Severe Childhood Autism: The Family Lived Experience

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Abstract

Background: There is limited literature that focuses solely on the experiences of families when a child has severe autism and includes data collected from multiple family members. Related review of the literature includes studies addressing family quality of life and qualitative studies on the experience of families with a child who has autism.

Objective: The goal of this study was to understand the lived experience of families with children who have severe autism by narrowing the focus to only families of children with severe autism and broadening the interviews to include multiple family members.

Method: The study used van Manen's (2014) phenomenological approach for data collection and analysis based on in-depth unstructured interviews of 11 families with 22 family members including mothers, father, grandmothers, an aunt, a sibling, and a friend.

Findings: Six essential themes were identified. First, families found autism a mysterious and complex condition. This included the misconception that autism is a mild disability, that autism is an invisible condition, the unpredictable nature of autism, and the challenges of assessing severity. Second, families dealt with startling and severe autism-related behaviors that were often self-injurious, harmed others, and damaged homes. Third, families dealt with profound communication deficits that resulted in isolation between the family and child. Fourth, families experienced unrelenting stress related to their lack of sleep, caring for a child with developmental delays, coordinating myriad health care services, cost and concern for the child's long-term future. Fifth, extreme isolation from their child, friends, school, the public, and health care providers ensued. Sixth was a strong dependence on families for support and formation of hybrid families which included nuclear and extended families and friends coupled with a compassion that seemed to blossom over time.

Conclusion: The findings inform health care providers about the need to recognize and provide better quality of care for children with severe autism and their families. Implications include the importance of education for health care providers on caring for these families. The findings emphasize the importance of developing appropriate health care policy to provide much needed resources for children with severe autism and their families.

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Chapter 1. Introduction to the Study

Autism (known as autism spectrum disorder or ASD) is the most prevalent developmental disability in the United States, affecting approximately 1 in 68 children (Center for Disease Control (CDC), 2014). It has been estimated that one third of these children have “severe” autism with significant functional challenges (CDC, 2014). However, there is variability in reported prevalence (CDC, 2014; Minnesota Department of Health (MDH), 2013) due in part to the challenges in determining severity.

Since the 1950s, following the dismantling of institutions for those with disabilities, (Minnesota Governor’s Council of Developmental Disabilities, 2014), most long-term care for those with developmental disabilities has been provided at home (University of Minnesota Research and Training on Community Living, 2009). The family is now the primary care provider for children with developmental disabilities, such as autism, throughout their lifetime.

Several studies have attempted to illuminate the experiences of families as they raise children with autism. In Family Quality of Life (FQOL) literature, which explores family well-being, there is evidence that the type of disability affects FQOL. For example, compared to Down syndrome and a control group, families of children with autism appear to have a lower overall FQOL and deal with more disruptive behaviors (Brown, MacAdams-Crisp, Wang, & Iarocci, 2006; Brown, Hong, Shearer, Wang, & Wang, 2010). The nature of these behaviors has not generally been specified, however, in the FQOL literature.

There is also evidence that the more severe the disability, the lower the overall FQOL (Boehm Carter, & Taylor, 2015; Gardiner & Iarocca, 2015; Pozo, Sarriá, & Brioso, 2013; Wang et al., 2004). Atypical autism behaviors also appear to have a negative effect on FQOL (Boehm et al., 2015; Brown et al., 2006; Davis & Gavidia- Payne, 2009; Gardiner & Iarroci, 2015; Pozo et al., 2013).

Most FQOL studies employ questionnaires with limited opportunity for subjective responses, leaving little insight into the child's behaviors, the nuances of the actual challenges, and the general family experience. Some studies include a variety of disabilities, or do not discuss autism severity, and/or they include children with milder disabilities. This is significant because autism is a spectrum, which can include mild to very severe cases. In addition, most studies survey only one respondent from each family, typically the mother, rather than assessing other family members, and this also narrows the perception of the family experience.

Phenomenological, qualitative studies attempt to provide a richer understanding of the family experience when a child has autism. They highlight the unique experiences that the families of children with autism encounter, including stress and isolation. For example, there is constant stress related to the ability to provide the complex direct care the child needs (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Dupont, 2009; Larson, 2010; Mulligan, Macculough, Good, & Nichols, 2012; Safe, Joosten, & Molineux, 2012). There is also concern over the cost of health care for the child with autism (Phelps, Hodgson, McCammon, & Lamson, 2009; Safe et al., 2012) and the constant concern for the future welfare of the child e.g., who will care for the child when a parent is no longer alive? (Desai, Divan, Wertz, & Patel, 2012; Kent, 2011; Phelps et al., 2009). The families also experience isolation since they avoid situations because of their child's autism behavior, such as tantrums or meltdowns (Phelps et al., 2009; Luong, Yoder, & Canham, 2009; Safe et al., 2012).

These qualitative studies, however, still lack information concerning the family experience specifically with *severe* autism and do not include the voices of multiple family members. The purpose of this research is to explore the multiple family members' experiences of living with a child who has severe autism.

Specific Aim and Research Question

The aim or purpose of this research is to interpret the meaning of the lived experience of family members who live with a child who has severe autism. This research simultaneously narrows and broadens the focus of previous research studies. It narrows the focus by including only families of children with severe autism in this study and broadens the focus by including all family members (mothers, fathers, siblings, and extended family).

A phenomenological approach is used to ask the study question: *What is the lived experience of the family living with a child who has severe autism?*

Due to the high prevalence of autism, even those in health care who do not specialize in autism will undoubtedly come in contact with the families of children with severe autism. To provide the best health care possible for both family and child, all health care providers need to be prepared to offer appropriate services when required. It is my hope that the information gained from this research will assist nurses and other health care providers to provide the psychological support and care for the children with autism *and* their families that is tailored specifically for children with more significant challenges. This is particularly important in a condition like autism that is on a spectrum, for which a "one-size-fits-all" approach to treatment is not sufficient.

I would also like to see the outcomes of this research used to effect change in health care policy regarding autism. Only when health care policy is evidenced-based and reflects the needs of the children and their families can it address the wide array of family experiences involved when living with a child who has autism.

Background

Developmental disabilities. Children with chronic illness are referred to as children with special health care needs (CSHCN) because of the intense amount of health care they require. CSHCN include a variety of congenital and/or acquired illnesses with varying severities.

Approximately 15% of children (11.2 million) children are considered CSHCN (Maternal and Child Health Bureau (MCHB), 2015).

Within the population of CSHCN are children with developmental disabilities, or those with more significant *functional impairments*. The definition of developmental disabilities is broad and varies between counties and states. The term developmental disabilities refers to those with significant chronic functional impairment that appears before the age of 22, and is cognitive, physical, or both (American Association of Intellectual and Developmental Disabilities, 2013). Autism is generally considered a neuro-developmental cognitive disability that predominantly involves the development of the brain.

A brief history of autism. The word autism is from the Greek word "auto" which refers to the isolated nature of the condition. It was first described by a Swiss psychiatrist, Eugen Bleuler, in 1911 as a type of schizophrenia (WebMD, 2015). Leo Kanner, in the United States (U.S.), in 1943 called the condition "infantile autism" and described it as combination of genetic predisposition and mothering styles (Kanner, 1973). Later, in the 1960s, with the acceptance of the psychoanalytic paradigm, autism was attributed to a mother's poor parenting and the term "cold or refrigerator mother" was coined (Nadesan, 2005). In 1998 the etiology was attributed by some to MMR vaccinations, although this claim was later refuted (Rutter, 2005).

Though no definitive etiology has been delineated, autism is now thought to be a combination of genetic and environmental factors that affect neurological development in the child (CDC, 2014; American Psychiatric Association (APA), 2013).

Defining autism. Autism is a broad spectrum of neurodevelopmental disabilities characterized by an impairment in social communication and repetitive behaviors or interests, both in varying degrees (APA, 2013). The variability in presentation of autism cannot be underestimated as manifestations can range from very mild to very severe, including significant social and behavioral challenges.

In the past autism was divided into specific categories based on severity, for example, the milder form was called Asperger's or PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified), but currently all severities of autism are referred to as "autism spectrum disorder" or ASD (APA, 2013; Autism Speaks, 2015). For the remainder of this thesis, because the focus is the more severe portion of the spectrum, ASD will be referred to simply as "autism."

The overall prevalence in children is 1 in 68, but there is a four-fold higher rate among boys (CDC, 2014). Approximately 9% (850,000) children with special health care needs have autism in the U.S. (MCHB, 2015). There is a slightly higher prevalence among Caucasians in national reports, but in Minnesota no racial difference is observed (MDH, 2013). The average age of diagnosis is 4 years (CDC, 2014), but it is typically first recognized at 12 to 24 months old; younger than 12 months if it is severe (APA, 2013).

Children with autism have two broad issues that are evident in early childhood and impair daily functioning. First, they have deficits in reciprocal or social communication (APA, 2013) related to an inability to understand another person's point of view and social cues (Strock, 2007). Often they do not respond to attention or affection, leading to isolated behavior (APA, 2013; Strock, 2007). Without understanding others, their emotions may lead to disruptive behavior or self-harming behaviors such as head banging, pulling hair, etc. (Strock, 2007).

Second, children with autism characteristically have behavioral issues that are repetitive and may involve strict routine (APA, 2013; Leekam, Prior, & Uljarevic, 2011; Strock, 2007), such as hand flapping, toe walking, rocking, and echolalia. The term "stimming" is used to refer to some of these repetitive behaviors as they seem to provide physical, visual or auditory self-stimulation (Volkmar & Wiesner, 2009). Behaviors may include intense interests in specific topics and they often have strict insistence on routine to maintain order in their lives (APA, 2013; Strock, 2007). Examples of maintaining a rigid structure include an intense interest in train schedules, or a need to follow one specific way home by car each day.

Sensory issues often occur and can be either hyper- or hyposensitivity (APA, 2013; Strock, 2007) to light, sound, temperature, and texture, smell and/or taste (Strock, 2007). Sensory issues and the need for routine can make daily activities, such as sleeping, eating, going to the doctor, or getting a haircut, a challenge (APA, 2013).

Many children with autism also have intellectual disabilities and/or language impairments (APA, 2013). It is estimated that 31% of children with autism have intellectual disabilities with an IQ of <70 (CDC, 2014) and about 25% have severe language impairments, speaking few to no words (DeWeerdt, 2013). Usually diminished IQ correlates with children with more significant functional challenges (APA, 2013; CDC, 2014) and their functional skills are usually lower than their IQ measurement (APA, 2013).

Autism testing. The first signs of autism usually involve a delay in speech and unusual social patterns (APA, 2013). Testing for autism generally begins with a developmental screening. If there is still a concern regarding autism, further testing is conducted. This usually includes one or more of three tests that are considered the gold standard for autism testing.

The autism tests most commonly used include: the Autism Diagnostic Observation Schedule or ADOS-2 (Lord et al., 2012), which is an assessment of interaction communication and behaviors administered directly with the child; the Autism Diagnostic Interview or ADI-R (Rutter, Le Couteur, & Lord, 2008), a developmental assessment, conducted with the parents of the child with autism; and the Vineland Adaptive Behavior Scale, an assessment of functional adaptive skills conducted with the parent or a teacher (Sparrow, Cicchetti, & Balta, 2005).

Challenges of defining autism severity. Currently autism severity is categorized by the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM Fifth Edition; DSM-5) into three levels depending on the amount of support needed and the severity of both social communication and behaviors (APA, 2013). In severe autism, Level Three, for example, children require substantial support and have severe deficits in social communication and inflexible repetitive behavior that severely limit their daily functioning (APA, 2013). An example would be a child with limited speech who infrequently initiates interaction, requiring 24-hour supervision.

It has been difficult to categorize autism and autism severity, however. The challenges are numerous and include, but are not limited to: autism is a spectrum of non-homogenous symptoms; the DSM-5 definition is based on a group of symptoms versus a functional assessment (Reiff & Feldman, 2014); and testing is often difficult as children who are severe may be nonverbal.

In addition, severity determination is intrinsically subjective so that what is severe to one person or family may not be considered as severe to another. To illustrate this: in one survey 14% of parents nationally rated their child as having severe autism (MDH, 2013) while in the CDC national survey, clinicians rated the prevalence of severe autism at 31% (CDC, 2014). (See Appendix A, The Challenges to Defining Autism Severity).

For all these reasons there has been an effort to clarify the categorization of autism based on a more holistic approach that focuses on the child's functional needs within the context of the family (Bölte, et al, 2014; Gardiner & Iarocci, 2015; Reiff & Feldman, 2014). It may be more telling to ask, "What are the challenges your child faces at home and how does this affect your family?" (e.g., toilet training, feeding self, etc.) rather than solely focusing on symptoms. This study uses the more holistic mode of classification, or rating, to assess severity and is discussed further in Chapter Three.

A brief review of autism treatment. Autism treatment is usually multifaceted and tailored to the specific child and family because autism affects children both psychologically and physically. In general, treatment involves teaching the child self-care and social skills to promote functioning in society (Volkmar, Cook, Pomeroy, Realmutto, & Tanguay, 1999). This usually takes the form of behavior modification such as Applied Behavior Therapy (ABA) or a similar program that utilizes positive reinforcement to modify behavior (Lovaas, 1987; Sallows & Graupner, 2005; Volkmar & Weisner, 2009). These programs often require very intensive schedules that require sessions every day for the entire day.

A variety of services are usually needed to address the child’s complex needs. For example, in addition to well-child medical care, dental care and behavioral therapy, the children may have physical therapy for coordination challenges, occupational therapy to teach adaptive skills, speech and language intervention to assist with speech challenges, and special education for learning issues and pharmacotherapy (Volkmar et al., 1999). These myriad services are usually instituted in the home and/or school and are typically coordinated by the parents, primary caregiver, or the autism specialist.

Current State of the Science: Autism and the Family

As mentioned, since the 1950s most long-term care for people with developmental disabilities such as autism is provided by families in their home (Minnesota Governor’s Council of Developmental Disabilities, 2014; University of Minnesota Research and Training on Community Living, 2009) with support by a wide range of health care and educational services.

Due to the complex needs for services by families with children with autism, the cost to the family may be staggering both financially and emotionally. School and ancillary support costs are disproportionately expensive (Lavelle et al., 2014). Amendah, Grosse, Peacock and Mandell (2011) describe average annual costs of $40,000 to $60,000 for behavioral therapy interventions such as ABA in autism prior to school age. The lifetime total cost for an individual with autism is estimated to average $1.4 million and $2.4 million for those more severely affected with intellectual disabilities, the majority of the cost attributed to special education and loss of parental income (Buescher, Cidav, Knapp, & Mandell, 2014).

The emotional cost of autism to the family in general has been explored in depth (Bristol, 1984; Gardiner & Iarocci, 2012). Parental stress, specifically, has been a primary topic. Sharpley, Bitsika, and Efremidis (1997) found elevated stress levels in parents of children with autism, with the behavioral issues in autism a significant causal factor. Parental stress has also been correlated with decreased functioning by the child (Hall, & Graff, 2011).

Dąbrowska & Pisula (2010) compared parental stress in families of preschool children with autism, Down syndrome, and typical development. They found parental stress higher in autism (Dąbrowska & Pisual, 2010). Lee, Harrington, Louie and Newschaffer (2008) compared parental stress in families of children with autism, Attention Deficit Disorder, and control groups, and found more parental concerns about learning issues, bullying, and achievement in families of children with autism.

Hoefman and colleagues (2014) found increased depression in the parents of children with autism: 40% had a high level of depression. A high rate of depression was also reported by other researchers (Benson, 2006; Sawyer et al., 2010). Benson (2006) found increased depression correlating with severity of autism symptoms and Sawyer and colleagues (2010) found increased depression in mothers correlating to the time pressure of caring for a child with autism.

Maternal stress has been described by Bristol (1984) in a series of research studies at the University of North Carolina. Maternal stress has been found to increase with the age of the child, severity of the social and cognitive deficits, and behavioral issues (Bristol, 1984). The invisible nature of autism has been shown to be a factor causing stress for mothers (Bristol, 1984) because outsiders are more likely to accept poor behavior from a child that is visibly disabled versus one that is not. Mothers often feel overwhelmed with behaviors associated with autism that stigmatize and socially isolate them (Lutz, Patterson, & Klein, 2012). They also express feeling overwhelmed by constant education/intervention issues and financial concerns (Lutz et al., 2012).

A meta-analysis of maternal depression in mothers of children with and without disabilities found there to be a statistically higher rate of maternal depression in the mothers of children with disabilities versus those without disabilities. Most, but not all, of the 18 studies included children with autism in their population (Singer, 2006).

Fathers' experiences living with a child with autism have also been explored, though less frequently. One study, which included other intellectual disabilities in addition to autism, revealed fathers appreciating life in general, struggling to be "a good father" and dealing with the unexpected nature of the illness (Boström & Broberg, 2013). Dąbrowska and Pisula (2010), in their comparison study of autism and Down syndrome, discovered fathers had less stress than mothers in the autism cohort.

Siblings of children with autism also are affected. It is known that siblings struggle as the child with autism monopolizes their parents' time and family time is difficult to procure (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011; Werner DeGrace, 2004). Families are often cleaved as one parent cares for the child with autism and the other parent cares for the siblings (Schaaf et al., 2011; Werner DeGrace, 2004). Siblings describe personal sacrifices and disruption of their lives by their sister's or brother's aggressive behavior and having to teach others about autism (Petalas, Hastings, Nash, Dowey, & Reilly, 2009). Parents describe guilt concerning the expectation that the sibling will need to care for the child with autism in the future (Lutz et al., 2012).

One note is that there are statistically fewer subsequent siblings born in the families of children who already have a child with autism (Hoffmann et al., 2014). The family experience when a child has autism will be further discussed in the review of the literature.

Significance and Innovation

This study builds on previous work in the field of autism in several ways. First, the study focuses on severe autism. Most other studies have included children with a variety of disabilities and/or range of disability severity. Autism includes a wide spectrum of conditions so the experience of families that have a child with mild autism may be very different than the families experiencing a more severe disability. Only one study was identified within this literature review that included *only* children with severe autism (Werner DeGrace, 2004).

Second, this study asks the families to define who they consider family and the defined members are included in the research dialogue. Again, most of the studies reviewed were based on one respondent, usually the mother, who reported the family experience. This study broadens the scope to hear the voices of additional family members, as defined by the family, rather than one spokesperson defined by the researcher.

Third, this study includes family interviews. Family interviews are difficult for logistical reasons and are rarely conducted. This study includes them because they can provide a wider lens into the lived experience of the family.

Fourth, identifying autism severity for this study is challenging and no concise functional instrument was available. Therefore, one product of this study is a measurement tool that I co-developed with Michael Reiff, MD, to assess autism severity. This instrument is available to other researchers in the future.

Lastly, this study uses Family Lifelines, a pictorial representation of family life from the time the child is born. I adapted this tool for use in this population.

Contribution to Nursing

There are at least three specific ways that this study can contribute to the field of nursing. First, nurses might use the increased knowledge to directly assist children with autism and their families. This might take the form of identifying services that are needed by the family and procuring them, such as respite care. Nurses could help families develop programs that provide respite care, such as parent-to-parent networks.

Second, nurses can utilize the information to educate other health care providers, especially those who do not specialize in autism, about the needs of families who have a child with severe autism. An example might include educating health care providers about the importance of preparing children with autism for clinic visits. This could include the use of Social Stories, which are books with photographs that detail the steps involved in visiting the clinic or hospital. It might also involve scheduling extra time for the actual clinic visits.

Third, this research might be used by nurses to develop health care policy. At the present time, autism is the most prevalent developmental disability in the United States and up to one third of these children are severely affected. Nurses can use this research to evaluate what is potentially needed for these families and develop and/or support health care policy that aids these specific families.

In general, because a large amount of the literature review has not focused specifically on children with more functional abilities, it will be important for nurses to understand how this research compares to the previous research and incorporate this information into developing evidenced-based care for families of children with severe autism.

Research Path

Here I would like to discuss the professional background as it relates to the topic of this research. The path was somewhat circuitous because unlike most thesis researchers, autism was not my primary area of interest before I chose it as my focus.

First, through my master's thesis on the siblings of children with cancer (Bessette, 1984) I recognized the need for research to include the voices of family members other than the parents. In that phenomenological study, I interviewed 17 siblings of children with cancer in their homes and it was clear that the siblings had needs that were frequently overlooked by their families and health care providers.

Second, as a pediatric nurse practitioner in hematology for three decades, I learned about the challenges of families who were dealing with a severe chronic illness; first with hemophilia and then dealing with AIDS during the 1980s. Through this experience I realized the importance of health care providers allowing families the opportunity to tell their story. Working at The

Boston Children's Hospital I saw families attempting to make sense and find meaning of the events of their lives, yet there were few health care providers that had the time to actually listen.

When I returned for a PhD at the University of Minnesota, I was fortunate to be included in Dr. Wendy Looman's investigation of quality of life in families of children with severe chronic illness. This was a result of a previous study that involved lengthy quality of life questionnaires to be completed by the parents. In that previous study, however, some parents were not completing the questionnaires or were completing them incorrectly, and a few of the mothers noted on their questionnaires that they were not pleased with having to complete the surveys.

Because of this, Dr. Looman planned to investigate the child's quality of life in a different way. In a qualitative study, we visited the homes of children with severe chronic illness to ask the parents, "What makes quality of life for your child?" From this experience I made two conclusions: 1. The child's quality of life was reflective of the family's quality of life, making it difficult to assess the two separately; and 2. There were rich qualitative stories about families living with severe chronic illness to be discovered, stories that were not elicited previously through the quantitative questionnaires alone, and could have been lost without this qualitative study. Many of the families with severe chronic illness shared some remarkable positive family events, e.g., parents roller blading while they pushed the child requiring oxygen in a baby jogger.

With the support of Dr. Looman, I focused my critical review of the literature on family quality of life (FQOL), a rather recent theoretical concept in the literature. In the review I discovered that FQOL appeared to be disproportionately altered specifically in cases where families had a child had autism. Additionally, there appeared to be a need to focus the research on families of more severely affected children with autism.

I then enrolled in a year-long course, *Advanced Qualitative Family Research Methods*, in the Department of Family Social Sciences. For that course, I conducted a pilot study to assess the family experience when a child has autism. Both of the mothers I interviewed had children with moderate autism. This fostered my interest in autism and confirmed my belief that more family members needed to be included in the research process.

Although I had extensive clinical experience in hemophilia and access to a hemophilia study population, I realized that recent advances in hemophilia treatment meant that these children were now faring much better than they had in the past and no longer had a "severe" chronic illness. On the other hand, there seemed to be an increasing need to understand the family experiences of those with children who had severe autism.

At this point I chose to focus my research on autism. To further my understanding I applied for and became a LEND fellow (Leadership Education in Neurodevelopmental and Related Disorders) at the University of Minnesota. This entailed a year-long intensive study of neurodevelopmental disorders through weekly meetings involving presentations from experts in the field. It also included several clinical rotations in which I was able to witness autism clinical evaluations. The LEND experience provided both the tools to understand autism and the keys to access the families who would ultimately participate in this research.

In addition, I attended a 3-day workshop on qualitative analysis in Nova Scotia in 2014 as part of the 33rd International Human Science Research Conference. There I met Max van Manen, who developed the Lived Experience phenomenology. This provided an opportunity to learn more about his theory and methodology, and to discuss my ideas for research with him directly.

Chapter 2. Review of the Literature

Aims

The goal of this review of the literature is to provide a broad overview of the families experience when a child has autism. Over the past four years I have evaluated research on this and related topics and found that the most relevant literature focuses on two areas. The first area is family quality of life (FQOL), studies that specify childhood disabilities, including autism. The second area is research on the qualitative experience of families with a child with autism. These two areas were selected because they provide a panoramic assessment of the research that exists concerning families of children with autism.

FQOL Research Including Children With Autism

It is important to review the theoretical background and development of the FQOL methodology to appreciate the related FQOL literature that will be reviewed.

FQOL as a research theory. The FQOL theoretical framework is derived from both a family ecological and quality of life (QOL) model. The ecological model was described by Hook and Paolucci (1970) in relation to families, while Bronfenbrenner (1979) described the ecological model in relation to individuals. Here development is compared to a Russian doll: the individual is nested within the family and society in a reciprocal relationship in which the individual and family are not only affected by the environment, but they also affect the environment in a feedback loop (Bronfenbrenner, 1979).

FQOL is also based on the QOL model, which was described by Ferrans (1996). The QOL model is strength-based, meaning it focuses on satisfaction with important aspects of a person’s life. Ferrans describes four domains she believes work in a synchronistic manner to comprise individual QOL: health and functioning, psychological/spiritual, social/economic, and family (Ferrans, 1996).

Quality of life is an important concept to consider in the child and families of children with disabilities particularly because a cure is rarely possible and maximizing individual and Family QOL is paramount. In fact, maximizing QOL has been described as *the* goal of health care for children with chronic illness (Clarke & Eiser, 2004; Guyatt, Feeny, & Patrick, 1993; Payot & Barrington, 2011).

"Family Quality of Life Theory" was developed by Zuna and colleagues (2010) based on both ecological and QOL frameworks. The FQOL theory was actually born out of studies on individuals with disabilities (Poston et al., 2003; Zuna, Turnbull, & Summers, 2009; Zuna, Summers, Turnbull, Hu, & Xu, 2010) and was stimulated by (1) the relocation of those with disabilities to care at home rather than institutions (Brown, Anand, Fung, Isaacs, & Baum, 2003; Gardiner & Iarocci, 2012; Hu, Summers, Turnbull, & Zuna, 2011; Samuel, Rillotta & Brown, 2012b), and (2) the need to develop health care related policy (Summers et al., 2007).

Family Quality of Life is described as "a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact" (Zuna et al., 2010), but the focus is the family rather than the individual (Hu et al., 2011).

More specifically, FQOL theory illustrates the effect of the person with disabilities (e.g., their specific characteristics) and external factors (e.g., services and supports) on the family unit as a whole. The family is altered by the person with a disability, but the family also experiences new strengths that are reincorporated into the family system. The family then becomes part of a reciprocal, ecological relationship with the child with the disability (Zuna et al., 2010). In addition, in true QOL style, FQOL is strength-based, meaning that it is assumed that intrinsic strengths lie within the family system.

FQOL as a research methodology. There are presently two main research tools used to measure FQOL: the Family Quality of Life Survey (FQOLS) and the Beach Family Quality of

Life Survey (The Beach FQOL Survey) (Gardiner &Iarocci, 2012; Samuel, et al., 2012b). Both instruments were predominantly developed with families of children with intellectual disabilities and were conducted by researchers in the field of special education (Brown, 2010; Poston & Turnbull, 2004).

The FQOLS was developed by the International Family Quality of Life Project in 1997 (Isaacs et al., 2007; Isaacs et al., 2012). The survey was based on the core domains of individual QOL that had been identified by the researchers, but the domains were used to assess families (Isaacs et al., 2007; Schalock et al., 2002).

The domains include: health, financial well-being, family relationships, support from other people, support from disability related services, values (including spiritual, cultural, religious and personal beliefs), career or preparing for career, leisure/ recreation, and community interactions (Isaacs et al., 2007). These domains are rated across six dimensions: importance, opportunity, initiative, attainability, stability, and satisfaction (Isaacs et al., 2007).

A sample question from the FQOLS in the domain of health under the dimension of satisfaction, would be, “How satisfied are you with the physical health of your family?” The responses are rated on a scale ranging from very satisfied to very unsatisfied. The questionnaire is predominantly a Likert-scale questionnaire with 151 questions, and includes a small subset of questions that elicit subjective responses.

The FQOLS was tested for validity and reliability. Content validity was assessed by pilot testing the domains and shown to be valid. The construct validity revealed a CFI >.90. Reliability testing revealed a Cronbach’s alpha of 9 domains and dimensions (α 0.62-α 0.92) (Isaacs et al., 2012).

The Beach FQOL Survey was developed concurrent to the FQOLS in the U.S. (Kansas), and tested predominantly in the U.S. with individuals and focus groups (Poston et al., 2003; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Rillotta, Kirby, & Shearer, 2010;

Samuel et al., 2012 b). Unlike the FQOLS, The Beach Family Survey has 25 questions with no subjective responses. Similar to the FQOLS there are several domains: physical and material well-being, family interactions, parenting, emotional well-being, and disability related support. Only one dimension, however, satisfaction, is used to rate each domain (Hoffman et al., 2006).

The Beach FQOL was found to have good validity and reliability results. Reliability testing revealed a Cronbach's alpha of the overall FQOL model (α 0.94) (Hoffman et al., 2006).

Selection criteria. The first review of the literature was conducted in 2013 for my Critical Review of the Literature requirement, entitled, "Family Quality of Life in Children With Developmental Disabilities January 2003 to May 2013" (Gorlin, 2013). Several of the research studies included autism as one of the developmental disabilities under investigation. In September 2015 this review was updated to capture more recent publications. The topic of this updated review was, "FQOL and Childhood Autism." The studies that included autism from the original review of literature were combined with the results from the updated review of the literature and the results are presented in Family Quality of Life (FQOL) Studies in Childhood Autism: Studies and Results 2003-2015 (see Appendix B**),** which is summarized below.

The references in this review of the literature include descriptive qualitative; systematic review of descriptive qualitative studies; single correlational/observational studies; systematic review of correlational/observational studies; single nonrandomized or RCT; and systematic review of nonrandomized or randomized control trials; dates of publication ranged from January 2003 to September 2015.

Research in this review included only studies that specifically examined the construct "family quality of life (FQOL)" and not other domains such as "resilience," "positive impact," or "well-being." Only research that provided a lens into understanding the essential aspects of FQOL was included in this review, rather than information about other topics, such as validation, or comparing FQOL research instruments.

This review also selected research with a focus of the family unit instead of a focus on the child with special health care needs or the individual parent/primary care provider. Family was defined as “People who think of themselves [as] part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis.” (Poston et al., 2003, p. 319).

All studies included a child (< 21 years of age) with disabilities and a study was not considered if the study *only* assessed adults or young adults with disabilities. Studies published from January, 2003 to September, 2015 were included in the review.

Search strategy. The original review of the literature in 2013, “FQOL in Children with Developmental Disabilities,” was completed with the assistance of expertise in health care library sciences. Ovid was used to search Medline as well as PsycINFO and CINAHL. Google Scholar was utilized in May after the original search to check for current publications. Search terms were limited to: “Family”; “Quality of life”; “Disabled children”; and “Developmental disabilities.” Of the 59 possible references that were individually evaluated for this review of the literature, 9 met the criteria. A manual search of the literature through reference lists netted 26 references with 14 appropriate for review. In May 2013, 1 additional reference was identified by Google Scholar and added for a total of 15 references.

For the current review of the literature in 2015, “FQOL in Childhood Autism,” a slightly different approach was used. PubMed was used to search Medline. Search terms were “Autism” and “Family” and “Family Quality of Life.” There were 154 articles that were identified. After careful review, only 3 studies met the criteria and were not duplicates of those previously reviewed. These 3 studies were added to the previous 9 research studies in the original review of the literature that included autism in their sample. This resulted in a total of 12 studies that met the criteria of studies that included FQOL and Childhood Autism.

FQOL studies including children with autism. It is of note that out of the 12 studies identified that included autism, only 3 included solely subjects with autism; the other studies included a variety of disabilities, with a variety of severities among study subjects (Gardiner & Iarocci, 2015; McStay et al., 2014; Pozo et al., 2013).

The first finding when reviewing the literature in this area is that FQOL was often related to disability type, disability severity, and/ or behavior (Boehm et al., 2015; Brown et al. 2006; Brown et al., 2010; Davis & Gavidia-Payne, 2009; Gardiner & Iarocci, 2015; Pozo et al., 2013; Wang et al., 2004; Werner, Edwards, & Baum, 2009).

In reference to type of disability, two related studies compared families of children with autism to families of children with Down syndrome and a control group of families that did not have a child with a disability. One study was conducted in Canada (Brown et al., 2006) and the other was an international comparison of FQOL in children with disabilities across several countries (Brown et al., 2010). Both studies found that the families that had a child with autism reported lower overall FQOL satisfaction, more behavior issues, and yet high satisfaction with family values. Both the autism and Down syndrome groups reported low satisfaction with disability services (Brown et al., 2006; Brown et al., 2010).

Severity was also noted to inversely affect FQOL, i.e., the more severe the disability, the less the families rated their overall satisfaction with well-being (Boehm et al., 2015; Gardiner & Iacocca, 2015; Pozo et al., 2013; Wang et al., 2004).

Boehm and colleagues (2015) in the U.S. assessed 425 parents of children and young adults transitioning to adulthood (aged 13-21 years old) with a variety of disabilities including autism. They found that the lower the support needs of the child (an indirect measurement of severity) the better the FQOL or family well-being.

Gardiner and Iarocci (2015) looked directly at child adaptive functioning, similar to severity, and its effect on FQOL in families of children with autism. In Canada, they interviewed

84 parents (mostly mothers) and 1 grandmother of school-age children with various severities of autism. In this case, the majority of children had mild autism. They found that the relatives of those children with better adaptive functioning rated satisfaction with FQOL higher than those with children who had more functional challenges.

This study is significant in its focus on autism and the researchers' attempt to define and report autism severity carefully. They used a variety of tests to define autism, severity and adaptive functioning, including the DSM, ADOS, ADI-R, The Vineland Adaptive Behavior Scale checklist, an additional behavioral scale, and the FQOLS. The researchers noted that this type of thorough evaluation was probably easier in Canada because the national health care system requires these tests for autism diagnosis; the tests are not required in the U.S.

Pozo and colleagues (2013) also noted that severity of autism affected FQOL. Like the previous study, it focused specifically on the families of children with autism. In their study in Spain, they interviewed 59 parent pairs of children and young adults (aged 4 to 38 years old) with autism spectrum disorders. They also used a variety of behavioral checklists and autism rating scales in addition to the FQOLS to assess the child's severity and found severity of disability had a negative effect on mothers' family quality of life, but a positive effect on fathers. They hypothesized that this was because mothers typically utilized problem-solving techniques to help the child, and fathers used avoidance techniques. As the researchers did not define the severity of autism of the children involved in this study, it is difficult to know if the sample included more mild or severe autism.

Behavior was also found to be a significant factor affecting FQOL in families of children with disabilities. Autism-related behavior often inversely correlated with FQOL, i.e., when behaviors escalated, FQOL decreased (Boehm et al., 2015; Brown, et al., 2006; Brown et al., 2010; Davis & Gavidia-Payne, 2009; Gardiner & Iarocci, 2015; Pozo et al., 2013). However, the specific autism-related behaviors were not generally defined in these studies because usually only quantitative results were reported.

Davis and Gavidia-Payne (2009) conducted a study in Australia, which interviewed mostly mothers, and found that the behaviors of the child, but *not* severity of disability, predicted FQOL. In this study the majority of the sample included autism, but also included other disabilities. Behavior was assessed in a separate behavioral subscale, but the specific autism-related behaviors were not reported.

Finances were also found to be an important factor in FQOL. Gardiner & Iarocci (2015) found that family income correlated positively with FQOL; the higher the income in the families of children with autism, the greater overall well-being. Davis and Gavidia- Payne (2009) found that family income in the families of children with a disability was one of the strongest correlations with overall FQOL or family well-being.

Family income was also assessed in relation to FQOL in a study that focused on low-income families of children with a variety of disabilities (Samuel, Hobden, LeRoy, & Lacy, 2012a). The families were predominantly families of color. Here 149 relatives, mostly mothers, participated in the study. The results showed that low socioeconomic status correlated with a high rate of dissatisfaction with disability services and lower FQOL.

Support from disability-related services was also found to be an important factor in the families of children with autism and other disabilities. There was often dissatisfaction with external services, such as health care or school services that the child with the disability received (Brown et al., 2006; Brown et al., 2010; Clark, Brown, & Karrapaya, 2012; Samuel et al., 2012a). In fact, in three of these studies, satisfaction with family relationships was juxtaposed to dissatisfaction with disability services, that is, the families were very satisfied with the their family relationships, but dissatisfied with outside disability services (Brown et al., 2006; Brown et al., 2010; Clark et al., 2012).

Clark, Brown, and Karrapaya (2012) assessed FQOL in 52 families of children (mean age 8 years) in Malaysia, with a wide variety of disabilities and severities, using the FQOLS alone. The severity of the disability was assessed using the short assessment from the FQOLS and although the majority of the children were rated as needing a high level of supports, the FQOLS rating and reporting scale was very short and somewhat unclear. Nevertheless, these researchers found high satisfaction in the domain of family relationships and low satisfaction in the domain of support from disability services, reflecting a common dichotomy in these families.

A high level of family relationship satisfaction among the families of children with autism and other disabilities was reported in several of the studies (Brown et al., 2010; Clark et al., 2012; Davis & Gavidia- Payne, 2009; Rilotta, Kirby, Shearer, & Nettlebeck, 2012). Davis and Gavidia-Payne (2009) in particular mentioned extended family members and noted that their support was more important than the support from friends. Unfortunately, in all of the FQOL studies little subjective information was presented about the immediate or extended families so little more information was gleaned about specific family relationships.

Lastly, the domain of "values," which includes the topics of religion, spirituality, culture, and personal beliefs, was an important factor in FQOL in many families of children with autism and other disabilities (Boehm et al., 2015; Brown et al., 2006; Brown et al., 2010; Rilotta et al., 2012). In fact, in all these studies, the dimension of "values" was rated higher than all other FQOL dimensions, but because the findings did not discuss the significance of this parameter, it is difficult to interpret.

One study observed that strong religious faith was a strong predictor for positive FQOL (Boehm et al., 2015). These researchers also assessed religious faith through an additional questionnaire, unlike other FQOL studies. In this study they found the highest correlation was between strength of religious faith and FQOL.

Discussion of methodology. First, there were challenges with the methodologies that the studies used. Most of the FQOL studies were conducted outside the US (9 out of 12; 9/12) which may make comparisons difficult because of cultural and health care differences. On the other hand, consistent themes identified even across countries may make the results more significant.

All of the studies utilized a cross-sectional quantitative research design except one, which utilized a semi-structured qualitative interview (Werner et al., 2009) and only two had control groups (Brown et al., 2006; Brown et al., 2010). This gave a snapshot in time of FQOL, but not an understanding of FQOL over time.

Usually one of two study instruments was used. The FQOLS (7/12) or the Beach Family Survey (4/12), and though they are similar, they have considerable differences. The Beach Family Survey only includes 25 questions and one dimension whereas the FQOLS included 151 questions with six dimensions. The FQOLS is a questionnaire format and some of the results are challenging to interpret because of the use of multiple domains and dimensions. In addition, though there are some open-ended questions in the FQOLS, usually only quantitative results were provided, giving a limited insight into the lived experience of these families.

The average total of children with disabilities represented in each study was 39 and the average age of the child with a disability was 12 years. Though all the studies included children with autism, most of the studies (9/12) included an array of developmental disabilities and referred to them as “intellectual” or “physical” disabilities, making categorization rather arbitrary. Only 3 studies of the 12 included *only* children with autism (McStay et al., 2014; Gardiner & Iarocci, 2015; Pozo et al., 2013).

The majority of studies focused on children who had milder rather than more extensive disabilities. Severity ratings, however, were often missing (4/12 studies) or were unclear, making comparisons between or within disabilities challenging at best. Only four actually rated the disability as “mild, moderate, or severe” (Brown et al., 2006; Davis & Gavidia-Payne, 2009;

Gardiner & Iarocci, 2015; Wang et al., 2004). This weakness is especially germane given that autism represents a spectrum from very mild to very severe so that the experience for families likely varies with severity. In addition, the literature supports that FQOL is affected by more severe disability, thus the severity of the disability should be clearly defined.

The FQOLS specifically assesses severity of disability, but only three out of the seven studies that utilized the FQOLS reported severity (Clark et al., 2012; Gardiner & Iarocci, 2015; Rillotta et al., 2012). This rating is based on the level of disability supports the child receives and the level of communication, but it includes only two questions. This rating scale, in addition to being extremely brief, is also complex and unclear.

Gardiner and Iarocci's (2015) research was the only study that clearly defined severity e.g., adaptive function, by additionally using the Vineland Adaptive Function Scale and a parent child behavior rating form. It is of note that these are fairly lengthy scales. The Vineland is comprised of 419 questions (Sparrow et al., 2005) and the Nisonger Child Behavior Rating Form-Parent version has 76 questions (Gardiner & Iarocci, 2015). This confirms challenges in rating autism severity and that the instruments used would be too lengthy for a qualitative research study.

The average number of respondents in the studies was 44, which is a fairly good sample. Though most (11/12) of the studies included other family members, such as a few fathers, grandparents, siblings, or aunts, by far the usual respondent was the mother and typically there was only one respondent per family. This was another weakness in the literature because it narrows the scope of the experience to the insights of one person in the family.

Discussion of themes. The results of the review of the literature revealed that type of disability, severity, and/or behavior, seemed to affect FQOL. In reference to the type of disability, families with a child with autism in particular seemed to have a lower FQOL compared with Down syndrome, experienced more behavior issues, but also had higher satisfaction with family values. In reference to severity, those with more severe disability and more behavioral issues had a lower overall FQOL. In addition, finances inversely correlated with FQOL. There was often a dichotomy of dissatisfaction with external health care services, but satisfaction with family relationship. There was also an overall satisfaction with values (including spirituality, religion, culture, and personal beliefs).

Qualitative Research on Families of Children With Autism

Selection criteria. The second review of literature that was completed for this research study involved qualitative versus quantitative research. The first review of the literature on the topic of Families of Children with Autism was completed in April 2014 in preparation for my Doctoral Research Prospectus entitled “Severe childhood autism: The lived experience” (Gorlin, 2014). The review was completed with the assistance of an expert in health care library sciences.

In September 2015 this review was updated and the research studies merged, the results of which are 16 studies presented in Qualitative Studies in Families of Children With Autism 2003-2015: Studies and Results in Appendix C, and summarized below. The references included qualitative studies published from January 2003 to September 2015, about a 13-year time span of research, that focused on the families of children with autism. Family was defined as “People who think of themselves part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis”(Poston & Turnbull, 2004, p. 96).

Only studies that provided a lens into understanding the essential aspects of the family experience in childhood autism were selected, rather than a review of literature or studies that focused on one family member, such as the father or a sibling. There was often significant overlap between parental experience and family experience and these were carefully evaluated. All studies included a child (<21 years of age) with disabilities. The study was not considered if the study *only* assessed adults or young adults with disabilities.

Search strategy. For the original review in 2014, the search engines SCOPUS and ProQuest Digital Dissertation were utilized with the search words “autism,” “family,” “qualitative research,” and “phenomenology.” Thirteen studies and 28 dissertations were identified. After careful review 9 met the criteria of the review.

To update the review of the literature in 2015, PubMed was used with the search words: “qualitative research,” “ autism,” “family,” and “lived experience,” or “phenomenology.” Fifteen items were identified and carefully reviewed; 7 fit the criteria and were added to the original review for a total of 16 studies on childhood autism. This included 4 unpublished dissertations.

Qualitative studies. Because all of these were qualitative studies, there was considerable information; presented below are the recurrent interfamily themes identified in the families of children with autism.

Stigma. Several researchers described a sense of stigma or disgrace that was experienced within the family. Stigma was described in reference to the invisible nature of autism and the child’s atypical behavior. The public generally believes that disabilities are physical, such as a person in a wheelchair; but autism is often invisible, not readily apparent until the child manifests atypical behavior. Because of this, families felt stigma or shame when the child had tantrums, for example, and felt they needed to explain to others that the child indeed had autism. (Farrugia, 2009; Hoogsteen & Woodgate, 2013).

Farrugia (2009), in an effort to understand stigma, interviewed 16 parents, mostly mothers, of children and young adults with autism. He described diagnosis as a positive event because it provided a medical explanation of the condition. However, due to the normal physical appearance of the child with autism, parents often felt a need to inform others that their child had a disability. This involved constantly teaching others so they could avoid stigmatization.

Like Farrugia (2009), Hoogsteen and Woodgate (2013) focused on the concept of invisibility of autism. They interviewed mostly mothers in an effort to understand families of children with autism in rural Canada. They found that one of the main challenges that families faced was the need to educate others that their child had autism because the disability is not visible. In this way they were able to help the child and themselves feel less marginalized.

Stigma or shame was described directly in reference to the child's behavior. This took the form of judgment by others specifically related to the child's frequent atypical behaviors (Dupont, 2009; Lutz et al., 2012; Safe et al., 2012). The result was feeling like a "bad parent" because the child did not behave as expected.

Dupont (2009) interviewed parents, mostly mothers, about their experience raising school-age to young adult individuals with autism (autism severity not specified). He described the embarrassment that parents felt not being able to control their child and the stigma they experienced. This occurred usually when the child was experiencing "meltdowns" or tantrums. Parents found that though they tried to intervene on many occasions, they ultimately felt a sense of helplessness and isolation.

Lutz and colleagues (2012) interviewed 16 mothers of children and adults with autism, severity not defined. They identified social challenges including feelings of stigma and isolation due to their children's behavior. Again, parents noted the perception that they were not in control or were "bad parents " because of their child's behavior; there was often a desire to remove the child and themselves from the situation, which led to further isolation.

In addition, Safe and colleagues (2012) interviewed seven mothers of school-age children in Australia to assess the mother's role in caring for the child with autism. The respondents echoed the theme of the public's disapproval of the behavior exhibited by the child with autism. Mothers described the embarrassment of being judged by others because they could not "control their child," referring to the child's inappropriate behavior. Usually they would return home after these encounters stressed and depressed. Some of the families found that even extended family members did not seem to have empathy for their situation.

Stress. Stress was identified as a universal experience shared by all the families of children with autism in these studies. The stress was multifaceted but focused around six basic issues: child behaviors, direct care provided or vigilance, decreased communication, cost of care, concern for the future, and care coordination.

The child's behavior as a source of stress was discussed in several studies. Bultas and Pohlman (2014) also interviewed mothers of preschool children with possibly mild autism (severity was not clearly defined) in the U.S. in three sequential interviews over a 6-week period. Though they sought to reveal resilience or a "silver lining" to the experience of living with a child with autism, they also identified chronic fatigue the mothers experienced from the inability to set a routine with the child due to the child's erratic behaviors.

Desai and colleagues (2012) explored childhood autism among families in India by interviewing 12 parents, mostly mothers, of children and young adults with autism. They described the persistent behaviors associated with autism, such as crying, difficulty sleeping, agitation, and flapping hands, which led to stress but also helped the parents finally accept the diagnosis of autism because the behaviors were persistent.

Larson (2010) interviewed nine mothers of predominantly high-functioning boys with autism to explore the maternal role in raising a child with autism. Stress and fatigue were related to the mother's constant effort to thwart or appease the child's "meltdowns" or tantrum behavior. Mothers described that they could not take breaks like other mothers, but instead were continually on call to meet the child's needs.

Lutz and colleagues (2012) and Lendenmann (2010) described specific behavior issues that were related to parental stress. Lutz and colleagues (2012) found that some parents were concerned about their child's safety (e.g., children who ran away) and the safety of other children, such as siblings. Lendenmann (2010) listed several stressful behaviors including tantrums (most common), constant crying, sleep issues, eating problems, running away, hyperactivity, and self-injurious behaviors (least common), as stress provoking.

Direct care and vigilance was also a source of stress for the families of children with autism. For example, Bilgin and Kucuk (2010) interviewed 43 mothers in Turkey to assess their experience raising a child with autism and related disorders. The researchers described the burdens and stress that mothers experienced concerning the unknown etiology of autism and the large amount of direct and complex care they needed to provide to the child. Larson (2010) echoed the daily need to provide direct care and teach and reinforce self-care to the children as a constant stress.

Safe and colleagues (2012) also discussed stress the family experienced in providing care to the child. In their study they interviewed the mother and discovered several reasons for the constant stress mothers experienced. This included the time it took to prepare the child for an event, for example, and talking to the child about what to expect due to the child's general inflexibility. It also included the time needed for planning the actual event, for example, what to bring and where to go to maintain safety and keep the child calm.

Family stress related to the child's lack of communication was described briefly in two studies (Lendenmann, 2010; Werner DeGrace, 2004). Lendenmann interviewed 16 parents (13 mothers and 3 fathers) of preschool children who had autism and low IQ testing, though severity was not further defined. The researcher described parental stress related to the child's inability to communicate in addition to the atypical behaviors and need for constant supervision. Mothers spent inordinate time trying to understand their child's needs, a challenge due to the child's altered ability to communicate. Werner DeGrace (2004) mentioned little about communication though only children with severe autism were included children in her study. She did note, however, that one parent was stressed because her child could not communicate his or her needs.

Stress was also related to cost for many families (Lutz et al., 2012; Phelps et al., 2009; Safe et al., 2012). Phelps and colleagues (2009) utilized a qualitative questionnaire to assess 80 caregivers, 97% of whom were mothers, of children with autism (severity not specified), looking at the experience of the caregiver. The parents described the high cost of autism care, particularly the cost of special services such as physical therapy (PT), occupational therapy (OT), and special accommodations. They reported being in debt to pay for services. In addition they discussed the challenge of being employed because of the time needed to care for their child at home.

Safe and colleagues (2012) also discussed cost concerns. Mothers described wanting to procure behavior therapy services for their child since the therapist was an emotional support to the family, but that at the same time that they resented the high cost of the services and the amount of time needed for the therapy.

Coordinating care for the child with autism was also a source of stress for these families (Bilgin & Kucuk, 2010; Bultus & Pohlman, 2014; Mulligan et al., 2012; Safe et al., 2012). Parents described the many professionals that visited the home to provide behavior therapy sessions (e.g., Applied Behavioral Analysis (ABA) therapy, PT, OT), the need to coordinate all the services and the long waiting periods for many services (Mulligan et al, 2012; Safe et al., 2012). Parents often noted the need for early educational and health-related intervention, but found it difficult to obtain these services (Bultas & Pohlman, 2014).

The future of the child with autism was also a source of concern discussed in many of the qualitative studies (Desai et al., 2012; Kent, 2011; Phelps et al., 2009). Phelps and colleagues (2009) noted several parents shared an overall concern that they weren't preparing the child adequately for the future or were not 'cobbling' together the right services that would prepare the child for the future. Desai and colleagues noted that the last phase in the trajectory of dealing with autism for parents was an acceptance, but it was also a time when parents realized that the child would probably not become solely independent, which was a grave concern. These parents worried, “Who will care for my child when I am no longer alive?” Kent’s (2011) research also echoed this haunting question.

Isolation. Isolation was an issue faced by many families as they raised a child with autism. Several families discussed the difficulty of leaving the home because of the child’s behaviors or fears. Bultas and Pohlman (2014) discussed feelings of isolation from extended family and friends who did not understand their situation. Other studies noted isolation from friends and the public who did not understand the child’s behaviors (Phelps et al., 2009; Luong et al., 2009; Safe et al., 2012) and some described avoiding situations outside the home that were uncomfortable for the child and family (Larson, 2010; Lutz et al., 2012; Schaaf et al., 2011).

Family dynamics. Specific family dynamic challenges were described, including lack of family time spent together, sibling issues, changes in marital relationships, and decreased extended family support.

The lack of family time together was often noted in these studies (Dupont, 2009; Farrugia, 2009; Kent, 2011; Schaaf et al., 2011; Werner DeGrace, 2004). Schaaf and colleagues (2011) interviewed four parents, mostly mothers of school-age children. They found that the families reported difficulty participating in activities as a family such as dinner, because parental attention was directed to the child with autism.

Werner DeGrace (2004) echoed this sentiment. Again, this is the only study that included only families of children with *severe* autism, although the means of assessment of severity was not discussed. Werner interviewed four mother/father pairs and the siblings of school-age children with severe autism in a cohort of families with whom she worked as an occupational therapist. All of the themes she identified involved the concept that family life was significantly disrupted and splintered. She states, “This resulted in the following themes: (a) whole family life revolves around autism, (b) robbed as a family, (c) occupy and pacify [the child], (d) fleeting moments of feeling like a family.” (Werner DeGrace, 2004, p. 545).

The families in this study reported that the child with autism controlled all situations because of their unpredictable behavior, such as spitting or meltdowns. As she notes, “The family identity had become ‘autism’” (Werner DeGrace, 2004, p. 548). The family had to cater to the child’s wants in order to appease or avoid unpleasant future behavior and therefore felt an underlying current that something untoward could happen at any moment. Because of the focus on the child, the family could not share family time together as a unit except when driving, since in that case, the child could not escape and was relatively content (Werner DeGrace, 2004).

Siblings suffered from the focus turned toward the child with autism. Though Werner DeGrace did not comment specifically on the experiences of the siblings, she reflected on the fractured nature of the family and their attention on the child versus the siblings (Werner DeGrace, 2004). Phelps and colleagues (2009) and Kent (2011) also noted that the siblings were jealous of the time their parents spent with the child with autism. Kent (2011) described insensitivity of some siblings to the needs of the child with autism and role reversals that occurred when the child with autism was older than the sibling.

Marital relationships were affected in the families of the children with autism (Bilgin & Kucuk, 2010; Bultus & Pohlman, 2014; Kent, 2011; Phelps et al., 2009). Bilgin and Kucuk (2010) described the inordinate amount of responsibility mothers accepted caring for the child compared to the fathers and the resulting marital conflict. Phelps and colleagues (2009) described relationship challenges due to differences in parenting techniques, limited time together, and differences in coping with the situation. Kent (2011), in a research dissertation interviewed eight parents, mostly mothers, about their experiences raising a school-age child with autism. They found that the problems with marriages were related to the stress surrounding the diagnosis, differences in opinions of treatment therapies, and school interventions. Additionally fathers often felt that the mother coddled the child with autism, which the father resented.

Another family dynamic highlighted in the literature was the lack of support from extended family (Bilgin & Kucuk, 2010; Bultus & Pohlman, 2014; Safe et al., 2012). Bilgin and Kucuk (2010) found that extended family sometimes helped the immediate family financially, but not emotionally. Bultus and Pohlman (2014) and Safe and colleagues (2012) described that parents felt marginalized from extended family members, who did not appear to fully understand autism.

Dissatisfaction with disability services. Families also discussed a general dissatisfaction with disability-related services (Bultas & Pohlman, 2014; Hoogsteen & Woodgate, 2013; Mulligan et al., 2012; Phelps et al., 2009; Safe et al., 2014). Bultus and Pohlman (2014) described the difficulty to simply obtain the limited services available. Hoogsteen and Woodgate (2013) noted many parents reported that they did not receive enough guidance immediately after diagnosis and needed to fend for themselves. In addition they needed to continue to battle for all health care and school services.

Mulligan and colleagues (2012) focused on the experiences surrounding the time of diagnosis and soon after. They found that the families voiced frustration in the long waiting lists to have the child diagnosed. These frustrations continued after diagnosis since there were limited services, which were difficult to obtain, poor follow-up and lack of coordinated care.

Phelps and colleagues (2009) found an overall dissatisfaction with the care in both the health care setting and school. They felt that they as parents were not acknowledged or heard. They also felt that health care providers in particular needed to learn more about autism to provide better care.

Temporal nature of the experience of autism. Some studies described a temporal nature of experience in the families dealing with childhood autism (Desai et al., 2012; Luong et al., 2009; Mulligan et al., 2012). Desai and colleagues (2012) in India, for example, discussed steps that families progressed through when dealing with autism. The first was celebration that the child was well, followed by a denial and temporary belief that the child did not have a long-term issue. When behaviors did not abate, they began to accept the situation. Lastly the families looked to the future with hope, but trepidation.

Luong and colleagues (2009) described a somewhat different trajectory. They described distinct phases that included denial at the onset, which changed to a sense of urgency to find a diagnosis. Next families became very involved in their child's care and rearranged their home and life to accommodate the child; some mothers, for example, left work. The next phase included social withdrawal due to the child's behavior and the feeling that people did not understand their situation. The last phase was spiritual coping and acceptance.

Mulligan and colleagues (2012) described a similar trajectory that began with a suspicion that there was a problem, but denial that the child had a serious condition. When behaviors did not abate they sought testing and were originally hopeful when they received the diagnosis. However the families then felt overwhelmed by the information and by grief as they tried to make sense of the diagnosis and struggled with the lack of coordinated care and services. They described the families then becoming case managers and experts due to the lack of coordinated services.

Positive outcomes. Lastly, several studies mentioned positive outcomes related to the experience of raising a child with autism. These included family cohesion, personal growth, and dependence on faith, religion or spirituality.

The closeness or bonding of families was discussed in several studies (Bilgin & Kucuk, 2010; Kent, 2011; Lendenmann, 2010; Luong et al., 2009; Phelps et al., 2009). Bilgin and Kucuk (2010) noted mothers often discussed cohesiveness within the family. Some families described learning about autism and caring for child with autism as a bonding experience (Lendenmann, 2010; Luong et al., 2009). Phelps and colleagues (2009) found that although there was family strain there was also a special bond that the family shared.

Personal growth was another positive outcome discussed in several studies. Bultas and Pohlman (2014) called these experiences “silver linings.” Positive outcomes included a positive outlook or joy, and finding a focus, purpose, or meaning in life.

Personal growth included increased compassion or empathy and sensitivity to others. Phelps and colleagues (2009), for example, described parents gaining strength such as selflessness, compassion for others (not just the child with autism), and a sense of peace during hard times. This was echoed in the studies by both Bultas and Pohlman (2014) and Kent (2011) in which parents reported less judgment and more understanding of others.

These experiences of personal growth also included an acceptance for what one has and a deep appreciation for the child with autism (Lendenmann, 2010; Safe et al., 2014). It involved appreciating the little things in life such as the child with autism’s small achievements (Dupont, 2009; Lutz, et al., 2012; Safe et al., 2012). Dupont’s (2009) study, for example, mentioned one mother burst into tears hearing the word, “Mommy” said for the first time.

Lastly, faith, spirituality, and religion were noted as positive outcomes by families in several studies. Dupont’s (2009) study found that while few families discussed religion directly, most discussed having faith in some form. Some families discussed the importance of religion directly. Luong and colleagues (2009) noted several of the families prayed regularly and that religion was an important source of strength. Other individuals felt that God had chosen them specifically to care for the child with autism (Dupont, 2009; Lendenmann, 2010; Phelps et al., 2009).

Discussion of methodology. There are points that warrant discussion from this review of the literature of qualitative studies of families of children with autism. First, in reference to the methodology, all of the 16 studies utilized a qualitative design and employed semi-structured interviews except one that used a questionnaire consisting of three open-ended questions (Phelps et al., 2009). All used phenomenological analysis except two; of those two, one used narrative analysis (Lutz et al., 2012), and one utilized discourse analysis (Farrugia, 2009). Overall phenomenology was an appropriate design to assess the detailed experiences of families.

The majority of the studies were conducted in the U.S. (10 out of the16) which made comparison between studies more realistic from a cultural perspective. The average number of children with autism was 19 and the majority were preschool or school-age (3-12 years old). The average number of respondents was 18 (though the median was 13), which is an adequate sample for this type of research.

Settings of the studies varied with only three utilizing the home solely for the interviews. Some interviews were additionally conducted by phone and some were held at schools or cafes. The majority of studies reported the length of the interviews; the average length was about 2 hours, but four were 1 hour or less, which is quite short for a single interview.

In contrast to the previous review of the literature, all the children in this review of the literature had only autism as opposed to a variety of disabilities. Like the previous review FQOL review of the literature, half of the studies (8/16) did not specify autism severity. One dissertation study stated that all subjects had IQs of 35-55 (Lendenmann, 2010) which could correlate with severity. Only two noted an actual severity; Luong and colleagues (2009) noted that their sample included children with "moderate to severe disability," and Werner DeGrace (2004) noted that the study included only children with severe autism.

Approximately one third of the studies included only mothers as respondents. Though most of the studies included mothers and fathers (11/16), and one also included siblings (Werner DeGrace, 2004), mothers still far outweighed fathers as respondents, and there was usually only one respondent per family. It was a strength of the research to have other family members involved, although no extended family members, such as grandparents, were included in these studies. There was an attempt to have some parents participate in paired interviews (5/16) although who actually participated in the interview was often difficult to decipher from the information provided.

Discussion of themes. There were several themes identified that appeared to be recurrent experiences for families in these studies. These included: stigma related to behaviors and the invisibility of the condition; stress related to behaviors, the direct care and vigilance needed, decreased communication of the child with autism, cost of care, future concerns, and coordinating care; isolation; family dynamics, including limited communal family time, the effect on siblings, and the effect on the marital relationship; dissatisfaction with disability services; temporal patterns; and positive outcomes such as family cohesion, personal growth, and faith, spirituality, and religion.

The review illuminated the varied but recurrent experiences of the families of children with autism, and also highlighted the benefit of using a qualitative approach to gain a broader understanding of the family experience.

Conclusions and Need for This Study

The conclusion from this broad combined review of the literature is that the family is significantly affected when a child has autism and yet the story of the experience of living with a child who has *severe* autism remains to be explored more fully.

There was significant overlap between the two reviews of the literature. For example both reviews found behaviors and cost of care to be significant issues for families. In addition, there was a dichotomy of the positive (family cohesion), yet simultaneously the negative, such as dissatisfaction in disability services. Lastly, both reviews highlighted that values of faith, religion, and spirituality were an important aspect of the family experience when a child has a disability such as autism.

After looking at the reviews of literature separately, a conclusion from the FQOL literature is that severity, significant behaviors, and autism specifically seem to affect the family well-being. However, the sample populations in these studies often included children that had a variety of disabilities some of which were milder in nature. The respondent in these studies was usually was also limited to one person, typically the mother.

The qualitative research supports the conclusion that the families have significant interfamilial challenges raising a child with autism. However, these studies include a wide range of autism severities or the severity is not defined. Again, these studies usually only included one respondent, who was usually the mother. It is also clear that the focus of these studies was the nuclear family, without inclusion and little reference to the extended family.

This review confirmed the need to narrow the focus of research to include only children with severe autism and simultaneously to broaden the participants to include other family members with the family as the unit of study. Only in this way could a clear lens into the family lived experience of severe childhood autism be obtained.

Chapter 3. Methods

Study Design: Van Manen's Phenomenological Approach to Inquiry

In van Manen's phenomenological approach, the building blocks are "lived experiences" (van Manen, 2007). The term "lived experience" was first coined by philosophers such as Dilthy, Husserl, and Merleau-Ponty, then adopted by van Manen; it refers to pre-reflexive experiences of everyday life (van Manen, 2014). These are the experiences that van Manen proposes should be examined, and infused with meaning to expose the phenomena under examination.

Van Manen portrays the phenomenon as "that which appears" [or occurs] (van Manen, 2014, p. 27). He describes phenomenology as a "meaning-giving method of inquiry" (2014, p. 28) about a phenomenon.

The goal, according to van Manen, is to identify a phenomenon or occurrence (e.g., autism) and use phenomenology as a tool to identify the lived experiences rendering meaning to that phenomenon. Ultimately van Manen's phenomenological approach focuses on the nature or "essence" of the phenomenon. This is the universal meaning of the phenomenon, that is, the essential themes that are based on the particulars of the lived experiences (van Manen, 2007).

Van Manen's approach to phenomenology was utilized in this research to study the phenomenon of families living with severe autism. Van Manen states that he does not promote a specific methodology, and that each phenomenon should rely on its own unique approach: "...we need to suspend the inclination to rely on a set of rules, a schema of steps or series of steps" (van Manen, 2014, p. 220). However, he does support the use of some simple guidelines when analyzing data and the use of epoché or bracketing of presumed ideas throughout the research process (van Manen, 2007).

Van Manen's phenomenological approach was selected for this study for two main reasons. First, it produces nuanced data that is essential to understand the actual experiences of families of children living with severe autism. Studying the experience in this way allows for gathering detailed interview text and observational information for thick description (Pals, 2006) that would be lost in a quantitative questionnaire.

Second, van Manen's approach allows the experiences to be co-defined between researcher and participant (van Manen, 2007). His approach would also be consistent with interviewing several family members versus one family member to gain a wider understanding of the lived experience for that family.

Reflexivity. The researcher's epistemological stance is usually reviewed before engaging in a research study. This is because, "Just as the artist is the primary instrument of the painting, the researcher is the primary research instrument in qualitative investigation" (McCaslin & Scott, 2003, p. 453). Because of this I will review my epistemological stance.

I support a post-modern, social constructivist paradigm, in which the individual co-constructs reality through social interaction (Holstein & Gubrium, 2011). Van Manen's phenomenology is consistent with this as he supports the observation that the meaning of experiences are co-created between the participant and researcher resulting in "the lived experience" (van Manen, 2007). A social constructivist lens is also often utilized in research that involves several family members because it supports that there are many "truths" or stories to be told about one experience (Reczek, 2014).

I also support feminist disability theory, within the critical genre, which challenges preconceived ideas of the disabled as weak and vulnerable (Garland-Thompson, 2002; Mertens, Sullivan, & Stace, 2011). I apply this to challenge preconceived ideas of the families of those with disability, leaving open the possibility for these families to have positive, meaningful lives.

Ethical considerations.

Consent. In December 2104, I applied to the Institutional Review Board (IRB) at the University of Minnesota to conduct this study. Appendix D is the consent that was used for the research study (see Appendix D, Consent Form for Adult Participants and Minors). The study was approved by the IRB in December 2014 (see Appendix E, IRB Approval).

Participant risk. The participant risks were clearly outlined in the application to the IRB. Risks associated with participation included:

1. Probing for personal or sensitive information which may elicit painful memories of the family's experience;
2. Possible invasion of privacy; and
3. Possible exposure to breach of confidentiality (collection of data with identifiers).

Precautions taken to minimize the risk included the following:

1. Sensitive information and possible painful memories: Any subject could refuse to participate or withdraw from the study at any time. The informed consent stipulated that participation was purely optional and that refusing to participate, not answer any question, or end the interview prematurely would not affect their health care. If an adult or child became distressed I assured them that I would assess if the participant wished to continue, and if not we would discontinue the conversation. It is of note that the majority of the participants did become upset and cried during the interview, but all wished to continue the conversation. This was especially pronounced among many of the fathers. I would typically wait and listen and they would regain composure and continue the interview.
2. Possible invasion of privacy: All efforts were made to allow the family members interviewed to direct the conversation. Additionally every effort was made to be sensitive to cues of distress allowing them time to answer. It was especially important to allow the mother and/or other members to have the opportunity to decide who wanted to participate in the study and plan accordingly. For example, though I said I wished to interview the family together, I would first meet the mother and other

members and let them decide how they wanted to progress. On a few occasions, a child with autism was very ill with seizures and hospitalized and we needed to cancel the home visit. In these cases, I simply asked mothers to contact me if they wished to participate in the future, without any pressure to do so.

3. Possible exposure to breach of confidentiality: This was addressed by data and safety monitoring described below.

Data and safety monitoring. Immediately after an interview was recorded and I returned home, the interview was downloaded on a separate backup hard drive that was stored in a locked drawer in my personal office. The original recording was sent for transcription and was deleted on the tape recorder. I obtained a signed confidentiality statement with the transcription service even though the service stipulates that their transcriptions are confidential (see Appendix F, Transcription Confidentiality Agreement).

When the transcription was returned to me, the transcript was immediately de-identified. The de-identified transcripts were stored on a personal computer with a passcode and anti-virus software in compliance with the University of Minnesota Information Technology (IT) department.

Any identifying information such as names on the Family Lifeline or in the transcriptions were deleted and replaced by a family identifying number. For example, interview respondents were identified as Family #10: father (A), mother (B), etc. The code linking the family name to the code number was kept separately from the data.

It was necessary to maintain identifying information. The names, addresses, and phone numbers of the family were maintained for the home visits and in case the family needed to be contacted to clarify information. This information was also kept separate from the data in a locked site.

It was stipulated in the IRB application that any identifying information and original audio recordings would be kept for 1 year from the time of interview. The de-identified transcripts and Family Lifelines would be kept for 5 years.

Recruitment

Inclusion criteria.

1. Family members are defined by one parent and include individuals who live in or out of the same household as the child with autism; may or may not be biologically related; and may include parents, siblings, grandparents, or others. The members must have ongoing consistent contact with the child with autism.
2. The child with autism must be diagnosed with autism and have significant functional challenges. This includes limited communication and requiring substantial support including the need for 24-hour supervision.
3. The child with autism is living at home and is 5-12 years of age (+/- one year).
4. It may be a one or two-parent family.
5. Siblings must be at least 6 years of age or older.
6. The family must be English-speaking.

Autism clinics and Autism Society of Minnesota. Two physicians agreed to allow me to recruit participant families from their clinic: the medical director of the Autism Spectrum and Neurodevelopmental Disorders clinic at the University of Minnesota, and a child and adolescent psychiatrist at Regions Hospital in Saint Paul. Both provided a note of permission for the IRB (see Appendix G and Appendix H, Permissions from Physicians to Collaborate). In addition, the director of marketing and communication at the Autism Society of Minnesota (AuSM) promoted the study on the Research Studies page on the AuSM website, which is sent out on a monthly basis.

A poster was developed (see Appendix I, Poster**)** as well as a flyer **(**see Appendix J, Flyer**)** for recruitment and both were approved by the IRB. The same flyer was used in the Research Studies page on the AuSM website. Word of mouth or the snowball effect was used in addition for recruiting purposes.

After receiving approval from the IRB, posters were placed in one clinic and flyers were placed in both clinics. Word of mouth was employed by contacting directors at various autism clinics and disability-related programs to discuss the study. People from these institutions would in turn refer me to other individuals in the autism community who they thought might be interested, and they would be contacted.

Many of the participants ultimately were referred through a private Facebook website that many parents of children with autism have joined. It is not affiliated with a medical community so several parents referred to it as an “underground” parent network. I was introduced to this group by a parent who had seen a study poster, e-mailed me, and then spoke with me at length by phone about the study. He in turn asked other parents on the website to assist in this “important autism research.”

Phone and e-mail recruitment. I began to receive phone calls and e-mails immediately after the flyers and posters were posted. When I was contacted, I would request a phone number to contact the parent. On the first phone contact, I would introduce the study and ascertain if the parent was interested in participating. If so, I would typically schedule a longer phone call at which time I could ask more questions to assess if the child actually met the study criteria. This second conversation usually lasted at least 1 hour and detailed notes were recorded.

Consultations and study revisions. After several phone conversations with families who were interested in participating in the study, it became clear that the original inclusion criteria were too restrictive and I sought consultation from my primary advisors and advice from a local autism expert.

Many of the potential participants noted that people whom they considered to be family lived nearby, but not necessarily in the same household. Examples included grandparents or aunts who cared for the child on a regular basis, but did not live in the same household. In addition, some of the parents were divorced or separated. I also found that all of the children of the families with whom I spoke had been given the diagnosis of autism, but only one had the actual diagnosis of "severe autism." It was clear, however, that many children had extensive functional challenges and could probably be considered for a severe designation.

In addition, several of the children with autism in the families were close to the required age, but shy of the age range. I had originally wanted to focus on a school-age cohort, but found that in the autism population, the children generally have significant developmental delays so that their chronological age does not match their developmental age; school can continue until 21 years of age. Thus, the distinction of "school age" seemed somewhat narrow.

For these reasons the original inclusion criteria were slightly broadened and the amendment was IRB approved (see Appendix K, IRB Change in Protocol). The new criteria included: expanding family members to include those outside the home; parents did not need to be married; severe autism was assessed by the Autism Functional Challenge Questionnaire (developed with Dr. Reiff); and the age range was broadened slightly to +/- one year. These revisions were ultimately reflective of the iterative process of phenomenology and more representative of the sample I was seeking to study.

Procedure for Data Collection

Data collection methods. Data collection occurred from February to June 2015. At the first visit I would introduce myself and ask if we could hold our interviews in a relatively quiet place where the participant could have privacy. As I set my recorder, I described the study again and discussed my hope to talk with any family member that was interested and also interview the family as a unit if possible.

The written consent form was signed by all the participants before any formal conversation began at their home. Assent was not needed, though it was available, as none of the participants were less than 18 years old. Two copies of the consent forms were signed so the participant could retain a copy. I would first ask if the parent had completed the Family Lifeline and/or if they had any questions. Typically they had received it, but were too busy to complete it before my arrival. At the end of the interview I asked them to complete the Lifeline at their leisure and they could either mail it to me directly or scan it and e-mail it.

Typically I would interview the first family member, usually the mother, on the first visit. If there were subsequent individual interviews, this would either occur on the same day or on following visits. Likewise, family unit interviews usually occurred on the day the mother was interviewed, but sometimes on subsequent visits. The mother usually made the decision about who would be interviewed and when the interviews would occur. In most cases it was clear that the mother wanted to become familiar with me before more family members were interviewed, since this was our first introduction.

There were four research tools that were utilized to collect data.

1. **Demographic Questionnaire.** This is a two-part questionnaire developed for this study. The first section includes basic demographic information about family members. Section 2 contains medical related questions about the child with autism including a detailed assessment of their medical needs. The demographic questionnaire was answered by one parent (see Appendix L, the Demographic Questionnaire).
2. **Individual and Family Unstructured Interviews**. This includes three sections: the Adult Interview for all adults in the family; the Sibling Interview for all siblings 6 years or older in the family; and the Family Interview for the entire family. The child with autism was not included in the interview due to limited communication skills.

This questionnaire was developed during a pilot project for this study, which involved interviewing two mothers of children with autism. The adult portion included several questions that were used as prompts during the interview. First, there were "grand tour" questions to gain an overall impression of the experience of living with a child with autism e.g., "What is your experience as a family living with a child with autism?" Following this were potential probes such as, "Can you remember when your child was diagnosed with autism?" The sibling section has similar questions, but they involved the experience of being a sister or brother to someone with autism. Lastly, the family section included similar questions aimed at the experience of the entire family. An example is, "Can you share with me what has been your experience as a family living with a child who has autism?" Because it is an unstructured interview the questions were used as a support to encourage dialogue **(**see Appendix M for Individual and Family Unstructured Interview).

3. **Autism Functional Challenge Questionnaire.** This is composed of eight open-ended questions, which assess severity of autism by means of a functional assessment. It includes questions concerning the original diagnosis, related health conditions, communication patterns, autism-related behaviors, self-care, need for supervision, and school and functional challenges.

   The questionnaire was based on the International Classification of Functioning Disability and Health (ICF) model developed by the World Health Organization (Raghavendra, Bornman, Granlund & Björck-Åkesson, 2007; World Health Organization (WHO), 2001). The ICF model is a bio-psychosocial model, which merges the child's physical and psychological functioning, their activities, and their participation within the family and society. Using the ICF model for autism, for example, would include an assessment of the child's neurodevelopmental impairment with the child’s ability to communicate *and* their capacity to participate within their family.

Prior to this family research, there was an effort to develop a functional assessment tool for autism based on the ICF model, but it was not yet complete (Bölte et al., 2014). Consequently, I developed this concise questionnaire in collaboration with Michael Reiff, MD, LEND staff and medical director of the Autism Spectrum and Neurodevelopmental Disorders clinic at the U of M. It was used during the recruitment process to assess the level of severity of autism of children. Severity was based on level of functioning challenges instead of a symptoms-based approach as defined in the DSM-5 (see Appendix N – Autism Functional Questionnaire). Using the Autism Functional Challenge Questionnaire, autism severity for the children was confirmed in collaboration with Dr.Reiff.

4. **Family Lifeline.** A Lifeline is a visual method used to illustrate life’s events with a timeline that links events and may include words, dates, or pictures. This tool helps to facilitate conversations and assists in organizing the chronology of events.

The Family Lifeline was adapted from the Lifeline methods described by Gramling and Carr (2004). In a previous study, with Dr. Looman, I implemented the “Child Quality of Life Lifeline” and the Family Lifeline was based on the success of this model.

The Family Lifeline is a pictorial representation of a family’s experience. It consists of a piece of paper with a horizontal line across the bottom. On the left end of the line is noted “Birth” [of the child with autism] and the right side of the line is labeled, “Now” [present time]. Above the line it states, “Please draw a picture that describes your family life experiences from before the time your child with special needs was born to the present moment. You may draw high points and low points,

> use pictures or symbols, names and dates--anything that gives a picture of your family’s experiences” (See Appendix O, Family Lifeline).

Journal. I maintained an electronic journal of the events that occurred throughout this study. In this journal I included analytic memos and field notes.

Memos. First, in the journal, I wrote memos, which consisted of a chronological list of all the meetings I had with advisors and consultants and other related information. I also wrote analytic, methodological and personal memos about the research process, e.g., when analyzing data I noted how to organize and carefully decipher the data.

Field Notes. I also kept field notes or observations, which were recorded after each home visit. These were separated into objective observations (what I saw) and subjective observations (my impressions of the home visit).

Data Analysis

Due to the scope of this thesis and the large amount of data collected, **t**he unit of analysis for this study is limited to *the family*. The intent was to identify essential family themes based on individual family participant interviews. Coding was accomplished by first coding each individual interview and identifying intra-family themes (themes that occurred within each individual family). Next inter-family themes (themes that occurred among families) were identified. The inter-family themes are those that are reported in the context of this study.

Coding interviews. Van Manen’s interpretive methodology was followed for the analysis of this study. The first step of identifying thematic statements or categories was accomplished though a selective or highlighted approach. Each de-identified transcript was reread and codes were identified as sections were reviewed. Codes were documented using Word Review comment balloons so the codes were numerically tied to the transcripts. Noteworthy sections were highlighted. This provided an organized way to maintain, communicate, and link the codes to the actual comments in a de-identified fashion.

The next step, linguistic transformation, was to document a summary note below the code**.** An example of a code is, “CHALLENGES OF RAISING A CHILD: CONSTANT NATURE/STRESS.” The linguistic transformation below it reads: “An interesting concept: As most children mature the parents would have more time together, but here the child does not mature so their care is very time-consuming and protracted.” This expanded the codes into a larger context that fostered some of them to ultimately become essential themes.

This coding process was accomplished by grouping each interview into two coding levels. Level one included the actual coding and level two involved incorporating the codes within the fabric of the preexisting codes. To do this, each participant was given a code number which represented the family and letter which represented their role in the family e.g., A for mother, B for father etc. Lastly, the “C” identified the comment number. An example would be 7AC88, which represented the 7th family, the mother, and comment #88. A different color was assigned to each set of family codes so the family responses were easy to identify. Level two included incorporating new codes into the existing code structure or creating a new code if necessary in an iterative process.

The third step in van Manen’s approach is collaborative analysis in order to ensure consistency of coding results. Five de-identified interviews were selected and sent to my advisor. She in turn reviewed them and compared her coding results to mine; they were generally a match.

The last step of van Manen’s method is identifying essential themes. To do this, a two-step process was used. First the master code list was reviewed and intra-family themes were identified by color code. Often these intra-family themes were not self-evident, but when reviewed by color, intra-family themes emerged more clearly. The second step involved reviewing the intra-family themes and identifying inter-family themes, which became the essential themes that characterized the family’s experience.

Coding Family Lifelines. The Family Lifelines were coded in a similar fashion to the interviews, using the same color codes where applicable. Again, a two-step process was utilized. The first step included coding the written information on the Family Lifelines. For example if the family wrote “grieving” on the Life Line, I would add this to the participant’s individual codes. The second step included interpreting the “essence” of the Family Lifeline or how I interpreted the portrayal of family life. An example was one Family Lifeline with a lot of challenging events written on the Lifeline in very small print. There were so many notations, in fact, that a magnifying glass was needed to read it. For this, I not only coded the words on the Family Lifeline, but interpreted the busy picture with the code “Constant Stress.”

Quality and Rigor

Quality and rigor of research data are concepts used in qualitative research and refer to the trustworthiness of the study (Lincoln, Lynham, & Guba, 2011). Lincoln, Lynham and Guba present criteria for study authenticity, which include: positionality and intense self-reflectivity; appropriate representation by the community; polyvocality of text; and reciprocity of the research relationship.

Positionality refers to the need for the researcher to clearly define his or her ontological position because it affects the quality of interpretation of the data. My ontological position was defined previously. Representation of the community was achieved by finding participants of varied race and religions from clinics which serve both urban and rural families. Polyvocality, or representation from more than one voice, was accomplished by interviewing various family members.

Reciprocity of the research relationship involves maintaining a non-hierarchical relationship with the participant. I attempted to achieve this by relying on my experience as a pediatric nurse practitioner. Through this experience, I have learned the importance of respecting and seeking the input of family members versus relying on a hierarchical medical paradigm.

Additional work to assure quality included a 3-day pre-conference workshop, held in Canada in summer 2014, on qualitative analysis with Max van Manen, who developed this approach to phenomenology. I had the opportunity to consult with Dr. Van Manen on this project during the workshop.

Frequent meetings were held with the physician consultants as I progressed in my study to re-tool the assessment of severity. I also had several meetings with my thesis advisors to discuss and guide the actual collection of data, which helped maintain quality and rigor.

Becoming a LEND Fellow (Leadership Education in Neurodevelopmental Disorders) at the University of Minnesota from 2014 to 2105 also helped guide this study. This entailed a year-long intensive study of neurodevelopmental disorders through weekly meetings on research and presentations from experts in the Minneapolis community. Several clinical rotations provided the opportunity to observe families in clinic which included clinical evaluations of children with autism.

The pilot study to assess FQOL in children with autism, with the mothers of two children with moderate autism, noted earlier, helped develop and inform the process of building quality and rigor into this research. My collaborative process with my advisor during analysis of the data was also a way to ensure rigor and quality. She reviewed my coding process and findings and we came to consensus on the coding and the development of themes.

Chapter 4. Findings

Participant Demographics

Family interview summary. Data collection occurred from February to June 2015. Table 1 is a summary of the interviews that occurred with the 11 families and 22 individual family participants. This represented 29 separate individual interviews. There were 7 family-unit (group) interviews from 6 families (one family had 2 family interviews). In the majority of the families interviewed in this study (8 out of 11), more than one participant shared their stories. These interviews were conducted during 19 home visits. The primary care provider was asked to identify who they considered family; Table 1 documents that almost half (5 out of 11) identified people outside the immediate family (e.g., those who lived outside the home) as family.

Twenty-eight families originally expressed interest in participating in the study. Seventeen families did not participate for the following reasons: 10 did not meet the study criteria (8 had children with milder autism; 2 had children older than 13 years); 2 had children with autism who were hospitalized at the time of our conversation; and 5 decided not to participate in the study, citing lack of time to dedicate to the study.

Table 1

Summary of Family Interviews

Members Identified as Family	Family Members Interviewed	Number of Individual Interviews and Number of Family Interviews	Family Living Outside the Home	Number of Home Visits
Mother Friend MGM Aunt Son*	Mom Friend MGM Aunt	4 Individual Interviews 2 Family Interviews: • Mom + Friend • Mom, MGM + Aunt	MGM Aunt	3

Members Identified as Family	Family Members Interviewed	Number of Individual Interviews and Number of Family Interviews	Family Living Outside the Home	Number of Home Visits
Mother Father Daughter*	Mother Father	2 individual Interviews 1 Family interview: • Mom + Dad	None	2
Mother Father Son*	Mother	1 Individual Interview No Family Interview	None	1
Mother MGM Son*	Mother MGM	2 Individual Interviews 1 Family Interview: • Mother + MGM	MGM	2
Mother Father PGM PGF Son *	Mother Father PGM	3 Individual Interviews No family Interview	PGM PGF	3
Mother Father Son * Son Son	Mother	1 Individual Interview No Family Interviews	None	1
Mother Father Daughter * Daughter * Friend Friend	Mother Father	2 individual Interviews 1 Family Interview: • Mother + Father	Friend Friend	2
Mother Daughter #1 Daughter #2 Son*	Mother Daughter #1	2 Individual Interviews 1 Family Interview: • Mother + Daughter	None	1
Mother Father MGM MGF Son*	Mother MGM	2 Individual Interviews No Family Interviews	Father MGM MGF	2

Members Identified as Family	Family Members Interviewed	Number of Individual Interviews and Number of Family Interviews	Family Living Outside the Home	Number of Home Visits
Mother Father MGM Son*	Mother Father	2 Individual Interviews 1 family Interview: • Mother + Father	None	1
Mother Father Daughter Son*	Mother	1 Individual Interview No Family Interviews	None	1

* Denotes child with autism.

Demographics of the family. Table 2 illustrates the demographics of the 11 families that participated in the study. Most of the families included two parents, but 36% were either separated or divorced. The mother was the usual person identified as the primary care provider, but one family said that the care was shared equally by the mother and father, and one said it was shared equally by the mother and maternal grandmother, who lived in the home with the family. Most of the families had one child with autism, but one family had two children with severe autism; in most of the families, the child with autism was the only child.

Table 2

Demographic Characteristics of Family (N=11)

Variable	Frequency	Percentage
Current Relationship Status		
Married	7	64%
Separated or Divorced	4	36%
Primary Care Provider		
Mother	9	82%
Mother + Father	1	9%
Mother + Grandmother	1	9%
Children With Autism		
One child with autism	10	91%
Two children with autism	1	9%
Siblings in Family		
None	7	64%
Older	2	18%
Younger	2	18%

Demographics of individual family participants. Table 3 illustrates the characteristics of the 22 individual participants in this study. Only half of the participants were mothers; the other half consisted mostly of fathers and grandmothers, along with one sibling, an aunt, and a friend, which afforded a broad insight into the family experience when a child has severe autism. Most were females from 31 to 60 years of age. A majority identified as White European American, but almost one third considered themselves either African American, Asian, or of multi-racial background. There appeared to be a 50/50 split between practicing Christian participants and half non-practicing, no affiliation, or agnostic participants. Most participants had either a two- or four-year college degree.

Table 3

Demographic Characteristics of Individual Family Participants (N=22)

Variable	Frequency	%
Relationship to Child**		
Mothers	11	50%
Fathers	4	18%
Grandmothers	4	18%
Aunt	1	4%
Friend	1	4%
Sibling	1	4%
Gender		
Male	4	18%
Female	18	82%
Age Range		
20–30	2	9%
31–40	7	32%
41–50	7	32%
51–60	2	9%
61–75	4	18%
Race		
White European American	15	68%
African American	3	14%
Southeast Asian	1	4%
Multi-Racial	3	14%
Religion		
Practicing Christian	12	54%
Non-Practicing Christian	5	23%
No Affiliation	3	14%
Agnostic	2	9%
Highest Level of Education		
High School Degree	3	14%
One–Two Years of College	8	36%
Four Year College	7	32%
Graduate Degree	4	18%
Occupation**		
At Home Care Provider	7	32%
Business	4	18%
Health Care	3	14%
Services/Sales	2	9%
Retired	4	18%
Education	1	5%
Student	1	5%

****** Percentage may not equal 100 due to rounding to nearest integer

Demographics of child with autism. Table 4 illustrates the demographic information of the children with severe autism. The demographic information about these children was predominantly elicited from the mother through a combination of the Autism Functional Challenge Questionnaire and the demographic questionnaire. The mean age of the child with autism was 8 years, mean age at diagnosis approximately 2 years, and time since diagnosis was a mean of 5 years. Few had concurrent conditions besides speech and language delay, which was one of the study criteria defining more severe autism. Formal autism testing was complicated and often not completed by the majority of the children due to the child's limited verbal skills and/or lack of cooperation. None of the children had reciprocal or conversational skills (give-and-take conversation) and most had no to a few words in their vocabulary. All required 24-hour supervision and many were not fully toilet trained or could not dress them-self fully. All could feed themselves, but had other significant functional challenges.

Table 4

Demographic Characteristics of Child With Severe Autism (N=12)

Variable	Frequency	%
Gender		
Male	9	75%
Female	3	25%
Age Range (Mean 8 years)		
4-5	3	25%
6-7	5	41%
8-9	0	0
10-11	2	17%
12-13	2	17%
Age at Diagnosis (Mean 2.25 years)		
<1 Year	0	0
1-2 Years	8	67%
3-4 Years	4	33%
Time Since Diagnosis (Mean 5 years)**		
2-4 Years	4	33%
5-7 Years	5	43%
8-10 Years	3	25%
Conditions in Addition to Autism*		
Speech/Language Delay	12	

Variable	Frequency	%
Developmental Delay	7	
Anatomic Neurologic Condition	1	
Eczema	1	
High Intelligence	1	
IQ and/or Autism Testing Reported by Parent		
Testing, Not Aware of Type and Result	3	25%
Testing, Aware of Type and Result	1	8%
Testing Not Completed Due to Child's Limited Verbal Skills	8	67%
Verbal Communication		
No Words	2	47%
Few Words, No Sentences	8	66%
Very Limited Sentences	2	47%
Activities of Daily Living*		
Requires 24-hour Supervision	12	
Cannot Completely Dress Self	7	
Not Fully Toilet Trained	5	
Type of School Attending		
Autism School	5	42%
Public School With Services	6	50%
Home School	1	8%
Health Care Related Services Received*		
ABA or Behavior Therapy	9	
Occupational Therapy	9	
Speech Therapy	8	
Physical Therapy	2	

* Total does not equal 12 due to multiple listings

** Percentage may not equal 100 due to rounding to nearest integer

Thematic Results

Overall themes and subthemes. The aim or purpose of this research was to interpret the meaning of the lived experience of families who live with a child who has severe autism. In this study six main essential themes with several subthemes were identified among the families, and are summarized in Table 5. These themes were identified by reviewing and coding both the interviews and the Family Lifelines. The Family Lifelines will be discussed separately following the main discussion of the Essential Themes. In order to maintain anonymity, each family participant is referred to by family code and comment number.

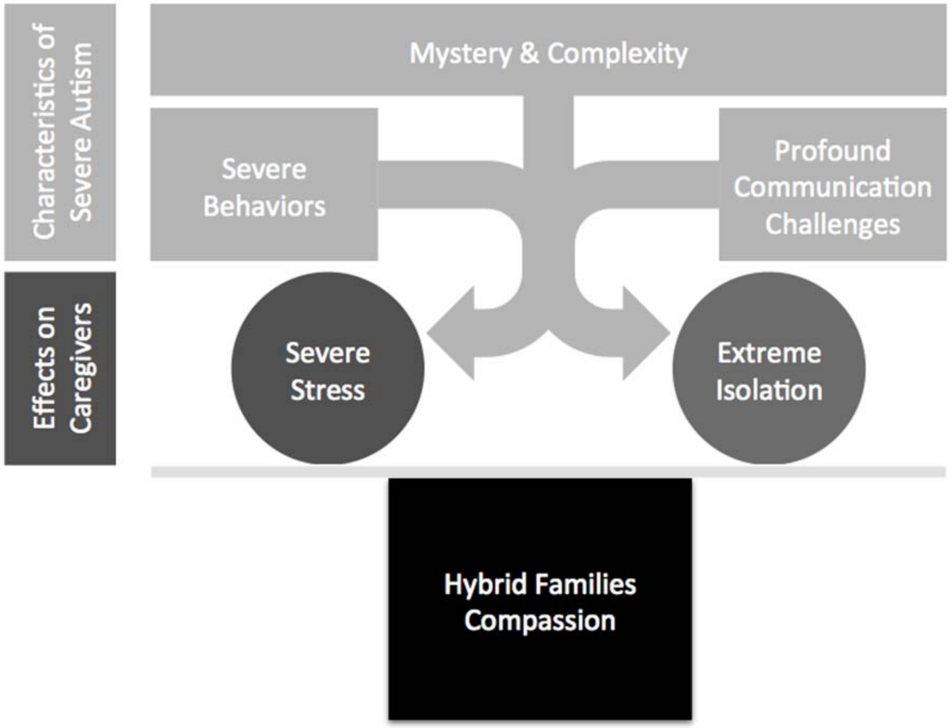
Table 5

Essential Themes and Subthemes

Essential Themes	Subthemes
Mystery and Complexity of Severe Autism	Stereotype and Stigma • Autism Is Considered a Mild Disorder • Invisibility of Autism • Constantly Teaching Others Unpredictability of Behaviors and Communication Diagnosis Challenges • Unknown Etiology • Testing Delay • Testing Challenges
Dealing With Severe Behavior Challenges	Child Size Specific Behaviors • Meltdowns • Repetitive Behaviors and Strict Routine • Sleep Issues • Elopement • Destruction and Altered Home Environment Aggression to Others • Family Members + Those Outside of Family Self-Injurious Behaviors
Dealing With Significant Communication Challenges	Communication Patterns Solitary or Parallel Play What Is Child Thinking? Altered Connection • Verbal Connection • Nonverbal Connection • Delayed Connection
Experiencing Severe Stress	Constant Nature of Stress Roller Coaster Experience Child's Delayed Development Teaching Activities of Daily Living Coordinating Services Cost Concern for Child's Future
Living With Severe Isolation	Friends • Obstacles to Meeting With Friends • Friends Without Children With Autism • Friends With Children With Milder Autism School • Lack of Inclusion + Low Expectations • Confrontations Public

Essential Themes	Subthemes
	Medical Health Care Providers
A Strong Dependence on Family	Hybrid Families: Nuclear, Extended Family and Friends Compassion • For the Child + For Each Other • Increase Over Time

Figure 1. Essential Themes



Essential Themes

Experiencing the mystery and complexity of severe autism. The first essential theme identified through this research was that families of the children with severe autism experienced autism as a mysterious and complex disability.

In reference to this, one grandmother said: “The mystery that autism poses, there’s a real element of mystery, of unknown. I believe that’s intriguing for us as human beings, the unknown. For autism …I’ve seen how broad the spectrum is, and in some ways heartbreakingly so”

(7DC11). Another grandmother prominently displayed on her Family Lifeline the words: "UNSOLVED MYSTERIES" (43BLL46). This is illustrated in the Family Lifeline #43 (See Appendix P**)**

The mystery and complexity of severe autism involved many aspects including the stereotypes and stigmas that the families experienced associated with the condition and the unpredictable nature of autism. Families also discussed the challenges they faced with simply trying to obtain a diagnosis for their child's serious condition.

Stereotype/stigma. There was a general consensus among the families that there are stereotypes or widely held beliefs about autism and the families experienced a stigma or feeling of disgrace associated with the label of autism.

Autism is considered a mild disorder. Many families found that there is a stereotype that autism is a mild condition. This was probably due to the fact that a form of autism, previously called Asperger's syndrome, is better known and more interesting to the public. Individuals with Asperger's (now considered on the mild end of the autism spectrum) are typically higher functioning and may have above average intelligence (APA, 2013). The stereotype of autism as a mild condition has been perpetuated in popular movies such as *The Rain Man* or *Temple Grandin.* In these movies, the protagonists have high functioning autism and are extremely intelligent.

For the families in this study, the majority of the children had developmental and speech delays and all had extremely limited communication. The families therefore found that their experience living with severe autism was very different than the depiction in the movies.

This is eloquently portrayed by one family member who wrote on her Family Lifeline:

> My view of what autism looks like started to change completely. It's not *Temple Grandin & Rain Man*. They can use a toilet and express themselves and earn respect from huge groups of people…they're not the face of autism. Not in my life. Autism is much more painful and degrading and trying and frustrating. Autism isn't genius, it's not "different ability." It hurts. (41BLLC51)

Another mother echoed this sentiment. Here she reflects back on the issue that her child is not like those with autism portrayed on the movie screen, but just a regular child with some regular needs. She said:

> TV has created this unrealistic, weird expectation of kids that are autistic… I'm like, 'He has autism; he's not magic.' …I get this question all the time: 'What's his special thing?' And I'm like,' What do you mean?' Because they saw *Rain Man,* and they think everybody's a savant…Or they saw *Touch* …and that was worse, because that kid was like super, super low-function on some things, but then was so smart and mystical on all these other things. I'm like, 'He's a 7-year-old. All he does is bug me for popsicles and cookies.' (43AC12+13)

Some parents reflected that they themselves had a stereotype about autism as a milder condition only to realize that their child who had severe autism had many more significant challenges. This father shared:

> You see movies like *Rain Man* and you think, 'Well, they're just really different, but they're still cool, and they're still fun, and they are still neat and lovable individuals.' But they certainly come with their share of heartbreak….
>
> I didn't understand that there were all these intimidating behavioral -- these really drastic behavioral challenges. It's not that they're physically handicapped that much; it's just that they're not going to learn like any other kid does, and you're going to have to make some lifestyle changes or else it's going to be pretty ugly. (39BC2 + 6)

Invisibility. The stereotype and stigma surrounding severe autism is also related to the invisible nature of the condition. Autism is not a physical disability, but generally is an invisible one. There is a stereotype or widely held belief by the public, however, that disabilities are physical or visible, and therefore autism is simply misunderstood.

Families discussed that the public cannot understand that their child's behavior could be related to a severe disability and so the child's behaviors such as tantrums, "meltdowns" or tantrums, crying, etc., are interpreted as lack of parental control and "bad parenting." Because of this, the families experienced a sense of stigma or disgrace. One family member discussed her frustration in this regard. She said:

> The frustrating thing about autism is that it's invisible, so I've heard more than once, 'Well, he doesn't look like he's disabled.' Would you like me to show you

> his certificate of disability? Or what can I do to prove it to you? He's really cute; he's really a charming little guy. He waves; he does stuff that, on the outside, seems like it's not so bad. I've heard people say before, 'Well, he doesn't seem like he's so bad.' Well, no, but you can come stay with us for a week if you'd like. It's a testament to his therapy [behavior therapy] that he doesn't seem so bad in public anymore. We still have meltdowns and really challenging times. He was getting nosebleeds in the winter because the air was so dry, and suddenly his whole face would be covered with blood, and he'd be smearing it everywhere. (41BC31+32)

This family also noted the difference in public opinion when the same child appeared in a department store in a wheelchair. The mother sometimes used a wheelchair to help contain him when they shopped and found, "People seem to be nicer to him when he's in a wheelchair, because it's like the wheelchair carries the connotation of disability" (41BC36).

Several families echoed the concern that they felt stigmatized and ostracized by others because of their child's autism-associated behaviors. One father made the analogy between a person with a heart attack and a person with autism to illustrate the issue. He said:

> So if someone's having a heart attack, people aren't ignorant about it, [they think] there's a heart attack happening, what can I do to help out?... They're not ignorant of the fact that this person's in distress, but ignorance about the spectrum disorder thing is a serious issue. That's what we deal with a lot, is that ignorance, because if [the child with autism is] struggling, since they're ignorant of it, all they do, or at least the rude ones, is treat it like you've got an unruly kid that you're not trying to manage. (10AC27)

Similar situations resulted in isolation for many families, which will be discussed further in this text.

Constantly teaching others. Because of the invisible nature of autism, families needed to continuously explain that the child had autism. The families described the constant effort to educate others about autism that added to the fatigue and stigma they already were experiencing. A few parents stated that they felt uncomfortable "making excuses for their child" and pointing out the child's shortcomings which they didn't want their child to hear. This is a comment from a family member describing her frustration in generally needing to educate the public about the child's severe autism:

> I guess the thing that really stings …when people, like cashiers, would try to talk to him, and you have to explain, ‘He doesn’t talk. He doesn’t actually know what you’re saying; he doesn’t really have any concept of language,’ and it feels like it’s become your duty to give everyone a crash course in autism, and that’s exhausting. It’s really not easy to have to – it’s like he gets re-diagnosed every time, because you have to explain. Sometimes you end up telling the statistics, and ‘Yes, he’ll have this for his whole life.’ (41BC33)

Unpredictability. Adding to the mystery and complexity of severe autism, families described the unpredictable nature of severe autism both on a day-to-day basis and throughout the child’s lifespan. They often voiced frustration that they could not predict what made their child have a good day or a difficult day. One mother summarized this when describing the unpredictable nature of her son’s day-to-day behavior. She said:

> Yeah, like yesterday was an amazing day. [Son] was so awesome all day. He was a rock star. He was a total rock star! Like yes, what did we do right today? How is this different? But there’s really no rhyme or reason, actually, that I can figure out. If I could figure it out, then I don’t think we could be having issues. (36AC116)

In reference to the unpredictable nature throughout the lifespan, many families discussed how autism, specifically the ability to talk, changed suddenly, usually when the child was about 2 years old. This is actually a hallmark of autism, that a child will have acquired an ability to talk and then suddenly there is a change in communication. Perhaps, however, in severe autism this change seems more abrupt because the change is from speaking to often not speaking at all, while in milder forms of autism the child generally retains some verbal ability.

A grandmother described her grandson’s experience at about 2 years old. She said:

> As time went on, one day he was talking, and he was saying 'juice' – it was along that line – and I remember his dad saying, 'He said "juice" last night.' And the next day, he never talked again. (43BC3)

Other families shared similar experiences where the child seemed to be communicating, smiling, even writing simple cards, then suddenly seemed to lose these skills.

Some families described how the children seemed to gain skills and lose them at random as they grew older. This added to the family’s frustration. A mother shared:

> No, he's always said a few things and that's about it, but that's just one area. He's [his progress is] very, very spiky, and I think this is common with kids with autism, although I have no scientific basis for this. This is probably the reason the divorce rates are so high, too, in all the stress that goes with it. You can see a skill become learned and you think, 'good.' Most people take that and run with it. They now have that skill. With autism is seems to be you can gain a skill and then you lose the skill. It varies so much, even with his behaviors and things like that…. It's never consistent. (34A57)

This left the families uncertain of the child's future. One mother even said (as she wept) that she would even prefer that her child had a more predicable condition like cancer because at least then she would have a better idea of what the child's future might hold (38C64).

Diagnostic challenges. Many families described the specific challenging experiences they faced when the child was diagnosed.

Etiology. The lack of knowledge concerning the etiology of autism was frequently discussed by the families of children with severe autism and added to the mystery and complexity of the disability. Families had a plethora of ideas concerning what may have caused autism. Some proposed that there was a genetic component and recalled relatives that they believed also had autism. Other family members thought autism might be caused by a particular food such as Kraft cheese, chemicals in food, pollution, or tainted water. There were a few families that attributed the etiology to MMR shots and recalled that their children had lost interest in toys or stopped speaking soon after the shot was administered. Interestingly, the families knew that the research refuted a causal link between vaccinations such as MMR and autism, yet because there was such a stark change from before and after the MMR, families found the study findings hard to believe.

Most families, however, concurred that the etiology was unknown, but they still wondered specifically if they themselves had any culpability in the child acquiring the condition. Here is an example of a mother discussing her frustration in not knowing what caused her son's autism and her concern that she might have some role in his acquiring severe autism. She said:

> I feel bad for [son] because as a child he's had to endure so much, and I feel that sometimes I'm seeking answers as to what caused the autism, and I'm frustrated with the fact – I feel like not enough research is done to kind of figure out what's

> causing autism. I know, perhaps, it can't help me with [son]. Ideally, I would like a cure for autism, which doesn't exist today, but I just feel like they should be doing more to find out what's causing autism and like why aren't people coming to [child's autism school] and asking parents to give information, like what is it that's common amongst all the parents that can help maybe say, 'Okay, we think it might be this,' and I don't know what that 'this' is. Is it because I ate too much chicken and not enough beef? Is it because of my age? …. I try to look for those commonalities, and it doesn't exist. There are couples that are young that have it. There are couples where one child isn't and one child is. There are couples where it's a girl sometimes and not the boy, and there's a boy and a girl. There are couples where both are [both the same ethnicity]. So there's no commonality, and it just drives me crazy. (44AC58)

One family discussed that they thought there could be a more esoteric cause to autism. This family espoused the use of naturopathy including a variety of herbs or oils, and also the testing of a variety of items that might be potentially caustic for the child such as tin and sugar. They also employed extensive dietary restrictions, a naturopathic doctor, a chiropractor, and discussed the possibility of using a naturopathic dentist to remove teeth amalgams (Family #45). Most of the families, however, had tried a variety of dietary and naturopathic interventions and shared that sometimes they would "try anything" if they thought it would make a difference.

Testing delay. For most of the families, there was often a long delay between from time the family realized their child might have an "issue" to the time when the child was formally diagnosed with autism. Many children were actually first identified as having developmental issues by an early preschool program like Early Childhood Family Education (ECFE) and because the possibility was raised, the family then sought formal autism testing.

Unfortunately there was often a long lag time from the time the children were identified as possibly having autism to the formal testing. This was due in part to limited supply of testing centers in both rural and urban areas. In this study, the families reported that they waited anywhere from 6 months to over a year to obtain autism testing for their child. One mother informed me that there was an average 8-month wait time in Minneapolis before a child could obtain autism testing. Her response was: "You need to know, Governor Dayton, that we need help here. There's a waiting list! Kids should be able to get diagnosed earlier, whether it be [a large local autism center] or [a large local autism clinic] or wherever" (16C145).

Another mother commented that there was a double standard in autism with respect to autism services. If someone had another medical condition they would not have to wait so long for testing. The mother remarked: "This is not acceptable. If you were told, 'I think you have cancer,' they're not going to tell you, 'Well, we'll get you a diagnosis in the next 6 months!'" (41AC44)

Some families shared that when they told their primary care provider that they were concerned about their child's development they were encouraged not to worry and that their child was, "Just a boy." Here one mother discusses her experience in trying to secure autism testing for her child. You can sense her uncertainty as she thinks something is wrong, and even that he may have autism, but she was told not to worry. She said:

> We felt like something was just different, but the doctor was like, 'Oh, he's a boy and he's the first child, so he's probably just behind.' I called, and they went, 'Why do you want to make an appointment?' I'm like, 'I don't know. I think my kid has autism.' I'm like, 'Is that weird? I don't know.' But I don't know what else you're supposed to do, if you had to get referred to anywhere. And he helped, but all he did was refer us to like a developmental pediatrician, which took me almost a year to get into. (38C7)

For those who lived in more rural areas, there appeared to be even more challenges to obtain an autism diagnosis. Two families actually moved closer to urban centers to be near an autism center. Another mother described her journey in trying to obtain a diagnosis, but she lived in a very rural area with few formal autism supports. Finally she used the computer to research the symptoms that she saw in her son and diagnosed her child with autism herself. She said:

> I just backed up my cursor again, and typed in '18-month-old flapping arms,' and the first thing I saw was this YouTube video that said '18-month-old flapping arms before autism diagnosis.' I'm going to cry; this story is hard to tell. So there's this little, tiny, adorable Italian boy with huge dark eyes, and the video wasn't in English; it was just him running around on his deck, you know, and his idiosyncratic movements were [my son]. And I'd never seen a kid doing any of that stuff that [son] was doing, ever. I had never seen the twirling string, the flapping arms. [crying] (41AC10)

Whatever the reason for delay in testing, the time lag left the families worried about the potential diagnosis. There was an added concern that if they did not obtain the proper diagnosis and treatment in a timely manner, the child would suffer additional harm from the lack of early intervention.

Testing challenges. Once the family was able to procure an evaluation for autism, the actual testing was often impossible to complete because the children with severe autism were often nonverbal and/or uncooperative. This challenge was echoed by several parents and in fact, the majority of the children in this study could not successfully participate in formal autism testing. A mother shared her experience in this regard. She said:

> And then there was another school psychologist that did another IQ test and said, 'I can't give you a number because this test is not set up for nonverbal kids, first of all,' and he said there were areas where he was really good and areas where he was not, so he could not get any kind of a reading on that. My feeling on it is that [son] is actually very bright, but he has a lot of these other things that interfere with his ability to communicate that, plus he will go out of his way to be obstinate. (34AC9)

Dealing with severe behavior challenges. The second theme that was identified in this research was families coping with the severe behavior challenges that the child with autism manifested. Many of these behaviors were stark and startling, but the families often discussed them in a matter-of-fact manner, probably because the behaviors had become so commonplace. Sometimes, however, the families would cry when they reflected on the more challenging behaviors. What is presented here is a fraction of the many examples of behavioral challenges that the families shared. Many behaviors crossed over; for example many meltdowns included self-injurious behaviors and/or aggression towards others.

Child size. Several families commented that the child's behaviors were concerning them because as the child got older, the child also got bigger and more difficult to manage. Many had been hurt by the child and they worried that this would increase as the child became stronger. The families voiced their concern about the child's size even with some children who were prepubescent and not very heavy, which probably indicated that the child's behaviors were also very severe.

One grandmother commented on her grandson: "He'll hurt you. He'll hurt you, baby. I love that he's big. The boy's big" (7DC6). This indicated that although she loved him she also recognized that he was potentially a threat to others.

A mother of one of the older children also noted the challenges of finding help because of a combination of her son's size and severe behaviors. She said:

> Nobody else wanted to take [son] on because he was problematic, especially size-wise, and sometimes volatility-wise. And then his occupational therapist was a tiny little woman, and she just felt afraid of [son] physically…. so we couldn't find anybody else that would be appropriate that was interested in doing that [providing occupational therapy], so all he gets for services now are through school. (34AC13)

Specific behaviors.

Meltdowns. Almost all of the families mentioned "meltdowns" or tantrums as the most common behavior their child with autism exhibited. These were often very extreme in which the child would cause self-harm (e.g., head banging, hitting self) and/or would harm others (e.g., scratching, kicking, biting, throwing items). Sometimes families attributed the meltdowns to the child not being able to express thoughts and needs verbally. Here a mother describes a typical tantrum. She said:

> When he's having one of his major tantrums, he will get put into his room and he will freak out in there for however long it takes. We can't even let him out early because he will just attack us, so we have to put him back in his room…. Oh yeah, hitting, grabbing, pushing. But when he's in his room he will become self-injurious, too. He'll bite his arms. (36AC56+ 57)

Several families described that their child would punch holes in the walls, use their heads to make holes, or throw toys that would dent the walls during a meltdown. Here a mother noted: "He was really bad with the meltdowns, like shaking, screaming, laying on the floor. Like all these walls, even now. When he was little, he was not so badly destroying, but those holes in my door, that's him!" (38C11). This was an interesting revelation and indeed there were several holes and dents that covered the walls caused by the children in many of the homes I visited.

Families worked tirelessly to try to socialize the child using ABA therapy or other positive behavioral modification so that they might successfully visit stores or other public spaces without the child having a meltdown. Here a mother described that it took years of hard work just to be able to visit a store successfully. She said:

> We've done a lot on our end to teach [the child] about these different things… 'You really need to stay close to Mom', and then I've tried to make a game out of it, like, 'You're going to have to get these different items on your list', or whatever it is that tries to keep her focus off of what can be just assaulting--lights, and people, and things like that. It has gotten better over time…. I don't have the fear that I once had, but we've also worked for years, honestly years, on doing that and not being afraid to go [to the store]. (10AC30)

Repetitive behaviors + strict routine. Many of the families described behaviors that the child performed that were repetitive, and that many also liked to follow a strict routine, e.g., lining up toys or needing to follow only one route home from school. The repetitive behaviors are also called self-simulating behaviors or "stimming." It is believed that the children do this either to increase their sensory stimulation or to calm themselves. Whatever the reason, the behaviors were varied and often unusual.

Some examples included twirling ribbons repeatedly like a rhythmic gymnast, flapping arms, watching the same video or commercial repetitively and reciting the text, twirling themselves incessantly in circles, or "scripting" which is verbally repeating something over and over that was heard or seen, such as a commercial or film trailer.

An example of "stimming" behavior was discussed by one mother. She noted:

> He likes to do a lot of horse playing, his idea of play. I don't know if he's seeking stimulation, but if he's sitting on my lap, he wants to poke his face into my chin. It's really…. A hard bone fetish. The longest time as a kid, as he was drinking milk, he'd play with the [my] elbow. (44AC24)

Another mother discussed her child’s repeated crying, which is another example of “stimming” behavior. She said that the constant crying affected her sleep dramatically:

> It just sounded so distressed. It had a very unusual sound to it, and it literally – and I’ve read studies about this, and I think this is amazing-- women actually do have some kind of primitive stress response to newborns crying so that they will care for them; it’s like a survival kind of thing. So, that stress response was turned on all the time in me. I couldn’t sleep through the night. (41AC68)

Two other mothers described that their child liked to be “squished” repeatedly by a person sitting on top of the child when the child was lying beneath a sofa cushion. This seemed to provide a calm sensory stimulation to the children, perhaps not so dissimilar to the “cattle calming machine” that was portrayed in the book and movie *Temple Grandin*.

Many families discussed their child’s need for strict behavioral routine or schedule. In reference to the need to follow a schedule, a mother noted how rigid their schedule is due to the child’s insistence on structure. Unfortunately this left little space for spontaneity for family events. She said:

> With [child], it's very rigid, very rigid, with schedule. With change, things like that, it's really difficult. Leaving a place when [the child] doesn't want to go, getting communication across, it has to be very structured. Independent play, it has to be structured or nonexistent. Engaging, eating – it pervades every aspect. It's way beyond language. It's everything. (39A25)

Sleep issues. The majority of the families discussed that their children had difficulty sleeping and this of course had ramifications on the family’s sleep pattern. This was very significant because it sometimes started at birth and was very severe, leaving the parents virtually without sleep. Families described the challenges of the child sleeping for short chunks of time then being awake most of the night. The parent needed to stay awake and alert when the child was awake to be sure that the child did not runaway or become unsafe. During the time the child is awake many described the child “scripting,” or repeating something they head over and over without cessation; this could cause families to lose patience.

It seemed that the children who suffered from sleep issues since birth were the children with more severe challenges. For example, one of these families noted that before the child was the age of 4 or 5 the mom was “a zombie” due to the lack of sleep (39CC32) and they had a “rocky marriage battling sleeplessness” (39ALL94). In another family, they noted that the family didn’t sleep for 4 years after the child was born (41BLL48).

To illustrate the severe effect on the family, this mother shared this family experience about life after her child with severe autism was born:

> It was really hard. I ate candy bars, I drank coffee in the middle of the night, and then sometimes he would surprise me and fall asleep, and since I’d had coffee, I’d have to take Nyquil to try to get to sleep so I could be sleeping when he was sleeping. The synergistic effects of Nyquil, coffee, Nyquil, coffee could not have been good for my body. I was just exhausted all the time. (41AC28)

As noted, this often had a significant effect on the parental relationship. Several parents said that the lack of sleep was affecting the parents’ friendships and their ability to have the energy to parent effectively. This mother describes how she and her husband are presently struggling with the child’s lack of sleep. She said:

> I think that [husband] and I need some counseling with a counselor just to talk about it; our emotions are raw, we feel stress all the time. I feel, as a family dynamic, we’re snapping at each other because we’re dealing with these challenges. An ordinary person looking in, I’m snapping at my [family member] or snapping at [husband], or [husband] snapping at me, and I think it’s all the stress from not sleeping. It stems primarily from not sleeping because [child with autism] doesn’t sleep well too. (44AC47)

Elopement. Families needed to be ever vigilant because the children often ran away or attempted to elope. Many families described the experience of barricading their home like a fortress so the child would not escape, including bars on all windows, multiple locks on doors, and sometimes alarms or chimes on doors. The families often felt more safe at home rather than outside the home because they were more familiar with the safety features in their home environment. This had ramifications as families often chose to stay home, leading in turn to family isolation.

There was a constant fear shared among families that the children would escape and each family could usually recount a time when the child had escaped. One mother described a time when her child ran away. She said:

> He used to be the classic elopement child who would just take off…. One time he was at a neighbor's way back there. The one time that was quite scary…that frontage road. Somebody picked him up out there. (34AC29 + 34AC30)

Several mothers had tried to place an emergency identification bracelet on their child so the child could be identified if he did elope, but the child would not wear the bracelet because of sensory issues. One mother also suggested that emergency responders should identify which children in the neighborhood had autism so they could be traced more easily if they did escape.

Many of the families, because they needed to watch their child so vigilantly, felt envy watching parents of neuro-typical children with a more lassiez-fair attitude towards childcare. Here a mother comments on watching other people parent their children. She said:

> When I see kids out playing by themselves, I'm just like, 'Oh my God, what is that like?' I'm like, I would never let him just play--I barely let him play in the back yard by himself long enough for me to come in and go to the bathroom and come back outside. I'm just to that point now, because I'm so worried he's going to climb the fence and decide to go to the park on his own or something's going to happen and he's not going to come back. I freak about that. That's why our house is still Fort Knox, so I can sleep and not be so freaked out. Because he used to take off running. (43AC96)

Destruction and altered home environment. Several family members described that the child liked to break/destroy items at home that required the family to alter their home environment so items would not be damaged. The destruction was rather pervasive and it took different forms. Families described food thrown at walls; knocking holes in the walls with a fist, head, or a toy; books being torn apart; and lamps and light bulbs being disassembled.

One mother shared an example of some of her son's destructive behaviors. The mother said:

> He just obsesses about an entire roll of toilet paper and he'll unroll the whole thing and put it in the toilet, does not use it appropriately in any way. He'll just unroll a whole thing…. He likes to stick things in the drain. He used to flush

> things down the toilet. So once we get past one, there will be something else that'll pop up…. He has a tendency to eat toothpaste…. to the point where he's eaten it and then gone into his room and thrown it all up, that sort of thing. So we hide that [toothpaste], too. (34AC24 + 25)

Several families described altering their home, e.g., leaving less items out so there would be less destruction. One mother said: "I would love to have cool lights and knickknacks. I love that stuff, but to be able to have it. I can't have it" (39A59). Another mother commented: "Yeah, and you have to realize, don't have anything expensive or of tremendous sentimental value that you can't replace, because you're going to have to lose it!" (34AC33). For some it was a loss, but for others it provided an opportunity to simplify and focus their life on what they felt was important to them, like the family. These families often joked that their decorating esthetic was "minimalist."

Aggression towards others. The behavioral challenges of several of the children with severe autism involved aggression towards others. This included aggression to immediate family, extended family, and those outside of the family.

For many families the aggressive behavior was so frequent that they clearly accepted it as a way of life. The mother below describes her son attacking the father on a recent plane trip. She said:

> He grabs us. He grinds his chin really hard into us. I don't currently have any bruises from him. He hits and kicks. He's bit us before. He just mainly grabs really hard, just kind of pinches. He gets physically aggressive with us…. For instance, [dad] just took him to go see [relatives]… and on the way home in the airport and on the plane he was attacking [dad] the whole time. [Dad] comes home and he's got scratches down his face and a bloody nose, bruises all over his neck, he's bitten up, because [son] was freaking out on him. Yeah, so that's really hard. (36AC51 +52)
>
> Another mother described common aggression from her son. She said:
>
> Oh, yeah, he'll sit on my head or he'll kick my head if I'm sleeping and he wants me to get up right now. Oh, yeah, he'll go 'Mom, get up,' and if I don't within five seconds, it's *whap* [italics added]. Or he'll sit on my head just to try to get me up, because he wants breakfast. (16C49)

One family discussed a sibling being attacked while the family was driving. Additionally this child would throw the car into park while the family was driving on the highway, so she needed to be restrained. One mother described receiving a black eye because her son threw a toy at her face.

The families also discussed extended family members, such as cousins being hit, or grandparents being hurt by the child. Here a grandmother describes her experience with the child. She said: "When he gets mad now, primarily…well, before the [medication] he would pinch me or anybody else, all the way up and down. Then the other thing that he would do is head-butt you, and it was very hard" (34BC36). Head-butting involves the child using his head to hit someone, usually hitting someone else in the chin or head, and can have significant results, such as breaking a person's nose.

Many families discussed the challenges of having a child who sometimes manifested aggression to people in public. This resulted in the family being ever watchful of the child and fearful that he or she might attack someone. Many families cited examples of the child hurting others in stores or people at school. The result was that the families often avoided going into public places with the child because the families were worried the child would attack someone.

Sometimes there were minor offenses, such as, a very young boy who liked to touch the sequins on the seat of women's jeans. But there was also significant physical aggression to others. One mother described that she needed to retrieve her child from school because the child head-butted the teacher. She said: "I picked her up in the morning 1 hour after I dropped her off because now we had to go to the hospital, because she had broken her [the teacher's] nose. (39AC27)

This resulted in isolation, which will be discussed further as an essential theme. Here the same mother described the challenge of venturing outside into public spaces with her child because she was concerned about aggression. She said:

> I'm on call 24/7…. I'm pretty much homebound…. If I can get her to Target, Target is usually her happy place, we can go there and buy some food, but even then it feels a little dangerous, because I don't know if she's going to attack somebody in the checkout line. I feel like I'm on eggshells, so we sort of walk close to the checkout line to see if the lines are short. (39AC45+ 46)

Some families described a progression that involved the child hurting him or her self, then harming others. This mother recalls her child progression in this way. She said:

> He was doing a lot more acting out, violent, aggressive behavior to other people. It used to be more he'd just bite his finger or he'd hit his own head. That was fine, but then he started to put it out to other people. Then I was getting worried about taking him out in public at all because I was afraid he could grab somebody else. If he feels in the mood, he just does it. There's no shutting off that switch until he's done. (34AC38)

Self-injurious behavior. There were several types of severe self-injurious behaviors in addition to the head banging that was mentioned previously. Examples included, but were not limited to: picking at skin, punching him or herself in the head or chin, and tying a blanket very tightly around the wrist. The families again described these behaviors in a matter-of-fact manner, but they would occasionally comment that it was painful for them because they felt that they could not protect the child from injury. Here one mother recalls the first few years of her son's life and his self-injurious behaviors. She said:

> It really was, seriously, the hardest thing that I have ever lived through, and it just seemed like it went on and on…. He just screamed and cried all the time, would throw himself into furniture and acted like he couldn't stand to be inside his own body-- like actually just so clearly uncomfortable. (41AC65)

Another mother described her experience watching her child hurt himself. You can sense her sadness when she recounts this story. She said:

> I think that's the nervous tic…When he gets frustrated, maybe he's over-tired or he can't communicate that something's hurting; he tends to take it out on his skin, mostly on his hands; you'll notice on his fingers. When I think about just getting a paper cut and how much it hurts, look at his hands and all the bruises he's got on his hands because he's given himself that…. he'll rub it [his cuts] on a very rough carpet. (44AC63)

Dealing with significant communication challenges. Dealing with significant communication challenges was the third theme that was identified among the families of children with severe autism. Since autism is characterized by limited communication, it is not surprising that all the children had limited capacity, but in severe autism, the majority of the children had such severe communication challenges that carrying on a conversation was simply not possible. This led families to constantly wonder about the thoughts and needs of the child. In addition, the fact that the children had such limited verbal communication was reflected in the family's emotional connection to the child.

Communication patterns. The children in this study varied slightly in their level of communication from each other, but all had significantly different communication than a neuro-typical child the same age.

A few did not use words at all and relied on assistive technology to communicate their needs. For example they might use an iPad and point to pictures. Two children used the Picture Exchange Communication System (PECS) in which the child pointed to photos that the family had placed in a scrapbook to help them communicate their needs.

A few could make very simple sentences. Most of the children in this study, however, could at best string a few words together to communicate. It is important to note that none of the children could carry on reciprocal give-and-take communication. When asked a question, the child would usually simply not respond.

To illustrate the type of communication used, a mother explained it clearly: "He'll say, 'More cracker,' 'More juice,' like two words, but for the most part he just grabs our hands and will try to show us. Or he'll say, 'More, more, more,' but a lot of the times you don't know what he wants" (16C16).

Sometimes the children just repeated what they heard, known as "echolalia." Someone might say, "Would you like toast?" and the child would repeat, "Like toast." This echolalic speech was often used by the child to repeat parts of commercials or film trailers, and though it would sometimes seem like the child was carrying on a conversation, it was actually a "script" or monologue. Families referred to this as "scripting." Most of the families tried to steer the children away from this type of communication and instead engage them in dialogue by using positive behavioral therapy approaches such as ABA. But overall the children could not have back-and-forth communication with their families or others.

Another mother described the type of communication patterns most typical in the children represented in this study. She said:

> Yeah. So as he's playing with toys, I feel like – he's got a plane in his hand, but he puts the plane in his mouth and he's biting on that plane. Or if he's doing something, he's just holding onto the plane and looking and he's like, 'Eeeee.' So, it's not appropriate behavior like, 'Oh, look at the plane' or 'The plane is flying.' Just, not even sentences, but just words – plane or flying, but it's a lot of the 'Eeeee.'(44AC37)

Solitary or parallel play. Because the children lacked reciprocal communication, several of the families commented that the child had challenges with social interaction and often opted to play by him or her self. Several of the children chose to stay in their rooms if given a choice and watch TV or videos, which they would then repeat in echolalia or scripting.

Overall the children would not interact with other children in the family, such as cousins, or with those outside the family such as friends, and instead carried on a type of solitary or parallel play. One mother in reference to this said about her son: "He's had play dates with his peers at their homes with me there, and a lot of times it's art projects. They're painting together. They're coloring together. But there's not a lot of conversation going" (16C39). Another mother commented: "He loves other kids. He wants to play with them, hang out with them, but he has trouble figuring out how to initiate, so he might maybe watch them more" (36AC6).

What is child thinking? Almost universally, participants said that they wished they knew what the child was thinking. This was the heart of the communication challenge for these families because the child could not share his or her thoughts or needs and this left the families at a loss. Several families felt that if they had better insight into the child they could meet the child's needs and focus their education efforts. One mother described her feelings about her child’s communication in this way:

> I just wish I had some concept of how he thought, because it’s like [I ask my child] ‘are you even here on this planet right now or this plane of existence, or are you in another zone? Why is there this disconnect here that is not here?’ It’s very strange. (34AC59)

Many held out hope that the child would slip back into talking as easily as they had slipped out of it and that the family would once again have a normal communication pattern, even though they knew this was very unlikely. Here a father expressed that hope:

> I really think that if we can get to a state where he’s able to communicate; I think that is his biggest hurdle…. If I could sit down and talk to him like I’m talking to you, well, I’d be really ecstatic about that. I’d love for him to tell me that he’s got a tummy ache or his ear hurts or, ‘Dad, I don’t want to watch this stupid program you’re watching,’ or something. (44BC21).

What if child is ill? There was a shared fear among the families that they would not be able to recognize if their child were ill and be able to help them because the child could not communicate his or her needs.

It was interesting that several families provided examples that their child had had an ear infection, but the family had no idea that it was occurring. The only sign of the ear infection was that they child acted differently or “was miserable.” However, when they brought the child to the doctor, the doctor often attributed the child’s altered behavior to having autism.

One mother described an ordeal of bringing her child to four consecutive doctors because of her child’s unusual behavior. The mother was sure there was an underlying medical issue, but the doctor did not examine the child, and instead attributed the child’s irritability to autism. Finally a doctor looked in the child’s ear. The mother recounted what she said to the provider:

> 'This is amplified, above and beyond. She's miserable. Something's wrong!' She's [the doctor] looking over her, and she had a nurse come in and help me hold [the child] down so that we would look in his ears, [the doctor is] like, 'Her eardrum's about to explode! She needs antibiotics right now.' So we got antibiotics in her, we got painkillers in her, and she calmed down immediately. (39AC80)

Some families expressed their sadness and helplessness at not being able to understand the child's needs when they were ill. This was eloquently discussed by one family member. She said:

> I guess the worst thing is hurting for [the child] when he is frustrated or upset about something, and you don't know how to help him, and he's so upset, and feeling like he's going to be that frustrated his whole life over things. I can't imagine anything more frustrating than having needs, and understanding what I need, but not being able to tell anyone else. Even something that can be fixed…. When [the child] starts crying, how do you know? What if he's trying to say, 'My stomach hurts so badly, and I don't know how to tell you,' and there's a way to fix it, but you can't just medicate him for everything every time. (41BC39)

Connection. All the families described the challenges in trying to communicate with their child with autism. What seemed to result was that the families felt not only a different or altered verbal connection to the child, but also an altered or different nonverbal connection to the child. For example, the child could not carry on a conversation, but they also did not hug or kiss like other children. Because of this there was often a delay in the connection and a feeling of isolation that the families experienced. Many families mentioned that years passed before the child seemed to recognize that the caregiver was a special person in the child's life, such as a mother or father.

Altered verbal connection. Families shared that they already felt isolated from others, but not being able to talk with the child made them feel additionally isolated. Some families verbalized that they wondered if the child understood that they as family members loved them. One mother explained the challenges of not being able to verbally connect with her child as an infant. She said:

> I feel like I haven't had the opportunity to enjoy him as a child. When a baby's born, every mom wants to cuddle with a baby and nurture the baby…. I have some regret in terms if we don't get to enjoy him as a child, because it's hard for us to interact with him or play with him. We'll try to play with him and he doesn't engage, so after a while we get tired and frustrated and say, 'Okay, I finally give up.' He does like the horseplay and stuff like that, but I just feel I don't get to enjoy him as a child….(44A57+59)

Other families echoed the feeling that they missed the reciprocal relationship with the child because the child could not communicate. One father made the metaphor of himself and his child to the book *The Giving Tree* by Shel Silverstein, in which he was the tree that continued to give and his child was the protagonist that kept on taking (39BC38+39).

Altered nonverbal connection. The families all described nonverbal communication that was different from that of a neuro-typical child the same age. For example, rather than cuddling, many of the children preferred rough and tumble horseplay with family and friends. This was thought to be a form of sensory stimulation for the child. Other families described the child preferring to be touched on the feet or head versus receiving a hug. One grandmother described how her grandson preferred fist bumps and tilting his head down to show his affection rather than cuddling. She said:

> He points his fingers at you. But he seems to be into fist bumps now, which I just found out when my sister did a fist bump with him and he responded. I tell him, because I'm his grandma, and every time I see him, I tell him how much I love him. I'll say, 'Give Grandma a hug,' and this is the way he's always been. He'll put his head down, and it's kind of close to your head, and that's as good as you're going to get; that's a hug… Sometimes I could, but sometimes I can't, and I don't know when, and I never want to push it. I'll take whatever I can get. So, his putting his head down by me is good! (34BC28 + 29)

Again, families worked tirelessly instituting positive behavior therapy to try to teach the child acceptable forms of social interaction such as shaking hands or hugging when appropriate, but in general the children seemed to prefer physical distance versus contact.

Delayed connection. Whether verbal or nonverbal connection, many of the families of the children with severe autism faced a delay in the time until the families felt some type of connection with their child with autism. Several families shared that the child had only recently said the word "mom." For example, one grandmother wept as she explained that her grandson with autism, who was now 13, had not yet significantly communicated with her daughter. She said: "No, he doesn't say 'Mom.' It breaks my heart. If he would only say 'Mom,' I would be so happy for [her daughter], but he doesn't" (34BC36). Another family said it was 9 years before the child said "Mom" (39C22) and another family noted that at age 7 the child was just learning how to cuddle (41AC8). One mother summarized this by wondering if her child recognized that she was the mom rather than just a miscellaneous care provider. She said:

> It seemed like for a while there, at the beginning when I used to work a lot, it seemed like he didn't even miss me when I was gone. And I'm sure he did, but it took a while before he got to the point--he was four when he started to get separation anxiety…. So it's different to have a little kid that doesn't seem like they super care if you're around or not…. And it's like, I know you like me, but does it matter if it's me or if it's somebody else? It matters because I'm around you more, but is it because it's mom? You're not requesting mom. (43AC83 + 43AC84)

Experiencing severe stress. The fourth theme identified among families of children with severe autism was severe and sustained stress. There was a constant nature to the stress that seemed at times overwhelming. There was an up and down roller coaster pattern to the stress. There was a sense that because of the child's delayed development, when other parents could relax, these families needed to continue caring for the child, which added to their anxiety. Constantly teaching the child, coordinating services, cost, and concern for the child's future were also challenges.

Constant nature of stress. The constant stress the families experienced was apparent with each and every interview. As one father said when he sat down to speak with me: "I'm glad that someone is doing this kind of research. Certainly it's been a challenge; I'm sure, if you've talked to [wife] at all, it's been a challenge!" (44BC1). He then placed his head into his hands and began to weep. In fact, the majority of the other family participants, including fathers, wept openly during our interviews.

Several families discussed that they were in dire need of a break. One mother discussed falling asleep in her car because it was the only quiet space available to her (39CC16). Another mother said: "How do I take care of myself? How do I just get breaks?.... I'm to the point where I'm breaking. I can't continue 24/7. I can't do it!"(16C95).

Families described their experience raising a child with severe autism as a grueling marathon. Others noted that they had been through so much--such as cleaning up smeared stool and vomit on furniture and walls--that nothing could phase them. Lack of sleep added to the marathon. Overall, the families described that their lives were strained and very different than the lives of others.

One mother summarized the all-encompassing stress that the family experienced by discussing their unique challenges. She said:

> They are children… I'm a mom; but it feels like that's a lot of where the similarities between me and my friends and their kids and kids at the neighborhood school, that's sort of where the similarities stop. Beyond that, the way we eat is different, the way we drive is different, the way we dress is different, the way we're home is different, the way we invite people over is different, the way we decorate is different, the way we play is different. Everything is different. The way we shop is different. The way we travel is different. (39AC38)

This mother went on to describe the many differences that make up their daily life. They do not eat together each night because the two children with autism would fight; they drive differently because they need to restrain one child in the car so she does to injure the sibling or try to interfere with the actual driving. They also needed to decorate their home differently because the children with autism would break items in their home. Again, this illustrated the strain that permeated their life.

Roller coaster. Several families equated their stressful experience to a roller coaster ride. One mother said it in this way:

> At first, when he got his actual diagnosis, it felt like we were on a roller coaster that had plummeted. And then, once we started learning a little bit more, I felt like we were on a slow incline again, back to normality. So this is a crescendo from normal to really loud, crazy stress, and now we're tapering back down…. (45C64)

They discussed the highs and lows of living with a child who has severe autism. For example, the highs included the joy they felt when their child accomplished even a small achievement, such as not having a meltdown at a store. The lows were numerous, but included an uncertainty about whether they were making the "right decisions' for their child. Fathers also specifically worried about their partner's stress at home while they were at work and who had limited ability to help during the daytime hours.

Child's delayed development. Some families noted that stress was related to the child not progressing as expected. The parent continued to care for a child that, although older, was developmentally still like an infant. Many families shared that they still carried a diaper bag for older children who were not totally toilet trained. They discussed the stress in public of a child who looks like he's older, but acts like a toddler.

Parents also discussed how the child's delayed development affected them as caregivers. Whereas parents usually look forward to a time as the child grows when they can lighten their need to be as vigilant, these families needed to continue their vigilant watch so that the child would be safe. One father described this experience. He said:

> I perceive that when kids are little, a married couple would have some tendency to have a period of time where they were kind of growing apart a little bit because taking care of a really little kid takes so much effort, but then they reach a point where the kid starts to become more capable of keeping themselves occupied and playing with friends. I imagine for most people that starts happening at a particular age, that it gets less time-consuming, but that has never happened with us. It's just going to stay. She's six and it's always going to be. (10CC2)

Teaching activities of daily living. Stress was evident as each family needed to constantly reinforce the child's appropriate behavior every day. They did this through modeling appropriate behavior either on their own or using a structured behavior therapy approach like ABA. Often, they hired ABA therapists who visited the families in their home (sometime all day 5 days per week) and/or primary care assistants (PCAs) who also reinforced positive behavior. Their aim was to teach the child to have appropriate daily living skills, e.g., brushing teeth, dressing, and appropriate social skills. Families discussed how tiring it was to need to constantly reinforce these behaviors. One mother shared:

> Okay, but I was just being honest about it's in the morning. We're on our clock, and that's what we do. I'll tell him to do it. He may do it. Sometimes he doesn't, and I'm in the middle of dressing or doing what I've got to do. He doesn't do it. I

> go ahead and do it, turn those pants around, give them to him, and say go back to your room, finish getting dressed. But it's just that he is not consistently motivated to get dressed like that unmanned [without help] and go brush his teeth. So it's lesson, lesson, lesson, lesson, lesson, lesson, lesson. (7BC30)

In addition, families continuously attempted to teach the child how to read social cues. For example they might have pictures of different facial expressions to teach the child which expression is happy, which is sad, etc. This is done in an effort to help the child become more socially aware of how people are feeling. This was a concern because several families worried that a child would not understand that someone was mad or a threat to them and the child could become endangered or even arrested when older.

Coordinating services. Another source of stress for the families of the children with severe autism was the need to constantly coordinate and juggle health care and related services for the child.

In comparison to other states, autism-related services were identified as rather good in Minnesota. Two families described in their Family Lifeline that they specifically moved to urban Minnesota just to procure autism services (Families #16 + #39). However, the need for these services outweighed the supply. Families were often placed on wait lists and/or did not have proper insurance funding to cover all the health care-related services the child required. In addition, families often described a high turnover rate in professional staff, which made adapting to new health care employees difficult.

The mother was typically the coordinator of all of these services, which usually came to the home and/or the school. For them, it was analogous to being a full-time orchestra conductor.

One of the biggest stressors was not having assistance in coordinating the services. Families depended on each other and word of mouth to locate quality and trustworthy services. There was little guidance about which services to use or how to coordinate the services, particularly from well-child health care providers. Some families described that they were told they needed certain services, but then were on their own to figure out the details. One mother discussed the stress of this responsibility in this way:

> I swear, I just don't understand why our system is so unpredictable and so difficult for people to navigate it, and I think if somebody were a high school graduate and got married, or didn't get married, and had a child when they were like 18 or 19 years old, and this child has the same level of disability as [son] does, what would they do? How could they possibly be able to handle this, or manage, or put it all together? (41AC76)

The exception to this was the large urban autism centers whose medical and psychology staff provided coordinated autism care and assisted families to find appropriate autism services. However, even though they gave valuable direction, many of these recommended services were in short supply, again presenting challenges.

Doctor's appointments. The actual clinic appointments were also a source of stress, especially doctor and dental appointments. Families described that many of the children were traumatized by past experiences so that every subsequent clinic visit, even for autism or well-child care, was traumatic. Families often had to lie across the child just to hold them down for simple well-child ear exams. They described long waits and some health care providers who were insensitive to the needs of the child and family. Because these children usually like routine, it was difficult for them to visit the clinic or hospital. Specific challenges in the clinic or hospital included the bright lights, unfamiliar equipment, and changing clinic rooms, which are common in long clinic visits.

Families tried to find any way to avoid visiting the hospital and they yearned instead for phone assistance. A mother summarized how traumatized her child became from visiting the clinic and the mother's desire to avoid the experience altogether. She said:

> This is a life-altering experience. It's traumatic every time we go into a clinic or a hospital – or even a place where they're not going to be poked or touched, just the psychologist. This is an event. Like, 'Can I just talk to you over the phone and you can bill for that? Do I really have to be within touching distance? (39CC43)

Visiting the dentist was an especially difficult experience. This may be due to the bright lights, instruments, the need for the child to lay back and cooperate, and the sensory issues of having the mouth manipulated. Here one family member commented on the challenges of visiting the dentist, which was echoed by several families of the children in this study:

> Trying to brush his teeth is like trying to diffuse a bomb because you have to lay him down, and that usually takes two people, because somebody has to hold his feet down. Otherwise, he'll be kicking you, or hold his hands because he doesn't like the toothbrush. He just doesn't like people messing with his mouth. You should see how hard he fights the dentist. Oh my goodness…. They have sort of a – it's not really a straitjacket…. And they strap the little Velcro – we call it a burrito, the little Velcro burrito – to the chair, [so] that they can examine him. (41BC18 + 19)

Cost. Health-related costs were also a pervasive issue for most families and appeared to cause inordinate stress. Several families relocated specifically to Minneapolis where there are quality services *and* adequate insurance coverage for the services, but still there were significant out-of-pocket expenses that all the families incurred. They spent money on hotels when they traveled to obtain services such as physical therapy, and they spent money out-of-pocket money for enrichment services and devices. Because there is not one universal treatment for autism, families were willing to try many programs or items that might help, such as audio programs that were guaranteed to help their child to develop at a faster pace, vitamins, or special diets.

Families discussed the concern that their salary might affect the health care benefits the child received and they weighed their job options in light of how much medical coverage they could obtain for their child. One father described his dilemma. He said:

> The [children] have coverage from Medicaid, and that's a big reason that we're in Minnesota, too. Some of the programs and the treatments you get are also funded by the state. But it's also expensive just [because] some of the treatments require lots of items that reinforce good behavior… At one point, I was offered a raise, and it was at a time when it was hard, so I was like, what if I get this and we lose some of the [insurance] funding and it becomes more expensive? So I have actually turned down a raise a couple of times. (39BC21 +23)

There was a lot of discussion among the families concerning private versus public insurance. The general consensus was that it was better to have public insurance coverage for the child because then most of the medical costs were covered. Those with predominantly private insurance felt they received only partial coverage and were always trying to make ends meet. Many families were concerned about the lack of private funding for ABA therapy, which is expensive. Many felt it was beneficial, but insurers would often not pay for it because of the lack of evidence that it works (it is indeed difficult to conduct these studies because of the confounding variables, but intensive behavioral therapy of some sort is generally thought to be beneficial by the health care establishment). One father, in reference to private insurers not commonly paying for ABA behavioral therapy said:

> My only advice in the health care industry would be get on board with ABA and start paying attention to funding that is a way to help kids who've got some of these spectral disorders. It's working and we're seeing it work…. I would say to the broader health care industry, cover intensive autism therapy--these kids need it--and start paying attention to the fact that ABA works. (10CC30+ 10CC31)

Concern for child's future. The last source of stress for families of children with severe autism was their concern for the child's future. There was a universal concern about the long-term care of the child and this was addressed by each of the families that was interviewed. They wondered aloud, "Who will care for my child when I die?" This was a question they seemed to ask from the time the child was very young. They also wondered where the child would live in the future. This mother typifies the pervasive concern for the child's future. She said:

> Yeah. But I don't know what's going to happen after me and [dad] die. I'll keep him with me, but my hope is that he would want to… I'm hoping that this co-housing thing where you could have a neighborhood of neuro-typical people and disabled people living in a community with a building in the middle where people can cook or people can come to eat that can't necessarily cook, I hope that this comes to be. (16C135)

There was a worry that if the child were placed in a group home in the future the child would not receive the appropriate care needed and especially not receive the love the family had provided. This terrified the families because they had worked so hard to care for the children and felt bereft when envisioning the child cared for improperly.

The concern for the child's future was shared by several family members, not just the parents. One grandmother shared:

> I'm sorry, (crying) but I'm just – and I'm scared to death because we don't have anybody in our family that can step up and say, 'If anything should happen to [mom], this is what we'll do,' and Mom has talked of that. (34BC61)

This seemed to be a difficult legacy for a grandparent to view as most grandparents, like parents, hope for security for their offspring.

Living with extreme isolation. Isolation was the next essential theme identified in the families of children with severe autism. Isolation was described by families, related but not limited to, friends, school, the public, and medical health care providers.

Friends. There was a feeling of isolation concerning friends in general. Families discussed the simple logistical challenge of meeting with friends because their schedules were so busy, leaving little free time. It was also difficult to bring their children to other peoples' homes because of the child's behaviors and the need to be vigilant about the child's safety in an unfamiliar space. Here one mother discusses the challenges they face in trying to meet with family friends. She said:

> We've tried to go eat with other people for dinner. They invite us for dinner; we don't get a whole lot of repeat come back (39AC40 + 41)…. Just having friends over, it's difficult, sometimes. We have to wait until the kids are asleep and then we can invite friends over, but then their kids are tired and so then they can't come over…. Some people do that [have friends over] for double dates and stuff, but we're not doing it to have fun; we're doing it because we can't come over and play cards. We'd love to come over and play cards…. (39AC 43 +44)

The families also discussed the challenges of meeting with friends who do not have children with autism. They often pretended they were having fun, but they felt a distance from their friends that seemed to occupy a different world, one in which these families did not belong.

Families also felt isolated from families who did not have a child as severely affected with autism as their child. It seemed that there was a gulf between the experiences of milder and more severe autism, a gulf that these families could not ford. In reference to this, one mother described that she attended an autism meeting and was disappointed that she did not find other children like hers. She wept as she explained: “Even there, I found the group, the table, but to me…. it’s like everyone [the children with autism] seemed – I don’t want to say better, but more functional” (38C39+40).

One mother discussed how she cleverly circumnavigated this issue by forming her own national phone network of families who have children with severe autism. This was one way to find friendship and empathy. She described her “underground phone network” like this:

> And you all just know that your phone's just going to randomly ring and someone's going to call you and say, 'So-and-so gave me your number,' and you're like, 'Hi! You're instantly my best friend. What do you need to know?’.... It's instant acceptance, and it's instant feedback. (39AC76-78)

School. Though there were several counts of positive experiences at school, specifically the early intervention programs that often led to diagnosis, unfortunately there was also the overwhelming theme of isolation experienced by the family at school. Families discussed the child often being separated from other neuro-typical children, and there were low expectations of their children at school. Lastly, several families described confrontations with school staff that ultimately resulted in the family’s expulsion from school.

Lack of inclusion and low expectations. Several families reported that their child was not included in the classroom like other children. For example, one child did not have an orientation to the school like other students and was not included in special holiday activities like parades (38C30 + 38C33). Another father described that his child was taken out of the classroom to wander about the halls because the teacher did not want the child to disrupt her classmates. This made the family feel ostracized from the school community in general. As this father astutely pointed out, separating the child with autism from the other school children robbed not only their daughter of the class experience, but it robbed other classmates of the opportunity to learn about disabilities and compassion. He described his experience in this way:

> There are all these other kids in the room, and what they [the teachers] do is they take their ignorance, and they defend their ignorance by saying [to the child with autism] 'get out of the room because I've got these other kids to take care of'-- well, that's stupid, because what they should be doing is saying don't take [the child] out of the room, I've got these other kids to consider. I want to help them learn what it means to interact with someone like this. (10AC34)

Several parents noted that they felt teachers had low expectations of the children with severe autism and taught them menial tasks instead of providing creative education opportunities. Several of the parents felt their children were receiving subpar educational programming that focused on menial tasks, like folding towels, versus quality learning. One mother noted,

> I have a lot of issues with autism education…. I happen to think that they're trying to put a bunch of square pegs into a round hole, and the ones that get through, okay, great, we'll work with them, and the rest of them we just dump off into the folding towels program. (34AC61)

Confrontations. Many of the families described that their children (and the family) had been let go from one or more schools and involved significant confrontations with school staff. It was unclear why these confrontations occurred, but they appeared to involve the family members advocating for the child in school. One mother discussed what it was like when her child with autism was let go from his elementary school without any warning to her. She said:

> No, zero transition plan, zero warning, zero anything. It was zero. I literally went to pick him up and I walked in the building and he wasn't there. I'm like, 'where's [son]? Where's [son]?' The director of the school kind of did this, come on over here, brought me in a room and said, 'As of today you are no longer welcome here. Here is your discharge paperwork.' I said, 'why are you doing this?' 'You're no longer welcome.' 'I said, 'why are you doing this? Why, because I was asking questions? Because I want to know what you're doing with my kid all day, because I want to come see him. You're doing this because of my questions?' she said, 'Your behavior is toxic to the staff and to [son].' I said, 'my behavior, I'm trying to look out for my son. I'm advocating for him. What are you talking about?' (36AC39)

Another mother echoed a similar experience when her child was "kicked out" of her public elementary school. She recounted:

> That's when the principal came down that day and told me, and I quote, 'Get the hell out of my school! I'm going to go get [your child].' I said, 'Don't you dare go get [my child], I will get [my child]!' And then we never went back. (10AC48)

Whatever the reason for these confrontations with the school, the families ultimately felt alienated and isolated from the school community, which is typically the hub of a child and family's life.

Public. The families also described feeling isolated from the public at large. They recounted the numerous times they encountered sneers and stares from others who assumed that the child's behavior was a reflection of bad parenting practices. Many recalled being publicly rebuked by department store staff because their child was having a meltdown. Though this was addressed earlier when discussing stigma, it warrants further mention here to highlight the full scope of the isolation these families experienced. The following exemplifies one of the many encounters with the public that were discussed. Here the mother describes her interaction in a department store with her daughter with severe autism. Note that they call the young girl "him" and "that." The mother shared:

> [They say] "What the hell is wrong with [the child]?" Things like that, or, " Get it under control; get *him* out of here! Why do you bring *that* in public?".… The loud speaker [is turned on at the store and they say] "What's going on?" and "Maybe if you can't get this under control you should leave!" We have left. Sometimes we haven't when you have a whole cart of groceries, and you're like okay, I know what's happened in the past, I just need to leave now. (10AC28+ 29)

Similar experiences were shared by other families. Often families needed to make a choice of explaining that their child indeed had a disability instead of leaving. Some families wanted assistance from others, some wanted to be left to deal with the situation alone. Most said they wished that those in the public would give them positive reinforcement and ask how they could help rather than giving suggestions about what they thought should be done.

Here is another example given from a grandmother about her family's frustration engaging with the public. A grandmother shared her daughter's experience:

> She [her daughter] told me a couple of years ago, 'I'm sick and tired of having to explain autism to people in the grocery store who look at you disgusted, as though, "Shame on you for not having control over your child" or "You've got a

> boy who’s 5 foot 6 and trying to crawl into the basket of the grocery cart.”’ And it’s like, you people, you’ve never had problems? You’ve never had anybody in your life with a disability? You certainly are harsh on the ones who do! (34BC40)

Medical health care providers. Lastly, in the families of children with severe autism, there was a theme of isolation from medical health care providers, particularly those that do not specialize in autism. While there were many positive references to providers that specialize in autism, the negative experiences seemed to outweigh the positive ones. The result was a general sense of isolation from the broader medical community including nurses and well-child care providers such as pediatricians.

Overall the families found that there were long waits in clinic and the health care providers were then rushed when they finally had contact with the families. A rushed manner did not jibe with the child that has autism; the child typically needs time and patience to adjust to new situations. It was also challenging for the families to wait for appointments because they had so little time to spare. Several families additionally complained about the many forms they needed to complete in clinic, only to find that the forms were never used by the staff. One mother described her experience bringing her child to the clinic in this way:

> We have this running joke about the forms that you fill out. You almost just want to write 'elephant princess dinosaur,' because you're going to hand it to them and they're going to ask you all the questions that were on the form, and it's like, why did I spend half an hour filling out the forms if you're not even going to ask me? Then the doctor comes in ten minutes later and asks the same thing, and you're like, 'I've sat here for 45 minutes repeating myself three times, and then when I talk to you, you don't even hear what I said…. I've already checked out, I'm done, the kids are done, and it's just like, 'Can I just have my prescription and go?' and it's like, 'Yes.' You don't even know if that was the right prescription, because they're not taking the time to listen. (39AC65)

For most, navigating the waters of well-child care was difficult because many primary health care providers knew very little about how to care for a child with autism. A few families directly recommended that autism, specifically severe autism, should be taught in medical school so the experience for families like them would be easier.

Many families needed to jump through hoops to obtain even minimal help from primary care providers. One family described trying to obtain a prescription from their primary care doctor before the child had dental work only to be stonewalled and redirected to several doctors for 2 weeks along with numerous phone calls. (36AC80+ 81)

To add to the sense of isolation, families described their frustrations when their child was hospitalized for non-autism related issues. One mother voiced her frustration that when her child was admitted to the hospital for an ear infection, and she requested medication to help calm him through a procedure, the doctor refuted that the child even had autism. The mother recounted that the doctor proclaimed: “He looks like a normal, typical boy. He doesn’t look like he has any disabilities or autism!” (16C52).

This misunderstanding by staff also occurred in nursing. One mother described her encounter with nurses at a nursing station when her child was hospitalized. The nurses were gossiping about her child leaving her to feel marginalized by the very individuals who are supposed to be supportive. She said:

> It sucks that you hear it being talked about when you’re passing the nurses desk. It’s like okay, everybody just stop; we’ve been walking the two halls and we heard you the whole way, so that’s fine, whatever. She [the child with autism] is still different, and so it gets talked about, but when it gets talked about, it’s still never positive…. She’s not this blob that has no feelings! (10BC25+ 26)

A strong dependence on family. The final theme noted in the families of children with severe autism was a strong reliance on the family for support. What resulted was a hybrid (a mixture or combination) family that was an extension of the nuclear family to include extended family and friends. This concept was evident from the onset of this study, as potential candidates for this research made it clear that they considered extended family members and friends outside the home as integral family members.

Along with the dependence on family came a compassion or empathy that was evident in all of the families that participated in this study. The families experienced compassion for the child as they cared for him or her and they developed a compassion for each other. This empathy seemed to grow over time as an experience of the families raising a child with severe autism.

Dependence on the nuclear and extended family. It is no surprise, given the experiences of the families of children with severe autism, that an inordinate amount of help was needed to raise the child. Families depended on their nuclear family members to help.

In several families, both the mothers and fathers discussed how interdependent they were upon each other's help and support. The mothers were usually the primary care providers and the fathers' roles were usually to provide the finances to support the child and family, and to help care for the child when they could. It seemed to be an evolutionary process and they both learned along the way. Here, when we met together as a family unit, a mother described the type of balancing she and her husband engaged in to care for the child successfully. She said:

> Yeah, I appreciate that he helps out, and we're starting to do a lot more of the 50/50 since maybe [husband] has realized how hard it is with [son]. Even putting him to sleep is like a 60 to 90 minute task, and if one person has to do that every day, it's overwhelming. We're taking turns sleeping with him so that one person can catch up on sleep that night that we're not sleeping with him. Even that, sometimes, doesn't work out because he's awake 6 hours at night. (44CC2)

Some fathers mentioned that they frequently felt at a loss of how to help when they saw their wives so tired after a day of caring for their child with autism. A father described his sadness at seeing his wife, but his determination to keep helping. He shared:

> It's difficult to be gone all day and come home and then understand where we're at. And then to see her hurt, and to be helpless to – you know, I can offer words of encouragement or something, to the extent that I can, but to know that there's a problem and it's wearing her down and eating away at her, and there's really not a lot I can do, except the way that I can help her is to keep providing income and keep us afloat and pitch in when I can, just step in the house and do the dishes. (39BC19)

Though there were few siblings in these families overall, there was a reference to how dependent a family was on the care that a sibling provided. Here the sibling not only provided hands-on care, but was an emotional support and friend to the parent as they both worked to meet the needs of the child with autism. Here a mother describes her dependence on the sibling for care. She said, referring to her son with autism:

> Well… we [female family members] are his guards, so to speak. He is the prince, and we're the guards. Because he has to be shadowed constantly, there's always somebody who's following him. [Sibling] actually does a lot of this so that I can work. (41AC5)

The extended family was often instrumental in helping the families of children with severe autism, and as mentioned, this occurred not only in the one-parent families, but in two-parent households as well. Usually grandparents, specifically grandmothers, were identified as the individual from the extended family that they depended upon, but an aunt was also identified in this study. The elder's role in raising children seemed to be not only a physical, but an emotional, support.

The dependence on extended family was evident from one of the first interviews of this research. In this family a grandmother described the interconnectedness of family. She said:

> It's just that I think it's important to be aware that with people of color, 'family' is very seldom used, the word family. When they refer to family, it's inclusive of more than the mother, the father, and the children. When you refer to your family, the word by definition for us includes wider than mother, father, and children. It's always wider….(7FC1)

Though this was self-identified in the families of color, it was important in other families as well. It was common in this study that grandmothers, grandfathers, and aunts played pivotal roles caring for the child and supporting the parent.

Parents discussed that extended family often helped with cooking, cleaning, and especially with caring for the child so that the parents could run errands, which were difficult to do when the child with autism accompanied them. Extended family members also took care of the child for short periods of time, so the parent could participate in exercise or take a mental health break. Some grandparents described recognizing that they needed to support the parents with a strong relationship so the parents in turn could have the strength to care for the child with autism.

One grandfather in particular helped to organize and plan child's financial care for the future (Family #36).

What was of interest was an insistence by extended family members that the care that they provided was different than the care that could be provided by someone outside the family. For example, the aunt in this study described that her role was to teach the child to love and this was something she could do uniquely as an aunt, and a skill she could not impart to another care provider. She said: "They [the children with autism] learn to love and soften and love to receive, but you don't know how to tell somebody else how to do it" (7EC11).

This perception of having a unique role in caring for the child was also evident in a comment by a grandmother who noted:

> I won't say I get 100% response, but for the most part I can do it. We'll be sitting here, and if he's eating lunch or something, I'll sing to [the child] him a little bit. I always try to talk to him because I just think that it's got to be important for him to hear me, and I do believe that that's one of the things I am. I am Grandma! (34B35)

Part of the extended relative's unique role seemed to be predicated on the fact that the relative was older and wiser than most. Several of the grandmothers and the aunt mentioned that being older they now had a greater understanding of others and appreciated people for who they are. This included accepting the child with autism for exactly who he or she is, a rather refreshing concept that was appreciated by the parents. As one grandmother remarked in describing her relationship to her grandson:

> So her [mom's] goals for him and frustration, I share them, but I have learned in the frustration. He's my darling. There's no shame in my game. I always say I only got one little egg and it's cracked. My one little egg and it's cracked. I love it! (7DC8)

Dependence on friends. Though friends were discussed previously, it is important to note that several individuals in this study considered friends as family. This seemed to be specifically important in one-parent households and in a family that did not have extended family geographically close, although it was also mentioned by other families.

In one family, a friend actually lived with the mother to help raise her child. She provided direct care to the child and also provided psychological support and respite time for the mother. In this case, the friend stepped in as a co-parent, setting limits and providing care and support that was very appreciated by the mother.

The bond of friendship was also evident in other families. Another mother discussed with me that she considers her church friends to be her family in part because her extended family did not live close to her. One of her friends also had a child with autism, which made this friend a very sympathetic ally. The mother shared this in our conversation:

> Mom: Our family here is largely people that we just extremely love like family. There's not a blood connection, but there's a heart connection, so they are our family. So my best friend, [name], she's my sister!
>
> Interviewer: You call her your sister?
>
> Mom: Yeah, and then I have another friend – she's actually coming over today…. She's my other sister. We're all very connected just by crisis or hardship.
>
> About another large family with whom they are close, this mother also said, “There's not a blood tie, but there's something that's just as strong, if not stronger, here. (39AC3)

Friends became one of the largest support networks for the families. This was especially true if the friends had a child with autism. There was an ease with these particular families because no one needed to explain if their child had “bad behavior.” A grandmother described her perception of how much these friends meant to the families of the children with severe autism. She said:

> [Mom] and [dad] are terrific, as far as building up a social network for him. They have friends over. With those types of families the parents have to come. One parent has to be there as well, but they have kind of a support group for their families. It’s wonderful because I think friends are so important and those families don’t have time to establish friendships, so they don’t get that support from the non-autism families. It just takes too much time. (36CC11)

Compassion. Within the family, the experience of compassion or empathy was noted as an important subtheme. Compassion was shown for the child and was shared by all family members as well. Over time the compassion between family members seemed to grow, which was indicated in several of the Family Lifelines.

Compassion/empathy for the child and for each other. Families described a love and acceptance for the child with autism. They described that the child helped them to slow down and appreciate the little things in life, such as the child's accomplishments, e.g., successfully navigating the checkout line in a department store without a meltdown. Several noted that they would not have traded this experience because they learned to love someone so totally and genuinely.

The devotion to the children was awe-inspiring. One father discussed the total devotion that he felt was necessary to raise a child with a severe condition like autism. He shared:

> The lesson I learned in that process was that those positive instincts you have to just really commit yourself wholeheartedly, to give your whole self to it, and to not be distracted by this desire to leave something for yourself. It's weird, because I hear some people talk about if you're going to be a good parent, you've got to leave something for yourself. I'm not entirely sure that's always true, because I look on that timeframe where we literally couldn't leave anything for ourselves. I think as a result of not having left anything for myself, that I'm somehow more satisfied with her success than I otherwise would've been. (10CC18)

Another family member, an aunt, echoed this sentiment. She called the total compassion that is given to the child a "love transfusion." She said:

> You do learn in life that you take everything about people you've learned and you use it to pull the person to you. All this love you think you've got, all this love you think you have inside of you, then transfer [it] through the "love transfusion" kind of thing. (7E31)

Families also described that they learned compassion for each other from caring and interacting with the child with autism. Some parents felt that their relationship had grown stronger because of it. One couple discussed this when we spoke together as a family unit. They shared:

> Mom: We've talked about divorce. We've threatened divorce…. That took years of work with each other and just being stubborn and not giving up on him, and him being stubborn and not giving up on me, that neither one of us was going to

> call it quits. So then it was like, 'Well, then that means we need to work hard.' So we just did, and now he's my soul mate. He was not my soul mate when I met him; he became my soul mate. (39AC53-55)
>
> Dad: Oh, yeah, for sure. I think there is no way we could still be married if both of us hadn't grown. I realized that there's a way to work together, and there's a way not to. It would be hard to do this if you weren't both working towards the same goal, and just understanding how hard it is for each other in a different way. (39BC18)

Several families felt that they had become better people from interacting with the child with severe autism, with more acceptance and empathy for others' struggles. Several families described that the child had motivated their family to learn more about autism and become active in autism health care policy. This was summarized nicely by a family member when she described that the child with autism changed her life and the life of others to become more compassionate individuals. She said:

> I think that they [children with autism] make everybody around them a better person, and I wish that those people were always treated kindly and lovingly, but I think that everybody that comes in close contact in their life with somebody with that kind of really severe disability learns how to be a better person just by being a little bit more kind and a little bit more patient, and I think you learn how to be more kind and patient to neuro-typical people too, and that you appreciate them more. (41BC44)

Compassion increases over time. The love and empathy that families shared grew or blossomed over time. This may have simply been attributed to adapting to the situation over time, but it might have been that compassion shared as a family was iterative. This was visually brought to light in two of the Family Lifelines.

In the first Family Lifeline (see Appendix Q - #39), the mother noted early in their Family Lifeline: "Grieving…. Naive, Didn't know the first thing about love-true love…" Later the mother writes, "Grieving… Joy from sorrow is strongest." At the end of the Lifeline denoting the present time, she notes with hearts drawn: "Grieving, joyful, hopeful…. Love wins" (39ALL100).

A second example of this is seen in the second Lifeline (see Appendix R-#45). The mother denotes the family's experience over time in which the word " STRESS" is most prominent. In the progression the words are: "Surface love> Stress> Chaos> Peacefulness again, inner love" with "inner love" being closest to the present time (45LLC67). These Lifelines illustrate that both families felt that the surface love they shared was transformed over time as they cared for their child with autism.

Family Lifeline (Lifelines)

The Family Lifelines were used in addition to the interviews to obtain a pictorial representation of the family's experiences and quality of their life from the time the child with severe autism was born. These will be discussed at length here.

As mentioned earlier, when possible, the Lifeline was sent by mail to the family's home in advance of our meeting. One parent was asked to compete it before my visit. Originally only 1 Lifeline was elicited from each family by one parent, but many of the family members liked the idea and wanted to complete them. Thirteen Lifelines were therefore completed from 10 of the 11 families. In 3 of the families, 2 Lifelines were completed. Of the 13 completed, those that completed them included: the mother (8/13), the father (2/13), an aunt (1/13), a sibling (1/13), and a grandmother (1/13). A few Lifelines are included in this document, but many are not because removing names did not provide anonymity.

Six Lifelines (6/13) actually illustrated a graph-like representation of family experiences over time, that is, when the horizontal line went up, child and family experiences were noted as improved, and when the horizontal line went down, experiences deteriorated. Others just documented their experiences using words without a graph. About half were rather simple representations and half were quite complex. There were four themes that were identified in the Family Lifelines.

Pictorial chronology. First, most of the Lifelines provided a pictorial representation of the chronology of family experiences. This may have aided the family in organizing their thoughts. As a researcher, it helped to clarify several of the events discussed in the interview and gave a structure to the family events.

Though each Lifeline was unique, there were three common themes identified in the Family Lifelines. These included: family well-being mirrored the child's well-being; stress was portrayed; and lastly, family well-being was affected by the severity of the illness.

1. **Family well-being mirrored the child's well-being:** For example, if the child was having difficulty, the family life was altered. The Lifeline from family #44 illustrates this concept (see Appendix S- #44**).** The child's overall well-being is reflected in the family's well-being which is portrayed in the happy and sad faces.
2. **Stress.** It was thought originally that there might be a temporal pattern to the family's experience in which there was a general improvement over time, but in fact this was not the case. Rather, what was most common was constant stress represented by peaks and valleys of some of the horizontal time lines, and/or a large amount of writing on the Lifelines depicting the many events in the family's life.

   The Lifeline from family #34 illustrates the family ups and downs or peaks and valleys (see Appendix T- #34). Here, with one of the older children in the study, one can see the stress that the family had experienced, particularly when the child was 12-13 years old during adolescence. Again, though it might be expected that there would be a general improvement over time, instead there are constant peaks and valleys that continue to the present time.

   The Lifeline from family #39 (see Appendix Q- #39) also illustrates the constant stress the families experienced. Here strain is illustrated by the very busy

Lifeline portrays the many family experiences. This Lifeline was so busy, in fact, that a magnifying glass was needed to decipher the small handwriting.

This theme was evident in several of the Lifelines as many of the families wanted more paper space to record their story. Though the Lifelines were originally printed on standard letter size paper (8½ by 11 inches), half of the families printed copies of the Lifeline and taped two or three together to obtain more writing space. In response to this, I started to print the Lifelines on legal size paper (8½ by 14 inches), but this was still not large enough for some and they continued to tape the legal size Lifelines together to obtain more room to describe their experiences.

3. **Family well-being was affected by the child's severity of illness.** There was a hint that family well-being was affected by the child's severity of autism. This observation is based on only five Family Lifelines, but there appeared to be a correlation. Though all the children were deemed to have "severe autism" three of the children had fewer functional challenges compared to the other children. In these families, the Lifelines portray their infancy as a relatively happy time for the family. There are notations such as, "Healthy Baby Boy" (44ALLC93; see Appendix-S #44)**,** "Best Baby Ever" (34ALL111; see Appendix T- #34) and "Very good baby, everything was perfect" (38 LL65; see Appendix U-#38). This was followed by an erratic up and down quality of life when the child started to have autism-related issues.

   In contrast, for the families of the two children who had the most significant functional challenges and used few words for communication, the family crisis appeared to begin from birth. In these Lifelines notations occur soon after birth, such as, "Child never sleeps" (39ALLC94; see Appendix Q-#39) and, "We were excited to have a baby in the house. He was immediately challenging though. Also his sleep patterns were HORRIBLE" (41BLLC48; Lifeline #41, not included for anonymity purposes). This indicated that the severity of the condition was reflected in FQOL from birth to the present time.

Reflections on Family Unit Interviews

There were six families (6/11) that participated in family unit interviews. Table 1 (referenced in Chapter #2) is a summary of the actual family unit interviews that occurred. Those that did not participate in family unit interviews specifically stated that their schedule was very busy and they usually relied on each other for child care so meeting together as a family would be a challenge. In four out of the six, all the family members identified participated and in two families there were a few members missing, specifically two friends and a maternal grandmother.

The family interview always followed the individual interviews as I found the individuals wanted to become familiar with me and gain trust before they let me interact with the rest of their family. The length of time of the family unit interview varied greatly between 15 minutes and 3 hours, but the average was 90 minutes. I found that in the family interviews that immediately followed individual ones, participants were often very exhausted and the interview was rather brief.

Nineteen home visits were conducted at the homes of the 11 families. Though I attempted to make two visits and separate the individual and the family interviews this was often not possible due to the time constraints of families. Therefore in 5 families (5/11) I made only one home visit, in 4 families (4/11) I visited the home twice, and in 2 families (2/11) I made three home visits.

In these interviews in general, I allowed the families to share what they thought was most important. Also, an attempt was made to ask questions of the entire families that had not been discussed previously. One question that was well received was, "If you could share something with each other that you haven't shared before what would you say?"

Some examples follow. Here a grandmother and her daughter (mom) spoke together:

> Grandmother: I say ‘I love you a lot,’ and I do love you and just admire you. I guess that’s what I would say to you, but I think I’ve said that in the past. I hope you feel that.
>
> Mom: Yep.
>
> Grandmother: And then it would be that I hope you can forgive me my sins when I say things that should have been filtered, and say, ‘Oh, Lord, she must have been in a bad place that day.’(34CC16)

Here is an example of a father speaking with his wife:

> I'll say that [wife] is a partner, and there's not one of us who is over the other. We both have tried in the past, to – I know I have, probably – to take the reins and be in charge, but raising… kids with autistic disabilities is definitely something that requires two people working together; and always being able to understand and feel what the other person's feeling; and always being self-aware, and making sure that they're not just pushing their own agenda, but actually listening and understanding what's best for the children. (39CC1)

And another heartfelt comment from another father to his wife:

> Dad: I would like to say I think you do a wonderful job; you do a lot more than I do, and I love you for it.
>
> Mom: Oh, thanks, honey; you do too.
>
> Dad: And, I know I cry more than you do.
>
> Mom: I think I cry a lot more when I’m putting him down to sleep and stuff like that; I tend to do it more in isolation. (44CC1)

My general reflections on the family interview is that it is beneficial to bring the family together for dialogue, but in general I obtained more heartfelt information when each individual was alone versus when they were speaking together. The individuals seemed to appreciate their privacy and were more guarded when other family members were present. An example is that when I spoke with someone and another family member would walk by or gently interrupt us, the interviewee (usually the dad) would sometimes say, “*I’m* talking with Jocelyn right now!” emphasizing the need to be alone. The conclusion was that it was paramount to hear more voices telling the story, but it was not particularly important to hear all the voices at the same time.

Reflections on the Home Visit

Taking into consideration several decades experience as a pediatric nurse practitioner and the year-long study as a LEND Fellow, nothing prepared me for what I discovered in this research. From my first home visit to the last, I encountered children who had *very* significant behavior and communication challenges, and families that were extremely stressed and dealing with inordinate isolation.

The home visits were vital to understand the full family experience. Entering someone's home is like watching a play with a backdrop painted by the family. I think it is the closest approximation to the truth that a researcher can obtain because the family feels relaxed in their own environment and they share much more than they would in a clinic setting.

At the culmination of each of the 19 home visits I wrote or audio recorded field notes which included both descriptive information, e.g., description of the home environment, and subjective information, e.g., my impression of the visit.

There were two themes in my field notes. First, many of the home interiors and exteriors were sparsely decorated. This may have been related to the fact that the children could break knickknack's, etc., so they were stored away. Whatever the reason there was usually a simple, Spartan environment both inside and out of the homes.

Second, despite the simple interiors, there was a warm feeling of compassion or love that was rather palpable when entering the homes. It was clear that these children were surrounded by support and concern.

Recommendations From the Families

All of the families shared suggestions concerning how things could be better in the future. Table 6 is a summary of the recommendations that were shared. They included advice for parents, friends, the public, and health care providers. Many of the suggestions may prove helpful for nurses as we begin to make plans for how to better provide care for the families of children with severe autism.

Table 6

Summary of Recommendations

Advice to Other Parents	Advice to Friends	Advice to Public	Advice to Health Care Providers
• Stay positive • Enjoy your child • Find friends with similar issues • Organize gatherings for families who have children with autism • Get involved in health care policy • Sign up for wait lists early • Explore all treatment options • Assemble a provider team you like and can call • Trust your instincts, if you don't like a provider, make a change • Prepare children for clinic visits, e.g., social stories • Remember there is a large teaching window, not a small one • Appreciate child's short and long-term accomplishments • Take care of yourself	• Ask families of a child with autism, "What can I do?" vs. doing something • Be flexible, e.g., leave voice messages vs. talking by phone • Remember all children have challenges	• Don't treat parents like bad parents • Validate caretaker then offer to help, e.g., with a meltdown • Ask, "How can I help?" vs. offering a service • Treat child like any other child e.g. ask what they like vs. only asking about their problems • Don't give advice • Be compassionate/understand difference • Learn about severe autism • Train store staff about autism • Usher families to front of checkout lines in sores • Legislation to fully cover autism costs	Clinic Visits: • Easier/ earlier diagnosis • Need coordinators/advocates for families from the time of diagnosis • Need interpreters for medical information • Be prepared for child: Develop a code system to alert providers that child has autism • Decrease wait times • Prepare children for visits and help parents prepare the children, e.g., social stories • More time for visits and use the same room • Need extra staff help in clinic • Use a team approach for scheduling and counseling • Provide phone advice vs. need to visit the hospital • Provide a written summary of the clinic visit • Allow more family input in decision- making • Combine visits when possible • Better follow-up from clinic

Advice to Other Parents	Advice to Friends	Advice to Public	Advice to Health Care Providers
• Arrange for a food delivery service • Call PACER Center for assistance with coordinating care • Schedule events early in the day, including clinic visits Partner Issues: • Don’t blame each other • Respect each other’s roles • Be flexible with chores • Apologize when needed			General: • Be patient/listen • Treat child as an individual • Parents need more mentors • EMTS should know who has autism locally • Provide respite care for parents • Encourage child’s physical activities • More support/play groups • Learn more about autism • Don’t ignore severe autism • Better dental care • Accept various types of treatment ideas • Provide home visits • Include autism in newborn screen • Ask parents vs. give advice

Chapter 5. Discussion of the Findings

Overall Findings

The aim of this study was to explore the lived experience of families of children with severe autism by both narrowing the focus to only include children with severe autism and to broaden the scope by interviewing more than one family member in order to gain a more expansive understanding of the family lived experience.

There were six essential themes identified in this study. The first theme identified was the family experiencing autism as a mysterious and complex disability. The families dealt with inaccurate stereotypes that the public held about autism and the stigma or shame that they often experienced. Autism is often misunderstood to be to be a mild condition because of preconceived ideas from the popular culture such as movies like *The Rain Man* or *Temple Grandin,* whose protagonists are highly intellectual verbal individuals with mild autism. In addition, autism is an invisible condition. Families shared that when their child had tantrums or meltdowns others did not recognize that the child had autism because it was not a “physical disability,” so the families often felt stigma or shame. Subsequently families needed to constantly educate others about autism to explain why the child was behaving in such a manner.

They shared the unpredictability of the child’s behavior and the abrupt changes they faced day-to-day and throughout the child’s life, e.g., the child suddenly losing the ability to talk. They also discussed the many diagnostic challenges they faced, including the dilemma that the etiology remains unknown and that testing for these children is difficult because their behavioral and communication challenges, which often made standardized testing impossible to complete.

The next theme included the family dealing with the severe behavioral issues of their child. The families shared their concerns that as the child grew, his or her behaviors became more difficult to manage. They discussed a panoply of significant and often startling autism-related behaviors that they encountered each day, including self-injurious behaviors such as head banging, biting their own fingers and arms, throwing themselves into furniture, and picking at their own skin resulting in open lesions. It also included harm to others, such as pinching, hitting, and biting, which resulted in welts and bruises; head butting which yielded a broken nose; toy throwing which caused a black eye; and generally attacking family and strangers. Behaviors caused destruction to their homes, such as holes in the walls and damage to furnishings in the home, e.g., smearing feces on furniture.

In addition to behavioral challenges, the families experienced the heartbreak of dealing with a significant lack of communication with their child. All of the children had profound communication deficits. A few children were nonverbal and a few could use simple sentences, but the majority had only a few words to their vocabulary and none of the children could carry on a meaningful conversation. For many there was a delay of several years (e.g., 7-9 years) before they had recognized a parent by calling her "mom," and some had still never said this. In addition, many did not show affection like hugging, but rather used nonverbal communication such as a head tilt, fist bump, or rough play.

This lack of communication left families wondering what the child was thinking. The family members worried that they would not be able to help their child if they became ill because of the child's inability to communicate basic needs. Subsequently the families often felt disconnected or isolated from the child.

Related to the severe behaviors and altered communication, families discussed the severe and unrelenting stress they experienced, which is the fourth theme identified. This was evident both in the interviews and also the Family Lifelines that provided a pictorial representation of the family's trying experience.

Many families described their lives as a "roller coaster" because of the daily challenges they experienced caring for their child. This was exacerbated by the lack of sleep described by all families because of the child's erratic sleep schedules and the need to maintain vigilance watching the child through the night. Some families described going without sleep for years after the child's birth.

They shared the frustrations of caring for an older child who acted like an infant because of delayed development, e.g., they needed to bring a diaper bag on outings. They also shared the constant need to reinforce good behavior all day, every day in an effort to model self-care and positive social skills. This involved constantly reminding and patterning behaviors for the child, e.g., "Time to get your coat," "Time to wash your hands," "Say hello," etc. This was frustrating and tiring for families.

As the families held the responsibility of primary care provider for the child, they were responsible for coordinating myriad health care providers, which resulted in additional stress. From the time of diagnosis there was little help in identifying and coordinating services. The best help came from specialty autism centers, but many families were not connected with these centers. They reported their frustration about the shortage of autism-related health care services like behavioral therapy, PT, OT, and speech each with long waiting lists. Families recounted the trials of simple visits to the doctor. For these families, one simple trip to a clinic could be exhausting because of the child's behaviors and long wait times that included tantrums and the need to hold the child down to help keep him or her calm.

The families recounted the high cost of autism care and the steep-out-of pocket expenses they incurred due to inadequate health care coverage. Some family members held several jobs to make ends meet and several needed to weigh health care coverage with employment options to procure the best medical insurance coverage.

The stress was constant; the families lived in the present moment and did not discuss plans for the near future. Although specific plans for the future care of the child were not discussed, a concern echoed by many family members was, "What will happen to my child if I die?" reflecting their concern for who would care for their child if not them?

The fifth theme identified was the extreme isolation that was related to the child's severe behavioral issues and profound communication challenges. The families discussed not being able to physically leave home because of the child's needs. They described being unable to meet with friends because of their busy schedules and inability to obtain proper childcare. They described not wanting to socialize with friends who had children who were neuro-typical because they had little in common. Families yearned to meet other parents who had a child as severely affected with autism as their own child, though this was a rare occurrence.

Frustration and isolation from school staff was common as their child was often marginalized and taught menial tasks, such as folding towels, or only drawing rather than learning educational content like other school children. Families referred to this as "baby sitting" versus "real school." Families felt further isolated from the public when their child had behaviors which were misunderstood. For example, they described being chastised over the loud speaker at grocery stores to remove their child from the store when the child was experiencing an autism-related tantrum. There was also isolation from health care providers including, but not limited to gossip about the child's behavior by nursing staff at the hospital, dismissing the diagnosis of autism by a physician, and general lack of patience by health care providers in clinic. These were the very people upon whom they depended, and yet the families felt dismissed mainly due to the health provider's lack of knowledge about autism.

In addition, as mentioned earlier, the families felt isolation from their child related to the delay and lack of communication. Families described being heartbroken by the fact that they did not know if the child realized that they were not just a childcare provider, but rather a dedicated family member called "mom," "dad," "sister," etc.

The last theme identified in this research was a strong reliance on family. In an effort to find the necessary physical and emotional support, families cobbled together hybrid families that often consisted of both nuclear and extended families and friends. This was a unique hybrid of support that seemed to help the families as they navigated through the difficulties associated with severe autism. The families in this study demonstrated compassion and empathy between the child and family members which appeared to blossom over time.

Family Lifeline discussion. The Family Lifelines gave a pictorial or graphic representation of the family's experience living with severe autism, providing a wider lens to understand the family's experience. The Family Lifelines offered a temporal chronology of family events that helped to clarify the family story.

Three themes were identified through the Family Lifeline illustrations. First, family stress was revealed in many of the pictures and was reflective of discussions in the family interviews. This was portrayed by graph-like representations that went up and down, similar to an EKG reading, reflecting the fluctuating stress throughout the family's life. Many Family Lifelines portrayed a large amount of writing and drawing that described the families' experiences since their child with autism was born, also reflecting the family's strain. In fact many families documented so many events with words and pictures that they taped several papers together to provide more space for description.

I had hypothesized that there might be a temporal relationship to the family's experience which generally improved over time. This was not the case, however, and instead stress prevailed throughout the Lifelines. This was particularly evident in the Lifeline of the eldest child of the study (13 years old) whose horizontal graph showed a downward trend in functioning during adolescence, but an overall constant portrayal of family strife (Lifeline #34; see Appendix T).

Second, it was found that the well-being of the child with autism was reflected in the well-being of the family, so that when the child was suffering, so did the family. Again, this was often represented by a spiked horizontal line graph or happy/sad faces that mirrored the child's experience.

Third, severity of autism seemed to correlate with family well-being; those with more severe autism revealed a family life that was severely impacted since birth, whereas children who appeared to be slightly little less severe experienced a relatively calm time from birth to the time of diagnosis, when challenges began. This last point needs further exploration as it involved only five Family Lifelines.

Discussion of Findings Within the Context of the Literature

In the present study the first theme identified in the families of children with severe autism was that families experienced autism as mysterious and complex condition. This included stereotypes or general beliefs held about autism, the invisible nature of the condition and challenges with testing.

In reference to the stereotype of autism, Hoogsteeen and Woodgate (2013) found that some parents perceived that autism was a very severe condition that included severe behavioral issues. These families were pleased that their children were *less* severely affected than the harsh preconceived stereotype they had of autism.

In contrast, the families in this study were found to originally hold a *milder* stereotype of autism, as did the general public, which was founded on popular movies like *Rain Man* and *Temple Grandin*. The families in this study were distressed to find that their children were *more* severely affected than the mild stereotype they anticipated.

Concerning the invisible nature of autism, Farrugia (2009) specifically researched the concept of stigma in families of children with autism and found that it was related in part to the invisible nature of the condition. They found that the public simply did not understand autism-related behaviors that occurred because it is an invisible disability. Hoogsteen and Woodgate (2013) similarly found that, especially in rural areas, families of children with autism spent a great deal of time teaching others that their child had a disability to avoid stigma associated with their child's behaviors. They called it "Making the invisible visible" (Hoogsteen & Woodgate, 2013, p. 233).

In this study it was also noted that the invisible nature led to a general misunderstanding of the condition. This was discussed by several families that recounted that others did not recognize that the child had autism and misinterpreted the child's behavior, leaving the family feeling stigmatized.

In reference to the challenges of testing for autism, standard testing was often not possible for the children with severe autism because the child could not answer the questions and/or they were not cooperative. This was reflected in the fact that almost all of the children in this study did not have formal autism testing. This was a topic, however, that was not discussed in the family research literature.

Autism-related behaviors were found to be a specific source of stress in this study and it was also reflected in the literature. In the qualitative literature, Bultas and Pohlman (2014) and Larson (2010) found fatigue among mothers due to the erratic schedule of the child, such as the child's lack of sleep. Only a few studies highlighted specific stressful behaviors such as crying, difficulty sleeping and general agitation (Desai et al., 2102; Lutz et al., 2012; Lendenmann, 2010) Although Werner DeGrace implied that behaviors were an issue in her research because parents tried to "occupy and pacify" the child due to the autism-related behaviors (Werner DeGrace, 2004, p. 547), specific behaviors were not delineated.

In the FQOL literature, autism-related behaviors were found to often inversely correlate with FQOL (Boehm et al., 2015; Brown et al., 2006; Brown et al., 2010; Davis & Gavidia-Payne, 2009; Gardiner & Iarocci, 2015; Pozo et al., 2013). This means that the more significant the autism-related behaviors, the lower the FQOL or family well-being.

In this study, however, autism-related behaviors were major findings and themes of the study, and families described behaviors that were more severe than that reported in the literature.

Autism-related behaviors included, but were not limited to: profound lack of sleep of the child and families that sometimes lasted for years, profound meltdowns, and elopement; self-injurious behaviors such as head banging and self-mutilation; significant aggression to others, including severe pinching, biting and head butting; and general damage to home property. The severity of the behaviors was a reflection of the condition itself, but the reason it was not highlighted in other studies may have been that many of the studies included a variety of disabilities that were milder in nature versus the focus on severe autism in this study.

The influence of the significantly altered communication was a major theme in this study, resulting ultimately in isolation from the child, but this was also not addressed fully in the literature. Only two studies discussed communication deficits directly and these were the two studies that included only children with more significant functional challenges (Lendenmann, 2010; Werner DeGrace (2004). Both studies found that family stress was specifically related to the child being unable express their needs. In this study however, the profound deficits in communication added to the stress the family was experiencing *and* resulted in feelings of isolation that the family felt from the child.

Stress was also a theme in this study and it was mentioned in several of the qualitative studies. In this study, unrelenting and severe stress was multifactorial. It related to the constant nature of providing hands-on care and daily education, e.g., teaching activities of daily living and modeling positive social skills. Similarly, two other qualitative studies described the constant nature of providing daily care for the child including planning/preparing for outings and providing the direct complex care (Bilgin and Kucuk, 2010; Safe et al., 2012).

Coordinating services was also noted as a significant stress in this study as the families had limited assistance from health care providers to assist them leaving the family as the main provider. The strain of coordinating services, long wait lists and difficulty obtaining services were found in other qualitative studies (Bilgin & Kucuk, 2010; Bultus and Pohlman, 2014; Mulligan et al, 2012; Safe et al., 2012).

Cost was another source of stress that was identified here and in the qualitative research (Lutz, et al., 2012; Phelps et al., 2009; Safe et al., 2012). This study described how families dealt with their financial issues by taking on additional work and only considering employment opportunities that offered the best medical coverage.

Concern for the future of the child and who would care for the child when the parents were no longer alive was also revealed as a stressor in the qualitative literature (Desai et al., 2012; Kent, 2011; Phelps et al., 2009). This was a very significant concern verbalized by many of the families in this study as well.

In this study, however, the stress appeared more pervasive, constant, and severe than that cited in the literature. Again there were many reasons for this stress as highlighted above, but additionally the severe behaviors, profound communication deficits of the children, combined with the constant lack of sleep, made for a potent combination that was unparalleled in most of the literature that was reviewed. The exception was the study by Werner DeGrace (2004) who again included only those with severe autism, and found a lack of family cohesion and profound family strain.

Isolation was found in this research and it was also described in the literature. Families of children with autism experienced isolation especially from friends and the public (Phelps et al., 2009; Luong et al., 2009; Safe et al, 2012). Some studies found families generally avoided situations outside the home that were uncomfortable for the child and family (Larson, 2010; Lutz et al., 2012; Schaaf et al., 2011).

In the present study families experienced isolation and rejection from health care providers who were frequently critical, impatient, and ignorant about severe autism in general. This seemed to dovetail with the dissatisfaction families reported with health care services described in several of the qualitative research studies (Bultas & Pohlman, 2014; Hoogsteen & Woodgate, 2013; Mulligan, et al., 2012; Phelps et al., 2009; Safe et al., 2012). Phelps and colleagues (2009) particularly found that parents felt their voices were not heard by health care providers, a finding, shared in this study. This overall dissatisfaction with disability services was also described in the FQOL literature in which there was a general dissatisfaction with external services, such as health care or school services that the child with the disability received (Brown et al., 2006; Brown et al., 2010; Clark et al., 2012; Samuel et al., 2012a).

Again, however, the isolation found in this study appeared more severe than that described in the literature. Here families shared being barely able to leave home with the child due to the difficulty of bringing the child to an unknown and potentially unsafe environment. Other family concerns included that the child might injure someone, the time constraints involved in traveling outside the home, and/or the lack of proper daycare for the child. In addition, there was the element of isolation from the child, which was not found in the literature.

A strong dependence on family was found to be a theme in this research. There was a strong reliance on both the nuclear and extended family found in this study, to the extent that the families often formed hybrid families. The connection to the nuclear family was echoed in both the qualitative research and the FQOL research, though there was little discussion about the importance of extended family.

In the literature, closeness or bonding of families was found in several studies (Bilgin & Kucuk, 2010; Kent, 2011; Lendenmann, (2010); Luong et al., 2009; Phelps et al., 2009). Bilgin and Kucuk (2010), for example, noted mothers discussed a cohesiveness of the family. Some found that learning about autism and caring for child with autism together as a family was a bonding experience (Lendenmann, 2010; Luong et al., 2009). Phelps and colleagues (2009) found that although there was family strain, there was also a special bond that the family shared. There was little to no mention of extended family supports, however, in these studies.

In the FQOL literature (Brown et al., 2006; Brown et al., 2010; Clark et al., 2012; Davis & Gavidia-Payne, 2009; Rilotta et al., 2012) satisfaction with family life was an important factor. Davis and Gavidia-Payne (2009) was the one research study to specifically mention the important role of extended family members and noted that their support was more important than the support from friends.

As mentioned, there was little discussion in the autism literature about dependence on the extended family and the building of hybrid families with those outside the nuclear family, as highlighted in this research. In fact most studies, though they found a bonding of the nuclear family, did not discuss the involvement of the extended family. This may be due to the fact that in several studies they defined family as limited to the nuclear members.

Lastly, family compassion was identified as a subtheme in this research study; while it was discussed in the literature, there appeared to be more of an emphasis on spirituality and religion than compassion/empathy itself.

Many of the qualitative studies discussed positive outcomes that families developed from the experience of living with a child with autism or a disability. There was discussion of experiences like personal growth (Bultas and Pohlman, 2014) and acceptance for what you have and who the child is (Dupont, 2009; Lendenmann, 2010; Lutz, et al., 2012; Safe et al., 2012).

In this literature there was more reference to spirituality and religion versus compassion. In Dupont's (2009) research, for example, it was found that a few families discussed religion directly, but all discussed having faith in some form. Some families found prayer and God important (Luong et al., 2009) and some felt God had chosen them to specifically care for the child with autism (Dupont, 2009; Lendenmann, 2010; Phelps et al., 2009).

Additionally in the FQOL literature the domain of "values," which includes the topics of religion, spirituality, culture and personal beliefs, was an important factor in FQOL in many families of children with autism and other disabilities (Boehm et al., 2015; Brown et al., 2006;

Brown et al., 2010; Rilotta et al., 2012). One study discussed that strong religious faith in particular was a strong predictor for FQOL (Boehm et al., 2015). This study on children with severe autism did not find spirituality and religion to be particularly associated with the families' coping strategies.

In only two studies was compassion or empathy discussed similarly to this study. Phelps and colleagues (2009) directly discussed compassion that the families gained for each other and Bultus and Pohlman (2014) discussed empathy that the families acquired for others' difficulties.

Lastly, the Family Lifelines demonstrated that severity of autism may affect family well-being since those children with the most significant functional challenges seemed to have a difficult time since birth. This was supported in the FQOL literature, as the more severe the disability, the lower the overall FQOL or family well-being (Boehm et al., 2015; Gardiner & Iarocci, 2015; Pozo et al., 2013; Wang et al., 2004).

In summary, this research found that family experiences were extremely stressful and stark, and this extreme was not reflected in the literature. In the qualitative research, in fact, several studies aimed to understand the experience of resilience, positive outcomes, or "silver linings" in the families of children with autism (Bultas & Pohlman, 2014; Dupont, 2009; Mulligan et al., 2012). Likewise in the FQOL literature there was a slightly positive outlook relating to the results. One study did reflect the severe stress of living with a child with severe autism, as was found in this research (Werner DeGrace, 2004).

New Literature That Supports the Findings

As much of this study focused on the importance and challenges of assessing severity in autism, it is of interest that a recent study is attempting to tackle this assessment challenge. In this subsequent review of literature one study was identified that discussed the difficulty of assessing autism severity (Gardiner & Iarocci, 2015). A recent research study by Zablotsky, Bramlett, and Blumberg (2015) attempts to understand how autism severity is assessed by families. The researchers sent standard rating scales nationally to mothers who had a child with autism and who had previously participated in national data collection on children with special health care needs. They subsequently assessed autism-related behavior and family impact. The results revealed that autism severity assessment by the family had little to do with the actual symptoms or behaviors of the child, but more to do with the impact of the child's condition or behaviors on the family. This supports the need to evaluate autism severity in relation to the child's functional challenges within the family, and also the need to explore the effect of severity on the family system.

The effect of profound verbal and nonverbal communication in childhood autism on the family is another topic of present research. Pioneering work includes understanding specific speech and language among children with autism (Ricks & Wing, 1975). The effect of altered language on the family was found in one recent study in Spain. This research assessed the language comprehension of 26 nonverbal children with autism compared to 26 neuro-typical children that were matched for age vocabulary. They found that overall lower language comprehension and severe communication challenges in the children with autism correlated with lower overall family well-being (Garrido, Carballo, Garcia-Retamero, 2015). This is an area in severe autism that warrants further research.

The idea of including extended families in autism family research and the formation of hybrid families are other topics that are beginning to receive attention in the literature. Several authors recently have discussed the limitations of present autism research because it generally does not include extended families (Cridland, Jones, & Magee, 2014; Kahana et al., 2015). Kahana and colleagues (2015) noted this deficit in the autism family literature and predicted that grandparents may play a pivotal role in supporting the family, though they are less commonly included in the research.

One study specifically addressed the importance of grandparents in raising children with autism and found that grandparents helped the nuclear family develop resiliency and strength

(Blanche, Diaz, Barretto, & Cermak, 2015). There is certainly room for more family research that includes and addresses the role of extended family members and friends in providing support networks.

Compassion is another topic that is presently under investigation within the families of children with autism. One researcher conducted two concurrent studies with two large cohorts of mothers of children with autism (Conti, 2015). These mothers were compared to a control group of mothers who did not have children with autism. The results revealed that the mothers of the children with autism had more compassionate parenting skills, better understanding of their children and more confidence as parents. Maternal satisfaction was found to be closely linked to compassionate parenting.

These findings are similar to the work of Jean Vanier, as described by Sider (2012). Vanier discussed the concept of noncompetitive anthropology based on the disability experience. This supports the notion that we become better individuals by participating in compassionate, accepting relationships with others who are vulnerable, such as those with disabilities. Vanier founded the International L'Arche Projects that provides opportunities for others to care for people with disabilities. An example of this compassionate, interdependent relationship, according to Vanier would include a family caring for a child with severe autism.

Implications for Nursing and Health Care Practice and Education

The information from this research can be used to provide direct care and psychological support to the child and family with severe autism and to the family, and may have direct implications for the development of health care policy.

Direct support to the child with autism may include, first, recognizing that many children who come to a well-child clinic or hospital may also have autism. This is important to identify because autism is often an invisible yet common disability, and may be overlooked in the health care setting. For example a child may be admitted to a hospital with a concurrent syndrome such as Fragile X or Rett's syndrome, and may also have autism (these often co-occur). Recognizing symptoms of autism will help to provide appropriate care for the child.

Further direct care may include spending more time with the child to prepare the child for routines and procedures in the clinic or hospital. An example is the use of "Social Stories" or photo stories of the people the child may meet and the procedures that they may encounter at the clinic or hospital. Because the children are often frightened of change and adhere to strict routine, allowing the child to remain in one room that has less stimulation, e.g., soft lights, and quiet music or silence, would also be beneficial. Scheduling the children with autism earlier or later in day when it is quieter might be less disruptive to the child, family and other families that visit the clinic or hospital. Shorter wait times for the child in clinic and longer times scheduled for the visit would be greatly appreciated by the child and families.

Further suggestions by the families in this study to health care providers, included instituting a color-coding system in clinic to alert health care providers to children who have autism so that the same room could be used rather than switching rooms. This could also serve to alert health care staff that more providers may be needed to assist the child with special health care needs in clinic.

Other suggestions about direct care were to provide better and more humane dental care, and to encourage families to participate in well-child prophylactic care such as dental hygiene, physical activity and nutritional health. Families also recommended that health care providers learn more about severe autism in general so the children are better understood and receive more patient and empathetic care.

The research findings may be used to support the family of the child with autism in new ways. On a local level, employing coordinators or advocates to assist families in obtaining and organizing health care services would be an important intervention to help families. These advocates would need to be knowledgeable about local services and federal and local funding sources available.

Families also identified the need for assistants in the clinic who can interpret the clinic visit and document all that transpired. This is being instituted in oncology clinics and could be very beneficial in autism clinics as well. In addition, using a team approach to coordinate future clinic visits would be helpful to streamline services, save the family time and money, and hopefully eliminate duplicate or unnecessary services. Another way to support families may include using phone triage rather than clinic visits when possible to help families avoid traveling to the clinic or hospital.

Assisting families in obtaining more supports, e.g., support groups or phone/e-mail contacts, could be another outcome of this research, since so many families felt isolated from others. Families also noted the need for mentors in their lives. Organizing mentors of parents who have experience raising a child with autism might prove an important resource for families new to caring for a child with autism and help the mentor as well.

In addition, as families experience such severe strain, organizing or identifying short-term respite care for the child with autism could be helpful, as could psychological support from social workers, psychologists, family, and friends. Home visits by clinic staff might be beneficial to gather more information about the family and also lend additional assistance.

From an education standpoint, sharing the family recommendations from this research with health care providers might prove very instrumental to raise awareness of providers about family needs, e.g., the need to have patient health care providers who are empathetic, take time to listen, and ask parents for their input versus giving advice.

Lastly, this research may prove a catalyst to health care providers to effect policy change. One obvious intervention that would help families would be to increase the number and/or scope of autism specialty clinics and services across the state to alleviate long wait lists to simply obtain autism testing and health care related services.

The use of a comprehensive autism treatment center model might provide centralized services so the families can receive several health care services at one time in one place. The comprehensive care model is used worldwide in hemophilia and has had excellent outcome results. Comprehensive autism centers could serve to direct and organize ongoing autism care and families would recognize them as a place to visit at least annually for direct care and support.

The families also noted a need for more behavioral therapy support services (e.g., ABA) and personal care assistants (PCAs), but both services are in short supply and often not reimbursed by insurance. Securing state funding for these services would certainly be beneficial to these families.

These are just some of the issues that need to be addressed by health care providers to effect policy changes at the state and national levels. It is the responsibility of all health care providers to use this information to make policy changes for these families. Health care providers are by definition leaders and it is hoped that they use information from this research to educate legislators about the realities faced by the families of children with severe autism. Health care policy should be evidenced-based, but if policy is based on milder forms of autism, then it is not accurate for one third of the childhood autism population who are left without proper health care policy representation.

Implications for Future Research

There are four specific topics identified in this research that warrant further research. The first is the need to understand the general experience of families living with a child with severe autism. The experiences that were shared in this research were more stressful overall than the experiences defined in the previous literature and it is doubtful that this type of information would have been evident by using a quantitative study design. This points to the need for more qualitative studies to explore the phenomenon of living with severe childhood autism. Longitudinal and ethnographic studies would help to further illuminate the family's lived experience. In addition, larger studies that use mixed methods should be conducted so that data can be generated to support health care policy. Future research using qualitative or quantitative design needs to consider how the severity of the condition of the child with autism is evaluated and defined.

More research is warranted on the effect of the child's limited communication on the family. The lack of verbal and nonverbal communication seemed to affect the family's connection with the child, and this needs to be more fully understood. A simple question might be, "How can bonding be promoted between child and family when there is little verbal and nonverbal communication?" Another question might be, "Is the child's receptive capacity greater than their verbal capacity and if so, how can this be assessed and harnessed to promote connection between the child and the family?"

There is also a need to explore the concept of the hybrid families in severe autism. For example, "Do other families of children with severe autism forge these hybrid families?" and if so "How do they sustain these relationships? An additional important question is, "What can we do as health care providers to promote these family supports?"

The concept of compassion and empathy should also be explored further. There is an area of research that suggests that interacting with others through compassion is a primary source of well-being. Perhaps these families have something to teach others about acceptance and empathy that will serve as a guidepost to other families of children with chronic illness who seek individual and family well-being.

Critique of the Study

Strengths of the study. There are several strengths of the study that have already been discussed, but they will be summarized here. First, only children with severe autism were included in the research and severity was assessed and described very carefully to provide a more robust understanding of the child's functional capabilities.

In addition, there was no instrument to easily assess severity of autism so I developed one with the help of my colleague. This proved to be a relatively easy assessment to use and yielded rather good results because all the children in this study had significant functional challenges.

Allowing the family to define their family members was another strength of this study. Further, interviewing some of the families as a family unit was also an important change from previous research and added texture to the lived experience of severe autism.

All of the interviews were conducted at the families' homes. Many of the studies in the review of the literature utilized home visits, but some studies did not specify where interviews were conducted, they were held at schools or cafes/restaurants, or some were conducted by phone. Being in the actual home of the family provided an opportunity to paint a more vivid picture of their daily lives.

Another positive aspect in this research was that the researcher had limited clinical experience in autism, but a great deal of general clinical experience. Having limited autism experience provided a simpler view of the family experience. For example, health care providers who deal with autism regularly may normalize some of the child's behaviors. I, however, had few preconceptions about severe autism so I was able to observe it with a fresh perspective.

Conversely, having a great deal of general clinical experience in pediatric chronic illness was a strength. Because I had years of experience speaking with families of children with very significant chronic illness in the clinic and hospital settings, I had the confidence to interview families not previously known to me. It took a great deal of experience to facilitate the conversations in a relaxed manner that encouraged honest dialogue. I feel that I would not have been able to accomplish this as a more novice clinician.

Another strength of this study was the use of phenomenology as a research method, instead of relying on a questionnaire. This allowed the family to convey their story in an open-ended way, instead of answering questions already selected in a questionnaire. In fact, in most of the interviews it was made clear that the research was about *their* story and they were in control of the content. This helped to facilitate the relationship with the families and it allowed for honest dialogue.

The use of the Family Lifelines also provided another tool to understand the lived experiences of the families and it was a creative outlet; many participants noted that they enjoyed completing them.

Lastly, the iterative process of this study was also one of its benefits. Being able to slightly amend the study criteria made the research more reflective of the population being studied. For example, being able to include those family members who lived outside the home and were not from two-parent families allowed those family members to participate, which enriched and informed the study.

Limitations of the study. There were several study limitations. First, the research included a rather small sample so it might not be reflective of the larger population of families of children with severe autism. However, the purpose of qualitative research is to investigate the context of an experience so that new knowledge can be transferred to other like contexts.

The average time since diagnosis to the time of the interview varied within the study with a mean of 5 years. This could be considered a limitation of the research because the varied times since diagnosis could result in very different family experiences. The long average time since diagnosis is theoretically very different than the experience of a family who recently received the autism diagnosis. On the other hand, a temporal perspective of the trajectory of the severe autism was illustrated.

A limitation is that only one sibling, aunt, and friend were included in the study and it would have been interesting to have more representation from siblings, aunts and friends. Though it was beneficial to have broader representation than only the mothers, mothers still made up half the participants and females still outnumbered males, so that there was unequal gender representation.

Another challenge of the study was that, though the focus was severe autism, autism itself is still a broad heterogenic developmental disability consisting of a wide a variety of symptoms. This may limit the transferability of the findings to other children with severe autism as those children may have somewhat varied symptoms, behaviors, and communication patterns.

Conclusion

The aim or purpose of this research was to interpret the experience of families who live with a child with severe autism. The goal of the study was to narrow the focus to include only children with severe autism while at the same time broadening the parameters to include all of those who were considered family. The results overall were somewhat startling as they were qualitatively different than much of the experiences reported in the literature, which often included children with a milder disability. The study findings illuminate the difficulties and challenges of families who have a child with severe autism. This new knowledge has important implications for nursing and health care practitioners to develop strategies to provide quality care to children with severe autism and their families. Additionally this knowledge can contribute positively to the development of new policy that can ultimately provide needed resources for children with severe autism and their families.

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Appendix A

Challenges of Defining Autism Severity

Table 1

Challenges to Defining Autism Severity

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1. Nature:
   - Non-homogenous spectrum of symptoms
   - Occurs with comorbidities and syndromes
   - Invisible vs. visible disability
   - Symptoms/functional challenges change over time
   - Subjective nature of severity: what is severe to one family may not be not severe to another
   - Stigma: People may not wish to refer to a condition “severe”

2. Testing:
   - No uniform biologic test or treatment, rather testing based on symptomatology
   - Testing nonverbal children is challenging
   - Tests are usually lengthy

3. DSM-5 Definition:
   - Lacks validity
   - Categorizations have changed, e.g., Asperger’s was once considered a separate entity
   - Subjective definition of severity
   - Based on rating of symptoms that include social communication and restrictive repetitive behaviors vs. functional challenges

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Based on: Reiff, M. I., & Feldman, H. M. (2014). Diagnostic and statistical manual of mental disorders: The solution or the problem? *Journal of Developmental and Behavioral Pediatrics*, *35*(1), 68-70.

Appendix B

Family Quality of Life (FQOL) Studies in childhood autism: Research and Results 2003–2015

Study Authors, Year, Place of Study and Study Description	Child Total & Mean or Age Range in Years	Type and Severity of Disability	Survey respondent total & relationship to child	FQOL Methodology, Type of Design and Results
Boehm, Carter, & Taylor, (2015) USA • FQOL during transition to adulthood for intellectual disabilities and autism	*Total:* 425 13-21 years Mean: 16 yrs	*Type:* • Autism: 43% (182) • Intellectual disability: 38% • Both: 12% • Other disability or blank 7% *Severity:* Not clearly reported: • Speech as mode of communication 84%, • Rare or no challenging behavior in public: 63%	*Total* = 425 Age range: 31-72 Mean: 48 Mother = 368 Father = 40 Grandparent =11 Other = 7 No information = 1	Beach Family Survey: Cross sectional quantitative design • Overall FQOL satisfaction rated high • Strong religious faith had strongest positive correlation with FQOL satisfaction • Behavior challenges and increased support needs had negative correlation with FQOL
Brown, R., MacAdams-Crisp, Wang, & Iarocci (2006) Canada • FQOL in families of children with Down syndrome, autism, and a control group	*Total* = 69 Mean: 8 yrs	*Type*: • Intellectual: o Down Syndrome 48% o Autism 26% (~18) o Control 26% *Severity:* • Down Syndrome 11% moderate or severe • Autism: 35% moderate or severe	*Total* = 69 Mother and father	Family Quality of Life Survey (FQOLS): Cross sectional quantitative design • FQOL satisfaction higher in control group in all FQOL domains • Autism compared to both groups: Lower in overall FQOL satisfaction-behavior thought to be a factor; high satisfaction of values (spirituality/religion). • Autism + Down syndrome: High satisfaction with family relationships, Low satisfaction with disability services

Study Authors, Year, Place of Study and Study Description	Child Total & Mean or Age Range in Years	Type and Severity of Disability	Survey respondent total & relationship to child	FQOL Methodology, Type of Design and Results
Brown, R., Hong, Shearer, Wang, & Wang (2010) • FQOL in several countries in families of children with a disability	*Total* = 270 Mean: 9 yrs Canada: Mean: 8 yrs Australia: Mean: 15 yrs Korea: Mean: 8 yrs Taiwan: Mean: 5 yrs	*Type:* • Intellectual and physical: o Autism o Down Syndrome o Cerebral Palsy o Other (amount not specified) *Severity:* • Not specified	*Total* = 270 Canada: N= 51 Mean: 40 Australia: N= 55 Mean: 49 Korea: N=81 Mean: 38 Taiwan: N=83 Mean: 38	Family Quality of Life Survey (FQOLS): Cross sectional quantitative design • FQOL satisfaction higher in control group in all FQOL domains • Autism compared to both groups: Lower in overall FQOL satisfaction-behavior thought to be a factor; high satisfaction of values (spirituality/religion). • Autism + Down syndrome: High satisfaction with family relationships, Low satisfaction with disability services
Clark, Brown, I., Karrapaya (2012) Malaysia • FQOL in Malaysia in families of children with disabilities	*Total* = 52 Mean: 8 yrs	*Type:* • Intellectual and physical: o Down syndrome/ Intellectual 39%, o Cerebral palsy 31%, o Other 24%, o Autism 8% (4)* *Severity:* • ~80% Level of support severe • ~30% Level of communication severe	*Total* = 52* Mother = 43 Father = 1 Other = 1 (*Total does not equal 52)	Family Quality of Life Survey (FQOLS): Cross sectional quantitative design • High satisfaction with family relationships & low satisfaction with disability services

Study Authors, Year, Place of Study and Study Description	Child Total & Mean or Age Range in Years	Type and Severity of Disability	Survey respondent total & relationship to child	FQOL Methodology, Type of Design and Results
Davis & Gavidia-Payne (2009) Australia • Impact of professional support on FQOL in families of children with disabilities	*Total* = 64 Mean:4 yrs	*Type:* • Intellectual and physical disabilities: o Autism: (34) o Speech + Language impairment: (28) o Developmental delay (19) o Syndromes (4)* *Severity:* • 16% severe	*Total* = 64 Mother = 60 Other = 4	Beach Family Survey: Cross sectional quantitative design • Severity of disability does not affect FQOL but intensity of behavior does • Disability services strongest predictor of FQOL • Support from extended family members more important than support from friends • Financial status positive correlation with FQOL
Gardiner & Iarocci (2015) Canada • Adaptive functioning and behavior problems and FQOL in autism	*Total* = 84 6-18 yrs	*Type:* • Autism *Severity:* • Mild: 52% • Moderate: 38% • Severe: ~10%	Total = 84 Mother = 75 Father = 8 Grandmother = 1	Family Quality of Life Survey (FQOLS): Cross sectional quantitative design • Better adaptive function (e. g. activities of daily living skills) had a positive correlation with FQOL satisfaction • Problem behaviors has inverse relationship with FQOL satisfaction • Family income positive correlation with FQOL
McStay, Trembath, & Dissanayake (2014) Australia • Age of child, maternal stress and FQOL in autism	*Total* = 140 Four groups Preschool N = 34, Early school N = 39 Middle school N = 40 High school N = 27 Range: 3-16 yrs	*Type:* • Autism • Asperger's disorder • PPD-NOS *Severity:* • Not defined	*Total*= 140 Mothers Range: 27-55 Mean: 42	Family Quality of Life Survey (FQOLS): Cross sectional quantitative design • Increase in behavior issues between early and middle school • Child age does not affect maternal stress or FQOL • Stress remains stable for family despite increase in behaviors and decreased professional supports

Study Authors, Year, Place of Study and Study Description	Child Total & Mean or Age Range in Years	Type and Severity of Disability	Survey respondent total & relationship to child	FQOL Methodology, Type of Design and Results
Pozo, Sarriá, & Brioso (2013) Spain • FQOL and psychological wellbeing in autism	*Total* = 59 Range: 4-38 yrs	*Type:* • Autism: 73% (43) • Asperger's syndrome: 2% (1) • Rett's syndrome: 9% • PPD-NOS: 17%* (All presently considered autism spectrum disorder) *Severity:* • Not specified	*Total* = 118 59 pair of Mothers and Fathers	Beach Family Survey: Cross sectional quantitative design • Specific behavior problems affect adaptation in FQOL • Severity of illness: negative effect on FQOL for mothers/ positive effect for fathers • Coping: fathers use avoidance/mothers use positive problem solving
Rillotta, Kirby, Shearer, & Nettelbeck (2012) Australia • FQOL in Australian in families of children with disabilities	*Total* = 42 Mean: 7 yrs	*Type:* • Variety of intellectual and physical disabilities: o Intellectual disability unknown: 38% o Autism: 26% (11) o Down syndrome: 9% o Other 21% o Cerebral palsy 5% o Fetal alcohol: 5%* *Severity:* • ~30% Level of support and communication severe	*Total* = 42 Mothers = 37 Fathers = 1 Grandparent/other = 4	Family Quality of Life Survey (FQOLS): Cross sectional quantitative design • High satisfaction with family relations and values e.g. religion • Approximately one quarter do not know where to obtain disability services

Study Authors, Year, Place of Study and Study Description	Child Total & Mean or Age Range in Years	Type and Severity of Disability	Survey respondent total & relationship to child	FQOL Methodology, Type of Design and Results
Samuel, Hobden, LeRoy, & Lacey (2012) USA • Family services and FQOL in low income minority families with children with disabilities	*Total* = 191 Mean: 12 yrs	*Type*: • Variety of Intellectual and physical disabilities including: o Other (ADHD) 38% o Intellectual: 21% o Autism: 26%(49) o Cerebral palsy: 15% *Severity:* • Not specified	*Total* = 149 Mother = 135 Father = 4 Grandmother/other = 7 Aunt = 2 Sibling = 1 61% African American 75% Poverty	Family Quality of Life Survey (FQOLS): Cross sectional quantitative design • Low satisfaction with disability services • More than half families need more help from disability services such as speech and occupational therapy, educational services, respite care, mental health • Barrier to services is lack of information
Wang, Turnbull, Summers, Little, & Poston (2004) USA • Disability severity, income and FQOL in families of children with disabilities	*Total* = 280 0-8 yrs	*Type:* • Variety of Intellectual and physical disabilities: o Speech & language: 49 % o Intellectual: 6% o Autism: 4% (~11) o Developmental delays: 14%* *Severity:* • ~12% Severe	*Total* = 264 Mothers= 234 Fathers= 30	Beach Family Survey: Cross sectional quantitative design • Severity of disability predictor of FQOL satisfaction • Family income is significant predictor of FQOL for mother, not father
Werner, Edwards, & Baum (2009) Canada • FQOL& relocation of child with a disability to a facility	*Total* = 17 13-55 yrs Mean: 31 yrs	*Type*: • All had multiple diagnoses: o Intellectual disability: 6 o Multiple intellectual and physical disabilities: 5 o Autism: 3* *Total does not equal 17 *Severity:* • 100% with behavior issues or mood disorders	*Total* = 16 Mothers = 7 Fathers = 3 Other = 6	Semi-structured Interview: Qualitative design • Stress, coping, emotional impact, family relationships noted before and after placement • Majority of caregivers report higher overall FQOL after placement and decreased emotional& physical exhaustion, guilt and worry

Totals do not equal 100% due to only partial listing of disabilities and/or those who have concurrent disabilities.

Appendix C

Qualitative Studies in Families of Children with Autism: Research and Results 2003–2015

Study Authors, Date, Location and Description	Child Total & Age Range in Years or Mean Age	Type, Severity + Severity Rating	Survey Respondent Total & Age Range in Years or Mean Age	Results	Methodology, Length and Setting of Interview
Bilgin & Kucuk (2010) Turkey • Mother's experience in raising a child with autism	*Total*: 43 36 Male 7 Female Range: 6-17 yrs Mean age: 9 yrs	*Type:* Autism and related disorders Severity: • Most with significant impairment in social, language and behavior • No severity rating	*Total* = 43 mothers Range: 23-60 yrs. Mean age: 36 yrs	• Stress and burden related to atypical behaviors • Isolation: lack of acceptance by society • Marital relationship suffers • Complexity of care challenging • Financial strain: financial support from close relatives, not emotional support	• *Methodology*: Semi-structured interview/ Phenomenology • *Length*: 30-60 minutes • *Setting:* School
Bultas & Pohlman (2014) USA • Mother's positive experiences with preschool children	*Total*: Not specified: ~11 Age: Preschool Age range: 3-6 months	*Type:* Autism *Severity:* • Borderline or clinical developmental problems • *Severity rating:* Child Behavioral Checklist	*Total* = 11 mothers Age range: 28-44 yrs Age: None	• Stress: fatigue from coordinating health care services and finding a routine for child • Isolation from friends and family • Positive results: child advocacy, positive outlook, joy in child's accomplishments	• *Methodology:* 3 Semi-structured interview over 6 weeks/ Phenomenology: Interpretive • *Length:* 1-2 hrs • *Setting:* Not specified
Desai, Divan, Wertz & Patel (2012) India • Parent's perspective of autism in family	*Total*: 10 9M/ 1 F Range: 5-23 yrs Mean age: 10.4 yrs	*Type:* Autism *Severity:* Not specified	*Total* = 12 parents 10 families Moms= 11 Dad =1 7 mothers, 1 father alone, 2 sets interviewed together Age range: 30-53 yrs	4 Temporal phases identified: 1. Celebration 2. Behavior first seem as temporary issue 3. Behavior as a permanent issue 4. Future concerns: Uncertainty	• *Methodology*: Phenomenology • *Length*:1-3 hrs • *Setting:* Various including home/clinic/school

Study Authors, Date, Location and Description	Child Total & Age Range in Years or Mean Age	Type, Severity + Severity Rating	Survey Respondent Total & Age Range in Years or Mean Age	Results	Methodology, Length and Setting of Interview
Dupont (2009) USA: Dissertation • Resilience in families	*Total*= 14 Age range: 6-29 yrs 9 M/ 5 F	*Type:* Autism = 7, Asperger's = 2, PPDNOS = 5 Severity: Not specified	*Total* = 14 parents Female = 12 Male = 2 Age range: 30-69 yrs 2 sets interviewed together	• Stress: Always vigilant/watchful • Stigma: judgment by others related to child's atypical behaviors • Family focus on child • Positive result: Appreciating child's small successes, faith/spirituality	• *Methodology:* Semi-structured interview/ Phenomenology • *Length:* Not specified • *Setting*: Family home
Farrugia (2009) Australia • Parent experience with stigma in raising child with autism	***Total*** **=** Not specified: ~16 Age range: 5-23 yrs	*Type: Autism* *Severity:* Not specified	*Total* = 16 parents Moms = 11 Fathers = 5 12 interviews: 11 mom alone; 1 dad alone; 4 mom + dad pairs	• Family focus on child's needs • Stigma: Due to invisible nature, families must explain autism to others to excuse behaviors. Feel like "bad parent" • Isolation from friends • Mourning or loss	• *Methodology:* Semi-structured interview/ Discourse analysis • *Length:* 1-3 hr • *Setting:* Most at home, 1 at work, 1 at cafe
Hoogsteen & Woodgate (2013) Canada • Lived experience of family in rural setting	Total = 33 Age range: 2-23 yrs	*Type:* Autism w/ comorbidities as ADHD *Severity:* 21% nonverbal *Severity rating:* None	Total = 28 parents 26 families Mothers = 22 alone Fathers = 2 alone Couples = 2 together	• Stigma; Due to invisible nature of autism, families must explain autism for acceptance • Dissatisfaction with health care system • Isolation • Mourning or loss	• *Methodology:* Semi-structured interview/ Phenomenology: Van Manen's • *Length:* Not specified • *Setting:* Not specified
Kent (2011) USA: Dissertation • Perceived impact on family dynamics	Total = 8 Age range: 5-13 yrs	*Type:* Autism, Asperger's, PPDNOS Severity: Not specified	Total = 8parents Mothers = 7 Fathers =1 Age range: 28-49 yrs	• Marital strain • Focus on child: Split parenting • Future worries for child • Sibling conflicts	• *Methodology:* Semi-structured interview/ Phenomenology: Interpretive • *Length*: 1 hr • Setting: All by phone except one

Study Authors, Date, Location and Description	Child Total & Age Range in Years or Mean Age	Type, Severity + Severity Rating	Survey Respondent Total & Age Range in Years or Mean Age	Results	Methodology, Length and Setting of Interview
Larson (2010) USA • Mothers perspective on vigilance	Total = 10 Age range: 3-14 yrs All males	*Type: Autism* *Severity:* All high functioning, but one *Severity rating*: None	Total = 9 mothers Age range: 27-47 yrs	• Stress/ vigilance: to help child with physical and social challenges leads to maternal fatigue • Isolation: Avoiding situations that might lead to behavioral outbursts.	• *Methodology:* 2-3 Semi-structured interview/ Phenomenology: Interpretive • *Length:* Not specified • *Setting:* Not specified
Lendenmann (2010) USA: Dissertation • Family life in preschool children with intellectual disability	Total = 15 Age range: 3-5 yrs 11 Male 4 Female	*Type:* Autism = 11 and PPDNOS = 4 *Severity*: Not specified, but all IQ 35-55 *Severity rating*: IQ	Total = 16 parents Mothers = 13 Father = 3 Age range: 26-48 yrs	• Stress: Total life change • Limited personal time related to decreased communication with child, supervision, behaviors • Positive: Personal growth, joy, hope, spirituality/faith	• *Methodology* Semi-structured interview/ Phenomenology • *Length:* Average 50 minutes • *Setting:* Parents home=15, Clinic=1
Luong, Yoder, Canham (2009) USA • Effect on family + coping in Southeast Asia parents-	Total = 14 Age range: 3-10 yrs 11 Male 3 Female (2 sets of twins with autism)	*Type:* Autism *Severity:* "Moderate-severe disability" *Severity Rating:* Not specified	Total = 9 parents 8 Female/ 1 Male	Temporal adaptation coping: • Denial • Empowerment/Redirecting energy • Reorganizing relationships • Isolation: people don't understand child • Spiritual strength/ Acceptance	• *Methodology:* Semi-structured interview/ Phenomenology • *Length:* Not specified • *Setting*: 9 face to face/ 2 phone
Lutz, Patterson, Klein (2012) USA • Family unit adaptation through the life span	Total= 16 Age range: 2-31 yrs	*Type:* Autism *Severity:* Not specified	Total=16 Mothers 10 mothers of children 6 mothers of adults	• Constant adaptation • Grief, anger, guilt, doubt; not temporal • Stigmatization; parenting ability questioned related to child's atypical behavior • Social isolation • Positive: Parent as advocate, appreciating little things, Spirituality	*Methodology:* Semi-structured interview/ Narrative analysis • *Length*: 3 hrs • *Setting*: 8 telephone interview, 8 face to face interviews

Study Authors, Date, Location and Description	Child Total & Age Range in Years or Mean Age	Type, Severity + Severity Rating	Survey Respondent Total & Age Range in Years or Mean Age	Results	Methodology, Length and Setting of Interview
Mulligan, Maccullough, Good, & Nicholas (2012) Canada • Parent experience with receiving diagnosis of autism	Total = 11 Mean age: 5 yrs	*Type:* Autism *Severity:* Variety of support services, but unspecified *Severity Rating:* Not specified	Total = 10 parents Mothers = 8 Fathers = 2 Mean age: 42 yrs	• Stress and Vigilance caring for child • Lengthy, complex adaptation to diagnosis • Steps: Something wrong> waiting>worrying> overwhelmed >grief >empowerment • Positive: Parent as advocate + case manager	• Methodology: Semi-structured interviews/ Phenomenology: Interpretive • *Length:* 1.5-3 hr • *Setting: Not specified*
Phelps, Hodgson, McCammon & Lamson (2009) USA • Qualitative analysis of caring for a child with autism	Total = 80 Mean age: 11 yrs Age range: 3-35 yrs 89% male	*Type:* Autism *Severity:* Not specified	Total = 80 caregivers 97% mothers	• Family: Strong cohesion in family vs. spouse + sibling strain • Social: Connections vs. isolation from friends • Services: School and medical dissatisfaction • Stress: Stigma, economic challenges + future care concerns • Positive: spiritual support, compassion, selflessness, advocate	*Methodology:* Qualitative Questionnaire with 3 open ended questions mailed to families /Phenomenology analysis *Setting:* Completed at home
Safe, Joosten, & Molineux (2012) Australia • Mothering a school age child with autism	*Total* = 9 Age range: 6-12 yrs	*Type:* Autism *Severity:* Not specified	*Total* = 7 mothers Age range: 29-50 yrs	• Constant stress + economic challenges • Stigma and disapproval by others related to child's behavior • Isolation • Frustration with health care supports e.g. waiting periods, high staff turnover	• *Methodology:* Semi-structured interview/ Phenomenology: Interpretive • *Length:* 90-170 minutes • Setting: Not specified

Study Authors, Date, Location and Description	Child Total & Age Range in Years or Mean Age	Type, Severity + Severity Rating	Survey Respondent Total & Age Range in Years or Mean Age	Results	Methodology, Length and Setting of Interview
Schaaf, Toth-Cohen, Johnson, Outten, & Benevides (2011) USA • Everyday routines of families: focus on sensory behaviors	*Total* = 4 Age range: 7-12 yrs	*Type: A*utism with sensory behavior issues ***Severity:*** Sensory processing measure	*Total* = 4 parents Female = 4 Male = 1 Age range: 40-43 yrs	• Need to be flexible • Isolation: Avoiding activities outside home + familiar spaces preferred by child • Family challenges: completing family activities e.g. dinner or participating in activities together	• *Methodology:* Semi-structured interview/ Phenomenology: vanManen • *Length: NS* • *Setting:* all at home
Werner DeGrace (2004) USA • Family unit experiences with severe autism	*Total* = 5 Age range: 9-10 yrs	Type: Autism *Severity*: Severe *Severity Rating:* Not specified	*Total* =14 family members Parent pair = 5 Siblings = 4	• Vigilance/ stress: Need to occupy and calm child • Family challenge: focus on autism + cannot participate in family activities as a family • Mourning: robbed of happiness	• *Methodology*: Semi-structured interview/ Phenomenology: Descriptive • *Length*: ~ 2 hrs • *Setting*: 4 at home, 1 at restaurant

Appendix D

CONSENT FORM–ADULT PARTICIANTS AND MINORS

The family experience of childhood autism

You are invited to be in a research study about what it is like to be a family member when one of the children has autism. You were selected as a possible participant because you have a child in your family that has autism. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Jocelyn Bessette Gorlin, MSN, RN, CPNP, a PhD student at the University of Minnesota School of Nursing in collaboration with her advisor, Cynthia Peden-McAlpine, PhD, ACNS, BC.

Background Information:

The purpose of this study is to help health care providers to understand more clearly what are the daily experiences and needs of parents, siblings and other family members when there is a child with significant autism. Though we have some idea of the experience of mothers, we have less understanding of what it is like for other family members such as fathers and siblings. The research question is, “What is the experience of family members living with a child who has autism?”

Procedures:

If you agree to be in this study, we would ask you to do the following things:

1. One parent will compete a “Family Lifeline” which is a picture that shows family life since your child was born.

2. One parent will answer basic questions about your family and your child with special needs.

3. Participate in an individual interview.

4. Participate in a family discussion where all interested family members will be present

The interviews will take place at the site that you choose, preferably your home. Each individual interview will last approximately 1½ hrs. The family group interview will last approximately 2 hours. The interviews will occur over at least two days, typically with individual interviews on one day and the family interview on a second another day, though the sequence may vary. All interviews will be audiotaped.

Risks and Benefits of being in the Study:

The study has several risks:

1. Asking for personal or sensitive information is very likely
2. Possible invasion of privacy is possible
3. Thinking and talking about your experiences could cause painful memories

In relation to sensitive information or invasion of privacy: You and your family member have the right to refuse participation or withdraw from the study at any time and there will be no consequences. The health care and health care related services that the child who has autism receives will not be affected in any way. During the interview, I will stop the interview approximately every 15 minutes or if I sense that there is distress to assess if you wish to continue the interview. If at any time you or a family member becomes distressed and wish to stop the interview at any time you/the family member have the right to do so and there will be no repercussions. Also if I sense that someone is distressed, I may end the interview prematurely. My name and phone number and the name and phone number of my advisor is provided and you may contact us. In addition we provide you with our contact information and provided a 24-hour hot line to call. Further counseling if needed will not be the financial responsibility of the researcher.

The benefits to participation are:

The possible benefit to you is the opportunity for you/ your family member to talk about your experiences when living with a child who has a severe autism. You may benefit by helping health care providers understand what it is like for families to live with autism so that we may in turn provide better care to families.

Compensation:

You will receive no payment for participating in this study.

Confidentiality:

In any sort of report we might publish, we will not include any information that will make it possible to identify you or the family member. The audio recordings and any transcriptions of this study will be kept private. Study data will be de-identified and coded according to current University policy to protect confidentiality. Because I am a mandated reporter for child abuse, if I believe there is a risk of child abuse or neglect, I will need to report this to the appropriate authorities.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota or Regions Hospital. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions:

The researchers conducting this study are: Jocelyn Bessette Gorlin and Cynthia Peden-McAlpine. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact us at:

Jocelyn Bessette Gorlin RN, MSN CPNP
University of Minnesota School of Nursing
Pre-doctoral Fellow in Children with Special Health Care Needs

School of Nursing University of Minnesota
Weaver-Densford Hall
308 Harvard Street SE
Minneapolis, MN 55455
E-mail: gorl0002@umn.edu
Phone: 952-938-6768

Cynthia Peden-McAlpine, PhD, ACNS, BC.
School of Nursing University of Minnesota
Weaver-Densford Hall
308 Harvard Street SE
Minneapolis, MN 55455
E-mail: peden001@umn.edu
Phone: 612-624-0449

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), **you are encouraged** to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

If you have any emotional distress that you feel needs immediate attention, you can also contact the Crisis Connection (http://www.crisis.org) which operates **The Crisis Hot Line (612-379-6363)**, a 24-hour crisis phone line which is free and confidential and accepts calls from anyone in need of counseling and support.

You will be given a copy of this information to keep for your records.

Questions to assess understanding:

1. Why am I here today?
2. What will happen if you don't want to speak with me or stop at any time?

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study. I consent for audio recording of the interviews.

Signature for Adult Self-participation in the study: ______________________ Date: __________

If Minor(s) Involved: Name of Minor(s): ____

Signature of parent or guardian: ______________________________________ Date: ___________

Signature of Investigator: ____ Date: ____________

Verbal Assent for a Child 6-17 Years of Age

My name is Jocelyn Bessette Gorlin. I am a nurse who is in graduate school and I am doing research. Right now I am interested in knowing what it’s like to be a sister or brother to someone who needs special care like _______. By knowing what it’s like, I hope to help other sisters and brothers like you.

I’ll be asking you some questions by yourself then I’ll ask you questions when you’re with your whole family. Anything you share I will not share with anyone. To remember what you say I would like to tape record your answers if it’s OK with you. Our talk will take about 60 minutes.

I want you to know that if you don’t want to begin talking or want to stop talking at any time, we can do that and nothing bad will happen. Your (mom/dad) already said it was OK for me to talk with you, but I wanted to be sure it was OK with you. Is it also OK for me to record our discussion with a “tape recorder”?

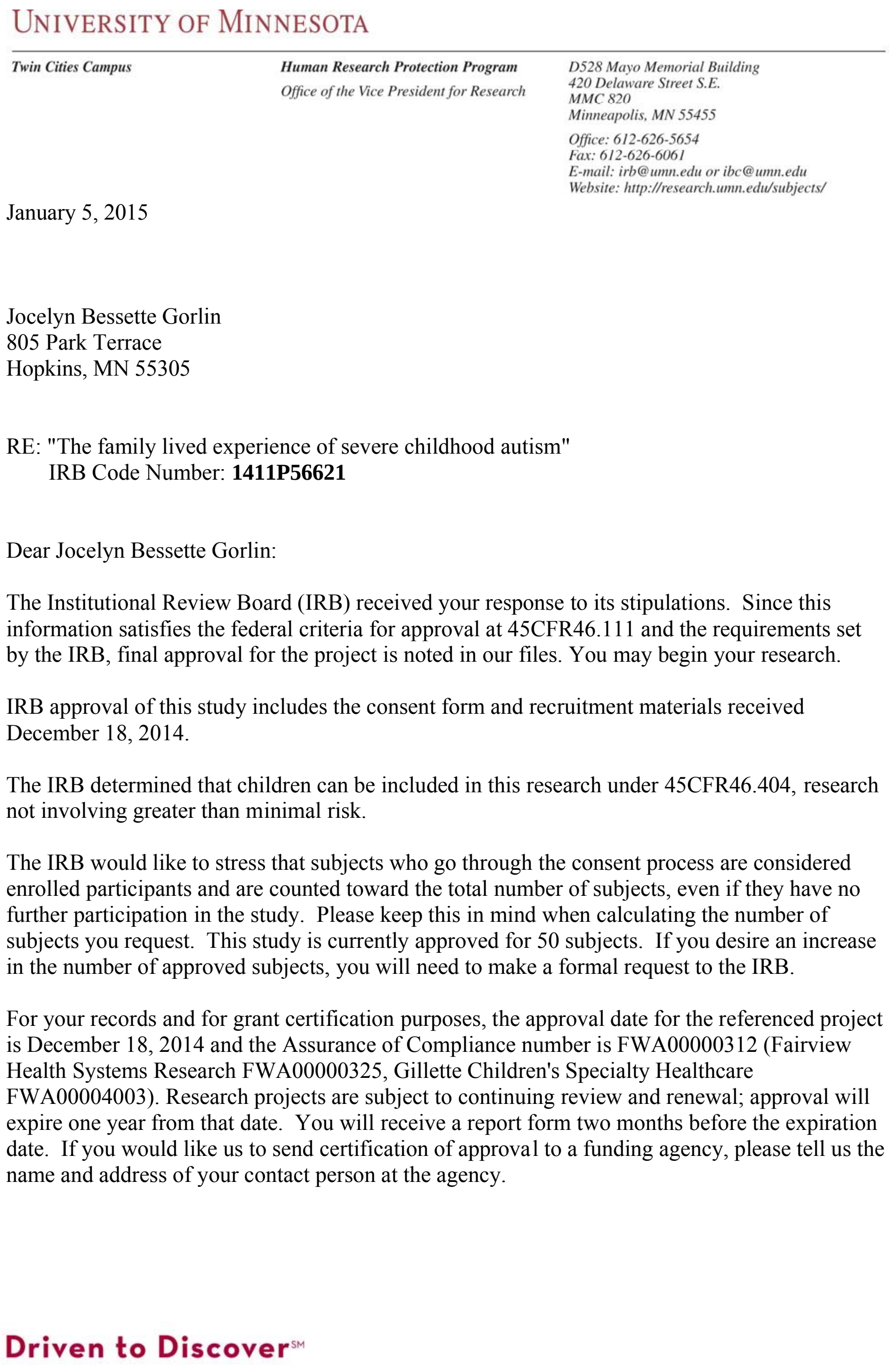
Question to be sure of understanding:

1. Why am I here today?
2. What will happen if you don’t want to speak with me or stop at any time?

Signature of Agreement: Researcher: ____________________________ Date: _____________

Appendix E

IRB Approval



UNIVERSITY OF MINNESOTA

Twin Cities Campus

Human Research Protection Program
Office of the Vice President for Research

D528 Mayo Memorial Building
420 Delaware Street S.E.
MMC 820
Minneapolis, MN 55455

Office: 612-626-5654
Fax: 612-626-6061
E-mail: irb@umn.edu or ibc@umn.edu
Website: http://research.umn.edu/subjects/

January 5, 2015

Jocelyn Bessette Gorlin
805 Park Terrace
Hopkins, MN 55305

RE: "The family lived experience of severe childhood autism"
IRB Code Number: **1411P56621**

Dear Jocelyn Bessette Gorlin:

The Institutional Review Board (IRB) received your response to its stipulations. Since this information satisfies the federal criteria for approval at 45CFR46.111 and the requirements set by the IRB, final approval for the project is noted in our files. You may begin your research.

IRB approval of this study includes the consent form and recruitment materials received December 18, 2014.

The IRB determined that children can be included in this research under 45CFR46.404, research not involving greater than minimal risk.

The IRB would like to stress that subjects who go through the consent process are considered enrolled participants and are counted toward the total number of subjects, even if they have no further participation in the study. Please keep this in mind when calculating the number of subjects you request. This study is currently approved for 50 subjects. If you desire an increase in the number of approved subjects, you will need to make a formal request to the IRB.

For your records and for grant certification purposes, the approval date for the referenced project is December 18, 2014 and the Assurance of Compliance number is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003). Research projects are subject to continuing review and renewal; approval will expire one year from that date. You will receive a report form two months before the expiration date. If you would like us to send certification of approval to a funding agency, please tell us the name and address of your contact person at the agency.

Driven to Discover℠

As Principal Investigator of this project, you are required by federal regulations to:

- Inform the IRB of any proposed changes in your research that will affect human subjects, changes should not be initiated until written IRB approval is received.
- Report to the IRB subject complaints and unanticipated problems involving risks to subjects or others as they occur.
- Inform the IRB immediately of results of inspections by any external regulatory agency (i.e. FDA).
- Respond to notices for continuing review prior to the study's expiration date.
- Cooperate with post-approval monitoring activities.

The IRB wishes you success with this research. If you have questions, please call the IRB office at 612-626-5654.

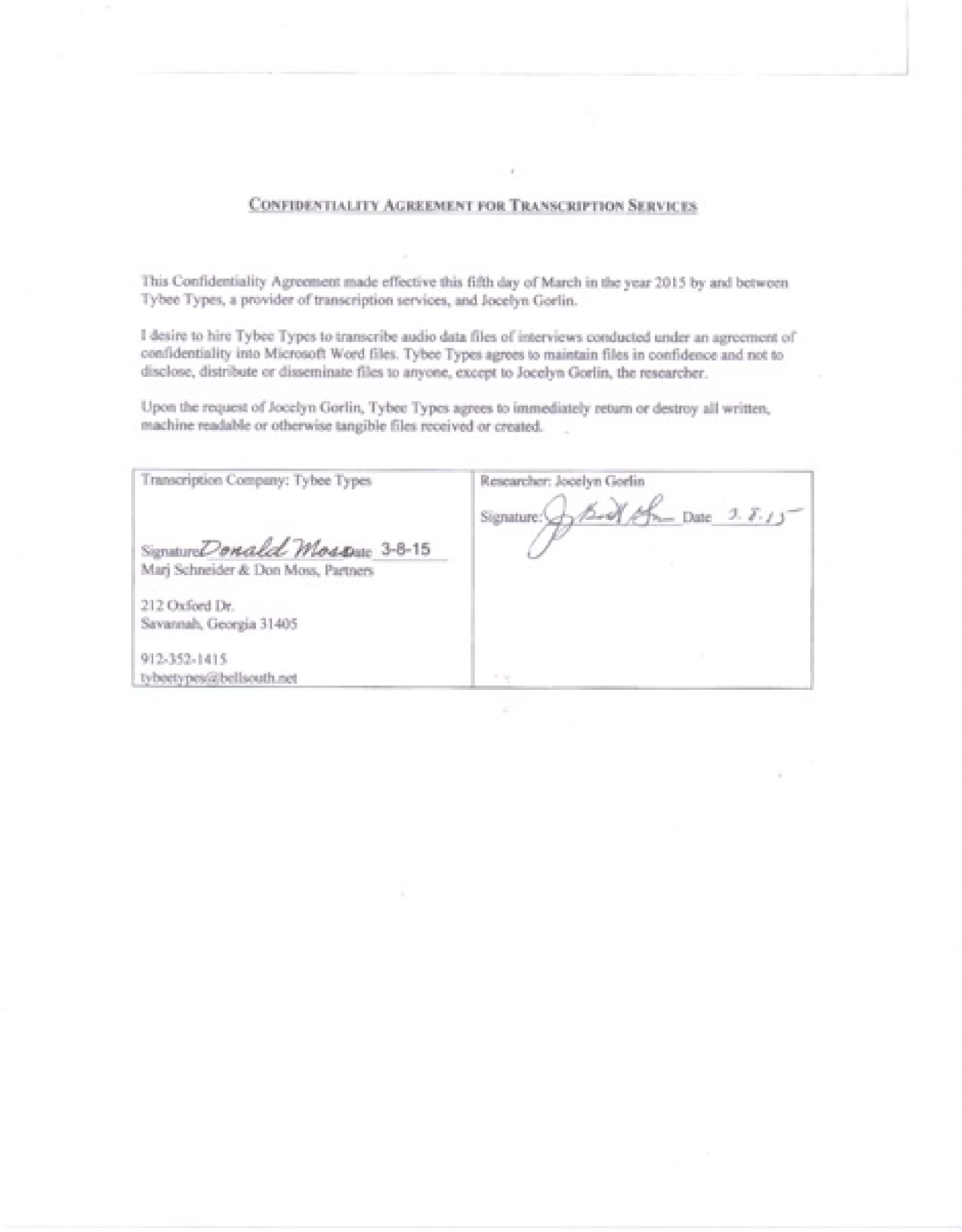
Sincerely,

Clinton Dietrich, MA
Research Compliance Supervisor

cc: Cynthia Peden-McAlpine

Appendix F

Transcription Confidentiality Agreement



CONFIDENTIALITY AGREEMENT FOR TRANSCRIPTION SERVICES

This Confidentiality Agreement made effective this fifth day of March in the year 2015 by and between Tybee Types, a provider of transcription services, and Jocelyn Gorlin.

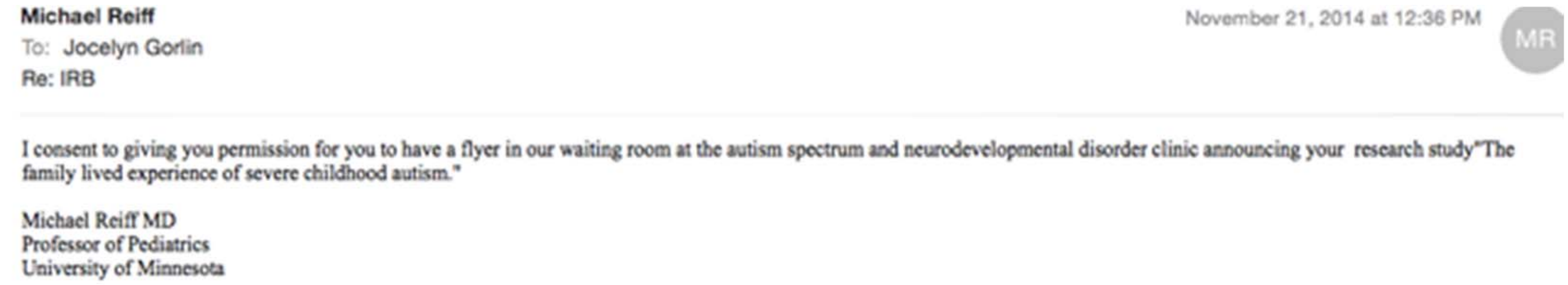
I desire to hire Tybee Types to transcribe audio data files of interviews conducted under an agreement of confidentiality into Microsoft Word files. Tybee Types agrees to maintain files in confidence and not to disclose, distribute or disseminate files to anyone, except to Jocelyn Gorlin, the researcher.

Upon the request of Jocelyn Gorlin, Tybee Types agrees to immediately return or destroy all written, machine readable or otherwise tangible files received or created.

Transcription Company: Tybee Types Signature Donald Moss Date 3-8-15 Marj Schneider & Don Moss, Partners 212 Oxford Dr. Savannah, Georgia 31405 912-352-1415 tybeetypes@bellsouth.net	Researcher: Jocelyn Gorlin Signature: Date 3.8.15

Appendix G and H

Permission from Physicians



Michael Reiff
To: Jocelyn Gorlin
Re: IRB

November 21, 2014 at 12:36 PM

I consent to giving you permission for you to have a flyer in our waiting room at the autism spectrum and neurodevelopmental disorder clinic announcing your research study"The family lived experience of severe childhood autism."

Michael Reiff MD
Professor of Pediatrics
University of Minnesota

Elizabeth Reeve
To: Jocelyn Gorlin
RE: IRB quick request

November 21, 2014 at 2:43 PM

Jocelyn, please feel free to submit this email to the Univ of Mn IRB. I am happy to have your flyer in my office. Please note that it will be there are not in the waiting room as I am the only provider who sees children at this clinic site. I will not consent subjects or discuss the study but will send interested families to you.

I give my permission for the flyer for the research study entitled: "The family lived experience of severe childhood autism" which Jocelyn Bessette Gorlin is conducting in partial fulfillment of her PhD in Nursing, be placed in my office from approximately January 2015 to April 2015. I acknowledge that Jocelyn Bessette Gorlin will replenish the flyers and that I have no responsibility to maintain them.

Elizabeth Reeve MD
Child and Adolescent Psychiatry
651-254-4786 for appointments

Appendix I

Poster

Autism Family Study

Seeking families to share their stories

Exploring the experiences of families who live with a school-age child (5-12 years old) who has autism. The study consists of individual and family discussions to identify strengths and concerns you may have. Interviews are arranged at your convenience.

Study conducted by experienced pediatric nurse practitioner currently pursuing a PhD at the University of Minnesota

612.716.6541 or Gorl0002@umn.edu

Gorl0002@umn.edu
612.716.6541

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612.716.6541

Gorl0002@umn.edu
612.716.6541

Appendix J

Flyer

Autism Family Study

Seeking families to share their stories

I am exploring the experiences of families who live with a school-age child (5-12 years old) who has autism. The study consists of individual and family discussions to identify strengths and concerns you may have. Interviews are arranged at your convenience.

Study conducted by experienced pediatric nurse practitioner currently pursuing a PhD at the University of Minnesota

612.716.6541 or gorl0002@umn.edu

Appendix K

IRB Change in Protocol

UNIVERSITY OF MINNESOTA

Route this form to: See instructions below	**Revised** October 2013

Change In Protocol Request

Instructions:

Use this form when submitting change requests to approved IRB protocols. This form is for use when the changes are initiated by the PI. Do not use this form to respond when changes are requested by the IRB. Please do not use this form when responding to changes requested in a stipulation or deferral letter.

Submit this form to the Human Research Protection Program:

U.S. Mail Address: **or**
Human Research Protection Program
MMC 820
420 Delaware St. SE
Minneapolis, MN 55455-0392

Electronic Submission:
Submit to: irb@umn.edu
PI must submit request using
University of Minnesota e-mail
Account.

FOR IRB USE ONLY:

IRB Protocol Information

IRB Study Number:	**#1411P56621**
Principal Investigator:	Jocelyn Bessette Gorlin
Primary Study Title:	Family Lived Experience of Severe Childhood Autism
Date of this Submission	3.31.15
Study Includes	☐ Drug(s) / Biologic(s) ☐ Device(s)

Indicate the type of change(s)	Additional information/requirements
☐Change(s) to Study Procedures/Protocol Amendment Protocol Version , Dated	**Does the change affect study design, change the study endpoint(s) or change the statistical method?** ☐ **No** ☐ Yes **Is this protocol under Masonic Cancer Center's Cancer Protocol Review Committee (CPRC) review?** ☐ No ☐ Yes, CPRC # If "Yes" is checked for *both* questions above, this submission (Change in Protocol form and any supporting documentation) must be reviewed by CPRC (CCPRC@umn.edu) prior to review by the IRB. CPRC will forward this submission to the IRB after CPRC approval. Submission to CPRC must meet the IRB signature requirement (signed by the PI or sent from the PI's x.500 UMN email account).
☐Notice of Closure to Accrual	
☐Recruitment changes/Advertisements	Attach a copy of the revised material (flyer, script, etc.) with the submission
☐Revised Investigator Brochure	Version , Dated
☐Updated consent form	Include both an updated form with changes highlighted and a "clean" version
☒Other	Briefly Describe:Changes to inclusion critera

1. **Briefly summarize the change(s). For protocol amendments, do not say "See summary of changes provided with amendment." Rather, summarize the nature of the significant revisions.**

The methodology for this study is phenomenology which explores the lived experience of individuals, in this case the family members of children who have severe childhood autism. As I have progressed though my study, however, I have encountered challenges with the original inclusion criteria during the recruitment process. I have met with my advisors regularly to discuss this and they have assured me that potentially altering the criteria to be reflective of the study population is common and is encouraged in the phenomenological process. For this reason I propose the following minor changes to the inclusion criteria of my study as I believe it renders the study more reflective of the population I wish to understand.

Original Inclusion Criteria:
1. Child in the family has autism 5-12 years of age
2. Sibling must be at least 6 years of age or older
3. Child with autism must be diagnosed with severe autism requiring substantial support (24 hour supervision), significant communication and functional challenges
4. Two-parent family
5. Family members are individuals that live in the same household as the child with autism, may or may not be biologically related and may include parents, siblings, grandparents, or others. Family member is defined by one of the parents.
6. Family must be English speaking

Proposed Inclusion Criteria:
1. Child in the family who has autism is 5-12 years of age (+/- one year)
2. Sibling (s) must be at least 6 years of age or older
3. Child must be diagnosed with autism and have significant functional challenges. This includes limited communication, and requires substantial support including the need for 24 hour supervision (Not actually diagnosed with severe autism)
4. May include one or two parent families
5. Family is identified by one parent and includes anyone who the parent considers family, whether biologically related or not, who has significant contact with the child. This may include parents, siblings, grandparents, or others (Not necessarily living in the same household)
6. Family must be English speaking

2. **Describe the rationale for the change(s):**

Rationale For Changes
1. Age Range of child with Autism:
Most children with autism are more mildly affected, having less significant functional challenges. Less than one quarter of the children with autism have significant functional challenges. I have spoken with approximately 25 families who wish to share their story, but many have a child with milder autism and/or the child that falls slightly outside the strict age guidelines.

In addition, though 5years old is usually considered school age, many of these children are in school for the special autism services at 4 years of age. Conversely the concept of transitioning is not yet a prominent issue at 13 where it might be at a later age. For all these reasons, I would like to slightly broaden the criteria to have the opportunity to potentially include families of children with autism 4-13 years of age.

3. Severe Autism vs. Autism with Significant Functional Challenges:
The majority of the the potential families with whom I have spoken for the study, state that their children do not have the specific diagnosis of "mild", "moderate" or "severe" autism. Through my LEND (Leadership Education in Neurodevelopmental Disorders) Fellowship, I have discussed this topic at length with Michael Reiff, MD, a LEND staff member and director of the Autism Clinic (ASD) at the University of Minnesota. He has confirmed that autism severity is difficult to discern in part because of the spectrum nature of autism and because of the narrow definition of autism in the Diagnostic and Statistical Manual of Mental Disorders (DSM).

Dr. Reiff has encouraged me to focus on the child's functional challenges vs. a diagnosis to assess severity using the World Health Organization International Classification of Functioning, Disability and Health (WHO ICF Classification). This classification focuses on the daily functional limitations or challenges that the child with autism encounters. This classification in fact correlates with my original definition of "severe autism" in that the child has significant functional challenges including the need for substantial support (24 hour supervision) and significant communication challenges, however, they would be referred to having "autism with significant functional challenges" vs. "severe autism."

4. Two parent vs. One parent family:
There is a high rate of divorce in the families of children with autism. In order for my study to reflect the actual population I wish to study, I would like to include families that are one or two parent families.

5. Family May Not Need be in One Household:
Through conversations with potential families, it is evident that several people are considered "family" (e.g. grandmothers) that live close by and have significant interaction with the child with autism, but they may not all live in the same household . Because these individuals are considered family, I propose that they be included in my family study.

3. **How will these changes affect the overall risk to subjects in this study?**

These changes do not affect the overall risk to subjects in the study,

4. **Do the changes to the study prompt changes to the consent form(s)?**

☒ **No.**
☐ **Yes. If yes:**

- **Attach a copy of the revised consent form(s) with changes tracked or highlighted as well as a clean copy.**

  4.1 Will currently enrolled subjects will be notified of the changes?
  ☐ **No**
  ☐ **Yes, explain below how they will be notified** (i.e. subjects will be re-consented with the updated form once approved, subjects will be provided with an information sheet, subjects will be told of changes at next study visit, etc.).

5. **List and attach all documents included with this request, including version dates:**

_______________________________ _____________________
Principal Investigator's Signature **Date**

Cancer Protocol Review Committee (CPRC) Use Only:

Appendix L

Study: The family lived experience of childhood autism

Demographic Questionnaire

Section 1 and 2 are asked only of one parent.

Section 1.
I'd like to ask you about your family members that live in your household.

1. Who are the members of your family? These are people who you define as part of your family even if they are not blood relatives, but they must live together with the child of interest.

Sex	Age	Relationship to Parents
_____	_____	_____________________
_____	_____	_____________________
_____	_____	_____________________
_____	_____	_____________________
_____	_____	_____________________

2. Who provides the majority of care for your child? ________________________________

3. Are there other members of your family or friends that are supportive or act as care givers?
   ____

4. What are the parent's occupations? ______________________________

5. What term best describes your family's religious or cultural background?
   ____

6. How would you describe the ethnicity (or Race) of the parents?
   - White
   - Hispanic or Latino
   - Black or African American
   - Native American or American Indian
   - Asian / Pacific Islander
   - Other: ____

7. What is the highest degree or level of school of the parents?
   - Some high school, no diploma
   - High school graduate, diploma or the equivalent (for example: GED)
   - Associate degree
   - Bachelor's degree
   - Master's degree
   - Doctorate degree
   - Other: ________________________

Section 2.

I'd like to ask you questions about the child with autism:

1. When was he/she diagnosed with autism? _______
2. What are the specific diagnosis and/or related conditions of the child with autism?
3. How would you describe your child's language/speech/communication patterns?
4. How would you describe your child's social interactions?
5. Does your child have any intellectual or language delays?
6. What functional challenges does she/he have?
7. Does your child have any specific behaviors related to autism?
8. What are the medical and other support services (e.g. language, OT, PT, education services, medication) that are needed for your child?

Appendix M

Study: The Family Lived Experience of Childhood Autism

Individual and Family Unstructured Interview

ADULT INTERVIEW:
I am interested in knowing about your family life living with a child who has autism.

Grand Tour Question:
- Could you share with me what has been your experience as a family living with a child who has autism?
- Can you describe a positive event when you were all together as a family?
- Can you share a challenging event when you together as a family?
- Follow-up on incidences described in the Family Lifeline

Potential Probes:
- Can you recall when your child was diagnosed?
- How is your child special? How would you describe him/her?
- How is your family alike/different than other families?
- Who/what has sustained your family through challenging times?
- Are there lessons you have learned as a family from your child?
- What advice would you give other *parents* of child with autism?
- What advice would you give to *health care providers* about how to help families of a child with autism?
- Challenges/joys?
- What are your hopes for the future?
- If you could have three wishes what would they be?

SIBLING INTERVIEW:
Unstructured Interview:
I am interested in knowing what it is like to be part of a family when your sister or brother has a special need such as autism.

Grand Tour Question:
- Could you share what it has been like living with a sister/brother who has autism?
- Can you describe a positive time when you were all together as a family?
- Can you share a challenging time when you together as a family?

Potential Probes:
- What's special/challenging about having a sister or brother with autism?
- If you could give a message to other sisters or brothers who have a sibling with autism what would you say?
- If you could give advice to parents/health care providers, what would you say?

FAMILY INTERVIEW:
I am interested in knowing about your family life living with a child who has autism.
Grand Tour Question:
- Could you share with me what has been your experience as a family living with a child who has autism?
- Can you describe a positive event when you were all together as a family?
- Can you share a challenging event when you together as a family?

Appendix N

Autism Functional Challenge Questionnaire

Questions and comments used to assess functional challenges/severity of the child with autism. Developed in collaboration with Dr. Reiff (February 2015) and based on ICF Classification of Functioning Disability and Health

1. *Was there an original diagnosis and severity given? Are there any related conditions such as speech/language and/or intellectual delays?*

   Comment: Usually there are speech and intellectual delays in severe cases, but not always. It is important to assess how "severe" the family perceives the autism is vs. the actual diagnosis, e.g., what is severe autism to one family may not be severe autism to another family.

2. *Are you aware of any autism testing that has been done: Vineland (functional) and/or IQ?*

   Comment: The children with more severe autism are difficult to test so many may not have had testing and/or families may not remember.

3. *How would you describe your child's communication patterns, e.g., words, words together, sentences, any reciprocal communication?*

   Comment: In severe autism there may be words, but little reciprocal communication.

4. *How would you describe your child's autism-related behaviors?*

   Comment: There are usually significant behaviors that may limit participating in a regular classroom.

5. *Can your child accomplish self-care?*

   Comment: There are usually limited self-care functions, such as brushing teeth, bathing, dressing, and feeding self.

6. *Is 24-hour supervision needed?*

   Comment: In severe cases of autism, 24-hour supervision is needed.

7. *What type of school does your child attend and what health care-related supports does your child receive both at school and home?*

   Comment: Often the child with more significant challenges will be in full- or part-time autism school (unless not available in their geographic area), a special education class or receive special services within a regular class e.g. para-professional time, physical therapy, occupational therapy, speech, and adaptive classes.

8. *What are three functional challenges your child experiences at home and how does this affect your family?* Comment: It is important to focus on functional challenges versus symptoms.

Interactions Between the Components of ICF. From: World Health Organization. (2001). ICF: International Classification of Functioning, Disability and Health, WHO Library Cataloguing-in-Publication Data, p. 18.

Reiff, M. I., & Feldman, H. M. (2014). Diagnostic and statistical manual of mental disorders: The solution or the problem?. *Journal of Developmental and Behavioral Pediatrics*, *35*(1), 68-70. 10.1097/DBP.0000000000000017

Appendix O

Study: The Family Lived Experience of Childhood Autism
IRB Code: # 1411P56621

Family Lifeline

Please draw a picture that describes your family life experiences from before the time your child with special needs was born to the present moment. You may draw high points and low points, use pictures or symbols, names and dates-anything that gives a picture of your family's experiences.

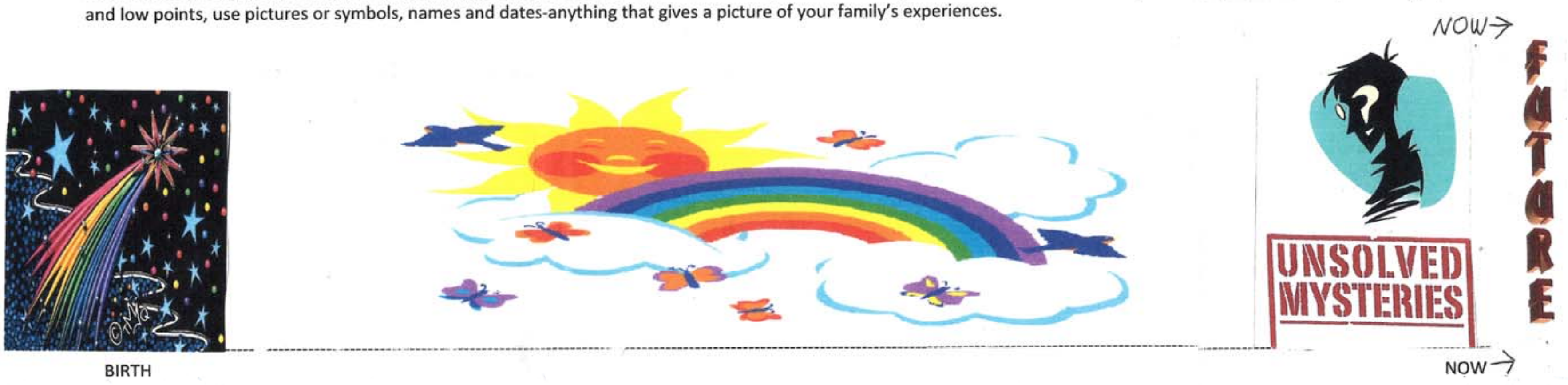
BIRTH NOW

Appendix P

Family Lifeline #43

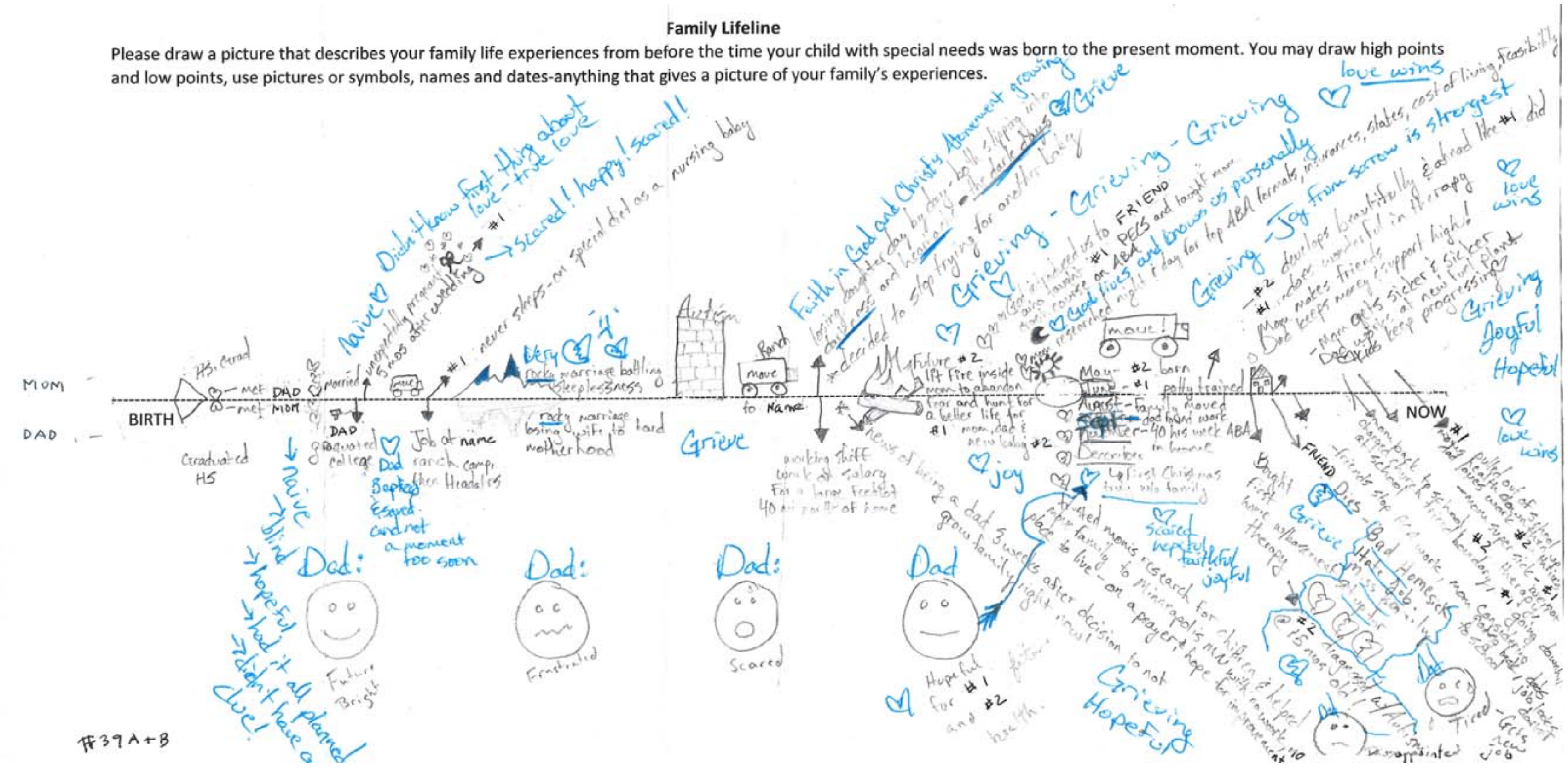
Family Lifeline

Please draw a picture that describes your family life experiences from before the time your child with special needs was born to the present moment. You may draw high points and low points, use pictures or symbols, names and dates-anything that gives a picture of your family's experiences.



Appendix Q

Family Lifeline #39



Family Lifeline

Please draw a picture that describes your family life experiences from before the time your child with special needs was born to the present moment. You may draw high points and low points, use pictures or symbols, names and dates-anything that gives a picture of your family's experiences.

#39 A+B

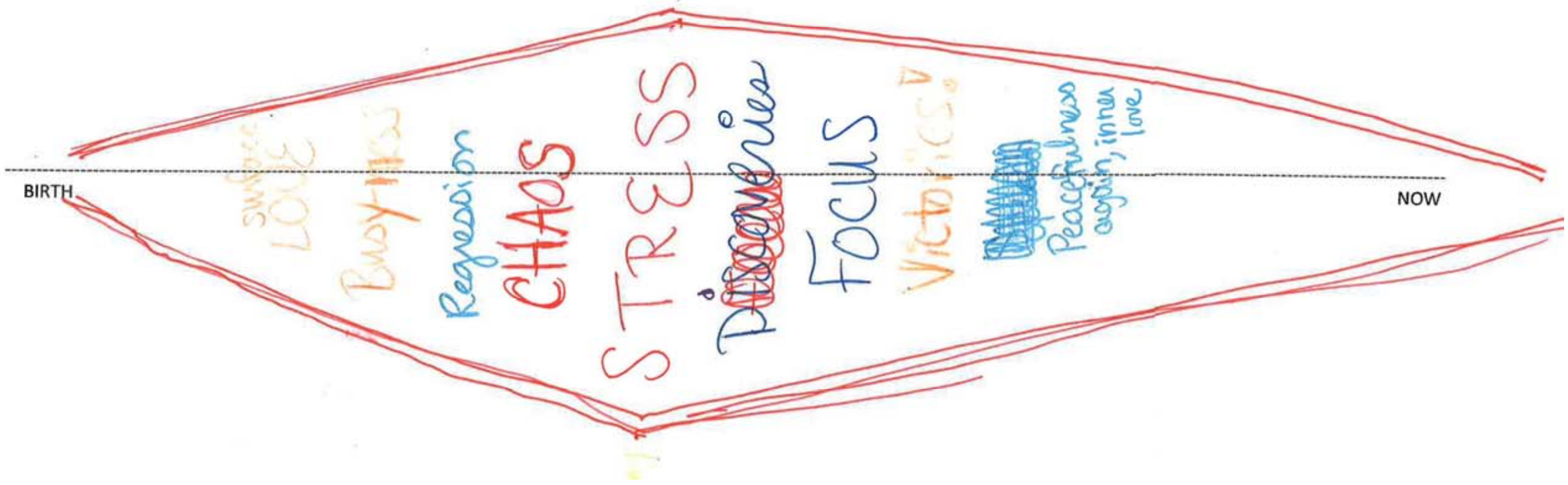
Permission granted by the author to use this Lifeline.

Appendix R

Family Lifeline #45

Family Lifeline

Please draw a picture that describes your family life experiences from before the time your child with special needs was born to the present moment. You may draw high points and low points, use pictures or symbols, names and dates-anything that gives a picture of your family's experiences.

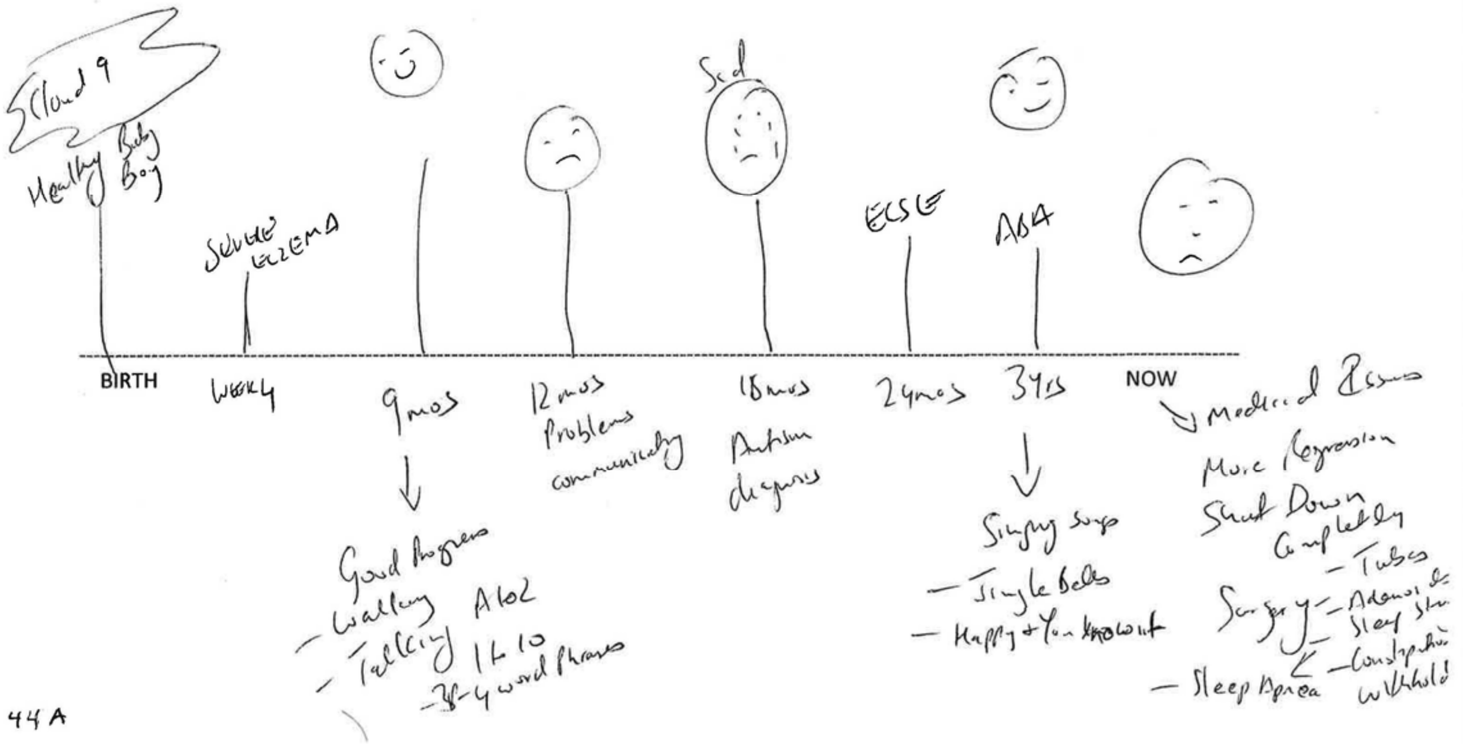


Appendix S

Family Lifeline #44

Family Lifeline

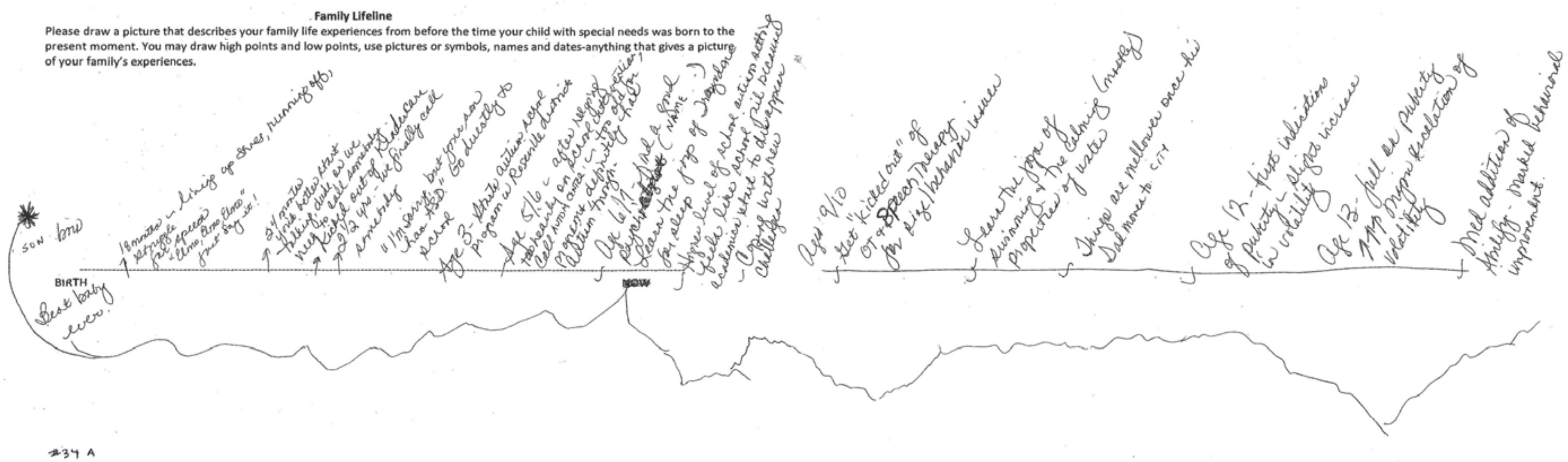
Please draw a picture that describes your family life experiences from before the time your child with special needs was born to the present moment. You may draw high points and low points, use pictures or symbols, names and dates-anything that gives a picture of your family's experiences.



44A

Appendix T

Family Lifeline #34



Family Lifeline

Please draw a picture that describes your family life experiences from before the time your child with special needs was born to the present moment. You may draw high points and low points, use pictures or symbols, names and dates-anything that gives a picture of your family's experiences.

SON born

BIRTH

Best baby ever.

18 months – lining up shoes, running off, struggle for speech "Elmo, Elmo, Elmo" just say it!

24 months – You'd better start talking, dude, or we need to call somebody

Kicked out of Kindercare

2 1/2 yrs – we finally call somebody

"I'm sorry, but your son has ASD." Go directly to school

Age 3 – State autism [illegible] program in Roseville district

Age 5/6 – after relying too heavily on school district [illegible] autism center [illegible] – too old for [illegible] moment definitely that autism though.

Age 6/7 – find a good psychiatrist (NAME) Learn the joys of trazodone for sleep :)

NOW

Higher level of school autism setting feels like school jail because academics start to disappear

– Coping with new challenges

Ages 9/10 Get "kicked out" of OT & Speech Therapy for size/behavior issues

Learn the joys of swimming & the calming properties of water

Things are mellower (mostly) once his Dad moves to CITY

Age 12 – first indications of puberty – slight increase in volatility

Age 13 – full on puberty ↑↑↑ major escalation of volatility

Med addition of Abilify – marked behavioral improvement.

#34 A

Appendix U
Family Lifeline #38