort as you answer the interview question. To avoid fatigue or discomfort participants may take a break (or breaks) when needed. In the event participants want to stop answering questions at any point they may indicate their desire to stop. Interviews will take place in the participant's home or designated private setting to help provide comfort and privacy. Emotional discomfort may also be minimized by including only parents of children with an Autism Spectrum Disorder diagnosis that is at least three years prior to this study. This will decrease the potential emotional sensitivity related to this topic. If the participant indicates the need to discuss their emotional discomfort with a professional, they will be asked by the researcher to contact their local crisis hotline and the researcher will provide the participant with a list of mental health professionals in their area. The researcher will also provide assistance to help address any emotional topics by answering any questions the participant might have.

A possible risk to you as part of your participation in this study is a loss of time. The maximum time you will be asked to volunteer is two hours; however, to minimize loss of time, all of the interviews will be conducted in a timely manner. Participants will be reminded that they may stop at any point without penalty to them.

Please let the Investigator know at once if you experience any problems and he will try to help you. Please note TWU does not provide medical services or financial assistance for injuries that might happen because you have agreed to take part in this study. You will also have contact information for the researcher should you want to contact him. You may also withdraw from the study at any point without penalty.

Participation and Benefits:

Your participation in this study is completely voluntary and anonymous. You will need to set aside approximately 1 to 2 hours to complete the interview portion. A potential benefit of your participation in this research is the opportunity to contribute to a better understanding of family resilience with children with an autism spectrum disorder. Another benefit is that you can elect to receive a summary of the study's results. Your request for a summary of the results will not be linked to any response you may have made as a participant in the study.

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Participant Initials  
Page 2 of 3

Questions:

If you have any questions about this research study you may ask the Researcher or the Research Advisor. They would be pleased to respond to any questions you may have concerning the research study; their contact information is located at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu).

Informed Consent:

You will be given a copy of this signed and dated consent form for your own personal records.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

- If you would to receive a summary of the results via mail, please complete the mailing information below:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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## APPENDIX E

### Demographic Information

### Participants Demographics

1. Interview Number: \_\_\_\_\_ Date of Interview: \_\_\_\_\_

2. Information about child:

Child's Age at Last birthday: \_\_\_\_\_

Gender of Child: Female: \_\_\_\_\_ Male: \_\_\_\_\_

Race of Child:

\_\_\_\_\_ Black \_\_\_\_\_ Caucasian

\_\_\_\_\_ Asian \_\_\_\_\_ Hispanic

\_\_\_\_\_ Native American \_\_\_\_\_ Other : \_\_\_\_\_

Age and grade when the child was identified as having an Autism Spectrum Disorder:

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Identify specific Autism Spectrum Disorder of child:

\_\_\_\_\_ Autistic Disorder \_\_\_\_\_ Asperger's Disorder

\_\_\_\_\_ Pervasive Developmental Disorder – Not Otherwise Specified (PDDNOS)

\_\_\_\_\_ Rett's Disorder \_\_\_\_\_ Childhood Disintegrative Disorder

3. Diagnostic Information:

Initial identification of an Autism Spectrum Disorder was determined by:

\_\_\_\_\_ School \_\_\_\_\_ Child's Doctor

\_\_\_\_\_ Psychologist (Private Practice) \_\_\_\_\_ (other) please explain: \_\_\_\_\_

Diagnostic information was shared with parent:

\_\_\_\_\_ over phone \_\_\_\_\_ written report

\_\_\_\_\_ verbal from professional \_\_\_\_\_ other: \_\_\_\_\_

Other diagnosis/medical conditions: \_\_\_\_\_

How correct do you believe the diagnosis is?

---

4. Education Information about the child with ASD:

Type of school: \_\_\_\_\_ Public \_\_\_\_\_ Private \_\_\_\_\_ Home-schooled

Education Placement:

\_\_\_\_\_ General Education, only

\_\_\_\_\_ General Education, with Special Supports (i.e. speech services, OT/PT, some mainstream classes)

\_\_\_\_\_ Special Education, full (Self-contained classes)

\_\_\_\_\_ Completed School

5. Family Information

Race of Parent/Guardian:

\_\_\_\_\_ Black \_\_\_\_\_ Caucasian

\_\_\_\_\_ Asian \_\_\_\_\_ Hispanic

\_\_\_\_\_ Native American \_\_\_\_\_ Other : \_\_\_\_\_

Relationship of participant to child with ASD:

\_\_\_\_\_ Mother \_\_\_\_\_ Father \_\_\_\_\_ Guardian \_\_\_\_\_ Other: \_\_\_\_\_

---

Family Composition: Please give relationship and age of all individuals living in your household (do not include name) to the child with the Autism Spectrum Disorder.

Relationship of Person Living in Household	Age

In which county do you currently live? \_\_\_\_\_

Type of living setting:

\_\_\_\_ Urban      \_\_\_\_ Suburban      \_\_\_\_ Rural

6. Educational Level of Parent Participating:

- Some High School \_\_\_\_\_
- High School Diploma or GED \_\_\_\_\_
- Some College \_\_\_\_\_
- Associates Degree or Vocational/Technical School \_\_\_\_\_
- Bachelor's Degree \_\_\_\_\_
- Master's Degree \_\_\_\_\_
- Doctoral Degree \_\_\_\_\_

7. Household Income Level:

- Below 20,000 \_\_\_\_\_
- \$20,000 - \$39,999 \_\_\_\_\_
- \$40,000 - \$59,999 \_\_\_\_\_
- \$60,000 - \$89,999 \_\_\_\_\_
- \$90,000 - 109,999 \_\_\_\_\_
- \$110,000 and Above \_\_\_\_\_

8. Parent Employment Information:

Type of employment: \_\_\_\_\_

Full-time: \_\_\_\_\_ Part-time: \_\_\_\_\_

Spouse's Employment Information:

Type of employment: \_\_\_\_\_

Full-time: \_\_\_\_\_ Part-time: \_\_\_\_\_

9. Do you have a religious affiliation? \_\_\_\_\_

If yes, what is your religious affiliation? \_\_\_\_\_

APPENDIX F

Follow-up Telephone Script

### Follow up Telephone Script

“Hello, this is Michael DuPont again”. “How are you today?”(Pause) “I am calling just to follow-up from our interview to see if you have any question or thought of some other information that you would like to add for the interview”. The participant will be given an opportunity to respond.

I will then ask the participant again “Do you have any questions you would like to ask me”. The researcher will answer all of the questions. I will then Thank them for participating in the study. If they requested a copy of the results, I will inform them, “You will receive the information in the mail at the address you provided during the interview”. “Thank you again for your time and your participation, good bye”.

APPENDIX G  
Counseling References

## COUNSELING REFERENCES

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AAMFT Therapist Locator  
at [www.aamft.org](http://www.aamft.org)

## APPENDIX H

### Research Model

## AN EXPLORATION OF RESILIENCE IN FAMILIES WITH A CHILD DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER

Research Questions	Interview Question	Themes
What meaning does the family place on raising a child with an Autism Spectrum Disorder?	Please tell me about your experience of raising a child with an Autism Spectrum Disorder.	a)balancing life around the child with ASD
What supports have been helpful in strengthening the family?		b) remaining watchful and alert c) reaching a point of acceptance
What communication processes are helpful in problem solving in families with children with an Autism Spectrum Disorder?		d) dealing with judgment e) gaining support f) relying on spirituality and/or faith g) learning to laugh h) celebrating small success