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# Inner Strength In Mothers Of Children With Autism Spectrum Disorders: Oral Histories

Jennifer Weathersbee Steinberg

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INNER STRENGTH IN MOTHERS OF CHILDREN WITH AUTISM SPECTRUM  
DISORDERS: ORAL HISTORIES

by

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A Dissertation

Submitted to the Graduate Faculty

of the

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for the degree of

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2017

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This dissertation, submitted by Jennifer Weathersbee Steinberg in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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Dean of the School of Graduate Studies

Date

## PERMISSION

Title            Mothers of Children with Autism Spectrum Disorders: Oral Histories of Inner Strength

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Jennifer Weathersbee Steinberg  
September 28, 2017

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## DEDICATION

I dedicate this dissertation to Sam and Eli, my sons diagnosed with ASD, who have sacrificed so much of my time and attention over the past six years. I once overheard their father tell them that my work might someday help other children and families like ours. For that, I am truly grateful. Nick, you are a wonderful father, and I am so fortunate to have married my soulmate.

I would also like to dedicate this to the mothers who volunteered their time to tell their stories. My life has changed for the better because of what I learned from these incredibly strong women. Hopefully others' lives will improve as well.

*Although...*

“Life doesn't have to be perfect to be wonderful” (Unknown).

## ABSTRACT

The purpose of this oral history study was to describe the lived experiences of mothers of children diagnosed with autism spectrum disorders (ASD) and to further inform the Theory of Inner Strength in Women (TIS) (Dingley & Roux, 2014).

Postmodern feminist oral history methods were used to answer the research questions which included: 1) What are the lived experiences of mothers of children diagnosed with autism spectrum disorder (ASD)? and 2) How do these experiences further inform TIS?

Interviews were manually coded directly onto the digital audio files using NVivo11Plus qualitative data management software. Three chronologic phases were identified among the 10 narrators interviewed for the study, including *in the beginning*, *everyday ASD*, and *afterward*. Overarching themes identified for each chronologic phase. The phase *afterward* only occurred after a chronologic, physical, or imagined distance from day-to-day activities and responsibilities of parenting a child with ASD. Mothers of children with ASD who participated in this oral history study did not achieve the outcome of the TIS, of living a *new normal* if they were not had not had the chronologic, physical, or imagined separation from day-to-day parenting that mothers in the *afterward* phase did. They did, however, tell stories which illustrated dimensions of inner strength.

The findings were consistent with previous research related to mothers of children diagnosed with ASD, but also makes a unique contribution in terms of implications for nursing practice and recommendations for policy. The data collected for the study has also been entered into the historical record for use by future qualified researchers.

# **CHAPTER I**

## **INTRODUCTION**

Mothering a child with an autism spectrum disorder (ASD) is a challenging undertaking. These women live their days tethered to the routine of their child while shifting from one situation to the next, using whatever “tentative workable arrangements” (Silverman, 2012, p. 122) are available until an issue arises. The challenge for many mothers of children with ASD is that of constantly adapting to new paradigms in the shadow of this lifelong invisible disability. Mothers of these children act often not only as parents but also paraprofessionals and amateur therapists to their children (Lilley, 2011). Many are advocates to improve awareness of the condition, improve outcomes, and promote understanding of their children, which can lead to “enlightened accommodation” as opposed to “intrusive rehabilitative technologies” (Silverman, 2012, p. 122). Once mothers find providers of recommended care and services for their child with ASD, the process of procuring such care and services can become compounded by myriad problems with funding and access.

### **Problem**

Persons with ASDs have a national prevalence rate of one in 68 births, or approximately 1.4%. This number has more than doubled since 2002 (Centers for Disease Control and Prevention [CDC], 2014a) and is 14,700% higher than prevalence estimates in the late 1980s (Mason-Brothers et al., 1993). From the 1960s through 1984, prevalence estimates remained static (Mason-Brothers et al., 1993). Although the reasons for such marked increases in prevalence are unknown and have been attributed to changes in diagnostic criteria and increased public awareness of the disorder, the increase



in children and their families living with ASD constitutes a public health crisis. The diagnosis of and subsequent mothering of a child with ASD constitutes a challenging life event. A diagnosis marks the formal beginning of stressful adjustments impacting the entire family, especially the mother who is most often the primary caregiver for an affected child.

Mothers of children with autism are under a significant amount of stress, contributed to by numerous factors, including the disorder's severity and phenotype (Ingersoll & Hambrick, 2011; Peters-Scheffer, Didden, & Korzilus, 2012). Along with literature related to the stresses, extant literature addressed the genesis of psychopathology, such as psychological distress and depression (Estes et al., 2009). Fatigue and social isolation were found to be the largest contributors to psychological distress and lack of well-being among mothers (Seymour, Wood, Gaillo, & Jellett, 2013; Skreden et al., 2012). These conditions decrease levels of energy and motivation needed to seek out information and physical resources that can help to mitigate their effects. Among other distressing findings in the literature related to parenting stress is the extent to which mothers experience dissatisfaction with their relationships (Ramisch et al., 2014; Weitlauf et al., 2014). This literature related to parenting stress has focused on stresses and outcomes experienced by mothers of young children at a set point in time. Absent in the literature related to parenting stress reviewed for this study (Ben-Sasson, Soto, Martinez-Petraza, & Carter, 2013; Hayes & Watson, 2013; Johnson, Frenn, Feethan, & Simpson, 2011; Zamora, Harley, Green, Smith, & Kipke, 2014) is how stressors impact mothers over time and considering societal, cultural, economic, and

political modifiers. This oral history study addresses this stress through histories shared by mothers of children with ASD living in Olmsted County, MN.

### **Purpose**

The purpose of this oral history study was to co-create narratives with mothers of children with ASD living in Olmsted County, MN and to build understanding of their experiences. This study bore witness and gave voices to these women through archiving the narratives produced. Through the archival process, these narratives became primary source material for use by future researchers.

I came to this study with an interest in the topic as the result of mothering two children diagnosed with ASD. I have firsthand knowledge and experience of some of the struggles that mothers encounter as they mother a child with ASD. The dimensions and outcome of living a new normal of the Theory of Inner Strength in Women (TIS) (Dingley & Roux, 2014) resonated with me, and I wondered whether the experiences of other mothers of children with ASD followed the same patterns. So, I proposed to answer that question in part through engaging in this study.

Through casual conversations with other mothers of children with ASD living in the upper Midwest, I had seen innumerable examples of inner strength. Through this strength and resolve to care for their children, many women preserved quality of life for themselves and their family through finding meaning in the experience. The collected narratives were used to further inform the Theory of Inner Strength in Women. The Theory of Inner Strength in Women was developed and tested with women living with chronic health conditions (Dingley, 2008; Dingley & Roux, 2003, 2014; Lewis & Roux, 2011). The theoretical model includes four dimensions: (a) anguish and searching; (b)

connectedness; (c) engagement; and (d) movement. The outcome of the theory is living a new normal (Dingley & Roux, 2014). The process of living with a challenging life event, such as mothering a child with ASD, is a catalyst for growth of inner strength.

The first formal diagnostic criteria for autism appeared in the 3<sup>rd</sup> edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed.; *DSM-III*; American Psychiatric Association [APA], 1980). Interestingly, that criteria included the original three symptoms identified in the first scientific paper published about autism by Kanner (1943). These initial diagnostic criteria included: (a) impairments in reciprocal social interaction, (b) impairments in communication (both verbal and nonverbal), and (c) a preference for repetitive, solitary, and stereotyped interests or activities (p. 250). These diagnostic criteria were narrow and excluded many children with clinically similar symptoms, indicative of Pervasive Development Disorder (PDD). This diagnostic manual, which was the first to include the autistic spectrum disorders as separate diagnoses, grouped them into a category called Pervasive Development Disorder, Not Otherwise Specified (PDDNOS) (APA, 1980). This diagnosis was confusing to many mothers and created a lack of understanding that autism was a type of PDD, although one with more specific diagnostic criteria (Silverman, 2012). The DSM-IV, (APA, 1994, 4<sup>th</sup> ed.), included more careful definitions of the PDD, including Asperger's disorder, atypical autism, disintegrative disorder, and Rett's disorder as well as continued inclusion of autism and PDDNOS.

### **Current Definition and Diagnosis of ASD**

Current diagnostic criteria for 299.00 Autism includes PDDNOS and Asperger's syndrome in the classification of *Autism Spectrum Disorders*. The diagnostic criteria

have established autism as a behaviorally-defined disorder with a biological basis, which marks a significant change with the publication of the *DSM-V* (2013), 5<sup>th</sup> ed. Since a scientifically proven biological explanation of ASD is yet to be proven, the onus of diagnosis is on practitioners to screen and recognize symptoms and distinguish them from other developmental disorders during ever-shortened routine appointments. Because of issues surrounding access to healthcare in the United States, including ongoing healthcare reform, this disparity could mean that children in lower income families with ASD are likely to continue to be underdiagnosed and underreported (Durkin et al., 2010).

### **Research Questions**

This study answered the following research questions:

1. What are the experiences of mothers of children with autism spectrum disorders?
2. How do the experiences of mothers of children with autism spectrum disorders inform the Theory of Inner Strength in Women?

### **Significance**

Many families have a difficult time adjusting to the idea that their healthy, happy child has a developmental disability such as an autism spectrum disorder (ASD). The diagnostic period can seem stressful (Hoogsteen & Woodgate, 2013), however the stress of living with ASD is overwhelming and stressful for the duration of family members' lives. Nurturing and caring for these children has many demands and stressors. These demands and stressors produce a cumulative effect of stress, affecting all aspects of life for both parents (Sikora et al., 2013) but especially the mothers of these children, who most often function in the primary caregiver role (Meirsschaut, Roeyers, & Warreyn,

2010). Maternal well-being, a topic in current ASD literature, has focused primarily on maladaptive behaviors (Gardiner & Iarocci, 2012). This study enhances the current rhetoric through the addition of narratives of acceptance, inner strength, and movement toward a new normal of mothering a child with ASD. These enhancements were framed in a social and cultural context through use of oral history methods.

The literature related to mothering an individual with ASD includes studies describing coping (Benson & Kersh, 2011) and supports to enhance coping (Zablotsky, Bradshaw, & Stuart, 2013), such as applied behavior analysis (ABA) therapy (Irvin, McBee, Boyd, Hume, & Odom, 2012). TIS is a gender-specific middle-range descriptive nursing theory, which articulates connections between inner strength as a facilitator of movement toward a new normal in the face of a challenging life event (Dingley & Roux, 2014). It includes four dimensions and an outcome of the process and has not yet been applied to women who are mothers and primary caregivers for children with ASD. Little of the current work with mothers of children with ASD focuses on resilience, and no articles were found through the literature searches conducted for this study that described inner strength in mothers of children with ASD.

This study informs specific areas of nursing practice, education, and policy making including those where nurses care for mothers of children with ASD. Nurses working in women's health, mental health, pediatrics and public health can use the findings of this study in their work directly with mothers of children with ASD as they help them to overcome and adapt to challenges occurring during the diagnostic phase and beyond. The importance of listening to the family story of mothers of children with ASD and finding ways to help mothers adapt through finding meaning in their experiences is

highlighted. As noted by Cohen (2016), stories of individuals and families are needed to inform health policy and drive change in legislation related to the provision of nursing care and research funding.

### **Operational Definitions**

For the purposes of this study, terms are defined as follows:

1. **Challenging life event:** an event which causes changes requiring the person experiencing it to adjust more than one aspect of their life (psychological, social, or physical) permanently to live a new normal.
2. **Inner Strength:** generally defined as “having capacity to build self through a developmental process that positively moves the individual through challenging events. While inner strength exists prior to the event, it is the experience of the event which initiates a tapping into the capacity of inner strength” (Roux, 2005, para. 1). The focus of inner strength involves the components of introspection, reflection, and self-acceptance, resulting in outward capacity. In contrast to resiliency, inner strength is gender sensitive with feminist theoretical origins.
3. **Mother:** a woman who identifies as the female parent, either biological, adoptive, or as a stepmother and assumes responsibility for the care, protection, and upbringing of an individual from a young age.
4. **Child with an autism spectrum disorder:** an individual diagnosed with an autism spectrum disorder was referred to as a child with an autism spectrum disorder because, in the eyes of their mother, an individual is always their child, no matter their age.

5. New normal: a state of equilibrium and relative comfort which is achieved after an individual has tapped into available psychological, social, and physical resources to grow in inner strength following a challenging life event.

### **Summary**

This dissertation is comprised of five chapters as follows:

Chapter I introduced some related background and historical context, the purpose, research questions and significance of the study, and operational definitions for which the study was undertaken. The chapter concluded with implications for nursing practice and suggestions for further research.

Chapter II provides an overview of the literature related to challenges faced by families, parents, and mothers related to and following a diagnosis of ASD as well as an overview of the Theory of Inner Strength in Women, which this study sought to inform.

Chapter III provides an overview of Feminist Standpoint Theory, Oral History Theory, and oral history methodology, which was the method used to answer the research questions to be answered. This chapter also addresses human subjects considerations and researcher's assumptions related to this study.

Chapter IV presents the findings of the study. Findings include a thematic analysis of the ten oral history interviews with mothers of children with ASD living in Olmsted County, MN at the time of data collection. Chapter IV also includes a thematic map developed after completion of a thematic analysis.

Chapter V includes a discussion of the findings of the study and offers an analysis of them considering extant literature. The chapter discusses how the mothers of children with ASD who participated in the study, including a conceptual map, inform TIS. The

chapter concludes with implications for nursing practice and suggestions for further research.



## **CHAPTER II**

### **REVIEW OF THE LITERATURE**

Chapter II presents literature on the topic of this dissertation and its gaps, which this dissertation addresses. It presents a review of research studies and theoretical works that are relevant to mothering an individual diagnosed with an Autism Spectrum Disorder (ASD) as well as an overview of the Theory of Inner Strength in Women (TIS). The following sections present the current state of the science on the concepts of mothering children diagnosed with ASD, caregiving and caregiver burden as related to mothers caring for their children with ASD, stress and its effects on mothers of children with ASD, and quality of life, coping, and resilience among these mothers. My personal experience provides context for understanding issues inherent to the problem to be addressed by this study.

The search strategy was developed with the research questions for this research study in mind:

1. What are the experiences of mothers of children with ASD?
2. How do the experiences of mothers of children with ASD inform the Theory of Inner Strength in Women?

A literature search was conducted using CINAHL, PubMed, MDCConsult, PsycINFO, Academic Search Premier, EBSCO, ERIC, Health Source, PsycArticles, Teacher Reference Center, and Google Scholar and PRO-Quest dissertations databases, using the following terms: children with special needs, family story, mother and autism or ASD, and resilience, coping, adaptation or inner strength. A combination of search

terms was included in this literature search. The search included articles and dissertations published in English without a specified publication date range.

Studies considered for this literature review included those that are qualitative, quantitative, and mixed methods. References from studies retrieved through the literature search described were reviewed for further insight and understanding of the pertinent issues. Public ASD and autism awareness websites were reviewed for sources of statistical information, which would aid in the descriptions that are part of this literature review. As mothers and their children with ASDs are part of a family, the impact on other family members was reviewed. In reviewing the literature to assist with the development of a holistic understanding of the family, a determination was made to include selected studies of and addressing the experiences of parents as a unit and of siblings.

### **Mothers of Children with Special Needs**

Children with disabilities and special needs require additional support from their parents, the educational system, and the healthcare system. Parents and, often, mothers usually become the coordinators of care and primary caregivers for these children. They navigate and balance complex and intertwined systems in coexisting worlds. When considering mothers of children with ASD, it is important to first consider mothers of children with special needs to situate this study within that larger context.

Landsman (2005) completed an anthropological study involving observation of 130 medical appointment visits at a newborn follow-up program in upstate New York, interviews with healthcare professionals and 60 in-depth interviews with mothers of children with disabilities over the course of two years. The study explored mothers'

struggle with experiencing and finding meaning in parenting a child with disabilities after expecting that not to be the case and struggling with the medical model and its presentation of a disability as a problem outside of the norm. While many of the mothers interviewed invested vast amounts of time and energy in finding a cure for their child, others discussed that disability rights advocates made them feel that they were “misplacing their efforts on correcting the impairment rather on addressing the disabling conditions of society” (p. 132). In other words, mothers who followed the medical model and sought to cure their child’s disability were not addressing the greater societal problems and were contributing to the devaluation of their child in the eyes of society.

When mothers were asked what their biggest concern was for their child with a disability, they responded “in terms of how the child would be treated by others” (Landsman, p. 134). Mothers, working to maximize the child’s capabilities, can help to minimize the disability in the eyes of others through changing perceptions. One mother, who participated in an ethnographic study of 17 children with disabilities, commented that she “let her child take the lead” (Penrod, 2000, p. 666). The study took place at a six-day summer camp and data included videos, photographs, and in-depth interviews with the mothers, (Morse, Wilson, & Penrod, 2000, p. 666) when deciding whether to try new activities, even if it meant that others will stare or comment on odd behaviors.

Mothering a child with special needs can be a challenging adjustment, requiring a mother to care for her child with a disability, while simultaneously advocating for her child. In addition to caregiving and advocacy roles, the mother must also navigate the healthcare and educational systems to coordinate care and services for her child with special needs. Through these experiences, finding meaning in and focusing on the

rewards of parenting are two foci, which allow parents to reframe their experiences in a positive context while still acknowledging feelings of sadness and guilt.

### **Early Intervention Services**

In 1986 the ratification of Public Law 99-457 (Education of the Handicapped Act Amendments of 1986), Part H required that states define developmental delay for the population aged birth to three years. It also required that an individualized family service plan (IFSP) be developed by a multidisciplinary team for each child and family enrolled in an early intervention program. The IFSP must articulate (a) child and family goals, (b) describe the criteria, (c) methods and timing to be used to evaluate goal attainment, (d) specify the services needed to meet each goal, and (e) identify the case manager who is responsible for ensuring the implementation of the plan. Parents or guardians are required to be members of the multidisciplinary team (Society for Research in Child Development, 1988). Following a child's third birthday, a child transitions to the preschool intervention program as established by Public Law 105-17 (Individuals with Disabilities Education Act Amendments of 1997, 1997).

For many parents, the IFSP is the first time they see their child's disability or degree of delay officially stated in writing. While that written diagnosis can be difficult to see, the difficulty for some can be compounded by the necessity of signing the plan to access early intervention services for the child, often during the same meeting (Landsman, 2005). Some parents expressed difficulty and delay in obtaining early intervention services for their children in a descriptive study, consisting of in-depth interviews of 13 families in Utah. Participants stated most often that their family physician was the greatest barrier to early access through either not validating parental

concerns, suggesting watchful waiting, or stating that the child was still within normal limits although the parent was concerned (Hendrickson, Baldwin, & Allred, 2000).

Early intervention is often the gateway to services for a child with disabilities. It is also a way to engage in the multidisciplinary team during the developmental stages of a child's education. It offers an opportunity to learn to navigate the bureaucracy and establish some assistance as the child transitions into preschool and school. Members of the multidisciplinary team can also assist with applications for services, such as therapies or medical assistance if it is determined that he or she would benefit, and the family has not already done so. If the screening process is accurate in identifying children who require services and the system can accommodate that number, then early intervention programs can ease the burden for parents and make the transition to school easier for children and families.

### **Person-First Language**

Person-first language is a semantic way of focusing on a person rather than on his or her disability. An example is stating *person with ASD* rather than *autistic person*. The focus shifts to the person from a problem. The American Psychological Association (APA) advises avoiding language that “objectifies a person by his or her disability, uses pictorial metaphors, uses excessive and negative labels, or that can be regarded as a slur” (2010, p. 76).

In contrast to the APA, the neurodiversity movement, including organizations such as the Autistic Self Advocacy Network (<http://www.autisticadvocacy.org>), advocates for people to rethink ASD through the lens of human diversity and not view individuals with ASD as persons to be fixed (Nicolaidis et al., 2015). Advocates for

recognition of neurodiversity do not use person-first language because they feel that “autistic individuals as possessing a complex combination of cognitive strengths and challenges” (Nicolaidis, 2012, p. 503). The mothers who participated in this study did not use person-first language and while they believed that their children had disabilities, were accepting of them as *autistic children*.

### **Overview of Autism Spectrum Disorder**

ASD is a developmental disability, which has a lifelong impact on an individual and their family. It is diagnosed by criteria which include deficits in areas of social communication and interaction as well as *restricted, repetitive interests, activities, and patterns of behavior* (American Psychiatric Association [APA], 2013). Most children are diagnosed prior to the age of 36 months as first signs present themselves during the early childhood development period. In some cases, however, these signs and symptoms are not recognized until a child does not meet predefined developmental milestones or begins to exhibit enough the diagnostic criteria (Cianfaglione, Hastings, Felce, Clarke, & Kerr, 2015).

ASD is defined as a disorder with a wide range of variability and a spectrum of presentations and symptom severity. Associated functional limitations sometimes develop over time and may not be present or fully established at the time of diagnosis (APA, 2013). The most current incidence estimate is that one in 68 children in the United States will be diagnosed with ASD, an estimate that has more than doubled since 2006 (CDC, 2014b). There is not a clear explanation for the increase in the numbers of children diagnosed with ASD from its addition as a diagnosis in the third version of its Diagnostic and Statistical Manual (DSM-III) (APA, 1980). However, there have been

several hypotheses, including increases in awareness of the disorders, increases in education of primary care providers for children, added legislation requiring screening for children prior to registering for kindergarten in many states, and changes in diagnostic criteria with subsequent editions of the DSM (CDC, 2014a). Estimates of intellectual disability, as an ASD comorbidity, varies across race and ethnicity with “approximately 48% of black children with ASD classified in the range of intellectual disability compared with 38% of Hispanic children and 25% of white children classified as having intellectual disability” in the United States (CDC, 2014a, p. 7).

In a study of children born in Iceland between 1992 and 1995, 99 were diagnosed with ASD. Of those diagnosed prior to age six, 40 were diagnosed with childhood autism, and 18 were diagnosed with other ASDs. Of the children diagnosed after age six, six were diagnosed with childhood autism, and 35 were diagnosed with other ASD. In 1992 the population of Iceland was 259,727 and in 1995 it was 266,978 (Statistics Iceland, 2017). Ten of the children diagnosed with other ASDs after age six were diagnosed with Asperger’s syndrome. It is of note that the age of children diagnosed the earliest (prior to age 3) have been found to have some of the most severe presentations and are more likely to have a diagnosis of intellectual disability as well (Jonsdottir, Saemundsen, Antonsdottir, Sigurdardottir, & Olason, 2011).

### **Challenging Behaviors**

ASDs are neurodevelopmental disorders, which affect social interactions, including emotional and behavioral interactions with others. These abnormalities of communication and social interaction have been shown to be closely related to sensory processing dysfunction in preschool aged children. The degree of sensory processing

dysfunction impacts the severity of the subsequent emotional or behavioral problems (Tseng, Fu, Cermak, Lu, & Shieh, 2011). Some of the problems associated with sensory-processing dysfunction include social and behavioral difficulties, distractibility, hyperactivity, and poor organizational skills. Behaviors often also include those of the self-stimulatory and self-injurious types. This behavior is important to note because mothers' quality of life has been associated, to a greater degree, with children's behavior issues more so than with the severity of autistic symptoms (Ben-Sasson, Soto, Martinez-Pedraza, & Carter, 2013; Johnson, Frenn, Feetham, & Simpson, 2011).

Other catalysts of problematic behaviors are anxiety and phobias, which co-occur in 50% or more of children with ASD and have been shown to impair functioning in many children with autism (Mayes et al., 2013). Families in the Netherlands of children with only an ASD diagnosis, rather than a dual diagnosis of ASD and ADHD, report a more positive family climate (Van Steijn, Oerlemans, Van Aken, Buitelaar, & Rommelse, 2015). The behaviors, consistent with a diagnosis of ADHD, increase "negative feelings about parenting, social relationships" as well as a negative impact on sibling relationships and on the marriages of parents of children with ASD (Sikora et al., 2013, p. 312).

One other associated condition, which commonly occurs with ASDs, is insomnia, occurring in 50-80% of affected children (Kotagal & Broomall, 2012). Insomnia in children is a condition which can adversely affect the quality of life and stress levels of mothers of children with ASD. While there are some pharmacologic interventions that have been shown to decrease insomnia in certain children with ASD, a universal medication regimen has not been found, which is due to the paradoxical effects for many ASD patients (Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008). The



requirement of supervising children during their waking hours can cause sleep deprivation for parents, who find themselves in the position of not being able to sleep, to ensure the safety of their children. This situation causes mothers to make a choice between the well-being of their child and their own well-being.

Challenging behaviors are often some of the most concerning aspects of ASD for parents. The behaviors displayed by children with ASD, such as sensory-processing dysfunction and phobias are often some of the symptoms, which cause mothers and close friends and family members to turn to health care and educational professionals for answers. It is often because of these challenging behaviors that the diagnostic process is initiated.

### **Diagnostic Process**

Most often, the mother of a child eventually diagnosed with ASD is the first to voice concerns and seek answers. Clarke (2013) described this phenomenon through a qualitative interview-based descriptive including 16 participants in Ontario, Canada. In another Canadian study, descriptive phenomenology was used with interviews from 10 sets of parents of children with ASD. Mulligan, MacCullough, Good, and Nicholas (2012) found that several themes from the diagnostic period emerged, including:

- (i) something is different, but what?, (ii) waiting, worry and uncertainty,
- (iii) receiving difficult information in a hopeful manner, (iv) feeling overwhelmed with information and emotion, (v) grief, relief and making sense of ASD,
- (vi) becoming an advocate, expert and case manager (p. 316).

Most often, the search for answers and assistance begins within the family and the network of social contacts with the mother attempting to normalize their child's

behaviors multiple times, using strategies suggested by family and friends, who had solved similar, if less severe, problems with other children. There have been times when friends and family members will deny or choose not to confirm the mothers' suspicions "in an attempt to decrease parental worry" (Mulligan et al., 2012, p. 316). When solutions offered through friends and family prove unsuccessful, mothers are more likely to seek out professional help from doctors, psychologists, speech therapists, and the internet, often embarking on searches involving *intensive mothering* behaviors to obtain answers and diagnoses (Clarke, 2013; Mulligan et al., 2012).

Often, autism or ASD is not the first diagnosis a child receives. In some cases, there are alternative diagnoses early in the process, which can range from hearing difficulties, speech delays, vision problems, and the umbrella diagnosis of developmental delay, or parents are told that their child "will grow out of it" (Sansosti, Lavik, & Sansosti, 2012, 87). The study, providing this evidence, had a concurrent embedded mixed methods design and was conducted with 16 parents of children with ASD recruited from a chapter of the Autism Society of America in Northeast Ohio. Sometimes, comments from people who are not part of the nuclear family about their observations of a child is what leads parents to seek professional assessment by a multidisciplinary team. The search for answers and a definitive label linked to funds, services, and support occurs after researching disorders with which those observed behaviors fit (Sansosti, et al., 2012).

Current best practice guidelines call for a comprehensive diagnostic evaluation for ASD completed by qualified professionals who can observe for the presence and appropriateness of the symptoms of ASD, including those related to social interaction,

communication, and repetitive behaviors. The six components of the evaluation are as follows: (a) a parent or caregiver interview, (b) a review of the relevant medical, psychological, and/or school records, (c) a cognitive/developmental assessment, (d) observation of direct play, (e) the measurement of adaptive functioning, and (f) a comprehensive medical examination (National Autism Center, 2015).

The diagnostic process for ASD can be long. In a study of 1047 parents in the United Kingdom, the average age was 3.9 years when parents sought diagnosis with 39% seeking diagnosis between ages two and five (Crane, Chester, Goddard, Henry, & Hill, 2016). Mothers and other family members can find the process to be arduous and can become frustrated by the inaccurate diagnoses received before initiation of the ASD diagnostic process. Often, when the diagnosis is received and the time comes to discuss treatments and interventions, parents and mothers are already frustrated with and disappointed in the system available to care for their child.

### **Treatments and Interventions**

NAC published Phase 2 of the National Standards Project (2015), which addressed the need for evidence-based practice guidelines for ASD. The center has described 14 established interventions for individuals under age 22, 18 emerging interventions for individuals under 22, and 13 unestablished interventions for individuals under age 22. Many parents have tried unestablished interventions, such as animal therapy, special diets, and shock therapy on the recommendation of professionals or parent-peers as part of the process of finding what will help their child. That process of seeking not only answers but also meaning is often fueled by hope that there will be an

intervention, which will alleviate some of the anticipated burden of providing a lifetime of care.

It is of note that parents have ethical agency over making treatment decisions for children with ASD. They often are required to make decisions for children who are not able to make their own, and those decisions are sometimes shaped by the parents' desire for a typical child. At times, the decisions for treatment have included interventions that are unproven, based on hope and the stories of other parents who have described anecdotal evidence, or research studies with weak or insignificant evidence, for example, a gluten-free and casein-free diet (NAC, 2015).

Some medical professionals have classified parents' decisions regarding treatment and interventions as reactive. They believe that parents are motivated by a desire for normalization or as a reaction to the grief and despair they experience as parents of a child with ASD. Parents' associated reactions often become more acute as their awareness of the all-encompassing nature of the diagnosis unfolds (Mulligan et al., 2012). These negative emotions are often exacerbated, causing a phenomenon of surplus suffering (Clarke, 2013), when attempts to access assistance and services are met with failure. One study, reported that Caucasian children whose parents have completed higher education are most likely to gain access to and utilize private support services outside of those provided by early intervention and public-school programs ( $B = .499$ ,  $SE = 0.125$ ,  $p < 0.0001$ ) (Irvin et al., 2012). The same study also showed, with the group of 137 families of preschool children with ASD that manifestation of greater sensory symptom severity earlier also impacted utilization of outside services. The 95%

confidence interval was not reported, which would have helped in interpretation of these results.

The desire and pressure to find treatments to provide the best outcome can cause a great deal of stress for families and mothers of children with ASD. Many sources of information exist, including books, mass media, the internet, friends, family, and the professionals who made the diagnosis or provide care. Mothers and caregivers are often aware that there are short windows of opportunity to qualify for services when they will be covered by public and private insurance. That is the time for professionals to listen and gauge understanding and the opportunity to help develop a plan for accessing services for the child and the family, when they will have the greatest impact for their children (Sansosti et al., 2012).

**Listening to the family story.** Family-centered theory was introduced in 1998 by Rosenbaum, King, Law, King, and Evans. The main concepts of family-centered care included in pediatric literature, as found through a comprehensive literature review, are as follows:

1. Recognizing the family as central to and/or the constant in the [child's]life, and the [child's] primary source of strength and support;
2. Acknowledging the uniqueness and diversity of [children] and families;
3. Acknowledging that [parents] bring expertise to both the individual care-giving level and the systems level;
4. Recognizing that family-centered care is competency enhancing rather than weakness focused;

5. Encouraging the development of true collaborative relations between families and health-care providers, and partnership; and
6. Facilitating family-to-family support and network, and providing services that provide emotional and financial support to meet the needs of families (p. 8)

These concepts provide the basis for listening to the family story. A study, using an eco-cultural approach and a sample size of 102 family member interviews, used family members' stories to develop an instrument to guide choices about interventions and accommodation domains to help with care of a child with a developmental disability (Bernheimer & Wiesner, 2007).

Literature about experiences of mothers of children with ASD is dominated by qualitative studies, which provide insight. One review article by Elder and D'Allesandro, 2009 was written for pediatric nurses and included advice about listening to family stories for the stages of grief (Kubler-Ross, 1969). The article advised listening to the stories for underlying questions and concerns, which might otherwise not be brought to light, including (a) confusion about symptoms, (b) medications, (c) siblings, (d) behaviors, and (e) the future. In another article, written by a nurse who was the mother of two children with ASD, a six-stage model to support families of newly diagnosed children with ASD was proposed following a review of the literature. She advocated for nurses to listen to the family story, especially the difficulties they have with caring for their children so that they are best able to assess their needs and plan how best to meet them (Estrella, 2013).

### **Mothers of Children with Autism Spectrum Disorder**

A mother of a child with ASD is likely to be the first person to note signs and symptoms of abnormal behavior. She is likely to ask questions at appointments with professionals, which initiate the diagnostic process for her child's diagnosis. This is a great deal of responsibility.

While, at one time, mothers were viewed by popular culture to be the cause of ASD in their child(ren) (Silverman, 2012), they have assumed the roles of advocate, therapist, and educator, much of the time in addition to that of mother or nurturer. Hundreds of studies of mothers of children with ASD have been published over the past 25 years and have focused not only on the stress and strains on individual (Hoogsteen & Woodgate, 2013; O'Connell et al., 2013) but also family well-being (Nealy, O'Hare, Powers, & Swick, 2012). Other studies have focused on contemporary stigma and mother blaming among mothers of children with ASD (Courcy, 2017; Thibodeau & Finley, 2017). Researchers have also studied and written about marriage and relationships (Benson & Kersch, 2011; Hartley, Mihaila, Otolora-Fadner, & Bussanich, 2014; Nealy et al., 2012).

Stigma and mother blaming were explored through two recent studies. Through a qualitative study, using semi-structured interviews with 13 Canadian mothers, Courcy & des Rivieres (2017) found that contemporary forms of mother-blaming related to a child's diagnosis. The interviews revealed two themes: mother blaming as related to the child's diagnosis and behaviors and blame for a lack of maternal involvement in an intervention program, which led to the absence of good behaviors. Mothers described that unveiling the child's diagnosis sometimes resulted in being labeled as a mother who over-reacts, which often led to discriminatory situations. The second way that mothers experienced

the first theme was through others interpreting tantrums and difficult behaviors as a lack of discipline or overly-permissive parenting. The second theme was expressed primarily as guilt for not detecting symptoms earlier, feeling guilty for not doing enough to participate in treatments, and feeling guilty for doing too much for children so that they do not become independent. Rigor was addressed in the study through inductive coding, thick descriptions, and dependability was ensured through presenting excerpts from interviews in the article. Saturation was achieved after 12 interviews.

Thibodeau and Finley (2017) found that adults were not more likely to rate the mother of a child with asthma as valuable than the mother of a child with ASD ( $N=98$ ,  $t(93) = 3.01$ ,  $p<0.01$ ). The study used regression analysis of data collected through use of two reliable and valid instruments, the Implicit Associations Test (IAT) and the Attitudes About Child Mental Health Questionnaire (ACMHQ) for the study. They found that subjects were willing to evaluate a mother of a child with ASD less positively than the mother of a child with asthma only when they were afforded an opportunity to disown it. The opportunity for subjects to disown the evaluation was accomplished through inclusion of questions referring to how others would perceive the mother or whether other people would invite her to their home ( $F(3, 91) = 3.00$ ,  $p<0.04$ ,  $R^2 = 0.09$ ).

In a study of 28 rural mothers of children with ASD living outside of Winnipeg, Hoogsteen and Woodgate (2013) completed phenomenological research that focused on mothers' need to "make the invisible visible" (p. 2). This was articulated through mothers' struggles to ensure that their children received the best quality of life while remaining in their home community. Mothers struggled to educate community members about ASD to help make the disability visible and present in the minds of community



members. Mothers also educated others to mitigate the effects on them of inappropriate and damaging reactions to challenging behaviors of their child. Participants described the perception that others viewed them to be bad parents. This study of rural Canadian mothers also discussed the continuum of the experience and the journey from diagnosis to finding and securing resources to acceptance and toward finding meaning in the parenting of their child with ASD.

Three individuals: a mother, a nurse, and a researcher from Ireland, published a mother's narrative and its analysis to enlighten professionals about the experience of mothering a child with ASD. The narrative includes poignant descriptions of the desire to commit suicide and the subsequent feelings of cowardice and guilt that followed. It includes explicit details about the mother's feelings of anger and hostility toward individuals who helped her, because the available assistance left so many unmet needs as well as the fatigue she experienced when she attempted to meet those needs herself. The narrative also discussed the guilt the mother felt when she was not able to divide her attention equitably between her son with ASD and her typically developing daughter. This single narrative presented many of the negative aspects of mothering a child with ASD, and the positive aspects of feeling that one has accomplished a great deal with each new milestone their child has met (O'Connell, et al., 2013).

While the child with ASD is greatly affected by their disability, he or she is not the only person impacted. His or her primary caregiver who is most often the mother in the United States is impacted, but so are all other family members. ASD is a lifelong condition, which causes a significant change to the family climate.

## **Impact on the Family and Family Climate**

A diagnosis of ASD often profoundly changes mothers' social lives. To avoid dire behavioral consequences for the affected child, it is common for the family routine to be preserved at the expense of engaging in outings or entertaining visitors (Sansosti et al., 2012). Several aspects of the peri-diagnostic process causes mothers of children with ASD to experience significant stressors. These stressors included grief about the loss of previous expectations for their child and the development of new expectations for a child with a disability (Benson, 2012). Following diagnosis, and while learning how best to cope with living with a child with ASD, families often experienced *decreased opportunities for fun*. These limitations included an inability to vacation or enjoy meals outside of the home due to potential outbursts or meltdowns in response to sensory overload or changes in routine (Nealy, et al., 2012).

This avoidance or perceived inability to enjoy fun activities as a family could lead to feelings of isolation for all members of the family and could decrease overall social support. One mixed-methods study of 104 parents in Northern Ireland, which combined semi-structured interviews with quantitative measures identified that the stress of not being able to participate in social activities without appropriate child care could lead to further isolation and could result in additional stress for mothers. The scales used in the study included the Vineland Adaptive Behavior Scale, the Gilliam Autism Rating Scale, and the Questionnaire on Resources and Stress. Overall, in this study, 51% of families experienced a restriction on socialization due to the child's difficult behaviors. Of the 104 parents, 29% felt that they "could not enjoy outings as a family," 27% "could not take the child to other people's homes," 23% were "not able to leave the child with a

babysitter,” and 17% “could not go shopping with the child” (Cassidy, McKonkey, Truesdale-Kennedy, & Slevin, 2008, p. 121).

The family unit is impacted when one member is diagnosed with ASD. These difficulties can involve feelings of deprivation, isolation, stress, and guilt. Different feelings can arise when a family of a child with ASD includes siblings.

### **Mothers and Siblings of Children With ASD**

Mothers described the impact of having a child with ASD on their other children in a predominantly negative manner. The inability to spend time and attention equally with siblings was a source of consternation for many mothers. Mothers expressed feelings of guilt because of their inability to reconcile the needs of each child, independent of the one with ASD. This could be due to the reduction of social opportunities and spontaneity that families experienced overall (Nealy et al., 2012). This impact of the diagnosis on siblings could be one where very little energy was available to be devoted to unaffected family members. Over time, the reluctance of parents to engage in functions with extended family members had the potential to limit extended family time for siblings and created feelings of isolation (Hoogsteen & Woodgate, 2013).

Nealy et al. (2012) conducted their study with eight mothers of children with ASD in North Carolina. Demographic information was collected prior to a face-to-face semi-structured interview. From an inductive analysis, four themes emerged: (a) emotional impact, including stress, worry and guilt; (b) family impact, including other children and the woman’s spouse; (c) social impact; and (d) financial impact (p. 193). The study illuminated that for the eight women who participated, the impact of mothering a child was great. The effects described included stress of being the primary caregiver for the

child, mothers' efforts to minimize negative impacts on others, the stress of social isolation, and the financial strain of affording for treatments and care for their children. The interviews were independently reviewed by two researchers and coded line-by-line, using an inductive approach.

While mothers generally feel that they experience greater parenting efficacy with their typically developing children, studies have shown that there are greater incidences of generalized anxiety disorder and major depressive disorder in siblings of children with ASD. These mental health disorders occur because of interactions with and consequences of having a sibling with ASD and are not mitigated by increased parental interventions (Bitsika, Sharpley, & Bell, 2013; Stampoltzis, Defingou, Antonopoulou, Louvava; & Polychronopoulou, 2014). The survey research, conducted in Australia by Bitsika et al., included 108 parents of children with ASD, of whom 104 were biological. The survey included several parts, including demographic data collection, an anxiety and depression assessment, using the Zung Self-Rating Anxiety Scale (SAS) and the Zung Self-Rating Depression Scale (SDS), which were based on DSM criteria for anxiety and depression. The reliability of these measures was discussed in the study as were cutoff scores for clinically significant results. The Connor-Davidson Resilience Scale (CD-RISC) was used to assess resilience, and its reliability was also addressed. Mothers with higher daily stress were found to have higher mean anxiety scores (SAS  $M = 50$ ,  $SD = 6.647$ ) and higher depression scores (SDS  $M = 51.196$ ,  $SD = 9.972$ ). Mothers with high CD-RISC scores were shown to have lower SAS and SDS scores, which did not depend on daily stress (Bitsika et al., 2013).

Some of the increased behavioral problems experienced by siblings of children with ASD include: “loneliness, alienation, bitterness, low levels of pro-social behavior, increased internalizing and externalizing problems, and peer difficulties,” as found in a study described only as *qualitative* (Stampoltzis et al., 2014, p. 475). The Greek study did not specifically name the process of qualitative research or name a specific method, which does not add to its strength as evidence. Siblings sometimes also experience feelings of hyper-responsibility and worry for their sibling’s behavior and well-being. These feelings could contribute to increased levels of anxiety and depression within this group.

In the United Kingdom, mothers rated their typically developing children as having lower levels of prosocial behavior ( $N = 168$ ,  $M = 8.07$ ,  $SD = 2.10$ ,  $p < 0.001$ ,  $d = 0.33$ ). The mothers in the study also rated their children as having increased behavioral ( $M = 2.11$ ,  $SD = 2.14$ ,  $p < 0.001$ ,  $d = 0.3$ ) and emotional problems ( $M = 2.66$ ,  $SD = 2.49$ ,  $p < 0.001$ ,  $d = 0.38$ ) than mothers of children without siblings on the autism spectrum. One sample t-tests were used to compare scores to the normal population of mothers’ ratings of 10,298 children. The instrument for measurement of sibling’s behavior was the Strengths and Difficulties Questionnaire. Participants were recruited the U.K.’s National Autism Charity (Griffith, Hastings, & Petalas, 2014).

While mothers of children with ASD tend to have warmer emotional relationships with their typically developing children, they experience guilt about how much time and energy they spend with their child with ASD. Mothers sometimes feel similarly about those with whom they have romantic relationships and friendships. In both sets of relationships, there can be resultant struggles or strengths.

## **Relationship Satisfaction**

Changes in spousal or co-parenting relationships as well as with friendships and social interaction can occur for parents of children with ASD. Parents often do not have knowledge of what the future will hold or which resources are available to help them to adapt to their dramatically altered future. This lack of knowledge, in turn, can lead to communication difficulties and decreased understanding of and responsiveness to the needs of the other partner in the relationship (Nealy et al., 2012). Those relationship changes can result in higher rates of divorce among this group of parents (Hartley et al., 2014), as found in a Midwestern population of 73 married couples. The study was intended to address division of labor in families of children with ASD; however, it also addressed marital difficulties, using both a daily diary and the Marital Adjustment Test.

In a 2010 study of 391 families, in Massachusetts and Wisconsin, Hartley et al. found that parents of children with ASD had a divorce rate of 23.5%. The divorce rate among parents of typically developing children at the same time was 13.81%. These families participated in a longitudinal study between 1998 and 2004 with matched samples and surveys at four different time points. These divorce rates were nowhere near the popularly quoted, but empirically unfounded, divorce rates of 80% for parents of children with ASD and 50% for other Americans (Freedman, Kalb, Zablotzky & Stuart, 2012).

In addition to the challenges and obligations of caring for the child diagnosed with ASD, parents often feel that they have a duty as a spouse to care for and support each other (Foo, Eng Hui Yap, & Sung, 2015). The Singaporean authors wrote that over time, the stress and burden of parenting a child with ASD caused deterioration in the

quality of spousal relationships, at least for the six parents interviewed. Fathers work outside of the home to provide economically for the family, and mothers were left to provide for the children with limited emotional supports due to the fathers' absence (Nealy et al., 2012).

In contrast to the work cited above through a longitudinal study over the course of three years of 136 parents from the United States (US), Benson and Kersh (2011) found that marital quality impacted the psychological adjustment of mothers of children with ASD. They found that there was a large correlation between marital quality and family socioeconomic status ( $r = 0.32$ ,  $p < 0.01$ ), as well as between marital quality and stressful life events ( $r = -0.31$ ,  $p < 0.01$ ). A high marital quality had a positive impact on child pro-social behaviors ( $r = 0.30$ ,  $p < 0.01$ ), including direction following, positive interaction initiation, and staying on task as measured with the Nisonger Child Behavior Rating Form (Benson & Kersch, 2011). These pro-social behaviors replaced some of the most challenging behaviors discussed above. Over the three years of the longitudinal study, the researchers found that parenting efficacy increased 39%, which was more than any of the other measured qualities in the study. This increase in parenting efficacy leads to the conclusion that, with adequate time to adjust, mothers are better able to adapt their expectations and to meet their new normal set of circumstances. This information was congruent with findings of Weitlauf, Vehorn, Taylor, and Warren (2014), who wrote:

The relationship quality and parenting stress explain a unique amount of the variance in maternal depressive symptoms, above and beyond the contributions of child-specific factors and that a more positive relationship may buffer the impacts

of parenting stress on depressed mood ... and a less positive relationship may exacerbate the impact of parenting on depressed mood. (p. 198)

Hock, Timm, and Ramisch (2012) found that the relationships of parents of children with ASD follow a pattern of three phases, including “ASD crucible, tag team, and deeper intimacy and commitment” (p. 409). The ASD crucible phase was described as encompassing the period of greatest contextual demands and emotional and cognitive reactions to the diagnosis of ASD. The tag team phase was described as the period when the couple focused primarily on parenting, sought stability and predictability, and as a period of conflict and distance as parents became able to find ways to parent within the context of ASD. The third phase, or deeper intimacy and commitment, was described as including an increased focus on the marriage, which was characterized by a greater closeness and intimacy. It is also the phase in which parents expressed confidence in the resilience of the relationship. In the case of this study, many negative impacts of an ASD diagnosis were articulated; however, the juxtaposition of the strengthened marriage after the couple’s successful struggle with adversity was articulated. The research team learned this through a grounded theory study with 19 participants, using Strauss and Corbin’s method in the US.

Other researchers have found that protective factors within the family context were predictive of relationship satisfaction, using the 37-item couples’ satisfaction index with a sample of 67 parent dyads raising at least 1 child with ASD. One protective factor was benefit finding as measured, using the benefit finding scale ( $\beta = 114.37$ , SE = 3.87,  $p < 0.001$ ). Optimism, as measured using the Life Orientation Test – Revised ( $\beta = 114.37$ , SE = 4.36,  $p < 0.001$ ), was also identified as predicting relationship



satisfaction of mothers of children with ASD. The group found that there were protective factors, which were also predictors of relationship satisfaction among mothers of children with ASD. These predictive factors included the following items: (a) optimism, (b) benefit finding, and (c) coping strategies (p. 1998). The authors also noted that parents experienced a stronger romantic relationship when they experienced positive changes and growth as the result of the ASD diagnosis (Ekas, Timmons, Pruitt, Ghilain, & Allesandri, 2015).

Through reviewing the literature, it is possible to find examples of a child's diagnosis of ASD strengthening and creating difficulty for mothers' ability to build and sustain relationships. Whether a mother or parent views their child's diagnosis as a positive or negative influence in their ability to build relationships could depend upon the length of time since diagnosis, the stage of the relationship, and the strength of the relationship prior to or because of diagnosis. Unfortunately, the studies found in the literature related to mothers' work, employment, and finances do not present such a dichotomy.

### **Work, Employment, and the Financial Impact of ASD on Mothers**

According to the qualitative study of 52 parents of children with ASD, conducted in the Midwest, the professional sacrifices parents of children with ASD make can be considerable and include leaving the workforce to provide full-time childcare and in-home treatment for their child (Altiere & Von Kluge, 2009). Employment sacrifices for mothers can include changing jobs to find one with a more flexible schedule or a reduction in hours to be able to spend time parenting their affected child. Some women decided to pursue employment in fields related to ASD to find an understanding

supervisor (Nealy et al., 2012). For many mothers of children with ASD, not working outside of the home caused an increase in parenting stress, which could be related to the constant demands of their role as well as the lack of respite (Hartley et al., 2014, Matthews, Booth, Taylor, & Martin, 2011).

Through a qualitative study, using open coding used in grounded theory, open-ended questions were asked of 112 parents of children with ASD. The participants were recruited through family support websites in the US. Some mothers reported that working outside of the home provided them with relief and “an opportunity to recover from family demands” (Matthews et al., 2011, p. 632).

For some women, it is not financially possible to leave the workforce to provide full-time treatment and care, which can become a source of stress, strain, and feelings of guilt for both the mother and for the family. Families with economic difficulties often required that mothers remain employed outside of the home to provide for basic needs for the child with ASD, including finding and paying for respite or day care and the purchase of therapeutic and safety devices (Baker & Drapela, 2010; Nealy et al., 2012). When mothers worked outside of the home, the other parent engaged in more caregiving activities, which was found to be related to lower ratings of parenting stress for mothers (Hartley et al., 2014; May, Fletcher, Dempsey, & Newman, 2015).

The survey research conducted by May et al. (2015) conducted in Australia with 80 subjects. The team found that for mothers, co-parenting quality is negatively correlated with parental stress ( $N = 80, r = -0.34, p < 0.01$ ). Autism specific parenting self-efficacy was also negatively correlated with parenting stress ( $r = -0.35, p < 0.01$ ).

Co-parenting quality and autism specific parenting self-efficacy were positively correlated ( $r = .23, p < 0.05$ ).

Many mothers of children with ASD experience effects on employment and finances because of the diagnosis and caring for their child. These can range from reduced employment options to making the decision to leave the workforce. Some mothers find that they must work outside of the home to provide for the basic needs of their families, but they do not have desirable employment options because of their obligation to meet caregiving needs for their child with ASD as well. This situation can exacerbate feelings of parenting stress.

### **Search for Help and Social Support**

For many families of children with ASD, family life begins to “revolve around the child” (Hoogsteen & Woodgate, 2013, p. 136) with the diagnosis. Every decision and choice that families make revolves around the child with ASD; when feasible, parents put much energy into searching for support for both the child and themselves. Without supports and with the singular focus of living with ASD, parents often experience fatigue, exhaustion, and burnout. For families seeking and requesting help, support is crucial to maintaining health and well-being (Bloch & Weinstein, 2009; Hoogsteen & Woodgate, 2013).

Many families who received a diagnosis of ASD by professionals were presented with the hope that the necessary interventions and services would be accessible as mandated by Public Law 99-457 Part H. These parental hopes were often dashed when families discovered the difficult task of obtaining the needed services. In some cases, services were not available. In other cases, the waiting lists were so long that they would

not be able to access the services until after their child had exceeded the age range with the most impact on the child's future. Once a child received a diagnosis, in many cases, the window of opportunity for the child to receive maximum benefit were very narrow. This lag in diagnosis and their inability to secure services can cause parents to feel powerless (Mulligan et al., 2012).

Social relationships often change and present challenges for families of children with ASD. Sometimes these changes occur due to the time-consuming nature of caregiving and providing therapeutic interventions for children, such as Lovaas or Applied Behavior Analysis (ABA) therapy (each of which has a recommended 25 hours per week minimum for maximum benefit) (Sansosti et al., 2012). Lovaas therapy and ABA are both behavioral therapies consisting of discrete trial training. Other times, these relationships are lost or strained because of a lack of understanding of the disorder and its associated symptoms and behaviors, including that individual differences exist in the presentation of the symptomology for each person with ASD (Nealy et al., 2012). Parents also may not maintain and cultivate social relationships out of a sense of duty to ensure that their child's behaviors do not inconvenience or hurt others (Foo et al., 2015). The feelings of isolation from family members who do not understand the disorder occurs frequently among mothers of children with ASD (Ramisch, Onaga, & Oh, 2014).

Many mothers also experience a fear of judgment from others, resulting in most positive statements about social relationships related to friendships formed through ASD support groups (Nealy et al., 2012). Such support groups as well as "organizations, conferences, journals, magazines, websites, and blogs" provide social networking and support opportunities for parents of children with ASD (Bloch & Weinstein, 2009). In a

10-year longitudinal study, Gray (2002) wrote about the impact on one mother having friends burst into tears when witnessing the violent outburst of her daughter with autism. Social rejection and stigma are daunting obstacles for many mothers of children with ASD.

Instrumental and emotional support are the two classifications of support discussed in literature. Instrumental support includes provision of care for the parent or child, including respite, financial assistance, transportation, or other supports, which directly accomplish tasks related to caregiving. Emotional support includes providing opportunities for the mother to engage in confidential conversations, providing reassurance, and/or providing a person for the mother to talk with when upset. Availability of both types of support has been shown to increase psychological adjustment in mothers of children with ASD (Benson, 2012).

In a study of parents of 143 children with ASD, the following open-ended question was asked: “What is your greatest service need?” A thematic analysis identified instrumental supports as nine out of the top 10 needs, including the following items: (a) respite, (b) planning for adulthood, (c) information about services, (d) access to supports over time, (e) integration and acceptance of children with ASD, (f) social skills programming, (g) local service availability, (h) services for difficult behaviors and aggression, and (i) better qualified professionals (Hodgetts, Zwaigenbaum, & Nicholas, 2015, p. 679). Respite, which topped the list above with 26% of parents in the above study identifying it as the single greatest need, was associated with increased mood “uplifts” and reduced daily stress related to parenting activities. The Canadian research team used regression analysis to find that disruptive behaviors were the greatest predictor

of unmet needs for families ( $B = 0.280$ ,  $SE = 0.084$ ,  $\beta = 1.322$ ,  $p < 0.001$ ) (Hodgetts et al., 2015).

In a 2016 correlational study of 122 single mothers of children with ASD, Dyches, Christensen, Harper, Mandelco, and Roper found that when offered, 59% of mothers accessed respite care, which was provided for one hour per day. This study showed a significant negative correlation between increased daily uplifts associated with this respite and reports of depression ( $r = -.17$ ,  $p < 0.05$ ). The researchers also showed a significant positive correlation between intensity of daily hassles and increased depression.

Parents often have difficulty reconciling the tension between grief and acceptance long after receipt of an ASD diagnosis. They often experience grief as they listen to the experiences of parents of typically developing children and crave the relative security of socializing with other parents who understand what it is like to care for a child with ASD (Solomon & Chung, 2012). In a study comparing the effects in a sample of 36 parent participants in on-line support groups as compared with 119 parents participating in face-to-face support groups, relationships established were as impactful using either forum (Clifford & Minnes, 2013). These relationships have been shown to moderate psychological adjustment and parental well-being, while online parent support groups were not. Maternal perception of a lack of informal social supports (both instrumental and emotional) provided by family and close friends were found to be linked to increased maternal distress and decreased well-being (Ekas & Whitman, 2011).

A group of US mothers of children with ASD, consisting of an initial sample of 142 and ending with a sample of 106 at year five, were surveyed regarding social

network characteristics and perceived social support. An average of approximately 15 close family members and friends were reported (Benson, 2012). This number is large, considering the propensity of parents of children with ASD to feel socially isolated. A social network with more inner circle members who provided instrumental and emotional support was linked directly to both perceived increased social support (point estimate = 0.078; 95% CI: 0.013, 0.164) and increased interpersonal strain (point estimate = -0.643; 95% CI: -1.410, -0.095) on maternal well-being. These relationships were established through structural equation modeling following descriptive analyses of the total support network (mean = 15.5; SD = 6.2), with 62% of those individuals described as being part of the mother's inner circle of family and friends. Following descriptive analysis, an examination of the bivariate relationships between network characteristics yielded only two significantly correlated relationships between maternal outcomes and parent, child, and family characteristics. Maternal education was positively related to perceived social support ( $r = 0.23$ ,  $p = 0.016$ ), and child symptom severity was negatively associated with maternal well-being ( $r = -0.25$ ,  $p = 0.011$ ) (Benson, 2012, p. 2604).

Mothers of children with ASD often have difficulty finding help and establishing support networks. They often live isolated lives due to behaviors exhibited by their children and the demands of caring for their children, often due to a lack of respite care for their child with ASD. When mothers and families do feel that they have adequate support networks in place, their self-perception of well-being is higher than for those who do not. This social support and connectedness has been shown to be correlated to lower rates of maternal depression as noted above (Benson, 2012).

## Caregiver Burden

Families of children with ASD are not able to live their lives without consideration for caregiving and for meeting the needs of the affected family member. Parents have a duty to care for and protect their children, and in the case of parents of children with ASD, that duty includes additional advocacy and often material participation in the provision of ASD services, including behavioral therapies (Foo, Eng Hui Yap, & Sung, 2015; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). In addition to formal caregiving responsibilities, parents and other family members also must consider the unique needs of the child with ASD. This consideration includes sensory hypersensitivities, which should be avoided. To maintain equilibrium and avoid meltdowns, measures often include the establishment of a strict routine, not changing furniture or its arrangement in the house and not taking vacations or inviting visitors into the family home (Schaaf et al., 2011).

Families of four mid-Atlantic children with ASD found that a routine provided stability and minimized difficult behavioral outbursts and meltdowns. While the routine provided for the benefit of the family member with ASD, all members of the family often needed to remain flexible and observant of the child for signs of sensory overload. Adaptive strategies included an escape plan for the individual with ASD so that unaffected members of the family could continue the activity, while the child with ASD and a caregiver left an event or situation with diminished predictability. This study had a low number of participants (n=4) and was presented as having employed a phenomenological design. There was not mention of achieving saturation, and the findings were presented with each child's results for the sensory processing measure,



which was completed by two independent researchers and based on the qualitative data collected for the study (Schaaf et al., 2011).

Caregiving involves much adaptation for families as well as consideration for potential difficulties, which could be encountered over the course of an outing, event, or activity. Sensory overstimulation often occurs at community events, such as sporting events, parades, and movies, where noise levels are high, and much movement and visual stimulation are present. Parents have also reported that they must remain constantly vigilant for fear that their child with ASD will run away. The concern about running away was particularly significant for outdoor events taking place in wide open spaces (Safe, Joosten, & Molineux, 2012; Schaaf et al., 2011). These modifications to routines, activities, and behaviors have potential of being isolating and restricting, and parents often felt that they were unfair to typically developing siblings, causing parents to feel guilt (Schaaf et al., 2011).

Mothers often assume the role of primary caregiver for children with ASD. If the family has opted to provide home-based ABA therapy for their child, they also often serve as the primary trainer and therapist. ABA therapy consists of discrete trials in a 1:1 setting and requires the child to complete simple tasks to earn positive reinforcement, such as applause, food, or a favorite toy. Tasks are very simple in the beginning of therapy and increase in complexity over time. Language, social skills, interaction, and other skills can be taught using this method (Silverman, 2012). The minimum number of 25 hours per week, which were necessary to demonstrate substantive improvement in laboratory settings, can place a significant burden on the family member providing the therapy (Tsai, Tsai, & Shyu, 2008).

In the first year after a child receives an ASD diagnosis, higher levels of general social support positively impacted the caregiver and family burden (McGrew & Keyes, 2014; Stuart & McGrew, 2009). Provider support and community social support were shown to impact marital adjustment to the diagnosis (McGrew & Keyes, 2014). Interestingly, a mother's positive appraisal of the diagnosis and the situation was indicative of increased caregiver burden, while positive appraisal of the circumstances was not linked to decreased caregiver burden (McGrew & Keyes, 2014).

In a Taiwanese study, increased functional dependence of a child was shown to be the main factor, influencing caregiver burden. The study used multiple regression analysis and had a sample of 50 mothers, ( $F(1,47) = 25.04$ ,  $\beta = 0.590$ ,  $R^2 = 0.348$ ,  $p < 0.001$ ) (Lin, 2011). In a study of Canadian parents of children with ASD and differences in caregiver burden across intellectual functioning (Vogan et al., 2014), parents, numbering 100% reported some level of caregiver burden with 54.9% reporting high levels of burden. In the overall sample of parents of children with ASD, "severity, medical comorbidity, internalizing problems, externalizing behaviors, parent age, and inability to pay for services" (p. 560) were highly correlated with caregiver burden. For the parents of children without co-occurring intellectual disability, inability to afford services was the only predictor of caregiver burden. Children who are higher functioning are often not able to access services through the existing system because they do not qualify for extant services for children with severe intellectual disability. The inability to qualify for services places much of the burden of care on families, sometimes from the time of diagnosis well into adulthood.

Through two separate focus groups of adolescents with ASD (N = 13) and their parents (N = 19), a team of Midwestern researchers explored perspectives on the challenges of transitioning to adulthood. Even after children have been diagnosed for years, mothers continue to experience caregiver burden as they assist with or make decisions about their child transitioning to adulthood. Fewer than 25% of adults with ASD live independently, work in jobs with a competitive application process, and have their own social network. That translates into many adult children with ASD being dependent on their parents and other family members for many years after they turn 18. In many cases, this dependence is due to a lack of services in communities. This dearth causes caregivers to feel “overwhelmed, anxious, and in great need of a break” during the transition to adulthood, which is an already stressful time for children with ASD and their families (Cheak-Zamora, Teti, & First, 2015, p. 555). Parents reported filling the need for services for their adult children by aiding independently in many cases, which causes some parents to feel simultaneously proud of themselves and overwhelmed by the provision of necessary care (Cadman et al., 2012; Cheak-Zamora et al., 2015). It is of note that caregivers of adult children with ASD experience levels of burden that equate with those caring for children with “acquired brain injury” (Cadman et al., 2012, p. 886).

The level of psychological stress that parents perceived and experienced was closely related to the level of unmet need and was indicative of the health of parents and their ability to continue to serve as caregivers (Cadman et al., 2012; Pozo, Sarria, & Brioso, 2014). For some families, the burden of providing care for an adult child with ASD 24 hours per day, 365 days per year became too great. These parents made the decision to move their child into a residence away from the family home.

Krauss, Seltzer, and Jacobson (2005), through a mixed-methods study, found that there were positive and negative aspects for mothers of both having the adult child reside in the family home and with having the adult child reside in a facility, such as a group home. Mothers from Wisconsin and Massachusetts experienced an increased peace of mind when cohabitating with their adult child. However, they also experienced greater levels of stress due to the problematic behavior and with constant caregiving. When adult children lived apart from their mothers, mothers reported that they had more free time and that they experienced less stress day to day; in some cases, they could seek employment outside of the home. The negative aspects of an adult child living apart for the mother included worrying about the quality of care because of frequent staff turnover. These mothers reported missing their child and not being able to visit them as much as they would like, and some even reported regret that they were no longer providing total care for their adult child. The decision to place an adult child in residential care is not taken lightly by most mothers and, per this study, created another opportunity for the creation of stress.

For mothers, caregiving is not something which ends at the end of the day or when a child with ASD turns 18. Caregiving requires a significant commitment of time, energy, and financial resources or coordination of care, if the care is not provided directly by the parent in most cases. For many with the transition to adulthood and the associated reduction in available services, families experience an increased burden when their children reach adulthood, if they continue to live in the home. Caregiving and caregiver burden present a significant source of stress and difficulty for many mothers of children with ASD.

## **Psychological Distress and Mothering an Individual With an Autism Spectrum Disorder**

Mothering an individual with ASD, as articulated above, can be a stressful undertaking. Fifty percent of mothers of children with ASD tested at a level of “immense psychological distress” (Kenny & Corkin, 2011, p. 16). Stress associated with parenting a child with ASD can impact many aspects of the lives of mothers, including emotional, financial, and physical dimensions. The chronic stress and associated crises that mothers encounter through parenting a child with ASD can lead to psychological distress, manifested as depression, anxiety, and other psychological disorders.

### **Parenting Stress**

Parenting stress has been defined as “the experience of distress or discomfort that results from demands associated with the role of parenting” (Hayes & Watson, 2013, p. 629). Parenting stress of children with ASD is experienced more deeply by mothers than fathers and is most often related to the challenging behaviors (especially sensory over-responsivity) displayed by their children (Ben-Sasson, et al., 2013; Johnson, et al., 2011). The Autism Diagnosis Observation Schedule, Generic (ADOS-G) score is the *gold standard* for diagnosing children with ASD, and a higher score is indicative of greater severity of symptomology. A study was conducted with 166 mothers of children diagnosed with ASD between the ages of one and 15 who lived in California and including greater than 50% minority participants. The research team learned through regression analysis that higher ADOS scores predicted higher parental distress scores, and that those children received more support services than children scoring lower on the

scale. The study also found that parents of girls experienced greater parenting stress than the parents of boys (Zamora, et al., 2014).

In extant studies of parenting stress in mothers of children with ASD, the high burden of caregiving has been demonstrated to contribute significantly to the manifestations of stress (Johnson et al., 2011; Tehee, Honan, & Hevey, 2009). The age of children with ASD was shown to moderate the level of parenting stress, as measured with the Family Stress and Coping Questionnaire (FSCQ-A). In an Australian study of 23 mothers and 19 fathers of children with ASD, aged 3-18 years, who were parents of younger and older children in the age range, reported higher scores. This decrease was hypothesized by the researchers to be caused by the initial difficulty with adaptation to life as a parent of a child with ASD and with the difficulties associated with the process of adolescents, transitioning to adulthood (Tehee et al., 2009).

In a US study of younger children (18-30 months) with ASD, problem behaviors were found to contribute significantly to parenting stress in mothers. The study used the 78-item Questionnaire on Resources and Stress, which has internal consistency alpha from 0.394 to 0.854; split-half reliability  $r = 0.85$  and  $0.89$ , and stability  $r = 0.80$ . Using this measure, the researchers demonstrated problem behaviors to contribute to parenting stress in mothers, using multiple regression analysis ( $N = 96$ ,  $B = 0.006$ ,  $SE = 0.002$ ,  $p < 0.01$ ) (Estes et al., 2013).

The stress of parenting a child with ASD can lead to manifestations of psychologic distress, including depression and anxiety. These manifestations are addressed most frequently in the literature focused on parenting a child with ASD. Mothers of children with ASD have been found to have higher levels of depression than

mothers of children with either other disabilities and/or with neurotypical children (Estes et al., 2009). This finding was replicated in a study, using a large data source consisting of 11,000 children representative of those born in 2001 (Jeans, Santos, Laxman, McBride, & Dryer, 2013). While the bulk of literature written about psychologic distress in mothers of children with ASD has focused primarily on depression, it is also important to consider other psychopathologies and their manifestation.

Two schools of thought exist regarding the increased incidence of depression in mothers of children with ASD. One holds that there is a genetic component to some cases of autism, and some mothers are predisposed to psychopathologies (Hodge, Hoffman, & Sweeney, 2011; Ingersoll & Hambrick, 2011). Another is that the stress of parenting a child with ASD creates a set of circumstances that is conducive to development of symptoms of depression and anxiety (Ingersoll & Hambrick, 2011). In a retrospective chart review in California, including 140 mothers of children with ASD and 302 mothers of children without ASD, researchers, using multiple regression, found the following psychiatric disorders to be significantly linked with the presence of a child's ASD diagnosis ( $p < .001$ ): (a) anxiety, (b) depression, (c) obsessive compulsive disorder, (d) somatization, and (e) interpersonal-sensitivity. The same study found paranoid ideation to be significantly linked to the diagnosis of ASD ( $p < .05$ ) (Hodge et al., 2011, p. 233).

An Australian retrospective cohort study ( $N = 277,559$ ) examined relationships between maternal psychiatric disorders, manifesting after birth of a child with ASD. It was discovered that depression and bipolar disorder occurred at a rate of greater than 3 times the rate occurring among mothers of children without ASD. The researchers

hypothesized that bipolar disorder and ASD have some common genetic factors and that the burden of care contributed to symptom expression of both affective disorders (Fairthorne, Hammond, Bourke, Jacoby, & Leonard, 2014).

Behavioral problems with children have been shown to be a predictor of parenting stress as well as parenting distress, such as anxiety and depression (Firth & Dryer, 2013; Rezendes & Scarpa, 2011; Zablotsky et al., 2013). Perceptions of parenting efficacy, using regression analysis in a survey research study of 134 mothers, were shown to directly mediate the relationship between parenting stress and increased depression and anxiety ( $F(1, 133) = 3.571, p = 0.031$ ) (Rezendes & Scarpa, 2011). The Depression Anxiety Stress Scale was used to measure depression and anxiety, and the Parenting Sense of Competence Scale was used to measure parenting efficacy in the study. Anxiety is due to concern about the child's future, including potential for independent living arrangements as an adult, career options for the child, and the child's general ability to adapt to adulthood (Nealy et al., 2012). Although the diagnosis of ASD can open doors to resources and can provide some answers for mothers, there is most often continual uncertainty about the future, which can be a source of stress (Bloch & Weinstein, 2009). Many mothers also experience anxiety after expressing their desire to have a neurotypical child rather than one with ASD and feelings of guilt related to their perceived failure to parent (Nealy et al., 2012). In a study of 1,110 mothers of children with ASD, the high stress levels, increased daily burdens, and lower quality of life (QoL) were found to have a high statistical correlation with increased depressive symptomology, especially when children experienced higher severity of behavioral problems (Zablotsky et al., 2013). When life circumstances are not easy to control, as is the case for mothers of children



with ASD, who often try to adhere to rigid routines and maintain a delicate equilibrium for their child always, it is not surprising that anxiety about what difficult situations could arise in the future, and depression occurs.

Several studies have been conducted that specifically measured the physiologic effects of stress. These studies include some which are purely physiologic and others that are both psychologic and physiologic. A study that combined both physiologic markers with psychologic indicators was conducted by Foody, James, and Leader (2015) and measured parenting stress, salivary biomarkers, and ambulatory blood pressure in mothers and fathers of children with ASD. The researchers reported that among the 19 parent dyads, mothers reported higher parenting stress, distress, anxiety, and depression, while fathers exhibited higher blood pressure; both parents exhibited lower than normal waking levels of cortisol, which is indicative of chronic levels of increased stress. The lower than normal waking cortisol levels were also found in a study of 82 mothers of children with ASD conducted by Wong et al. (2012). That study also showed that stressful life events did not cause marked increases in cortisol levels in midlife (average age of participants was 51.4 years) and illustrated the sustained toll that the high stress levels of mothers causes on the endocrine system.

Parenting stress of mothers and fathers of children with ASD have been studied from psychologic and physiologic approaches. Mothers experience parenting stress more deeply than fathers. They were also more prone than fathers to depression and other psychologic disorders believed to be caused by parenting stress.

## **Quality of Life**

Broadly, quality of life (QoL) is defined as the quality of a person's life as he or she perceives it and is a term related to well-being. Aspects of life, which contribute to its quality, include those of an emotional, social, and physical nature. When discussing QoL in health care, health-related QoL (HRQoL) refers to how disease, disability, or a disorder impacts the life of an individual over time (Centers for Disease Control and Prevention [CDC], 2016). In the literature related to mothers of children with ASD, several different types and measures of QoL have been utilized, including HRQoL, psychological QoL, and social QoL. Measures include several that were developed as either generic measures of QoL or for use with populations of which families, parents, and mothers of children with ASD are subsets. In studies focused on HRQoL, mothers surveyed reported that they experienced a lower HRQoL as a byproduct of both general and parenting stress (Johnson et al., 2011; Reed, Sejunaite & Osborne, 2016); so the physiologic effects of stress are not only present but also perceived by mothers. Quality of life in this body of literature was also discussed in conjunction with stress (Reed, Sejunaite, & Osborne, 2016).

Psychological QoL is often decreased for mothers of children with ASD. In several studies, mothers of children with ASD were found to be more likely to be diagnosed with depression than mothers of typically developing children (Benson, 2010; Cappe, Wolff, Bobet, & Adrien, 2011; Cianfaglione et al., 2015; Hodge et al., 2011). Worry and anxiety is common in parents of children with ASD due to the behaviors such as those who are not socially acceptable (Stuart & McGrew, 2009); self-damaging (Bitsika, Sharpley, & Bell, 2013; Rezendes & Scarpa, 2011), or for which the mother

might be blamed (Hall, 2012). Mothers also experience anxiety and depression related to their concern about their child's future (Lin, Orsmond, Coster, & Cohn, 2011).

One study conducted by Zablotsky, Anderson, and Law (2013), comprised of a survey of 224 mothers of children with ASD, measured maternal QoL, using the Parental Depression History Questionnaire (PDHQ). The PDHQ only addressed the emotional and social dimensions of QoL. Analysis of those dimensions, using logistic regression analysis, showed that mothers who reported higher levels of autism symptomology were more likely to report a negative life impact due to changes in their relationship with their spouse or life partner (OR = 1.02, 95% CI: 1.03 – 1.03,  $p < .001$ ). They were also likely to report a negative impact due to relationships with extended family members (OR = 1.03, 95% CI: 1.02 – 1.04,  $p < .001$ ). Negative impact was also reported in relationships with friends (OR = 1.03, 95% CI: 1.02 – 1.04,  $p < .001$ ). These mothers also reported a decreased ability to engage in their career or education (OR = 1.03, 95% CI: 1.02 – 1.04,  $p < .001$ ), and effects on their financial situation (OR = 1.03, 95% CI: 1.01 – 1.04,  $p < .001$ ). It is of note that this study was conducted prior to development of the QoL or the Quality of Life Scale, which were both developed and tested in 2014. The five areas measured in the Zablotsky, et al. study also address several, but not all, of the domains in the Beach Center Family Quality of Life (FQOL) Scale, which has been used to measure the QoL of families with children diagnosed with ASD (McStay et al., 2014).

Mothers of children with ASD also may have decreased social QoL. One reason for this decrease is all of the activities and expectations leading to caregiver burden (Cadman et al., 2012; Lin, 2011; Stuart & McGrew, 2009; Vogan et al., 2014). One other reason for decreased social QoL in mothers of children with ASD is the isolation related

to the social stigma of parenting a child with an invisible disability (Hoogsteen & Woodgate, 2013). A lack of respite care is another factor that can have a significant impact on a mother's ability to participate in social activities (Harper et al., 2013).

Family QoL, as measured by the Beach Center FQOL Scale for families of children with intellectual disabilities, includes measurement of 10 domains (family interaction, parenting, daily life, financial well-being, emotional well-being, social well-being, health, physical environment, advocacy, and productivity). This instrument was used to measure FQoL in several studies, comparing the effects of maternal stress levels on family QoL (Estes et al., 2009; McStay et al., 2014). While the Family Quality of Life Survey–2006 was not developed to measure FQoL specifically in families of children with ASD, it was found to be concurrently valid with the Beach Center FQOL Scale, using a sample of 62 families of school-aged Canadian children with intellectual disability and/or ASD ( $r=0.63$ ,  $p<0.01$ ; Perry & Isaacs, 2015).

The literature related to mothers of children with ASD includes several different measures of QoL, including that of health and family in addition to general QoL. Among these measures there have been several instruments used, so it is difficult to find a consistent measure of QoL over time and across culturally and geographically diverse populations. In the studies reviewed for this literature review, all studies found a decreased quality of life among mothers and parents of children with ASD when compared to other populations.

### **Coping and Adaptation**

Mothers of children with ASD, even prior to receiving a diagnosis, learn to cope with challenges and adapt their lives to meet the unique needs of their child. The process

of diagnosis can take a considerable length of time, and behaviors of children can be severe. Families adjust their lives to accommodate life with a child, sibling, or grandchild with ASD.

Coping is defined by Lazarus and Folkman (1984) as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 141). This definition considers the unpredictable changes in situations that arise when mothering an individual with ASD. The Lazarus and Folkman definition of coping also takes into account the stress involved with the efforts mothers are making to adjust thinking and behavior in reaction to their situations.

The predominant instruments used in studies of parents and mothers of children with ASD to measure coping are the COPE and the Brief COPE scale, which are freely available for use and measure 14 subscales: (a) self-distraction, (b) active coping, (c) denial, (d) substance use, (e) use of emotional support, (f) use of instrumental support, (g) behavioral disengagement, (h) venting, (i) positive reframing, (j) planning, (k) humor, (l) acceptance, (m) religion, and (n) self-blame (Carver, 1997; Carver, Scheier, & Weintraub, 1989). Four categories of coping strategies that are used predominantly by parents of children with ASDs have been identified, including active-avoidance, problem-focused, positive, and religious/denial (Hastings et al., 2005, Table 1).

Table 1. Predominant Coping Strategies Used by Parents of Children with ASD.

Coping Strategy	Examples
Active-Avoidance	

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	Substance use, self-blame, venting of emotions
Problem-Focused	Planning, acting to address problem, seeking instrumental social support
Positive	Humor, positive reframing, acceptance and emotional social support to cope
Religious/Denial	Drawing on religion or spirituality or pretending that the problem does not exist

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Hastings et al. 2005

In quantitative studies focused on maternal stress and coping, several researchers found that maladaptive coping strategies resulted from circumstances, such as the presence of child problem behaviors, increased stress, or fatigue, and the maladaptive coping strategies were likely to result in engagement of maladaptive coping strategies. Benson (2010) conducted a factor analysis of the Brief COPE to identify four dimensions of coping: (a) engagement, (b) distraction, (c) disengagement, and (d) cognitive reframing. Benson argued that the previous dichotomization of coping strategies of parents of children with ASD into problem-focused and emotion-focused was an oversimplified representation of coping behaviors for this population, and reported that distraction ( $R^2 = .212$ ,  $p < 0.001$ ) and disengagement ( $R^2 = .226$ ,  $p < 0.001$ ) coping strategies were significant predictors of depression in mothers of children with ASD (p. 223). Active-avoidant and religious/denial coping are maladaptive or ineffective strategies. These coping strategies were found in a study of 65 mothers, conducted by Seymour et al., to be increased by presence of child behavior problems (measured using the Brief Developmental Behavior Checklist-P24;  $d = 0.39$ ,  $p < .001$ ) and maternal fatigue (measured using the Fatigue Assessment Scale;  $d = 0.26$ ,  $p < .01$ ; 2013, p. 1553). In a

study of 153 mothers of toddlers, which also used the COPE scale to measure coping, Smith et al. (2008) found lower levels of emotion-focused coping and higher levels of problem-focused coping to be associated with higher scores of maternal well-being (as measured using dimensions of depression, mood states, and personal growth).

Coping strategies detailed in a series of 16 interviews, which were analyzed using narrative inquiry methods, included: (a) seeking for information, (b) support from family and friends, (c) spirituality, (d) social withdrawal, and (e) engaging in advocacy activities (Lutz, Patterson, & Klein, 2012). The study included participants who were at various life stages to provide a lifespan perspective, and the stories included glimpses into the evolutionary nature of the role of mothering an individual with ASD. Examples of coping strategies that were effective with a young child became ineffective as the child grew and matured. The stressors encountered by mothers changed as did the available supports and effective coping strategies, which was consistent with the findings of other studies that described autism as the “center of a cluster of stressors which accumulate and interact over time” (Marshall & Long, 2010, p. 106).

If coping is a moment-to-moment, day-by-day process, then adaptation, which occurs over a longer timeframe for mothers of children with ASD, is an approach to adjusting to the challenges of their life circumstances over time and with consideration of the future. Mothers of children with ASD make many adjustments to their lives as responses to stressors that arise because of their child’s symptoms, behaviors, and responses. Some of the adaptations to mothering a child with ASD from the literature have included: (a) changes to employment or career trajectory (Baker & Drapela, 2010);

(b) changes to socialization patterns (Hock et al., 2012); and (c) reliance on family or friends for instrumental and emotional supports (Benson, 2012; Zablotzky et al., 2013).

Mothers of children with ASD must constantly cope with situations and accommodate the unique behaviors and preferences of their affected child or children. They do this coping through many different approaches, which have been categorized into four groups most frequently used by parents of children with ASD, as noted above. Adaptation is coping, which occurs over time and can include changes to employment and career, finding instrumental and emotional support, and changes to socialization patterns.

### **Resilience**

Only one study specific to mothers of children with ASD was found as part of this literature search. Bitsika, Sharpley, and Bell (2013), an Australian research team, conducted a study on the buffering effects of resiliency on stress in parents with children with ASD. With a sample of 72 mothers, they found using the Zung Self-Rating Anxiety Scale (SAS), Self-Rating Depression Scale (SDS), and Connor-Davidson Resilience Scale (CD-RISC) as measures. These have all been used extensively and have acceptable reliability and validity. There were significant negative correlations between mothers' CD-RISC total scores and (SAS:  $r = -.430$ ,  $p < .001$ ; SDS:  $r = -.505$ ,  $p < .001$ ). For mothers participating in the study, there was a significant main effect for personal daily stress ( $F(2,15) = 21.895$ ,  $p < .001$ , Wilks Lambda, partial eta squared = .745), and for resilience ( $f = 8.603$ ,  $p < .005$ , Wilks Lambda, partial eta squared = .534), but no significant interaction between daily stress and resilience.



## **Theory of Inner Strength in Women**

The Theory of Inner Strength in Women (TIS) is a middle-range nursing theory developed initially through knowledge generated with phenomenological and grounded theory studies in the early and mid-1990s by Gayle Roux and later Catherine Dingley. The theorists have worked to further refine and test the theory as they have progressed through their research careers. While the theory was originally intended as a descriptive framework for inner strength in women who have experienced “challenging life experience[s] or illness” (Dingley & Roux, 2014, p. 39) in the literature, it has been primarily applied to women who were experiencing chronic illness.

The foundation of TIS was provided through a phenomenological study for which nine women were interviewed and asked to “articulate their subjective experience of inner strength” (Rose, 1990, p. 56). The result of the study was the identification of essential themes of inner strength, including the following items: (a) embracing vulnerability, (b) authentic interrelating, (c) employing humor, (d) being one’s real self, (e) balancing and centering oneself, (f) remaining quiet and calm, (g) understanding one’s own abilities and capacity, and (h) embracing vulnerability (p. 62-67). These essential themes are visible as the foundation for the dimensions of TIS, which would emerge over time.

In 1993, Roux completed a phenomenological study of 18 women with breast cancer. She found that there were four essential themes in the narratives related to the phenomenon of inner strength in living with breast cancer: (a) “coming to know,” (b) “strength within of she who knows,” (c) “connection of she who knows,” and (d) “movement of she who knows” (p. 40). These themes represent a position of power

and strength in the face of adversity for the participants in this study and continued the foundation of the strengths-based approach to understanding the phenomenon of women growing in inner strength following a devastating diagnosis.

From a metasynthesis of qualitative studies of inner strength by Roux, Dingley, and Bush (2002), the Theory of Inner Strength in Women emerged. The conceptual model included five constructs: (a) “knowing and searching,” (b) “nurturing through connection,” (c) “dwelling in a different place by re-creating the spirit within,” (d) “healing through movement in the present,” and (e) “connecting with the future by living a new normal” (p. 88). These constructs elucidate the concept of movement from the state of illness or crisis to a state of healing, acceptance, and adaptation as well as integrate spirituality into the theoretical model.

The Inner Strength Questionnaire (ISQ) was developed and tested following this metasynthesis and includes four scales to represent the four concepts of TIS at the time: (a) engagement, (b) connectedness, (c) anguish and searching, and (d) movement (Dingley & Roux, 2014; Lewis & Roux, 2011; Roux, Dingley, Lewis, & Grubbs, 2004; Roux, Lewis, Younger, & Dingley, 2003). As the theory has been applied, “living a new normal” has been integrated as the outcome of the theory (Dingley & Roux, 2014).

### **Concepts of Inner Strength and Resilience**

The concepts of inner strength and resilience are related. In comparing two concept analyses, one for resilience (Earvolino-Ramirez, 2007) and one for inner strength (Dingley, Roux, & Bush, 2000), the two concepts were found to be similar in that they both addressed overcoming and recovering from adversity, but were divergent in that resilience was described as being more *protective* or “*bouncing back*” (Earvolino-

Ramirez, 2000, p. 76) where inner strength was described as a transformative growth process following a challenging experience or event. Earvolino-Ramirez included the following defining attributes for resilience: (a) rebounding/ reintegrating; (b) high expectancy/self-determination; (c) positive relationships/social support; (d) flexibility; (e) sense of humor; and (f) self-esteem/self-efficacy. Dingley, Roux and Bush included the following defining attributes for inner strength: (a) a process of growth and transition; (b) point of confronting a life experience or event; (c) a deepening of self-knowledge; (d) a cognition of one's needs and sources to meet those needs, (e) connectedness with others; and (f) focused and balanced interaction with the environment. While there is some overlap between the defining attributes of the two concepts, there are some significant differences. Resilience is more of a reaction to a negative event or a series of events, and inner strength is a developmental and transformative process of growth in inner strength as individuals move through adversity.

### **Epistemology**

TIS is a feminist theory based on *a posteriori* knowledge, or knowledge gained through lived experiences following a challenging life event from a feminist standpoint. Roux, Dingley, and Bush (2002) presented TIS as an alternative women's perspective to the *androcentric* view of strength. Meaning is developed individually for each woman, through living through the experience of growth in inner strength and through each of the four dimensions of the theory while adapting to a new normal. That adaptation is the outcome, following the presence of a challenging life experience or illness as a catalyst (Dingley & Roux, 2014). The behaviors of women who are adapting to life following such an event are believed to contribute to and provide a basis for the meaning and inner

strength, which will allow them to live a new normal and experience psychological well-being and healing.

### **Ontology**

TIS assumes that inner strength is built and developed in women through experience with adversity in the form of challenging life experiences or illness. The phenomenon of inner strength is described as nascent in all women as a human response to a difficult or challenging life circumstance. The theorists described TIS as a “circle of inner strength,” which ends with women “nurture[ing] others and acknowledge[ing] that extending themselves to others became a source of strength” (Dingley & Roux, 2014, p. 33).

TIS is a middle-range gender-specific nursing theory comprised of four dimensions and an outcome. The four dimensions are as follows: (a) engagement, (b) connectedness, (c) anguish and searching, and (d) movement and the outcome is living a new normal (Dingley & Roux, 2014). A tool has been developed and tested, which measures inner strength in women, called the Inner Strength Questionnaire (ISQ). The theory has been applied to and informed by several populations but not yet mothers of children diagnosed with ASD.

### **Gaps in the Literature**

The experiences of mothers of children with ASD are well documented in the literature through both quantitative and qualitative studies. While de-identified data may be archived and made available to further researchers, qualitative data used for the studies included in this literature review were not available for additional analysis and reinterpretation. Mothers and families of children with ASD have not been able to bear

witness to their experiences because their interviews were not archived and entered into the historical record. This study, which employed a postmodern philosophical framework, not only created data for analysis in this study but also generated narratives that provided mothers of children with ASD with a voice, which can be heard by future researchers.

Research in inner strength had not yet been conducted with the population of mothers of children with ASD. TIS had not been applied to this population although, through the literature review, many of the concepts and dimensions of the theory were found to be present, including adaptation, coping, overcoming stress, emotional well-being, anguish, grief, hope, and the search for information and solutions. The presence of these concepts in the literature related to mothers of children with ASD created an opportunity to inform TIS through this study.

Through this review of the literature, several additional suggestions for further exploration possible through this study were elucidated. Shtayermman (2013) stated that it would be beneficial to explore mother's expectations about their child's future as that appears to be linked to elevated levels of anxiety among parents. Additionally, Ekas et al. (2015) suggested focusing research on the romantic relationships of parents of children with ASD as well as strategies mothers have employed for positive reframing of life, following the diagnosis. This reframing has implications for enhanced resiliency, coping, and growth of inner strength. Social support and societal factors as contributing to parental adjustment was suggested by Estes, et al (2013) as an area for further investigation.

## **Summary**

This chapter summarized extant literature related to mothering an individual diagnosed with ASD. The literature presents the current state of the science of social supports and relationships, caregiving and caregiver burden, parenting distress, quality of life, coping, adaptation and resilience as well as the Theory of Inner Strength in Women. The study described here filled a gap in both qualitative data collection in nursing and an opportunity to further inform the Theory of Inner Strength in Women.

## **CHAPTER III**

### **METHODS**

Oral history is defined by the Oral History Association (2010) as “a way of collecting and interpreting human memories to foster knowledge and human dignity” ([www.oralhistory.org](http://www.oralhistory.org)). Uniquely, oral history is both a process and a product - the process of using an interview to co-create a narrative and then to preserve that narrative in a way that will allow it to become part of the historical record with its own emerging theories. This method has been used extensively in the disciplines of history and the social sciences. Oral history as a research method has been used in the discipline of nursing as a method for archiving life histories of nurses but not frequently as a method for collection and analysis of narratives with the intent of understanding experiences, as is the case in the discipline of sociology.

Oral history has been described as having six characteristics. The first is that it is an interview or exchange between an individual asking questions and another who is answering. Another characteristic is that it is recorded, processed in some way, and made available to others. A third characteristic is that it is historical in intent. A fourth characteristic is that it is understood as memory and as a subjective account of the past. A fifth characteristic is that the interview is planned and conducted in depth. Lastly, oral history is oral and not reliant upon transcripts (Shopes, 2011). The interview must be carefully choreographed by the interviewer but still allows for serendipitous reflections,

which will provide insights that could only have been co-created through the partnership and shared authority of the two individuals involved in that interchange.

Oral history is unique within the discipline of history in that oral historians co-create their own primary sources. This creation and the challenges associated with interpretation and analysis of these sources have caused oral historians to draw upon conceptual and theoretical frameworks from across many related disciplines, such as storytelling, folklore, sociology, and the study of memory. Oral historians have also created their own interpretive frameworks, including those of composure theory, the cultural circuit, and shared authority (Abrams, 2010). This theory development is a testament to the maturity of the discipline, which began as a top-down movement focused on collections of life stories of eminent figures and has evolved into a method for bearing witness, giving voice, and empowering those who narrate and enter their experiences bottom up into the historical record.

The following sections of this chapter describe the theoretical framework for this oral history study, the philosophical underpinnings of the methodology, the relevance of oral history as a method for nursing research, and a detailed description of the research design.

### **Theoretical Framework**

Feminist approaches to oral history have included exploration of issues related to subjectivity and intersubjectivity. Research methods, influenced by feminism and in which feminists engage, are motivated by an ideological position that seeks to explain and understand women's subordinate positions in a patriarchal society while simultaneously liberating them in the present (The Personal Narratives Group, 1989).



Feminist standpoint epistemology argues that those occupying subordinate roles understand their condition of oppression with less distortion than those occupying positions of privilege. Chinn (2000) suggested that feminist research values differences in populations and helps to shed light on perspectives of women. To counter the argument that some critics make that women's voices have less legitimacy in a society in which they are structurally oppressed, postmodern feminist oral historians aim to create an interview environment and experience conducive to expression of women's *honest voices* (Hekman, 1990). Measures to accomplish this include the following: reduction of the perceived power between interviewer and narrator, focusing narrative on the inner self rather than the social self through use of introspective questions, and treating the interview as a conversation or shared experience. The give-and-take exchange between interviewer and narrator in many oral histories sets the stage for the shared authority advocated and articulated by Frisch (1990).

### **Feminist Standpoint Theory**

One aim of this study was to build an understanding of the lived experiences of mothers of children with Autism Spectrum Disorders (ASD). This study empowered these individuals through bearing witness and giving voice through use of oral history methods. The second aim of this study was to inform the middle-range nursing Theory of Inner Strength in Women (TIS). Because of the aims of the study and the method used, Feminist Standpoint Theory was appropriate to provide a theoretical framework.

While there are differences between Smith (1987) and Harding's (2004) conceptualizations of Feminist Standpoint Theory, both include theses of situated knowledge "from the point of view of a woman's place" (Smith, 1987, p. 7) and

epistemic privilege (Crasnow, 2014; Intemann, 2010; Wylie, 2004). Ontology of feminist standpoint theory has largely been ignored in the literature as a way of moving away from the male model of thought and considering that it is not possible to talk about the experience of women. There has been a dearth of recent exploration of the ontology of feminist standpoint theory, primarily because feminist standpoint theorists recognize that women “hail from a diverse range of class, cultural, and racial backgrounds, inhabit many different social realities, and endure oppression and exploitation in many different shapes and forms” (Brooks, 2014, p. 78). Because of these diverse and ever evolving experiences of women, feminist standpoint theory and epistemology, too, is evolving.

### **Oral History Theory**

Oral history is a research methodology that is historical in intent but interdisciplinary in practical nature. Because of that juxtaposition, oral history theory has developed through cross-disciplinary exploration of interpretive frameworks. It has evolved from roots in the disciplines of not only history but also the social sciences, including sociology, political science, anthropology, psychology, and the study of memory as well as traditions of literary analysis, including narrative inquiry, folklore, and storytelling (Abrams, 2010).

### **Postmodern Oral History Philosophy**

That no one entity can know the truth as perceived or experienced by another is central to the postmodern philosophical framework. Postmodern thought rejects experiences within the constraints of overarching theoretical frameworks and places the focus on individuals’ relationships. Relations, reactions, thought, and being are explored in the context of an innumerable set of variables, including the interconnectedness of all

people. In essence, postmodern oral history philosophy, ontologically, recognizes that in an oppressive construct, one cannot produce more than a partial story. Postmodern thought is defined as having these features: “1) irreducible multiplicity; 2) the irreducible unthinkable in thought; and 3) irreducible chance” (Plotnitsky, 2010, para. 7). It can be concluded that an oral history study with postmodernist philosophical underpinnings will have potential for similar features in the context of oral history methodology – a series of endless stories as interpreted by future researchers through the lens of their experiences and thoughts.

Alessandro Portelli, an oral historian whose work history detailing the Resistance uprising and the subsequent Nazi massacre at the Fosse Ardeatine in March of 1944, articulated so much about memory, orality and the processes embedded within oral history. He wrote: “Oral sources are never anonymous or impersonal... the rememberer and the teller are always individual persons who take on the task of remembering and the responsibility of telling” (2003, p. 14). There were several examples of memories constructed differently by individuals. Among these, Portelli noted that the people he interviewed had different perceptions and memories of the length of time between the uprising and the massacre, ranging from one week to several months. Nobody, however, was able to recall the correct amount of time (24 hours) that passed. These people were not misremembering, but had constructed memories of events based on what had been presented to them through telling and retelling of stories or what they remembered after creating meaning from their own lived experiences.

Experiences in a postmodern context are culturally and socially constructed without universal rules or foundations of moral judgment, requiring reflexivity for

individuals engaging in intellectual activity. Postmodernism rejects the metanarratives of modernity and presupposes a simultaneously complex and simple relational narrative between agents. The narrative is complex because of the irreducibility of variables, thought, and chance. It is simple because the co-created narrative is what it is supposed to be in that moment between those individuals. Each individual is rooted in a social and cultural environment with a network of “relationships, roles, and practices – with [their] own local shared conception” (Vogel, 1994, p. 113). The narrator and interviewer co-create narratives which they believe to be true, after processing and making sense of them. One of the most important jobs of the oral historian is, according to Frisch, “to use our skills, our resources, and our privileges to insure that others hear what is being said by those who have always been articulate, but not usually attended to” (1990, p. 71). For these reasons, a postmodern oral history study is well-suited to inform the TIS.

### **Relevance of Oral History in Nursing Research**

Nurses, as part of their professional skillset, possess the ability to establish meaningful personal connections with individuals in their care. The meaning generated through interactions between patients and nurses is co-created in much the same manner as it is in oral history and other narrative research. Gadow (1999) described co-creation of relational narratives between nurses and patients as a postmodern turn in nursing ethics. She wrote, “nursing has (re)discovered narrative as a form of coherence in the absence of encompassing certainties” (p. 65), and Sandelowski (1994) encouraged nurses to use narrative interventions to create emancipatory narratives, which have the capacity to allow movement toward a self with possibilities. Those ideas are in alignment not only

with the practice of postmodern oral history but also as the feminist standpoint theoretical framework that aided this research.

Nurse researchers have used oral history as a method for chronicling the progress of the profession as well as the life histories of individual nurses. The postmodern feminist oral history methodology has also been used in concert with critical social theory as “advocacy oral history” (Falk Rafael, 1997) to work toward bearing witness to the struggles of public health nurses and their work for underserved populations in Southern Ontario. The American Nurses Association, in *Nursing’s Social Policy Statement*, defines nursing as “the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations” (2010, p. 13). The statement above provided guidance for withholding names of narrators and their family members from this dissertation.

Narratives, co-created, analyzed, and interpreted, employing oral history methodology, can be used to enrich nurses’ knowledge base as well as contribute to understanding of nursing practice and inform the theories and frameworks used. At the same time, oral history methodology can also enrich historical understanding in a socio-cultural context. Boschma (2007) used oral histories and narrative analysis to analyze family responses to psychiatric care and mental illness to build understanding of the meaning of mental illness and an ambivalence to dominant frameworks of associated care.

## **Research Methods**

The aims of this study were as follows: (a) to add to the historical record oral histories of mothers of children with ASD living in Olmsted County, MN and (b) to inform the TIS through a study of women who have experienced challenging life events other than their own chronic illness. These aims were met through this oral history study. Data was collected through semi-structured interviews, consisting of open-ended questions conducted with the purpose of co-creating narratives of the lived experiences of these mothers. To guide the interviews, a list of questions was utilized (Appendix A). This list of questions was developed to elicit life histories, which will contextualize experiences, considering socio-cultural influences, encompassing the interplay between past and present interpretation of that past by each individual narrator. Interviews were digitally recorded in audio format.

### **Participants and Setting**

Narrators in the study met several inclusion criteria. First and foremost, they were mothers (biological or adoptive or step mother) of a child diagnosed with ASD. Secondly, the child needed to have had the diagnosis for two or more years. Participants were required to speak English and live in Olmsted County, Minnesota at the time of their interview. They also had to be willing to spend 60-90 minutes in an interview by the researcher at a mutually agreed-upon location. Finally, each participant agreed to have her interview materials, including digital recordings, notes, and any other items she contributed archived following completion of the study.

Purposive and snowball sampling were used for this study. Narrators included my personal contacts as well as contacts referred by individuals after participating in the

study. One narrator was recruited through leaving a recruitment flyer in the mailbox of a home with an “Autistic Child” sign in the front yard. Data saturation occurred following analysis of the ninth interview, and then a tenth interview was conducted with one additional mother of an adult child with ASD to ensure saturation. A letter, describing the study, which included contact information for the researcher (Appendix B), was provided to narrators who indicated that they knew of another mother of a child with ASD who met the inclusion criteria who might be interested in participating.

Narrators were recruited in Olmsted County, Minnesota. The county had a prevalence of ASD that was 40% higher than the national average in 2015 (Rochester Public School District, 2015). The community is home to numerous organizations, providing medical, educational, and supportive services to children with ASD and other special needs (Appendix C). The study was conducted in this location to help establish a baseline viewpoint of how mothers in a resource-rich environment move toward a new normal after diagnosis. Most of the oral history interviews were conducted in narrators’ homes, although a few were conducted in more public locations, such as coffee shops or a meeting room at the public library.

### **Protection of Human Subjects**

The University of North Dakota’s Institutional Review Board approved this study prior to commencement of narrator recruitment or interviewing. Due to the nature of oral history, each individual who chose to participate in the study is identifiable as the narrator of her story once archived. No confidentiality could be expected by nor was any offered to individuals who elected to participated in the study. Narrators were informed of the interviewer’s status as a mandatory reporter of child abuse. It was determined to

use abbreviations for the mothers' and children's names in this dissertation and in nursing publications out of respect for the children's vulnerability and the tradition in research reports in the discipline of nursing.

The original digital recordings from this project were made available for narrators' review and validation. Each narrator was given a digital copy of her interview on either a CD or a flash drive and had the ability to seal portions of the recordings. Each mother was told that she could discontinue participation in the study or request to seal all or part of her interview at any time prior to archival of their oral history. All interview recordings and materials are archived in the Special Collections Library at the University of North Dakota.

Potential narrators were contacted by e-mail or telephone following their initial expression of interest in participation. Narrators were asked a series of questions to determine whether they meet inclusion/exclusion criteria (Appendix D). Narrators were then sent or given a copy of the description of the study and an informed consent form (Appendix E). A follow-up phone call was made by the interviewer to explain the informed consent process and to answer any questions that a narrator had about any aspect of the process. The interviewer completed the informed consent process with each narrator, and then the potential narrator was asked to complete a demographic information form.

Narrators had the right to refuse to participate or to discontinue participation at any time during the study. They were asked to give their time freely. Childcare was offered; however, none of the mothers requested it. Potential risks associated with this study were considered to be minimal. There were no known risks to the participants, but



emotional discomfort did occur for many women during the interviews. For some mothers, unsettling memories were recalled, and they became emotional during the reflection. None of the women experienced distress, but the plan for that occurrence was for me to pause or cease the interview and determine with the mother whether she desired to take a break, postpone the interview, and/or seek an outside referral source for counseling. The interview would have been paused or ended if the emotional distress experienced was severe. If a narrator experienced major emotional distress, counseling would have been advised, but that action was not necessary.

### **Data Analysis**

For this dissertation, the objective of the oral history analysis was to discover and interpret underlying meaning within an interview to connect the individual and the collective through stories about the lives of mothers of children diagnosed with ASD. As a qualitative research study, using a postmodern oral history methodology and feminist standpoint theory as a framework, the narratives were co-created through the interview process were intended to generate themes, which contributed to the understanding of lives of mothers of children with ASD living in Olmsted County, Minnesota. The intent was not to generate generalizable knowledge about the group without recognition of each individual narrator, contributing to the conversation.

Interviews remained in their raw format because I believe that transcription adds an additional filter, which could add distance between the truth and meaning of narratives (Brown, 2005). Through the process of transcription, meaning can be lost through elimination of utterances, variations in volume, pauses that could indicate potential disagreement, variations in the velocity of speech, and nuances of inflection.

Maintaining the primary source material digitally can be viewed as “restoring orality to oral history” (Shopes, 2011, p. 460). The availability and use of digital recordings allow for researchers to analyze and interpret interviews in an “ongoing, contextually contingent, fluid” manner to construct meaning (Frisch, 2006, p. 113) and, for that reason, is in alignment with the theoretical framework and philosophical underpinnings of this study.

**Thematic analysis.** Collected narratives of mothers of children with ASD were interpreted, using thematic analysis. For the purpose of this study, thematic analysis was employed to engage in discovery of patterns of meaning. This analysis was accomplished through inductive development of codes or themes to categorize narrative data co-created through the oral history process. This analytic process was chosen due to its use of chunks of data and, even entire stories, without stripping them of their context.

Through thematic analysis, these co-created narratives were coded in a way that “captures the important concepts within a data set” (Ayres, 2008, p. 867). In this context, a theme maintained relationships between concepts and actions and remained embedded within its original context. This method was congruent with the philosophy and framework for this study.

**Process.** The data analysis process for this study began with immersion in the data. This immersion was accomplished through repeated listening to the interviews as a means for facilitation of inductive coding. The process of listening and re-listening to interviews occurred over the course of approximately 10 months. The interviews were imported into the NVivo 11 Plus software package for qualitative data management and were accessed utilizing that software throughout data analysis. The choice to use a

software package was made for several reasons, the first was that the data remained in the raw form of digital audio. Memo writing could be accomplished and linked to the raw data, using the features of the software. The second reason was that the project could be worked on portably. A laptop computer allowed for the entire project to be carried for spontaneous recording of relationships, memos, and other ideas related to data analysis and interpretation.

The data analysis process for this study followed the process articulated by Kvale and Brinkmann (2008) and included the following steps:

1. Listen to recorded interviews and make notes about first impressions. This step commenced as the first interview is being recorded.
2. Relevant phenomena were labeled to begin to code the interviews. This labeling included phrases or stories repeated in several places, statements that surprised me, information that a narrator said was important, or data applicable to TIS. Every attempt was made for me to stay close to the data, as described above.
3. Themes were created by bringing several codes together. I dropped initial codes that no longer seemed important. Creation of themes was done at a general, more abstract, level to conceptualize data.
4. I labeled themes and described connections between them. This labeling and description consisted of the new knowledge about the world from the standpoint of narrators and myself.
5. I then drew a thematic diagram to represent the data.

The last phase of data analysis for this study included a final review of the interviews to validate the identified themes. Narrators who chose to participate in the study were asked to review the themes identified through this study and were asked to validate the accuracy of the researcher's interpreted meaning from their standpoint.

### **Rigor**

In oral history with postmodern philosophical underpinnings, it is accepted that each person has not only unique experiences but also unique interpretations of those experiences. It was, therefore, necessary to articulate how trustworthiness of these research findings would be established and maintained (Thomas & Magilvy, 2011, p. 152-154). The four elements of rigor in qualitative research are as follows:

(a) credibility, (b) transferability, (c) dependability, and (d) confirmability.

#### **Credibility**

Credibility was established through reflexivity, including creation of a reflexive statement by the researcher. Validation of each interview through a review of the recording for accuracy was completed by each narrator. None of the mothers desired any changes or to not include all or part of her interview in the archival process. If there had been a desire to change something, it would be noted and kept with the interview data. I strove to present an accurate representation of the findings across the interviews co-created throughout the course of this study. Credibility was strengthened through the collaboration of the researcher with the dissertation committee members.

#### **Transferability**

Transferability was established through a detailed and accurate geographic and demographic description of the population interviewed for this study. In the postmodern

tradition, a range of experiences on which to inform the Theory of Inner Strength in Women were incorporated from among mothers of children with ASD living in Olmsted County, Minnesota.

### **Dependability**

Dependability was established through the descriptions provided above with regard to (a) purpose, (b) narrator selection, (c) interview procedures, (d) data analysis, and (e) interpretation procedures as well as the techniques incorporated to establish credibility. An audit trail was maintained throughout the research process, beginning with the proposal.

### **Confirmability**

Confirmability was established through reflexivity, thus allowing narrators to select their contributions to the narrative. I asked for clarification of points or terminology not understood at the time of the interview and asked a few questions during the analysis phase when I was seeking additional information. These points are discussed in Chapter V. Recording notes in a reflexive journal about my personal feelings, biases, and insights were incorporated to establish confirmability. The journal was scanned and added electronically to the NVivo11Plus files to be accessible whenever and wherever coding data.

### **Trustworthiness**

Due to the nature of oral history, findings were not intended to be generalizable. The narratives co-created through these interviews are unique to the narrator-interviewer dyad. Due to the loosely structured format of oral history interviewing and to the understanding of subjectivity and intersubjectivity, it was anticipated that each interview

would be influenced by the standpoint, perceptions, and experiences of both individuals involved.

### **Ethical Considerations**

One critical element of study design was the ethical framework within which the study was conducted. Deciding this aspect of the study helped me to make decisions about how to resolve ethical conflict when it arose at any phase of the project. For the purposes of this study, employing an ethic of care was crucial to the process because every person is vulnerable in their grief, and grief is transient; events or memories can cause grief to resurface. Experiencing extreme emotions can cause lapses in judgment (Bucciarelli, Khemlani, & Johnson-Laird, 2008), which could contribute to narrators sharing stories they might not otherwise have shared. I was dependent on each woman for her stories to engage in a research project, and each woman was dependent on me to treat her stories, reputation, and well-being with care. I also had an obligation to consider vulnerability of each mother's child and think about ethics of care as applied to each interview. Before and while telling their stories, the women were vulnerable to the interviewer-narrator power difference, which often exists (Herron & Skinner, 2013). To mitigate this vulnerability, I communicated the interview guide ahead of time, so that narrators could prepare emotionally for the conversation that would take place.

Oral history has evolved to a form of history perfectly suited to collecting, archiving, and interpreting histories of groups and individuals who might historically not have had a voice. It has been used for gathering social histories and has been used to chronicle "history from below" (Dunaway & Baum, 1996). This impetus to include non-elite persons in the historical canon has created opportunities for exploitation. However,

some historians may argue that this inclusion gives those individuals a voice, which they might not otherwise have had (Feldstein, 2004). The recording of voices through audio, video, or transcription increases exposure of narrators to exploitation and creates opportunities for misinterpretation and disregard for narrators in favor of investigating and articulating that which might never be understood by others than the narrator and the interviewer (Ahern, 2012). One of the safeguards against this misunderstanding is the process of interview review, i.e., to give each narrator an opportunity to read or listen to their words and answers to interview questions and then to make decisions, regarding whether or not to include portions of their interviews in the historical record (Oral History Association, 2010).

### **Limitations**

This oral study included mothers of children with ASD living in a small geographic area. The knowledge generated through this qualitative inquiry was not intended to be generalizable. The geographic area in which the narrators live has many resources available for medical, educational, and supportive care of children with ASD, so the experiences of the women studied through this inquiry were not typical of many mothers of children with ASD who live in areas with more limited resources.

It was possible that narrators who chose to participate in this oral history may have had difficulty articulating their experiences through storytelling. In some cases, I needed to take a more active role in guiding the interview. In the time allowed for each interview (60-90 minutes), it was not possible to co-create a narrative, encompassing all facets of the life of each woman, so there could be circumstances, perspectives, or nuances that were not fully understood by the researcher. As narrators validated their

narratives, my asking additional questions provided an opportunity to mitigate that limitation.

### **Researcher's Reflexivity**

I am the biological mother of two boys who have been diagnosed with ASD. I have had the opportunity to meet and talk with many other mothers of individuals with ASD, although only superficially, until completing this study. I have seen the recognition and connection between us when we discover that we are living very different lives that are also similar in many ways. I can remember feeling lost when learning about my first son's diagnosis, which was also delivered with a diagnosis of a rare seizure disorder with a very grim prognosis. There were many times when my husband and I cried in despair.

I live a socially isolated life. I cannot have visitors come to my home because it is too disruptive to the routines upon which my sons depend to maintain balance and not fall apart into strings of violent outbursts and crying that can last hours. The delicate balance in our home is maintained with great effort by myself and my husband. There is a fear that nobody will understand why we don't have any glass in pictures (the reflections upset my older son, and he would break glass whenever he had an opportunity to do so), or why we purchase 12 of the same t-shirt or have purchased enough red Adidas sneakers to last until my younger son wears a men's size 10.5. It was not until I could talk and share with other mothers in similar situations that I could realize that doing the best I could do was *enough*, and that these quirks were part of the difficult and cyclical *new normal* that I had established for my family when coming to terms with the new circumstances of our lives.



I am a nurse, and throughout the diagnostic process and the processes of developing individualized education plans (IEPs) for my sons, I felt completely inadequate. I did not understand how to navigate the systems in my community and felt I was failing my children. I completed the paperwork to apply for medical assistance and disability for my children six times before giving up and deciding not to pursue that support. There have been times when I have felt that I have had an advantage because of my education, but there have definitely been others when I have felt that it has disadvantaged us, because the intake social workers were not willing to offer assistance with navigating the system.

Through conducting the Midwestern Farm Widows Oral History study in 2014, I learned about the power of oral history to unite a community and offer support through simple sharing of experiences in narrative format. For the women who participated, they found sources of strength in their community through the stories others had shared, could build solidarity, and offer support to at least two other women of whom I am aware. In conducting interviews and engaging in analysis and interpretation, I heard stories of several women who were part of that study who had mothered children with special needs and found strength in their stories. I began to realize that that my experience could benefit others like me.

I began to search for a nursing theory that would help shape my findings and discussion of that study and learned about the Theory of Inner Strength in Women. The dimensions of the theory resonated with the work I was completing with the farm widows, and I began to think about opportunities to further inform the theory through work that would be exceedingly meaningful to me on a personal level and help to carry

me through the challenging task of completing a dissertation in nursing. I saw a need for someone to aid in transference of understanding of the experiences of mothering a child with ASD to others in my community, and I wanted to contribute to the development of nursing knowledge. This study was the next step on my journey to offer support to women with similar circumstances, and I plan to work toward advocacy for families of individuals with special needs well beyond the end of my nursing career.

### **Relevance of the Methodology**

I believe that oral history affords an opportunity for nurses to contribute to the historical record and to preserve some of the qualitative data that we are collecting for research purposes. I firmly believe that the nursing discipline's qualitative studies will not be as relevant as time passes because they leave a lack of primary source material: the source of information required to validate historical authenticity. If *history is written by the victors* and no primary source material exists, as time passes, then nursing as a profession and as an academic discipline will not be *victorious* in the battle for legitimization of qualitative research. Viewing this study as a potential to both give voice to these women and to bear witness to their lives, articulating the importance of their advances to live a new normal after the challenging life event of learning to live with and support a child with ASD, becomes an important mission.

Recognition of the unique impact of the combination of social standpoint, geographic location, and other external factors upon the experiences of each individual mother of a child with ASD is imperative. This research methodology allows for that as part of the process. Creation of a collective voice, while recognizing and preserving

individual identities of narrators, is one of the most beneficial qualities of this research methodology.

### **Researcher's Assumptions**

This study is based on the following assumptions which I hold:

1. Mothers of children with ASD shared stories about their lives and how their child's diagnosis has impacted their experiences.
2. The lives of mothers of children with ASD have been impacted by the experience of caring for, protecting, and participating in the upbringing of a child with ASD, and these mothers created meaning from the related experiences.
3. Narrators relayed stories that they believed to be true.

### **Conclusion**

Chapter III provided an overview of Feminist Standpoint Theory, Oral History Theory, and oral history methodology. It also included a description of methods used to answer the research questions. This chapter also addressed human subjects considerations related to this study and includes sections addressing rigor and reflexivity.

## **CHAPTER IV**

### **FINDINGS**

The oral histories collected and analyzed for this study were co-created together by each mother and myself. Each narrator was asked to share the story of her life as the mother of a child or children diagnosed with ASD. Her experiences were unique, and they were shared as she remembered them at the time she shared her stories. Over time, the focus of each woman changed. For example, a mother who was searching for answers to questions about why her child is not meeting developmental milestones would have a very different focus from a mother who knows that her adolescent child has ASD and will need to transition to a living situation outside of the family home. In addition to historical factors, each woman's experience was also greatly impacted by social, cultural, and economic factors.

One reason oral history is conducted is to give voice to individuals who might not otherwise have the opportunity to share their stories. For that reason, I presented narrators' stories in context and with very little editing and paraphrasing. Presenting the data in this way provides readers with the ability to easily follow how themes have been developed as part of the audit trail. This chapter was organized into the following sections: (a) an introduction to the narrators, (b) a discussion of overarching themes and subthemes from narrators' stories, and (c) a summary including findings considering the research questions. The research questions for this oral history study were:

1. What are the experiences of mothers of children with autism spectrum disorders?
2. How do the experiences of mothers of children with autism spectrum disorders inform the Theory of Inner Strength in Women?

### **Narrators**

Ten mothers of children with ASD participated in this study. One of the narrators was Native American; otherwise, all others were Caucasian. Attempts were made to recruit narrators of many ethnicities, including those from Hmong, Somali, and West African communities, as well as the African American community, however none of these mothers were willing to participate and have their interviews recorded or archived. I did have one Hispanic mother of a female child with ASD scheduled for an interview who cancelled four times before deciding not to participate in the study. I also had recruited one Indian mother of an adopted female child who cancelled three times prior to deciding not to participate in the study as well. The ages of the mothers ranged from 32 to 63 at the times of the interviews. All the narrators had children with ASD who were male, with 82.4% of Americans with ASD being male (Autism and Developmental Disabilities Monitoring Network, 2012), so this does not seem unusual.

The mothers interviewed for this oral history study were all residents of Olmsted County, Minnesota. The county population was estimated to be 153,102 in June 2016 (<https://www.census.gov/quickfacts/fact/table/olmstedcountyminnesota/PST045216>). Of those, approximately 60,000 are employed by Mayo Clinic (<http://www.mayoclinic.org/jobs>), making the population heavily health care oriented, which is reflected in the narrators included in this study. The geographical area includes

Mayo Clinic and has many resources, including two centers providing therapy to children with ASD as well as a developmental pediatrician. The public-school system has a long-standing intensive autism program as well as a robust early intervention and early childhood special education program for children diagnosed with ASD in early childhood. There are also many therapeutic and adaptive programs available throughout the community and formal and informal support opportunities for mothers of children with ASD. One of the narrators moved to the community with the express intent to increase her child's access to services, and several of the narrators expressed that they would not move their children out of the community because of the availability of programs and services available in the community compared with those in areas in which more family members were living. The tables in Appendices F and G provide demographic information about the mothers and their children.

**M.M.**

M.M. was 61 at the time of her interview. She was born in Austin, MN and grew up on a farm in Grand Meadow, MN, which is an agricultural community in Mower County, approximately 25 miles from Rochester, MN, the largest city and county seat of Olmsted County. She was the mother of three children, two typically developed adult children from a previous marriage who were approximately 20 and 18 years older than their younger brother, D., age 15 at the time of the interview, who had been diagnosed with autism at age three. M.M. was working part-time as a bookkeeper for a chain of hardware stores and for the family farm during the day while D. was in school. Her husband was a crop farmer who was still living primarily on the family farm, which was in Traverse County, MN, approximately four hours away by car. In the past year, he had

purchased an airplane and had obtained a pilot's license so that the commute time could be decreased to just over one hour. He could spend more time in Olmsted County with the M.M. and D. over the winter months when there was less work to do on the farm, but in Spring, Summer, and Fall, the mother and D. had done the bulk of the commuting.

**M.D.**

M.D. was 32 years old at the time of the interview and her son, J., was 10. She had been a single mother up until four months prior. She was born in Cambridge, MN and spent her childhood there. She described it in an idyllic manner:

I guess I would describe it as probably typical. It was good. My dad always worked, my mom was usually at home. We were homeschooled; I was homeschooled until fourth grade and then I went to public school. And then my mom also did daycare, so we always had kids around, running around the house.

One of my best friends grew up right across the street, and we're still friends.

M.D. became pregnant with J. when she was 21 and delivered him when she was 22, following an uneventful pregnancy. J.'s father was only part of his life for a brief period.

J. was diagnosed with autism at age four after M.D., her parents, and younger brother moved to Olmsted County. At the time of the interview, she and J. lived with her new husband and their six-month-old boxer puppy. She had recently completed a Doctor of Nursing Practice degree and had passed the certification exam to practice as a psychiatric mental health nurse practitioner. She had plans to move the family to a community approximately 50 miles away at the end of the school year.

**M.H.**

At the time of her interview, M.H. was 38 years old. She had four children and lived in a smaller community in Olmsted County with her family. She worked as a nurse practitioner, and her husband worked as a registered nurse. The family had two boys and two girls with the second-oldest boy, A., age 16 at the time of the interview, who was diagnosed with autism. A. was not diagnosed until age 12 because of his complex presentation. At the time of the interview with M.H. he was living in the same city with his parents in a group home for individuals with ASD who have low IQ and violent behaviors.

M.H. grew up in a household with both parents, a younger brother, and two half-siblings. She wanted to become a doctor when she grew up. She had been a caregiver throughout her childhood, describing herself as the “first-responder on the playground” but made the decision to become a nurse after spending a summer as a surgical assistant at the local hospital and seeing first-hand what a surgical residency entailed. She was a young mother, having given birth to her first child at age 21 and A. at age 24. Her family’s ASD journey was one of the most difficult with multiple hospitalizations, several arrests for violent behavior, and a lengthy diagnostic process, involving multiple care systems over a large geographic area.

**M.W.**

M.W., born in Rosburg, OR, was 42 at the time of the interview. She is Native American and was adopted by couple of Norwegian heritage at the age of three days. M.W. has four children, ranging in age at the time of the interview from 24 to six years. She described the first as her “Asian baby,” the second and third without ethnic or racial



descriptors and her youngest as “half-black.” Her son, K., age seventeen-and-a-half at the time of the interview, received an educational diagnosis of Asperger’s Syndrome at age six. It was not until much later that he received a medical diagnosis.

M.W.’s parents divorced when she was a child. She spent most of her time living with her mother in New Hampshire, where her mother worked cleaning hotel rooms to support them. What M.W. talked about most regarding her childhood was struggling financially, and when asked what she thought about when she imagined becoming a mother someday, this situation is what she described:

I’d always envy an aunt of mine. It was my father’s sister, so my aunt on his side. I’d always envied her because she was a stay-at-home mom, and she had three great looking kids, and they seemed to have it all put together. A real American sort of family, lived in a nice house, always had fairly new cars. The bills were paid, and it was just the opposite of the struggle of my mom’s situation. We really had a tough time financially, but she was a woman who would never give up. And so I envied that situation. I always wanted to be a stay-at-home mom. And I believed in the family life of a husband, and a wife, and children and building a home, buying a house. And that was a dream to me, really, because that wasn’t something I grew up with, but it definitely was something I was shooting for.

M.W. had a scheduled C-section for K., following an uneventful pregnancy. She was divorced from K.’s father when he was a young child and has since remarried and divorced. M.W. is not currently married and lives 100% of the time with her three youngest children and her mother, in her mother’s house, close to K.’s high school and her youngest daughter’s elementary school. She was working as a temporary laborer at

the time of the interview because the job gave her flexibility to leave and “take care of K.’s issues” as well as attend classes for her own education as an addictions counselor.

**S.N.**

S.N. was born in 1973 in Rochester, MN and very succinctly summed up her childhood:

We had a lot of money, and I was super embarrassed [laughter]. And my parents were total workaholics and never were home. And, yeah, I have an identical twin sister, and she verbally abused me all the time, and my parents never set limits.

So, I was neglected as a child emotionally, and it was not fun.

She is a registered nurse who has worked in the same job for the past 14 years, and, when asked, she said that she did not want to have children. Her husband gave her an ultimatum, “let's either go to the Peace Corps or have kids,” and she decided to have children. After an initial fetal loss, she became pregnant with natural twins and gave birth by C-section at thirty-two and six-sevenths weeks to two boys. One son was typically developing, and the other, S., age 10, was diagnosed with Down Syndrome and autism.

At the time of her interview, S.N. worked five shifts in a two-week pay period over the course of seven days and then cares for her children the following week. Her ex-husband has a similar schedule and works as a nurse on a sister unit with the same scheduler who accommodates their requests. She attended several support groups each month but does not have many friends because S. is non-verbal, and she feels that there are very few trustworthy respite caregivers available in the community.

**M.B.**

M.B. was 43 at the time of her interview and was born and raised in Boone, IA.

She described her childhood as follows:

I grew up in a two-parent home, and in rural Iowa, town of 200 people, and so had a-- my mom did Avon and things, and was pretty much a stay-at-home mom. I did have a sister with special needs, and she had a-- eventually when she was older, she was five years older than me, she was diagnosed with schizoaffective disorder. And then I had a brother who had some speech issues, but overall we didn't have a lot of money, my dad was a shoe salesman, but I was very well loved and taken care of, and was in a lot of activities and would do 4-H, and mom was a Sunday school teacher, and we'd help her. We were just talking about this last week. We would help her when she was doing bible school, make all these funny things, and we made this little statue called, "No Name Newton." He was out of Paper Mache and Pringles cans and all these things.

She believed that that experience had given her a perspective, which helped to create opportunities for her typically developing daughter to feel loved and included. P., her oldest child, age 17, was diagnosed with "Asperger's with low IQ" when he was age five. P. was overdue by one week, so M.B. had a biophysical profile in the clinic and was admitted to labor and delivery for induction of labor because the baby's heart rate was abnormal. Prior to delivery, her obstetrician artificially ruptured the amniotic membrane, and she delivered very quickly.

At the time of her interview, M.B. worked full-time as a nurse practitioner, and her husband worked full-time as a custodian. They both lived at home with their teen-age

daughter, and P. lives in a group home in the same city. M.B. has had many struggles with P.'s violent and highly sexualized behaviors and had difficulty finding an appropriate placement for a minor outside of the family home.

**M.F.**

At the time of her interview, M.F. was 41 years old. She was born and raised in Rochester, MN, the daughter of a funeral director. She was sent away for high school in Faribault, MN because she “got into trouble” when she was in middle school. She describes her vision of motherhood when she was a middle-schooler:

I had this vision of being this gypsy type of mother who would have babies and stick them in a Kelty backpack and trek around Europe [laughter], living on-- I don't know what money, but just had this very kind of organic earthy tree hugger type of vision for myself and having a child. I didn't at all see sleepless nights or a kid throwing a tantrum and saying, "I don't want to go back to Berlin." Or-- we would just get on a train and everything would be-- and I that's kind of my theme throughout life, I always have this utopian vision of how things will be and then I get a little bit smacked around when I realize the reality of how things tend to actually play out.”

At the time of her interview, M.F. was the mother of two children, a 15 year-old daughter diagnosed with mosaic Down Syndrome, and S., age 14, was diagnosed with pervasive developmental disorder – not otherwise specified (PDD-NOS). S. was diagnosed at age three, partly because early childhood special education was involved with his sister.

The family had lived in Wisconsin and Colorado, but moved to Olmsted County because it is where family lived when they returned after her husband lost his job in 2002. S. lives at home with both parents and attends a new charter school for children who have difficulty assimilating to the large middle and high schools. M.F. had worked for five years to raise funds and open this charter school with a few other people, including local experts on ASD. The school is called Beacon Academy, and it opened in 2014.

**J.H.**

J.H. was the mother of two sons with ASD, A., age 24, who was diagnosed with autism, and L., age 17, who was diagnosed with Asperger's Syndrome. She was age 50, married to her only husband and the father of all five of her children, and a stay-at-home mother. She had been a labor and delivery registered nurse prior to moving to Olmsted County for her husband's schooling to become a certified registered nurse anesthetist (CRNA). Her boys were diagnosed at 18 months and at 3 years of age.

J.H. was born and raised in Macomb, IL, where all of her family still lives, which is approximately five and one-half hours driving distance from Olmsted County. She shared a story about her childhood, which she believes foreshadowed her adult life:

I played with dolls all the time. My sister and I played, and I was a gymnast and we'd set up my gymnastics mats on their ends and make walls of houses. And all my dolls had names that started with A [laughter]. And I had one really super floppy doll, and I pretended that she had muscular dystrophy. And I took this doll to the doctor, that was always how I played, was that I was taking this doll to the doctor's office, and bringing all my other children along. And then my life

imitated how I played as a [laughter] child, because that is what it was like when I became a mother. But that's all I really wanted to do as a kid. Some people know they want to be a nurse, or a doctor, or whatever and all I ever wanted to do was be a mom.

J.H.'s first child was typically developing, so it wasn't until her second that she noted discrepancies between developmental milestones and A.'s development. A. is non-verbal and lives in a group home in the same city as his family. Her third child, L., born seven years after A., was also diagnosed with ASD but Asperger's Syndrome at the other end of the spectrum. At the time of her interview, L. still was living in the family home, and J.H. had plans for him to attend college in the community when he completed high school.

**K.L.**

K.L. was born and raised in Des Moines, IA and was 59 at the time of her interview. She described her childhood as follows:

Well, I essentially was an only child. I had an older half-sister, but she's older by 19 years, so she already was married and had her own family. So I had a nephew who was actually older than me, but we played together growing up, so it was not a problem. I also had a half-brother who I probably only met, that I can recall, twice in my whole life. So, my mom and my dad both were married to someone else before they married. So, I was an only child. I loved to read, so that was my biggest pastime. And I loved watching TV. I liked listening to music. I had friends I played with. I guess it wasn't until I was in, well, ninth grade that I can remember-- well, my dad was an alcoholic, and so that had its own problems.

And he would disappear for periods of time, and he was unfaithful to my mom. So that was kind of crazy. But growing up, at least while I was in elementary school, I, for the most part, liked school. And I felt loved. But again, I was just kind of a quiet, shy kid. I really liked my own company. I guess I was used to my own company because I didn't have siblings. And I did have my nephew and my niece, and we would play together some. But I spent a lot of time on my own.

K.L. became Mennonite before marrying her husband and found a great deal of strength through her relationship with God throughout her adult life. She is the mother to four children, the oldest of whom, D., age 29 at the time of her interview, was diagnosed with atypical pervasive developmental disorder at age three and one-half. He was born six weeks early and was jaundiced. As a result, he spent six weeks under bilirubin lights before he was discharged from the hospital after his birth. K.L. and her husband spaced their children with at least two years between each subsequent child, and she read many child development and parenting books as a new mother.

K.L. had studied social work in college and graduated but describes the following conversation with her husband, regarding the decision to be a stay-at-home mother:

I got my degree. I worked some. But deep down, all I ever wanted to do was be a mom. And so when my husband and I got married, we waited four years before we had our first. And he said to me, "Would you consider staying at home with our children?" "Yeah." I mean [laughter], he felt it was very important, at least for those first few years, so I had that support from him, and I wouldn't trade that.

K.L. volunteered in her children's schools and at the public library throughout their school years. At one point in time, after over 10 years of volunteer employment, she was

offered a paid position at the public library, and she is still working there although in an unbenefited position because she does not want to learn to drive the bookmobile. D. lives independently in a government subsidized apartment near public transportation, which is his primary means of getting to the two part-time jobs for which he has applied and obtained without assistance.

**N.B.**

N.B., at the time of her interview, was 63 years old and the mother to M., her 36-year-old son with Asperger's Syndrome. She grew up in Clinton, IA, which is approximately five hours driving distance from Olmsted County, and she described her childhood very succinctly: "It was the 60s, fun. Kids were sent out, and didn't come home until dinner. I think I had a pretty normal childhood. Big family, seven kids, I was the youngest of seven." N.B. attended college and became a dietician, moving to Olmsted County following graduation.

She is the mother to two other daughters, one older and one younger than M. N.B. described her pregnancy with M. as abnormal because she had migraine headaches for which she took Tylenol, although she normally abstained from all other medications. She described the birth as normal: "he was full term, Apgars were a 10, so there wasn't any problem that I noticed right in the beginning. He's a full-term, full weight baby."

M. lived in the family home until he moved into a cooperative group home, owned by the parents of five individuals with ASD. He has a job at a grocery store and works with the assistance of a job coach. N.B. still works full-time outside of the home, as does her husband. The other children live outside of the home as well.



## **Chronology of Mothers' Experiences With ASD**

The chronology of a mother's experience of parenting a child with ASD followed a pattern. The pattern, which emerged through analysis of the interviews collected, included three distinct phases: *In the Beginning*, which includes the pre-diagnostic and diagnostic periods; *Everyday ASD*, which includes the phase during which the mother lives with her child or provides for her child's day-to-day needs, materially or emotionally; and *Afterward*, which is the period following a crisis or a critical process, which causes the mother to grow in inner strength in a way that she is able to look at the phase of *Everyday ASD* in a retrospective manner. A crisis could include the following: the child's life-threatening event or a mother having to make a conscious decision to mother and support the child through an arrest or institutionalization when a spouse might not have been supportive. A critical process could include a successful application for guardianship or making posthumous arrangements for the care of an adult child.

### **Overarching Themes**

Overarching themes from this study are arranged into three groups, based on the chronology of mothers' experiences with ASD. The themes that fall into the chronological phase titled *In the Beginning*, referring to the pre-diagnostic and diagnostic periods, include the following: (a) *something wasn't right*, (b) *someone finally listened*, and (c) *hit by a truck*. The themes that fall into the chronologic phase titled *Everyday ASD* include the following: (a) *outsiders can't understand*, (b) *too much and never enough*, (c) *easier apart*, and (d) *mother as hero*. The themes that fall into the chronologic phase titled *Afterwards* include the following: *all worth it* and *letting go*.

## **In the Beginning**

**Something wasn't right.** Typically, a child was born, and the mother parented the child for a period during which she began to make observations that something was not right with her child. She underwent a search for answers through a variety of avenues, including (a) the medical system, (b) the educational system, (c) her support system, and (d) any source of information available until she was able to begin to find answers. At times, the search for information and answers became extremely difficult, especially when the well-being and future of the mother's child was at stake.

M.M. described her decision to become pregnant with D. in a matter-of-fact manner:

And then I remarried about 18 years ago. Yeah. And then the guy that I married had never been married and I didn't have children. And so, I said "Well, I'd have another kid," and my daughter just graduated from high school. I thought if it works out I would, and then I got pregnant, and then I had D. And he's 15 now.

She continued to talk about the pregnancy, describing it as "great" because she didn't get "sick" as she had with her other two children. She described the experience as enjoyable until the last month:

The last month, though, I got high blood pressure. The last few weeks. And they put me in and they tried to induce labor and I started, and then quit. And they ended up sending me back home for a week. And then I came back in and they tried again, and then they did a C-section because they thought his head was so big. Yeah. And I wonder if that wasn't really hard on him. And it has to be that

they would do that and he was almost nine pounds. And he was two weeks early still.

D. was born on August 28, 2002 in a rural access hospital in Minnesota, which had 25 beds and 10 births per month. M.M. signed up for Traverse County's Ages to Stages program where D. was seen by a public health nurse on a regular basis to check that he was meeting milestones.

M.M. describes her feelings about D.'s delay, and her feeling that *something wasn't right*:

Yeah, well, at six or eight months, whenever they babble, he hit all those, but then he just kind of quit developing at that point. And so, it was around two years of age, and I took him to the doctors and I said something wasn't right. "Oh. Well, boys sometimes don't talk that soon." And finally, when he was almost three, I said, "No, this isn't right because I've had two children and he should be talking more." I got a hold of the school too, to get him into pre-school, and they too said, oh, there was nothing going on. But the first day of pre-school they called me and said, "Yes, something's going on here."

The experience of having several people tell the mother that nothing was wrong with her child was not unique to M.M. For S.N., who had a child with Down Syndrome, she learned that she needed to advocate for her child in order to obtain diagnostic tests:

So then, I got pregnant. And we had a miscarriage. And then we got pregnant again. And I naturally had twins. And we never got that Trisomy 21, that test in the first trimester because we weren't going to do anything different if our baby had Down Syndrome. And, of course, our baby wouldn't have Down Syndrome.

But they were born at 32 and six-sevenths weeks. So, what is that? Like eight weeks early, seven weeks early. So, they were in the hospital for 33 days. And I kept telling the NICU doctors, "Hey, my kid has Down Syndrome." And they're like, "No. He doesn't. Premies just look squished and weird." And I'm like, "No. I think he has Down Syndrome. You need to do an echocardiogram, and do some lab work on him, and look at his simian crease." And I was telling them all, "And his epicanthal folds." And then, the day we are discharged from the hospital it came back positive that yeah, he has Down Syndrome.

Following that diagnosis, she used her ability to network within the community and became connected with a support group, which is how she first began to have concerns about her son:

So there used to be this really active good family group in town for Down Syndrome families, and it used to meet quarterly at this church, and there was this awesome pizza party. And the thing about it is the church had this gym. So all the kids could go to the gym and play, and then it was nice because there was tons of kids with Down Syndrome there, and you could compare your kid... And then I noticed at age two that my kid would sit in a corner and rock. He wouldn't want to engage with any of the other kids, even the other two-year-old with Down Syndrome didn't do that. So, I knew we were in trouble, and something was wrong.

Even for M.F., a mother who was going through the Birth to Three program with a sibling who was just under one year older than her son, S., who was eventually diagnosed with ASD, her concerns were not addressed:

...so, we were doing Birth to Three with [his sister] and there were definitely some things as S. was progressing and I was like, "Hmm." You know, he's not babbling, he's not doing all the stuff, he's not interested in other people or other kids, necessarily, and so I had brought it up to some of [his sister]'s special ed teachers and the speech therapist, especially, and she assured me, "Don't worry, he's young, he's not even a year. Things will probably even out." And I just chalked it up to that.

However, in retrospect, she remembered a story about S. later and some behaviors, which are indicative of ASD and her not associating them because of her lack of knowledge:

...he definitely showed some signs that I had not seen or expected in [his sister]. He really was particular about his toys, they had to be in certain order, they had to be a certain way and this was as early as two. I mean he started doing PAIIR with other 17-month-old kids, and he had really no interest in playing with them. He would sit down with a pile of books and just flip through the books all on his own, and really just showed no interest in other kids, which I thought was, "Huh, that's odd." But it didn't-- not knowing anything about autism at that time, it didn't strike a chord with me.

M.B. had an experience of having her child meet most milestones until he was 18 months old but was not listened to by her provider when she asked questions about her son's concerning behavior:

...he hit most of his milestones until he was about 18 months, and then he really kind of fell off. We asked his doctor at 18 months if it was normal for him to rock in his car seat, and the doctor said, "No, that's fine. That's normal." I don't think

he understand exactly what we meant or the extensiveness of it, because then you'd have that 18-month appointment, and then you really don't realize-- you don't really have another appointment for quite a while, and then it's-- yeah, so he was hitting the milestones, but then he definitely, between 18 and 24 months, he definitely fell off a lot of his milestones.

M.B. continued the story with a description of some of the other concerns she and her husband had about his behaviors and development:

...we'd have to teach him-- almost teach him expressions and things like that, and that piece. And we noticed that he was definitely-- we'd sit in church and he definitely looked different than the other kids as he got in that two-year-old-- it was like his expressions were a little bit different. And so, we know it was-- we thought maybe he was-- we kind of kept going with-- he's just a slow starter, delayed. He walked close to, I think close to 18 months. I mean he was late on the walking side, but not that late. And he was potty trained and things like that, but it was just-- when he was three and we took him to preschool, the teacher didn't tell us until about two to three months in that he was basically walking around the room pulling things off the walls during story time. And we wondered why all the kids had these cute crafts they would come out with them, and he never did because he never did them. So that's when they kind of started the process of-- he was three and a half. And then, by the time he was four, that's when we had-- we kind of got in essence fired from one preschool.

The experience of not having the support of the school and not having answers about why her son was behaving the way he was drove M.B. and her husband to move their son, P.,

to a public preschool so that they could have access to an assessment for him. Within one week of moving him to that school, the teacher at the new school had made the referral:

So, we took him to another preschool and we decided that at that point if they said he needed assessment and things like that, we'd have them do it and then we'd go from there. And that was a more experienced preschool and they, within a week, early, something's really wrong, and where they got the- it was not a church-based one so they were able to get the assessment much faster, because when you're in private school you get put on the list, you're at the bottom, and the public-school stuff. And this had Head Start in it, so it seemed like they got a much faster assessment. And they had paras there for children that were hard of hearing and deaf, so they had staff, so they were okay with him being there, but when we took him-- once he was diagnosed, we took him out of that preschool and they put him in the special ed preschool in the school system. So, he had three preschools that year between three and four.

Retrospectively, the mothers were disappointed that they were not able to do more to make their children comfortable earlier, especially in the case of M.F., who remembered her son crying inconsolably for months as an infant. She posited the reasons for her son, S.'s inconsolability:

And looking back, it all made sense. The fact that he had so many-- it was all sensory issues, looking back, is what I chalk it up to. But obviously, he can't tell you that, that his clothes are ridiculously itchy, or the light is too bright, or the noise scared the heck out of him or whatever. But it all kind of came together

when we realized that like, "Oh, that's why he screamed for five months straight. That makes sense."

For the mothers whose stories were included in this section, the feeling that *something wasn't right* was initially mother's intuition. That feeling and suspicion planted the seeds for the questions to the educators and health care providers who eventually listened. Listening to the family story triggered initiation of the assessment and diagnostic processes that eventually led to their children's ASD diagnoses.

**Someone finally listened.** Once the mother began to find someone to listen to her concerns and began to receive answers through screenings, assessments, and diagnostics, she and her family sometimes received a diagnosis of ASD, or of another disease or educational concern, which continued the search for knowledge and answers. Some of the mothers of children with ASD who were interviewed for this study did not receive definitive diagnoses of ASD until they were in elementary school or beyond. For those women, the search for answers and for someone who would listen to their concerns overlapped their living with ASD although without a formal diagnosis and the access to services that one could provide.

M.D., one of the mothers of a younger child at the time these interviews were conducted, truly felt that her child was disappearing. Then, she started the diagnostic process and felt validation when the team came together to weigh in with their expertise:

And I was like, "Holy crap. This kid is really smart. Okay. Cool." And then it was about-- I think he was about two and a half or three-ish when his-- this expansive vocabulary that he had just shrunk. And just stayed the same. He didn't use all the words anymore. He could still count. I mean, that's kind of-- he



still had that. No eye contact. You could walk in a room and that kid wouldn't even blink. He would get so absorbed in what he was doing and the [laughter] lining things up in whatever order he thought they should be in. And you know what they call edging with the wheels and he was going like this on them [laughter], rolling the little things along the table and watching them real close. I don't know. It was actually really awful. Awful, awful. It's like watching your kid just disappear into this pit, and you can't get him out.

At that point, we were in a lot of transition, so I kind of waited until we were down here in Rochester. And he was probably four by that point. And I started by getting him in to see a primary care doctor. And I expressed some of my concerns and she validated that, and then referred us to developmental peds where we saw the developmental pediatrician. And then there was a social worker and someone else did all the testing, the ADOS testing and all that stuff. Oh, and OT. So, they had a-- it was a really nice, big team approach and they didn't tell me anything I didn't already know. But it was nice to know that I wasn't crazy.

That feeling of validation from professionals of a mother's belief was echoed by S.N., who described the extraordinary measures she took to obtain a diagnosis and a validation from a local autism center. They allowed her to place her son without a diagnosis on the waiting list for ABA therapy months before he had a formal diagnosis, which was a significant break in protocol:

And I was so paranoid that nobody believed me, and this is what I did. I went to Bluestem because my child's had MA-TEFRA since he was two because we've

had so much medical stuff. So I took him to Bluestem, and he saw their developmental pediatrician who's retired now. I can't remember his name. And he had me fill out a gagillion forms. And from my forms, yes, he has autism. But at the same time, I saw this awesome doctor, at Mayo, who has now left, and I loved her. And she just examined S. and listened to me a teeny bit and he was six and a half with autism. And yeah. Which is really incredible she was able to do that because people with Down Syndrome are very delayed and my son is very delayed. He can't talk still at 10. So, she was phenomenal. So, I had both those people. And then, the people at Rochester Center for Autism knew my kid because he would go there for music therapy. And they all knew my kid had autism before I did because they would see him. And so, they have this rule at RCA, you can't apply to be on the waiting list until you get your ASD diagnosis. But they let me apply months before because they knew my son had autism, and they didn't tell me that's what they believed, but yeah.

For S.N., being allowed to put her son on the waiting list at the autism center was the first sign that she was right about her feelings that something other than Down Syndrome was affecting her son, S. That experience made her believe that she was on the right path as she sought an ASD diagnosis for her son.

M.F. had the experience of not having a definitive diagnosis for her son, S., and recalled the angst she and her husband felt as they were going through the lengthy diagnostic process:

And my husband and I were both asking, "Is it autism? Does he have autism?" and no one would use those words. They were like, "Well he qualifies for

services under the autism spectrum disorder category." And she finally just said, "Yes. He has autism." And she was the only one who was willing to just put it out there. And I asked her several years later, like did you get in trouble for that or were you not supposed to say that he has autism? And she was like, "We do need to be careful because we can't-- we aren't diagnosing your child. That has to be done by a doctor. Yes, I feel like they were much too-- parents are dying for just something to hang on to, and something to grasp ahold of and if you just keep dancing around the word autism but never really say autism it just leaves the parents feeling empty." And so, the fact that she recognized that and she had the guts to just be like, "Yes, he has autism," was exactly what we needed at the time.

M.F. was fortunate to find a professional who was willing to talk with her and tell her what she felt she needed to know out of compassion and understanding. For M.F., the teacher sensed that telling the parents that their son had autism was what they needed to hear, although it was outside of her scope as an educator to give a medical diagnosis. The family continued their diagnostic journey and did ultimately receive a diagnosis of PDD-NOS for S.

The theme *Someone Finally Listened* was woven through all the mothers' narratives. There was a universal sense of relief when another person recognized and validated with what the mother had been concerned. The validation from a professional led to assessment and diagnoses within a short time in most cases, although, in a few, the chronology was different.

After knowing that something wasn't right with a child and bringing up concerns to family, friends, and her son's primary care provider, M.H. was truly relieved when he

was referred for additional testing. When she told her story, she used many nonverbal communication techniques, including staccato rhythm in the telling, emotive facial expressions, and emphatic hand gestures to get her frustration with the system across. She also rested in her chair when she finished telling the story, as though relieved that someone had listened:

I think some-- Yeah. I mean, people would say-- although everybody develops-- and he was never outside of the range of developmental milestones to the point where it was like, "Yeah, we need to make that referral." You know what I mean? He walked at 16 months. So it was like, "Okay, not so far out of whack there." Everything was just delayed but not outside of what you would say would be so normal. He was 15 months that he walked. So, no, I didn't really feel like we had been heard until we were seeing his nurse practitioner for a well visit when he was three. And I think maybe he was maybe three years old and two months or something. And she was talking to him about potty-readiness, was asking if he showed any interest in going to the bathroom. And I said, "No, not at all." And so, then she had-- I think we had the potty at the house. And she had said, "A., when you go home, you're going to learn to use the potty." And said something else to him. And she said, "A., is that okay? Do you understand?" And he looked at her and said, "Helmet." And she turned, and she looked at me, and she's like, "Is that unusual?" And I'm like, "Nope. This is what I'm telling you." No. For him to randomly say some word that had absolutely nothing to do with anything that was-- he was always kind of in his own little world.

At that time, though, M.H. and A. did not receive a diagnosis. They had to wait until he was 12 for that to happen. Following years of varied psychiatric diagnoses, several hospitalizations, and a charge for assault filed against A. by a nurse caring for him, which excluded him from ever returning to the local psychiatric hospital, they received his ASD diagnosis:

And we had gone back the next time, and he says to me, after I think we had visited with me and A. again, and then had A. step out. And he said, "I don't want to hurt your feelings, but your son has autism." And I thought, "Why in the hell would you think that was going to hurt my feelings [laughter]? You weirdo. You're a psychiatrist." Just like, "What a strange thing to say?" And okay. And I felt like-- and I remember that day, leaving-- and it was just A. and I, leaving and texting [my husband], and saying-- well, he actually didn't say autism, he said Asperger's at that time, despite the fact that A. had a low IQ, said that A. had Asperger's. But at the time, he didn't know enough to know that-- as a psychiatrist, he probably should've [laughter] known better, but it was like, "Okay." So they had sent [my husband] a message and he had-- and then he texted me back and just said, "Now what?" And I think just said, "Now, we just move forward," or, "now we start the rest of our lives."

M.H. and her husband's reaction, their recognition that the diagnosis did not change their son but could change how they and others approached thinking about A.'s needs and how to meet them. Their situation, a diagnosis at age 12, was not typical either for children of the mothers interviewed in this study or for the studies included in the literature review conducted as part of this dissertation.

The recognition that *Something wasn't Right* on the part of a professional, in addition to other people in the mother's circle of influence, was often the validation many of the women interviewed for this study needed. They were looking for *Someone to Finally Listen*, someone to look beyond what could be seen in a short office visit. Each mother needed someone to help initiate the diagnostic process so that she could begin to get help for her child.

**Run over by a semi.** Once the mother receives a formal diagnosis of ASD and does some research to learn what the lifelong impact of that could be, the impact can be substantial. For some mothers, who have already done research or who have pre-existing knowledge of ASD and the life of a child and the family affected by ASD, the impact can be both substantial and immediate. The stories provided by the mothers who participated in this study described a combination of *aha* moments and beginnings of major depressive episodes when they learned that their children were diagnosed. The one thing that the mothers had in common was that they universally embarked on a crusade to make their child's life the best it could be following the news.

M.M. had to push her family physician for a referral to have D. seen by a neurologist at a clinic approximately two hours from their home. She went to the appointment not knowing what to expect but hoping that she would receive a diagnosis and recommendations for treatment. Instead, she and her husband were given very different advice:

Well, the neurologist-- it was pretty sad because we had no idea about autism and he was pretty rude. He goes, "You know, your kid's got autism and that's the way life is. He's yours you're just going to-- don't be spending a lot of money trying to

fix things. Yeah. Just kind of deal with it. He's your child now." And we were just so taken back, like, "We can't do anything?" "Well," he said, "Save your money."

For M.M., learning that her child had autism marked the beginning of a crusade to learn what she could do to help her child. She was devastated to hear from a person she considered to be expert that there was nothing to be done. She remembered looking for any information she could find about autism almost as soon as the family returned home. Within a few weeks, she had signed up for her first seminar in a nearby city.

M.B., a mother whose son, P., was diagnosed within one year of M.M.'s son's diagnosis, had a different experience at a large academic medical center across the state:

And what was really hard for me, was when we did the assessments, all the checklists and the this and that, realizing, when I looked at the curve, because I had knowledge to kind of understand the test because of my nursing background and stuff, and realizing how, basically, a lot of his skills had stopped at two. And initially our doctor-- we initially went to our family doctor, and he felt bad about this later, and we said, "They're saying he's autistic." And he's like, "Oh, he's not autistic, he talks." Well, you can be autistic and talk very well [laughter]. And you can have-- and he was actually-- when he was finally diagnosed it was more on the line of the Asperger's, but it was Asperger's with low intelligence, which isn't truly a DSM. Well, now it's five criteria. But that's what the doctor said, he said, "He has Asperger's traits, he just doesn't have that really high piece of intelligence." But it's not that he doesn't-- he has some of that, but it's so incongruent, his IQ. But yeah, that was definitely-- it was interesting.

M.B. continued by describing the emotional effect of the diagnosis and uses the analogy of *being run over by a semi*:

I think the most difficult thing is just the emotional drain of it. But you kind of go into autopilot for a while like, "Okay, if I got to take on this appointment then we got to do this, we got to do that and blah blah blah." And then even though I already knew kind of what was going on, hearing it officially from someone else was kind of like I got [laughter] run over with a semi or something. Looks like, "Yeah. Okay. I knew this was coming, why is it so hard but?" Yeah, and it was kind of-- some of it was the timing too because there were a lot of stuff in the media around that time about, "Vaccinations cause autism, blah blah blah." All that stupid crap, so then you start thinking, "Wow, shit. Did I do something?" And I very specifically, I made this decision to space out all of his vaccinations and all of that stuff just to be safe, thinking—

M.B., who at the time of P.'s diagnosis, was in school to become a nurse practitioner. She was not the only mother interviewed who had education as a health professional at the time her child was diagnosed. J.H. was also a registered nurse when her son was diagnosed. She remembered also wondering whether she had done something to cause her son's autism:

It was a pretty big blow, I think, just knowing at the time. The little I knew about autism, I was like, "Oh man, this can't be happening to me." And being an OB nurse and doing everything that I was supposed to do. Not drinking, taking my vitamins, eating right, cutting out caffeine, all that stuff, and delivering babies for



people who would come in. No prenatal care, or addicted to drugs. It's like, "I did everything right. How can there be something so wrong with my baby?"

For M.H., however, the diagnosis caused her to become extremely angry because of the lost time that an earlier diagnosis would have given her son for early intervention and treatment. She was enraged at the psychiatrists who missed the diagnosis and, in her eyes, caused her son to have a lower quality of life for many years.

I think I was so frustrated just at-- I mean, happy that somebody had given us a name, perhaps, instead of developmental delay, that had explained everything for all those years of-- but at the same time, frustrated. Like, "Are you shitting me? All this time, that you said that this-- I mean, you watched my kid for 28 days in your freaking hospital and my kid couldn't get therapy for autism because he didn't have a diagnosis for autism, but yet--" so, I mean, being frustrated with that, frustrated with the care that we had gotten before that. And then, in retrospect, finding out what care can look like for autism at another facility was amazing. And so, at that hospitalization then at the University of Minnesota [inaudible], he was hospitalized then after being transferred from the Anoka facility when things were just so dysregulated. And they went night and day in terms of the hospitalization. "Of course, you can stay with your child 24 hours a day."

The diagnosis was given at an academic medical center other than the one where her son had previously been seen and, following it, the treatment and understanding of A.'s behaviors in the new health system were very different:

And I mean just-- and the psychiatrist there, just so understanding and laughed when I told her that they told me that I could never bring A. back because

aggression was an exclusionary policy at their facility. She laughed, she's like, "Where do they come up with this stuff? How do they think that they can do that? What?" And it just was so empowering too, to think, "Okay. I'm not off my rocker. That place is wrong. There's something wrong with that place." And that they don't treat autism correctly or know what the hell they're doing. And so that was really frustrating and I was really angry.

That day, after he got admitted, I remember just leaving. I talked to my dad on the phone, and just being so pissed off and screaming at the top of my lungs in my car by myself, so fucking mad, like, "Argh," and mad at myself that we just took Mayo for what they said because that's what they said. And so we just kind of-- and then my dad was saying, "Hindsight is 20/20, and you just have to move on." And he was right, and I knew that I did, but it still didn't change that I was angry about it, but we did move on.

All of the mothers did eventually move on, but S.N. was affected greatly by the diagnosis of her son, S. Although she had worked very hard to obtain the diagnosis of autism for him, she did not fully comprehend the magnitude of loss of hope the diagnosis would cause until after she had the conversation with his doctor:

Well, most of the population lives in denial of everything. Because when you have a child with Down Syndrome, it's a major diagnosis. But then when you get another major diagnosis like autism, it's just devastating. I had to take two months off of work, nursing, because it was so devastating to me, but I knew my kid was autistic since he was two. So, four years I waited for that diagnosis, but it

was so devastating that someone took my hope away, that, "You're right. He does have autism."

Like S.N., N.B. had also known that her son had a medical diagnosis since early childhood. M. had been diagnosed with mental retardation, which was later revised to developmental delay, since the age of three. When N.B. was first given that diagnosis, she had the following reaction:

Oh, it was like a death. It was the death of my son. And that dream you have when you're pregnant, and you dream that you're going to have this son and what he's going to do. I had to sort of let that dream die. And then I had to fall in love with the son I had, and not the son I thought I had. So yeah, it was devastating. It was devastating. Because you don't know what the future is. You don't know if they'll ever have friends, if they'll ever be married, if they'll ever be sort of normal, if people will ever like him, if you well be the only person to love them. So, yeah, it was devastating.

But when she received the diagnosis of Asperger's with low IQ when M. was in middle school, she did not react in the same way. She questioned the diagnosis, comparing it with her mental image of an individual with ASD:

Somebody said the word, autistic, to us and I don't remember who it was, and it was like, "Oh my goodness, I know what that is. That's when those kids sit and spin and stim and--" That's the only picture I had. But my son was very affectionate, so in some ways, he didn't fit the autistic square. He was always very affectionate, but he wouldn't give you eye contact, and he had these kind of overstimulation - couldn't go to fireworks, didn't like fire engine noises - I mean,

he had that kind of self-protective things that autistic have, so I guess we could see that.

Ten years had passed between M.'s initial diagnosis of developmental delay and his diagnosis of Asperger's Syndrome with low IQ, and she had had time to live with M. and his behaviors, making the diagnosis more palatable as she became more educated.

### **Everyday ASD**

The activities of mothering a child with ASD were described by the narrators of this study to be overwhelming, challenging, time-consuming, and frustrating. The mothers shared stories of finding allies and of learning how to navigate difficult situations to make their children most comfortable at home, at school, and in the world. Their stories of *everyday ASD* elucidate the lived experiences of day-to-day mothering of a child with ASD.

**Outsiders can't understand.** Life as the mother of a child with ASD can be challenging for multiple reasons. Two subthemes emerged from the stories were *unsupportive others* and *supportive selves*. The theme *Unsupportive others* includes stories about how mothers lived their lives in a certain way to shield themselves from comments and stares from people who would not understand the behaviors of their children or how to support the mothers. *Supportive selves* refers to stories about how the mothers gravitate toward other mothers of children with ASD as friends because they understand what they are experiencing to which other people are not able to relate.

**Supportive selves.** The theme of *supportive selves* was most clear in stories narrators shared about their experiences connecting with others in the ASD community, such as other mothers of children with ASD, teachers who had dedicated their lives to

educating children with ASD, and community services administered by other parents of children with special needs. The stories, which form this theme, are many fewer than those which contributed to the theme of *unsupportive others* of which there were many.

M.D. has had a unique experience among the narrators in that she watched and helped as her boyfriend, then husband, became an ASD insider. As a single mother, she was frequently unable to engage in social activities with her friends because of the amount of time and energy she gave to parenting J., “up until a year and a half or two years ago that was my full-time job, and then my other full-time job was just part-time on top of that.” She described finding out who her “real friends” were:

Yeah. People you think are friends and then-- I just can't always go out and do the fun stuff they want to do and it's not always fun to have a kid traveling along with you either, much less a kid that might have some public meltdown stuff happening.

She told about how her son, J. has been a full-time job on top of her other full-time job. M.D. also told about how she met her husband and how he developed the understanding of ASD necessary to become supportive of both her and J.: “now I have my husband, who's come into our lives and he's really stepped up and learned a lot of this stuff, and how to help J. get through meltdowns and with his behavior and stuff.” J. worked intensively on ABA through a local autism center, which offers parenting classes which M.D.'s now husband could attend. M.D. believes that these classes helped significantly to improve his ability to assimilate into their household and family.

M.M. moved from an agricultural community with very few resources to Olmsted County because she was seeking additional services for her son, D. What she found in addition to the resources was a community with other mothers of children with ASD:

And it's just such a small world because it turned out, we just came up and looked at this house and it was great, and then it turned out that the boy next door has autism, and his mother is on the board of directors of Rochester Beacon

Academy. I was like, "Well somebody sent us here." If you believe in miracles.

From the connection through her neighbor, M.M. learned that there was a charter school in her new community, which had been created to give opportunities to adolescents with ASD and other conditions that make learning in a traditional school environment difficult. The school was founded by the mother of a child with ASD and offers an environment conducive to learning for children with ASD.

K.L. had the experience of finding an understanding ally in the woman in charge of bussing for her sons' public school system:

I remember one day when they were in Kellogg, and they came home. And [my second son] said, "Mom, there were some kids teasing us on the bus." And he was really, really upset. And so initially, mama bear kicked in. I thought, "It's because D.'s got autism, and this isn't going to happen." So, I called the bus company, and I got another mama bear, and I love that. She said, "You know, I was just at Kellogg today dealing with another problem." I mean, I decided I'm just laying out that-- I'm going to just say it. "He's got autism, and there's somebody teasing him and his brother." She's, "I know what you're going through. I'm on it." And sure enough the next day, she did it. She took care of it.

Having had that experience, K.L. decided that it would sometimes be easier to disclose D.'s disability to garner support and find others who would understand and who could become allies.

Other mothers chose to disclose their child's diagnosis of ASD when it would benefit their situation and increase understanding and support from others. One of the mothers, M.B., articulated the need to disclose the diagnosis to not miss opportunities for vital assistance. This advice was given as part of a story about the huge gift of understanding and support through a 20-year supportive relationship that two women from their church developed with the family:

I think sometimes we miss out on that piece of who's out there that can help us, but part of that is transparency. And it's hard to know who you can trust, who's not going to judge you or think that you're a bad parent. And I think you just learn that anybody can see the bad in someone, sometimes God is sometimes the only one who can see the good.

The belief that others can find common understanding and empathy through disclosure of a child's diagnosis was echoed by other mothers, including S.N., who finds activities and venues for her children's entertainment at places where staff and patrons are accepting of individuals with differences. She said, "So we go to the Y all the time, and you just kind of frequent the places where people are nice and accepting, and then, yeah. But it's not easy." This sentiment was echoed by other mothers who had stories included under the subtheme *Unsupportive others*.

*Unsupportive others*. For the mothers interviewed as part of this study, there were many examples of interactions with people without children with ASD or special needs

who were not supportive. Sometimes the lack of understanding or support occurred with individuals who had spent much time with the child or family as in the case of family and educators. Sometimes people made comments or facial expressions in passing or after witnessing an outburst or a behavioral display. In any case, these interactions caused mothers to question their parenting skills and feel as though they were powerless to build better situations for themselves and their families.

J.H.'s son, A., was nonverbal and diagnosed with severe ASD. He had challenging behaviors, which made venturing into public spaces for outings difficult for the family. J.H. shared how comments and expressions impacted her and her children during a time when she was sleep deprived and without help from family, friends, or her spouse. Her family and friends lived in another state, her husband was enrolled in a rigorous academic program, which required him to be outside of the home for 80 – 90 hours per week, and she was parenting her children without assistance:

A. was a screamer. And I mean, I had more than one person, on more than one occasion, walk up to me in the mall and tell me to shut my child up. And how bad you feel anyway, and then to have somebody else trampling on your feelings, and your child. It became just easier to stay at home, or I took the kids-- I had a double stroller, and I took them on a lot of walks when the weather was good.

J.H. further separated herself from people at a time when friendship and contact with others in her community could have provided much needed respite. When she told this story, her tone was angry, and she had tears in her eyes.



M.M. had the experience of receiving a diagnosis for her son and then working with school district administrators to get him access to services. In doing so, she was then met with resistance from the school itself:

So, then we just got into the school system more and got him a paraprofessional right away. But I was in a small school there and they were not accommodating at all. They didn't even want him to be in circle time with the other kids because they didn't want to bother the other kids. And all the kids sat still at that age.

She not only had that experience with the school, however. At family gatherings, she found that she needed to advocate for D. So that his cousins would spend time with him:

They don't understand. I don't know. I think maybe they try. But people, they don't understand either what they should do or not do. And I tried when they were littler because he has cousins of his age, but I was the in-law, so I think I was kind of perceived as being pushy. And then I felt bad because you try, but what do you do about tell the other kids to maybe to play with him or something, and then you feel really bad, of course, because nobody wants their kid not to be played with. Because the kids would, "We don't have to play with him." They'd even say that. And I remember one time, years ago I was pretty upset. Wasn't that what family's supposed to be?

M.M. told both of those stories with a great deal of emotion. Having had the experience of watching as her son was rejected by their family was extremely difficult for her. In fact, she said that she does not attend family events with D. anymore and that she has not since he was a young child, because of the way that watching him as he was excluded made her feel.

M.M. was not the only mother who shared a story about family members who did not know how to be supportive of the child with ASD and the behaviors and life changes associated with it. K.L., whose child was diagnosed in the late 1980s, shared a story about her mother's lack of understanding about how she should parent her son, D.:

My mom, she just didn't quite understand. Her response, when I first told her the diagnosis, was, "Well, you don't spank him enough," and, "You should get him a dog." So that just kind of stopped it for me. I couldn't go any further with that. I'd like to say I have lots of friends that have been supportive, but I can't really honestly say that I've had a lot of in-depth discussions with friends about the autism.

When K.L. talked about her experiences with D. and how her mother reacted, she decided to limit her disclosure to outsiders. After noticing that she did not talk about her son's ASD with her friends, she said that she also realized that she was not including them in a very large part of her life. Her friendships became superficial because they did not involve so much meaningful knowledge of her life.

The experience of having an outsider with limited knowledge of her child's disability as a person in a position to, under normal circumstances, provide counsel was not unique to K.L. M.W. shared a story about her son's teacher suggesting corporal punishment as a solution to his behaviors, prior to either a medical or educational diagnosis as late as the early 2000s:

And so, I went to the one teaching meeting with the second-grade teacher, and he was an older gentleman kind of as old as my grandpa would have been. But an older gentleman and he just took me aside, and he was like, "Ma'am, I really feel

that he would be more successful in school if you would give him a proper spanking. And if you could teach your child how to behave in school, we would all be better for that." I'm like, "Well, I don't know why you're talking about that. I'm not going to beat my child because you said that he wasn't behaving in your classroom." So that didn't equate to me. I didn't really know how to take that other than kind of grit my teeth and kind of scowl and go, "Well, you don't tell me how to parent," because it wasn't solving anything. None of these comments that everybody was making was helping with anything. And all I could see was this struggle in my child about how incredibly uncomfortable he was to even be in this atmosphere, didn't want to be there.

All of the mothers interviewed shared stories about how those living outside of their paradigms simply couldn't understand their lives, their children, and the unique behaviors that are part of ASD. The stories shared involved not only strangers and others without knowledge of ASD but also family members and teachers. N.B. shared a story about neighborhood children chasing her son home while they shouted insults at him at a time before autism awareness campaigns. M.H. talked at length about the family's many experiences with psychiatrists as they tried for years to find a definitive diagnosis for her son, A, learning that they were all manifestations of ASD. S.N. told a story about riding on a ferry and having many onlookers gape at her son as he crawled on the floor of the boat screaming without the ability to verbalize his fear or sensory overload. M.B. told a story about not wanting to share that her child was living in a group home because of how people who had seen his violent outbursts would comment about her "failing as a

mother.” Altogether, the stories about ASD outsiders who were unsupportive far outweighed the stories of support in terms of interview time.

**Too much and never enough.** Mothers of children with ASD are pulled in many directions. Many of the mothers interviewed for this study worked full-time in addition to raising their children, including those with ASD. Some completed college or graduate school while raising their families. Some were single parents while raising their families. Many had gone through the process of applying for government-sponsored social services to afford recommended therapies, such as applied behavioral analysis (ABA), which was not covered by many health insurance plans until the Affordable Care Act was passed. The theme of *too much and never enough* refers to *too much*: to do, to learn, and *never enough* time or other resources, except for love. Love, however, was something that mothers needed to learn to share with their children on their own terms.

***Too much to do and never enough time.*** For many mothers of children with ASD, there is too much to do in the limited time available. Ranging from medical and therapeutic appointments, the commitments of mothers of children with ASD are numerous. Appointments with social workers to secure services for children with medical diagnoses took time for the mothers as did meetings with the schools. If mothers wanted more than what was offered or the services that were being offered were not adequate, the time required for these appointments and meetings would be much greater.

With two children with special needs, M.F. found that she was spending the greater part of each day engaged in activities related to the care of her children:

And so, then it started with him, then we have the barrage-- so now we've got two kids seeing therapists three times a week. By this time though [his sister] was

doing an out-of-home program. So, there were therapists that were coming to the house to see S. while [his sister] was at a Ben-Franklin-type of early-childhood programming. So that was pretty crazy. So, as you can imagine, at this point, I'm certainly not working at all.

M.F. spent much time early on in her children's lives with this grueling routine. After her children were in school, she did not return to the workforce until her son was in middle school. Then, it was to be a paraprofessional in the charter school for children with ASD and other learning disabilities that she helped to found.

When she was a mother with children who were preschool age, J.H. moved with her family to Olmsted County, MN. She found that she couldn't sleep because her son, A., did not sleep more than a few hours per night. When he wasn't asleep, he was screeching or screaming. Her husband was attending the nurse anesthesia program for the 30 months following their move to the area and was out of the house for 80 – 90 hours per week required for its successful completion. J.H. found that she became depressed but was not able to do much about it, due to the demands of her family:

Well, when we first moved here I spent probably every day for three years crying. I mean, seriously it was pretty miserable. I had no family, no friends. When you have a child with autism, you are now doing this, or that, because they like their routine, and their schedule, and you just can't go and do, and meet... But pretty much Frank was in school long hours, and I was basically home alone with the kids for years. And it was not easy. It was not fun, and I mean, if I didn't have crying to do I didn't know what else to do.

She did not find friendships in the area until many years later, when her A. moved out of the house and into a group home close to the family.

For M.W., finding time to interact with educators (her son did not receive a medical diagnosis of ASD until age 17) and help them understand that there was a need to address him holistically and ask him how his needs could be met was an exhausting undertaking:

The Asperger Syndrome, the autistic spectrum, all those things, those were just words. They didn't really define anything for me, and they really didn't define anything for the school. It was just a way for them to say, "Okay, at the top of this IEP, this is what we're going to put at the top," but that didn't change the way they viewed his behaviors. They viewed his behaviors as more of a defiant disorder or like he was just a danger to the other students. And so I said, "that's what my son really is, and I'm not sure why you're not connecting with him the way I would. I don't understand why it gets to the escalation that it does here when it doesn't at home."

And it just became a huge battle, a battle of who was more right to understand K., but no one really asked K., other than, "Well, what do you think we need to do for you to behave yourself?" Not one sentence had ever been said to him about, "Well, we understand that it's pretty tough being on the spectrum and that we might have to figure out different ways to work with that." If he had been born without a limb, it'd be easier and take less time and energy to find therapy for him and help him live without a limb than it was to deal with this.

M.W. spent many years working temporary jobs so that she could have the freedom and time to leave the workplace when her son needed her support. From the time she and her husband divorced until the present day, she has had this working arrangement. While she says that she was willing to make the sacrifice for her family, she is resentful that she does not have a career because of the need to be immediately available to go to the school at a moment's notice.

These stories and many others were included here to illustrate the extent to which mothers' time was required for advocacy. Without that time, children of the mothers interviewed would not have been able to grow and develop in environments conducive to their learning. Without the mother's time, each of these children would not have been able to access services that aided in their development.

***Too much to learn.*** For mothers of children with ASD, there is much concrete learning to accomplish. The mother has been expected to learn about ASD and common symptoms. The mother has been expected to learn about available therapies, treatments, medications, and how to navigate the medical, educational, and social services systems in place, regardless of the year of diagnosis or the age of her child. The mothers interviewed for this study, however, also learned how to create opportunities for experiences and integration into *normal* life for their children. For all mothers interviewed, this experience was memorable.

K.L., as the mother of a child with ASD who was born in the 1980s, parented her child D. without the benefit of awareness groups and many books aimed at parenting children with ASD. She had to teach herself to convince her son to engage in non-

preferred activities, such as wearing a winter coat or visiting family through addressing concerns he might have due to his concrete logic:

It's funny because I just remember. I don't even know how old he was. I mean, he was in school, in elementary school. But I remember saying to him one day, "Well, D., I think you need to take your winter coat." "Well, mom, winter doesn't start until December blah, blah, blah, blah, blah, blah." I'm like, "True. You're right, D. It doesn't start until December 22nd, but, sweetie, it's cold outside [laughter]." I mean, so just having to kind of try to think ahead. And we would try to go to Iowa every month to visit family. And I would let him know we're going to be going to family. We're going to see grandma and grandpa. But there's times we wouldn't go because somebody got sick or because there was snow, and so then I had to learn to say, "We probably are going to be going unless--" and you had to try to figure out all the things that might prevent you from going, because he'd be locked into, "We're going to go. This is what we're going to do."

M.W. shared a story about learning that her son's fears and difficult behaviors did not always result because of the reason(s) she anticipated. She talked about the need to decide which activities are truly important:

So, you learn to figure out what's important in life and what you really want to do with him. And that was hard when he was younger, because you'd do something that you would think he thought was fun. Taking him to a carnival should be fun. Taking him to the movies should be fun. He once told me, and this was like 8 months, 10 months, 12 months after it happened, he said me, "Oh, the reason I got



sad and screamed at the movie, and made you take me out, is because I was scared of the hamster on the screen." And I'm like, "Great to know, Bud," but it's eight months later [laughter].

M.W. continued by telling about how her family had left family gatherings, her son had needed to leave school, and how she had not made friends because of the unpredictability of K.'s behaviors. She shared that she hadn't learned how to tell others about her strategies for minimizing the impact of his outbursts until he had almost completed his secondary school education.

For mothers of children with ASD, compromises always need to be made. Providing knowledge of how to best interact with a child with ASD is something several mothers discussed. S.N. shared a story about the introduction of an adaptive communication device and how she has educated her son's teachers about what she learned through interactions with her son:

So I drove him to Gillette five times. Sorry, not Gillette. Yeah, Gillette. Five times, last spring. And we got him a communication device. That's \$7,000 that MA paid for. And so that's what we're working on because now he can talk to everyone. And he loves to tell jokes in his classroom at school. And he can only handle five minutes in the typical classroom. And that's okay. That's what it is. Of course, he wishes he could do more, but he can't, so. But, yeah. And I noticed the beginning of the school year, he was spending no time in there, and I'm like, "This isn't okay with me." I've made a list of 16 things they could do to adapt. And I've sent them all these pictures because he's preschool so he loves to look at

himself in pictures. Not every special ed teacher was meant to work with autistic kids, you know?

Even with her suggestions, the teachers were not able to accommodate her child in the classroom for more than the few minutes she described above.

For all of the mothers interviewed, the suggestions they make to others do not always work for other's children. Each child interacts and reacts differently with other people than they do with their mother. This difference in interaction was frustrating to the mothers interviewed for this study, because it limited their options for their children and offered few options for respite as well.

*Never enough resources.* The experience of not having access to the resources a mother feels are necessary for her child was universal among the women interviewed for this study. Whether due to a lack of funding, a lack of a diagnosis, or because a child was not the correct age when access became available, the mothers told many stories about experiences related to a lack of resources. For mothers who were excellent advocates for their children and for those who were able to navigate the system, these shortages were felt less dearly. For those who struggled within the confines of the existing system, these were felt more acutely.

K.L., whose son was born prior to availability of many resources specifically designed for children and individuals with ASD, found many times that the timing was not right for her son, D. While not thrilled about missing out on opportunities, she was reluctant to discuss her disappointment because she felt that there were many other children who were able to benefit at other times:

And this will show my bad side because, throughout his life, things have come up, but he's already been too old for it. After he got diagnosed and he started school, then there was a lot about intensive therapy with two-year-olds, identifying it and working it with them in their homes. And then this thing with Mayo Clinic. And I contacted Kim at SEMCIL, and she's, "Oh, I'm sorry. It's for high schoolers." "Oh [laughter]." But he's kind of a trailblazer in a way, I suppose, because my friend, at the library said to me-- because she has a son who just graduated from high school. And we've talked over the years about our guys, and she said, "But you give me hope that [my son] can do it someday, that he can live on his own," I said, "Thanks."

K.L. believes that her son is able to function at such an elevated level because of the commitment of her nuclear family to D.'s success in life. She talked at length about the interventions they employed to integrate her high-functioning son into family activities as well as her commitment to advocating for him in the school system.

M.D. had accessed Applied Behavior Analysis (ABA) therapy for her son; however, the autism center was insisting on providing 40 hours per week. The waiting list for the ABA provider in her area that did provide part-time ABA was much longer than the provider she was able to access. She was not willing to sacrifice the social interaction opportunities available to J. through the public-school system:

Yep. Yep. That's right. So, he had just started doing that and that was a half day, and I did not want to take him out of that. When the kids start ABA, a lot of times they want them to go for a full 40 hours a week. And I just wasn't willing to take him out of that. So they were able to do a part time thing, where he could go to

school in the morning and do his 20 hours. And then he did his 20 hours of ABA and home therapy after, so he kind of-- ...had some long days... Yeah, he did. For a preschool aged kid, that's-- I wasn't willing to give up the social experience that he would get. They really do and you can teach them these concepts until you're blue in the face, and they can regurgitate it back to you, word for word, exactly what you said, but it's another thing to actually apply it in the moment. And I didn't want him to lose out on that, so they finally agreed to it which was good. He did that for about a year and a half and they graduated him.

This story is highly unusual to hear regarding the center about which she spoke. At a time when the State of Minnesota was being critiqued for providing full-time ABA therapy as part of the Medical Assistance program, M.D. pushed back because she believed it was the right thing to do for her child. She also refused full-time therapy because she did not want to tax the available resources in hopes that another family and child with ASD could benefit from the funding she was not using.

M.B. specifically addressed the issue of resource allocation. She offered an explanation of her philosophy for accepting and accessing resources necessary for her child, P., and her family:

Don't use something you don't need, but ask for what you need, and don't feel bad, because, if your kid was diabetic and they needed a sugar-free snack, you would ask for a sugar-free snack and you wouldn't feel bad about it. If your kid needs two seats, because he can't sit next to someone or he'll-- because he might whack them when he's stimming, with his beads – P. likes beads [laughter] - or whatever, then you ask for the extra seat. And you don't have to feel bad because it's-- and

remember the law. Even if you don't feel like it, the law's on your side, because there's the Disability Act, and all of that, says that they have to accommodate him in schools....

M.B. was much more conscious of the law than other mothers who were interviewed, because she and her family had needed to access many resources due to her child's behaviors. They also endured the process of voluntarily entering their son into the foster system, which will be discussed as part of the theme *easier apart*.

**Love.** None of the mothers interviewed expressed feeling that they did not love their children with ASD. In fact, several of them discussed behaviors exhibited by their children, which made it difficult for them to love them in the way they expected. These stories express the emotions experienced by mothers who were not able to connect to their child with ASD in the ways they had with older siblings.

M.H. told a story about how it felt to parent her second son after feeling successful as the young mother of his older sibling:

And I felt very disconnected from A. in a way that-- because he didn't express love. And I can say that now. He wasn't a snuggler or-- but yet, he said he always wanted to get-- was always searching for his new family because he wanted to go and see other people and was going and trying to-- meeting other people, but I never had that deep connection with him. So I was definitely struggling at that point to-- I always felt like an amazing mom with [his brother].

I knew I was a really a good mom. I was. I was a young mom. I was only 18 when I had him, but I was a very-- I knew I was a great mom. We did things. We'd sign up for community ed classes, and it was a very positive experience

where I felt really good about that parenting. And then it wasn't, with A., something was off but I didn't know what it was, but we couldn't put our finger on it. And I was trying but it just never felt like I was being successful. And then so much time was taken up with that process that then I felt like maybe I wasn't as good of a mom to [my older son] either. And so, at that point, really started to not feel as good about my parenting skills.

M.W. shared a story about not feeling as though she could not console her son when he was an infant:

It became a little more stressful with it because I felt so bad that I wasn't doing enough, but I felt like I was doing everything that I knew how to do. And he just still could not be consoled. It was tough because I wanted to bond with him, and he wasn't really into it. He didn't really think much about it. He wasn't missing me. He was just upset to be upset. He didn't like a pacifier. He didn't like a swing. He just didn't like anything but to have someone rock him and just constantly pay attention to him, so it was a lot tougher from the get-go. And I didn't know if I was more stressed, if my stress was showing towards the children because now I'm a mom of three young children all under the age of six. Just I didn't know if it was me showing my stress that made him stressful, so I just tried really hard to make him feel better, and love him more. I don't really see it any other way than just I tried my best to love him the way he needed to be – from the time he was a baby until now that he's a grown man.

These stories both illustrate the extent to which mothers of children with ASD question their parenting efficacy. In both cases, the mothers questioned not only their

ability to love the child with ASD in a manner that was acceptable to him, but also their ability to effectively parent their other child(ren). For both mothers, these reactions to their love were devastating and resulted in subsequent bouts with depression and anxiety.

The theme of *too much and not enough* emerged from mothers' stories about the desperation to advocate, provide, and care for children with ASD. This desperation arose for the mothers because of a lack of time to accomplish all that was necessary for the best care of their child with ASD and a lack of adequate and available resources. For some of the mothers, the child's response to expressions of love that they were used to providing for older siblings at the same age resulted in feelings of depression, anxiety, and a questioning of parental efficacy.

**Easier apart.** The theme *easier apart* emerged from stories told by several of the mothers interviewed. They talked about conversations or thoughts they had had about living apart from their spouses if they were married and how they believed it might be easier to live apart so that they could have some time away from their child with ASD. The mothers who had children living outside of the family homes shared stories about how it had become easier to live separately, but the decision to do so had been extremely difficult in some cases. Mothers who were not living with the fathers of their children with ASD also shared stories about how it was easier to live in different households.

For M.B., the decision to live apart from her son was fairly easy to make. Her son was displaying hyper-sexual behaviors as he moved into puberty and was also becoming increasingly violent. She shared stories about respite providers with years of experience not being able to safely care for her son and then shared the rationale behind putting her P. into foster care:

But, yeah, so that was basically kind of the behavioral end of-- instead of like going into foster care, you'd go into this piece. Because in the state of Minnesota, which annoys me, but in the state of Minnesota, there are no group homes for children. You have to put your kid into foster care. So, P., actually we had to put them into voluntary foster care in order for him to get placed at a group home. And now what's interesting with that is we still didn't give up any of our rights to make decisions for him and we were all part of the process. And it was a very rare situation that someone does this, because, typically, what happens is people wait until something bad happens and someone gets a broken arm or something happens to sister, and they tell you, you have to put them in foster care, so it's not voluntary. So we voluntarily put him in foster care so he could be in a group home. So that piece of feeling like a failure and not being able to handle him... And it's hard sometimes, because when you see other-- this kind of goes with that judgement piece too, because sometimes it's hard when I'm at activities. Like when he was doing special needs hockey, or adaptive hockey for hockey last year. And there were a lot of kids that were living at home or things like that. And I felt like, "Oh, I'm the parent who can't handle it." So [laughter] I'm the one who has the kid at the group home, but I still was very involved in his life, and we went to meetings and we have him at our house every weekend. My mom's my cheerleader and she's like, "[Daughter], you do a lot with him. You're fine. You're doing all the things that you can." And so, it's nice now to get to move from parent failure to guardian hero [laughter].



M.B. even articulated one of the benefits her family is going to experience as a result of their decision to put their son into a group home:

One of the things the psychiatrist said right before, when he was in the hospital, right before he was put in a group home was, "This way you're going to get to enjoy him when you have him. You're going to get to do the fun things and not just be doing the care things," and that's really true. He's doing well enough-- we're all excited. He's doing well enough and he's stable enough that-- we haven't flown on a plane with him in over five years [laughter] because I call it Psychotic Break by Disney [laughter]. Sorry, I have some autistic parent humor. But yeah, so Psychotic Break by Disney. And I love Disney and I go all the time, as you can see by my office all my Mickey Mouses. And we just kind of said, "We're never taking him on a plane trip again. We're just not going to do that." And he's calm enough now that we're actually-- as a graduation, he socially graduates this year, not academically, and he's actually going to be at [high school] another year. But we're taking him to my brother's for a four-night trip. He really likes to eat and Boise, Idaho is where they live, and they have all these neat restaurants and things like that.

Both M.B. and her husband were really looking forward to the trip and believed that they are now going to be able to enjoy the trip together. In contrast to the trip she referenced earlier, they are anticipating a very different experience. As she puts it, now they can “enjoy their time” with P.

M.H. described a similar situation in that her son A. was violent when at home prior to moving into a group home. Below, she discussed the decision for her son to move into the new facility and the episode, which was the catalyst for the move:

So, when this opportunity became available for him to be in the group home-- and that is what he wanted. He did not want to live with us. He had made that very clear. He did not want to be in the same house as [his father], and by that time, me either. He didn't want to be with me. But in the previous times, like when he had wanted to go to Generose, it was because he wanted to get away from his father because he just had this very-- again, how [my husband] dealt with that during that time, I can't tell you, other than just to push it away and not-- when A. was out of sight, then it was, I think, out of mind for [my husband], that he can-- and I think that in general, men can compartmentalize things a little better than we can, so when [my husband] left for work, that was it. He's not the one they're going to call. I mean, he didn't have to worry about it. He didn't think about it unless I told him something....

Yeah, so A. was able to come home, spend Christmas with us, and very scary for all of us because we didn't know. I mean, the time before that that he had been home was-- I guess he had come home for Thanksgiving for two days and that had gone okay, but before that, in October before he had gone to Wisconsin, had not been a good experience. I mean, he had been-- and again, those medication changes and things with the antipsychotics that he-- it was not A. I mean, he would have this blank-- I mean, as he was physically assaulting me and punching me in the face over and over again. It wasn't my child inside of

him. And I knew it's not him. You know what I mean? And as I'm sitting there crying and the girls are observing this and seeing this, and we don't know what to do, just that he-- I knew that it wasn't him is how I could-- it wasn't. I mean, there was nothing behind those eyes. And just knowing that those damn medicines in his body-- and we never would have wanted them for him. And it had so many negative experiences with weight gain and all those stupid medicines before. But at the time, didn't feel like we had any other choice but to try something because he couldn't function.... He needed to move into the group home. It was just so much better for everyone.

For S.N., whose son was only 10 at the time of her interview, *easier apart* refers to her decision to divorce her husband and its consequences:

So I've done a lot of fighting, and I feel alone in the world, and it's miserable. But I keep fighting, and I knew I had to get divorced to get my kid to get an autism diagnosis. So I did that... And I'm blessed to be divorced because my boys go to their dad's every other week. And then when they're gone, I work my five shifts because I'm just 0.5 as a nurse. Then I have all this extra time to do yard work, and I love yard work, and I garden.

She can live a more balanced life by living separate from her husband and feels that she is better able to function as a result of the respite she receives through having 50% shared custody. However, as S.N. looks to the future, she is concerned about the possibility of parenting her twins full-time:

And I just feel bad for him. He doesn't want to go to dad's ever. Dad doesn't let him use his communication device there. Dad thinks he should sign, but dad can't

even sign. So, I just feel bad for him that he gets all these mixed messages. And he's always signing, "Mom." So, what I do at both places, I do a calendar, and I take it, and I write an M for Mom or a D for Dad. And they put it up at his desk so he can always see where he's going that evening. And I feel really bad for him. And most judges, when a kid's 12 or 13, the judge will let the kid choose where they'll live. But physically, I don't think I have the strength and the energy to have him full-time. But he would love to be at my house full-time. So, I don't know –

S.N. was not the only divorced mother interviewed as part of this study. M.W. shared similar feelings about being divorced from the father of her son with ASD:

I was glad to be out of the marriage because I felt there was no help there anyway. It was just a long string of disappointment and depression that it really wasn't something I could have been excited about anyway.

Whether as a result of the choice to have the child with ASD live outside of the family home or to divorce a spouse who was felt to hinder the mother's ability to parent her child, the theme of *easier apart* was echoed frequently. For the mothers who shared stories encompassing this theme, the time apart could refer to time away due to family support or respite services or even time spent at work, regardless of the rigor of the job. In general, this theme validates the literature related to parenting stress and the toll it takes on mothers of children with ASD.

**Mother as heroine.** The theme *Mother as heroine* includes stories of a mother caring for, supporting, and advocating for her child with ASD. It is also about the mother defending her child. The theme is about becoming better at those things. It is about

learning to mother in a way that is different from the mother's impression of what motherhood would look like before she had a child with ASD. The theme *Mother as heroine* is about the mothers, interviewed for this study, learning to become the mother that her child needed. It is about each mother developing confidence in her abilities and building knowledge of her child's needs as well as the educational and social services systems to advocate successfully.

J.H. was the mother to one neurotypical child and her son with ASD during the time he was preschool-aged. She developed strategies for not only maintaining the comfort of her son, A., but also creating opportunities for her daughter to participate in normal activities. She also found creative ways to maintain the health of both children; however, she sacrificed her own comfort and health in doing so:

And it wasn't just A., it was having another child, who was a typical child, trying to keep them involved in things, and yet not be able to be involved. Put her in gymnastics, but not be able to sit at gymnastics and watch her, because I had to be in the car with A. And A. didn't sleep. He didn't sleep. And he was up, he'd scream all night, and I didn't sleep. And then we'd get in the car in the afternoon, after kindergarten, and [his sister] would say, "Would you drive around so we can take a nap?" It's like, "Okay." And I would drive the car around, and [my daughter] and A. would fall asleep in the car. But the problem was I never slept [laughter]. So, it was very stressful.

The stress that J.H. endured through those early years with her children, while her husband was not at home, was challenging. In retrospect, she could laugh about the adversity she overcame.

K.L., as the mother to four children, the oldest of whom has ASD, decided not to immunize her children because of her belief immunizations had contributed to her son's condition. Her story of taking all of the children immunizations as older children and the way that she collaborated with the nurse in the clinic to accomplish the goal of the day illustrated her ability to preserve her son's dignity. It also demonstrated her ability to avoid a situation that could have deteriorated and become dangerous while still caring for all her children:

And so I remember when he was 14, and because I'd held off on immunizations, it was time to get one of the immunizations that you have to get like three. So, you have to go, and then you wait a month or two. And you go, and then you go. So, I took all four kids [laughter] to go get the shot after school. He wouldn't get out of the car. He didn't want a shot. I thought, "Oh my word. He's as tall as me. How am I going to get this kid? Wrestle him?" Somehow, he came with me, but he wasn't going to get shot. "I'm not going to get it, Mom. I'm not going to get it." And in my mind, you're thinking, "You're 14 years old. Stop acting like a baby." But he's not your typical 14-year-old.

So I get in there, and finally, I just thought, "[Self], put your ego at the door." And I went up, and I said, "My son is autistic. My son is terrified of getting a shot. I do not know what to do." I loved her. She just said, "Don't worry, Mrs. L. If we have to wait--" because it was already 4:30. She says, "If we have to wait till everyone leaves the building, and we have to go out to the waiting room to give your son his shot, we'll do it. Don't worry."

So I sat. And so [my second son] goes in first, and he [laughter] always laughs. I'm not sure why he laughs. Every kid goes in and gets their shot except for D. And D. was nervous, and he had to go to the bathroom. So, he had to go to the bathroom, and the bathroom took him right by the waiting room. So, when he comes out of the bathroom, there's two nurses. But they had the sweetest voices. "D., come on in, hon. Let's get this done. Let's do this [laughter]." So he got his shot, and he was like, "Okay." And so she said to me, "Okay, we got two more to go [laughter]." I said, "I know." She was, "I'm scheduling you for the very last appointment of the day. And we know what to do."

Overcoming hurdles through collaboration with healthcare, educational, and social service providers was one thing that the mothers echoed in their stories. M.B. used the information that her son had ASD to smooth public situations. She viewed this disclosure as a way to provide him with necessary support when it might not otherwise be available:

And, generally, I think people were-- we were blessed with supportive people, but sometimes in public-- I call it playing the autism card [laughter]. I learned, as he's grown up, that when I need support from-- I learned not to be so reactive, because sometimes you get embarrassed because you're-- well, if we're at the mall and he called the African-American clerk chocolate [laughter]. And that's a very-- that would be okay if you were three or four, but he was like eight or nine, so it's not okay [laughter] at a certain age when it's not really socially appropriate to do that. But you kind of learn when to say, "Oh, he's autistic, that's why he's doing that." So, I call it playing the autism card, when I know if it's a situation that's going to--

if it's a safety issue, you've got to tell people what's going on to keep him safe, but if it's just that he's having a tantrum and someone's staring at me, if their kid's having a tantrum I don't ask them why. So, if he's not really endangering himself, or if they're accommodating him because of his autism, and his other issues, if it's not going to provide extra services for him, I've learned that I don't have to play that card, I can keep that card to myself and... I can use it when it benefits him, because as he's gotten older, he's still a teenager, and he's 18 in January, and he doesn't want everyone to know his business unless they need to know his business.

M.W. viewed herself as a heroine because of how she defended and supported her son through his school years. She kept a job that allowed her to leave whenever there was a crisis at school, which her son was ill-equipped to handle alone. She advocated for him through the individualized education plan (IEP) process each year and recognized herself as the advocate for her child who was able to make school more comfortable through the support of those plans:

Probably not till middle school. By then, I'd had enough, by then I had pretty much picked so many fights. We had been to so many schools. We had been put through so many different approaches. We had been put down by so many folks saying that it was our job as a parent to get him to behave and that it was us that was failing K., and he was not conforming. So, by the time middle school came around, I had become a pro at being an advocate for my child enough to I have a wake of a couple of teachers and a few administrators that don't care for me so much anymore. I did. I raised a huge stink. For my entire experience with



schools and K.'s childhood, that's all I've done is fought for him. There were so many different approaches that I honestly could tell you that I believe the school system has actually physically abused my child more than I would ever think to as a parent. And he still has nightmares about those experiences. He still is extremely upset. He feels robbed of his childhood because no one knew how to help him. But overall, by the time he was in middle school, I had mastered the idea of what an IEP meant, what it did to protect my child because then I felt I had a little more leeway to drop what I was doing, walk off my jobs, go pick him up, put fires out at school, sit in the classroom, and prove to them that my son was not a behavior problem, because as soon as I sat down next to my son, he was well behaved.

For other mothers, learning as much as possible following an ASD diagnosis became paramount in terms of priorities and created opportunities to save the day and their child through knowledge of interventions. While not all interventions described in the literature worked, M.D. found that she was able to find some that helped her to *figure out* how to help her son through understanding more about ASD:

I looked around on the internet a lot and you get such random stuff on the internet, you don't know how credible it is. So, I ended up ordering a bunch of books, I don't remember what the one was called, but that one was really helpful. It wasn't like a For Dummies book, but it kind of was [laughter]. You know what I'm talking about, like the blah, blah, blah for dummies [laughter]. I can't remember what it was called now. So then after you get some of the basics figured out, you have like this-- it's like this need or this want to get inside their

head and try to figure out how they're perceiving things and how they're-- how can I get in there, how can I be a part of this instead of just watching it from the outside?

This story of information-seeking and the desire to have success with helping her child was not unique to M.D. N.B., whose child was born 29 years earlier, also sought information as part of her process, although she had the goal of *fixing* her son rather than understanding him:

Yes. And I think it was harder on [my husband] than me because I switched into, "I'm going to fix him. I'm going to find out what's wrong with him and I'm going to fix him." And I think for my husband, he wasn't in my way of thinking, you know, like I'm going to fix this kid. He was like more something, "This is what we have," you know. So, I tried all sorts of things. Diets. Did sensory integration which I thought was very helpful. They didn't have the, you know, what they have now where you have the-- help me out here. Where you have the-- they do the feedback all the time.

The difference, over time, of viewing ASD as a condition to treat, or *fix*, versus something to "understand" about a person was a key difference between the mothers of children who are in their 20s and 30s versus those who were pre-adolescent at the time of interviews for this study. This change could be due to the increase in both autism awareness and access to information for laypersons.

For M.B., when several events occurred simultaneously, the feeling of extreme overwhelm was relieved, in part, by her faith in God:

But there's just been moments like when Dad was-- I graduated from nurse practitioner school, my dad had an esophageal variceal bleed, almost died. We were looking at losing funding for P. [His sister] was having daycare issues, and just all these different things happened, all at once. It was just the idea that even in all the turmoil and things like that, he always led us the right direction. Even sometimes when I forget to ask, He leads me in the right direction, because he's just that faithful... And part of being human is being sinful, but God made a way so that we didn't have to-- yeah, he gave us Jesus to take care of that and to-- and he does carry our burdens... And I don't know how people who don't believe in God survive this kind of stuff, I don't. And I know they have other ways and other traditions, but without my faith, I don't think I could've done this.

Stories of spirituality and faith were shared by other mothers and belief in a higher power was described as a source of strength. For M.B., her relationship with God and her faith allowed her to survive through difficult times, such as that described above. Of the mothers interviewed, only one, M.W., described herself as a non-spiritual person. Her stories focused more on her struggles to overcome obstacles than many of the other women interviewed.

The theme of *Mother as Heroine* includes stories of mothers advocating for, supporting, and understanding interventions that would help their children with ASD to have better quality of life. The idea of saving the day with an intervention that allowed a sibling to engage in typical activities, finding a way to support a child in the classroom, or discovering a way to “save” a child was universal in all of the mothers’ stories. For these mothers of children with ASD, it sometimes took more than the mother, though. It

was often a collaboration with others, which, when successfully navigated, made mothers feel as though they had the power to be the mothers they so strongly desired to be.

### **Afterward**

For several of the mothers who were interviewed, there was a difference in the way that they spoke of the experience of mothering their children with ASD. Even for those who were still engaged in the day-to-day activities of parenting, there was a retrospective quality to the stories. I remembered more smiles during the conversations, and there was more laughter interspersed with the stories. They had more fortitude when they spoke about their experiences, and they seemed to have developed a greater store of inner strength than the other mothers.

What that group of mothers had in common was that they had either endured a crisis, which sounded terrible as I listened to the stories or their children were adults living on their own. For the adult children living on their own, the parents had either completed the process of petitioning the court for guardianship or they had planned for posthumous care of their adult child with ASD. Guardianship is defined as the court appointing a person who “has authority to make decisions on behalf of the protected person about such things as where to live, medical decisions, training and education, etc.” (Minnesota Judicial Branch, 2016, para. 1). For the mothers who had experienced a crisis with their child with ASD, the theme that emerged from their stories was *all worth it*. For the mothers who had completed a critical process, the theme that emerged from their stories was *letting go*.

**All worth it.** For the mothers who had endured crises, such as nearly having a child die and multiple arrests for assault followed by a series of institutionalizations, a

conscious decision to want to mother the child was made. Universally, the mothers expressed gratitude for their children; however, these mothers had transcended the difficulty of day-to-day parenting and expressed acceptance of their responsibilities – not as responsibilities but as labors of love.

A., J.H.'s son with ASD, nearly died of a hemorrhage after having his tonsils removed as a teenager. As a child who did not need much sleep, who was non-verbal, and who became violent enough to be a danger to his siblings while living at home, his upbringing was a challenge to his mother. Below, she describes how that event and almost losing his life caused a metamorphosis, which resulted in her becoming a woman with much inner strength:

But I'll tell you what, I was on my knees praying when A. had his hemorrhage. He was so close to-- he had a lung collapse, he had aspiration pneumonia, I mean, it was bad. He had that death rattle, and they had to suction him all the time, and it was just unbelievably awful. I mean I would have bargained with Him to do anything to save that child.

And I always worried that I didn't love A. as much as I loved the other kids, because he was so much work, and so hard, and had this and that, the medicines, and this and that. Everything was just so complicated, and nothing could be easy. We couldn't just go out to eat, or whatever. Even try taking a 13-year-old boy on a road trip by yourself, and trying to change his diapers. I mean, yeah, there's more family bathrooms now, but back when A. was 13, there wasn't. I mean, I used picnic tables to change diapers, and things like that.

And so, I think that I evolved, and also I had a new appreciation for the fact that I did love this child, and I would do anything for this child. And this child was just as important to me as all my other kids. And I'd lay down my life for him, just the same as I would for every single one of them. And I think I needed that. I think that there's some kind of a guilt, or some kind of a something that just wouldn't let me feel like I was worthy as a parent, or something.

I worried that I was not a good enough mother, or else I would have this child fixed. And I think at that point, it was just something happened, something kind of clicked that it's like, "You know what? You've got this child, and you love this child. You're doing the best that you can with him, for this child, and that's what you can do." And you've just got to sometime say, "Nobody gets it." I mean, even the family who you love dearly, they don't necessarily get it. They don't get what you go through every single day. And people don't get that just because A. isn't at home, doesn't mean that I don't worry about him every day, and think about him every day, and holidays. My family is Illinois. So now I have the decision, "Okay. Do I go spend Christmas with my family and leave A. in the group home? Or do I stay here and disappoint my family back home, so that A. can come out of the group home for the day, because you know staff taking care of him doesn't want to be working on Christmas."

And so, I just had to become strong enough to say, "You know what? A. is not going to be alone for the holidays. He is my family too." And even though it's just another day to him, and means absolutely nothing, he opened one present and he didn't even care about that. We opened all the rest of his presents for him

and everything, but the fact is that he deserves that. He's our family, we're his family, and even though those people back there are my family too, and I love them dearly, he's my child, and he's not going to spend Christmas alone in a group home. And I just felt like I just caved under to everybody for so long, and I finally-- after A. had this big almost death experience, got the nerve to say, "Hey, you know what? This is how it's going to be. Everybody's welcome to come to our house, but he's not staying there alone."

She went on to describe her feelings about being A.'s mother and her relationship with him and the growth of her own inner strength:

And I think we sometimes tend to just be too hard on ourselves. And I am so grateful for the fact that we still have A. with us, because we came so close to losing him. And he is a blessing. I have met so many, so many neat people. And I've learned so much about myself, the patience, and stuff that you don't think you have. When we lived in our old house-- before we had [our younger two children], we had enough rooms to have a guest room, and I had worked so hard, so hard to get this guest room all done. It was just gorgeous. And I mean, it was done for two hours and A. got in there. And I mean, it was just awful. And [my husband] came up and just like, "You know, honey, I hate to tell you this. A.'s gotten in there." And he had just thrown everything everywhere and it was a disaster. And I just laughed. It's like that's when A. thinks that of my decorating [laughter]. And you've just got to be willing to laugh, or else cry.

Sometimes that's the answer, too. But it's like, "Okay. This is not important." When it boils right down to it, whether my bedspread and my walls

are beautiful, it doesn't matter. What matters is that you've got quality time, and love to give to everybody in your family. And whether they're perfectly normal, and functioning on their own, or need somebody to feed them, and bathe them, and toilet them, doesn't matter. They're family and you'll love them all just the same. I don't know. I think about back when we moved here, and how sad and depressed I was all the time, about everything. And how everything was such a fight. And I'm not going to tell you that it gets better, and that it's not a fight, because it still is. Every little thing you want to do, it seems like it's a fight. But now I know it's a worthwhile fight, and I think that's everything you do, you do it for a reason, and they're the reason.

That's how I feel. I wouldn't change it for the world. I sure would like to know what he thinks, sometimes, though [laughter]. If he could just tell me what - I went to Possabilities this afternoon-- well, this morning. They needed some - he plays with shoestrings, all the time, shoestrings, and they were out. So I took some shoestrings out there, and he was-- he bounces on a therapy ball on a trampoline. He sits on it and he bounces, and he bounces all day long.

And everybody who has never seen it just totally freaks out the first time they see him. But he has impeccable balance. He's always had impeccable balance. But he was so happy to see me when I walked in there, and he took my hands. And he was bouncing on that ball, and my arms were getting sore from holding his hands. But he was holding my hands so tight, and he just smiling, smiling. And it's like, he has never been able to say, "I love you, Mom." And I would love to hear those words. But in that instant, you know it. I mean, you see



that smile on his face, and him holding your hands, and you know he loves you.

But that's the icing on the cake there. That smile. Nothing better.

For M.H., whose son, A., had been arrested multiple times for assaulting caregivers and medical professionals as a teenager, even a story about those dark times, ended with a positive note:

And so I remember I was up at church and got the phone call that they were going to take him to jail and just called [my husband] and I just said, "I have to go."

You know what I mean? And I felt like-- I mean, I really don't think that he felt like I should, like, "You got people here to take care of." But my kid's in the jail. I have to go! And driving, just taking the girls home because the girls were up at church with me, and taking the girls home to him and giving them to him and him not looking at me because he was upset that I was going to go, and me trying to justify or explain why I have to go, why I have to be there. I don't know...

I mean, as I'm sitting there while my little baby is in orange jumpsuit and his little handcuffs. And I'm by myself because [my husband] had to go to work, and he is so done at this point, that after all the different things that-- and he can see that it's tearing our family apart. I mean, A.'s three hours away. He had gotten arrested the night before for being aggressive towards the staff at the residential facility that he was in as they were trying to tweak with his meds and figuring out what to do and things. So, I did, went, and then was with him after they moved him. He was probably there for a few weeks and at that time, I took time off of work again. I mean I couldn't-- I would go and see patients and then I would come back, and in between, see patients in my office and cry, and then go

try and see another patient and just because, I mean, I was looking at my phone and looking at the email and trying to see what's happening with him today and I tried.

And, I finally decided that I had to surrender A. to God. I had to accept that all I could do was to be his mother – to be there for him and to do the best I could for him... And that became my sole focus. I stopped looking at the little things that I couldn't do anything about. I started looking at what I could do – what I could do for him. I became a lot stronger through that... Through those terrible times, I became better.

Possessing an ability to focus on the positive that came from a negative experience is one attribute, which contributed to this theme. Believing that parenting a child with ASD for both J.H. and M.H. was a hardship that had value and created a positive perspective.

That positive reframing afforded the mothers an opportunity to see value in the lives they had lived. Becoming a better mother and a stronger person through those trials allowed both women to view the experiences, occurring afterward, with a different perspective, and the chronologic distance from the very worst of their experiences provided opportunities for both to almost transcend the day-to-day difficulties of parenting their children.

**Letting go.** For mothers of children with ASD who had lived past the experience of engaging in a critical process, such as involvement in application for guardianship or planning for posthumous care, the theme of *letting go* emerged. These mothers had spent 18 or more years raising their children, and all children with ASD of mothers with stories contributing to this theme were living outside of the family home. That chronologic

distance from diagnosis and day-to-day parenting provided them with a different perspective, which was retrospective in nature. This retrospective view allowed for a more comfortable new normal for these mothers than for those who were continuing to parent a child at home.

M.B., as a mother completing the application process for guardianship of her son, P., reflected on her experiences as a parent:

You also learn as a parent that some decisions are really hard and they're not things-- putting P. into a group home was one of the hardest things I've ever done in my life. And we had to. I mean, he was having violent behaviors. He was getting on the Internet and having sexualized behaviors, and our daughter was four years younger than him, and she wasn't safe. If we didn't do something about his behaviors, we could lose them both if something bad happened and-- but it's in that hard decision, although it was very hard and very heartbreaking, and haven't really experienced too much else in life that was harder than that, out of that, we've seen him get so much better because-- it took time, and it was a struggle to get him to the right place, but now he's been in a group home. He's doing so much better that we're going to actually be taking him out of the behavioral group home into a regular group home.

And one of the other things too, and this is how you feel as a parent. Often, I think autistic parents, or at least I felt like this early on, and you feel like you're the parent failure. Like you haven't done the right thing and you are never-- you're just like the lousy parent. And it's very interesting because we're transitioning into, we've had to do all this paperwork to be his guardians. So, as a

guardian, you're an advocate and you're actually, in some ways, you're honored because you're helping the court out, you're helping the public out by taking care of somebody with special needs and advocating for them after they're 18. And so I feel like I'm going from this lousy parent who just survived [laughter] to, "Now I get to be hero guardian of my kid [laughter]."

And I know that sounds dorky, but part of that is the transition between finally accepting that I did the best I could, and that no matter-- was I angry? Did I yell sometimes when I shouldn't? Did I get stressed out when-- we did everything that we could to keep him in our home. We had behavioral specialists in our home. One of the first night though, we'd had-- was it the third-- I mean, we had people coming from the state that were experts in handling really difficult kids and things like that. And the first night the behavioral specialist is there. He'd never done this before. He walked into his room and peed on the floor. And it was just-- there were just so many different things. So, we tried that. We did the autism school, how he had psychiatrists and counselors, and we had done all these different programming. And he was in special ed, and it was like we just couldn't make headway because normal life was too stressful.

The recognition that, for her, the passing of time and distance from the stress of parenting her son every day had alleviated her burden:

Sometimes you don't want to be an overcomer, but [my husband] and I are often called overcomers. Sometimes I wish I'd just had a smaller mountain to climb. Can I have the bunny slope next time instead of the cliff [laughter]? But it's the idea of that we are overcomers, and I think we're at a-- yeah. I think if you'd

interviewed me like five years ago, or-- yeah, I would be a lot more heart-- and it's not that my heart wasn't broken, but I'm not heartbroken right now. That had probably healed some, and part of that is I talk. I talk. I have people to talk to. I talk to my mom.

The chronologic distance afforded her with the opportunity to reflect on her ability to overcome crises and parent her child as effectively as she was able. This distance also allowed her a more positive, albeit removed, view of her life as the mother of a child with ASD.

K.L. reflected on her experiences parenting her son, D. In doing so, she was able to recognize some of his strengths. Her need to reframe her relationship with her son and their situation is illustrative of much thought and consideration about their life together:

I don't want to think of D. as a problem. I don't want to do that. And I've had lots of conversations with God about that. Forgive me for thinking D.'s a problem that I have to deal with, that I have to fix. And that's where the coping would come in, whereas D. and I have good relationship. I really think we do. But I try to meet him where he is. He loves to talk about movies. Okay, he likes to go to movies. I'll go to movies. This is something we can do together. He likes to talk music...

Yeah, I'd rather not say coping because then it is-- I don't want to think-- I don't want to think I'm suffering. I do suffer at times, but that's because I feel sad for him. Not for me. Not anymore. I used to. I mean, I think usually we all, as parents, have this idea we're going to have this perfect baby, and this baby is

going to be a genius, because, of course, our babies, they'll be geniuses. But he has proven me wrong over the years.

He wanted to be in a talent show. And all of our kids took one-year piano, even D.. Well, he tried out and he didn't get in. It's like, "Sweetie, you got to practice. If you're going to be in the talent show, you can't just say, 'I'm going to be in the talent show,' and think it's going to happen. So, practice." And he got in the talent show and he played. Did I ever think that was going to happen? And he's like, "Mom, I want to be an actor. I want to be in a play." So, for at least a year, he and I worked backstage at Civic Theatre where he just helped with stuff. And he tried out for a play, and he got in the play. And I would never think he would do that.

For these mothers, the stories included acknowledgement of the time that had passed since active day-to-day parenting. N.B. talked about how her self-care activities would have been very different if she was asked about them years earlier, when she was engaged in parenting a child with ASD in the home. The recognition that the most demanding years of parenting were behind her affected her response to the question about how she takes care of herself was mindfully addressed:

My son is doing so well now. This would be different if you had asked me when I was someone like you, a young mom with young children. I would have needed that so much. My son is out of the house, so I have strong connections of friends. I go out a lot. I have a book club. I have women coming tomorrow night just to eat dinner. I mean I think that's really important to have those. And I do think we as women are so concerned about our kids, that I don't think we realize that if we

don't take care of ourselves, we can't take care of our kids as well if we're burned out... They need it, they really do.

For the mothers of younger children, stories of this sort were not present in the interviews. Without chronologic distance from the experience of parenting a child with ASD on a daily basis, it was not possible for the mothers interviewed to allow themselves the luxury of thinking about anything other than the issues at hand: health and safety concerns, educational concerns, and general day-to-day problem-solving.

### **Thematic Model**

Through the analysis process, a thematic model was developed to represent the experiences of mothers of children with ASD (Figure 1). The recognition that perspectives and the ability to take time for reflection changes with time is depicted in the model. For the majority of mothers interviewed as part of this study, the pre-diagnostic and diagnostic period lasted until the child was 3-6 years old. The *Everyday ASD* phase of the model ranged from the time of diagnosis until the family endured a crisis or engaged in the guardianship process. In both of these cases, mothers had to make a conscious decision and exert much effort to retain the responsibility for their child's care. This mindfulness created opportunities for reflection about how each mother's life was impacted positively by the experience of parenting her child and allowed her to transcend beyond focusing on day-to-day activities through either a realization that her care and love were *worth it* or through *letting go*.

### **Summary**

This chapter presented the findings of the oral history interviews co-created with the narrators who participated in the study. Each mother's oral history was analyzed and

stories were coded and categorized into themes and subthemes. A thematic model was developed, which represents the experiences of the ten mothers of children diagnosed with ASD who were living in Olmsted County, Minnesota at the time of their interviews. The next chapter will present a discussion of these findings, including limitations and implications for nursing practice, research, and policy.

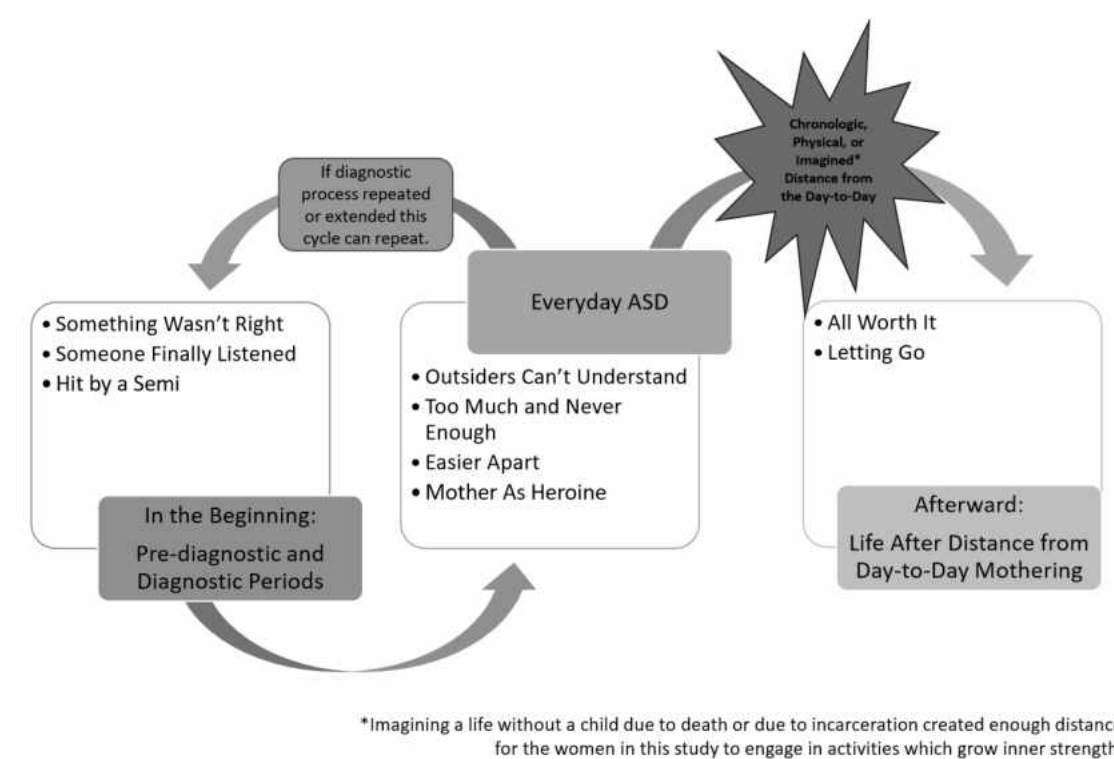


Figure 1. Oral histories of mothers of children with ASD: A thematic model.



## **CHAPTER V**

### **DISCUSSION**

The mothers of children with autism spectrum disorders (ASD) who participated in this study as narrators had varied demographics and experiences. Their children were varying ages ranging from 10 to 36, and their experiences with the diagnostic process, securing resources, and the simple act of mothering were also unique to each individual. These women lived in the same geographic area, Olmsted County, Minnesota, although their experiences occurred over a range of approximately 35 years.

The mothers of children with ASD who participated in this study did so at differing stages of their lives and, as a result, added depth and variation to the experiences captured through recording, analyzing and archiving of their histories. Differing external factors, such as the advent of autism awareness campaigns and increasing prevalence of the disorder in the community where the women lived at the time of their interviews impacted each mother's reminiscence. Availability of accurate diagnosis and appropriate medical, therapeutic and social services differed for each mother. These differences depended on geography, economic situation, symptoms, severity, and time of diagnosis as described in the Chapter IV.

The first aim of this research study was to describe the experiences of mothers of children with ASD. The second was to use these oral history interviews to further inform the Theory of Inner Strength in Women (Dingley & Roux, 2014). Each woman's stories contribute to a synergistic overlay of the thematic model within the context of the theoretical model as all dimensions of the theory were represented. A discussion of the

manifestation of each conceptual dimension in the interviews are discussed as part of the theoretical implications of this research study.

### **Limitations**

One of the limitations of oral history is that it is not intended to contribute to generalizable knowledge. The stories shared by each narrator are unique to her experiences and her interpretation of those experiences. For that reason, the findings of this study are specific to the women who narrated the oral histories used for this analysis.

The specific findings of this study apply to only the ten narrators from Olmsted County, Minnesota, so a limitation is also the small geographic area from which narrators were recruited. I attempted to recruit narrators from a wide variety of ethnic backgrounds, including African American, Hispanic, Hmong, Indian, Somali, and West African which are represented in this community, but only the included narrators were willing to be interviewed and recorded. The findings of this study can be used to inform the Theory of Inner Strength in Women, but further studies, using different research methods, will be necessary to inform the theory for the general population of mothers of children with ASD.

### **Genesis of Inner Strength in Mothers of Children With ASD**

Mothers who co-created oral history narratives for this study did not all perceive themselves to have the quality of inner strength (IS). There were several reasons for this perception, especially for those who were still engaged in parenting a child with ASD who lived in the family home. Very different perceptions and conclusions about the experience of mothering a child with ASD could be heard through the voices and stories

of women who had been afforded the opportunity to remove themselves from these day-to-day activities of parenting.

### **Theory of Inner Strength in Women as Informed by Mothers of Children With ASD**

Based on the findings of this study, The Theory of Inner Strength in Women (TIS) (Dingley & Roux, 2014) was supported. However, in the case of mothers of children with ASD, challenging life events occur repeatedly and frequently and subside only when the mother no longer is primarily responsible for day-to-day care. While many facets of the theory apply to this group of women during the time they are actively parenting, the findings of this study support adaptations of TIS when applied to mothers of children with ASD.

TIS includes four dimensions and one outcome, which is “living a new normal.” Inner Strength is described as a composite of the following four dimensions (Dingley & Roux, 2014):

1. Anguish and Searching, which involves the fear, vulnerability, and searching for meaning through processing the challenging life event.
2. Connectedness, which describes the nurturing of supportive relationships with self, family, friends, and a spiritual power.
3. Engagement, which describes the self-determinism, reframing, and engaging in possibilities.
4. Movement, which describes the dimension of movement, rest, activity, honest self-appraisal, and balance.

Elements of these dimensions and the theoretical outcome of “living a new normal” for women in this population were present. However, those mothers who were in the phase

of life and mothering where the child with ASD was either more cherished due to a near loss or living outside of the home exhibited all dimensions. These findings will be discussed in the following several sections.

### **Overwhelming and Stressful**

Universally, mothers of children with ASD described the experience of parenting their child as overwhelming and stressful. Mothers shared various stories related to the difficulties they encountered as they lived through the processes of diagnosis and finding effective parenting strategies. They also discussed an inability to meet some of their own basic physiologic needs due to the responsibilities and stress of mothering their children. Mothers also discussed the inability to cultivate friendships and supportive relationships with people whom they did not perceive to *understand* their situation. A lack of time and energy in addition to the stress and apprehension experienced when outsiders were not able to understand their family life caused this inability.

Life prior to a child's diagnosis of ASD was stressful and overwhelming for the mothers interviewed for this study. The process of finding health care providers and educators who were willing to listen to the family story contributed to that difficulty. The diagnostic process often took one or more years. In the case of M.H., the diagnosis was not made until her child was 12 years old. These narrators' descriptions of receiving the diagnosis and how it changed their lives are vivid. Stories offered insight into a life event described as being *run over by a semi*. These stories echoed the findings of Mulligan et al. (2012) and Sansosti et al. (2012).

Following diagnosis, most mothers began to engage in *intensive mothering* (Clarke, 2013). Many embarked either on a period of intense investigation of available

interventions. N.B. told stories of trying to *save* or *fix* her child. M.D. shared stories about seeking information from many sources, including the internet, books, health care providers, and educators as she gained access. M.M. shared stories about travelling to cities hours away to attend workshops, including one aimed at priming her to participate in policymaking. These women also told stories about the fight to access proper care and supportive services for their children, which supports the findings of Hodgetts et al. (2013). Mothers from the Hodgetts et al. study articulated that an extraordinary level of involvement was required of the parents and that it was essential to establish therapeutic rapport with providers. In fact, many of the mothers from Olmsted County shared stories of moving the care of their children at least one time or piecing care together from multiple organizations when their stories were not acknowledged and considered.

The mothers of children, diagnosed with ASDs, reported very clearly that day-to-day parenting overwhelmed them. The women described modifications of routines, activities, and behaviors were exhausting to keep. The stories of mothers, including M.W., J.H., and S.N., support that activities of day-to-day parenting are isolating and produced feelings of guilt. The guilt sometimes came from the lack of attention they could pay to their typical children. Schaaf et al. (2011) reported on this phenomenon as well. For some, activities of day-to-day parenting overtook any time that would have been available to mothers for employment outside of the home, as in the cases of J.H. and M.F. Parenting responsibilities also affected decisions to find or remain in jobs with accommodating scheduling as in the case of S.N., or flexibility to leave to tend to the child's needs as in the cases of M.W. and M.M. Altieri and Von Kluge (2009) wrote of a similar experience for mothers who were interviewed about experiences of mothering a

child with ASD. Mothers who participated in this study did not verbalize the view that work was respite from life at home, which varies from the findings of Matthews et al. (2011).

Mothers of children with ASD from Olmsted County shared stories of difficulty in meeting basic physical and emotional needs. A child's insomnia or inconsolability sometimes resulted in mothers' inability to get adequate rest, which is consistent with the findings of Estes et al. (2013) and Kotagal and Broomall (2012). Safety concerns and the need for constant vigilance were described by several mothers. These findings support the work of Safe et al. (2012) on caregiver burden related to constant vigilance required of parents of children with ASD. These stories were included as part of the theme *too much and not enough* in Chapter IV.

The theme *outsiders can't understand* included stories that support mothers' difficulty connecting with others due to the nature of parenting a child with ASD. Several mothers, including S.N. and M.W., found it easier to live apart from their spouse because of a need for respite due to manifestations of ASD through their child's behavior. Hartley et al. (2014) reported an increase in the divorce rate among parents of children with ASD. With this small group of narrators, it is difficult to make an inference regarding overall divorce rates to fully support this work; however, eight of the 10 women interviewed did discuss marital difficulties, resulting from the overwhelming and stressful experiences of parenting a child with ASD. That two of the 10 women interviewed was divorced was in alignment with the 23.5% divorce rate among parents of children with ASD found by Hartley et al. in their 2010 study. It is of note that the

perception of spousal support was most present in mothers with lower education levels, which are consistent with the findings of Benson (2012).

Stories, describing depression due to parenting stress and social isolation, were shared by several of the mothers who participated in this study. Some women shared names of medications they were taking for depression or anxiety. When asked whether a mother felt her spouse or the father of her child shared the same burden and experienced stress and depression, several women shared that they were more affected than their spouses. Foody et al. (2015) also found that this difference in affectation through their study of physiologic differences in mothers and fathers of children with ASD.

Respite, which was described by Hodgetts et al. (2015) as the greatest service need of mothers of children with ASD, was also shared as a need by narrators from Olmsted County. Regardless of a mother's stage of parenting, at the time of her interview, a universal expression of desperation for relief from the duties and responsibilities of parenting, if even for a short while, was articulated. The availability and accessibility of respite for mothers can provide opportunities for mothers to distance themselves from the day-to-day activities of parenting a child with ASD. This distance can be used to meet the basic physiologic and psychologic needs. Adequate respite was believed by the group of mothers of children with ASD interviewed for this study to provide time and preserve some of their energy to engage in self-care and health promotion activities.

One topic discussed by every mother interviewed was the perception of outsiders that difficult behaviors were her fault or that she could, and should, be able to control them. Mothers shared stories about this guilt being stressful and overwhelming. Several

shared stories included threats to call police for a child's behavior. Mothers also shared stories about educators and health care providers suggesting they engage in corporal punishment or find other ways to correct behaviors without outside intervention or resources. These stories about feeling like a failure as a parent due to the perceptions and suggestions of outsiders are congruous with those articulated by Nealy et al. (2012).

### **Overcoming and Accepting**

The stress of mothering a child with ASD ebbs and flows with many repeated cycles of crises and resolutions lasting various lengths of time over the overall timespan of each woman's experience. Parenting a child with ASD requires a mother to have the ability to constantly adapt to responses from and accommodate the needs of her child. These repeated cycles, as described in stories of narrators participating in this study, require problem-solving and intuition as a precursor to adaptation. This is in alignment with the work of Lutz et al. (2012), which focused on the repetitious and cyclical nature of a mother's care for her child with ASD. Many of the interventions for ASD are backed only by anecdotal evidence (NAC, 2015). This difficulty is due in part to the fact that one intervention, which works for one child's unique needs may not work for others. The constant search for interventions, was articulated by mothers participating in this study to be constant. The search contributed to feelings of being overwhelmed and stressed among this group. A suggestion for further research is to focus on tailored interventions, based on each unique child.

In the literature about caregiver burden as experienced by parents of children with ASD, many families provide in-home care for adult children (Cheak-Zamora et al., 2015), which was not evidenced in the stories of the women interviewed for this



study. Olmsted County, Minnesota has many available services and resources for individuals with ASD and their families (Appendix C). It is for this reason that all of the adult children whose mothers participated in this research were living either in group homes or subsidized housing with personal care attendant support. Mothers who shared their stories as part of this study shared that they were doing, or had done, the best they could with what was available as resources. As part of the dimension of engagement in TIS, these descriptions are included (Dingley & Roux, 2014).

Mothers universally said that they had done the best they could to care for their children and their families. They acknowledged that they could have always used more resources and support. By the time of her interview, each mother had accepted that her child had ASD and that her life was much different than she thought it would be when she was pregnant and expecting to raise a typical child. It is of note, and possibly linked to the community in which they live, that none of the mothers used person-first language, preferring instead to refer to their children as *autistic*. When asked about this use of non-person-first language in a post-interview conversation for clarification, one of the mothers, N.B., responded with, “Why should I sugar-coat things? My son is who he is, and I love him for who he is.” This acceptance of children as the individuals they are and the rejection of person-first language is supportive of the neurodiversity movement. When questioned about knowledge of the movement only one of the mothers, M.F, who was studying to become a speech-language pathologist, was aware.

### **Distance from the Day-to-Day**

As described through stories forming the themes *all worth it* and *letting go*, mothers needed distance from the day-to-day activities of parenting their children to

begin to appreciate the phenomenal work they had done and the amount of inner strength they had built through the experience. In some cases, this distance was physical, such as in the case of mothers whose children were living outside of the family home in their late teen or adult years. In other cases, which is a unique finding not evident in the current literature, mothers who nearly lost their children either through illness or incarceration were also forced to imagine a life missing daily contact with their child with ASD. This imagined separation granted psychological distance to the mothers and allowed for reframing, connectedness with a spiritual power and family or friends, and movement toward recognition of this inner strength. This distance from day-to-day parenting could be similar to the time from a cancer diagnosis which was found to be a predictor of QOL by Dingley and Roux (2014).

Mothers who had achieved distance from day-to-day parenting of children with ASD through reframing of their situations were able to recognize the need for self-care, as in the cases of N.B., K.L, and M.B. But these women commented, in retrospect, that they never had time or energy to truly engage in mental or physical health promotion activities while enmeshed in those overwhelming and stressful activities. For a mother who loves and is ultimately responsible for the care of her child, there is little opportunity without a completely trustworthy respite provider. This respite was very difficult to find for women who had either witnessed abuse of their children or had forms of abuse suggested by professionals as a means for correcting challenging behaviors. This is another reason to implement multidisciplinary continuing education related to the family experience of raising a child with ASD.

Cheak-Zamora et al. (2015) wrote that families experienced caregiver burden far beyond the traditional ages of childhood. This was not described in stories of mothers who participated in this study. At the times of the interviews in late 2016 and early 2017, there were many opportunities for adult children with ASD to live outside of the home in a variety of safe settings in Olmsted County. According to the mothers, while there could be a waitlist for accessing these services, most adult children were placed within months after applying.

Stories contributing to the themes of *too much and not enough* and *outsiders can't understand* articulated that finding appropriate and trustworthy respite options for mothers of children with ASD could alleviate much of the stress and overwhelming feelings of day-to-day parenting, if only for a short while. Temporary distance provided through respite could give mothers time and energy to engage in activities, comprising the dimensions of TIS. The mothers could move toward a new normal with a recognition that they possessed the strength to overcome and adapt to whatever happened in a more positive way. In the case of S.N., spending every other week away from her children while they are with their father, gave her time to garden, take walks, prepare for and attend meetings and appointments without the stress of being called to assist with her child's behaviors. It also offered the knowledge that she would have several days to recharge before she would be the primary caregiver again.

### **Genesis of Inner Strength**

Simply mothering a child with ASD is not enough to achieve the full outcome of living a new normal as theorized by Dingley & Roux (2014). The mothers interviewed for this study, although living in an area with many resources for individuals with ASD,

were not able to fully realize the benefits of the inner strength they had been cultivating. They were not able to achieve a new normal through living in a state of equilibrium and relative comfort achieved after tapping into available psychological, social, and physical resources to grow in inner strength following the challenging life event of mothering a child with ASD until transitioning to the *afterward* phase of mothering. This genesis of inner strength did not occur because were not able to fully engage in the activities tied to three of the four dimensions. The study results shown that finding meaning, connecting spiritually and with others, and movement from the situation required chronological, physical, or imagined distance from the day-to-day activities of parenting.

When a child with ASD lived in the family home and their mother was the primary caregiver, it appeared to be impossible, without significant respite, to escape the repetition of the rapid cycle of crisis and resolution, which drove much of a mothers' interactions with the child. One could review these stories and determine that several elements of each dimension in TIS are present to an extent through the above-mentioned cycles. However, the lack of distance from the catalyst for stress, in this case a child with ASD, prevented mothers' recovery and healing necessary for movement toward living a new long-term normal. In essence, the mother was building resilience and growing in inner strength, but not able to achieve the outcome of TIS.

The true genesis of Inner Strength in Mothers of Children with ASD is a conscious and transformative process with foundations building throughout all the phases of time spent actively parenting. When given time and distance from that stressful and overwhelming day-to-day activity fraught with crises, uncertainty, and difficulty, mothers

could engage in all four dimensions and fully realize living a *new normal* as described by Dingley and Roux (2014).

### **Conceptual Model of the Genesis of Inner Strength**

I developed a conceptual model to graphically represent the concepts discussed in this chapter (Figure 2). The conceptual model of the genesis of inner strength in mothers of children with ASD, living in Olmsted County, MN, allows for recognition that inner strength is building through overcoming and adapting to stressful activities of day-to-day parenting whether *in the beginning* or during time living with *everyday autism*. It also recognizes that for mothers to achieve living a new normal as the outcome of TIS, they must have some chronologic, physical, or imagined distance from day-to-day parenting to engage in all four dimensions of the theory. The activities, described by Dingley and Roux (2014) of the dimension of “anguish and searching,” was the only to be fully engaged in while actively parenting by the mothers interviewed for this study. For the other dimensions of TIS to describe this group of mothers, distance from the day-to-day, whether real or imagined, was necessary to begin to live a new normal.

The imagined distance occurred when mothers were forced to think of living without their child, as in the cases of J.H. and M.H. Imagining a life without a child due to death or due to incarceration created enough distance for the women in this study to engage in activities that grow inner strength. Those two women, who experienced imagined distance from their children, were able to live a new normal and view the experience of day-to-day caregiving retrospectively. Their paradigms changed from viewing a child as a *problem*, *challenge*, or *burden* to viewing the same child as a person they were grateful the mother still had in her life.

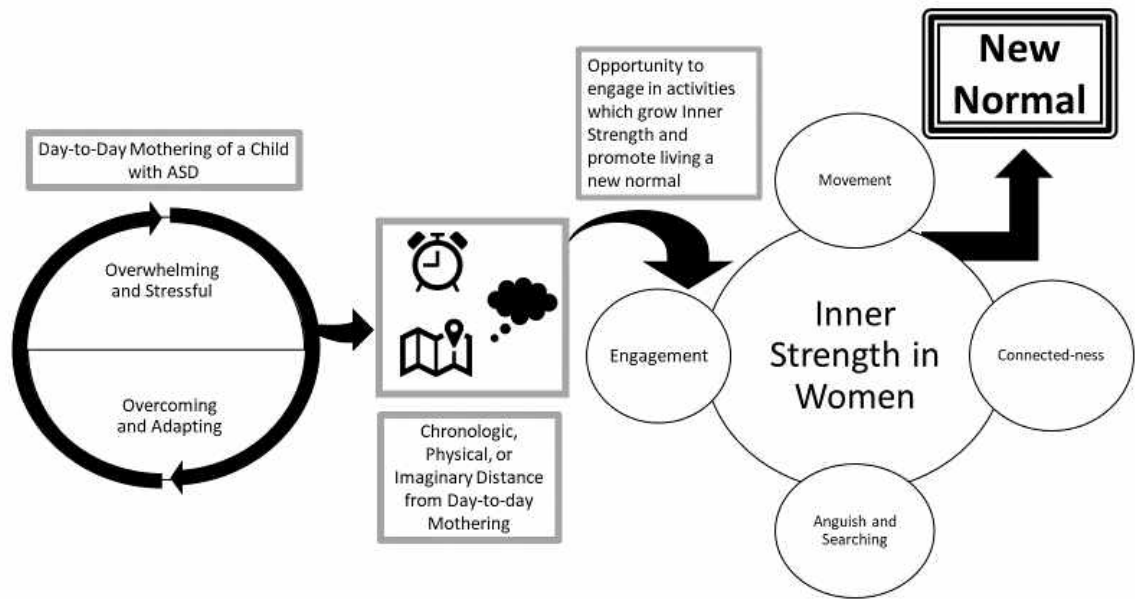


Figure 2. Conceptual model of the genesis of inner strength in mothers of children with ASD. Adapted with permission from authors (Dingley & Roux, 2014).

### Mothers' Validation of Thematic and Conceptual Models

Mothers who participated in this research study were all given the thematic model and the conceptual model for review and validation, following completion of the analysis. Each of the narrators felt that the models were representative of their experiences. M.D., a nurse with a doctoral degree, stated after seeing the conceptual model that she had wondered why she never felt *strong*. She said that the conceptual model and its explanation made “perfect sense.” Other mothers responded in agreement with all aspects of the models. S.N. noted that she felt that both the thematic and conceptual models described her life as did the two mothers with adult children living outside of the home, N.B. and K.L. The mothers who had experienced the imagined distance from their children with ASD, J.H. and M.H., both noted that they believed those experiences to have been great catalysts for development of inner strength, although seeing it visually

made great sense. After sharing the thematic and conceptual models with the mothers who participated as narrators, both are fitting products of this research study.

### **Contributions to and Implications for Nursing Practice and Policy**

This study has implications for the advancement of nursing science by contributing to nursing knowledge about mothers of children with ASD. These histories shared by narrators have been used to further inform the Theory of Inner Strength in Women (Dingley & Roux, 2014). The findings of this study can be used to impact nursing practice in nurses and other health professionals caring for children with ASD and their mothers through the following suggested interventions.

Nurses, caring for children in any setting can enhance patient care through several measures brought to light in the findings of this study. Listening to mothers' concerns about their child's development and bringing them to the attention of the primary care provider at appointments along with referral information may help increase early detection of ASD. Often, primary care providers are allotted very little time to directly observe and interact with children and may not recognize the signs and symptoms without being alerted to a concern. For many of the mothers interviewed as part of this research, it took several visits or seeing a different doctor or nurse practitioner to initiate the diagnostic assessment process.

For nurses caring for children with ASD, the findings of this study offer several implications for practice. The first is that an assessment of a mother's stress levels has the potential to inform the nurse about her capacity for caregiving at any given time. For some of the mothers interviewed for this study, the responsibilities of maintaining the delicate equilibrium for a child prone to difficult and, sometimes, dangerous behaviors

interfered with their ability to meet their own basic needs. For this reason, a nurse who assesses or recognizes the need for intervention when the stress and responsibility of caring for a child with ASD are overwhelming can make necessary referrals for social services. Services should include respite, which will give these mothers some distance from the day-to-day parenting.

Nurses working in the specialty of women's health can also benefit from the findings of this study. For mothers of children with ASD in their care, they can emphasize the importance of self-care and health promotion activities. As these women have little extra time and energy, if any at all, to increase engagement and the likelihood that recommendations will be followed, the activities should require little time to complete. Good examples of brief interventions, such as deep breathing exercises can help with calming and centering.

Advanced practice nurses can use the information provided in this study, also. Listening to the family story, whether caring for mothers or children with ASD, has the potential to provide great insight. These insights can provide opportunities to foster the growth of inner strength for this group of women through provision of care with the family in mind.

Health policy can be informed by this study in several ways. These stories can provide exemplars for policymakers which may fuel legislative change. The experiences of mothers' difficulty finding trustworthy respite care providers, calls for mandated education covering issues of abuse and the inappropriateness of corporal punishment for misbehavior. This study also suggests opportunities for policy creation such as



implementation of multidisciplinary education regarding listening to family stories as sources of information for meeting needs of the child and his or her family.

### **Recommendations for Further Research**

This study highlighted several areas for further nursing research. Further understanding of the underlying reasons mothers of children with ASD choose to move from one provider to another or from one healthcare system to another is recommended. Also, development of a psychometric measure for capacity of caregiving for mothers of children with ASD could help nurses and other care providers understand when additional resources are needed to benefit the child, the mother, and their family. Decisions about which healthcare provider a family sees can be dictated by circumstances, such as availability, compatibility, and cost or insurance coverage. For any individual with a complex chronic condition, such as ASD, continuity of care is essential to maximize benefits for patients. Yet, the mothers interviewed for this study all had several providers over the course of their son's childhood. Developing a better understanding of what guides parents' decision-making on this issue could contribute to quality of life and care improvements.

All mothers interviewed as part of this study expressed feelings that life had been overwhelming many times over the course of their time parenting a child with ASD. As such, added research to develop a measure of inner strength and capacity for caregiving in mothers of children with ASD would be of great benefit. A more extensive qualitative study, followed by survey research to lay groundwork for a psychometric measure, is suggested to achieve this.

The final recommendation for nursing research related to this study is to conduct more nursing research using oral history as a method. Oral history as a qualitative research method offers an opportunity for data preservation through archival as part of the historical record. In years to come, nurses will be left with little historical primary source data and only researchers' interpretations of qualitative findings. When future researchers have access to interviews, as in the case of this study, the rigor of their study is enhanced, and my audit trail becomes less critical because this raw data is available for others to review.

### **Conclusion**

Mothers of children with ASD live challenging lives as they engage in the day-to-day activities of parenting. Listening to and understanding the stories they share about their difficulties and successes can provide nurses with vital information which can be used to enhance the care of their children. The enhancement of care can be achieved through listening to stories. Tailoring nursing interventions for these mothers has potential to improve psychological well-being of mothers and to improve ability to care for the family. Distance from the day-to-day activities of parenting, based on the findings of this study, is necessary for mothers to grow in their inner strength and achieve a healthy new normal.

## **APPENDICES**

## **Appendix A** **Interview Questions**

**TITLE:**           *Mothers of Children with Autism Spectrum Disorders: Oral Histories*

**PROJECT DIRECTOR:**           *Jennifer Steinberg*

**PHONE #**                           *651-385-5922*

**DEPARTMENT:**                   *Nursing*

Some of the interview questions could include:

- Where and when were you born?
- What was life like for you when you were a child?
- How did you decide to become a mother?
- What was your pregnancy experience like?
- What were your experiences with doctors and early childhood educators when your family was going through the diagnostic process?
- What was the diagnostic process like when you learned that your child has an autism spectrum disorder?
- How has your life changed since your child was diagnosed with an autism spectrum disorder?
- How do you cope with the challenges of parenthood?
- What supports have you found in your family, social network, and community?
- What do you do to take care of yourself?
- What advice would you offer to other mothers of children with autism spectrum disorders?

## Appendix B Snowball Recruitment Letter

Mothers of Children with Autism Spectrum  
Disorder: Oral Histories

CONDUCTED BY JENNIFER  
STEINBERG, NURSE HISTORIAN



Everyone has a story to tell. Every story has the ability to teach, impact, and uplift others.

Using the techniques of transformational reminiscence, and under the advisement of Dr. Gayle Roux, a Nurse Researcher from the University of North Dakota, I am seeking to conduct face-to-face interviews with women who are mothers (biologic or adoptive) of children with Autism Spectrum Disorder. The recorded conversation would be about:

- Your early life,
- Pregnancy,
- Motherhood,
- Your experiences with doctors and early childhood educators when your child(ren) were young,
- The diagnostic process when your child(ren) was/were diagnosed with ASD,
- How you cope with and have adapted to the challenges of mothering a child with ASD,
- Supports you have found in your family, social network, and community,
- How you take care of yourself,
- And advice that you would offer to other mothers of children with ASD.

If you, or a woman you know, might be interested in participating, please feel free to contact me for more information, or pass this note along. I have conducted oral history interviews of nurses, women widowed while living on working farms, and am hoping to find up to 10 mothers so that this study will be a more accurate reflection of the truth of the lived experience of mothering an individual with ASD. This is an important story to tell. Please consider calling for more information or to see if you qualify to participate in the study.

No compensation will be offered, but you will receive a copy of the digital recording of your interview if you choose to participate.

Jen Steinberg, MS, RN  
651-385-5922 (telephone) or Jennifer.steinberg@und.edu (e-mail)

**Appendix C**  
**Special Needs Service Providers Available in Olmsted County, Minnesota, 2015**

List of Olmsted County, Minnesota Special Needs Service Providers, 2015

Table 2. Special Needs Service Providers in Olmsted County, Minnesota.

Category of Service	Name	Description
Accessibility	Accessibility Solutions	Services to make homes safe and accessible
Mobility	Anderson's Wheelchair	Durable medical equipment sales and service
Mobility	Med City Mobility	Durable medical equipment sales and service
Education	Augsburg College – CLASS Program	Program through post-secondary college to provide disability services and accommodations to academically qualified students at Augsburg College
Education	Learning Rx Brain Training	Tutoring with Applied Behavioral Analysis (ABA) methods
Education	Minnesota Autism Center	Therapeutic support with ABA
Education	Minnesota LIFE College	Programming on social development, access to community resources, and social living community program
Education	Minnesota State Academy for the Deaf	American Sign Language emersion school and residence
Education	Rochester Center for Autism	Provides ABA therapy and assessment services

Table 2 cont.

Education	Rochester Community and Technical College	Includes disability support services for academically qualified students
Education	Rochester Community and Technical College – Occupational Skills Program	Nine-month diploma program designed to teach individuals with mild to moderate disabilities vocational training skills in a work setting
Education	Rochester Public School District #535	Student support services for individuals with disabilities while they are enrolled in K-12 educational programming
Education	Rochester Public Schools Transition to Adult Program	Program for students beyond the 12 <sup>th</sup> year of school who have additional areas of need addressed through IEP goals focused on life skills
Education	University of the Child	Programming for children diagnoses with pervasive development disorder
Employment/Day Program	Ability Building Center	Rehabilitation and employment services for persons with disabilities and other special needs
Employment/Day Program	Ability Options	Recreation and leisure program to compliment work programs of Ability Building Center
Employment/Day Program	Opportunity Services – Rochester	Rehabilitation and employment services for persons with disabilities and other special needs

Table 2 cont.

Employment/Day Program	PossAbilities of Southern MN	Program providing work and community opportunities through supported employment, school to work, and youth recreation
Health/Therapy Services	Bluestem Center	Diagnosis and treatment of neurodevelopmental disorders
Health/Therapy Services	Dentistry for Children & Adolescents	Dental services, including sedation, for children with special needs
Health/Therapy Services	Jenny Kruse Music Therapy, LLC	Music therapy for individuals with neurological and cognitive disorders
Health/Therapy Services	NAMI of Southeast Minnesota	Support, education, advocacy, and support programming for individuals with mental illness and their families
Health/Therapy Services	Southeastern Minnesota Center for Independent Living, Inc. (SEMCIL)	Independent living skills programming including: budgeting, using public transportation, time management, meal planning and preparation, leisure and social skills, housing, housekeeping skills, and employment
Health/Therapy Services	Stanley Jones & Associates Therapy Services	Homecare and rehabilitation outpatient provider specializing in physical, occupational and speech therapy services
Health/Therapy Services	Zumbro Valley Mental Health Center	Mental health provider specializing in education about community resources, referrals to medical, social, and educational services, and advocacy assistance



Table 2 cont.

Recreation/Activities	Bikes for EveryBody	Adaptive bicycles and equipment to explore the world of cycling
Recreation/Activities	Ironwood Springs Christian Ranch	Camp with activities tailored to individuals with special needs
Recreation/Activities	Rochester City Parks & Recreation Department – Adaptive Recreation Program	Therapeutic sports and leisure program for individuals ages 3 years through adulthood with developmental disabilities
Recreation/Activities	PossAbilities Youth Recreation Program	Integrated and adaptive recreation program for individuals ages 2 – 21
Recreation/Activities	Recreation Lanes	Unsanctioned bumper bowling league and sanctioned league for individuals with intellectual and physical disabilities
Recreation/Activities	RideAbility	Therapeutic, recreational, and instructional horseback riding lessons and equine-related activities to individuals with disabilities and their families
Recreation/Activities	Rochester Community Education: Adults with Disabilities Program	Classes in areas of hobbies and crafts, leisure, physical fitness, music and art, and community awareness for individuals with disabilities
Recreation/Activities	Special Olympics Minnesota – Rochester Area	Non-denominational Christian religious education for children and adults with intellectual disabilities
Residential Programs/Services	Alpha-Services	Group homes, respite care, youth transitional housing, and corporate foster care for adults with serious and persistent mental illness

Table 2 cont.

Residential Programs/Services	ARSY, LLC	Group homes, respite care for children and adults with developmental disabilities
Residential Programs/Services	Bear Creek Services	Residential support and housing for individuals with developmental disabilities and traumatic brain injuries
Residential Programs/Services	Cardinal of Minnesota, LTD	In-home supportive services
Residential Programs/Services	Hiawatha Homes, Inc.	Residential services for children, adults, and families with developmental disabilities, traumatic brain injury, specialized medical needs, ASD, and other health disabilities
Residential Programs/Services	Howry Residential Services	Adult foster care, in-home support, behavior services, family counseling, and independent living skills programming
Residential Programs/Services	Minnesota State Operated Community Services (MSOCS)	Campus and community based programming for individuals with mental illness, developmental disabilities, chemical dependency, traumatic brain injury and individuals who pose a risk to society
Residential Programs/Services	REM River Bluffs	Group homes, respite care for children and adults with developmental disabilities
Residential Programs/Services	MAINS'L Services, Inc.	Residential group home for children and adults with mental health concerns
Residential Programs/Services	SMB Homes Adult Foster Care & Residential Services	Residential group home

Table 2 cont.

Residential Programs/Services	Wing House	Transitional care facility for survivors of traumatic brain injury
Resources and Services	ARC of Southeastern Minnesota	Non-profit organization providing support, education and advocacy to persons with intellectual and developmental disabilities and their families
Resources and Services	Disability Linkage Line	State-wide information and referral resource for Minnesotans with disabilities or chronic illnesses, their family members, and service providers – free of charge
Resources and Services	Epilepsy Foundation of Minnesota	Epilepsy education and awareness programs, referral services, advocacy, youth and family programs
Resources and Services	Minnesota Council on Foundations	Most comprehensive searchable database of grants
Resources and Services	Minnesota Hands and Voices	Support services and referral for deaf children and their families
Resources and Services	Minnesota STAR Program	Assistance with assistive technology
Resources and Services	Olmsted County Department of Social Services	Assistance with identifying developmental delays, planning services with schools, public health, and other community resources; assistive equipment for child; obtaining in-home medical or therapy services; finding respite care; connecting with financial or medical resources

Table 2 cont.

Resources and Services	PACER Center	Advocacy center with parents of children with disabilities helping other families and parents
Resources and Services	Parenting Plus Through PAIR	Early childhood family education for parents with cognitive disabilities
Resources and Services	People Achieving Change Through Technology	Equipment loan program for assistive technology and device demonstrations
Resources and Services	PLAN of Southeastern Minnesota	Program providing supplemental care for persons with developmental or physical disabilities, mental illness and/or brain injury on behalf of parents or other caregivers who are no longer able to do it themselves
Resources and Services	Project C-3	Program to improve transition to adulthood outcomes
Resources and Services	Region 10 Quality Assurance Commission	Organization that assess the quality of programming and services for individuals with disabilities and their families
Resources and Services	Rochester Families.com	Website for families in Rochester, Minnesota that contains information about classes, activities, and resources for youth with special needs
Resources and Services	Rochester Public Library	Adaptive computer workstation

Table 2 cont.

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Resources and Services	RT Autism Awareness Foundation, Inc.	Support, advocacy, awareness, education, and supplemental funding for Project Lifesaver tracking bracelets for children with ASD so that they can be found if they run away
Resources and Services	Social Odyssey	Organization to enhance awareness and understanding of developmental disorders
Resources and Services	United Way of Olmsted County	Organization to unite people with resources, operates information and referral service

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**Appendix D**  
**Inclusion/Exclusion Questions**

Name:

Are you the mother of a child or children with ASD or autism?

How many children with ASD or autism do you have?

How old is/are your child/children?

How old was your child when diagnosed?

Have at least two years passed since your child was diagnosed?

Are you willing to participate in a recorded conversation during which you will be asked questions about your life and your experiences as the mother of a child with ASD?

Are you willing to have the interview archived for use by future qualified researchers?

# Appendix E IRB Approval Form

1

## THE UNIVERSITY OF NORTH DAKOTA CONSENT TO PARTICIPATE IN RESEARCH

**TITLE:** *Mothers of Individuals with Autism Spectrum Disorders: Oral Histories*  
**PROJECT DIRECTOR:** *Jennifer Steinberg*  
**PHONE #** *651-385-5922*  
**DEPARTMENT:** *Nursing*

### STATEMENT OF RESEARCH

A person who is to participate in the research must give his or her informed consent to such participation. This consent must be based on an understanding of the nature and risks of the research. This document provides information that is important for this understanding. Research projects include only subjects who choose to take part. Please take your time in making your decision as to whether to participate. If you have questions at any time, please ask.

### WHAT IS THE PURPOSE OF THIS STUDY?

You are invited to be in a research study about mothers of individuals with autism spectrum disorders because you identify as the mother of an individual who has been diagnosed with an autism spectrum disorder.

This study is intended to provide future generations a view of the lives of mothers of individuals diagnosed with autism spectrum disorders, including their life experiences through the time of each interview. In particular, the plan is to gather reflections of parenting, relationships, family life, and activities related to care of and advocacy for a child with an autism spectrum disorder during the years leading up to each interview. Copyright of the interview will transfer to the University of North Dakota.

### HOW MANY PEOPLE WILL PARTICIPATE?

Six to twelve people will take part in this study at the University of North Dakota. Interviews will take place at a mutually agreed-upon location in Southeastern Minnesota.

### HOW LONG WILL I BE IN THIS STUDY?

The time commitment required to participate in this study will be the time it takes to complete this informed consent process, approximately 1-2 hours for your interview, and approximately 1-2 hours to review your interview to verify its accuracy before it is analyzed and archived. The digital video recording of your interview will be maintained in Jennifer Steinberg's personal office at 713 Memorial Pkwy SW; Rochester, MN 55902, until a permanent archival home is determined. They will be available to qualified researchers by appointment.

Approval Date: <u>SEP 12 2016</u>
Expiration Date: <u>SEP 11 2017</u>
University of North Dakota IRB

Date: \_\_\_\_\_  
Subject Initials: \_\_\_\_\_

**WHAT WILL HAPPEN DURING THIS STUDY?**

When you participate in this study, you will be contacted by the researcher to set up an appointment for your interview. The time and location will be mutually convenient. Most oral history interviews take place at narrators' homes.

You will be asked questions about your life, your experiences as a mother, your experiences as a member of your family, and your experiences related to the diagnosis of your child with an autism spectrum disorder. Some of the questions could include:

- Where and when were you born?
- What was life like for you when you were a child?
- How did you decide to become a mother?
- What was your pregnancy experience like?
- What were your experiences with doctors and early childhood educators when your family was going through the diagnostic process?
- What was the diagnostic process like when you learned that your child has an autism spectrum disorder?
- How has your life changed since your child was diagnosed with an autism spectrum disorder?
- How do you cope with the challenges of parenthood?
- What supports have you found in your family, social network, and community?
- What do you do to take care of yourself?
- What advice would you offer to other mothers of individuals with autism spectrum disorders?

**WHAT ARE THE RISKS OF THE STUDY?**

Risks associated with this project are considered minimal. You may have some emotional discomfort in the reflection upon challenging life events. If so, you may discontinue the process at any time.

**WHAT ARE THE BENEFITS OF THIS STUDY?**

If you choose to participate, there will be no monetary compensation. The only benefit to accrue to you will be the personal satisfaction of sharing your story of your life and your experiences as a mother of an individual diagnosed with an autism spectrum disorder.

**ALTERNATIVES TO PARTICIPATING IN THIS STUDY**

The alternative to participating in this oral history study is not participating.

**WILL IT COST ME ANYTHING TO BE IN THIS STUDY?**

You will not have any costs for being in this research study.

Approval Date:	SEP 12 2016
Expiration Date:	SEP 11 2017
University of North Dakota IRB	

Date: \_\_\_\_\_  
Subject Initials: \_\_\_\_\_



**WILL I BE PAID FOR PARTICIPATING?**

You will not be paid for participating in this study.

**WHO IS FUNDING THE STUDY?**

The University of North Dakota and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

**CONFIDENTIALITY**

Due to the nature of oral history, you will be identifiable as the narrator of your particular history. No confidentiality can be expected, nor is any offered if you choose to participate in this project. In any report about this study that might be published, you may not be identified. Your study record may be reviewed by Government agencies, the UND Research Development and Compliance office, and the University of North Dakota Institutional Review Board.

You should know that there are some circumstances in which we may have to show your information to other people without your permission. For example the law may require us to show your information to a court or to tell authorities if we believe you have abused a child, or you pose a danger to yourself or someone else.

If we write a report or article about this study, we may describe the study results in a summarized manner so that you cannot be identified.

The digital audio and video recordings from this project will be made available to you for your review. You have the right to edit the recordings and request that they be erased as well as discontinue participation in the study at any time prior to the time at which your interview is archived.

**IS THIS STUDY VOLUNTARY?**

Your participation is voluntary. You may choose not to participate or you may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. Participation in this project is entirely voluntary, and your decision whether or not to participate will not change your future relations with the University of North Dakota, the College of Nursing and Professional Disciplines, or any of the members. If you decide to participate, you are free to discontinue participation at any time without penalty.

**CONTACTS AND QUESTIONS?**

The researcher conducting this study is Jennifer Steinberg. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Jennifer Steinberg at 651-385-5922 during the day or after hours. Jennifer Steinberg's advisor at the University of North Dakota is Gayle Roux, PhD, NP-C, FAAN. Dr. Roux can be contacted at 701-777-4534.

Approval Date: <u>SEP 12 2016</u>
Expiration Date: <u>SEP 11 2017</u>
University of North Dakota IRB

Date: \_\_\_\_\_  
Subject Initials: \_\_\_\_\_

If you have questions regarding your rights as a research subject, you may contact The University of North Dakota Institutional Review Board at (701) 777-4279.

- You may also call this number about any problems, complaints, or concerns you have about this research study.
- You may also call this number if you cannot reach research staff, or you wish to talk with someone who is independent of the research team.
- General information about being a research subject can be found by clicking "Information for Research Participants" on the web site:  
<http://und.edu/research/resources/human-subjects/research-participants.cfm>

**I give consent to be videotaped during this study.**

Please initial:     \_\_\_ Yes     \_\_\_ No

**I give consent to be audiotaped during this study.**

Please initial:     \_\_\_ Yes     \_\_\_ No

**I give consent for my quotes to be used in the research.**

Please initial:     \_\_\_ Yes     \_\_\_ No

Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subjects Name: \_\_\_\_\_

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date

I have discussed the above points with the subject or, where appropriate, with the subject's legally authorized representative.

\_\_\_\_\_  
Signature of Person Who Obtained Consent

\_\_\_\_\_  
Date

Approval Date: <u>SEP 12 2018</u>
Expiration Date: <u>SEP 11 2017</u>
University of North Dakota IRB

Date: \_\_\_\_\_  
Subject Initials: \_\_\_\_\_

**Appendix F**  
**Mothers' Demographic Information**

**Table 3**

*Mother's Demographic Information*

Mother	Age	Number of Children	Profession	Ethnicity	Household Income Range
M.D.	32	1	RN	Caucasian	\$100K – 150K
M.H.	38	4	Nurse Practitioner	Caucasian	>\$150K
M.F.	41	2	Paraprofessional	Caucasian	\$60K – 80K
M.W.	42	4	Temporary worker	Native American	<\$40K
S.N.	43	2	RN	Caucasian	\$40K – 60K
M.B.	43	2	Nurse practitioner	Caucasian	\$100K – 150K
J.H.	50	5	Mother	Caucasian	\$100K – 150K
K.L.	59	4	Librarian	Caucasian	\$100K – 150K
M.M.	61	3	Bookkeeper	Caucasian	\$100K – 150K
N.B.	63	3	Dietician	Caucasian	\$100K – 150K

**Appendix G**  
**Children's Demographic Information**

**Table 4**

*Child(ren)'s Demographic Information*

Mother	Age(s)	Diagnosis	Age at Diagnosis
M.D.	10	Autism	4
M.H.	16	Autism	12
M.F.	14	PDD-NOS	3
M.W.	17	Asperger's Syndrome	6
S.N.	10	Autism, Down Syndrome	6
M.B.	17	Asperger's Syndrome with low IQ	5
J.H.	24 & 17	Autism, Autism	1.5, 1.5
K.L.	29	Atypical PDD	3.5
M.M.	15	Autism	3
N.B.	36	PDD-NOS	13

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