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STRESSES OF MOTHERS CARING FOR AN OLDER ADOLESCENT
DIAGNOSED WITH AUTISM: A PHENOMENOLOGICAL EXPLORATION

A Dissertation

Presented to the Faculty of
Antioch University Seattle
Seattle, WA

In Partial Fulfillment
Of the Requirements of the Degree
Doctor of Psychology

By
Linda Mason
Antioch University Seattle
August 2012

STRESSES OF MOTHERS CARING FOR AN OLDER ADOLSCENT DIAGNOSED
WITH AUTISM: A PHENOMENOLOGICAL EXPLORATION

This dissertation, by Linda Mason, has been approved by the committee members signed below who recommend that it be accepted by the faculty of the Antioch University at Seattle, Washington in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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Date

ABSTRACT

STRESSES OF MOTHERS CARING FOR AN OLDER ADOLSCENT DIAGNOSED WITH AUTISM: A PHENOMENOLOGICAL EXPLORATION

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A review of the literature provides ample research about caregiver stress in relationship to healthcare needs, aging, and mental illness. However, there is limited research about caregiver stress in regard to families that care for a child with disability. Further limited in scope is research about mothers who care for an older adolescent with diagnosed autism. This qualitative phenomenological study explored the lived experience of six mothers caring for an older adolescent diagnosed with autism. The question about what causes stress resulted in findings: isolation, coping with their child's challenging behaviors, and frustration with the establishment. The question about what helps to relieve stress resulted in findings: professional behavior or support teams, support from others, and church or spiritual connection. The question about what are the rewards or joys experienced resulted in finding: their child's accomplishments. Implications of the present study are discussed in regard to recommendations for clinicians, advocacy groups, and organizations to create guidelines for services and intervention for mothers who care for an older adolescent diagnosed with autism.

The electronic version of this dissertation is at Ohio Link ETD Center:

www.ohiolink.edu/etd

Dedication

I want to dedicate this dissertation to the mothers who graciously volunteered to be interviewed for my study. Their openness, courage, and experience contributed to a better understanding about being the caregiver for an older adolescent diagnosed with autism.

A special dedication is to my family and friends who gave me encouragement and strength during my years of study. A notable dedication goes to my son Andy who was the inspiration for this dissertation.

Acknowledgements

A heartfelt appreciation goes to Dr. Patricia Linn, Dr. Melissa Kennedy, and Dr. Nancy Rosenberg who generously gave their time for my dissertation committee. Their wisdom, professional knowledge, and support provided me with constructive guidance during the dissertation process.

A special thank you to the faculty and staff at Antioch University Seattle for their presence that provided me with a wonderful educational experience.

It is important to acknowledge Horace Mann's 1859 humanitarian message for Antioch University's commencement, "be ashamed to die until you have won some victory for humanity." His words are the school's motto and displayed at the entrance of Antioch University Seattle. They served as a guiding light for me during my education and continue to be a reminder to be of service to humanity as I move into the future.

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Chapter 1: Introduction

Statement of the Problem

A review of the literature provides ample research about caregiver stress in relationship to healthcare needs, aging, and mental illness. However, there is limited research about caregiver stress in regard to families that care for a child with disability. Further limited in scope is research about mothers who care for an older adolescent with diagnosed autism.

The population of children with autism has increased dramatically in recent years. In 2006 the Department of Health and Social Services estimated 1 in every 150 children is affected with Autism Spectrum Disorder (ASD). In 2012 the Centers for Disease Control and Prevention (CDC) released data that about one child in 88 is identified with an Autism Spectrum Disorder. Their report stated that ASD occurs in all racial, ethnic, and socioeconomic groups. In addition, ASD is about five times more common (1 in 54) among boys than among girls (autismspeaks.org). The numbers are staggering and indicate that this disability affects a large percentage of the population in America. This increase impacts society and educational systems, but the greatest impact is on the families and caregivers.

The responsibility of caring for a child with autism presents parents with unique and complex care demands. Consequently, the requirements of this specific caregiver role could result in stressors that contribute to physical or mental health problems. Studies of caregivers for a child with autism indicated emotion coping scores were associated with greater parent and family problems. In addition, the severity of autism

was the most influential and consistent predictor of stress. Time pressure of daily care responsibilities experienced by caregivers can compromise their mental health and well-being (Lyons, Leon, Phelps, & Dunleavy, 2010; Sawyer, Bittman, La Greca, Cretenden, Harchak, & Martin, 2010).

Primary caregivers or parents of children with autism are challenged by their situation (Shieve, Blumberg, Rice, Visser, & Boyle, 2007) one that necessitates the identification of the specific stressors that may adversely affect the caregiver of a child with autism. Research is necessary to identify the specific stressors that affect this population to provide beneficial information to delivery systems such as mental health providers and support groups (Simon-Tov & Kaniel, 2011).

History of Caregivers for Children with Disabilities

Prior to the 1960's the majority of individuals with disability were placed in government-run institutions. This included children with physical disabilities or those with cognitive challenges, such as Down syndrome and autism.

Deinstitutionalization gained momentum during the civil rights movement. The Civil Rights Act passed in 1964 prohibited discrimination based on race, religion or national origin (Schwartzberg, 2005). This paved the way for other anti-discrimination and inclusion laws that were designed to further The Civil Rights Act. These movements specifically addressed the disability community and created necessary legal avenues for enforcement. In 1973 Section 504 of the Rehabilitation Act was enacted to prevent discrimination toward otherwise qualified people with disabilities by recipients of federal financial assistance (Schwartzberg, 2005).

The Civil Rights Movement encouraged advocates for the rights of people with disabilities to move forward politically. These advocates consisted of parents and family members who challenged professionals and doctors by refusing advice to institutionalize a family member (Schwartzberg, 2005). In addition, they began a movement toward inclusion in the community and schools. Their advocacy resulted in the passage of the Education for All Handicapped Children Act of 1975 that became a federal law. In 1990 the Americans with Disabilities Act passed in both houses of Congress and became known as IDEA 94 142, the Individuals with Disabilities Education Act. These changes increasingly placed the responsibility of caring for an individual with disability upon family members (Schwartzberg, 2005).

Definition of Autism

Leo Kanner first identified the classification of autism as a disorder. Kanner (1943) observed features such as autistic aloneness, desire for sameness, and islets of ability as common features with some variations in detail and the existence of additional problems.

Early theories varied as to the etiology of autism. One theory developed by Bruno Bettelheim (1967) attributed this disorder to “refrigerator mothers” and absentee fathers. His theory was that mothers who were distant and unloving toward their child created an environment that contributed to their child’s autism. This placed the burden and responsibility of an autism diagnosis on parenting methods with the emphasis on mothers as caregivers. Further research began to consider other factors such as genetics, the environmental effects of diet or pollution and childhood immunizations in an attempt to explain the etiology of autism. Additional research about the causes of autism will be

dependent on the “combination of epidemiology with more basic science laboratory studies” (Rutter, 2005, p. 231).

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) defines Autistic Disorder as,

A pervasive developmental disorder with impairments in social interaction, communication, and restricted repetitive and stereotyped patterns of behavior in addition to presenting with delays or abnormal functioning onset prior to age 3 years in language, social interaction and symbolic or imaginative play. (DSM-IV-TR, 2000, p. 75)

There is a separate category for Asperger’s Disorder, which presents with similar social interaction deficits but different language acquisition profiles.

Among the markers associated with Autistic Disorder is that a normally developing child displays interest in others while a child with autism tends to be exceptionally interested in objects. Language development can range from a child with the ability to speak to a child that is non-verbal. In general, the non-verbal child with autism rarely uses facial expressions or gestures to communicate needs as contrasted with a hearing-impaired child who will find ways to communicate without speech (Frith, 2002). Often the child with autism will display restricted interest in activities and behavior that could include stereotypic motor movements such as hand flapping or flicking, rocking, spinning, or scratching.

This caregiver study focused on older adolescents who were diagnosed with Autistic Disorder. The caregivers in this study will be mothers who are currently caring for their child who was given this diagnosis a minimum of three years prior to the interview. To provide a global view, the initial literature review included research about caregiver’s stress within a variety of situations. This view was narrowed to include

caregivers of a family member with a disability. The completion of the literature review focused specifically on caregiver stress as it related to mother's caring for their children with autism.

Chapter 2: Literature Review

Defining Caregiver Stress

Stress is defined as reaction to the accumulation of physical, mental, and emotional strains or tensions on an individual. Chronic stress occurs when the situation is ongoing. Some responses to stress may include sleep disturbance, muscle tension, mood swings, and difficulty with concentration. Depression and anxiety as a result of stress can lead to emotional problems and isolation. The experience of stress varies with each person with a variety of effects according to life circumstances (Spencer, 2003).

Families consisting of a member with a disability are often challenged by their situation. A portion of these challenges can be attributed to stressors affiliated with the caregiver role. Among the reasons one assumes a caregiver role include a child with developmental disability, a serious accident, an aging family member with physical or mental decline, and disability related to war injuries. In addition, families are impacted when a member is diagnosed with mental illness, which results in another form of disability.

The range, definition, and care requirements for a specific disability impact families in a variety of ways. Awareness of this variance is important for understanding the emotional, psychological and physical challenges and their clinical implications.

Caring for a child with developmental disability can lead to chronic stress that can impact various life domains (Simon-Tov & Kaniel, 2011). These life domains affect social, career, relationship and treatment decisions, to name a few.

Caregiver Stress and the Family System

According to the 2005 Cornell University American Community Survey a total of 39,708,000 Americans age 5 and over have a disability with 894,000 individuals residing in Washington State. The number of children with disability age 5 to 15 years old is 2,875,000 nationally with 62,000 in Washington State.

It is estimated that 4.6 million Americans have an intellectual or developmental disability with approximately 61% receiving care from family, 15% receiving care from a spouse, 13% living in their own home and 11% living in supervised residential settings. Families often carry both the financial and emotional burden of care because state agency supports for families have lagged substantially in comparison to funding out-of-home care (Family Support Policy Research Brief, 2006).

Often disorders such as Autism are not identified until after age two. In 2006 the Department of Health and Social Services estimated that 1 in every 150 children is affected with Autism Spectrum Disorder. In 2011, the number of children diagnosed with autism was estimated to be 1 in 110 children and 1 in 70 boys, making it the fastest growing serious developmental disability in the U.S. This disorder has continued to increase because currently in 2012 the Centers for Disease Control and Prevention (CDC) released data that about one child in 88 is identified with an Autism Spectrum Disorder (autismspeaks.org). The numbers are staggering and indicate this disability will impact a large number of families in America.

Caring for a child with developmental disability impacts a family physically, financially, and emotionally. Parents of children diagnosed with Autism Spectrum

Disorder typically report higher levels of parenting stress when compared to parents of typically developing children. Parents receiving their child's diagnosis of autism may experience emotional reactions such as depression, shock, grief, anger, denial, and loneliness. (Autismspeaks, 2012; Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Erguner-Tekinalp & Akkok, 2004; Phelps, McCammon, Wuensch, & Golden, 2009).

Quality of life and adjustment of parents caring for a child with autism is significantly impacted. A study of 160 parents utilizing questionnaires and self-report suggested:

Parents who perceive their experiences as threatening or as a loss were more disturbed by autism in most parts of their life, reported greater dissatisfaction with the assistance they received from others and employed more emotion-focused coping strategies. (Cappe, Wolff, Bobet, & Adrien, 2011, p. 1286)

In addition, the study findings indicated that parents employing emotion-focused strategies experienced more stress and guilt and felt more disturbed. This study attributed parental stress to be a result of enduring their autistic child's behaviors such as lack of social or emotional reciprocity, disturbed sleep, self-injury, agitation, feeding problems, toilet training, stereotypy, and other unusual behaviors. Conclusions revealed that parents that used emotion-focused coping strategies experienced a decrease in well-being.

Implications are that problem-solving rather than emotion-focused strategies may reduce the stress associated with caring for a child with autism.

Caregiver stress was measured in a descriptive, cross-sectional study with 75 participants who were primary caregivers for a child with autism (Hall & Graff, 2011).

The conclusions of this study suggest:

Parenting a child diagnosed with autism results in recognized low adaptive behaviors for the child, high stress levels for parents, increased need for family support, and coping difficulties for parents. Parents reported that their child had

low levels of adaptive behavior in the areas of socialization, communication, and daily living skills. (p. 19)

The participants in this study expressed dependence on family networks to provide support, encouragement, and respite care for their child with autism. They reported that using professional services as family support networks was not beneficial (Hall & Graff, 2011).

Margalit and Ankonina (1991) compared families who were caring for a child with disability (n=71) with families caring for nondisabled child (n=77) to clarify emotional impact as related to stress resistance factors such as personal coping and family climate. Findings (using MANCOVA measures) indicated that parents of children with disabilities reported:

higher levels of negative affect, adopted more avoidant coping strategies, and differed in their familial interrelations and the opportunities for personal growth available to them in their families. (Margalit & Ankonina, 1991, p. 289)

Both fathers and mothers of children with disabilities reported significantly less emphasis on family inter-relational mood, reduced opportunity for personal growth, increased use of avoidant coping, and increased negative affect as compared to parents of nondisabled children. However, none of these studies “gives voice” to caregivers via qualitative methodology.

Results from a study by Oelofsen and Richardson (2006) found mothers and fathers of preschool children with developmental disability reported high levels of parenting stress, with 84% of mothers and 67% of fathers scores falling within the clinical range. In comparison they found parents of normally developing children had scores of only 5% of mothers and 10% of fathers within the range of clinical stress based on results from the Parenting Stress Index.

The National Survey on Drug Use and Health found the highest rates of depression in caregivers compared to other occupations. Care providers who helped severely disabled individuals with daily needs reported depression lasting two weeks or longer (Freking, 2007).

A study utilizing the Family Stress and Coping Interview (FSCI) found parents of children under the age of 21 years demonstrated greater stress levels than parents of younger or older adults. However parents of older individuals with higher levels of maladaptive behavior were found to experience more stress than other groups (Nachshen, Woodford, & Minnes, 2003).

Mothers as Primary Caregivers

Among stressors for mothers is their child's initial diagnosis of autism and severity of the disorder. How these stressors translate to stress as perceived by the mothers is at least partly related to how mothers make sense of their situation and their attitudes towards their children and their parenting role (Mak, Ho, & Law, 2007).

The Interactive Autism Network Project (IAN) studied thousands of participants who completed the Depression History Questionnaire, which reported the challenges raising a child with autism. Both fathers and mothers responded to the questionnaire with a result that mothers responded by more than 10 to 1 compared to fathers (IAN Project, 2009). This is a significant number that demonstrates the mother's role as primary caregiver.

Caring for a child with autism presents the mother with stressors unique to that disability. Challenges such as language delay or lack thereof, repetitive movements, tantrums, social interaction, and behavioral problems increase the level of caregiver stress

(Gray, 1994). The externalizing problem behaviors that are exhibited by the child can further impact caregiver stress (Lecavalier, Leone & Wiltz, 2006).

Maternal depression and adaptability was researched by Baker, Seltzer, & Greenberg (2011) whose study followed mothers over a three-year period. Findings indicated mother-child relationship quality did not predict change in maternal depression or child behavior problems. In addition, mothers who viewed their family as higher in adaptability demonstrated a decrease in depressive symptoms.

A study examined the influences of children diagnosed with autism spectrum disorder on parent gender and child age through utilizing the Methods and Materials questionnaires to determine general perceived stress and coping, social support, and information/education accessed. Study participants consisted of mothers (n=23) and fathers (n=19). It found mothers experienced a greater caregiver burden when compared to fathers (Tehee, Honan & Hevey, 2009). The impact of general perceived stress was increased for mothers as compared to fathers who cared for a child with autism.

A comparison study of mothers raising a child with an intellectual disability (ID) and mothers raising a child without an intellectual disability was conducted by Emerson (2003). Results indicated mothers raising a child with ID reported that their child's difficulties resulted in greater social and psychological impact. In addition, families supporting a child with ID were found to be significantly economically disadvantaged when compared to families supporting a child without ID.

A study of 30 families that compared mothers raising a child with autism to those raising a child with Down syndrome found higher levels of stress within the autism group. Mothers caring for a child with autism experienced significantly more stress with

parenting than other mothers in the study experienced (Dumas, Wolf, Fisman, & Culligan, 1991; Eisenhower, Baker, & Blacher, 2005).

Another study compared mothers caring for a child with Down syndrome (n=25) with mothers caring for a child with autism. This study found that mothers of children with autism presented higher stress levels on seven of the 15 scales of the Questionnaire on Resources and Stress (QRS) (Pisula, 2007). This indicated that higher levels of stress are experienced from the unique requirements of caring for a child with autism.

In addition to family and marital problems a mother may become isolated from friends and some mothers blame themselves for their child's autism (Hutton & Caron, 2005). A combination of these effects could contribute an increase in stress experienced by mothers.

Studies conducted with a variety of cultures found caregivers for autism reported greater maladaptive behavior problems and lower personal well-being relative to other diagnostic groups, regardless of culture. For example, Latina mothers reported higher depression symptoms and lower morale, but they scored higher on positive impact from their child than did Anglo mothers (Blacher & McIntyre, 2006). A study of 368 Chinese families looked at stress and coping strategies of families caring for children with autism and other developmental disabilities. Its findings indicated parents of children with autism experienced more stress and used planning as a coping strategy to a greater degree than parents of children with other developmental disabilities (Wang, Michaels, & Day, 2011). The researchers suggested that stress levels were extremely high which may be due to cultural expectations in a society where parents attach great value in regard to the academic achievement of their children.

The majority of studies referenced indicated the effects of raising a child with a disability resulted in stress for the caregiver. However, few studies identify the specific causes of stress or what helps to relieve the stress. Also, fewer studies addressed the impact of autism on mother's stress. This study attempted to identify and clarify these questions in regard to mothers caring for an older adolescent diagnosed with autism. The majority of studies conducted about caregiver stress utilized a quantitative approach, which measured the quantity of the subject rather than the quality. The information gathered from a quantitative study limits a greater understanding about the phenomenon being explored. This study allowed for the participant's "voices" to be heard and provided a richer insight into their "lived" experience. The focus of older adolescents diagnosed with autism indicated that mothers in this study had been caregivers for over a decade. This created unique and necessary research in that the subjects are mothers of an older adolescent diagnosed with autism and have been caregivers for many years. Increased knowledge about their experience can guide psychologists, advocates and policymakers in their attempts to provide resources and services.

Chapter 3: Method

Participants

The participants were 6 women who were the mothers and caregivers for an older adolescent between the ages of 15 and 21. In addition, the older adolescent was in high school and had been diagnosed with Autistic Disorder. The diagnosis was made a minimum of three years prior to the interview and was categorized according to DSM-IV-TR criteria. Mothers of children diagnosed with related disorders such as Asperger's Disorder, Rett's Disorder, or Childhood Disintegrative Disorder did not participate in the research. The participants varied by marital status, age, culture, number of children in the family, economic status, educational level, and ethnic identity.

Study participants were recruited from the greater Seattle, Washington area through community resource centers that specialize in autism. These centers were contacted with information about this study along with a request to inform potential participants. Phone and email were used to describe and distribute study information. Every attempt was made to insure cultural, ethnic, and economic diversity through distribution of information in a variety of communities that contain a diverse population. The email information that was distributed by these groups stated as follows.

I'm looking for mothers who care for an older adolescent ages 15 to 21 with diagnosed Autism (not Aspergers). My purpose is to have a one-hour interview with the mother to find what things related to caregiving cause stress and what helps to relieve the stress. All information is kept confidential and the participants can discontinue at any time. The goal of this study is to provide a better understanding of caregiver stress that can be useful for support groups, policymakers, advocacy, and improved resources. The participants will be given a free copy of the Autism Guidebook for Washington State supplied by FEAT of

Washington.

Anyone that is interested can contact me at 206-xxx-xxxx
or email lmason@antioch.edu

Thank you.

Linda Mason, M.Ed

Doctoral Intern Clinical Psychology

The groups that distributed this email included Families for Effective Autism, University of Washington CARE Clinic, and Washington State Parent-to-Parent Support Groups.

The mothers contacted the researcher and were screened for their potential as participants in this study. The main criterion for the mother to participate was to be the primary caregiver. Additional criteria were that her child was an older adolescent in high school, and have had a diagnosis of Autism Disorder for a minimum of three years. If the mother met the inclusion criteria, a one-hour in-person interview was scheduled. The location of the interview was determined by the participant with a research requirement that the interview was conducted in a quiet environment that insured confidentiality.

At the beginning of the interview, participants signed and received a copy of the study's informed consent form (Appendix A) and completed a Demographic Questionnaire (Appendix C). The interviews were audio recorded for verbatim transcription.

Results from the Participant Demographic Information Questionnaire (Appendix C) found that older adolescents in the study ranged in age from 15 to 21 years with a mean age of 18.5 years. There were five males and one female who were first diagnosed with autism within an age range of eighteen months to ten years, with a mean age of diagnosis of four years. Ethnic and racial identity included one African American; one Asian; one mixed race of Alaska Native, Caucasian and Filipino; and three Caucasian. The majority of older adolescents used several methods of communication: four total

verbal; three some verbal with gesture; one sign language; three visual pictures; three electronic device, and one used gesture only.

Parent information included two self identified as lower class and four self identified as middle class. The mother's highest level of education ranged from one High School degree; two Community College degree; and three College degree (BA/BS). Three of the mothers were married and three single. Of those single two were divorced and one widowed. One of the mothers worked full time; two worked part time; and three were stay at home. Half of the mothers had other children and half no other children. Within the having other children group, two of the mothers had one child and one mother had two children. All of these mothers indicated that the other children who lived in the home and ranged in age from 18 to 23 years.

Research Design

The purpose of this study was to identify new information about the stress and relief from stress that are unique to mothers caring for an older adolescent with autism, using a phenomenological approach. A phenomenological qualitative study enables an understanding of the research question at a deeper level through descriptions of how the individual experiences the phenomenon. In contrast to quantitative studies about caregiver stress, this qualitative approach allowed the mothers' *voices* to be heard and further develop descriptions of the fundamental quality of their experiences to be further developed. This phenomenological study provided greater opportunity to hear the *lived* experience of the individual participants and descriptions of their commonalities or differences of the phenomenon being studied. In addition, the descriptions reflect the meaning of participant's lived experience as interpreted by the researcher (Creswell,

2007). However, there is less emphasis on the interpretations of the researcher and a greater focus on a description of the participant's experience.

The researcher's objective was to reserve personal judgments and experiences to enable an open perspective toward the phenomenon being studied. This concept is known as "bracketing" or "epoché" where personal experiences are set aside in order to explore other's lived experiences with a sense of originality. Bracketing "a process of setting aside one's beliefs, feelings, and perceptions to be more open or faithful to the phenomenon" (Creswell, 2007, p. 269). I as the researcher made every attempt to remain open and non-judgmental while retaining awareness of the effects of my own views in relationship to the phenomena being studied.

According to Stewart and Mickunas (1990) phenomenology has four philosophical perspectives. These perspectives focus on a return to the traditional tasks of philosophy that is a search for wisdom, a philosophy without presumptions that suspends judgment and the intentionality of consciousness in a reality that is perceived as it relates to the individual's experience.

Procedures

An application for Approval to Use Human Subjects (Appendix A) was submitted the Chair of the Institutional Review Board at Antioch University Seattle. The Informed Consent Document (Appendix B), the Participant Demographic Questionnaire (Appendix C), and list of questions presented to the participants were also submitted. Participants were recruited as volunteers from the community and were informed about this study through local support groups.

After obtaining human subjects approval and informed consent (Appendix A) an individual face-to-face interview was scheduled by phone or email. Each participant was informed that I was also a mother and caregiver of an older adolescent with autism. All of the interviews were conducted by the main researcher (myself) and each participant was given an Informed Consent form (Appendix B) to sign prior to the interview. On the day of the interview participants completed a Demographics Questionnaire (Appendix C) and then a one-hour open-ended interview with three initial question and several probes (Appendix D).

Interviews were audio-recorded. Confidentiality of participants was maintained by the use of letters and numbers rather than names applied to the raw data in transcription and on the Demographic Questionnaire. Each audio recording was transcribed verbatim for data analysis by me and a Health Insurance Portability and Accountability Act of 1996 Privacy and Security Rules (HIPPA) compliant transcription service. Any identifying information was omitted from the final report. For example, when a mother referred to her child or husband by name, the name was replaced in the final report with “my son” or “my daughter” or “my husband” to further insure confidentiality. Each participant was verbally informed that I had a son with diagnosed autism.

The time and location of the interview was determined by the participant or interviewer and coordinated by the interviewer. The criterion for the location was that confidentiality was maintained during the interview process.

Participants were assigned an identification letter and number for confidentiality and completed a demographic questionnaire. Child information questions included

the child's age, sex, ethnic/racial identity, age when autism was diagnosed, and the child's main mode of communication (Appendix C). Parent information questions included socioeconomic identification, marital status, level of education, mother's employment outside or in the home, the number of other children in the family, the other children's ages, and number of other children living in the home (Appendix C).

At the end of each interview, the mother was offered a free therapy session with a trained psychologist to address additional stress generated from talking about her caregiver role. Each participant received an "Autism Guidebook for Washington State" provided by Families for Effective Autism Treatment (FEAT of Washington).

Interview Questions

The initial interview questions:

"Please describe the stress you experience while caring for your child."

"What things are helpful to relieve the stress?"

"What are the rewards or joys you experience while raising your child?"

Follow-up or Probe Questions:

"Can you give me an example?"

"Do I have this/ understand this right?"

"Please tell me more"

The open-ended interview questions were presented to participants to allow their definition of stress to emerge.

Evaluation

The researcher and a HIPPA compliant transcription service transcribed all audio recordings verbatim. Each written transcript was read several times, contemplated across

several days as an “immersion” process, and then re-read several times by the researcher with the intent of formulating an overall view. From these initial readings significant phrases and sentences were identified as applicable to the participants’ lived experience and were selected by the interviewer. The selected phrases and sentences that proved significant formed the basis of meaning. The meanings were clustered into themes, which enabled a view of the themes that are unique among the participants. The results were integrated into a comprehensive analysis and answer of the research questions.

Role of the Researcher

I personally recruited and screened participants for this study and interviewed each participant face-to-face in a location that insured confidentiality. I personally reviewed all the interviews and questionnaires for each participant.

The researcher for this study has a son born in 1989 with Down syndrome and later diagnosed at age five with autism. Within this dual diagnosis the autism proved the most pervasive and challenging. Caring for my son is both rewarding and stressful. My personal journey ignited interest for this study because I carry the history of my own stress in relationship to being a mother caring for a child diagnosed with autism.

The awareness of my personal experience was highly relevant in conducting this study. It served to enable my vigilance in regard to not allowing my own experiences to influence my interactions with the participants. The study questions were purposely simple and open-ended to allow for the fullest expression from the participants.

As a researcher I have over twenty years of volunteer service to local support groups for people who have a family member with a disability. This work includes being a founding board member in 1992 for Down Syndrome Community of Puget Sound. I

remained on as a board member and newsletter editor until 2001. In addition, I was a founding board member of Families for Effective Autism Treatment of Washington State in 1996 and remained a board member and newsletter editor until 2001. In 2002 I was a founding board member for Family Autism Network that co-coordinated with Children's Hospital Eastside to provide Silverlinings, a summer program for children with autism. My experience with these groups encouraged the necessary skills to interact with families in a supportive, safe, and compassionate environment. These skills likely contributed to fostering a rapport and an atmosphere of sensitivity for the participants in the study.

To further understand the role of the researcher in this study, a journal was employed to gather my reactions, experiences, and self-reflection to be entered after each interview (Appendix E). This personal view was intended to expand the lens through which this qualitative study was conducted and potentially assist in the process of bracketing my findings.

Anticipated Outcome

The goal of this research is to put a "human face" on the problem of caregiver stressors that is unique to mother's caring for an older adolescent with autism. It provides an opportunity for these mothers to have a voice in regard to their lived experience. It will enable them to be heard as community members within our population and identify their common features. Increased knowledge about stressors and effectiveness of coping strategies provide information about under what conditions these strategies may be either beneficial or harmful for this population. This knowledge has "direct implications for treatment and parent education efforts" (Lyons, Leon, Roecker, & Dunleavy, 2010, p. 516).

In the Role of the Researcher section several themes emerged that were anticipated in this study. The major causes of stress were found to be due to behavioral issues, safety concerns, and isolation. Among the conditions found that help relieve the stress were acceptance, support groups, respite, and hope. Among rewards and joys were personal growth and experiencing the child's achievements.

Identification of major stressors and strategies that help relieve the stress will provide guidelines for services and intervention with this population. The outcome of this study is to 1) provide guidelines for clinicians working with mothers and families caring for a child with autism and 2) provide data to advocacy groups and organizations to guide them in their efforts in support and to lobby for resources. An informed description of this phenomenon will enable policy makers, organizations, support groups, and psychologist to improve their delivery system to this population.

Chapter 4: Findings

The purpose of this qualitative phenomenological study was to identify causes of stress, what helps to relieve the stress, and the joys or rewards that are common experiences among mothers caring for an older adolescent with autism. The goal of this study is to allow a better understanding about the lived experience of the participants. These findings were drawn from in-depth, face-to-face interviews with six mothers caring for an older adolescent. Seven major findings emerged from this study.

The request “Describe the stress you experience while raising your child” resulted in three major findings: isolation, coping with challenging behaviors, and frustration with the establishment. In addition, a few mothers communicated the cause of stress surrounding caring for their child with autism included marital problems, exhaustion, and grief.

The question “What things are helpful to relieve the stress?” resulted in three major findings: professional behavior or support teams, support from others, and Church or spiritual connection. A few mothers reported stress relief from activities, personal psychotherapy, and problem solving.

The question “What are the rewards or joys you experience while raising your child?” resulted in one main finding: their children’s accomplishments. A few of the mothers reported sharing together and love as a source of reward or joy.

Description of Experienced Stress

Finding 1: Isolation. All of the participants indicated that they experience isolation. Their isolation resulted from a reduction in contact with family and friends, limited social opportunities, and exclusion from support groups or organizations. Isolation was often expressed as feeling misunderstood, judged, or rejected by others.

An important finding of this study is that all of the participants experienced isolation. The source of isolation varied but resulted in similar emotional reactions of feeling separation from others and their community. This finding can be relied on in that all of the participants had the experience of isolation in common. Participants expressed isolation from family and friends in the following ways:

So you lose a little bit more, a little bit more. Your friends that you used to have that could come by, you lose them, you lose family. I can't tell you how many friends have told me about family members that have disowned them. I mean, they don't come right out and say, "We don't like you." But you get the messages. You don't get the birthday invitations, and you don't get the reunion invitations, and you don't get the graduation invitations, and you don't get them, and eventually you, Shit, really? Did my niece graduate from college? And it dawns on you, Oh, right. I didn't know because you didn't invite me. And you didn't invite me because my son would be there. So, you lose a little bit more, a little bit more, a little more. Pretty soon, one day you wake up and you don't even recognize yourself anymore. I used to be cute. [laughter] ...I used to have a life. I used to be fun. Not anymore. So, I can't think of the last time I... And every year, I say, I'm gonna do it differently this year, I'm gonna do it differently. I don't know how, but I'm gonna do it differently. I haven't figured it out yet. I'm hoping someone else will and I can follow their model. (P 6)

I have some girlfriends from high school that told me I was being selfish, and what was the other word she called me - selfish for insisting that if they went out to dinner, that I would have to bring... If they wanted me there, that I'd have to bring my daughter, that I was being selfish. Because all I was doing was setting a boundary, and explaining the situations. They were going on a Saturday; I don't have caregivers on Saturday. The caregiver I had was very new and very small in stature, and was having problems keeping her under control. It was a dangerous situation to be left alone with her very long. I usually only left her alone to go grocery shopping, which is right by. I even asked her, okay, they are insisting. They are calling me selfish and uncaring, or whatever..... It was a common restaurant, so I asked them to go and I'll meet them there. And granted, I ended up being a half hour late because my daughter's care always makes me late. And

all they did was glare at me the whole time I was there, and barely even speak to me, and the whole dinner only lasted an hour. The caregiver even made a comment, "All that, just for an hour?" I mean, if it had been a whole evening of stuff we were doing together, but just for dinner. They made all sorts of excuses about, this was before she turned 21, "Well, we've decided we're going to have it in a bar, because one of our friends can't afford dinner." And yet, they all bought dinner, in the bar. The same priced dinner that they would have had in a regular restaurant. They just did it so that they would have a way of excluding her. I made a comment to one of the girls that called me selfish on the phone, when I talked to her on the phone before that email. And I said, well, that won't matter next year, because she'll be over 21. And she got real silent. I mean.... So that's why I'm isolated. (P3)

I'll tell you, I severed... When the kids were littler, I severed a friendship with a family that I thought was gonna be my best friend. Because we went on vacation, because we were really good friends, we went on vacation and we realized they could not tolerate my son. And ever since then, they'd stop inviting us to parties, and I said, "If you love me, you'll love my son. You don't just love me." So they stopped inviting me and family, they invited me, and I said no, if they're not gonna take my family, that's it. So I think you learn who your friends are, and you deal. (P4)

And same thing, I think, with all my friends, they can't do it either. They don't call me on the one day that they have, "Oh shit, I've got a day off! He's staying with his daddy, or he's staying with grandpa. Who am I going to call?" And you look at your phone, and you go through the list, and you think, I'm not even gonna bother because I know she can't go. She can't go. I can't call any of my friends and say, "What are you doing in 30 minutes?" [laughter] That would be a joke, wouldn't it? How stupid would that be? (P6)

A similar account of limited opportunities to meet with friends because of her caregiver responsibilities was communicated by P1 “ Even calling a girlfriend for coffee is hard because you never know if you're really going to make it there or what's going to happen when you get there, what you're going to do.” P3 expressed it this way, “My daughter’s great but it's different, the relationship with a child is not the same as the relationship with other adults, and so not having a lot of adult interaction, and even with the caregivers.” The challenges surrounding friendship was articulated by P5 “It was stressful just to hurry and do everything. I didn't get to go out and go to a movie with the girlfriends. I can't remember when the last time I did that.”

The problem of finding someone to care for your child in order to go out to have a

break, go to dinner or take a vacation is generally stressful for most families. This stress is increased for a mother if her child is in high school with serious behavior problems or extensive care needs. Isolation from family and friends who could be a source of support is particularly acute in this situation. One mother P1 shared her dilemma by stating, “My husband has a brother who's in the area, but we have close to no communication with them ... So, we have no family for support. To go on a vacation, number one, you have to come up with the additional finances to go anywhere to care for your child. But number two is finding someone who's able to care for your child.” In addition she described the isolation of not being able to go on a vacation:

And we've just gotten where we never go anywhere. We used to have a beach cabin, and he hated the beach cabin. And so, was just... The beach cabin this was to me, it was just an anchor around our necks. I hated it because he hated going out there. And so, I hated going out there. To go out there was just a waste of time. Going on vacation with my son is hell. I guess it kind of quit us going on vacations because we would go places because it was so stressful once he got past (elementary) school age, it became more evident because he didn't fit in as typical anymore. So, that's another stress area for us, is lack of vacation. My husband's boss gave him a trip to Hawaii for 20 years of service. And so. The whole trip was paid for. And so, then we just had to come up with someone to care for our son. And if I go look at the date of it, that's got to be at least... It could be 10 years ago that he gave that to us, and we still haven't used it because vacation just doesn't... Yeah, we just can't do it. (P1)

In addition to limitations of family and friends for relief from isolation, availability of having family members to call to confide in or express emotions was limited due to their child's autism. The stress generated through lack of family members understanding their situation was articulated by a few of the mothers:

And lack of understanding, and friends and family lack of understanding, lack of care. And that's the thing that I think families need to understand, that this isn't your sister's child. This is your family too. This is your niece. This is your nephew. This is your granddaughter, grandson. It's not about helping the mom, and if you don't think that the

mom asks you in the right way or that the mom has an attitude, you're not gonna help. No, you should take it as a family responsibility. Not to be helping the mom - who might be your sister or brother, or whoever, the dad or whatever - it's that that family member that's disabled is just as much your family member as it is the mom's family member, and that you should be offering to help just because you're family.... So many people, like I said family members, all they want to do is push me away, that it's my problem. No, it should be considered as much of their problem as mine because she's still her niece. She's still my sister's niece, she's still my brother's niece, she's still my nephew's cousin. (P3)

You have to be silent about it too because nobody wants to hear it. Yeah, and it's never ending. So, I have to parcel out my whining or my feelings, I have to parcel them out. I can talk to my sister every couple of days, but I know, after a while, she's gonna get sick of me. I can only talk to my cousin every once in a while because people get tired of hearing it. (P6)

Lack of their family members being able to understand the extent and demands of the caregiver role was a reason given by a participant as a cause of stress and increased isolation from family. This was articulated by P3 when she stated, “My family doesn't really understand. They don't understand the level I'm at. They have no concept and they think I over-react. But in reality, I think I under-react to everything that's going on.” She further expressed her stress about this situation:

And then my sister's lecturing me last week, "Well, you need to have a life of your own, separate from your daughter." I'm like... I thought of it later, well, I should have said, "So, what are you saying? Are you saying you're going to take her for me one night a week, and watch her for me?" Give me a solution to that. Sure, that would be the great thing, but how am I supposed to accomplish that. And what I did say to her, I said, "I have more of a life of my own with her with me, than I do if I leave her with a caregiver wondering if they're going to show up or need to go home right away, or strand her there alone. (P3)

Formal support groups or organizations were referenced in regard to not providing what normally would be expected from these types of groups. Some mothers expressed social isolation that occurred within the autism community or other culturally identified supports such as church:

We had to leave the church because they did not want me bringing her to any of the women's activities and played a lot of dirty tricks about going behind my back to fire us. We brought up a collection to pay for you to have a sitter so you can have a "Mom's day out." What all that really means is that "we don't want you to bring your daughter." Instead of talking to me about a situation that happened, they just, for a whole year, talked behind my back and made these other plans without involving me at all. My daughter enjoyed going to those yearly luncheons and I thought I had planned pretty well for the last one. But she was in a stage where she would get up too loud when she wanted... But at the time she was into puzzles and every time she got a puzzle piece, she would laugh and clap. I could understand if she was screaming, that's disruptive, but she would just laugh and clap and get a little too loud and evidently a restaurant patron cornered one of the ladies after we left in the restroom and yelled at them. And so that's when they decided to try to find ways to keep me from bringing my daughter. And it's like, that wasn't my daughter's fault, it wasn't my fault, and I bet the reason the lady yelled at them is she probably complained to management and they told her it's a family restaurant and they had no right to complain, and we had every right to be there. And it would have been nice if the church ladies had stood up for us instead of gotten upset and blame me for it. (P3)

Formal support groups for autism could be helpful but they also created stress for a few of the mothers. Initially, it was a place the mothers expected to find support but at times found the opposite to be their reality:

And I bet, if you've made your rounds and went to every support group meeting that happened across the course of the two or three months, you'll find three, four parents. Where are the rest of them? They're home, suffering. They're home. They can't go to those damn support groups. I've been wanting to go to a meeting for years, can't, no child care. They have great support group meetings they talk about all kinds of things: Special ed and the law, dietary, social skills, whatever. There's probably three parents in each one. (P6)

Although P4 was more involved in formal support groups than any of the other participants she described her experience as, "You don't go out in public. So I think the key... It's helpful that you have friends on the same boat that understand it. But do we have dinner parties with our friends with kids with autism, and let them bring their kids with autism? Not really."

This study was conducted with mothers caring for an older adolescent, therefore they had experienced years of social isolation and its impact. One mother conveyed the emotional reaction to this stress:

And I know you really need to do something, you really need to find something, a hobby or something that you can do when my son, the rare occasion when he's not here. So, I might get a couple days off from his dad and I usually end up staying home because I can't think of anything to do. I always talk myself out of it. "Oh, so, you have the day off, what are you gonna do today? Well, you could go to a movie. And that's depressing as hell, going to a movie all alone. And you could go eat, you could go out and eat; also, equally depressing to sit at a restaurant all alone.... So, I'll stay home. And at the most, I'll get something, like on the days that I can afford it, I'll go to one of my favorite Italian restaurants and I'll actually stand there and think, "This is a really cute little restaurant, nice ambiance, you should stay." And then, I'll look around and see all those happy couples and I can't do it. So, I'll get my food and I'll come home and I'll eat here at home. And then my son comes back. It's like he wasn't even gone. But I can't remember, I can't remember, I know that I used to be a fun person. I used to be. And I don't remember. (P 6)

Social isolation from the community was expressed by P4 as the difficulty she experienced being in public. As she explained, “the disability in and of itself is very isolating. You don't go out anymore because people judge you, people judge your child, people judge your parenting skills because they don't know what they're dealing with here. The deficit is social.” The problem of feeling conspicuous and judged in public was acute for this mother. Later in the interview she stated:

With my son, you know he's not normal so you know that there's something wrong. So immediately, that human tendency for giving tolerance kicks in, right? So, yeah. So in a lot of ways, I think he's easier, but in a lot of ways, too, I mean it's still isolating because of the stares. He still stands out. (P4)

Some mothers expressed their experience of social isolation in the following ways:

I want to say about stress, is just constant feelings of inadequacy. Constantly feeling like I'm failing her. Like, I can never do enough for her. And, the feeling of isolation, you just start to feel like, you know... (P3)

I think, when you start noticing early on his peers are advancing, and getting the nuances, and your kid just doesn't get it. And they're falling behind and then they start to notice.... Yeah, middle school was tough. I think just the age again, speaking with his teacher the other day, his middle school teacher, they can start to see how different they are from their peers. They really recognize and see it at that age. And not quite knowing where they fit in and me as a parent, seeing that they really don't fit in either world. (P2)

Because like I said, the disability is just so isolating... I think that, it's isolating as disability is like a big shift." (P4)

The start of social isolation was experienced by one of the mothers as awareness of her child's differences when he was a toddler. She communicated her experience:

Oh really it started at the playground when he was floppy, he had that low muscle tone and he couldn't stay on a swing and parents would say, "Well, what's wrong with him?" And he started to be the educator of disabilities and then I kind of got tired of that role. Well, there's nothing wrong with my kid. He's just fine the way he is. We just want to take him out to play. He wanted to join in and a lot of times the kids would feel uncomfortable.... But they'd know something was off. Kids are perceptive that way. (P2)

The impact of isolation can result in the mothers' main opportunities for social interaction being limited to their child's caregivers or therapists. This was specifically the case for P3, a single mother, who felt confined to her home most of the time and dependent on caregivers for her daughter. She described her experience "I guess I felt that talking to strangers was safer because you might never see them again, so it didn't matter what you tell them. The caregivers are strangers who come into my home. I also don't have much of an outside support system, so I talk to them too much."

Finding 2: Coping with challenging behaviors. All of the participants expressed stress about coping with challenging behaviors. Stress surrounding their child's behaviors included physical aggression toward the mother or others, safety issues, and their child's unusual conduct.

Aggression from the older adolescent was a source of stress. One mother had recently admitted her son to a local children's hospital psychiatric inpatient unit due to his violent behavior. She stated that his aggression had accelerated one evening to the point of uncontrollable destruction in their home. She estimated repairing the damage he

caused that night would be about \$10,000, and this was not the first time he had displayed such violence. Her emotional statement follows:

Yeah, behaviors and safety, and wondering how long I'm gonna be able to do it. How long am I gonna be able to take this before I snap? And we read, there aren't a lot of them. Honestly, I think that the numbers should be much, much, much, much higher than they really are but we've all read the stories about parents who've snapped and regardless of what you think about it, there is a limit. There is a limit to how much a person can be expected to do and, I think, part of the stress is not being able to scream. No matter where I am, I can't scream. (P6)

Another mother expressed years of coping with her son's aggressive behavior and her struggle to find help:

He's a challenging little guy though. His behavior makes him pretty challenging because he just gets motivated. One time they sent someone out to help me during the summer, and she later shared with me she didn't think I was gonna make it. She thought that I would go. Well, she just didn't think I was gonna make it. (P1)

Physical aggression in the environment was a common experience among the mothers interviewed. The majority of mothers communicated events where their child displayed aggression toward her or another person:

Well, the reason that he's on the Core Waiver is because he's aggressive. I took photos of all the bruising, black eyes, I took pictures of everything. (Researcher's note: this references the physical abuse that her son did to her) I need more services, I need more services. The thing is they give me a caregiver, a caregiver that's not trained with autism, a caregiver that's not trained in behavior. They're like, "I don't know what to do." They'd call me on the phone, "Your son is in downtown Seattle laying on the floor, he won't move. I don't know what to do," and I'm at work or that particular time I was on the bus. I'm going home. What can I... "Get a sheriff, get security, get someone to help you." That's all that I could tell them to do. Fear for even... Cell phones are great, now that I have them, but I'd hate for them to even ring because it was for my son. It's just like, "Oh, something else that I have to do. (P5)

Yeah, I keep trying to get him there. Yeah, because physically he was big enough that I couldn't do it anymore. Like, the biting, the kicking, the hitting, even just going through it and having to get your nephew to come with you. Because my nephew could be in the back, or he could intervene while I'm driving. (P1)

And that's the frustrating thing, is that I always feel like I'm blamed for her situation. Blamed for her behavior when she does have a problem in public. I try to explain it, it's not my fault, it's not her fault, we do the best we can, I do a lot of behavior-management. It's often not enough. When I try to train the caregivers a lot of times they won't even take the job. I've done without a caregiver for over two months, currently, and the person I hired quit after the first day. Because they look at the care plan, they see the possibilities for violence and don't want to come back. (P3)

Trust me. Even the camps, the only one I've found that takes him is Easter Seals because he's physical. He beat up kids. He hit counselors. He got sent home last time from Kiwanis. I won't do Kiwanis again, we've done it twice and he's been sent home both times. He wasn't even there a day and it was over something stupid. They got into a heated discussion because he had yogurt and threw the container on the ground. And they said, "Pick that up" "I'm not picking it up, you can't tell me what to do." So then it gotten to be power struggle and then they pushed and then my son hit and then they called up, "Gotta come and get him." (P5)

One of the mothers had recently acquired a behavioral support team through a state program. People trained in behavior management came into her home, assessed the situation and provided a treatment plan to address the aggression. She referenced the reason for being given professional help:

Yeah, and part of it was to protect me also because I'm the punching bag for my son. And the physical, it bothers me, but it doesn't... I called the police on him last year, probably last year about this time actually, and he ended up in children's (reference to a local children's hospital psychiatric inpatient unit) (P1).

It is important to remember that one of this study's criteria for participant inclusion was that the mother was caring for an older adolescent. While reviewing the interviews about physical aggression directed toward the mothers, a compelling reminder is that the child is often as big or bigger than the mother or other caregivers. P3 who was single and primary caregiver was matched in size with her daughter. She communicated her situation "When I am tired, she gets even more demanding and gets abusive towards

me for not giving in to her needs for attention”. Another mother graphically described an aggressive incident toward her and a caregiver:

One day he got mad at me, I don't remember what I did. He grabbed me by the hair, he had me down by the hair. He had me pulled all the way to the floor. Then started kicking and screaming and I'm trying to... I don't miss any of that. And that was just this last year that he did that. He would come in and even the caregiver, my son got pissed off, I don't know what he did, he kicked him in the groin. The guy dropped to the ground and he took off. My son, oh, he still runs. He's definitely a runner. (P5)

Safety issues were included in coping with challenging behaviors. The majority of mothers expressed stress about the impact of their child's behaviors in regard to safety issues. This experience of stress was communicated by P3 about her daughter, “So to describe the stress, it's hard to describe. It's just all I can think of is the causes of the stress without really, the constant worry where she is. Is she gonna be safe? Is she safe right now? “

Another mother articulated her experiences with safety concerns:

Yeah. He did a lot of dangerous things and uncontrollably. I mean, we would be camping with some friends and he would take the friends glasses and break them, and crunch them up. All the stuff that he did at school.” In addition she described her son's obsession to run away, “*Yep. Public school, he ran and then they put him in private school, then he ran at private school, was picked up on I-90 by two attorneys. Yeah, and that was featured on TV. (P5)*

Some mothers described incidents when their child's behavior posed a serious “life or death” safety concern:

Things can go wonderful. And then, you come around the corner and there's a tripwire because... For some stupid little reason that you don't even know what it is. And so, you can't leave him with people like I used to when he was little. Like, he would have died for a Cheesy. He'd do anything for a Cheesy. And so, if you'd go any place with him, you had to have a firm grip on him at all times because you didn't know when some person was going to cross the street with a bag of Cheesies in their hand. And then, suddenly you lost your kid, and he's heading off to be hit by a car or something. (P1)

When he was younger, oh, we'd go to the zoo. He got into the zoo. One of the zookeepers

left the Komodo dragons cage open and my son went right in. And I'm screaming and everyone's looking at me like, "No!" Running around the corner, grabbed him. (P5)

Safety concerns often stemmed from their child's lack of appropriate judgment or response to dangerous situations:

Just never got through and so we'd have these pockets of awareness and pockets of misinformation that he's interpreted differently than was intended. His perceptions were skewed so you worry about also interactions in the public. How he's going to be received; you want your child to be received well and also, him being safe. The judgment calls were not there for him. He made poor judgment choices and he's pretty erratic and impulsive. (P2)

It was a busy street and then my son going to bolt and escape. It was stressful for me that I couldn't just sit and watch him. No, I couldn't. I mean there was a fence, but if he would climb that fence, he's big enough now... And go to the next neighbor. (P4)

So I hold or, she can take off like a three-year-old without you expecting it and run you or push you right into and out of the car. And so I've learned a certain way of holding her hand then I have to stop her from tripping before hurting herself. Where in school she has fallen at least three times in the school that she got hurt just from tripping or whatever. At home, when I'm with her, she trips over a root on a path and I keep her from hitting the ground by grabbing her. (P3)

And one person took my son, one time, and they never took him again. [laughter] And he really liked her. She actually is a special ed teacher now because of him. They took him for a weekend and they freaked out because... Or they took him for just a Saturday or something, and took him to a movie, and he tried getting out of the car when the car was moving. And I guess it was a nightmare, they were freaked out that he was gonna fall out of the car and he would, you know... Yeah. They didn't do it again, they did it once. (P5)

Coping with their child's unusual behaviors was conveyed as a source of stress.

These behaviors could take place either in public or private and resulted in a stressful situation for the mother. Some mothers offered descriptions of times that their children's behavior was stressful in public places:

He eats too fast and then he throws everything up on the table. And when we're at a restaurant, let me tell you, he gags and the table is full of his vomit that he's thrown up. People have left the table. People have... And he did it at a wedding. I'm like I've gently took my napkin, covered up his plate and took it away. I tried to do it as quickly as I can so people... One person noticed and the other person didn't figure it out because I had

already gotten a napkin over it. (P5)

But, this is part of the challenge, is trying to get her to communicate, and this is actually one of the stressors of her behavior. When she wants attention, she fills her pants. And that's how she gets my constant attention, and then of course, the caregivers get upset. (P3)

It's hard to take him out because he loves long stuff and when you take him shopping, he doesn't care about the clothes that you're going to buy, he likes taking out the tape, the side, the tape on the side of the shirt, M, M, M, M or S, S, S, S... L, L, L, L. He rips them at Gap, I mean, and puts them all together to make a long string. We take him to the mall, he heads... We take him here, he heads straight to the Gap. We would say, "No.". (P4)

In addition to unusual behaviors in public places, unusual behaviors created stressful situations at home where it was a challenge to find ways to cope with the situation. Three mothers expressed stress about their child's unusual behaviors when coping with their child's behaviors in the home. This was particularly difficult when school was out and there were no breaks in the day for the mother:

His magazines are there, so he has a lot of even interest in very narrow region. And sometimes that's another stress though, is just managing those interests can be very stressful also because he is a little obsessive compulsive when he gets his little interests, like National Geographic magazines. But he only wants ones that have something to do with Asia. I can pick out one, and of course it is never the right one. He doesn't tell me that, but he just... Or he has it already or something so I just... We would tell people not to buy him gifts because he has a very set highly, motivated interest. But until you find it... And sometimes we think he has a photographic memory because he never... If you buy him the tape that you know he'd like and he has it already, it's just going to be upsetting to him. And there is no sense in people buying them for him because if they do, the stress level just gets high (P1)

I mean spring break is difficult. Once they get out of their routine they don't know what to do with themselves and you don't know how to engage them. Well, you know how to engage them, but it's stressful." (P3)

We just tell people that they have to be in the same room with him and know what he's doing at all times. And any noise they hear, they need to find out what it is. (P1)

The day-to-day resistance that I used to get from him, the teaching him to do basic things through the years, because of this processing disorder, whether he was getting it or not, how disabled he was or not, how to intervene correctly, approach correctly. [chuckle] There's a lot of guess work involved, so it's like raising three children.... You know, he

had his chores, but it was always like cracking a whip. You know, he just was not a self-starter or motivator. I was getting to feel like his jailer. (P2)

And then, cook your meal or the meal for your family, and then, a meal for my son because he never ate the same things we did. And then, my husband never came home usually until at least seven, and my kids couldn't wait that long. And so, I was cooking three different meals every night, and it just was like, "God, put me over the edge." I just hated doing it. It surprises me how easy it is to cry too with it. (P1)

Finding 3: Frustration with the establishment. All of the participants expressed frustration with the establishment that created stress in their caregiver role. The establishment included schools, camps, state funded respite providers, medical providers, government run programs, and non-profit organizations designed to service families with autism. The use of the word *frustration* is used but has a broader context to describe the participant's responses, which included exasperation, disappointment, anger and dissatisfaction.

Schools presented frustration for the mothers for a variety of issues. Every older adolescent in the study was currently attending high school. The majority of the mothers communicated experiencing stress surrounding interactions with their child's school in the following ways:

One of the biggest stresses for me too is probably school, is because of the lack of services provided by schools. And then, what was really hard for me to understand is that there are always laws governing schools. And then, there are always things to advocate with the schools. And then, we're in Seattle public school systems, and unless you want to have an attorney represent you, there really are no laws. And even if you want to have an attorney represent you and you win, there still are no laws that are enforced. And that was probably my biggest stress, and it was realizing that I didn't know that.... And so, you just felt like you were kind of going insane because you'd be talking the law and you'd be saying this is what it's supposed to be, but that's not reality. And so, the laws and the actions don't match up. And then, I think also maybe the laws work for some people because they have deep pockets or they have high-functioning kids that fit into what the school districts have decided to do. (P1)

It changes but I don't know that it ever gets easier, it's just the mechanisms that are there

changed. School is still sucky. I don't know that that'll change. Not in my lifetime; probably not. United States stinks with schools. They don't support their disabled kids or whatever. And even now for jobs and everything else, and to find jobs and training and everything, they're not supported. All the cuts in all of our wonderful government system come from elderly and disabled. And the poor. The most vulnerable get cut. I just shake my head going, I don't know where your head is. (P5)

It's a document (reference to autism awareness) and you can take it and you can give a copy to every person that your child comes into contact with, the principal, the bus driver, the counselors, the speech therapist, the janitors, everyone. You can print it out. You can print the whole thing out, take it to the school and guess what they're gonna do with it? They're gonna toss it because I tried. (P6)

When I wanted to hold my son back because he always seemed to be like a year, an extra year would help him. It was always a number crunch. We can't do that or a funding crunch. That was very frustrating to me. (P2)

The thing with each program is that you may get it for one school year, and then the next teacher doesn't do it, doesn't know how to do it, doesn't have any inkling of doing it, of carrying it on, or doing anything. A prime example in high schoolthey had no schedules, no nothing for him. From 9th grade on was just a waste. The attitude there in the high school stinks to have a principal say... We ask about peer mentors. "Those kids don't want to be around those kids." Yeah. What an attitude. And I wanted to say, with a vice principal's attitude like that, probably they don't. (P5)

Well, school has not proven that they're capable of implementing a device in her school program. When I told them I wanted them to create a task list between now and the end of school for all of her jobs, they're just, "Oh well that's going to take away her independence," I'm like, No it's not, it's going to give her more independence because, you're going to teach her to focus on the task list instead of completely coming to you." And even the job coach, I showed you a picture today of the job coach, has gotten her to independently put five rows of hangers up without any cues, until the end. And the aid that's been working with her since the beginning of school year could not get her to do that. She was constantly... Every time, my daughter wanted her attention, she'd give her the attention and then complain about it, that she couldn't do it. (P3)

I took him to church until I got calls from the school that it was a problem. And I had to quit going to church Because my son can't talk about church at school. And he was going around repeating the sermon and telling kids, "Have you repented today? If you haven't repented, you're going to hell." And he would go on and on and all about the sermon. He would rant and rave and perservate on that sermon. And they said, "We can't have that, he can't do it in the public school." (P5)

School districts often provide a mediator when parents are unable to reach an agreement with their child's teachers or principal. This is generally considered a last

resort for parents who have made every attempt to obtain an appropriate education for their child. P1 describes her experience with mediation after meeting with her son's school and first being told a program would be implemented that was later denied and never put into action:

So, I think that's my high stress level, is people telling you you're not reality and just keep saying that this isn't how it is, or that we'll do this and we won't do that, or allowing meetings to go on that are just not reality. We did the... What's it's called when you... Oh, mediation, excuse me. We did mediation with the school district, and we spent 10 hours in the meeting. And my husband and I got out. We sat down in the car and we looked at each other, and it was like, "What just happened? Did anything happen whatsoever?" And the mediation was so biased towards school district that it was just a waste of everyone's time. And I was so disappointed in the mediator... her whole purpose is to make nothing happen. You're sitting there, "What is going on?" You just don't know. My biggest stress level is feeling like you don't know where to push. There's nothing to push against. Everything is passive, and you keep pushing and pushing, and you keep stepping back and stepping back, and stepping back. And everything just goes passive. And when you're trying to advocate for your child, it's just so hard, and not to say I don't have the answers because it is so complicated.... And so, he went into high school, and Seattle was saying your neighborhood high school is good. They want to send my son somewhere else, and I was kind of tired of the long distances. They'd had him away from our home because the further they get him away from the home, the less chance they have of the parent being involved. And so, they'll do great things to get distances. Anyways, I chose the local school, and it's even worse than anything we've experienced. But I keep my mouth shut. (P1)

Respite programs are intended to provide relief for caregivers. All of the mothers in this study had access to a Washington State program that included *respite hours*. The number of hours is determined by the state according to the disabled individual's level of care needs. The state funded hours are given on a monthly basis to provide a caregiver, AKA respite provider, to help the disabled individual in the home or community. On paper it appears to be a beneficial resource for families. However, some mothers in this study reported it increased stress through finding, training or obtaining understanding from respite providers:

Because her care is so demanding and if the caregiver is here, I'm usually grocery shopping or running errands. So I haven't taken a nap when the caregiver is here for probably over a year, when it's just something I used to do because I can't get caregivers to be here long enough. When I try to hire for a shift, they don't want to work, they'll agree to it, "I don't want to leave at ten, can I leave at nine?" So then putting her to bed an hour earlier makes her get up at 5 in the morning. It's such a Catch-22 and this whole system is set up that, if you have a more complicated case, all they do is give you more hours. It would make a lot more sense to have maybe certain numbers of hours, and yes,

we do need somewhat more hours, but when it gets to a certain point, start increasing the pay instead of simply getting me over 200 hours. Great, I have 200 hours, but if I can't get anyone to work them. (P3)

They took my son while I worked. As soon as I got home, it was my turn, so I got no time for me, zero, for the most part. Yeah, I may be able to run as fast as I can to the grocery store, but then they would be calling me, "When are you going to be home?" The caregiver is like, "Well, I've got to leave at 7." And it's like, "Well, I'm still at the grocery store, I'm in line." So there's stress from that. It was stressful just to hurry and do everything. (P5)

Even with working with a company that supplies respite providers, we tried to hire someone through them. And they didn't even do the bare minimum screening of, are you available these days? You're only available these days and you have to take a bus, and it's going to take you three hours on the bus? No, I don't think this job's for you. Things like that, it's just like don't even waste my time sending me these people. And then, one probably one of the best people we ever got from them is... They didn't do the reference checks. And then, when they did the reference checks, she had done something when she was 19 in Ohio, and because across state lines, she would never get approved to do it. And that's the thing. It's really hard finding respite. That's what I found, too, just finding anybody. And then, you finally get someone that then having them work with all the needs to like, that can really understand the things they need to watch, the things that they can't do Yeah. And then, when we do, we end up not using the hours because we can't get the trained people. (P1)

The worst of it is the caregivers are very judgmental and not understanding. They don't respect your home, when they come into your home. And the caregivers don't last very long, so I'm constantly having to do the work myself.... I think the caregivers get judgmental towards me for that as well. How do I live my life in my own home while they are in my space, in my face? I am always way too open with the caregivers, and as I face more stress in my life, they get overwhelmed. (P3)

My son got kicked out of school for the month of December. They didn't have someone to take care of him during the day so we brought him home. So, it's just a lot of communications, and you're afraid to... I'm afraid, as a stress, to push with the state because they hold the money. And I'd been warned by someone else not to push because this was this person's project, and... Not to push. And I guess I pushed. And so, I learned quickly that we'd be without funding. (P3)

Washington State provides respite providers for families with the intention of relieving stress, but as noted above, many of the mothers reported that respite could result in increased stress. When a mother reaches the stress point of no longer being able to

care for her child the next step is to request out-of-home placement. The concept is to enable temporary relief for a mother while her child is cared for in a group home. Two mothers had resorted to this as a temporary source of relief but at times found it stressful:

The year my son was in the group home was another just year of stress because we were learning to deal with the reality of turning our child over to a group home, and we were told this wonderful picture by this woman who was a PhD and what her plans were, how she was gonna run the homes, and stuff like that. Nothing materialized that they said would materialize, and the state... If you go to the state, they would push back with anger on us. And the communication just was really bad. (P1)

When he was in the group home also, they... I don't know how we got into this situation, but they wanted us to consistently take him home. And so, it ended up that we would pick him up Friday night. My husband would drive downtown in the traffic, pick him up Friday nights, and then my son would get returned on Sunday nights. So then my son wouldn't let us return him on Sunday nights, and then, it got so it would be Monday morning my husband would drop him off. He'd drive over, drop him off at school, and my son could handle that. And so, every Friday night my husband would spend two to three, sometimes four hours, picking him up and bringing him home. (P1)

Well, I was frustrated because I feel like I have no control anymore. After having a 100% control of my son, and everything that is with him, and going with an agency that wants a 100% control and me none, and it's like "Uh... ". And then to hear that he's not getting to school on time.... It's not the same but I'm still stressed about him. I'm still worried about him. Because there's just not... Yeah, I knew they weren't going to be able to give the same service level that I give, but I thought that they would do a heck of a lot better than what they do. They don't get autism at all. (P5)

In addition to stress surrounding state establishments, two mothers expressed frustration with non-profit organizations that were designed to support and help families with autism:

I don't blame any one particular organization. I think, it's just the nature of the beast but I think that after a while, most autism-specific organizations lose their way. They lose their way because they become kind of self-fulfilling. So, in other words, an organization gets a grant to do something, whatever it is, and then after a while, it becomes we've got to renew that grant. When 'we gotta renew the grant' it becomes less and less about the kids and the parents and more and more about maintaining that budget. Last year you got the grant, you've got to get it next year. If you don't get that grant you've got to get another grant next year. They just remove themselves further and further away and, I think, they're doing a really shitty job when it comes to providing family support. (P6)

I went to some support groups for awhile and I didn't really get much relief from that. I didn't want to just sit around and talk about how bad it was. I needed what would've been nice to have had a daycare type thing where all the moms took turns taking the kids or doing something to give moms relief. (P5)

Are there any support groups that provide child care? There are tons of support groups. If you go online right now and type in Autism Support Groups, parents, Washington State, dozens and I can't go to none of them. (P6)

Two mothers conveyed stress surrounding establishments that provided camps for children with special needs:

They had the Saturday Club but it was far away and it wasn't convenient and it was only for a couple hours. And for the most part, most of the services, if they have aggressive behavior then they won't take them. (P5)

But no, I can't take my child to the campfire summer camp. But they still get to carry the badge of taking kids with autism. No, you don't. You lie. You have that on there, what you really mean is Asperger's and you should say so. Don't give people all this hope, that stupid children's hospital camp guide, it's a complete waste of your damn time. (P6)

The medical establishment was another source of stress experienced by a few of the mothers:

I got so upset because they were pushing me around and were refusing to do the procedure because they didn't have procedures in place to handle a child that large, with that many behavior issues. "Well the staff who made the appointment, they're not trained to do that." "Well why not?" "Well they don't have access to the fact that she's 170 pounds, so we didn't know she was 170 pounds." Well isn't that what they should be doing? Isn't that what they should be trying to do? And so I insisted that they continue with the procedure and get her the five people to hold her down to get the IV in her leg, and the doctor just glared at me. In fact, the hospital did step up to the plate and even got the administrator to come and talk to me, and she calmed me down and brought me a latte. So I was totally in the right and yet this person who witnessed the whole thing so I was totally in the right and yet this person who witnessed the whole thing, her whole comment was after that, that it was too stressful, put her in a home. And she didn't even at all get why I was so upset. (P3)

I had two girlfriends who are nurses also, and I call them, and I'd say, "the hospital wants me to come over," and they said, "Don't do it. Don't do it." Even my friends who were nurses, they said, "Don't do it, because they just want you to take care of him instead of the nurse having to take care of him for the behavioral task." So, they pushed. I

mean just having this tug of war. And I finally went. When I went though, I ended up having to stay there. They wanted me to stay with my son. And so, I ended up staying at the hospital with him. And they're not set up really to accommodate a parent or a guest, or whatever I was. I want to say the lock was broke on his door so other people could get into his room. And so, even for me having to dress and undress in this environment was difficult. They couldn't find a bed for me. Well, they wanted me to sleep in some room, and I was like, "I'm not gonna go sleep in the hallway in that room." It was a little room with chairs in it, but it did have a Murphy bed. And there's no way I was sleeping in that room. And so, I don't know what I ended up doing, if I slept on the floor or what I did. I don't even know. And then, you got to see what it was like. All the doors are locked. You have to have permission to do everything. Same with me, if I had to go to the bathroom had to get someone to unlock the bathroom. (P1)

What Helps Relieve the Stress

Finding 4: Professional behavior support teams or state funded resources.

Four of the mothers who had access to professional behavior support teams or Washington State funded behavioral support programs expressed experiencing relief from these resources:

When you talk about ways to lower stress, the things that have lowered stress for me was the year that we had the problems at elementary, which was my son in fifth grade. We had someone from Children's Home I believe it is, in Seattle. His name was "Jay", and "Jay" would come and meet with my husband and I, but it was really more focused on my husband. "Jay" brought my husband more into the process, and it was the first year that he was really responsible for being the advocate for our son. And they were trying to keep me out of it because I was just way too stressed out to continue to deal with it. (P1)

One mother had access to a Washington State funded WRAP program that provided a facilitator to work with the parent, provided *wrap-around* services, and coordinated all of the people involved in her daughter's care. This included making a list of the mother's self-identified needs, organizing resources and contacting relevant people to communicate and attend group meetings:

Actually, we really did accomplish a lot this year, but the teacher, if it haven't been for the WRAP program, and the people with WISE and with the King County who were able to give outside support, that and only then, was the teacher willing to get us the Goodwill

position. Because, she could say no to me for three years, she couldn't say no to these other people. And when she had a room full of almost 20 people. (P3)

Another State funded program titled “children’s intensive behavior support waiver program” (CHIP) provided a team of professionals trained in behavior management:

The CHIP waiver program, I'm not saying that every kid needs 400 hours a month, some kids can get by with less, but that the thoughtful approach that they take to figuring out what the behaviors mean, possible responses, interventions, and then, going back to check in to see how things are going. When the people presented my plan, the 37-page plan for my son, I introduced them to his afternoon aide. So, we had five women sitting around the table, four, one woman in there with my son, and my son also had a male assistant. (P6)

A Washington State waiver program had recently provided out-of-home placement for one mother’s son that she articulated was at times frustrating but currently a source of stress relief:

It's only been two months, but I can tell you how much better I feel, healthy-wise, everything, being able to come home and not have that is unbelievable. It's like, to some extent, a weight's been lifted off my shoulders. Yeah, I'm still getting involved with what's going on. Yeah, it's really frustrated, but it's not that day-to-day But I didn't even realize how bad the stress was until he's been gone for a couple months, and me noticing it, everybody else noticing how I've changed. What difference there is in me. Now I actually have a chance to maybe date. Before it was always a hurdle. I met people. They didn't want to have anything to do with me when they found out I had a child with autism. And I understand that but I can't change it. (P5)

Finding 5: Support from Others. In response to the question about causes of stress, several mothers had expressed some frustration with the establishment on the topic of support groups, family, or organizations. However, the majority of mothers conveyed that at times support from others, in particular those that understood their situation, helped to relieve the stress:

My sources of information for lowering my stress has been the mothers from a local support group. Yup. It's support from women you've met in the past. And you run across them in the future, and then, you find out what's going on with their child I've learned that from a woman who came to a meeting. And I thought she seemed very organized and bright. And so I wrote her name down and her phone number, and used it, how many years later, probably 8 years later. So, that's been... My network has been from the support group really, and people you may not know well, but I keep their numbers..... I printed off a phone list so I can call people and stuff. That is the most valuable thing I have with regards to autism because I can call people, then talk to them one-on-one and get help from. Even if you don't know, you can still call them. And so that's really what my support group is. (P1)

Yeah yeah so it's... I mean the people that you meet when the kids are newly diagnosed are the same people that would help you. So it's really important. They're the same people that would help your kids, really. And yeah, so the more... I mean there's a lot of changes in the community and the disability, particularly the autism community. There's a lot of changes, but there's a lot of things that stay the same. The battles are the same, it just looks different. But then I can say that any family that the typical kids can say that as well. There is still challenges but the challenges are different. They look different. With us, it's the same thing. It's the same thing I think it helps but... There's a lot more... There's a network. There's a robust network. (P4)

I will say that some of the parents that ... you know, my son, some of the kids he went to school with, we had an informal support group. We'd get together socially and we'd end up sharing some resources. We did that kind of quarterly for about two years. Just before it got really intensive in the last year or so, with transition and job seeking and graduation for some of the kids.... I used to go out and work, I work out. I used to work out with weights or I don't jog but I would walk a lot. I have a wonderful support group of girlfriends and we'd get out and do stuff. (P2)

Yeah, and so I think that the typical sibs are... I think they're such blessings and they're must haves [chuckle] when you have a kid with disability. Because they're one of the stress relievers, you get to experience normal lives. I certainly... When my older son was in high school, I get stressed, I go watch his baseball game and I feel typical. Or I go out with him shopping and I feel typical. I'm able... It's a gift because I'm able to experience both worlds and be thankful for both. Oh I think typical sibs like that. (P4)

He was doing well with that group, the parents are wonderful in that group. Next weekend with their booster club I'm staying in contact because we're gonna go to their dance and stuff because my son's behavior was just awesome. We went to state and I really have to tell you that the parents... I didn't have to do much. They all helped. (P5)

I think, things will get better when I go back to work because I'll have people that I can take my mind off of things, worry about other people's problems for awhile. So, maybe things will improve then, I'll actually know someone. (P6)

Finding 6: Church or spiritual connection. Four of the mothers communicated relief from stress through their church or spirituality:

I'd love to be the mom. I created traditions for our family, that kind of thing that was important to me. In those days, I did go to church. [laughter] That was a stress reliever. I still have a strong faith; it's just altered a little bit. Expanded, I should say. (P2)

Right now, I volunteer at our church. On Sunday morning, I make coffee. And it's my biggest freedom time because my husband is usually home on Sunday mornings. He sleeps later than I do. I can get dressed, and I could get out of the house before our son is awake. And I get to go and make coffee and set up the church stuff in the morning, and I don't have to have permission from my husband to go. I don't have to get a babysitter or hope that I can get someone. And I know every Sunday morning, I can go and do this, and maybe have a few conversations. And I don't have to make the arrangements if I don't show up. The minister's gonna do it. (P1)

A lot of prayer As a Christian, one thing the Lord is taught me to do when I have problem come up my first reaction to everything is always fear and overwhelmed, overwhelming emotions and I have learned to deflect it. To just say, "Okay Lord, show me my warriors, show me my weapons, show me what I need to do." And it takes the focus away from the problem to; what are the solutions the Lord is putting in front of me. (P3)

We had a really good pastor at that time. My son would run up, "Hi, did you come up to say hi?" "Yeah." I got a little bit because the one girl that was dedicated to my son would take him down to Sunday school, and I got church by myself uninterrupted. (P5)

Rewards or Joy

Finding 7: Child's accomplishments. The majority of mothers reported experiencing reward or joy in their child's accomplishments. These often were expressed as something that could be interpreted as a small achievement but was of great importance for the mothers:

When my my son is successful at something like, let's see. It could be little, like he can swallow a pill now. He can swallow pills. Oh my God, that was huge. I seem to worry about that. I can do generic drugs now because he can swallow a pill. Or when he finally calmed down enough to fly on an airplane. Or he can ride a ferry ride. He can do ferry rides pretty easily. So, those things. When he succeeds at something that we've either

been working at for a really long time or just something little that just makes my life way more convenient. Learning to go wipe himself without using an entire roll of tissue. It doesn't sound like much but I was going broke on tissue. Just on tissue alone, that container right there, at one point, this is just last year, would last me a week. That would last me a week. With only two adults in the home with my son and me, he could go through all of that. So, little things like that. I can't say that I have any joy that's not directly involved with my son. (P6)

Maybe they have to wait a little bit until after they swipe their debit card. I mean, it's those little things that you teach them. It doesn't matter if there's a line coming up, you have to let him finish. He has to swipe his card, I don't care how long it takes.

[laughter] (P4)

That's a joy too when you know that they can do it, and other people are saying, "No-no," and then you see them do it and they prove it to everybody. (P3)

So a lot of the reward that you feel after all these years is seeing the changes and the progress from all of your effort. Even though I lay awake nights thinking, I should have done that or I could have done that differently or it is good to just get real and say, "Job well done." (P2)

The reward for me was my son... that I've been a good mom and I've done the best job that I can. That's a huge reward for me and for people to... Family, tells me all the time, "I couldn't have done what you did. I just couldn't have done what you did. You did a great job." I have an aunt she's like "there's a lot of kids that don't achieve what he does. And you bring him everywhere. You brought him to the wedding. He's included in everything that you do." (P5)

Sharing together was conveyed by half of the mothers as being a source of joy or reward:

My son has a terrific sense of humor. So the joys of being able to laugh together when he really gets the belly laugh. The routines, I remember when he was younger, our family walks, story time before bed, my introduction to children's literature that he and I share and when we were told that he was diagnosed with auditory processing disorder, yeah, that he didn't process auditory very well. I started reading to him every night. And it's by God made a huge difference because he needs getting a reader (a person who will read material to him for better comprehension). He loves it. And they don't have to have pictures in them. (P2)

Yeah, so I think it's always special when you can find something that the whole family can do because that's the one thing that makes life normal or makes you feel that everything is normal because you can do these things so when we went on vacation

all of us in Europe together, I was happy. It was just a joyous time, it was the highlight of my year, for the first time all of us there. (P4)

Yeah, she has great sense of humor. One day I forgot to finish, do her bath properly. I don't know why. I was just super tired. I washed her face and I washed her hair, and that's it, and I started getting her out of the tub. She refused to get out the tub. I was like, "Why won't you get out of the tub?" And then I remembered, "Oh! I haven't washed your body!" And we laughed about it, but the funniest thing was the next day, when I gave her next bath, and I finished washing her hair, and I said, "Wasn't it funny yesterday when I forgot to wash your body?" She just laughed with me. And, when she watches movies, she laughs at the appropriate times. If I forgot something she'll laugh with me, and she laughs at me. I am beginning to learn she has a way of laughing when she recognizes something. (P3)

Love was communicated by half of the mothers as a source of joy or reward while caring for their child:

I believe because it's your child. I do love my son. Unconditionally, I love my son. (P1)

The reward in it was my goal in life was to be a mom, and to be the best mom that I could be. And I really can say honestly that I've done that. So that's the reward in it. For a child to come up and give you a hug or a kiss or I love you, or... One year, my son, who doesn't do it very often, he'd give me something for Mother's Day. (P5)

We do a lot of tickles I think of her hugs and then I think, when I am having a bad day, I remember the hugs I remember the tickling and she gives the biggest bear hugs and the biggest kisses on the cheek in her way of doing it. And the smiles that she gives you are just so wonderful. (P3)

Additional Minor Findings

In addition to the seven main findings, three minor findings emerged as a cause of stress among the mothers caring for an older adolescent with autism. These included the following: marital problems, exhaustion, and grief. Additional minor findings about what helps relieve the stress included having a personal psychotherapist, being able to problem solve, and engaging in family activities were expressed by a few of the participants.

Three of the mothers interviewed for this study were married and three of the mothers were single at the time of the interview. Two of the married mothers conveyed problems in their marriage that were related to having a child with autism:

But also looking back on the stresses of all marriage, it's amazing. I don't know how people stay together but we did my husband had mentioned to me, "Well you know honey, there were a couple - not a couple" he says, "there were some months there where I didn't feel like I wanted to come home." That just amazed me. He was from a pretty abusive first marriage where he would say he didn't want to go home. Now in this case it was because my son and I were loggerheads and he didn't want to hear it. (P2)

The stresses I feel are the tugs between my relationships with my husband and my son, and their needs, and not having enough time, not feeling that I've done enough to take care of all of his needs through the years. And then disappointment, sometimes, from my husband, resentment because, I mean, God help us if we'd have another child, poor kid would have been neglected.... And, so my husband was the breadwinner, even though he felt sick, he had a heart attack at 50, and has just kept on, kept on, and been... A wonderful spouse, and provider, and father. But, you know, there's disappointments in having a kid that doesn't respond to you on a level that we all agree that we don't have of intimacy with our kid. So those are kind of emotional stressors. (P1)

And my husband, he goes off to work, and you're left with what you have to deal with I don't think your spouse really knows your reality. And I don't think I know his reality either. I just think that's how life is. You don't know each other's realities until you have to do the job. (P1)

These same two mothers expressed marital problems with their husband not fully understanding the situation:

So in a sense I had to train my husband how to treat his son too and there was some resentment there.... I'm very involved and I've been privy to a lot more information than my husband because of it. So, that is one of the stressor is conveying to him, all the information and all of the knowledge that I've learned about our kid that he just doesn't get and then his guilt over that--That he experiences sometimes because he wasn't there. You know, we each had our roles. (P2)

And my husband just wouldn't help us with it. And I wanted him to set some standards and do it, and he wouldn't understand it. (P1)

One of the single mothers communicated that problems in her former marriage may have increased the stress due to caring for their child with autism. This mother

stated that her husband committed suicide several years ago and described her experience in the following way:

My late husband did the same thing and I probably took my stress out on him as well, verbally rather than the abusive, but actually it got close to physical, but it never went. Although he ended up killing himself due to the stresses in life that he couldn't handle.... And even though my late husband's family hates me, she's still their family too. But part of the problem there is they blame her for his death because they feel that I shouldn't have insisted that we keep her at home. They've never said that to me, but they've always been judgmental of me and how I handle it. (P3)

Three of the mothers mentioned exhaustion as a cause of stress in their caregiver role as follows:

Describe the stress. I'm totally exhausted all the time, always. My knees hurt. My arms hurt.... To talk about stress, how do you handle these things? Basically, I live my life on emergency mode, 24/7. (P3)

Pretty much all day long. I remember reading awhile back that a related or compared raising a child with autism to active duty military. Yep, I can definitely relate to that. I think, it's more like active, for like firefighters being on guard 24/7, you always have to be ready for whatever might happen. It's not just the stress of worrying about him every day but having to be ready all the time, all the time. And for whatever happens, I have to be ready. Up, awake, and willing and able to give my son everything that he needs. It's exhausting. (P6)

I think the stress of always being on the go, but there was a fire lit under me, for some reason, I just... It was okay. This is what I was ... supposed to do, you know. And it's only in the last few years looking back, I realized how much we did and it makes me tired. (P2)

There is only so much a person can do. To me, it's like having a, I don't know if you've ever had a... when you get off of the airplane, you have a buzzing in your ear, just this nonstop buzzing. It's like having nonstop buzzing no matter what is going on in your life; bill problems, job problems, spouse problems, whatever. Right there, it's buzzing all the time. Sometimes, it's really loud. And sometimes, you can actually stop and maybe ignore it a little bit but it's always there. So, no matter what anybody else might be dealing with, they don't have that nonstop buzzing. Yeah, because it's everything. It's at school. It's at home. It's just everywhere Everything is thrown on the mother's shoulders. You have to become everything. You have to become an attorney, and a nurse, and a nutritionist, and an educator, and a behaviorist, and an advocate, and a defender, all rolled up in one. And they're all on duty 24/7. That's just too many roles for one person to carry on. (P6)

Grief was a source of stress for two of the mothers. This emotion was expressed as it related to caring for their children with autism:

Yeah, well, I think... Like I said, I think the grief part for us is, and I don't mean to minimize the loss of a loved one, I think it's worse than losing a loved one because when you lose a loved one you grieve and you know it's done, right? I mean you grieve, and it never goes away, that grief and that missing the person, but it heals a little bit. There's no scab to pick. There's always the memories with them. But with our kids there's... You grieve and you think everything is okay because they are doing so well and then when you transition to another stage or when graduating high school, you pick on that scab again and then you grieve again because, "No, my son is not like your son who's going to go off to college." Or, "No, my son is not like your son who's part of the football team or the soccer team." You always pick on that wound and it's always going to be there and it never ends, it never ends. (P4)

And then he would start to internalize some bad feelings about himself and that breaks your heart. It breaks your heart. And you take care of that grief, but it washes over you at different times, which is really interesting. You're never over it. And the expectation from when you have a child is totally different. And then there's other parents that say, "Well, it's like that with any child." Well, they don't get it. It isn't like that with every child. I think they're trying to help and placate you and say, "Well, really? It's not that different." Well, yes, really, it is! (P2)

Additional comments about what helps relieve the stress included having a personal psychotherapist, being able to problem solve, and engaging in family activities. Two of the mothers mentioned having a personal psychotherapist was helpful to relieve the stress:

She was the only person that I've gone to that really helped me in more ways than one. Just the stuff she made me do, homework. She made me... See a side of me that I hadn't really seen, or wasn't aware of. You know how sometimes you're so focused and my face would be.... She did a thing, she goes, "Looking at you in the waiting area, I don't see a happy person." "You don't?" "You're not smiling, you're not da da da," whatever. "Oh, I don't look happy, do I?" It made me look at myself with what I'm telling everybody about me. Body language. Oh, that's why that's so important. Oh... So I just tuned out the world and was off in my own little thing. She didn't help my son, she helped me. I once saw her for me. She made me write down things that... "What do you do for fun? What do you like to do?" After I wrote them down, "Fine, I want you to do at least two of these for next week before I see you." "What?" Oh. So I really had to work at finding time for me. And

she helped with work. She helped an issue at work, she would help with issues at work. (P5)

I did, for the first time, reach out over the summer trying to find a therapist. And it was slow-going because of my insurance, it wouldn't accept ones that I bonded with over the phone interviews, and then I just gave up but before my car accident last month, I have been going pretty regularly for about two months to somebody with PhD. It's very good. And started talking things out with her, so I think I'll go back. You know, for the most part, I've done that with my girlfriends, but at a certain point, you don't want to go into some with the detail, or burden them with some of the heavy stuff. So it's time for a professional (P2)

One mother found stress relief through problem solving by conveying:

I think what relieves stress is solving that which gives you stress, finding a way around that which gives you stress". ... Sure it's stressful because you do things that are not things that you would normally do. But it's like I said ... you find a solution. That's the only solution to stress, right? You can't fret because it's still going to be the same. (P4)

In addition, this mother stated that family activities provided stress relief as follows:

The trick is, though, I think, that you find or parents find a family activity that all of them can engage in. For us, that's hiking and that's bicycling, because my son hikes, he bicycles and he snowboards. So, those are the things that we think is the semblance of a normal family where you find things that are common to all of you. (P4)

Summary

The preceding section presented seven major findings that emerged from the study and six additional minor findings. These were presented and organized according to the research questions. The *voice* of each mother gives the reader an opportunity to enter deeper into the reality and life experience of these participants.

A finding in this study was that isolation was experienced by all of the participants. This finding emerged when the mothers were asked to describe their experience of stress. Several factors were articulated that related to their experience of isolation. These included isolation from friends and family, limited social opportunities,

and exclusion from support groups or organizations that were intended to offer help or relief.

The second finding was that all of the participants experienced stress as a result of coping with their child's challenging behaviors. These behaviors included physical aggression toward the mother or others, safety issues, and their child's unusual conduct.

The third finding in this study was the participant's frustration with the establishment. The establishment included schools, camps, Washington State-funded respite providers, medical providers, government-run programs, and non-profit organizations designed to service families with autism. The use of the word *frustration* was used but has a broader context in describing the participant responses, which included exasperation, disappointment, anger, and dissatisfaction.

The fourth finding was that relief of stress was obtained through professional behavior support teams or Washington State-funded resources. Four of the mothers in this study had access to professional behavior support teams or Washington State-funded resources such as *wraparound* services and expressed experiencing relief from these programs.

The fifth finding was that many of the participants found that support from others was helpful to relieve the stress. Often the other people were also parents of a child with autism or involved in the disability community.

The sixth finding was that the majority of participants communicated that church or spiritual connection was a source of relief from the stress.

The seventh finding was that the majority of participants experienced joy or reward in their child's accomplishments. These often were expressed as something that could be interpreted as a small achievement but was of great importance to the mothers.

In addition to the seven main findings, three minor findings emerged as a cause of stress among the mothers caring for an older adolescent with autism. These included marital problems, exhaustion, and grief. Three minor findings emerged in regard to what was helpful to reduce the stress: having a personal psychotherapist, problem solving, and engaging in family activities.

Three of the mothers interviewed for this study were married and three of the mothers were single at the time of the interview. Two of the married mothers conveyed problems in their marriage that were related to having a child with autism. One of the single mothers communicated problems in her former marriage that were related to caring for their child with autism.

Three of the mothers mentioned exhaustion as a cause of stress in their caregiver role. This included physical and emotional exhaustion due to the intensity and demands of their caregiver role.

A source of stress for two of the mothers was coping with grief. This emotion was expressed as their individual experience of grief as it related to caring for their child with autism.

In response to what helps relieve the stress, two of the mothers mentioned having a personal psychotherapist was helpful.

One mother found stress relief through problem solving and finding solutions for the situation. She also mentioned that family activities where her son could be included was beneficial for relieving the stress.

Chapter 5: Discussion

The purpose of this qualitative phenomenological study was to identify causes of stress, what helps to relieve the stress, and the joys or rewards that are common experiences among mothers caring for an older adolescent with autism. The goal of this study was to allow a better understanding about the lived experience of the participants. An informed comprehension of this phenomenon will enable policy makers, organizations, support groups, and psychologists to improve their delivery system to mothers who care for an older adolescent diagnosed with autism.

Data collection involved in-depth, face-to-face interviews conducted by one person, myself, as the main researcher. Each interview was audio recorded and transcribed verbatim with participant's confidentiality assured through assignment of a letter and number in place of names. Confidentiality was also assured if a child or husband's name was mentioned during the interview the name was replaced with *my son* or *daughter* or *husband*.

The data were analyzed first through an *immersion*, a process where I read each transcript several times. After a few days of contemplation about the interview I re-read each transcript several more times to further absorb the meaning and themes that emerged. These emergent themes were organized according to the research question and written in the left margin of the transcript for reference. Further readings allowed for organization of categories and subcategories that were noted in the left margin. The right margin was used to clarify the themes through questioning to determine if they had a

better fit into another category, were viable to include as a theme, or were better reserved to use as an insightful story for my journal. Separate papers were used to record the number of each participant's response within each identified theme. For example, the theme of isolation was referenced by P1 three times, P2 ten times, P3 eight times, P4 four times, P5 four times, and P6 six times. In addition to indicating that all of the participants experienced isolation, recording the number of references for each individual indicated the extent of the experience. This type of reference was contrasted with additional minor themes such as exhaustion that was referenced by P2 one time, P3 one time, and P6 three times.

The study was based on three main research questions:

1. Describe the stress you experience while raising your child.
2. What things are helpful to relieve the stress?
3. What are the rewards or joys you experience while raising your child?

These research questions were addressed in the Findings section through presentation of the categorized data into a narrative. This Discussion section analyzes, interprets, and synthesizes the findings. It is organized by the following analytic categories:

1. *The experience of what causes the stress* included experiencing isolation, coping with their child's challenging behaviors, and feeling frustrated with the establishment.
2. *The experience of what helps to relieve the stress* included having professional behavior or support teams, support from others, and church or spirituality.
3. *The rewards or joy experienced while raising their child* was the child's accomplishments.

This section attempts to illuminate and provide greater understanding about the meaning of the findings. This process is described by Bloomberg and Volpe (2008):

Analysis is intended to depict a more integrated picture, and what emerges is a layered synthesis. Throughout the process, the elements that continued to frame the analysis were (a) connective threads among the participants, (b) ways in which participants understand and explain these connections, (cc) unexpected as well as anticipated relationships and connections, (d) consistency or inconsistency with the literature, and (e) ways in which the data go beyond the literature (p. 139)

In addition, the process of bracketing will continue to be employed throughout this section. A summary follows this section with an examination about my assumptions, which were identified in the Introductory section. In addition, my personal reflection about each interview is available in the journal (Appendix E) to allow the reader to have deeper insight into the development of this discussion about the findings.

The Experience of What Causes the Stress

Finding 1: Isolation

The experience of isolation was expressed by all of the participants. This theme emerged when participants were asked an open-ended question to describe the stress in their lives while raising an older adolescent with autism. Their isolation was experienced through a reduction in contact with family and friends, limited social opportunities, and exclusion from support groups or organizations. One of the mothers, P6, expressed it this way when she said, "You have to be silent about it too because nobody wants to hear it. Yeah, and it's never ending." Another mother, P3 communicated an experience of being excluded from a social group because of her daughter's behavior and ended by stating "So that's why I'm isolated."

The implications of social isolation affect an individual's quality of life through psychological issues such as depression and compromised physical health. This study focused on caregivers for an older adolescent that indicated the potential to further exacerbate their stress through experiencing over a decade of coping with their child's autism.

The isolation experienced by families of autistic children can be severe. Isolation may occur for a variety of reasons and leave parents lonely and depressed. Many parents have a difficult time socializing with parents of "normal" children, and some may feel they no longer have anything in common with the social circles they were once involved in. As the autistic child grows older, and the difference between him and his peers becomes more obvious, the isolation often becomes extreme. Friendships may dissolve as caretakers abandon hobbies and outside interests. (Ketcham, 2012, p.1)

A study among caregivers for children with autism found a sense of isolation and lack of engagement (Thompson & Mahmoud, 2011). In addition, results included problems with staff training and attitudes, as well as the tension created by having to decide whether to engage in mainstream or special provisions. The conclusions from this study suggested that barriers such as needing special provisions for their child be considered when encouraging families to engage in leisure activities. Social or community inclusion of a child with autism is often a delicate balance between how the child reacts in specific environments and how accepting others are who are in the environment. This study supported some of my findings about isolation in that social activities are encouraged by others and desired by the mothers but the logistics of their situation creates a barrier. Similar experiences of isolation and barriers to social activities occur in caregivers of a child with physical or developmental disabilities (Akkus, 2011; Baillargeon, Berbier, & Normand, 2011). These studies indicated that being in the role of a caregiver can create social isolation, hopelessness, the need for respite, and the

difficulty being included in child care programs or services. Social connection is necessary for quality of life and caring for a special needs child can result in restriction through isolation.

A term was developed by Sperber (2011) was called *Autism Isolation Syndrome* to explain the challenges and difficulties of the caregiver's experience. The main elements in this syndrome are emotional isolation from self, physical isolation from others, and social isolation. The range of emotions in the early stages of this syndrome include grief, anger, sadness, and guilt. Coping with these emotions alone or suppression of these feelings can result in depression and depletion. A study by Bourk-Taylor, Law, Howie, & Pallant (2009) found the prevalence of depression in mothers of children with developmental disabilities was estimated to be 10%, and the risk is even higher for mothers of children with autism.

This type of experience was expressed by P6 as "...a little bit more, a little bit more, a little more. Pretty soon, one day you wake up and you don't even recognize yourself anymore."

A theoretical and empirical review of the literature by Hawkley and Cacioppo (2010) proposed the *Loneliness Model*:

Perceived isolation is tantamount to feeling unsafe, and this sets off implicit hyper-vigilance for additional social threat in the environment. Unconscious surveillance for social threat produces cognitive biases: relative to non-lonely people, lonely individuals see the world as a more threatening place, expect more social negative interactions, and remember more negative social information. This self-reinforcing loneliness loop is accompanied by feelings of hostility, stress, anxiety, and low self-esteem and represents a dispositional tendency that activates neurobiological and behavioral mechanisms that contribute to adverse health outcomes (p. 220).

Remembering negative social information was expressed by P3, “So many people, like I said family members, all they want to do is push me away, that it's my problem.” This same mother described physical problems that she attributed to her stress due to a car accident and the lack of respite help, “And also have to try to take care of her. It's not surprising I came up with, three weeks later, atrial fibrillation showed up. And it happened at two o' clock in the morning, and I called a girlfriend that I had known for 20 years, and she came over, and I'm having this heart incident, not knowing what to do.” This mother's compromised physical health due to being a caregiver was explained in a study by Godfrey and Warshaw (2009):

They (caregivers) may very well be neglecting their own care, which is going to adversely affect not only their own health, but also their ability to care for their family member. Under stress, symptoms and conditions that are common to women, namely depression, anxiety, and inadequate sleep, will be aggravated. (p. 1740)

The condition of isolation aggravates positive aspects of living such as health and well-being. A caregiver who is isolated due to lack of respite can develop adverse emotional and physical reactions.

Although I had expected the finding of isolation in this study to be a cause of stress, the extent and variety of isolation was an unexpected result. In regard to my personal experience I was unaware of how deeply isolation had affected my own life until reviewing and analyzing the interviews. I had identified loss of friendship within the first years of Andy's birth. For instance, I had joined a mothers group when my older son was born and had developed several friends over the next four years. When Andy was born I discontinued the group and focused on his developmental needs, forming relationships with his therapists but not with friends. Gradually, friends from the mother's group or

others I had known for years began to drop away. I barely noticed because at the time I was busy putting most of my focus on his therapies and education.

I became very involved with support groups to the extent of being a board member and newsletter editor. At the time I was married which gave me the respite to step out of the caregiver role in order to attend meetings. This involvement went on for over a decade and at the time I convinced myself that this was my friendship group. In retrospect, as a result of my findings in this study, I now realize that it was more about meetings and problem solving with others rather than developing friendships. The people in the group were more like coworkers that met for a specific purpose. One participant in this study, P4, who had a history of similar involvement in support groups and articulated my experience, “It's helpful that you have friends on the same boat that understand it. But do we have dinner parties with our friends with kids with autism, and let them bring their kids with autism? Not really.”

Her statement increased my awareness about the denial I experienced during years of substituting a support group for close friendships. It rings true after many years of meeting and sharing with others in the group I never associated outside of the group because the needs of our children required constant attention. We met as an extension to help our children but not to help ourselves in the process. For many years I realized my social life revolved around associating with others who had a child with a disability but I did not understand the void it left by ignoring the human need for close friendship.

Finding 2: Coping with challenging behaviors

All of the participants expressed stress about coping with challenging behaviors. Stress surrounding their child's behaviors included physical aggression toward the

mother or others, safety issues, and their child's unusual conduct. Many of the mothers had resorted to a variety of out-of-home placements that were a temporary solution. These included group homes, assisted living, or a psychiatric hospital inpatient unit. At the time of the interviews, two of the mothers had recently (within two months or less) placed their son in a group home and one mother had admitted her son (a few days before the interview) to a local hospital inpatient psychiatric unit. Another mother referred to out-of-home placement when her son was in elementary school and was currently seeking a group home.

Caregiving for a child with challenging behaviors creates increased difficulty and stress. According to Bourke-Taylor, Law, Howie, & Pallant (2009):

Mothers are known to be particularly stressed when their child behaves in ways that are difficult to manage. In these circumstances maternal health may be compromised and mothers therefore need more support. (p. 491)

It is critical to remember that the participants in this study cared for an older adolescent diagnosed with autism that could present with more severe behavioral issues than others diagnosed under the "umbrella" of Autism Spectrum Disorders. For example, Cappe, et al. (2011) found:

There are wide variations in symptom severity for both disorders, whereas some individuals with autism spectrum disorders are nonverbal and some have significant comorbid disorders, others are relatively autonomous and possess remarkable intellectual abilities (p.1279)

A study conducted by Matson and Rivet (2008) found that frequency of challenging behaviors increased with the severity of autistic symptoms. Among the behaviors that increased were self-injurious behavior, such as harm to self, aggression or

destruction, stereotypy such as repetition of vocalizations, body movements, or unusual object play, and disruptive behavior.

The mothers in this study often referenced their child's challenging behaviors as a major source of stress. A few of the mothers communicated examples of when they had been physically attacked by their children. This was particularly concerning as their child became older, bigger, and stronger. One mother P1 expressed "Yeah, because physically he was big enough that I couldn't do it anymore. Like, the biting, the kicking, the hitting." Another mother P5 described taking photos of the physical abuse she experienced for documentation to receive state services, "... he's aggressive. I took photos of all the bruising, black eyes, I took pictures of everything."

Aggression in 1,380 children and adolescents with Autism Spectrum Disorders was studied by Kanne and Mazurek (2011) who found that parents reported that 68% had displayed aggression to a caregiver and 49% had displayed aggression to non-caregivers. This study demonstrated that aggression toward caregivers is common. The mothers in my study referenced aggressive behavior toward themselves and other caregivers but did not refer to non-caregivers. Possibly there were incidents when their children were aggressive toward non-caregivers and the participants did not mention these during the interviews.

Two of the mothers had a history of admitting their son to a hospital inpatient psychiatric unit on several occasions during the past decade. This was due to uncontrollable aggressive behavior in the home. Johnson and Meyers (2007) identified several factors that lead to hospitalization of children with autism. These factors include aggression toward others, deliberate self-injurious behavior, temper tantrums, and rapidly

changing moods. One mother P1 articulated, “Yeah, and part of it was to protect me also because I'm the punching bag for my son. And the physical, it bothers me, but it doesn't ... I called the police on him last year, probably last year about this time actually, and he ended up in Children's.” The reader can only imagine the extreme stress experienced by a mother forced to make the painful decision to place her child in a psychiatric unit.

Challenging behaviors does not only include aggression. Often the mothers in this study cited unusual behaviors that were a source of stress. High frequency repetitive or ritualistic behaviors independently predicted challenging behavior (Oliver, Petty, Ruddick, & Bacarese-Hamilton, 2012). These behaviors can be demonstrated as unique for individuals with autism but often result in caregiver stress. For instance, ritualistic behavior was described by P4 “It's hard to take him out because he loves long stuff and when you take him shopping, he doesn't care about the clothes that you're going to buy, he likes taking out the tape, the side, the tape on the side of the shirt ... and puts them all together to make a long string”. Unusual behaviors often contributed to stress such as those communicated by P5, “He eats too fast and then he throws everything up on the table. And when we're at a restaurant, let me tell you, he gags and the table is full of his vomit that he's thrown up.” Safety was also a major concern for most of the mothers as described by P3 “It's just all I can think of is the causes of the stress without really, the constant worry where she is. Is she gonna be safe? Is she safe right now? “

My personal experience does not include physical aggression from my son but he has a wide range of unusual behaviors, which pose safety issues that are a major cause of stress. For example, he will do inappropriate things such as eat food still in the wrapper, play with toilet water, and is obsessed with dumping houseplants, water containers, or

anything containing liquid with no awareness of hot or cold (Appendix E). Coping with these challenging behaviors results in being on guard 24/7 at home and in public.

One mother communicated the stress of being on constant alert and on guard to her child's behaviors:

I remember reading awhile back that related or compared raising a child with autism to active duty military. Yep, I can definitely relate to that. I think, it's more like active, for like firefighters being on guard 24/7, you always have to be ready for whatever might happen. It's not just the stress of worrying about him every day but having to be ready at the time. And for whatever happens, I have to be ready. Up, awake, and willing and able to give my son everything that he needs (P6).

All of the mothers expressed stress in relationship to their child's behaviors. The time and energy necessary to cope with the behaviors dilute the potential for them to decrease their experience of isolation. In addition, the behaviors within the context of social norms further isolate the mothers from mainstream culture.

Finding 3: Frustration with the establishment

All of the participants expressed frustration with the establishment that created stress in their caregiver role. For these mothers, the establishment included schools, camps, state funded respite providers, medical practices, government-run programs, and non-profit organizations designed to service families with autism.

This finding may be surprising among readers that are well meaning and assume establishments such as agencies and schools would provide the necessary resources to help families with autism and thereby reduce the stress. However, all of the mothers often discovered that establishments designed to accommodate their child were lacking and even created additional stress. Many establishments for children with disabilities are not prepared to provide a support system that extends beyond their capacity and all the mothers in this study had an older adolescent with autism that presented with unique

behavioral challenges. For example, an older adolescent with aggression toward others or one who requires diapers needs a high ratio of assistants to child. Possibly the child could participate in activities provided by these entities if the parent were able to provide a 1:1 assistant, but this places an additional burden on the parent.

A study by Li-Ching, Harrington, Louie, Newschaffer, & Craig (2008) compared parents of children with autism to those with Attention Deficit Disorder and a group typical control group. Their results indicated the following:

Overall, families of children with autism reported a greater level of child caring burden, less frequent attendance of religious services, a greater likelihood to quit a job because of child care problems, more school days missed, more repeated grades, less participation in activities/events, and less involvement in community services, compared to families of children with ADD/ADHD or unaffected children. (p.1155)

Some mothers in my study reported reduced attendance at church and less involvement in community services. This was expressed by P5, "I took him to church until I got calls from the school that it was a problem. And I had to quit going to church." A problem with church attendance was expressed by P3 when she described needing to hold her grown daughter's hand for safety reasons, "Like I said this was in church. Everybody knew who she was, knew who I was, knew why I'm holding her hand to walk, but I still was embarrassed by it. So now it's still not that much accepted even. With people that's their first stare." Although P1 reported that church attendance was possible because her husband was able to stay home with their son, "Right now, I volunteer at our church. On Sunday morning, I make coffee. And it's my biggest freedom time because my husband is usually home on Sunday mornings." However, being able to attend a community service such as church was dependent on a reliable person to have personal time, willingness, and understanding of the situation. One mother solved the problem by

going at a different time from her husband in order to attend church and described her experience:

We'd always alternate and make shifts. When it was church, we'd always have shifts. Nobody knew us as a family because they'd never seen us all together. Nobody knew that my husband and I were married to each other because in church, I'd go to 8:30 and he'd go to 10:00. And when they'd see us together and, "Oh, so you're..." "Yeah." They never knew that. We'd been going to that church for ten years (P4).

The mothers in this study expressed their strategies to cope with their frustration with an establishment where they do not feel comfortable bringing their child. The experience of restrictions regarding community activities that most people normally attend created frustration and additional stress for the mothers. In addition, this has the potential to further increase stress among mothers who value family togetherness time as a priority.

The reasons for this finding of frustration with the establishment are complex. I can refer to several examples when this experience was created in my own life. First, my son makes unusual vocalizations and flaps his hands in public that could result in disturbing sounds for other people in the area. This discomfort is my own assumption and prevents me from taking him to many establishments where I feel his behavior could be disruptive. Possibly other people would be accepting but my reaction is to avoid stares and embarrassment, which was a response echoed by many of the mothers in the study. First, most of our culture is not ready to accept disruption in their personal space such as in church or movie theater and I feel responsible to recognize this reality. Second, there is additional stress associated with trying to control the behaviors while in public so it becomes easier to stay home and avoid the problem all together. However, with these

decisions comes a sense frustration because inclusion should not be limited and every person regardless of disability deserves to be mainstreamed and accepted into society.

Another reason for avoidance of including their child with autism was presented in a study by Li-Ching, et al. (2008):

The lesser participation in activities/ events and involvement in community service reported by families of children with autism may result from the challenges that accompany separating a child with autism from the home environment. This reasoning can also hold true for the reports of less frequent attendance of religious services and higher child care burden. (p. 1155)

This study called attention to an additional challenge often confronted by mothers caring for a child with autism. Often just the action of transitioning from one place or activity to another will result in their children exhibiting problem behaviors.

Most of the mothers communicated frustration with the establishment in regard to respite services. This finding may be surprising for the reader who assumes state provided access to respite providers should help alleviate the problem. However, participants in my study expressed that respite often created greater stress. This finding was explained by White and Hastings (2004):

Parents may experience stress if they perceive that the support resources available to them are inadequate to deal with the threat to their well being posed by the demands of caring for a child with an intellectual disability. Research studies have revealed unhelpful relationships with services. In particular, disagreements with services, such as those related to their apparent inability to provide an individualized service, may exacerbate parental stress. (p. 181)

Although all mothers in my study had access to state respite programs that could provide up to hundreds of hours per month for respite, they expressed stress surrounding locating a reliable provider, having a trained provider to meet their child's needs, or experiencing stress over the lack of privacy or having outsiders in their homes.

The problem with respite care was described in a study by Abelson and Geoffry (1999):

The need for respite care is commonly argued by presenting the most serious cases of families with children with severe disabilities. However, respite care options frequently exclude or inadequately serve those families with a child most at risk for institutionalization. (p. 96)

The difficulty with finding a reliable provider was expressed by P3, “When I try to hire for a shift, they don't want to work Great, I have 200 hours, but if I can't get anyone to work them.” Another mother P1 communicated “It's really hard finding respite. That's what I found, too, just finding anybody.” P5 had respite that created more stress from trying to return home before the shift was over and stated, “So there's stress from that. It was stressful just to hurry and do everything.”

My personal experience with respite is similar to the mothers whom I interviewed. I had respite hours for my son but often could not find a provider. This may be due to the extensive care demand for a child with autism resulting in a reduction in the number of people available to take on this task. Another explanation for the problem of finding a respite provider was communicated as follows:

So it's such a Catch-22, and I can't get anyone to do this much work for \$10 an hour. The agencies get paid 16, but the agencies aren't gonna share their load and they're gonna take their profit margin. It would make sense to say, "You're getting 16 an hour. I'm doing this much work for you, is there anything I can do so that you can pay the caregiver 13 out of that?" But they won't. (P3)

Another mother also expressed low pay as being a reason for the difficulty in finding a provider:

Now, he came back to me after two years, which is unusual, and I need to keep him. And right now, he's making \$11.50 an hour and somehow I have to figure out how to keep him. He's worth a hell of a lot more. (P6)

The problem of pay scale and training as part of the difficulty with finding providers was expressed:

And I guess that's the other piece that you get this money for rest of that and stuff, but you can't find a skilled person to work at that rate, and we're not training. So, we haven't been set up to train a person. (P1)

An additional establishment resource that normally could provide respite consisted of special needs camps or day programs. However, a few mothers found this option closed due to their child's extensive behavioral needs. This frustration was expressed by P5 "And for the most part, most of the services, if they have aggressive behavior then they won't take them." Another mother P6 explained it this way, "But no I can't take my child to the campfire summer camp. But they still get to carry the badge of taking kids with autism."

An exploration by Brookman, Boettcher, Klein, Openden, Koegel, & Koegel (2003) recognized this problem of camp inclusion:

The purpose of the camp program described in this article was to address the concerns raised by families in our community about the lack of inclusive activities for children with autism over the summer months. Based on our conversations with parents, we found that they often experience significant stress during the summer due to this lack of services and disruption to routines. (p.249)

Their attempt to solve this problem and design an inclusive program is discussed in the Conclusion section.

School was a source of frustration and stress for the majority of the mothers although in 1997 the Individuals with Disabilities Act (IDEA) was passed to insure parental involvement in the education of their child with disabilities. Unfortunately, the intention of this legal mandate is not always fulfilled, even to this day:

In spite of these factors, evidence suggests that the arena of interaction between parents and education professionals is often fragmented and poorly integrated. Confusion, frustration, tension, and less than optimal levels of cooperation often emerge, affecting the overall efficacy of service delivery and the eventual well-being of those being served. (Stoner, Bock, Thompson, Angell, Heyl, & Crowley (2005, p. 48)

The majority of the mothers in my study experienced frustration with the establishment of school as being adversarial rather than cooperative, displaying commitment to the welfare of their children. Attempts to have their children's needs accommodated often exacerbated their stress and resulted in a negative relationship with the schools. P1 felt their legal rights were not taken into consideration, "...and unless you want to have an attorney represent you, there really are no laws. And even if you want to have an attorney represent you and you win, there still are no laws that are enforced. P5 expressed it this way, "School is still sucky. I don't know that that'll change. Not in my lifetime." Another mother P2 struggled to meet her son's needs and articulated her experience "We can't do that because of a funding crunch. That was very frustrating to me." Additionally, P5 had frustration as teachers or programs change each year and stated, "The thing with each program is that you may get it for one school year, and then the next teacher doesn't do it, doesn't know how to do it, doesn't have any inkling of doing it, of carrying it on, or doing anything."

The conflict between caregivers and the school is often attributed to funding issues. The participants in my study had children with behavior challenges that often require additional resources. For instance, a one-on-one (1:1) assistant during school hours could provide additional behavior support and help with an individualized educational program. This is appealing to a mother because her child has a better chance to be successful. However, a 1:1 presents a high cost for the school district and therefore a reluctance to assign a person except in the most severe cases. Only those students who are documented for severe health or safety reasons obtain a 1:1 for the school year and

even this is very rare. Conflict develops on both sides and often results in an adversarial relationship between caregivers and school districts.

Inclusion was not specifically mentioned by the mothers in my study but can aggravate frustration with their child's school. Although the law states the *least restrictive environment* must be used for children with disabilities this may not be carried out, especially for those with serious behavior issues. Some school districts carry out this law by having *contained classrooms* in the building, which allows the special needs children to be present but not necessarily included with peers or school activities. I have observed these schools where often the *contained* rooms were far away from the main classrooms with few opportunities to be part of the mainstream.

One mother P1 was frustrated enough with the school to request mediation. Her experience resulted in additional stress and frustration, "We did mediation with the school district, and we spent 10 hours in the meeting. And my husband and I got out. We sat down in the car and we looked at each other, and it was like, 'What just happened? Did anything happen whatsoever?' And the mediation was so biased towards school district that it was just a waste of everyone's time." (P1)

My personal experience with frustration and the establishment of school is expressed in my reflection after interviewing P1. Hearing her struggles reminded me of the difficulty I had during my son's school years (Appendix E).

Relief from Stress

The question "What things are helpful to relieve the stress?" resulted in three major findings: professional behavior or support teams, support from others, and church

or spiritual connection. A few mothers reported stress relief from personal psychotherapy, problem solving, and activities.

Finding 4: Professional behavior support teams or state-funded resources

Four of the mothers in my study had access to professional behavior support teams or Washington State funded behavioral support programs and expressed experiencing relief from these resources.

When you talk about ways to lower stress, the things that have lowered stress for me was the year that we had the problems at elementary, which was my son in fifth grade. We had someone from Children's Home I believe it is, in Seattle. (P1)

The Seattle Children's Home program referenced by P1 collaborates with families and support communities to improve functioning of the child in relationship to emotional and behavioral problems. This outpatient service employs a family-centered approach to assist families to identify formal and informal supports to meet their needs. Their behavior support team provides 8-12 weeks of in home support which include 1) completing a Functional Behavior Assessment to help the family understand the meaning of their child's behavior 2) creating a Positive Behavior Support Plan with the family to work positively with the child 3) supporting the family through modeling strategies, providing feedback and guidance 4) consulting with schools and community providers 5) providing individual or family counseling 6) collaborating with case managers 7) participating as members of community based teams, and 8) providing the family with resources for community supports and ongoing services. The goal of this program is to "assist children in the successful transition to adulthood by providing the child and his or her family the necessary tools and skills to do so, building on the systems strengths and goals." (seattlechildrenshome.org)

This program was helpful to relieve the stress for P1, which may be due in part to her willingness to collaborate with the professional team. A study provided an examination of this process:

If professionals and parents can accept the challenge of taking on new roles and expectations by working creatively and cooperatively with each other and by establishing an atmosphere of mutual trust and respect, children with diverse needs and capabilities can benefit enormously (Wood, 1996, p. 173).

The necessity of collaboration between the family and professionals was studied by Marshall and Mirenda (2002) with results that indicated:

It is important to note that the benefits of family-centered positive behavior support are not achievable without the expenditure of considerable time and effort on the part of both the consultant and the family. The consultant and the family are required to enter into a reciprocal contract of commitment to both the collaborative process and the implementation of the behavior support plan that results from that collaboration (p. 216).

Another Washington State program similar to Children's Home Society was employed by P6 who expressed the following when asked about what helps relieve the stress, "The CHIP Waiver program ... but that the thoughtful approach that they take to figuring out what the behaviors mean, possible responses, interventions, and then, going back to check in to see how things are going."

Studies have shown that professional support and service provision can help families adapt to the demands of caring for a child with an intellectual disability (King, et al., 2009). The success of a professional behavior support program is described by Snell (1997) as having five phases:

Typically, collaborative behavior support planning requires professionals and family members to participate together in five successive phases that involve reciprocal information sharing, creative problem solving, and shared decision making. The five phases include: 1) building relationships between the family and the professionals 2) conducting a functional assessment of the behaviors of

concern 3) identifying natural routines as contexts for intervention 4) developing behavior support plans related to each of the routines, and 5) implementing and revising the support plans as needed. (p. 219)

One mother, P3, had access to a program that was similar to the previous two but differed in that it was defined as a *wraparound* program. This mother had a history of conflict with her daughter's teacher that had resulted in a communication breakdown. Professionals from a variety of programs were brought into the relationship to help problem solve and relieve some of the tension. In response to the question about what helps to relieve the stress she responded, "Actually, we really did accomplish a lot this year, but the teacher, if it haven't been for the WRAP program, and the people with WISE and with the King County who were able to give outside support."

The wraparound approach was developed to provide individualized and coordinated services for children with emotional behavior disorders to help the children and their families. A study by Bruns, Walrath, & Sheehan (2007) found that this approach differs from the previous two discussed:

They were less likely to have a master's degree, more likely to be employed by a mental health agency, and they reported substantial differences in how they were trained and supported to implement wraparound, compared to providers administering other treatments. Wraparound providers were also less likely to describe themselves as therapists, counselors, or clinical social workers and more likely to describe themselves as case managers. (p.164)

Another study found few differences in the implementation of wraparound services across community or school-based programs as a vehicle for application of the wraparound approach. In addition, they identified wraparound characteristics that differ slightly from the behavior programs discussed previously:

There are 10 key characteristics of the wraparound approach: (a) services and supports must be community-based; (b) services and supports should be

individualized, strength-based, and address the needs of children and families across multiple life domains; (c) the approach must be culturally competent and focus on the unique values, strengths, and social and racial make-up of the families; (d) families must be viewed as full and active partners in the approach; (e) the approach must be a team- driven process where the team works together to develop, implement, and evaluate the plan of care; (f) wraparound agencies must have access to flexible, non-categorized funding; (g) wraparound plans must include a balance of formal and informal supports; (h) communities, agencies, and teams must provide services on an unconditional basis; (i) treatment plans should be developed and implemented on an interagency basis; and (j) outcomes must be identified and measured for the child and family at every level of service. (Nordness, 2005, p. 309)

One of the differences emphasized in behavior programs as compared to wraparound is the use of a Functional Behavior Assessment that is conducted by a trained professional. However, the wraparound service is developed and implemented on an interagency basis, which would include a child's behavior support team and behavior plan. A team approach appears to provide the best potential for positive outcomes and relief from stress as the mothers in this study reported this type of intervention as being most helpful.

When my son was in elementary school the Seattle Children's Home professionals came to my house to develop a toileting plan for my son. He had years of teachers and therapists working on this problem but had made little progress. The people assigned to his case did all of the steps referenced in the paragraph about their procedures and goals. In my case, the behavior plan they provided was good but not effective for my son. Overall, even though we did not reach our goal, they helped reduce my stress through the support of people that cared, a place to call when problems arose, and a sense of hope for the future.

Another Washington State program that was mentioned by P5 as a source of stress relief was a recent out-of-home placement for her son, "It's only been two months,

but I can tell you how much better I feel, healthy-wise, everything, being able to come home and not have that is unbelievable. It's like, to some extent, a weight's been lifted off my shoulders.”

Although this mother currently experienced stress relief she also communicated dissatisfaction with the facility where her son resided. She indicated that he would probably return home in the near future because she wanted to find a more suitable placement.

Finding 5: Support from others

In response to the question about causes of stress, some mothers had expressed frustration with the establishment on the topic of formal support groups, family support, or organizations. A few of the mothers had described stress with organized support groups that were designed to help families with autism. Some frustration was attributed to not being able to attend the group due to lack of a caregiver. One mother P4 attended groups but found limited support outside of the group, “But do we have dinner parties with our friends with kids with autism, and let them bring their kids with autism? Not really.” A possible reason for reluctance to use established support groups was found in a study by Hall and Graff (2011), “Responses offered by parents in the current study suggest they have little or no desire to join social groups where they would be expected to discuss private family information with strangers” (p. 20).

However, the majority of mothers conveyed that informal support from others helped to relieve the stress that they described as informal rather than organizational. Severity of their children’s autism is a contributing factor for mother’s ability to use formal supports. A study by Benson (2006) found that informal parent support helped reduce stress and

depression while formal social support was not found to be effective for stress reduction. The use of social support could lead to reductions in stress, depression, and anxiety for mothers of children with autism as well as increased life satisfaction for both parents (Dunn, Burbine, Bowers, & Tantleff, 2001). Another study examined informal supports:

Parents' perception of the helpfulness of informal sources of support had the most consistent associations with parental well-being. Thus, it did not appear to be the number of these informal supports that was adaptive for parents in this sample. This finding could be specific to parents of adolescent children who may be more likely to have to rely on smaller informal support networks. (White & Hastings, 2004, p. 187)

When asked about what helps relieve the stress, P2 stated she found support from others at her son's school, 'I will say that some of the parents that ... you know, my son, some of the kids he went to school with, we had an informal support group.'

Connecting with other people who share similar circumstances appeared to be a viable avenue toward support from others. School, therapy waiting rooms, and autism events are some places that mothers can meet and develop support, 'I mean the people that you meet when the kids are newly diagnosed are the same people that would help you. So it's really important.' (P4)

Another mother P1 described relief from stress through support from others by having a person available to talk, 'That is the most valuable thing I have with regards to autism because I can call people, then talk to them one-on-one and get help from. Even if you don't know, you can still call them. And so that's really what my support group is.'

One mother P4 found that support from others was from her older, typical son who provided her with a sense of normalcy. She described this by stating, 'When my older son was in high school, I get stressed, I go watch his baseball game and I feel typical. Or I go out with him shopping and I feel typical.'

My personal experience is similar to the mothers interviewed through feeling supported by having a person to call or going places with my older son. Since my son requires a 1:1 assistant before I can go any place, the phone or Internet becomes especially important when needing support from others. The mothers I call are women I have met at places such as my son's school or in waiting rooms during therapy appointments. Also, I have met wonderful women when I was able to attend a formal support group but I would define my relationships during these meetings as more of a co-worker. However, some personal connections were made and I can contact them at any time and feel heard and understood.

Finding 6: Church or spiritual connection

Although a few mothers expressed stress from attempts to include their child in church activities or attend as a family, the majority of mothers communicated relief from stress through their church or spirituality. According to a national poll, religion/spirituality is one of the most important coping resources for caregivers; 73% reported that they pray to cope with the demands of caregiving (Caregiving in the U.S., 2004).

The definition of spirituality is problematic due to lifespan processes within different cultures and religions. To address this issue, Jernigan (2001) presented spirituality as "the individual and collective organization (centering of life) around dynamic patterns of meanings, values, and relationships that are trusted to make life worthwhile (or at least livable) and death meaningful" (p. 152).

Spirituality is further defined as "one's personal relation to the sacred or transcendent, a relation that informs other relationships and the meaning of ones' own

life” (Sinnott, 2002, p.199). However, Sinnott separated spirituality with religion by referring to religion as practices and beliefs related to a particular dogma system.

Despite this attempt at separation, many authors use the terms *spirituality* and *religion* interchangeably. One longitudinal study defined religiosity as the “importance of religion in the lives of the participants as reflected by their attendance at a place of worship or by the centrality of religion in their lives or both.” In this study the materials and procedure for coding religiosity were the same as for spirituality (Wink & Dillon, 2002, p. 85).

In the context of this study it is important to consider the differences between church attendance as a religious experience and one’s own sense of spirituality. This is because the mothers had expressed stress due to the difficulty surrounding inclusion of their child in an organized activity such as a church service. However, this study found that the mother’s belief or spirituality helped relieve the stress and was not necessarily reliant on attendance at a place of worship. One mother P2 expressed her faith as “expanded ... In those days, I did go to church. [laughter] That was a stress reliever. I still have a strong faith; it's just altered a little bit. Expanded, I should say.”

The expanded spiritual experience was explored in a study Leblanc, Driscoll, and Pearlin (2004):

Many such aspects of religious and spiritual identity lie beneath the relatively superficial measures of church attendance and frequency of prayer on which survey researchers typically rely. Put one way, religious coping may be most fully understood as the attempts of each individual to either conserve or transform what is of significance or value to him or her personally. (p. 418)

The participants in my study were women, which may account for the finding of spirituality being a stress relief. This was explored in Tisdell’s (2002) qualitative study

of women's conceptions about spirituality. The findings found themes of self-awareness development, interconnectedness of all things, and a relationship to a higher power that is related to how the individual constructs meaning in life. Although all participants were socialized to a specific religious tradition, only one remained active. It was found that spiritual development was a spiral practice of moving away and then reframing of spiritual attitudes from their origins. All of the participants described "spiritual experiences that facilitated healing as causes for ongoing development of true identity" (Tisdell, 2002, p.134).

One mother, P3, expressed her spirituality and faith as a source of stress relief, "To just say, Okay Lord, show me my warriors, show me my weapons, show me what I need to do. And it takes the focus away from the problem to what are the solutions the Lord is putting in front of me."

This mother had previously expressed increased stress through attempts at including her daughter in church activities. However, she continued to pursue her religious and spiritual convictions. A phenomenological study by Speraw (2006) explored caregivers of a child with disabilities and their faith:

The majority of participants in this research described serious disillusionment or crises of faith as a result of the behavior of their clergy and fellow congregants, yet none had completely abandoned faith or lost hope. Four figural themes stood apart: (1) parents and caregivers believed that their children had a spiritual connection to God, (2) for the most part, those connections were either devalued or completely unrecognized, (3) parents were left on their own to educate their children in their faith, and (4) participants' personal experiences of faith were dramatically impacted by the ways in which a religious community responded to their children. (p. 221)

Church attendance was a response from one mother when asked about what helps decrease the stress although some of the mothers expressed wanting to attend but were

unable unless someone was available to care for their children. Church provided not only spirituality but also an opportunity to connect with others. One mother, P4, solved the problem by taking turns with her husband while P1 was able to attend while her husband stayed home with their son, “And I know every Sunday morning, I can go and do this, and maybe have a few conversations.”

Personal involvement with church, religion, faith or spirituality was important to help the mothers relieve their stress. Regardless of the approach employed for this experience, it appears to be a viable resource for reduction of stress. This could be partially explained in a study by Wills (2009):

Spirituality as an inner resource produces awareness of one’s inner self and a sense of being part of a deeper spiritual dimension and community. Spirituality can help people to relate better with others. In summary, spiritual resources give a feeling of strength and they are a guide to find significance in life. (p. 52)

Rewards or Joy

Finding 7: Child’s accomplishments

The majority of mothers reported experiencing reward or joy in their child’s accomplishments. These often were expressed as something that could be interpreted as a small achievement but was of great importance to the mothers. Joy and reward were expressed by P6, “When my son is successful at something like, let’s see. It could be little, like he can swallow a pill now. He can swallow pills. Oh my God, that was huge.”

Although their children’s accomplishments may appear small to others, it becomes a large accomplishment for mothers caring for a child with autism. A portion of this reward may become part of the healing process as described in a survey by Marsh (1995) conducted with families caring for a child with disability:

The mothers in these families agree that, just as a growing child never stops changing, healing is not a single point they reach, but an ongoing process of development, with setbacks as well as successes. They clarify that recognizing the growth and focusing on the successes help to move the process of healing forward. (p. 125)

The process of caring for a child with autism involves a variety of therapy, advocacy, and the mothering that takes on the role of educator. The time and effort required may result in the main reward being the child's accomplishments, "That's a joy too when you know that they can do it, and other people are saying, "No-no," and then you see them do it and they prove it to everybody." (P3)

A study comparing children with disability to a group of non-disabled peers found that the mothers of children of disability tended to assume the role of educator (Dileys, Cartelli, & Doster, 1976). In addition they found, "Mothers of the children with learning disabilities dispensed more rewards and asked more questions. Each of the mothers recognized the importance of continued encouragement and support for their child's efforts lest he get discouraged and stop trying" (p. 375). Continued encouragement and support was summed up by P2, "So a lot of the reward that you feel after all these years is seeing the changes and the progress from all of your effort."

A survey conducted by Baskin and Fawcett (2006) found, "Mothers we surveyed show immense love for their children and hope for their progress. No matter what their areas of achievement, most women said parenting their children gave them much gratification." (p. 10). This was supported in a statement by P5, "The reward for me was my son ... that I've been a good mom and I've done the best job that I can."

The challenges of caring for a child with autism can be enormous but regardless of these challenges the majority of mothers in my study found reward and joy in their

child's accomplishments. This may be especially important to offset the extraordinary demands they cope with such as isolation, challenging behaviors, and frustration with the establishment. The reward and joy of experiencing their children's accomplishments may also contribute to their healing process.

Limitations

Examination of this study reveals certain limitations that are expected within a qualitative design of this nature. For example, researcher bias can influence the study overall despite attempts at *bracketing* and inclusion of a personal journal (Appendix E) to address this issue.

The demographics of the participants created a limitation in this study because all were residents of a large metropolitan area that offered a variety of resources. Some of these resources included support groups and therapies that may not be available in rural areas. Although this study found some mothers expressed frustration with formal supports mainly due to inability to attend, the majority of mothers found relief from stress from informal supports such as other people who were available to call and understood their problems. Mothers in rural areas may experience an entirely different reaction to questions about what causes or relieves the stress. Findings such as isolation and frustration with the establishment may be considerably different in a rural population.

Self-selection of the participants was limited to mothers who were willing to discuss their experience. There is the possibility that a mother who is extremely stressed may not be willing to take the time to participate in a study or decline due to potentially increasing stress through an interview process. On the other hand, mothers experiencing serious behavior challenges and stress related to their child may be more inclined to

discuss problems as an avenue to find relief by talking with another person as in a therapeutic setting.

Delimitations

The focus on an older adolescent that was in high school limits the research question response of mothers caring for this age group since there could be specific stressors that become more significant during older adolescence, which may account for findings such as isolation and coping with challenging behaviors. For example, physical development during this period may increase the dangers associated with behavior problems and the family may be more likely to be considering the upcoming transition to adulthood. Furthermore, availability of support from informal sources may begin to reduce during this period due to care demands of adolescent changes.

This was a gender-specific study since only female participants were interviewed. The research design excluded the male experience of raising a child with autism. A father raising a child with autism could contribute different results in regard to his experience about what causes stress or helps to relieve the stress. Findings from this population limited the study in regard to additional information that could be helpful to support men in their role as fathers raising a child with autism.

The use of an audio recorder could create challenges during an interview that vary with each individual's response to the instrument. Awareness of this effect is important for greater sensitivity about how it could factor into the final interpretation. This issue was raised by P2 when she stated in her email, "It's a bit odd for me being recorded and this may have 'blanked me out' at times, making me feel a bit disjointed." Although this was the only participant that commented about the use of the recorder, a possible solution

to this problem would be to place the recorder in a non-visible position, although the participant would still be aware of being recorded due to the need to be informed and signed consent for audio recording. Although my recorder is small and fairly unobtrusive it must be placed within a few feet of the person being recorded, which is generally on a nearby table. Possibly a disguised audio recorder could potentially reduce the visual effects that contribute to self-consciousness on the part of the interviewee.

Future Research

This study focused on caregiver stress experienced by mothers with older adolescents currently attending school. The caregiver role shifts considerably when the child graduates from school, which alters daily routines to the extent that a dependable school program is no longer available. Many families are caught off guard by the additional daily responsibility of caring for their child during the respite hours that the school previously provided. The life changes generated from this shift in responsibility could cause a different view of stress expressed by mothers that was not activated during this study. Furthermore, availability of support from informal sources may begin to change during this period. A study about the caregiver role during early childhood, elementary, or middle schools, or adulthood could result in different findings from this study and provide additional insight.

Research should explore the phenomenological experience of mothers caring for an adult with autism to yield information about the stress or relief from stress that develops after the child leaves school. For example, a study conducted by Grant and Whittell (2000) found that as children with autism grew older, their parents became more resigned to their role as caregiver and had increased confidence in coping ability. This

would provide guidance for program development, support systems, and clinicians working with this population. The provision of accommodating functional informal or formal supports can assist in development of caregiver enrichment (Phelps et al. 2009).

In 2012 the Centers for Disease Control and Prevention (CDC) released data that about 1 in 88 children are identified with an Autism Spectrum Disorder. This statistic indicates that within the next few decades there will be substantial need for supports and resources as these children with autism reach adulthood. Future research is necessary to identify these needs to best prepare for and provide a quality of life for the many decades they will experience as adults. These changes affect the individual with autism, their families and the community:

Transition to adulthood is a time of change for individuals with developmental disabilities and their families and therefore is likely to require new adjustments and increased use of coping strategies by parents as they must deal with concerns about their adult son or daughter's work, community living and socialization. (Glidden & Natcher, 2009, p. 1000)

This study, as well as the majority of studies about disability, tends to focus on the negative impacts such as stress, depression, resource demands, and caregiver burden. This may be due to western culture, which tends to view autism as a disease within the medical model rather than it being understood within the social model and neurodiversity model (Antonetta, 2007; Kapp, 2011). Most researchers assume that all areas of being a family member, caregiver, or individual with disability create an adverse environment. These studies often compare the impact of an individual with disability to individuals without disability to identify the deficits or problems within the family (Quittner, Opiari, Regoli, Jacobsen, & Eigen, 1992). However, there are many positive impacts that families experience as a direct result of the disability. Additional research is necessary to

identify the favorable effects that disability generates within the family framework. This information could provide a deeper understanding to clinicians and programs in regard to their delivery systems and decision-making process.

Cultural and ethnic identity must be addressed in future studies in regard to mothers caring for an older adolescent with autism. I was unable to include cultural and ethnic identification in relationship to mothers raising a child with autism. This is an important factor in regard to the lived experience and how individuals within a culture define stress. Awareness of cultural influences is necessary for development of appropriate interventions. For example, a study conducted by Kapp (2011) found that Navajo culture employs a wellness model called *Hozho* to better address the needs of individuals with autism. This view emphasizes harmony rather than western interventions through science and technology. A study conducted in the People's Republic of China found that parents of children with autism used planning as a coping strategy and experienced greater stress as compared to parents of children with other disabilities (Wang, Michaels, & Day, 2011). Chinese families reported discrimination against individuals with disabilities and school rejection of children with autism although parents continued to make sacrifices and decisions according to Chinese culture (McCabe, 2007). Although these studies provide valuable cultural insights, there is a paucity of research in this area.

This study identified some minor findings about the mother's experience of caring for an older adolescent with autism. These included exhaustion, marital problems and grief. Future studies should explore these domains to provide a greater understanding

about the lived experience of caregivers in relationship to caring for their child with autism.

Conclusion

The intention of this study was to explore the lived experience of mothers caring for an older adolescents diagnosed with autism. The conclusions from this study will be discussed in accordance with the research questions and the findings. The main findings about what causes the stress were experiencing isolation, coping with challenging behaviors, and feeling frustrated with the establishment. These three findings are not separate but interconnected in a holistic pattern wherein each stressor affects the other. For example, coping with challenging behavior limited the participants' abilities to interact with family, friends, and the community, which led to increased isolation. The experience of frustration with the establishment was connected to their child's challenging behaviors through the increased burden of retaining respite providers, frustration with their child's school in their attempts to obtain additional resources, and difficulty attending formal support group meetings due to a lack of having a person available to watch the child.

The question about what helps relieve the stress resulted in the participant's experience of professional behavior or support teams, support from others, and church or spiritual connection. These three findings are interconnected in that all reflect a form of support. The stress of experiencing isolation, coping with challenging behaviors, and feeling frustration with the establishment are mediated through these various supports. For example, engagement with a professional or support team often went beyond the

treatment of the child to include the family, school, and community in the intervention plan.

When the mothers in this study were questioned about their experience of reward or joy, their children's accomplishments were the main source. In most respects, the primary conclusion of this finding appears similar to mothers caring for a typically developing child. The role of motherhood contains widespread challenges that vary with each child and requires effort on the part of the mother to provide the best she can to enable her child's development.

Recommendations and Clinical Implications

The goal of this study was to identify what causes stress and what helps relieve the stress that will increase awareness to improve guidelines for services and intervention for mothers caring for an older adolescent diagnosed with autism. The outcome of this study was to 1) provide guidelines for clinicians working with mothers and families caring for a child with autism and 2) provide data to advocacy groups and organizations to guide them in their efforts in support and to lobby for resources. Following are recommendations to achieve these goals.

Exploration of the phenomenological experience of mothers raising a child with diagnosed autism offers significant clinical implications. The clinician must consider the family unit in regard to caring for a child with autism due to the unique requirements of this role. A better understanding of this role will contribute to the overall view of the client and provide important information as the clinician constructs the presenting problem, case formulation, and treatment plan.

One mother described a treatment plan with her psychotherapist that was helpful:

She was the only person that I've gone to that really helped me in more ways than one. Just the stuff she made me do, homework. She made me ... See a side of me that I hadn't really seen, or wasn't aware of. You know how sometimes you're so focused and my face would be... I have my mind is going, I'm sitting in the waiting area or walking. She did a thing, she goes, "Looking at you in the waiting area, I don't see a happy person." "You don't?" "You're not smiling, you're not da da da," whatever. "Oh, I don't look happy, do I?" It made me look at myself with what I'm telling everybody about me. Body language. Oh, that's why that's so important. Oh... So I just tuned out the world and was off in my own little thing... She made me write down things that... "What do you do for fun? What do you like to do?" After I wrote them down, "Fine, I want you to do at least two of these for next week before I see you." "What?" Oh. So I really had to work at finding time for me (P5).

Treatment plans for an individual who is a caregiver must include knowledge about the disability and how it impacts the family unit. According to Olkin (1999) "Families of children with disabilities will be the major source of influence on their child's development and self-acceptance, but their stance cannot be assumed to be positive or facilitative, and as such families are important targets for intervention." (p. 75).

Clinicians should be open to evaluate their own assumptions about the effects of disability on family systems. Olkin (1999) developed principles to guide the clinician while working with this population. These include a framework for therapy that understands the minority model of disability, family system theory, and is an expanded biopsychosocial model. Individuals with disability and their families are part of a bicultural model that lives both in the disability community as well as the greater nondisabled society. Adaptation of a therapeutic systemic model can help create a family inclusive plan that may lead to modify the diagnosis, case formulation, and treatment plan to better integrate disability issues.

The positive impact and strengths that caregivers develop should be included within their treatment plan. A study by Phelps, McCammon, Wuensch, & Golden, (2009) concluded:

It is essential for professionals to constantly monitor levels of stress and enrichment, paying equal attention to both when working with this population. These areas of enrichment lead to the possibility that professionals could build upon these strengths of caregivers when addressing the overwhelming stressors they encounter. Many caregivers become well informed about the disorder and learn how to navigate the system to provide for their children's needs. Although exhausting, these experiences can empower caregivers and make them feel that they have overcome great obstacles on behalf of their children. It is necessary to allow caregivers to share these enriching outcomes. (p. 139)

The role of the clinician in a therapeutic environment must consider the unique needs of a mother caring for a child with a disability such as autism. According to Olkin (1999):

The clinical role must go beyond the armchair, to help mobilize supports for continued education. This includes finding mentors; talking with resource teachers, counselors, and principals; encouraging and supporting the family; finding practical solutions (e.g., transportation, places to study, and access to assistive technology); and locating and utilizing community resources (e.g. church, support groups, and volunteers). The effects of low education combined with disability are especially strong for people of dual or triple minority status – women, people of color, and the elderly. (p. 23)

One mother, P3, was currently using a *wrap-around* service provided by Washington State included a facilitator to coordinate supports, services, and team meetings. The above quote indicates this role can also include a clinician to best serve the client. Although the logistics of the amount of time necessary to provide this extensive system of support can be overwhelming for a clinician it is important to be a team member. Clinicians are not in the role of social workers but it is vital to know the appropriate referrals in the community for their patients (Godfrey & Warshaw, 2009).

Enabling the client's self sufficiency begins with an awareness and understanding about her situation. For instance, the WRAP facilitator for P3 arranged a team meeting to include her daughter's teachers, therapists, doctor, family members, friends, respite providers, and anyone directly involved her care. Not everyone invited was able to attend the meeting but it is notable that P3 invited her personal psychologist who did attend and found it useful for a deeper insight in regard to her treatment plan.

Advocacy Groups and Organizations

It is essential to note that all of the mothers in my study had access to Washington State-funded resources. A few mothers expressed stress with using those resources such as obtaining respite providers but many mothers reported relief from stress through state provided services. Some of these consisted of WRAP programs, CHIP, Children's Home for behavioral intervention, a local children's hospital inpatient unit, and out-of-home placement to address severe conditions. The critical information about these Washington State-funded services is that the older adolescents in my study were enrolled about the mid 1990's when their parents were presented with a *waiver* option. The purpose of this option was to waive their child's rights to life in an institution in place of receiving similar supports, services, and funding in the community. The goal of the state was to eventually close the institutions and enable people with disabilities to live in their community. State-provided resources are often administered through the Department of Developmental Disabilities (DDD) and generally include a case manager, Medicaid in the form of medical care or Medicaid personal care (MPC) respite hours, behavior management services, and other state resources mentioned in my study.

A reference about the importance and help from these state resources was articulated by one mother:

There are so many different facets of the stress... Stress from 24/7, no relief, I have no family. My friends won't take him anymore because of his severe behaviors. I'm totally alone in caring for my son, for the most part. The only thing that I have is the DDD services that I do get. Ultimately that's it (P5).

Tragically, access to Washington State resources for individuals with disabilities has dramatically been reduced over the past few decades. According to data from Aging and Disability Services Administration as of October 2010, Washington State had 5,913 individuals with disabilities on a wait list to receive services. In addition, the wait list included 1,197 high school graduates class 2011 with disability seeking employment assistance and 10,217 seeking assistance for employment for disabled individuals age 21-62 that are not in a day program. The ARC of Washington State estimated that as of July 2011 there were a total of 16,852 individuals with disabilities that were on a wait list for services (arcwhatcom.org). This translates to awareness that the services the mothers in my study have available due to their child's waiver are not available to others in similar need. In 2011 a new waiver was introduced as Children's Intensive In-Home Behavior Support to reduce the number of children entering state institutional care. Currently, there are 893 individuals approved for this service but they have been placed on a wait list for that service (arcwhatcom.org).

It is important to include these statistics in this section about recommendations because my study found state-funded services helped to decrease mother's stress and lack of access to these services would be problematic. As P6 stated, "Waiting until your child completely disintegrates. Your family implodes, then you get the help. And by then, the remediation, all of those steps is double the amount of money. If you had just studied, if

all of us should be getting that.” This mother was commenting on the difficulty connected to receive state-funded services or supports until a serious event occurs that forces state involvement.

An increase in pay for respite providers could help resolve the problem of funding and keeping this necessary resource. In view of the mother’s needs it is recommended and vital that policymakers, advocacy groups, and individuals continue to lobby on the behalf of individuals with disabilities. The ARC recommends that people advocate at the legislative, regulatory, legal, and grassroots levels. This is recommended as part of a social justice responsibility that we all share as part of the human condition.

The ARC of King County Washington State advocates promotion of community-based services for all individuals with developmental disabilities. Their focus is on what is right for the individual and a fundamental belief that having a disability is a normal part of life and that this vision should be reflected in the values and actions of the state and nation.

Recommendations for non-profit organizations designed to help families with autism were offered by P6, “I’m sorry, where are all of our nonprofits that are supposed to be doing something to help us? Why are you not giving grants out to some of these speech clinics to subsidize them for the poor people that they’re taking care of?” She continued with an idea for a solution to provide services to children with autism, “if you really wanna be responsive, raise some money. Even Children’s Hospital has an uncompensated care. Do a guild just like Children’s.” Her solution to help relieve frustration with the establishment was to involve nonprofit groups in direct services for the children through providing resources such as grants, scholarships, or guilds.

This same mother recommended an increase in the number of people that advocate for resources, services, and the rights of individuals with disabilities. She observed that professionals benefit monetarily from clients in the autism community but rarely give back in the form of advocacy for that population. Her frustration was stated, “All of these consultants that have made big bank from our kids, I think, they owe us a lot because in the process of the creating of all of those waiting lists and all of that, we have given them more value than they actually are worth.” Her recommendation for this problem was, “What are you doing to give back? If not an actual donation, why are you not at the School District advocating for our kids? Why are you not over at OSPI demanding that school districts be more accountable and more transparent?” She has a valid point in that professionals and service providers for this population should give back, if not in the form of donations, at least in the form of advocacy.

Several of the recommendations in this section are suggestions from the mothers as a result of their lived experience. Their ideas provide valuable contributions toward intervention, support, or positive outcomes for them and their older adolescent with autism.

Implications of the present study provide recommendations for clinicians, advocacy groups, and organizations to enable strategies that will produce guidelines for services and intervention for mothers caring for an older adolescent diagnosed with autism. Improved quality of life could be accomplished through addressing their stress with a better understanding about their experience of isolation, coping with challenging behaviors, and frustration with the establishment. In addition, it is important to include a positive emphasis and encouragement of their children’s accomplishments.

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Appendix A

Application for Approval to Use Human Subjects

Antioch University Seattle

Application for Approval to Use Human Subjects/Participants

This application should be submitted, along with the Informed Consent Document, to the Chair of the Human Participants' Protection Committee.

Name of Researcher: Linda Mason

Phone Number:

Email Address: lmason@antioch.edu

Department: School of Applied Psychology, Counseling and Family Therapy

Advisor (if researcher is a student): Dr. Pat Linn

Date Proposal Submitted: 6/27/11

Title of Research Project: **STRESSES OF MOTHERS CARING FOR AN OLDER
ADOLESCENT DIAGNOSED WITH AUTISM: A PHENOMENOLOGICAL
EXPLORATION**

Funding Agency (if applicable): N/A

Project Purpose(s):

The goal of this study is to identify stressors that are unique for mothers who care for an older adolescent between ages 15 to 21 who is in high school and has a diagnosis of Autistic Disorder. Past studies provided information about caregiver stress but few addressed mothers and the related stress of caring for an older adolescent diagnosed with autism. This qualitative study will provide an opportunity for the mothers to have a "voice" in regard to their lived experience. The outcome of this study is to 1) provide guidelines for clinicians working with families caring for a child who is affected with autism 2) provide information to advocacy groups to support mothers and 3) provide information that may be useful in caregivers' efforts to lobby for resources.

Describe the proposed participants: (age, sex, race, or other special characteristics, such as students in a specific class, etc.)

Participants will be six to eight mothers of an older adolescent who has been diagnosed with Autistic Disorder. The child's diagnosis will have been made a minimum of three years prior to the interview and must be categorized according

to Diagnostic and Statistical Manual of Mental Disorders Fourth Edition, Text Revision (DSM-IV-TR) criteria. Mothers of children diagnosed with related disorders such as Asperger's Disorder, Rett's Disorder or Childhood Disintegrative Disorder will not participate in the research. The participants may vary by marital status, age, culture, number of children in the family, and ethnic identity.

Describe how the participants are to be selected:

Participants will be selected from the Greater Seattle area. Community resource centers specializing in autism will be contacted with information about this study along with a request to inform potential participants. Flyers, phone, and email will be used to describe and distribute study information. The centers to be included, but not limited to are: Families for Effective Autism, CARE Clinic, King County Parent Coalition for Developmental Disabilities, and Washington State Parent to Parent Support Groups. These groups will inform members and supply interested mothers with contact information.

Describe the proposed procedures in the project. Any proposed experimental activities that are included in evaluation, research, development, demonstration, instruction, study, treatments, debriefing, questionnaires, and similar projects must be described here. Copies of questionnaires, survey instruments, or tests should be attached (use additional pages if necessary).

The participants will be given an Informed Consent form (Appendix A) to sign prior to the interview.

On the day of the interview participants will complete a demographics questionnaire (Appendix B) and then one open-ended interview with one initial question and several probes (Appendix C).

Interviews will be audio-recorded. The audio recording will be transcribed verbatim for data analysis by the researcher and HIPPA compliant transcription service. Any identifying information will be omitted from the final report.

The participants may request a summary of the written report from the researcher.

The time and location of the interview will be determined by the participant or interviewer and coordinated by the interviewer. A criterion for the location is that privacy is maintained during the interview process.

At the end of each interview the mother will be offered a free therapy session with a trained psychologists upon request. Each participant will receive a free "Autism Guidebook for Washington State" supplied by Families for Effective Autism Treatment (FEAT of Washington) for her collaboration in the research.

The methodology for data analysis is a qualitative phenomenological approach. The audio recordings will be transcribed by the researcher and a HIPPA compliant transcription service. The analysis will consist of highlighting the significant statements of the participants' experiences. The researcher will then develop clusters of meaning from the significant statements and group them into themes, which will be used to write a description of the participants' experiences.

Will questionnaires, tests, or related research instruments not explained above be used?

Yes No *If yes, attach a copy to this application.*

Will electrical or mechanical devices (biofeedback, electroencephalogram, etc.) be used?

Yes No *If yes, attach a detailed description of the device(s) and their use(s).*

Will audio-visual devices be used?

Yes No *If yes, attach a detailed description of the device(s) and their use(s).*

A Sony digital voice recorder ICD-PX312 will be used to record participant interviews. Data will be encrypted and will be stored in two safety deposit boxes at Chase Bank Northgate Branch.

Current Risk (Acknowledge and describe any psychological, social, legal, economic or physical discomfort, stress or harm that might occur to research participants. How will it be held to an absolute minimum?):

- 1) There is a possibility that these interviews may result in the production of increased anxiety, emotional pain, additional stress, anger, or unwanted psychological harm. To guard against this process of unintended infliction of emotional pain or induction of stress, the participants will be presented with an Informed Consent form (Appendix B) that addresses the possibility of these issues. To further guard against psychological harm, the examiner is a skilled therapist with five years of experience in clinical psychology practice. In addition, the examiner has over twenty years of experience as facilitator and member of support groups for parents raising a child with disabilities.
- 2) Participants will be informed that they may drop out of the study or refuse to

answer questions at any time without consequence.

3) If the participant feels that her rights have been violated, the participant will be encouraged to file a complaint with the Antioch University Institutional Review Board.

Future Risk (How are all research participants protected from potentially harmful future use of the data collected in this project? Specify whether participation will be anonymous or confidential; and specify measures to ensure anonymity or confidentiality. If audio or video tapes are used, state specifically who will see them and the date they will be destroyed. All data must be maintained in a secured situation for at least one year after analysis and longer if the report is publicized.):

- 1) To guard against accidental or purposeful exposure of the participant to any violation of confidentiality, the researcher will list and remove any identifying information out of the final report. The interviews will be conducted in a private manner.
- 2) Participant responses are confidential and included as only quotes in the final report. Audio-recorded data will be reviewed by the researcher and a HIPPA compliant transcription service.
- 3) All research participants are protected from potentially harmful future use of the data collected in this project by the storage procedures initiated by the Antioch Center for Psychology (Psy.D.) Program standards. The standards meet the University's policies and procedures requirements about storage and destruction of gathered personal information.
- 4) The collected data will remain anonymous through an assigned number and other criteria that could violate confidentiality and anonymity. Each participant will be assigned a number rather than a name. After four years, the data will be destroyed in a professional manner: on the computer data.wav files it will be deleted, removed from the hard drive, erased from the digital recording device and recycling bin. If I am unable to personally destroy the data, a trusted individual such as a University Psychology faculty member or licensed psychologist will be appointed, be given access to the safety deposit box key, and follow instructions to destroy the data.

How do the benefits of the research outweigh the risks to human participants? This information should be outlined here.

- 1) This study provides an opportunity for mothers to have their experiences heard and the results may benefit other mothers caring for an older adolescent with autism to provide better understanding or insight.

- 2) Their experiences can inform advocates and support groups as to how to better serve mothers caring for an older adolescent with autism.
- 3) Clinicians and care providers can be better informed as to therapeutic delivery systems for this population through potentially identifying the unique needs and development of improvements in the delivery system.
- 4) This study may be constructive in the formation of additional studies to address questions or hypotheses surrounding the study findings.
- 5) The risk to the human participants is minimal, consisting of a one-hour open-ended interview that has the potential to provide greater understanding and resources for this population.
- 6) Open-ended questions will be presented to the participants to allow their definition of stress to emerge and allow for a better understanding of their shared experiences. A summary of the final report will be offered to all of the participants.

Are there any possible emergencies that might arise in utilization of human participants in this project?

Yes No *Details of these emergencies and provisions for dealing with same should be provided here.*

What provisions will you take for keeping research data private?

- 1) The researcher will arrange a time and place for the individual interviews with each participating volunteer. The participant will be given the opportunity to suggest a location that meets their comfort level with the criteria that it retains confidentiality during the interview process. Suggested locations are a private room at community center or public library that will be selected and secured for the interviews. The data will be placed in two secure and locked boxes with the researcher maintaining the privacy of the files.
- 2) Any and all data to be destroyed will be done as per Antioch's standards and policies and procedures.

Attach a copy of the informed consent document as it will be used. (see Appendix A)

STATEMENT OF AGREEMENT: I have acquainted myself with the policies and procedures regarding the use of human participants in research and related activities and will conduct this project in accordance with those requirements. Any changes in procedures will be cleared through the Committee.

Signature of Principal Investigator(s) Linda Mason Date 6/27/11

For Research Conducted by Students: This research involving human participants, if approved, will be under my supervision. I have read and approved this proposal.

Faculty Advisor: _____

Advisor Signature _____ Date: _____

PLEASE SUBMIT AN ELECTRONIC COPY OF THIS INFORMATION TO:
HSRC@antiochseattle.edu. Please also submit one hard copy to the Academic Dean's office.

By completing and submitting this form I certify that:

- The information provided in this application form is correct.
- I will notify my Advisor/Committee Chairperson and the Chairperson of the Review Committee in the event of any substantive modification in the proposal, including, but not limited to changes in cooperating investigators and agencies, as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study will be promptly reported.
- Any significant new findings which develop during the course of this study which may affect the risks and benefits to participation will be reported in writing to my advisor/Committee Chairperson, the Chairperson of the Review Committee, and to the participants.
- The research may not and will not be initiated until final written approval is granted.

- This research, once approved, is subject to continuing review and approval by the Advisor/Committee Chair and Chairperson of the Review Committee. The Principal Investigator will maintain complete and accurate records of this research.

If these conditions are not met, approval of this research could be suspended.

Linda Mason	0320768
Name of Principal Investigator:	Student ID #

lmason@antioch.edu	6/20/11
Email Address	Date

As Advisor/Committee Chair, I assume responsibility for ensuring that the student complies with University and federal regulations regarding the use of human participants in research. I acknowledge that this research is in keeping with the standards set by the University and assure that the Principal Investigator has met all the requirements for review and approval of this research.

Pat Linn	
Name of Advisor/Committee Chair	Date
plinn@antioch.edu	
Email Address	

Appendix B

Participant Informed Consent Form

ANTIOCH UNIVERSITY SEATTLE

Consent/Assent Form

Stresses of Mothers Caring for an Older Adolescent Diagnosed with Autism: A Phenomenological Exploration

Researcher

Linda Mason, M.Ed.
Clinical Psychology Doctoral Student
Antioch University Seattle
24-Hour Phone xxx-xxx

Researchers Statement

The Antioch University Seattle Psy.D. Program supports the practice of protection for human subjects participating in research and related activities. The following information is provided so that you can decide whether you wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time, and that if you do withdraw from the study, you will not be subjected to reprimand or any other form of reproach.

Procedure

You will be participating in an approximately one-hour interview. This interview will be conducted at a location decided by you or a private place located by the interviewer. This location should insure your privacy during the interview process. You will be asked a variety of open-ended questions regarding your experience of being mother who cares for an older adolescent with diagnosed autism. Questions include “Please describe the stress you experience while caring for your child”; “What things are helpful to relieve that stress?” and “What are the rewards or joys you experience while raising your child?” The interview will be audio taped to allow for transcription. The researcher and a HIPPA compliant transcription service will have access to the audiotapes and transcripts. The researcher will perform all of the interviews.

Risk

Discussion about caring for an older adolescent with autism may increase awareness of stress and parenting concerns. Some open-ended questions may cause you to think about things that are uncomfortable. You may inform the researcher at any time about concerns or topics that are uncomfortable. Every effort will be made to reduce or eliminate any questions that may cause discomfort. You have the right to end the interview at any time. Assigning you a numbered code for reference purposes and removal of identifying information will protect your privacy.

You will be offered the opportunity for a therapy session at Antioch University Counseling Center with a psychologist at your request. You will be given a complementary resource book, "Autism Guidebook for Washington State supplied by Families for Effective Autism of Washington (FEAT) that contains local and national resources about autism for future reference.

Confidentiality will be protected in all reports by deleting any identifying information. All research documents and/or audio materials will be destroyed following completion of the study. Consent forms will be kept in two locked safety deposit boxes for seven years and copies will be made available to you upon request. You will be given a copy of this Consent form.

Benefits of Research

The goal of this research is to identify causes of stress and ways to relieve stress that are common among mothers caring for an older adolescent diagnosed with autism. Participants may receive a summary of the final report upon request. The results from this study will provide advocates with information to identify needed services. The identification of stressors and ways to reduce it will educate clinicians and enable them to provide informed services.

Researcher

Signature _____
Linda Mason M.Ed Clinical Psychology Doctoral Student

Date _____

Participant's Statement

I have read the above statement and have been fully advised of the procedures to be used in this study. I have been given sufficient opportunity to ask any questions I had concerning the procedures and possible risks involved. I understand the risks involved and assume them voluntarily. I likewise understand that I can withdraw from the study at any time without being subject to reproach. I may also ask for a summary of the results of this study. I understand that should I have additional questions I may contact Ms. Mason at XXXX. If I am not satisfied with the manner in which this study is being conducted I may contact the Human Subjects Committee, which is concerned with the protection of volunteers in research projects. The Human Subjects Committee can be reached at Antioch University Seattle, 2326 Sixth Ave. Seattle, WA, 206-441-5352.

Signature _____ Date _____
 Subject and/or Authorized Representative

Interview Audio Recordings

I agree to have my interview tape recorded _____ Yes _____ No

Signature _____ Date _____
 Subject and/or Authorized Representative

ANTIOCH UNIVERSITY SEATTLE CONSENT FORM

I, (print name) _____, grant permission to Linda Mason (investigator's name) and to Antioch University Seattle the use of the audio recordings of me for purposes of collecting data for the investigators' research project. I agree that my name and identity:

- may be revealed as an alias (made-up name or number)
- may **not be** revealed

in descriptive text or commentary in connection with the recordings. I understand that no compensation will be given now or in the future for use of the audio recordings and they shall remain the property of the investigator. The tapes will be kept for 4 years in a locked vault and destroyed thereafter.

 Signature of participant

Date _____

 Telephone number

Appendix C

Participant Demographic Information

Demographic Questionnaire

ID# _____

Child Information

Child's Age: _____

Sex (please circle one): Female Male

Ethnic/racial identity: _____

When was your child diagnosed with autism? _____

What is your child's main mode of communication? Please circle one:

Total verbal Some verbal with gesture Sign language Visual pictures

Electronic device Gesture only Other

Parent Information

With what socioeconomic class do you identify? Please circle one:

Lower Middle Upper

What is your highest level of education? Please circle one:

High School degree Community College degree (AA) College degree (BA/BS)

Master degree Doctorate degree

Are you currently married, single, separated, or divorced? Please circle one.

Do you work full time, part time, or stay at home? Please circle one

Do you have other children? Yes No

If Yes: How many _____ Ages _____ Living at home? #Yes ___ #No ___

Appendix D

Semi-Structured Interview Questions

The initial research questions:

“Please describe the stress you experience while caring for your child.”

“What things are helpful to relieve the stress?”

“What are the rewards or joys you experience while raising your child?”

Follow-up or probe questions:

“ Can you give me an example?”

“Do I have this/ understand this right?”

“Please tell me more.”

Open-ended questions will be presented to participants to allow their definition of stress to emerge and extrapolate a better understanding of their shared experiences.

Appendix E

Journal of Reflection

The inclusion of a journal in this study is important for several reasons. It will enable the reader to have a better understanding about my personal views, the lens through which I make interpretations, and how these views could affect the final research findings.

The history of caregiver stress that I experienced while caring for my son with autism is part of the lens through which I view other people's experiences. A positive impact of this history is that I have an expanded understanding about the stress involved as a caregiver for a child with autism. This enabled a rapport and increased comprehension with the mothers I interviewed. On the negative side, my personal experience could pre-dispose me to evaluate the participant's experience with a greater emphasis on the stress that we have in common. Awareness about these factors is critical to assist in *bracketing* for this qualitative study. Therefore a journal can contribute to increased awareness on my part and on the part of the reader.

A qualitative study requires self-reflection in order to contribute to the validation of the work. According to Creswell (2007),

Clarifying researcher bias from the onset of the study is important so that the reader understands the researcher's position and any biases or assumptions that impact the inquiry. In this clarification, the researcher comments on past experiences, biases, prejudices, and orientations that have likely shaped the interpretation and approach to the study. (p. 208)

The inclusion of a journal will provide an avenue to address the issue of researcher bias that Creswell considers an important element for the standards of validation and evaluation.

This journal will include my personal history about raising a child with autism and my experience of the stress, relief from stress, and my rewards and joys of raising my son. It will also include comments about my experience with the participants as I listen to their responses during the interview about caregiver stress.

Qualitative research is a form of inquiry in which researchers make an interpretation of what they see, hear, and understand. The researchers' interpretations cannot be separated from their own background, history, context, and prior understandings. After a research report is issued, the readers make an interpretation as well as the participants, offering yet other interpretations of the study. With the readers, the participants, and the researcher all making interpretations, we can see how multiple views of the problem can emerge. (Creswell, 2007, p. 39)

Inclusion of my responses and thoughts about the interviews and participants is an attempt to provide greater insight into the issues that Creswell considers important in a qualitative research design. Although every effort was made to *bracket* my interpretations there is an inevitable link that occurs with the participants when I hear shared experiences.

Personal Experiences of the Researcher

My son's caregiver requirements rate at the higher end on the spectrum for individuals with disability. I first gained this knowledge as a result of completing the Department of Developmental Disabilities (DDD) questionnaire that rated my son as among the highest level of need in most categories with the exception of the "medically fragile" categories. The first time a DDD case manager gave me this questionnaire was

when my son was six years old. I answered the extensive questions honestly and to the best of my ability. Today, I still remember the shock I felt after the case manager left as I began to reflect on my answers and the significant amount of care needs that I provided every day. It was a life style that had increased over the years without my gaining a perspective and because I took each day in stride I was unaware of the impact. My interview with the case manager was a “wake up call” as I began to realize the full extent of my role as caregiver.

The daily care needs I experienced when he was six years old changed little during my future annual reviews with DDD questionnaires. The majority of their criteria for level of care revolved around health and safety needs. I have listed some of them in the following narrative.

A major source of stress revolves around my son’s behavior problems either in private or public. Some examples of the behavioral issues that create stress at home include his need to be constantly supervised or he will do inappropriate things such as eat food still in the wrapper. In the past he has eaten foil wrapped candy and paper wrapped ice cream bars. He requires someone to unwrap his food and total food preparation although he is capable of feeding himself. He cannot get himself a glass of water or make a request if thirsty because he is non-verbal and rarely uses his alternative communication device.

The bathroom must be continually monitored since he will play with toilet water. He will turn on tub/shower water inappropriately and will get in while wearing clothes with no awareness of hot or cold adjustments. He has flooded bathrooms when not monitored.

He is obsessed with dumping houseplants, water containers, or anything containing liquid with no awareness of hot or cold. At home every glass of water or cup of coffee must be placed out of his reach or carefully monitored. For instance, I cannot go outside for more than a minute because of his behaviors.

Safety is a major issue since he will wander outside if a door is unlatched and prefers to walk in the middle of the street. He has no awareness of traffic or street safety.

In addition to behavioral problems he has medical issues that require 24-hour care due to nighttime wandering, plus he has diagnosed sleep apnea and requires nighttime positioning due to sleep disturbances.

In 2010 he was diagnosed with seizures as a result of having a grand mal seizure during the night. This medical condition is very common among individuals with autism.

He is incontinent with a toileting requirement of total assistance with Depends. He is on a bathroom schedule but occasionally will soak through his Depends which in turn will soak whatever he is sitting upon at the time. It requires a complete change of clothing, sometimes even shoes and socks.

The behavioral issues extend to when I take him in public places. Stress develops around safety concerns when walking near traffic, in a restaurant where he could dump a stranger's or his own drink, and the embarrassment of being the mother of a grown male and needing to take him in the women's restroom.

The above narrative describes some examples of my son's health and safety issues but does not include stress experienced because of school and inclusion problems. An important concern for me was to find special education teachers that were committed to seeing their student's potential abilities and working to develop individual plans to

maximize those abilities. It was a struggle to achieve this goal during his school years with the exception of his early pre-school years and second through sixth grade. Middle school and high school were a constant source of stress with struggles to keep him out a placement that would be isolating and labeled for “multiple handicapped” students. Although the law states that schools must provide “the least restrictive environment” for special education students this is not the general reality. My experience was that often these students were placed in contained classrooms, sometimes in a portable building or rooms isolated from the rest of the school with few opportunities for inclusion with other students. Some of my experience with school stress is additionally described in this journal entry with my reactions during the interview with P1.

A treatment plan in the form of therapies is critical for any child with disability. A diagnosis of autism opens a floodgate of therapies that can vary from beneficial to a waste of time and money. I gave my son private speech and physical therapy in addition to those provided by his school. When he was diagnosed with autism I made an informed decision to provide him with an Applied Behavioral Analysis (ABA) home program. This required about thirty hours a week of structured intervention by a team of several trained assistants. In addition, a professional ABA program manager was employed to monitor and develop the program according to his progress. The ABA approach was difficult to implement but resulted in some positive changes. It was not a miracle cure but rather enabled him to develop to the best of his abilities. Consequently, I continued the intensive in-home ABA for about two years and still use some of the strategies for school and in the community. The difficult task of making decisions about which therapy to choose creates a great deal of stress. Further discussion about my challenges with this

issue is included in my reflection during the interview with Participant 2 when she raised the problem of stress as related to therapy.

The above list contains just some examples of my daily experience of stress while caring for my son. As a result I recognize that stress creates a variety of emotional responses similar to grief that Kubler-Ross (1969) describes as denial, isolation, anger, bargaining, depression, acceptance and hope. Personally, these are not stages that I pass through in a linear way but rather tend to be circular and re-occur depending on the situation during the moment.

It is important to emphasize the rewards of raising my son with autism. Many joyful and rewarding experiences help to relieve the stress. For instance, the first time he made eye contact, pointed at a picture in a book, or learned to fasten his own seat belt at age 10 years. These are things most mothers expect with a normally developing child when major milestones are reached on time but contained the same amazement and joy for me when I see some of these months or even years after the normal time line.

Over the years my experience of acceptance has evolved in a positive way to include not only my son's disability but also an acceptance of life's challenges. He paved the way for my world-view to expand and be more inclusive of differences.

In 2005 the Science of Mind magazine made a request for submissions on the topic of "Disguised Blessings" for their October issue. I immediately thought about the relationship with my Andy and how often I considered him a blessing in disguise. I wrote about my experience and it was accepted for publication. My written submission that appeared in the magazine is included here as an example of acceptance in the role of caregiver:

Standing in the hospital shower, my tears mixed with the water streaming down my face; I had just been told that my newborn son had Down syndrome. I was filled with grief over not having a perfect child and how that was going to alter my future; my goal to travel to India to find my guru and enlightenment evaporated. The future would have to be about finding therapists and special programs for little Andy.

The years passed, and at a slower pace, Andy learned the same skills as other children. But, by age five, despite years of therapy, Andy couldn't talk – he had autism. Fortunately, he had a team of therapists and teachers to help him develop to the best of his abilities. While they taught him to turn the pages of a book, he taught me about life.

For Andy, water in a container had to be spilled, running water splashed, and puddles redistributed. Before I realized the hazards of his water obsession, I placed flowers on a table in a favorite vase. Moments later a crash sent me running to find the vase shattered on the floor, flowers strewn about, and water running through it all. “You broke my favorite vase,” I cried. In the midst of my distress, I looked up at him and froze.

Free of malice, his face radiated pure happiness while watching the water flow through the broken glass. His reality about the situation was one of appreciation. In that moment I saw the vase being transformed into a different object of beauty. I felt the existence of transformation as a new awareness of no death, only change, and experienced the fullness of being completely in the moment. I felt God's presence and a profound sense of peace. Andy is sixteen now and does not talk, but his pure spirit continues to open other lines of communication. The day he was born I didn't realize I had received a blessing in disguise- Andy was my guru. (Mason, 2005, pp.106-107)

Hope remains a strong influence to help relieve the stress while caring for Andy and the challenges of autism. In difficult moments hope remains under the surface of awareness but re-appears when I witness his progress, no matter how small. It is hope that sustains me and led me into the role of advocacy. It promotes a strength that continues to grow, as I understand the future can hold positive potential for my son's well-being and other individuals with disability.

In addition, I find stress relief in support groups that address the life challenges and rewards of caring for a child with autism. It is an opportunity for connection and community. Support groups help me through knowing that others have similar

experiences with suggestions or advice about how they cope with issues that arise. They create an environment of empowerment that is possible with other people with a common bond. It is similar to being a member of a club, although this is not a club most people would choose but we join together with a shared interest. Support groups enabled me to benefit both as a giver and receiver and to experience a greater connection with others. Although I benefited in many ways from support groups for autism it was not the same as having close friendships. This was an insight I gained as a result of my study and it is referred to in the Discussion section.

The following paragraphs contain examples of my observations during the interviews, which include my emotional responses, and reactions toward each participant. In addition, there are some stories shared by the mothers that provide greater appreciation about their life. These are presented for deeper insight into the development of my findings and the lived experience of mothers raising an older adolescent with autism.

Participant 1

The first participant requested that we conduct the interview at her home in the Seattle area. When I arrived she greeted me with a warm smile and enthusiasm about being part of my research.

Her home was very inviting with a comfortable sofa facing the fireplace, a formal dining room and sparkling kitchen. Everything appeared organized and designed to project a welcome feeling for all that entered. I reflected on this first impression because of the pleasant sense of normalcy I experienced within the environment. It reminded me that autism can be found in all types of homes and does not distinguish among those families affected.

We sat at her kitchen table to begin the interview. She appeared relaxed and smiled occasionally as I explained my research and reviewed the paperwork. We exchanged some pleasant conversation and then I began the interview.

When I asked my first question, “Please describe the stress you experience while caring for your child?” she immediately became teary-eyed and reached for a tissue. I was touched at a deep level by the emotions a mother can feel when her child has a disability such as autism.

She began to talk about the difficulty in dealing with her son’s school and the challenges of getting him access to an education that would meet his unique needs. She expressed years of frustration about the school system where her son was placed in unsatisfactory classrooms and refused to provide a 1:1 assistant that would enable her son to work at his full potential.

Her distress about school challenges resonated with me and brought up personal memories that were painful. The stress I experienced during my son’s school years ranged on a scale of 1 to 10 with most in the 5 to 7 range. His first grade situation was so stressful it is rated 10 because he was placed in a “contained” classroom that was isolated from the rest of the school. Several of the other students in his classroom had severe behavioral problems such as banging or throwing objects across the room. My son had never demonstrated any aggression but after a few weeks in the class he began to hit his head and throw things. It was frightening to see because my son had never exhibited these behaviors in the past. When I met with the teacher to find a solution I was told there was nothing they could do to change the program such as placing my son in another classroom or have an aide remove him when there were undesirable behaviors to witness.

I met with the school principal who had the same response. Finally I went to the Director of Special Education for the school district and was told, “The law states we must give your son an appropriate education – not the best.” His response led me to seek help from Washington State Office of Superintendent of Public Instruction (OSPI) for mediation but that also resulted in a closed door. In the meantime, my son’s behavior was increasingly alarming as he began to refuse to get on the school bus, threw objects more frequently, and hit his head with greater force.

Consequently, I made a difficult decision that is not uncommon in the world of disability, which is to move to another school district known for its ability to provide better services. Moving creates another type of stress that compounds the stress of caring for a child with autism. I have met parents that moved to other states and across the country leaving jobs, family, and friends behind in order to provide the best opportunities for their child with autism.

My son’s new district was an improvement and he had productive elementary school years with a 1:1 assistant and teachers that worked to develop the best of his abilities. These years were a respite from school stress that was generally high on my list of concerns.

Unfortunately, the relief was short lived when he entered middle school and the newly appointed special education manager insisted he should attend a K through 8 school that had a *contained* classroom for children that she referred to as “multiple handicapped” for students that had more profound disabilities. It was also where the most severe behavioral students were sent.

I went to visit the classroom and it was worse than my expectations. The students with disabilities were in *contained* rooms entirely disconnected from the rest of the school. Their only contact with regular students was at lunch and even that was shortened since they arrived early to get their lunch at a designated table for their group. The only inclusion I heard about was from the teacher who enthusiastically told me, “We have one student who goes to the high school every day for a drama class.” In other words, the others stay in the *contained* room all day without inclusion. The most dramatic moment was when I saw a six foot tall, young man about 17 years old walking down the hall after lunch. He towered over all the other students and appeared very unhappy.

This visit affected me in two ways. One was that my son would not be attending that school. The second was that something must be done to rectify the situation, which I began to do by calling the district’s Director of Special Education. I told her that having high school students in a school with children in kindergarten was “inappropriate” to use the State’s legal definition. I described the student I saw and told her he belonged in a regular high school with other students his age. I also talked with school principals, teachers, and anyone of influence that was receptive to the problem.

The following school year a new program for students with profound or severe disabilities was implemented at a nearby high school. I’ll never know if it was due to my efforts at being a “squeaky wheel” or other parents willing to tackle the problem. My happiest moment was when I went to the new high school and once again saw the tall young man from the other school, walking beside other students his size, and he had a big smile on his face.

However, I still had a struggle ahead to have my son placed in an appropriate middle school with a life skills program. I was told that he was too low functioning and should go to the school I had toured and found inappropriate. After weeks of debate I convinced the district to give him a chance in a school that had a life skills class and opportunities for inclusion. As a consequence, over the next few years, he did very well and was appreciated by staff and students.

High school was another hurdle with the familiar ups and downs to get my son in a class that would enable his best abilities and allow opportunities for inclusion. The school experience was a roller coaster of stress sometimes in a cruise mode and other times full-blown frustration.

This example from my personal experience of stress in relationship to school is necessary to write in this journal for several reasons. One is to explain my response and feelings while interviewing Participant 1 and hearing her tearful account about the difficulty she has struggled with for years. A second reason for my journal is to provide insight about my responses in regard to past school experiences that were activated during the interview and how they could affect the *bracketing* process that is important for a qualitative study. The third reason is for the reader to have a greater insight about the intense stress that a common place such as school can generate for a mother who is already coping with the stresses of caring for her child's autism.

Participant 1 was tearful during the entire one-hour interview. Talking about her son had opened the floodgate of emotion. She had spent years trying to give her son the best opportunities with positive outcomes but was extremely challenged by his aggressive behaviors. When her son was about seven years old his aggression became unbearable,

which forced her family to make the tough decision to put him in out-of-home placement. He remained there for several months until his family felt ready to resume having him live in their home.

Although her son was young when the decision was made to have return to live at home the aggression continued as the family attempted to find ways to adjust and cope. For instance, P1 described wearing a down jacket and helmet when she went into his room because “if he bit her it would lessen the impact.” Talking about these attacks appeared very difficult for her but she was candid and open about trying to manage his behaviors.

She stated that the most positive help came in the form of support groups where she met other parents that understood her experience because they were having similar experiences. Her source of support was not from people during group meetings but from the individuals she met there and contacted later. Also, she was recently assigned a behavioral team that worked to design a program at home to reduce her son’s negative behaviors. She appeared hopeful that this team could provide guidance and support to relieve some stress.

I understand that behavioral issues can be among the stresses that occur while raising a child with autism. During this part of the interview I felt relief that my son never exhibited any aggression outside of the throwing incidents in first grade. His behavioral issues such as dumping containers or obsession with water seemed mild in comparison.

When I asked her, “What are the rewards or joy you experience while raising your son?” she appeared challenged to answer. Her first response was that she loved him very

much but it appeared a strain for her to express concrete examples of rewards or joy since the current behavioral difficulties overshadowed their daily life.

I find it important to remember that each interview takes place at a particular time and place in each mother's life and their responses are a reflection of that reality. An interview conducted during the time that her son was in out-of-home placement or when his aggression was reduced could result in the mother having other statements and reactions to my interview.

Participant 2

The second participant's 19-year-old son resided in out-of-home placement as of two months prior to this interview. He continued to attend the same high school as he did when he still lived in his parent's home. This mother expressed both relief and stress about this new living arrangement. She expressed relief as being able to "live her own life" and improve the relationship in her marriage, which had been neglected for years due to her son's care needs. She was finally able to begin therapy to address her personal emotional needs that were put on hold during many years of her caregiver role. Although her son's new living arrangement offered positive things, she expressed a mixture of relief at having personal time but problems adjusting to the reality of her son not living at home.

Most of her stress about being a caregiver revolved around anxiety to provide her son with every opportunity to maximize his potential. She was active in finding therapies and activities that could deliver positive results. This became a "full time job" and she expressed frustration about making choices between therapies because of financial

constraints. Decisions were difficult because there was no sure way to know if one therapy over another would produce the best outcome.

Her experience of stress about therapies activated my emotional response about years of upsetting memories in regard to therapies. I recalled the difficult decisions of being forced to choose one therapy over another due to financial realities. Over the years statements I have heard from parents were, “treatment for autism is expensive” and “it’s not covered by insurance.” There are some companies that offer speech or physical therapy but draw the line with behavioral therapies such as Applied Behavioral Analysis (ABA). Ironically, behavioral intervention is what many families need to provide a good treatment plan for their child with autism. I was able to get speech therapy for my son but was on my own with ABA. It was very expensive and time intensive but appeared to offer the best intervention when he was first diagnosed. In retrospect it helped by teaching him to imitate, respond to requests, point to objects, and follow directions. However, he remained non-verbal and today I view ABA as maximizing his innate abilities but not a miracle cure that would make him normal. I also tried speech therapy, physical therapy, sensory intervention therapy, vision therapy, auditory training therapy, music therapy, and several others. Today, years later, I still wonder if I did enough or if a therapy I didn’t try for him could have made a major positive difference. This is a stressful reality that I shared with P2 during the interview.

She described her son’s school environment as being very good and it was not a source of stress. He was in a school district that provided inclusion in programs where all students were taught to accept individual differences. This contrasted to my experience and Participant 1 where school was a strong source of stress.

The interview went well and she appeared most responsive to the question, “What things are helpful to relieve the stress?” This animated her and she offered several activities such as walking, being with friends, and church as helpful. Her engagement with this question affected her to the extent that she sent me an email within an hour after completion of the interview. The contents of this email are important to include because they were not recorded but consist of information that she wanted to add for the study.

The complete email follows:

Just a follow up to today's interview ... I was remiss in not mentioning a few ideas concerning stress and my relief valve! It's a bit odd for me being recorded and this may have "blanked me out" at times, making me feel a bit disjointed. I hope you got what you needed, an informed and honest account! I did want to add that gardening has been a great stress reliever for me; in fact I go so far as to call it my therapy. It is something where I can create and learn patience in the process. I wander the nurseries as well and antique malls to clear my headspace. Hobbies yes but therapy too. I also mentioned cleaning houses when my son was in school full time. I enjoyed this as well because I got 'instant' results to counter the painfully slow process of endless therapies with him. Hope you can add these thoughts in! And thank you for the opportunity to help other parents with your project. It's a great idea.

The question about what helps relieve the stress affected this participant and she wanted to include additional information that was not in the interview. Gardening, going to nurseries or the mall, and cleaning houses are similar in that they offered an opportunity for her to be out of her home and have some personal time.

Participant 3

This interview took place in this single mother's home at her request since it was problematic for her to go places due to her daughter's intensive care needs. This was particularly emotional interview for me because this mother's daughter required caregiver challenges that are very similar to those of my son. For instance, her daughter is nonverbal, not toilet trained, makes inappropriate sounds in public, needs to be held onto while going through parking lots or crossing streets, and must be watched constantly due to behavioral issues. She uses the same communication device as my son, a Chat PC, which they use mainly for food requests although many other choices are programmed into the device.

Listening to Participant 3 describe the intensity of daily stress related to caring for her daughter and the difficulty finding respite providers was almost like hearing myself describe the same issues. Respite from my son's considerable daily care requirements is important to help relieve the stress but especially challenging to find reliable helpers when the care needs are extensive. Sometimes help can be available from family members or professional services that specialize in caring for people with disabilities. In addition, school provides another type of respite with a dependable routine where my son will be occupied, educated, and cared for at least several hours each school day. The flip side of this type of respite is that summer vacations present with stress since the dependable yellow bus does not arrive each day. There is a scarcity of options because most summer programs require that I provide a full time assistant for my son due to his functional abilities.

However, there were several examples that she communicated that stood out as being much more difficult than I had experienced with my son. The major difference is that her daughter tends to become violent or aggressive toward her mother or respite providers. Fortunately my son is not aggressive but in fact very compliant. The problem of aggression makes it almost impossible for Participant 3 to find a reliable person or respite provider to help with her daughter's care. Her frustration with the issue of respite providers was her main focus of discussion. Even when the topic would be about another area of stress she kept coming back to the lack of respite. This focus could be due in part to the fact that she is a single mother and stated that her family members don't understand or help with the care of her daughter and that reliable respite is almost impossible to find. She expressed frustration that her daughter had aunts, uncles, and grandparents but they were not as involved as her family was with a normal family member. This led to an increased sense of isolation.

Of interest during this interview is that P3 contrasted to P1, in that she appeared to welcome the audio recorder. P3 demonstrated this several times during the interview by asking to hold the recorder and keep it recording while she walked around rooms to care for her daughter.

One request was to keep the audio recorder on during an incident was when her daughter was making loud, inappropriate sounds and the mother decided to give her a time out for the behavior. This mother asked that the entire process be audio recorded for a better understanding of her daily routine. She told her daughter to sit in a chair while she set a timer for her to remain quiet for three minutes. Next she went into a nearby bathroom while requesting me to join her and closed the door so that her daughter

had no visual contact. When the timer went off we returned to the room where her daughter had remained in the chair. Seeing her daughter sitting alone and looking confused gave me a sense of sorrow. I felt sorry for the daughter because the sounds were part of her disability and difficult for her to control. I felt sorry for the mother because the constant sounds were a source of tension and frustration.

The mother made another request when she attended to toileting issues because her daughter is incontinent and she wanted me to be present during the diaper changing procedure. It was a procedure that took at least fifteen minutes while her mother knelt on the floor in front of the changing mat. Many people experience diaper changing for a small child but here was a 170-pound-female having a diaper changed. It is almost impossible for most people to imagine the physical effort required and the psychological impact after years of diaper changing. I could relate in part since my son is not toilet trained and wears Depends rather than diapers. I felt fortunate that he will use the toilet if he is taken there on an hourly basis. However, occasionally he has accidents so I understand what is involved with changing a 210-pound person. Physically it can be exhausting with dozens of wipes, a shower, clean clothes, and sanitation of the area. My emotional response varies from frustration, acceptance, depression, or numbness from years of the same routine. I struggled to not let my own reactions become assumptions about what this mother was experiencing and remained quiet to allow her voice to be heard.

Overall, the interview went well and seemed almost therapeutic for this mother to have an opportunity to talk about her stress. She appeared comfortable when she held the audio recorder while attending to her daughter such as to put on a video or get a toy. She

said it was important to have the audio record in order to fully explain her daughter's care requirements while she was engaged in the effort.

Participant 4

This participant appeared comfortable with the audio recorder and expressed interest in being part of the study. She was active in the community as an advocate for autism resources and supports.

Despite her involvement in the disability community she expressed sadness from the isolation of friends and family that was a result of raising a child with autism. She described years of being unable to participate in normal family events or activities. For instance, she described how her husband would go to an early church service while she watched their son at home, then they would "trade off" so she could attend the later service and her husband watch their son. After years of this routine, a church member happened to see them shopping together and was surprised to find out they knew each other, let alone being a married couple.

I related to her descriptions of social exclusion and the restrictions that result from having a child with autism. Over the years, and to this day, I am uncomfortable taking Andy to a public event where people are expected to be quiet and listen such as a church service. Also, being unable to participate with family or friends resonates with many sad memories of not attending the event or finding a "sitter" for Andy while I went without him. This created another sense of loss and guilt that gradually led to not going to the events. It was easier to stay home than exclude him or watch others relating in a way that was not available to me.

Participant 4 shared an extraordinary story about her son that took place last year. I found it a good example of the type of stress a mother experiences that cannot be understood through quoting phrases that only capture part of the experience. Her story involved her older, normally developing son's graduation from college in Europe. At first, she said they would be unable to attend because her son with autism panicked and had tantrums when they attempted to fly years ago. But the thought of parents not attending an important family event, as their son's graduation became a cause that she decided to tackle. It was one of those moments when the necessity of the event overcomes the challenges to make it happen. Her story is included here to demonstrate the incredible emotional, psychological, and time demands a mother endured in order to have a typical family experience. The following is her account of the strategies she employed to enable a family event.

About a year ago we went to Europe for my older son's graduation --he went to college for four years and he graduated last year. My son with autism ... up to about a year ago has a deafening fear of flying and he would not fly. The last time we attempted flying, before last year, is 10 years ago... Yeah, 10 years ago, when he was 11. We flew to another state, and I kid you not, he cried the whole way. He screamed, not cried, he screamed. Thank God it was pressurized at that level, so it was muffled scream. But the stewardess at the time was so unbelievably kind. She came with apple juice, she came with... I mean she gave it everything that she could to help me but he fell asleep screaming for five minutes, and then when he woke up he screamed again. So we never tried it ever since. And so this time I said, "By hook or by crook, we're going to Europe as a family." I mean there's no two ways about it. So we set out to prepare for it. Two years in the making. [laughter] I knew we would... My goal was to go to Europe as a family for my older son's graduation. So, two years passed and then we were going to prepare. So his therapists were bringing him most days to the airport to desensitize him with the noise and everything. My husband works with an airline company so we were at ...the flight museum... we were able to be climbing and looking at planes and seeing the inside. We took short trips on airplanes. And we were going to bite that bullet and fly cross-country, so we went to our doctor to find the right dosage of sedative because I wanted him fully aware of what was happening. I didn't want him out of it. I want him... The edges, the anxiety edges to be out, and I want him to experience the whole thing. Because I know that once he experiences it, he'd love it. Because he's a creature of height. He would sit on top of a tree... He loves heights, so I knew that he would love this experience, if only

he would get past that fear. So I've always said that parents experts of their child. I mean, you know what makes your kid not work. I mean, you know how to about this. So the trick is really to find a solution that solves that stress. To me that stress was I got to get a vacation. [laughter] So we found the right dosage. So we experimented with it. And one dosage knocked him off, not gonna work. It was clonazepam. It was a Valium. That's why... And I really just use it for major events and major things because I don't want him to build a tolerance for it, because it's my magic pill. When we go to a fine dining restaurant, pop that pill and he sits nice, and that's great. And then I prepare. So the day of reckoning arrives for our cross-country trip. Because this was the big trip that would simulate the Europe trip in length and in flying time anyway, the longest flying time, because we we're gonna go... Yeah, so anyway, so we're gonna go to the cross-country. So I alerted the airlines that my son was autistic. If we could get priority boarding. And they said sure. And I said priority boarding, not first class priority boarding, I want better than first class, I want ahead of first class. And then I explained that my son was autistic and they said sure. Talked to TSA and then I booked it so that so that there was nobody behind us and the person in front of him would be his brother. So I booked it so that our seats were right next to each other, so even if he kicks his feet it was his brother's seat and nobody would yell at us, right? A lot of planning. And then I had a Plan B. If he would not get on the plane, I rented a car with a carry-on, so that if he truly cannot get on that plane, they will drive cross-country and we would meet them there. So I had all this planned. I mean that's the stressful thing but this is what you need to do. So anyway, so the day of reckoning arrives, the day when... He was fine, blah blah blah. So we board now. It's boarding time now. So they call us to be the first ones to board. I tell you in the middle of that Skyway, I mean, he panics, he flails and then I just remember we didn't prepare for a Skyway. All the practices we had were tarmac boarding. Because it was in flight museum, you do stairs, you don't do tubes. He could see the entire plane in our preparation. This was the tube. He could not see what was there. He was flailing, he was flogging and he was... He had Valium already but he was still verbalizing. He sat and planted himself in the middle of the Skyway and was, "No! No!" He was anxious. So I told the boys go sit. Go. I said we're gonna get him in by hook or by crook. So they boarded. First-class comes in. Oh, and I prepared three by five index cards that says, "Hi, I'm (name), I'm 18 years old. I have a fear of flying and if you hear me crying that's just me. But that's okay. Don't worry. My mom knows to put on my video. So... Blah blah blah. And I get agitated too during landing. But don't worry because my mom is beside me. Blah blah blah." So, you know, so I prepared this index card. So first-class passengers come in. They look at this child, he's flailing. So I pass out the cards but I had 200 of those. So I pass out the cards... And economy class comes in... This is a movie, right out of a movie scene. I cannot... So economy class comes in, I pass out these... Look, I told you the stares are the most difficult thing for me. Why I developed those three by five cards is because of my fear of stares or my non-tolerance for stares. So, I don't like people staring at me. So, what can I do? Well, I pass out those cards. "What are you staring at, this kid has autism... I mean shame them. [laughter] And shame them, too, if they're judging. So I pass out those cards along. So, five minutes before they were to close the door, the captain comes out and says, "Mam, you've got five minutes, we need to close the doors, we're going to be late." "I will, I will." So I told my husband, I said, "We need to force him in because I know this kid, once he's in here he'll be fine." And he says, "Are you

crazy? We force him in, if he kicks or flails at one of those passengers and hits those passengers, you've got a lawsuit and you'll be kicked out." So, he says, "We are not going to force this kid in," and he's right. You force him and he goes like that and you're out of there. Yeah, once they get bigger what can I do? So, this stewardess has a five-year-old kid with autism says, "Mam , let me help." I knew. I said, "Yeah, go ahead. You can't do anything. If I can't do anything, you certainly can't do anything." [laughter] So she goes, "Come on, (name)," "No! No!" he says. She gives up and says, "You're right." Now what can I do? "You've got two minutes," she says. And then I said to my husband, "we need to go in or else you're going to take the rental car and drive." Well, my husband is a black belter, so he gives our son a grip, that takes his hand behind his back and he is behind him. It doesn't hurt until you do not do what the guy behind you wants you to do, which is to move forward. If you move this way it's going to hurt, because it's going to lock it. Our son had no choice but to move forward. I was holding his left hand and my husband was holding his right hand. He was moving. The three of us were moving. So we go through the Skyway, enter the plane, first class. Remember we were at the back, so we have to go all through this hall... I'll tell you, the minute we showed in first class the people clapped. "Oh (name), good job! High five." And he was like this and I mean I was smiling. I was so glad, and I was so touched. I mean that everybody... So we sit down, okay? And I promised him, when he was crying, that I was going to show him his movies. So, the minute he sat down I pulled out his iPad, click on his video clips, and true to form he lifts his window and he looks out at the clouds. He loved it, he forgot his movie. And once we were cruising altitude, the stewardess brings in a bottle of wine compliments of the captain for the parents... Yeah. Was it stressful? Sure. But at the end of this... Sure it's stressful because you do things that are not things that you would normally do. But it's like I said, you find around it, you find a solution. That's the only solution to stress, right? You can't fret because it's still going to be the same.

When I listened to this mother's story it affected me with a variety of emotional responses. I am reminded and feel the anxiety of having a child with behaviors that cause people to stare or judge are among the most difficult challenges to feel in public.

However, being part of society is necessary because I believe that community inclusion is important for individuals with disabilities well-being and to increase public education toward acceptance.

P4's accounts about her months of preparation to take an airline flight with her son gave me profound respect for this mother's commitment to create an environment where he could be successful and give their family a sense of normalcy. This story

represents just one vignette from many events during her nineteen years of similar stories where she found the courage, creativity, and the resources to tackle a variety of problems.

Participant 5

At first this participant appeared nervous or rushed which made me appreciate the time each mother takes from her schedule for the interview. She wanted us to sit on the couch so I placed the audio recorder between us on the seat.

When I asked the first question about causes of stress her response was immediate.

There are so many different facets of the stress. There's the day-to-day stress of dealing with the behaviors. Then there's the stress of school, there's the stress of work. There's the stress of providers, not finding providers, not getting services, not being able to take time off from work when you need. Stress from maybe losing your job because of all of it. Stress from 24/7, no relief, I have no family. My friends won't take him anymore because of his severe behaviors. I'm totally alone in caring for him for the most part.

She continued to describe her son's aggressive behavior that had resulted in him leaving her bruised and battered. I felt incredible compassion toward this woman who was committed to being a good mother yet suffered physically over the years while caring for her son. I was affected emotionally as I would be from hearing about any person's experience of physical violence but with the additional feelings of remembering that her son has autism and this behavior can be part of the disorder.

She had experienced the challenges of coping with her son's behavior for nearly two decades. During the interview her voice was slightly anxious and she spoke quickly

as if to download years of information about her stress. She told a story about coping in public with her son's behavior when he was younger:

I had someone one time, when my son was littler. We went to Toys R Us and he was having a huge meltdown and I was sitting there with my legs across him. I had his legs and sitting on him and holding him and he was screaming bloody Mary. He'd been screaming good 15 minutes. Some lady came up, "Do you need any help?" "No, thank you." Well, then she wanted to give me all of this advice and whatever else. And then a guy walked by, "Well, I think maybe he needs a good spanking." And I'm like, "Oh, whatever." And I just would tune it all out and just when he's calm, "Fine, we're going to the car.

Over the years I had heard almost identical stories from many of the mothers that had a child with autism and had experienced similar responses from people in public places. These stories changed me in a major way in that when I am in public places and hear a child scream or tantrum I no longer assume the parent is to blame. Part of my journey has been to have a better understanding of autism and not to be judgmental. It also strengthens my commitment to inclusion.

As the interview continued I learned that this single mother had brain surgery in 2000 and currently has heart issues and a pacemaker. She had to physically cope with health problems in addition to coping with her son's challenging behaviors. Despite these overwhelming conditions she had to struggle with DDD for help to be able to continue caring for her son at home. She described one of her efforts to get increased services when her son was younger through a conversation with his case manager.

She didn't think he needed... Because he was over, outside the birth to three and at three they close the account. I said, "No, no, no, no, no, we're not closing the account, because he's in the school system. No." So that's why I called her up, I say, "No, no, no, no." So she's, "Well, I'll give you a little bit of this," and she opened up the door crack, and from then on, I just kept pushing and, and then I need more services, we need to push him up, we need to push him up to a different level. "I need help. If I'm not gonna be around, you guys are gonna have him. I have no family, his dad's deceased," and that helped.

Listening to her story was similar to my own situation when I was physically challenged to meet my son's daily needs. Although he was fortunate to be placed on a Waiver program at age six years it remained difficult to receive supports and resources. Although the intent of Waiver programs are to provide whatever level of care the individual required to remain in the community, I felt that the case managers were more like gatekeepers. Over the years I heard many stories from families that pounded on the "gate" for help without results. The only time I heard about additional resources being provided was when the parents threatened to stop caring for their child, as in the remarks of P5, "... you guys are gonna have him."

Her statement resonated with me as I recalled similar circumstances during a time when I was concerned about being physically impaired due to surgery. This created the realization that potentially I may not be able to meet his care needs and could require additional help with my son's care. I also experienced a "reality check" that a day could arrive when I could not care for him at all and there was no place to turn. The gravity of being unable to provide care with no place to turn created a very real sense of fear about the future. Consequently, I called his case manager and my conversation is recalled in the Epilogue section of this journal. Frustration, fear, and anxiety are some of the emotions experienced when mothers are driven to the point of desperation within a system that rarely responds to pleas for help.

Participant 6

This single mother requested that we meet at her home because she found it was the most convenient. I had called her the day before our meeting to confirm the date and she informed me that her son had a recent behavior outburst that resulted in serious

destruction to their home. She said he had caused enormous damage by throwing and tearing things apart. I felt sensitive to her situation and offered to reschedule but she insisted that our interview continue as planned.

When I arrived at her home my first impression was a sign posted outside her door that stated, “Alert, a nonverbal person with autism resides here and would be unable to respond in an emergency.” It was a statement that could not begin to convey the numerous additional challenges that dwell inside the homes of people with autism.

She answered the door while talking on the phone, waved me to a nearby chair, and continued to converse in what sounded to be an anxious tone. Later she informed me she had admitted her son to a local children’s hospital psychiatric ward the previous night. Her phone conversations since last night had revolved around doctors, rescheduling therapists, cancelling appointments, informing the school, and to the people involved in her son’s schedule and life.

She told me that her son’s behavioral outburst had resulted in about ten thousand dollars in damage to their home. She also expressed anxiety that it was a rental home and she would be responsible for the repairs. Her son’s behavior was uncontrollable to the extent that she was forced to call 911 for help and eventually admit him to the hospital. She tried to bravely hold back tears while talking about this event but I could see them softly roll down her cheeks. I felt appreciative that despite her recent trauma she still wanted to have the interview. Possibly, she felt that being able to talk about the experience was therapeutic at this point in time.

This mother was similar to the other participants in my study in that they all had a child diagnosed with autism. A requirement for inclusion in my study was not having a

diagnosis of Asperger's Disorder, which the lay population often refers to as High Functioning Autism (HFA). P6 articulated her frustration with the exclusion she experienced from parents and groups that claim to be part of the autism community but do not understand the enormous variation among those diagnosed.

And how about this, how about you just stop with the dividing us up? We already have problems working with one another as it is, stop it with this Asperger's high functioning profoundly autistic crap. I get so sick. I wanna go online to Autisms or King or any of the other online because everyone prefixes their comments with, "Well, I have an HFA son." You know what? I don't care. Because one, they don't even exist. The DSM does not designate HFA. That's some shit that somebody made up to make themselves feel better... I'm not quite Asperger's because that's what everyone aspires to be, to differentiate yourself from me, from the rest of us, from the ones that are in those Autism-is-a-World videos which I think, kind of went overboard. We're not Asperger's but I don't want you to think that I have one of those little demon children. So, I have an HFA kind of child, you can relax a little bit. And all they're doing is segregating us and making... I mean I've talked to a lot of parents online who've said the same thing. "Why don't you speak up?" "Because we get drowned up by the HFA Asperger's crowd." So, I'm glad that next year they're being taken out of the ASD spectrum, I'm glad... Because you've been kind of segregating yourself. You aspire to be something different. So, I'm glad that we are now gonna be something different. So, the HFA crowd is trying to make everyone believe, actually, were like part of the Asperger's, we just don't wanna be a part of you. And it just divides us even more and it makes people who have straight 299.0 or profoundly autistic kids, it makes us shut up. We don't wanna say anything because we don't wanna be seen as the whiners, the people who will ruin it for everyone else. But no, I can't take my child to the campfire summer camp.

The insight that P6 provided is important to enable a better understanding about a problem that is rarely discussed in the autism community. There is a problem that segregation exists even among those diagnosed with autism spectrum disorder. Her comment was that the severity of her son's disorder made it difficult for him to be included in activities designed for autism. She was upset about people using HFA to describe their children because she felt it contributed to discrimination by making them appear more normal than others at the more profound end of the spectrum.

After the interview I went to use the bathroom located next to the kitchen where we had been sitting. When I entered the room and started to close the door it jammed. I saw that the knob was barely attached to the door because the wood surrounding it had been hatched away as if by a blows from a hammer. The door hinges were loose and the toilet seat had been ripped off. I stood there stunned as the reality of this mother's experience became visible. It was one thing to hear about a violent outburst and thousands of dollars in damage to their home but to actually see it caused a deeper understanding of her experience. Additionally, I realized this was just one room of many in their home where visible damage had occurred. This mother's verbal description of stress was one thing but seeing a real life demonstration was a powerful example.

Epilogue

The following excerpts are from the journals I wrote during my son's school years. I have selected some entries that I feel relate to or expand on the findings and interviews in my study. This is an attempt to provide the reader with greater insight into my history and the views that may have influenced my perspective about the study.

I wrote the following entry after attending a party with my son that was given for children with special needs. The majority of the children at this event had Down syndrome. This entry reflected my isolation, grief, and acceptance.

Andy is at a large party for special needs children. The other children talk, play, and relate to each other. My son retreats to a lonesome corner to twirl a prized find – a jump rope. The other children see the rope as an opportunity to play but for him it is an opportunity to escape further into the world of autism. These are among the most painful times to watch other children that are considered disabled but still able to interact and want to be part of our world. Autism continually pulls toward isolation. It steals the child away and imprisons him within an invisible wall. We can still see the child as we attempt to break down the impenetrable force surrounding him. Occasionally the child looks outward – beyond his prison. He looks and makes eye contact with the depth of discovery. Those are the times the veil is lifted to reveal an innocent child forced into a

world not of his making. Those are the times that encourage us not to give up and save the child. Life on the edge of disability can be cruel.

Most parents that have a child with disability do everything within their power to overcome it. Their own lives become shadows of their former selves as the family takes on a new identity. They are no longer included among the norm as their lives become a swirl of therapists, medical professionals, social workers, support groups, and advocacy to name a few. This mass takes on a life of its own to challenge the core of a person's being. It is through these challenges that we are invited to become a better person. This transformation of identity takes on new forms as old skins are shed during the metamorphosis. The eyes see with a different lens that creates new views of who we are as people. The world is no longer familiar as the ground breaks free, crumbles and reforms anew. It is a lonely and painful process that is never completed but growth and personal transformation are not necessarily easy. Doors of kindness, compassion, understanding, caring, acceptance, and trust are waiting to be opened.

The next entry reflected coping with challenging behaviors while being in public when my son displayed unusual behavior. These behaviors result in unwanted stares and sometimes comments from others. It expands the topic of coping with challenging behaviors as expressed by P5 when she was trying to control her child's behavior while at a Toys R Us store.

Magazines and public places often present a view of families that display the norm with bright-eyed children and parents who fit into society. Then there are the rest of us that look or act differently. Being with my son in public places is always challenging because his sounds or actions are unpredictable. He may hiss, blow "raspberries" that sound like passing gas, flap his hand or both hands, stick out his tongue, pinch both cheeks by pulling them to the point of facial distortion, or grab a stranger because her purse strap or his tie looks like a great object to twirl. Over the years I began to accept the stares or curious looks while I tried to make myself invisible. The feeling of being uncomfortable in public never goes away but it will never prevent me from allowing Andy to participate in the community. One reason is the only way he can learn appropriate behaviors is by being part of the community. The other reason is that this is one way people in the community can learn about acceptance of others that are different. If I did not take Andy to public places people would not have the opportunity to grow and learn about diversity. Discrimination would continue. Fear of the unknown would continue.

The following entry reflected the stress of being in public places while coping with challenging behaviors but included additional insight into cultural differences. It

caused me to reflect on the variety of ways people view disability and consider the effect of culture on those views.

While entering the computer store, a dark-skinned man with fine features stood in his security guard uniform by the front door. He smiled and said "Hello" as I entered with Andy in tow. I responded but my son was in his own world and not acknowledging the presence of another person. The man cheerfully said "Hello" again directly at him but received no response. The man looked confused so I stopped to explain, "He's autistic and he can't talk." The man lurched forward and an excited expression appeared on his face. "I can make him talk" he said softly, "I can make him talk." The sincerity of his words had me frozen in place and ready to receive. He faced Andy and placed his long fingers around each shoulder, placed his face within inches of Andy's face and said, "Look at me." The man's eyes were burning with passion and contained a fire that came from deep within his soul. Andy, surprised by the action, looked into the brown eyes that were fixed on him. The man moved even closer and locked his gaze, "Devil be gone!" he shouted. The words rolled from the depth of his being, he was committed to his cause and purpose. "Devil be gone!" he repeated. Suddenly I snapped out of my trance to realize we were standing in a computer store, surrounded by bright lights, and curious people. But this man was so sincere, he had a mission, in his heart he really wanted to help and make Andy talk. Although the event seemed odd in our society I thought about cultures where this is common and a way to help others. "What the heck" I thought, "I've tried just about everything to help Andy talk except Dolphin therapy and here is a man convinced he had the answer.

"Devil be gone," he repeated a third time and then he was done. He released his grip but Andy grabbed hold of his hands and held on tight. Maybe my son sensed the purity and compassion of this man wanting to help him or maybe he just wanted to hold the dark-skinned hands. The scene was so intense that I didn't notice or care about the other people in the store. It was a unique moment when a human from a culture in another part of the world reached out in the best way he knew to help another in need.

I left the computer store with my intended purchase but also left with much more than a material object. I left with the magic of experiencing a cultural exchange, being transported thousands of miles, and thousands of years into a place of compassionate humanity. I left with Andy still not talking but he had a content look on his face. He had connected with another culture, human connection and by being Andy brought out another person's kindness for me to see.

This next entry reflected my frustration with the establishment when I was about to undergo hand surgery. I realized that having only one useful hand for several weeks would make it difficult to care for Andy. Consequently, I called his case manager to find out what help options would be available until I recovered. I wondered what people do in

this type of situation and worried about not meeting his daily care needs. I told her about the upcoming surgery with the potential for problems.

My first question to her was, "What happens if I can't manage to care for him?"

Her: "Find some one to help and pay."

Me: "I don't have that much money."

Her: "Then ask family members."

Me: "I don't have any family here, they all live out-of-state they are unable to help."

Her: "Get friends to help."

Me: "All my friends have kids with disabilities and they're already maxed out."

Her: "Then ask your church members."

Me: "I go to church but I can't imagine very many people volunteering."

The conversation continued along this line until I became frustrated and discontinued the debate. Later I thought about a normal situation where friends or church members are willing to help those in need by bringing meals, cleaning, or doing chores. However, I think they would be overwhelmed by the extraordinary effort required to help in a home with Andy who is the size of an adult. For example, a few nights before he had pooped in his pull-ups and within minutes he dug it out, threw it on the floor, and around the room. He stepped on it and his hands spread it to more objects. It took hours to clean him up and clean the room. Would well-meaning volunteers from a church be ready for that type of scenario?

The following entry is about my experience of joy in my son's accomplishments.

It was at a school party that included children with disabilities and normally developing children.

Today was the Harvest party at Andy's school and the room was filled with over a hundred parents and children. Mingling with the group and part of the experience were special needs kids from two classrooms. My son was among the few that required an assistant to prevent him from running off or doing something erratic like taking food from someone's plate or dumping their drink. Still he was able to be part of the group. When the adults were seated there was an announcement that all of the children had prepared a song to sing. Some children sat in neat rows on the stage; taller children stood, and in the back row stood Andy while being held in place by his assistant. The children began to sing a moving song about being thankful. As the song neared the end, from the middle of the back row a giant paper sun was held high. It was very touching and gave a greater meaning to their song. Suddenly, with amazement, I realized it was Andy! He was being helped but stood there happily being part of the performance while holding up the sun. I felt incredible joy that although he cannot sing he was still included and even had a place of importance in the event.

Lastly, this journal entry reflected a view of my understanding about disability and life in general as a result of caring for my son.

We all live under the thin veil of illusion. The illusion is that things such as our job, family, friends, or neighbors have a sense of permanence and that the security of time continues without change. Our rational mind knows that eventually things change such as jobs end or family and neighbors go away. These changes are an inevitable part of life. Our non-reasoning mind sees things in a state of permanence until a life altering experience or event forces the knowledge that some unknown territory is ahead and things change.

For instance, we drive along the same street for years and one day an accident blocks our path. We may have been fortunate to miss being in the midst of it but the act of driving around it demonstrated that this sort of thing happens. When we pass that spot in the future we might be uncomfortably reminded of the event. There is vulnerability in acknowledging how close we live to the thin veil – how the illusion creates security in a world where nothing is really permanent.

In summary, my life journey with Andy was what inspired me to study and write about mother's caring for their children with autism. Caring for Andy presented many challenges but has contributed more to my personal development than anything I could have imagined. Among the good things that Andy has taught me is that life must be lived as it presents itself. Being in the moment is the only place of permanence. This is what I have learned from my son. Andy is in the moment and he accepts each day as new. His past is the moment, his future is the moment, and he has no expectation for tomorrow, and no regrets about the past. His unbridled happiness is demonstrated over simple things such as an ice cream cone, music, a song, or a good meal. He has taught me to enjoy and appreciate life just as it is in the moment. He has enabled me to become an advocate for disability rights and inclusion.

Each person, regardless of differences, deserves respect, human dignity, and inclusion within the community. Supporting mothers in their caregiver role is an important step toward achieving these goals.

