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**RECONSTRUCTING AUTISM:**  
**A PHENOMENOLOGICAL STUDY OF THE RELATIONSHIP BETWEEN**  
**PARENTS AND THEIR CHILDREN DIAGNOSED WITH AN AUTISM**  
**SPECTRUM DISORDER**

**PROFESSIONAL DISSERTATION**

**SUBMITTED TO THE FACULTY**

**OF**

**THE SCHOOL OF PROFESSIONAL PSYCHOLOGY**  
**WRIGHT STATE UNIVERSITY**

**BY**

**LAURA ELIZABETH SOLOMON, Psy.M.**

**IN PARTIAL FULFILLMENT OF THE**  
**REQUIREMENTS FOR THE DEGREE**  
**OF**  
**DOCTOR OF PSYCHOLOGY**

**Dayton, Ohio**

**September, 2012**

**COMMITTEE CHAIR: Julie L. Williams, Psy.D., CRC, ABPP (RP)**

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**WRIGHT STATE UNIVERSITY**  
**SCHOOL OF PROFESSIONAL PSYCHOLOGY**

June 2, 2011

I HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER MY SUPERVISION BY **LAURA ELIZABETH SOLOMON** ENTITLED **"RECONSTRUCTING AUTISM: A PHENOMENOLOGICAL STUDY OF THE RELATIONSHIP BETWEEN PARENTS AND THEIR CHILD DIAGNOSED WITH AN AUTISM SPECTRUM DISORDER"** BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY.

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Julie L. Williams, Psy.D., ABPP (RP), CRC  
Dissertation Director

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## Abstract

This study aims to serve as a deconstruction of the experience of parenting a child with an autism spectrum disorder (ASD). The increasing number of families with children affected by ASDs has led to many questions about the impact of ASDs on the family unit; however, the voice of parents is sorely missing in the extant research. The history of ASDs and disability in general continues to impact the ways families, society, and professionals treat families affected by ASDs, and particularly the ways they view and value the parent-child relationship. Six mothers of children with ASDs were interviewed about their experience parenting a child on the autism spectrum and their relationship with their child. Interpretive Phenomenological Analysis (IPA) was used to give voice to the parents' collective experiences. Clinical implications and limitations of this study, as well as directions for future research, are discussed.

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## Dedication

This dissertation is dedicated to all of the parents who took the time to share their lives with me. Your stories and your voice are so appreciated and needed. Thank you for the ways you challenge, shape, and inform the world through your stories, and for sharing yourselves and your magnificent children with the world.



## **CHAPTER 1**

### **Introduction to the Study**

#### **Statement of the Problem**

The Center for Disease Control's Autism and Developmental Disability Monitoring Network reported that one in 150 eight-year-old children were diagnosed with autism in 2007 (Rice, 2009). The growing autism "epidemic" and the increasing number of families affected by children on the autism spectrum has led many researchers to examine how having a child on the autism spectrum impacts parents and families. Many studies have examined maternal stress and marital stress (Easter Seals, 2008; Sanders & Morgan, 1997; Tunali & Power, 2002), while other researchers have examined how parents cope with their child's diagnosis (Dale, 1996). Still other studies have examined resiliency of parents and ways of coping within the family system (Tunali & Power, 2002). A common theme of this research has been that parents of a child with autism must change their role and expectations as a parent and redefine themselves and their relationship with their child (Cashin, 2004; Fleischmann, 2004; Tunali & Power, 2002). However, there is a gap in the literature surrounding the construction and redefinition of the relationship between children with autism and their parents. This gap is widened by societal perceptions of autism and the fact that parent-child relationships are defined by a neurotypical society. This study attempts to bridge the gap that has been created by these deficits by uncovering the phenomena of the relationship that occurs

between children with autism and their parents. Further, this study attempts to serve as a deconstruction of the experience of parenting a child on the autism spectrum, such that the parents of these children are allowed to define and reconstruct the experience as they live it.

### **Purpose of the Study**

The purpose of this study is to examine the phenomena of the parent-child relationship based solely on the lived experience of parents of children with autism. Historical attributions for autism, societal perceptions of disability, and current and historical models of disability affect how medical professionals, society, and parents view the parent-child relationship. These outside constructions and perceptions may impede viewing the relationship from the parents' perspective, which could prevent a genuine understanding of the intimate experience of living with and loving a child with an ASD. In an attempt to account for this frequent oversight, this study will use a qualitative, phenomenological approach as a way of deconstructing current perceptions of how parents of children with autism relate to their children by suspending all preconceived notions about relationship, attachment, and disability. Thus, it is hoped that parents of children with a diagnosis of an autism spectrum disorder will be afforded the space to define and reconstruct the parent-child relationship in a way that both illuminates and encompasses their experience.

One of the most critical factors affecting how the relationship between parents and their child with autism is perceived is the medical model of disability. This model, which currently pervades societal and medical thinking, is based on the assumption that an individual with a disability needs to be fixed or cured. One result of this framework is

the wide-spread perception that having a child with a disability is a “burden” and particularly a burden that taxes the physical, mental, and emotional resources of all members of the family. Most of the current research conducted was framed within the medical model, and operates under this assumption, thereby seeing to discover what parents need to cope effectively with the burden of having a child with a disability (Olkin, 1999). However, by focusing on the “burden” the child brings on the family and operating only within the medical model, it seems that much of the current research ignores and denies the true experience of parents and the nature of their relationship with their child.

Literature on the parent-child relationships in psychology has traditionally used attachment theory as a way of describing and defining the developing relationship (Colin, 1996). Historically, autism was described as a pathological style of attachment rather than the developmental, neurobiological disorder it is now understood to be (Exhorn, 2005). Although the attribution for autism has changed, and knowledge and understanding of the disorder has increased, individuals with autism are still considered to be people withdrawn from all interpersonal relationships. Often, the layperson’s knowledge of autism is limited to the stereotypical “Rain-Man...or autistic rocking in the corner” (Siegel, 2003). In the past, mothers were blamed for their child’s diagnosis. Further, traits and characteristics such as cold mothers and absent fathers were believed to lead to diagnoses of autism in children (Exhorn, 2005). Although this is no longer believed to be true, parents, and particularly mothers, still shoulder much of the burden of the diagnosis (Siegel, 2003).

It is generally agreed upon, albeit with some contention, that children with autism spectrum disorders do form attachments, although they cannot be measured in the same ways as the attachments of children without autism (Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004). However, the majority of the observations and interpretations made by researchers are well-grounded in the medical model and use typically developing, securely attached children as prototypes. Further, the studies examining the attachment of children with autism are grounded in qualitative and subjective interpretations of attachment based on the prototypical behavior seen in securely attached, typically developing children. Treatments stemming from these observations assume that, because the attachment of children with autism differs in qualitative observation from the attachment of typically developing children, that these children need to be moved towards a more typical display of attachment behaviors. This study posits that, before engaging in treatment modalities that attempt to change the parent-child bond, an understanding of the parent-child bond should first be established such that clinicians and researchers can develop a working knowledge of what, if anything, the parents see as needing to change in their relationship with their child.

A common theme throughout the literature and media by, and for, parents of children with an autism spectrum disorder is that parents redefine the parent-child relationship as they raise a child on the autistic spectrum. Various theories on the redefinition have occurred, including explaining redefinition as a way of coping with uncontrollable and chronic stress, a way of reducing cognitive dissonance (Tunali & Power, 2002), and as a way of understanding the changes occurring within the parent's sense of self (Cashin, 2004). However, this study argues that redefinition is a natural and

necessary process that occurs as parents recognize that, as a family with an individual affected by a disability, they no longer fit into the experience known and explained by society. As parents living with a child affected by autism, redefinition of everything from daily life and routine to relationship must occur as a way of finding a place where they can understand and own their experience. Therefore, providing parents the opportunity to define their relationship with their child outside of preconceived notions about attachment, children, and disability, is an essential step in gathering the information necessary to truly understand the experience of parenting a child on the autistic spectrum.

## CHAPTER 2

### Literature Review

According to Kogan et al (2009), the number of children diagnosed with an Autism Spectrum Disorder (ASD) is increasing at an alarming rate. The current estimated number of children diagnosed with ASDs varies widely, with one large study published by the journal, *Pediatrics*, estimating that 1 in 91 children were diagnosed in 2007 (Kogan et al, 2007), and the Center of Disease Control (CDC) estimating that 1 in 150 children were diagnosed the same year (Rice, 2009). The dramatic increase in the number of children diagnosed leads to particular concern about the effect of society's view of disability on these children and their families.

An understanding of the history of disability is important in understanding the current social conceptualization of disability, and in understanding some of the challenges faced by families of children with disabilities. Initially, disability was understood through what is now called the moral model; however, as time progressed, the popularity of the moral model declined and gave way to the medical model, which continues to be the most prevalent view of persons with disabilities. This model continues to inform medical and mental health professionals, as well as set the backdrop for society's view of persons with disabilities (Brzuzy, 1997; Donoghue, 2003; Marks, 1997). Within the disability community, an alternative model for conceptualizing

disability, known as the minority model, is becoming increasingly prevalent among persons with disabilities and their allies (Brzuzny, 1997; Donoghue, 2003; Marks, 1997).

Because of the pervasiveness of the medical model within the medical community, and the neurodevelopmental and biological nature of ASDs and their treatments, parents of children with ASDs must exist primarily within this model. However, in their individual relationship with their children, and in conversations framed outside of the typical medical model explanations of disability, many parents move into an alternative framework that may be more congruent with the minority model. Uncovering the points at which the parents' views converge and diverge from each of the models may be an essential part of providing parents with the support they need to successfully navigate the challenges of raising a child with an ASD.

One of the most prominent diagnostic criteria in ASDs is impairment in developing appropriate relationships and social skills. Historical conceptualizations of ASDs range from the idea that persons with an ASD are lacking a soul to the idea that ASDs represent a pathological style of attachment (Wing, 1997). Currently, the medical model acknowledges that ASDs are neurodevelopmental or neurobiological disorders, with diagnostic criteria focusing on the differences in social interaction, communication, and relationship (American Psychiatric Association, 2000). Although mothers of children with ASDs generally acknowledge the qualitative difference in the nature of their relationship with their child, they often find their relationship to be profound and engaging (Cashin, 2004; Fleischmann, 2004). The minority model of disability, which is based on the concept that a person is only as "disabled" as the society in which they live prevents them from achieving, assimilating, relating, and living in the ways they are able,

thereby giving parents alternative ways of conceptualizing, valuing, and understanding their child and their unique relationship. By examining ASDs and disability through a minority model lens, it becomes possible to view the concept of relationship, and the values and parameters commonly placed on that concept, as a socially constructed idea. Within this framework, it becomes possible to define relationship in ways that encompass, rather than exclude, the familial and relational bond between parent and child. With this alternative definition, a greater level of acceptance, and more supportive interventions for people with ASDs and their families, may be possible. Further, this definition would make it possible to not only assist parents in coping with the societal stressors and complications that often accompany having a child with special needs, but also to promote acceptance of persons with disabilities in general.

### **Autism Spectrum Disorders**

Autism is one of five disorders falling under the category of Pervasive Developmental Disorder (PDD) in the Diagnostic and Statistical Manual, Fourth Edition, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000). The umbrella of PDD describes individuals affected by Autistic Disorder, Asperger's disorder, Childhood Disintegrative Disorder, Rett's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Although each of the disorders encompassed by PDD is unique, they contain three common features: impairment in social interaction, impairment in communication, and repetitive and stereotyped interests and behaviors (American Psychiatric Association, 2000; Exhorn, 2005). Autism occurs four to five times more often in males than in females and, while no definitive explanations for



autism have been found, the etiology of the disorder, including biological and environmental factors, continue to be explored.

### **Models of Disability**

As previously stated, historical models of disability have a significant impact on the ways society continues to conceptualize disability. As such, each of the three major models of disability will be discussed.

#### **Moral model.**

The oldest model of disability, the moral model, considered disability to be a test of faith or divine retribution for sins for both the individual with the disability and for his or her family. Within this model, disability becomes a physical expression of moral or religious impurity or wrong-doing or, conversely, serves as an expression of sanctity that places the individual apart from the rest of the world (Olkin, 1999). This model conceptualizes the family or person as responsible for the disability and posits that the “cure” for the disability lies in faith. Persons with disabilities were viewed as not fully human, and were frequently hidden from society and deemed unable and unworthy of forming relationships with others (Altman, 2001; Brzuzy, 1997; Marks, 1997). The language stemming from this model continues to affect the language used to discuss disability, particularly in that the underlying assumption of undesirability and weakness necessitating care and compassion stemmed from the idea that persons with disabilities have sinned, or possess a moral weakness necessitating “Christian duty” and acts of mercy (Altman, 2001; Brzuzy, 1997; Marks, 1997; Olkin, 1999).

### **Medical model.**

The medical model, or normalcy model, which emerged in the mid-1800s and is the most well-known and wide-spread model of disability, assumes that any sort of defect or abnormality in the body needs to be cured so the individual can function normally in society (Brzuzny, 1997; Olkin, 1999). Landsman (2005) found that mothers of children with disabilities typically encounter the medical model first when interacting with medical professionals diagnosing and labeling their child. At this stage, mothers often report feeling unsupported, or feeling as though the medical professional had dismissed their child because of their diagnosis and atypical development. Parents frequently encounter the medical model again as they begin early intervention or therapeutic services: in this rehabilitation version of the medical model, professionals begin moving children towards the goal of approximating typical behavior, and placing pressure on parents to move their children towards normalcy (Landsman, 2005).

Researchers Landsman (2005) and Ong-Dean (2005) found that the medical model was not only the most common view of mainstream Americans, but also the most common perspective of mothers of children with disabilities. Parents of children with disabilities develop an interest in disability out of necessity. Ong-Dean (2005) argues that parents are often led by their investment in their children to adopt the medical model as a way of understanding and explaining their child's disability. However, he also acknowledges that the literature available to parents, and particularly the literature available to and utilized by Caucasian, middle-class parents, emphasizes the medical model as a way of both understanding and advocating for their child. This literature provides parents with facts, arguments, and justifications for and about their child's

diagnosis, advises parents of ways of observing and assisting their children, and encourages them to be critical and knowledgeable consumers of medical knowledge. Through this, the information available to families also assists in shaping the medical model of disability. Finally, this information provides parents with ways of explaining, understanding, and caring for their child that further emphasizes the medical model to the exclusion of other perspectives (Ong-Dean, 2005).

It should be acknowledged that the models are not only abstract concepts, but are frameworks that effect the way individuals with disabilities view themselves, the way they are viewed by their families and society, and the way health professionals develop and implement “treatment.” Most treatment modalities used for children with autism and their families are based in the medical model and work under the assumption that children should learn to interact in “normal” ways, and thereby become more “normal.” Further, many of the treatment modalities assume that the relationship and attachment between children with autism and their parents is pathological or non-existent, and that the same treatments used for increasing the bond between parents and their NT children can be used with children with autism.

### **Minority model.**

The social or minority group model of disability, in contrast to the medical model, posits that disability is not located within the body or mind of the individual, but within the “excluding and oppressive social environment” (Marks, 1997, p. 88). Individuals ascribing to the minority group model state that disability stems from institutionally based oppression as evidenced by a social environment that fails to account for individual differences (Landsman, 2005; Marks, 1997). Further, disability within this model can be

seen as a culmination of social, economic, and political forces interacting in ways that place barriers between the individual and their environment. Therefore, individuals with disabilities may not view themselves as limited, but rather, coping with a lack of acceptance and general intolerance from society (Brzuzy, 1997).

When considering disability through a minority model lens, it is essential to also consider the principle of social constructionism. This theory assumes that, outside of the current system of oppression, power, and privilege in which discrimination and stereotypes were created, variables such as race, ability level, and sexual orientation, would hold a different significance (Johnson, 2001). Part of the power inherent in socially constructed reality is the fact that, when a value-laden name or label is assigned to a person or concept, it becomes true, such that the process that created it is forgotten and it acquires previously unforeseen significance (Johnson, 2001). The language used to define and describe disability plays a significant role in the social construction of disability as labels such as retarded person, blind man, and cripple diminish the person to being wholly encompassed by the one trait or variable that identifies them as different and, therefore, inferior (Johnson, 2001).

Rather than seeing behavior as stemming from the individual, social constructionism understands human behavior as a creation of society and individuals' attempts to understand the connection between themselves and others. Further, to sufficiently understand the interaction of individual and society and adequately comprehend people's behavior and experiences, multiple perspectives and levels of analysis must be understood (Dale, 1996). The intention of acknowledging that disability is a socially constructed concept is not to state that there is no difference between

individuals with and without disabilities, or that having a disability does not have an effect on the person's life. Instead, it serves to acknowledge that the interaction of several societal factors form an individuals' ideas about reality, and therefore perpetuate societal perceptions based on the ideas of people in positions of power and privilege (Donoghue, 2003; Johnson, 2001). The impact of the social construction of disability becomes evident when considering descriptions able-bodied individuals use when meeting a person with a disability. In one study, seventy-four percent of people stated that they felt pity when encountering individuals with disabilities; 58% said they felt awkward or embarrassed; 16% reported feeling anger because of the inconvenience caused by persons with disabilities; and 9% of people reported feeling resentful of the special privileges they perceived people with disabilities as receiving (Olkin, 1999).

Although parents of children with disabilities can be strong advocates of the minority group model, they are sometimes viewed by proponents of the minority model as misplacing their attention on addressing the problems of the child, rather than the problems in society. However, for parents, little information is available about alternatives to the medical model (Landsman, 2005). Research in this area has found that few mothers were aware that their desire to seek a cure for their child's disability was viewed as negative by disability rights advocates. In spite of this desire to "cure," Landsman (2005) also found that some women withhold their desire to find a cure for their child in an attempt to lead a life in which they celebrate their child's achievements and enjoy the unique lifestyle, perspective, and gifts their child brings to their family. However, the pressure of the dominant medical model led mothers to express hesitance

about this shift in perspective for fear that if they did not attempt to “fix” their child and desire a life without disability, they would be considered bad mothers (Landsman, 2005).

Another example of the way mothers’ concerns are congruent with the minority model is the fact that the most common concern named by mothers of children with disabilities, regardless of social class and educational level, is the fear of how the child will be treated by others. This indicates that although parents may continue advocating for a cure or a way to move their child closer to normalcy, they also recognize that the larger problems and obstacles that arise for their child are not resulting from their child, but from the effect of the larger society. This discrepancy may be accounted for by the conclusion that mothers of children with disabilities exhibit more confidence in their ability to change their child than in changing society (Easter Seals, 2008; Landsman, 2005).

### **History of Autism Spectrum Disorders**

Similar to the importance of understanding the broad implications of the models of disability, it is also important to have a fundamental understanding of the history of ASDs in particular in order to fully understand the transformations the diagnosis has undergone. Further, understanding the history of the diagnosis assists both in understanding and in uncovering the overt and covert beliefs held by society, parents, and professionals alike. Finally, understanding the history of the disorder also sheds light on the ways diagnosis, mental health, and treatment can continue to move forward, and the areas in which these domains continue to need to change.

#### **Moral model.**

In regards to autism spectrum disorders, Lorna Wing (1997) cites several cases throughout history that likely describe what is now known as autism. In particular, early cases of “changeling children” (p.13) taken by fairies have been cited as early attempts to understand the onset of autism spectrum disorders (Wing, 1997). Further, stories of individuals lacking in social understanding and possessing interpersonal deficits, such as the stories of Brother Juniper, a follower of St. Francis of Assisi, and the case of Hugh Blair, who was described as having a “silent madness” (Wolff, 2004, p. 202) in spite of his ability to write out the Lord’s prayer, could be reflective of a person who would currently be diagnosed with an autism spectrum disorder (Wing, 1997; Wolff, 2004). Kanner (1964) cites an additional historical case of supposed autism discussed by Martin Luther, who suggested that the child be taken to the river and drowned because he was possessed by the devil and had no soul. While the idea that these individuals would be diagnosed with an ASD today is largely speculative, the understanding of how these people were viewed and understood by the people of the time provides an understanding of the early shaping of societal understanding and perception of persons with disabilities in general, and ASDs in particular.

### **Medical model.**

While the basis of autism is still unknown, many of the initial theories have had a lasting effect on both medical and societal perceptions of autism, and many of these ideas continue to influence individuals affected by autism and their families. Autism was first identified as a disorder separate from childhood schizophrenia in the early 1940s by two doctors simultaneously: Dr. Leo Kanner in the United States, and Dr. Hans Asperger in Austria. Kanner’s definition of “childhood autism” or “early infantile autism” evolved

into what is now classified as autistic disorder, while Asperger's definition described individuals with a higher IQ and higher verbal abilities, and developed into the current diagnosis of Asperger's Disorder (Exhorn, 2005). In spite of Kanner and Asperger's separation of autism from childhood schizophrenia in the early 1940s, it was not until 1980 that the DSM-III reflected the shift to a separate diagnosis of "Autism Disorder." The diagnostic criteria have changed continuously with each edition of the DSM since the DSM-III. Siegel (2003) cites the changing criteria as part of the reason for the increase in the number of individuals diagnosed with autism: the diagnostic criteria have become more broad such that individuals previously diagnosed with autistic features, schizophrenia, and schizotypal personality disorder are diagnosed, likely more accurately, with an ASD.

When Dr. Kanner identified autism in 1943, he believed that the disorder resulted from a lack of maternal warmth and an absence of fathers in the lives of their children (Kanner, 1973). In his book, Childhood Psychosis: Initial Studies and New Insights (1973), he stated his initial belief that parents of children with autism were highly intelligent, sophisticated, and obsessive individuals with poor social skills, and believed that this affected how they raised their children. By the 1950s he revised this theory by stating: "some ten percent of the parents do not fit the stereotype, and...those who do have raised other normal...children. Moreover, similarly frigid parents are seen who do not give rise to autistic offspring" (Kanner, 1973, p. 97). So, while Kanner still believed that the majority of parents were responsible for their child's autism due to their own personality traits and parenting styles, he also began to acknowledge that some parents were exceptions to the characteristics he had previously noted (Siegel, 2003).



In the 1960s, child psychologist Bruno Bettelheim stated that autism was an emotional disorder stemming from poor parenting, particularly from the mother. Bettelheim believed autism was caused by “refrigerator mothers” who were “narcissistic, cold, and uncaring” women who failed to develop an appropriate bond with their child (Exhorn, 2005). Further, Bettelheim drew parallels between the behavior of children with autism and “concentration camp inmates” (Ong-Dean, 2005, p.151), suggesting that autism was a symptom of withdrawal resulting from conditions similar to those experienced in concentration camps. Although he acknowledged that the “destructive mother” (p. 151) creating these conditions is a figment of the child’s imagination and the parents are not actually trying to destroy their children, he felt the image “has its source in reality, namely the destructive intents of the mothering person” (Ong-Dean, 2005, p.151). While Bettelheim’s view was obviously extreme, this view was held by many professionals and society in general for a considerable period of time, leading to significant impact on professionals, parents, and the direction of future research.

Similar parallels were subsequently drawn by other researchers between autism and attachment styles: many researchers described infants with an avoidant attachment style as “autistic.” One researcher in the early 1980s wrote of children classified as having an avoidant attachment style:

One baby stared and appeared to be “in a trance” at times, almost to “be autistic.” Another avoidant baby rocked repeatedly, had odd vocalizations, his face was “devoid of affect,” and he seemed “attached to objects and the environment more than people”...Clearly here...there is some symptomatic link to the cardinal attributes of autism. (Parkes & Stevenson-Hinde, 1982).

While theories no longer state that autism is an emotional disorder due to uninvolved or unemotional parents, and individuals with autism are no longer described as having an avoidant attachment style, Kanner and Bettelheim's theories continue to have lasting effects on the perception of autism in the medical community, and in general societal understanding (Siegel, 2003).

Although autism was listed as a separate diagnosis in the DSM-III, it was still described in terms of children's attachment, namely the fact that the child does not develop typical attachment behavior. In 1987, the DSM-III-R expanded on this definition slightly, stating that the manner in which children with ASDs convey their attachments is "bizarre," particularly in that they do not seek comfort when distressed (American Psychiatric Association, 1987). In 1994, with the publication of the DSM-IV, a second shift occurred that began moving away from attachment-based classifications, and included children with language difficulties and poor social and play skills. The final shift to the DSM-IV-TR has continued moving further from the attachment based explanations and focuses on the social, communication, and developmental aspects of the disorder (American Psychiatric Association, 2000).

In May 2013, the American Psychiatric Association is publishing the next edition of the Diagnostic and Statistical Manual (DSM-5) with updated diagnoses and diagnostic criteria. In this edition of the DSM, the diagnostic criteria for ASDs are expected to change dramatically. The three major domains of impairments will be collapsed into two, with major impairment required within the domains of social communication/reciprocity, and stereotyped and repetitive behavior. Further, the diagnosis will not be split into separate diagnoses of autism, Asperger's Disorder, and PDD-NOS. Rather, the

most recent proposed changes (dated January 26, 2011) indicate a single diagnosis of Autism Spectrum Disorder, which is then separated into three levels of severity. These changes are supposed to better reflect current knowledge of clinical presentation of ASDs, and to streamline diagnostic criteria for a more accurate diagnostic process (American Psychiatric Association, 2010).

**Minority model: neurodiversity and “curing” autism.**

It should be noted that, within the community of individuals with ASDs, there is currently a “neurodiversity movement” beginning in response to the traditional medical model treatment. In particular, individuals diagnosed with Asperger’s Syndrome or High Functioning Autism (HFA) argue that ASDs are not a disability, but a diversity variable. Although persons who ascribe to the neurodiversity movement framework acknowledge that they may be different neurologically, cognitively, and behaviorally, they argue that they do not suffer from an ASD, but that it is part of their identity, and thus they do not need to be cured (Fenton, 2007).

An article “Don’t Mourn for Us” was written by Jim Sinclair (1993), a man diagnosed with an ASD. In this article, he addresses parents whose children have been diagnosed with ASDs about the grief they experience when their child is diagnosed. He writes:

...when parents say, “I wish my child did not have autism,” what they’re really saying is, “I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.” ...This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams

for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces (Sinclair, 1993).

While the minority model is generally embraced by individuals with high functioning autism and Asperger's Syndrome, parents may be largely unaware of this point, particularly parents of children who are younger and/or more severely affected. The impetus then lies on clinicians, professionals, and allies of persons with ASDs to expose parents to this view, as well as listen for the places where it may arise independently in treatment, and find ways of supporting the family as they move towards embracing disability in this way.

### **Attachment**

Bowlby and Ainsworth, two prominent researchers in the field of attachment and important founders of attachment theory, define attachment as an enduring bond, characterized by a desire to maintain closeness with a specific individual, particularly in times of stress and uncertainty (Colin, 1996). Colin (1996) emphasizes that it is the emotional bond which is the attachment, rather than the behaviors. Further, attachment is based on a long-lasting relationship to a specific person, typically the primary caregiver and, as children grow, the primary attachment figure serves as a secure base from which the child can come and go to explore their world (Colin, 1996).

#### **Overview of attachment theory.**

Based on research regarding infant's attachments, Ainsworth created three categories of attachment: Avoidant, Secure, and Resistant. Securely attached children were generally described as more autonomous and socially confident, as well as more flexible and affectionate with their mother. They were also more likely to ask others for

help, had better social skills, interacted more with peers, and engaged in more social and pretend play. In contrast, avoidant children were more likely to ignore their mother, smiled at their mother less, were friendlier to strangers, and directed more anger, aggression, and noncompliance towards their mothers. Finally, resistant children appeared ambivalent towards their caregiver, were very distressed during separation from their caregivers, and had difficulty settling down upon their reunion. They demonstrated more angry and resistant behavior, appeared more unhappy and helpless, and typically sought proximity and resisted interaction (Colin, 1996; Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004). In typically developing groups of children, 65 percent tend to be classified as having a secure attachment, 20 percent are classified as avoidant, and 15 percent are identified as resistant (Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004).

### **Research on attachment.**

In the study of attachment, naturalistic observations and the “Strange Situation” procedure were the methods often used to discern a child’s attachment style (Colin, 1996; Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004). Initially, Ainsworth used naturalistic observation by observing families for approximately 72 hours over one year, recording behaviors and interactions involving attachment systems, and rating the mother’s sensitivity, cooperation, acceptance of the child, and accessibility. Although naturalistic observation was the best of the three developed measures, it is used infrequently because of the time and expense inherent in conducting longitudinal studies.

Desiring a more standardized method, Ainsworth developed the Strange Situation as a way of measuring attachment, exploratory behavior, and affiliative behavior in children 11-18 months old. The procedure consists of eight episodes which take place in a toy room unfamiliar to the child. The episodes become increasingly stress provoking, beginning with both the caregiver and the stranger in the room with the child, and moving through the baby being left alone, and the baby being in the room with the stranger only. The researchers code the infant's behavior across four categories of proximity and contact seeking, contact maintaining, resistance, and avoidance (Colin, 1996).

### **Autism and attachment.**

As discussed above, autism was traditionally identified as a failure to develop typical attachments and demonstrate appropriate attachment behavior (Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004). Kanner wrote of his initial observations of children with autism, "the comings and goings, even of the mother, did not seem to register" (p.296) and "the father or mother or both may have been away for an hour or a month, at their home-coming there is no indication that the child has been even aware of their absence" (Dissanayake & Crossley, 1997, p. 296). Although today it is generally acknowledged that children with an ASD do demonstrate attachment behavior by seeking comfort from attachment figures during times of stress, discriminating between parents and strangers, and increasing closeness with caregivers upon reunion, many researchers continue to state that children with an ASD are often less securely attached than NT children (Dissanayake & Crossley, 1997; Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004). Further, Hoppes and Harris (1990) argue that, while children with autism demonstrate attachment behavior

with the caregivers, the quality and strength of the relationship varies substantially from the bonds formed between NT children and their caregivers.

The results of the Strange Situation procedure and the subsequent classification of attachment security of children with ASD varied between studies. Based on a meta-analysis, Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes (2004) found that children diagnosed with an ASD were significantly less secure in their attachment to caregivers than their NT counterparts. Severity of the ASD, co-morbid mental retardation, and diagnosis on the autistic spectrum (i.e. autism or PDD-NOS) had an effect on the degree of attachment security observed. It was concluded that parents of children with an ASD, particularly with low-functioning autism, were “less able to establish a secure attachment relationship...because of the severity of the impairment in reciprocal social interaction with their child” (Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004, p. 1131).

Hoppes and Harris (1990) explored the idea that mothers perceived their relationship more positively when they viewed their child as having a more secure or positive attachment. In comparing mothers of children with Down’s Syndrome to mothers of children with an ASD, they found that mothers of children with an ASD perceived their children as less strongly attached, and therefore felt less “gratified and reinforced” by their child (Hoppes & Harris, 1990, p.369).

In reviewing the literature on autism and attachment, it is important to note that the research done on children with an ASD has been conducted using the Strange Situation procedure. To date, the Strange Situation procedure has only been normed on NT children; further, all of the research done on children with an ASD has utilized the

Strange Situation with children both chronologically and mentally older than the 21 month upper age limit used in the norming of the Strange Situation. Additionally, because children with ASDs typically view consistency as highly important, and have difficulty coping with disruptions and separations, researchers have shortened the separation time, or modified the time spent with the stranger for children on the autistic spectrum (Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004). In the research conducted by Hoppes and Harris (1990), the questions asked contained the underlying assumption that mothers and their child with an ASD will relate, communicate, and experience the bonds in attachment in the same way as parents and their NT children. Questions such as “Does your child’s disability interfere with his/her ability to be close and loving in his/her relationship with you,” “Do you ever feel like your child views you or treats you more like an object in his/her world than like a mother who is very important to your child,” and “In general, does your child worry about or make an effort to win your approval” preclude other ways of viewing relationship, attachment, and gratification in relationship by assuming that the relational bond of attachment, love, and satisfaction in the relationship cannot be present if the child does not attempt to win approval, demonstrate affection in typical ways, or treats the mother differently than a NT child would (Hoppes & Harris, 1990).

### **Families of Children with an Autism Spectrum Disorder**

The research conducted on families of children with disabilities in general, and children with an ASD in particular, is extensive. According to Olkin (1999), much of the research on families of children with disabilities can be characterized as an examination of the “burden” the family experiences as a result of having a child with a disability.



Specifically, Olkin (1999) outlines three assumptions that most studies on families of children with disabilities contain: “(1) Having and caring for a child with a disability is a burden; (2) this burden will tax and strain the family’s resources in every respect; (3) we need to understand more about how families cope with this burden” (Olkin, 1999, p. 93). These assumptions become apparent throughout all the research outlined in this study, and subsequently, each study appears to operate from the medical model assuming that there is something inherently “wrong” with the child, and that the family system must cope with and adapt to the problem and “burden” within their family. Positive aspects of parenting a child with an ASD are briefly discussed; however, it should be noted that most of the questions asked of parents in the studies automatically contain the assumption that the child is a burden on the family, without considering other sources of the burden (i.e., limited resources and societal myths). Further, it is assumed that the family members desire to cure their child. Finally, it is important to recognize that the relationship between parents and their children is not acknowledged, and the effect of the relationship on the studies is not outlined.

#### **Parental reactions to their child’s diagnosis of a disability.**

When a child is diagnosed with a disability, most research suggests that parents go through a period of crisis and mourning their changed expectations for their child. Similar to the stages of grief commonly accepted in psychology, stages of accepting the diagnosis of disability have been constructed. These stages consist of shock, denial, sadness, anger and anxiety, adaptation, and reorganization. Another proposed model of acceptance is the “chronic sorrow” model, which suggests that parents experience grief at all stages of their child’s life, although grief and acceptance can coexist and the parent

can still function as a caring and competent caregiver. A third theory proposes that a parent's reactions are dependent upon their interpretation of the child's disability based on their expectations and experiences had by themselves and by their child (Dale, 1996).

Dale (1996) cites an additional model known as the "model of meaninglessness and powerlessness." She states that two of the most common experiences named by parents learning of their child's disability are feelings of meaninglessness and powerlessness. This model suggests that because reality is socially constructed and individuals understand and make meaning of their world and experiences through their interactions with others. Parental reactions to a child's disability are, therefore, based upon their prior experiences with people with disabilities, as well as what they learned about disability before and after the child's birth (Dale, 1996).

Several positive aspects of parenting a child with an ASD were also raised. Dale (1996) recognized that many of the initial negative emotions that arise upon diagnosis dissipate with time and the building relationship between children and their parents. Further, the way in which the diagnosis is delivered and the process of diagnosis have a significant impact on parent reactions. It is often overlooked that many parents experience positive emotional reactions, and deeply value and cherish their child, even though some disabilities can affect the formation of the parent-child attachment (Dale, 1996). Parents often provide a different perspective of coping with diagnosis. One well-known example is the essay "Welcome to Holland" by Emily Perl Kingsley (1987). In this essay, Kingsley likens the process of accepting and raising a child with a disability to having a long-planned trip to Italy rerouted to Holland. She acknowledges that Holland is "slower-paced" than Italy, and states that the "loss of [the] dream" of going to Italy

will not go away; however, she concludes by stating “if you spend your life mourning the fact that you don’t get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland” (Kingsley, cited in Canfield, Hansen, McNamara, & Simmons, 2007, p. 4). In spite of this view often shared by parents, the medical model assumed by society and professionals, as well as the negative view of disability in general, often neglect the positive aspects involved in parenting a child with special needs (Dale, 1996).

### **Familial stress, adjustment and resiliency.**

It is widely acknowledged that families with children with an ASD experience higher levels of stress than families with only NT children (Easter Seals 2008; Konstantareas & Soula, 1992; Sanders & Morgan, 1997 Tunali & Power, 2002). Sanders and Morgan (1997) examined stress levels in parents of typically developing children, children with Down’s syndrome, and children with autism. As they predicted, parents of children on the autistic spectrum and parents of children with Down’s syndrome reported more stress than parents of NT children as measured by the Questionnaire of Resources and Stress. A study published by Easter Seals (2008) further explored the particular concerns parents of children with autism had for their children and how these concerns differed from parents of NT children. The researchers found that, while parents of NT children report a decrease in their concern about their child’s future as the child reaches adulthood, parents of children with an ASD maintain a high level of concern for their child. They also reported a higher level of concern about their child fitting into society, obtaining housing, working, and accessing transportation. Parents were less likely to feel comfortable with their child’s ability to make important life decisions, find a life partner

or spouse, develop a strong religious affiliation and be valued by their community (Easter Seals, 2008). In addition to pessimism about their child's future, Sanders and Morgan (1997) found that parents of children with an ASD and parents of children with Down's syndrome endorsed more negative characteristics about their child. The researchers noted that the pessimism and negative characteristics endorsed by parents in both groups are concerning, particularly because they place the families at higher risk for withdrawing from social support and activities that assist in alleviating stress (Sanders & Morgan, 1997).

In spite of the increased levels of stress experienced, multiple researchers have found that families with NT children and families of children with an ASD do not differ significantly in terms of their adjustment and ability to maintain a healthy family environment (Sanders & Morgan, 1997; Tunali & Power, 2002). Sanders and Morgan (1997) found that, based on the results of the Family Environment Scale, there were no differences between the parents of children with Down's syndrome, parents of children with an ASD, and parents of typically developing children on scales measuring cohesion, expressiveness, conflict, independence, achievement orientation, moral-religious emphasis, control, or organization.

As an explanation for the positive adjustment and family environment in spite of chronic stress, Tunali and Power (2002) determined that parents of children with an ASD must redefine their expectations for their child and redefine their views on life in general as a way of coping with the stress they experienced. According to Tunali and Power (2002), parents cope with chronic and uncontrollable stress by finding alternative ways of fulfilling their needs and by redefining fulfillment of those needs. For example, they

found that mothers of children with autism: place greater emphasis on parenting and less emphasis on career, place less emphasis on individual leisure activities, place less emphasis on other peoples' opinions about their child's behavior, and have a higher tolerance for ambiguity than parents of NT children (Tunali & Power, 2002). The researchers saw these findings as being indicative of parents redefining their needs as a way of reducing cognitive dissonance: by redefining fulfillment of needs, they were able to reduce the threats that could jeopardize their ability to fulfill their individual and their family needs (Tunali & Power, 2002). However, it should be noted that Tunali and Power (2002) also provide an alternative explanation for their findings: the differences between mothers of children with an ASD and mothers of NT children that appeared in the study may reflect actual differences in the parent's experiences.

In regards to family life, a study by Easter Seals (2008) found that families with a child with an ASD did not receive more support from their extended families and their daily routines were more time consuming; however, they also found that they were more likely to eat dinner together at home more than five nights per week and were generally more family-oriented. Gray (1997) found that families of high-functioning children with an ASD saw "normal family life," as defined by their ability to socialize, the "emotional quality" of their family relationships, and the routines comprised in normal family life, as unattainable. However, he stated that the concept of normalcy is a manifestation of the way individuals construct reality, and that parental perceptions of abnormality were the result of attempting to fit into a socially constructed family life based on families with only NT children (Gray, 1997). In conclusion, the findings of the study indicated that

the families are attempting to define their family life through the socially constructed view of family and normalcy.

**Acceptance of individuals with severe disabilities.**

Although the majority of the research cited falls within the medical model framework and ascribes to the three assumptions named by Olkin (1999), Bogdan and Taylor (1989) conducted research on the relationship between individuals with severe disabilities and their caregivers that falls outside of these assumptions. They attempted to discern how the able-bodied people in the relationships described the person with the disability, and how they “sustain their beliefs in the humanness of the disabled people” (Bogdan & Taylor, 1989, p.136). The researchers found that the people without disabilities in these relationships had developed an “accepting” relationship of intimacy and love such that “the difference is not denied, but neither does it bring disgrace” (Bogdan & Taylor, 1989, p.137).

From examining these relationships, Bogdan and Taylor (1989) described four dimensions of acceptance that were apparent in the relationships. First, the individuals without disabilities in the relationships believed that thinking and communicating were separate constructs. Because the ability to understand, think, and remember is often a defining characteristic of being human, individuals who are unable to communicate or demonstrate their ability to reason and comprehend are often viewed as less human. However, in the context of relationships with individuals with a severe disability, Bogdan and Taylor (1989) found that by separating thinking and communication, they saw the individual with the disability as having “full thinking capacity” (p. 139) although they were unable to express their thoughts in a typical manner. By becoming more attuned to

nonverbal communication and interpreting more subtle cues, they felt they were able to understand the individuals in ways that professionals and other people were unable to understand. Thus, acknowledging the individuals thinking ability was an essential element of acceptance and of seeing and understanding the “humanness” of the other (Bogdan & Taylor, 1989).

The second element of acceptance was “seeing individuality in the other” (Bogdan & Taylor, 1989, p. 141). By viewing individuals with disabilities as people with distinct personalities, likes, dislikes, feelings, motivations, and histories, they become individuals and people beyond their disabilities. A third dimension of acceptance was “viewing the other as reciprocating” (Bogdan & Taylor, 1989, p. 143). Research on relationships often states that, in order for a relationship to be considered positive, it must be considered reciprocal by both individuals in the relationship. They found that the person without disabilities in the relationship felt as though they had gained various positive traits due to their relationship, such as being more accepting and caring, and also felt a sense of accomplishment and self-worth. They reported a sense of companionship from their relationship and felt they had made new relationships they would not have found otherwise (Bogdan & Taylor, 1989).

Finally, the nondisabled individuals in the study “defin[ed] a social place for the other” by accepting them as part of the “human community,” and thereby as “one of us” (p.145). By including individuals with disabilities in their definition of family, providing them a role in the family, and integrating them into the routines of daily life, they became part of the system such that “things are not the same without them” (p.145) and their

absence would result in a negative change in the family or social group (Bogdan & Taylor, 1989).

### **Parents views of parenting a child with an ASD**

Another study falling outside of the medical model framework was a study conducted by Fleischmann (2004) on narratives written by parents of children with an ASD. In this study, he examined parents' feelings and attitudes towards their children as described in unprompted narratives parents wrote about their children. He found that in seventy-five percent of the narratives, the positive aspects of being a parent of a child with an ASD were presented immediately in an introduction. Although the stories underscored the complexities of parenting a child on the autistic spectrum, they also described the "positive essence" (p.37) of their child, told stories with gentle humor, and emphasized their positive relationship with their child. Most of the parents described experiencing a sense of happiness and satisfaction, and described positive changes to themselves since their child's diagnosis of autism (Fleischmann, 2004).

The parents involved in Fleischmann's study identified a period following their child's diagnosis when they experienced grief, shock, powerlessness, guilt, and anger (Fleischmann, 2004). Within the narratives, three themes arose summarizing the experience of parenting a child with autism. These themes were: parental empowerment and positive changes to the self of the parent; advantages to living life with an individual affected by autism, including parent and child quality of life; empowerment of the child in terms of the child's accomplishments; and ways the parent felt they had learned from their child. All of the narratives identified in this study had positive outcomes in terms of the child's ability to meet challenges as well as in terms of the parent's "faith, optimism,



and efficacy” (p.40). Fleischmann (2004) concluded that parents viewed themselves as “daring mountain climbers” (p.41) who felt that having a child with an ASD increased their ability to cope and adapt, and made them “better human beings” (Fleischmann, 2004, p.42).

Cashin (2004) conducted a phenomenological study about the experience of parenting a child with an ASD. It was concluded that the major shift that occurred was due to changes to the parent. While Fleishmann (2004) found that most parents in his study identified the change as positive, Cashin (2004) found the changes to be more negative. He identified the majority of the change as occurring in terms of the parent’s way of “being-in-the-world” (Cashin, 2004, p.166). The parent’s social interactions, sense of self, and sense of competence were altered, in addition to living in a manner that seemed restricted and repetitive, and coping with chronic anxiety and exhaustion (Cashin, 2004). Parents in this study reported less social contact, less spontaneity, less belongings due to financial strain, and “less self” (p.167). Cashin (2004) found that parents felt that autism dominated their lives such that their lives were consumed by parenting, and particularly by autism. In contrast to Fleishmann (2004), Cashin (2004) found that parents felt their relationship with their child was dominated by autism, such that it began to act negatively on the self of the parent as the child and his diagnosis became inseparable.

Positive aspects of parenting a child with autism were also outlined. For example, parents described connecting with their child as a positive and triumphant time of mutual engagement and enjoyment, such that each knew what the other was thinking in regards to their shared activity. Patience was a second positive element described as coming out

of the parent-child relationship (Cashin, 2004). However, even the positives were underscored by negativity in terms of the necessity of change in the self of the parent, and the rarity of the positive moments (Cashin, 2004).

Kasari and Sigman (1997) examined how parents' perceptions of their children, and their stress related to parenting, were linked to the way in which they interacted with their children. Using samples of NT children, children with Down's Syndrome, and children with an ASD, the researchers found that parents of children with an ASD described their child's temperament as more difficult, and reported higher levels of stress related to parenting. The researchers further reported that parents of children with Down's syndrome perceived their children differently than parents of children with an ASD, particularly in that the parents and that perceptions of children with an ASD were more linked to interactions than they were for the comparison groups. The researchers hypothesize that because of the deficits children with ASDs face in social interaction skills, parents perceive their children as more difficult temperamentally, experience more stress related to parenting, and believed that their child's interactions influenced their perceptions of their child. Because of this, Kasari and Sigman (1997) state that more research should be conducted on how caregiver perceptions affect interactive behavior; however, this research has not yet been conducted.

### **Qualitative perspective**

The benefit, integrity, and reliability of qualitative research is a point that has resurfaced frequently in the field of research. Historically, quantitative research has been viewed as superior to, and more favorable than, qualitative research. Quantitative researchers often dismiss qualitative methods, stating that they lack objectivity and are

“unscientific...exploratory, or subjective” (Denzin & Lincoln, 2000, p.8). Qualitative researchers argue that, when attempting to use research to answer a “how” or a “what” question, qualitative research is often preferable over quantitative research as qualitative research provides a means of further exploring a topic, providing a detailed view of the gathered information, and working within a natural environment setting (Meloy, 1994). Qualitative research can be broadly defined as an interpretive practice that exposes concepts, phenomena, and ideas through working within the natural environment and through analyzing and understanding the meanings people ascribe to their lived experience of the phenomenon. Qualitative methods further acknowledge the fluid and subjective nature of individuals’ lived experience, and thereby require research methodology that acknowledges, utilizes, and accounts for the intersection of personal beliefs, experiences, culture, and actions (Denzin & Lincoln, 2000).

### **Interpretive phenomenological analysis.**

Interpretive phenomenological analysis (IPA), one method of qualitative research, focuses specifically on a concept or phenomenon. While IPA is actually a complex research methodology, it is often simplified to being seen as a means of collecting and sharing unheard voices. While this method has been primarily used in the social sciences and does serve to provide understanding of the lived experiences and meanings behind a specific phenomena, it also extends beyond this simple definition (Creswell,1998; Larkin, Watts, & Clifton, 2006). Phenomenology is based in philosophical traditions, particularly the philosophical discussions of Heidegger, Sartre, and Husserl. From the basic tenets of these philosophers, four themes and considerations for phenomenological research are apparent. These include the fact that phenomenology is based on: (1) A

search for wisdom, rather than empirical science; (2) a suspension of all judgments and attitudes about what is real during the research process; (3) understanding that reality is inextricably linked to one's awareness of it; and (4) the denial of subject-object dichotomy in that reality is perceived within the meaning an individual holds for their experience (Creswell, 1998).

Several constructs contribute to the understanding and development of IPA, including interpretivism, philosophical hermeneutics, epistemology, and social constructionism. Of these constructs, interpretivism posits that within IPA, actions and their meanings are understood and explored in an attempt to “understand how social reality, everyday life, is constituted in conversation and interaction” (Denzin & Lincoln, 2000, p. 192). The goal of the research, then, becomes to discern the meaning behind the actions of others (Denzin & Lincoln, 2000). Philosophical hermeneutics is an additional component of IPA, and argues that, although the goal of understanding meaning remains, the researchers' bias and worldview constantly cloud their perspective, such that true knowledge and understanding of another person's perspective can never be achieved. In this way, all understanding is also interpretation using judgments and biases. It is only through testing these preconceptions, and naming and addressing biases and judgments, that one can arrive upon a mutually negotiated meaning through interpretation. Deeply rooted in epistemology, the goal of this research is not to generate solutions to problems, but “to clarify the conditions in which understanding takes place” (Denzin & Lincoln, 2000, p. 196).

Expanding on this concept, the concept of social constructionism suggests that knowledge is not able to be “found” or “discovered,” but rather, that knowledge is

constructed in the context of cultural practice, understanding, language, etc. Aspects of society such as language, political views, ideologies, and values are ubiquitous constructs that have a significant and constant effect on the way individuals, including researchers, conceptualize and understand their personal and social worlds (Denzin & Lincoln, 2000). As such, IPA accounts for this subjectivity by allowing for discussion of the context surrounding the subjects, researcher, and the phenomena being studied. Subsequently, this subjectivity is not only acknowledged, but is considered to be a strength in the methodology.

Larkin, Watts, & Clifton (2006) discuss several of the primary goals of IPA. In particular, they describe IPA researchers as attempting to gain an understanding of the participants' world and describe the nature of their world based on their descriptions. However, it is critical to recognize that in this attempt to understand, neither genuine understanding on the part of the researcher, nor true explanation of the essence or fullness of the experience or phenomena is completely possible. As such, the resulting description is a conglomerated construction of the reality between the participant and the researcher. While the researcher searches for and aims to create a "coherent, third-person, and psychologically informed description," this is ultimately impossible, and the researcher must be content to only attempt to be as close to describing the participants lived experience as possible (Larkin, Watts & Clifton, 2006).

The challenge of IPA lies within the distinction made by Heidegger between phenomenology, or the conceptualization of something as it is, and interpretation, which reveals something as something different (Dreyfus, 1995). Larkin, Watts, & Clifton (2006) lament the fact that psychological research typically ignores the people involved

and forgets the original intent and basis of phenomenology as understanding the subjectivity of being a person-in-context. An additional challenge in this research is finding a means of fading the distinction between subject and object—both in terms of the researcher-participant, and in terms of the person and the phenomena in question. However, through balancing conceptualization and interpretation, and through fading the subject-object dichotomy, the researcher is able to discuss broader and more global issues, such as the social construction of the phenomena, in addition to the individual's relationship to the phenomena. An additional challenge in IPA is the blurriness that can arise between narrative therapy and qualitative research. While the purpose of therapy is clearly intervention based, and the purpose of qualitative research delves more into the realm of understanding, the process of the interview and the act of storytelling is often seen as therapeutic in itself (Romanoff, 2001). The ultimate goal of IPA, however, is to create a textual description of the experience or issue being studied, while never losing sight of the person, the interaction, the subjectivity, or the importance of the act of giving voice.

Finally, the issue of power and privilege inherent in the researcher position presents a concern. When the researcher does not fall within the group being studied, it presents a particular challenge in negotiating issues such as trust and rapport during the interview process. Other challenges surrounding understanding and suspension of judgment may arise during the interpretive process. Acknowledgement of these issues, and some degree of transparency on the part of the researcher is essential to true understanding, giving voice, and compiling an accurate textual description of the phenomena. In a community of individuals who have experienced extensive

marginalization and vulnerability, such as the marginalization that may be experienced by people with disabilities and their families, the identity and stance of the researcher become a critical element of the research process (Green, 2003). As such, attempts should be made on the part of the researcher to address these issues prior to beginning the research process, and to continue revisiting them throughout the duration of the project.

### **Conclusion**

Because of societal and medical views of disability as a tragedy, and the view of children with disabilities as a burden, it is typically assumed that all areas of both individual and family life will be affected by an individual's disability within the family system. While Cashin (2004) states that "autism in the parent-child relationship not only dominates the relationships but also begins to act on the self of the parent" (p. 168), Olkin (1999) states that a child with a disability in the family results in more specific changes in the family, rather than all encompassing changes. While the fact that change occurs appears undeniable, the nature of the change, and the parents' reactions to the changes, varies between studies. When analyzing parent narratives, which were based solely on the parents lived experience without prompts or direct questions, Fleischmann (2004) found that parents described their children in positive ways, and indicated that their children had a positive presence in their lives, and had affected them in positive ways. In most of the above studies, the element of the relationship between the parent and child was not discussed. By leaving out the element of relationship, the aspect of humanness as discussed by Bogdan and Taylor (1989) is neglected, and it may be easier to assume that the child is a burden that stresses and strains the entire family system.

Olkin (1999) states that the majority of the extant research on the impact of childhood disability within the family system has focused on the stress, deficits, and challenges faced by these families. The resulting picture created by this research is one of emotional distress and global anxiety and stress. Olkin (1999) questions what the difference would be if, rather than assuming that stress is a primary factor in the family system, it was assumed that “families could view disabled loved ones as members of a legitimate social minority community instead of victims of medical tragedy” (p. 93). She further states that, if that assumption was made, it could lead to “an easier adjustment and outcome for all” (p. 93). By exploring the lived experience of parents of children with an ASD, and discussing their relationship with their child without comparing or contrasting them with a “normal” family relationship prototype, the families can be allowed to define their own reality without attempting to fit into a socially constructed reality that leaves no room for their lived experience.



## **CHAPTER 3**

### **Method**

#### **Participants**

Participants for this study were recruited from two organizations in the Greater Dayton, Ohio area. The first organization, Roads to Recovery, is a parent-founded, non-profit organization that serves children with autism and their families through offering educational opportunities for children and support for families by “embodying [their] collective experiences, resources, and hope for those who continue to be affected by autism” (Roads to Recovery, 2009). The second source of participants was the internet list-serve, Dayton United Against Autism, run by the organization Dayton Area Families for Effective Autism Treatment (DAFEAT). Of the six participants in this study, five were recruited through Roads to Recovery, and the remaining one participant was recruited through Dayton United Against Autism list-serve. Inclusion criteria for this study required participants to be the biological parent and primary caregiver of a child, age 18 or younger, with an autism spectrum disorder. Exclusion criteria included adoptive and foster parents, step-parents, and parents of children without a diagnosis of an autism spectrum disorder.

#### **Materials**

All materials used throughout the course of this study were approved by the Institutional Review Board at Wright State University. Paper copies of the flyers

advertising the study were provided to each family enrolled at Roads to Recovery (See Appendix D). The flyer advertising the study was sent to Dayton United Against Autism members via email on two occasions (See Appendix E). On the day of the interview, each participant was provided a consent form detailing their participation in the study to review and sign (see Appendix A). Next, participants were given a brief, anonymous demographic sheet to complete asking information such as the parents' gender and ethnicity, the gender and ethnicity of their child, their child's diagnosis, and the number and ages of other children in the household (see Appendix B).

Interviews for this study were conducted by the primary investigator. All interviews were audio taped and followed the Interview Protocol (Appendix C). In this interview, the primary investigator read a short paragraph detailing a rough outline of the interview's course, and then read the participant the poem, "Welcome to Holland" by Emily Perl Kingsley. This poem about a mother's experience parenting a child with special needs served to prime the participants for the questions and conversation to follow.

The participant was then asked a series of eight questions about the poem and about their experience parenting a child with an autism spectrum disorder (Appendix C). The first question asked participants to describe their understanding of the poem. The second and third question took this one step further by asking them to reflect on how the poem was similar to or different from their own experiences. The fourth question asked participants who and what had been most helpful, and who and what has been most hurtful, in their experience parenting child with an ASD. This question sought to tap into how the parent had navigated the journey of parenting a child with special needs, as well

as to give them the space and opportunity to share the experiences that have moved them, stalled them, and perhaps hurt them on their journey. The next question asked the parent how other peoples' beliefs have affected their relationship with their child in an attempt to examine the impact of the social construction of disability on the family and determine the parent's level of awareness surrounding this issue. The sixth and seventh questions were based on the "Diversity Walk" activity in which persons who identify with a particular minority group are given the opportunity to answer the following questions: "What do you want other people to know" and "What do you never want to hear again" (Reid, n.d.). These questions give the parent the power to begin speaking back to the "others" they have identified in the prior interview questions, as well as the opportunity to think about and speak back to the misconceptions held by society. These questions are purposefully vague to allow oppressed group members to articulate their thoughts without oppressive or constricting societal impressions impeding the expression of their experiences. The final question asked parents whether there was anything else the interviewer should have asked regarding their relationship with their child.

### **Procedure**

Human Subjects approval was obtained through the Wright State University Institutional Review Board Panel (IRB), and permission was gained from the directors of both participating agencies, as neither agency had its own IRB. A letter from the director of Roads to Recovery was obtained indicating her agreement in allowing this study to be conducted using the parent members of Roads to Recovery. The director agreed to allow the researcher to provide supply each family associated with Roads to Recovery with a letter (Appendix D). A letter from the director of DAFEAT was also

obtained indicating her agreement to allow the researcher to send a letter to the parents on the Dayton United Against Autism listserv (Appendix E). Contact information for the researcher was provided in the letter, and individuals meeting the eligibility requirements outlined in the letter were encouraged to contact the primary researcher.

Participants who contacted the researcher set up an hour long meeting with the researcher at a location that ensured confidentiality of the participant. The researcher first asked the participant to complete the consent form and demographic form, and then began the interview protocol. Interviews were conducted in a semi-structured format, following the questions outlined on the Interview Protocol (Appendix C).

Following the interviews, the sessions were transcribed and sanitized to remove any identifying information. Analysis of the data followed the phenomenological approach described above in an attempt to uncover an understanding of the essence of the parent's lived experience of the relationship between themselves and their child diagnosed with an ASD.

## **CHAPTER 4**

### **Results**

#### **Participants**

Seven participants responded to this study; however, one participant withdrew due to time constraints and difficulty obtaining childcare. Of the six remaining participants, all were eligible to engage in the study. All six participants were female (100%), and each of the participants identified as Caucasian (100%). Two of the participants (33.33%) identified their partners as a different ethnicity than themselves: one parent (16.67%) identified her child's father as African-American, while another (16.67%) identified her husband as Asian (Korean). In regards to socioeconomic status, five of the participants identified as "middle SES" (83.33%) while one identified as being in the "lower SES" bracket (16.67%).

Five of the participants (83.33%) had a male child diagnosed with an ASD, while one (16.67%) had a female child. Four of the children (66.67%) were identified by their mother as "white," one was described as "multiracial" (16.67%) and the last child's ethnicity was described as "1/4 Korean, 3/4 Caucasian" (16.67%). The children's ages ranged from 3.5 to 18 years, with five of the children (83.33%) under age nine (mean = 7.53 years). Diagnostically, three of the children (50%) were diagnosed with Pervasive Developmental Disorder, Not Otherwise Specified (PDD, NOS) and two (33.33%) were diagnosed with Autistic Disorder. The remaining child (16.67%) had not received a

formal diagnosis of an ASD from a psychologist or developmental pediatrician; however, he was being seen by a Defeat Autism Now (DAN) doctor who believed him to have PDD, NOS; he was receiving autism-related services through the state of Ohio; and was receiving therapies for children with ASDs which appeared to be effective in furthering his development and skills. Therefore, it was believed that for the intent and purpose of this study, this participant likely met criteria for an ASD. The age at which the child was diagnosed ranged from 22 months to 12 years (mean = 3.85 years). The amount of time elapsed since diagnosis also ranged widely, from 6 months prior to the interview to 7 years (mean = 3.65 years).

Four of the children (66.67%) had comorbid medical, psychological, or behavioral issues, including asthma, Attention Deficit/Hyperactivity Disorder (ADHD), Generalized Anxiety Disorder, and Wiscott-Aldrich Syndrome. An additional child was in the process of being assessed for ADHD. Five of the families had other children (83.33%), all of whom lived in the home. Of these families, two identified the NT sibling as older than the child with an ASD (33.33%), and 3 families identified the NT siblings as younger (50%).

### **Interview Responses**

All of the participants answered every question on the interview protocol. One participant asked to skip the second half of question four (“Who and what has been most hurtful?”) because she felt she would “cry a lot” on that question. She was asked towards the end of the interview if she would like to return to the question, and was given the option of skipping the question completely. She opted to answer the question and the interview was completed.

**Question 1: What is your understanding of the mother's message in this poem?**

Most of the participants were familiar with the poem, "Welcome to Holland" from their own reading prior to the interview. While they all seemed to have a similar understanding of the message, they each had slightly different interpretations. Most of them saw the author as stating that, although her life had turned out differently than she expected, she still had something "beautiful." Most participants further identified a point of "acceptance" and a point in which the mother must have shifted her expectations such that she was able to move forward into the belief that she still had something "beautiful" in her "real life," and was not stuck imagining a life she did not have. One mother, whose child had been diagnosed for the shortest period of time, disagreed with the point of "acceptance" named above, stating "...you get to a point, I don't want to say acceptance, because I don't think you ever really accept what is, I think you always work towards what could be. But you get to the point where you realize you can't change certain things."

Another mother, whose child had been diagnosed for the longest period of time, said that she felt the author of the poem must have been "pretty seasoned, because you're not going to get that sort of perspective...from a parent of a child who is newly diagnosed. It takes time to be able to relate to that poem." Her interpretation was slightly different than the other mothers' in that she described the mother's message as a "message of hope," and stated that the mother was "seeing her child's worth." Finally, she felt that the poem relayed the message that "disability doesn't mean you're not going

to have a life full of riches and wonderful memories and experiences,” and expressed a desire that more people were able to understand the Kingsley’s message.

**Question 2: In what way does this poem represent your experience?**

All of the parents indicated that the majority of the poem represented their experience parenting a child with a disability. One mother expressed some hesitancy about embracing the message of the poem. Although she stated that the poem was “very moving and extremely real of how it does feel,” she also stated:

...sometimes I think about it as maybe that is the path that I’m on and sometimes I think that maybe I’m going to have another child someday and I’ll be able to experience some of that other world, but I’m not sure if that’s going to happen.

Like this mother, all of the parents acknowledged that there was more of a struggle in the beginning. The mother whose child had been diagnosed the longest stated, “now that he’s 9 years old, I guess I relate to it because I see the wonderful things that he brings because he is who he is,” and stated that parents “have to go through the seasons” to reach the point of acceptance articulated in this poem, although she also acknowledged that some parents never reach that point.

Another mother stated that, in comparison to her two other NT children, she had to “learn a whole different way of relating” to her daughter with an ASD, as Kingsley described needing to learn the language of Holland. She continued following Kingsley’s analogy, stating that the new way of relating was “not an ugly thing, it’s a beautiful thing. She’s such a sweet innocent person. [laughs] And she’s herself. She can’t be anything else.”



**Question 3: In what way does this poem not represent your experience?**

One of the parents noted that the poem indicated that the child's disability was present from birth, and that this is not the experience for parents of children with autism who "think everything's okay, and then it's not." Another parent stated that the woman who wrote the poem had a child with Down's Syndrome and, as such, his disability was likely more visible than autism spectrum disorders. She noted that her experience raising a child with an ASD differed because "people don't know that I'm in Holland," and she had to explain that her daughter did have a disability, whereas for other children, it was readily apparent.

**Question 4: Who and what has been most helpful? And most hurtful?**

Many of the mothers cited their husbands as the people who had been "most helpful" in their journeys parenting children with ASDs. Other important people cited were "tutors" (Applied Behavior Analysis therapists), other family members (particularly mothers), Defeat Autism Now (DAN) doctors, and other mothers of children with ASDs. One participant cited "school" as being helpful, while another mother stated that her child's experience at public school had been one of the more "harmful" experiences. Most of the mothers discussed information, the internet, books, and resources as helpful, but felt they had to seek out these resources on their own. None of the mothers cited traditional medical professionals as helpful; however, one mother specified that doctors are helpful when they are "on our side," and defined these physicians as persons who believed her child could "get better." One mother cited several people as "helpful," and stated that she felt they were helpful because they helped her know that she was being

held “accountable,” and she appreciated knowing that “there are people...who understand what we’re going through.”

In terms of who and what had been most hurtful, each of the parents seemed to have multiple stories they could share in this area, and their responses varied widely. One mother of an older child with autism stated that “other kids” were the most hurtful, and that children and their parents did not seem to feel “comfortable,” as evidenced by their facial expression and words. Other people’s judgments were further described as hurtful, particularly people rolling their eyes at their child’s behavior or not understanding the choices that have to be made when choosing to discipline their child in public. Another mother described other children as “cruel,” and became tearful when discussing her fear about how other children would react to her son as he grew older.

Grandparents were described as “hurtful” by two mothers in terms of them doubting and disagreeing with the parents’ views of what caused their child’s autism. Another mother cited parents of typically developing children as “annoying,” particularly when they complained about things that their child did. She provided an example of parents who complain that “[their] child talks too much, he never shuts up,” and stated “[that is] normal and fine and it’s just not the same, it’s not what I go through. So that’s hurtful to hear stories about complaining about typical kids. That’s very hurtful.”

Doctors’ reactions and beliefs were repeatedly described as hurtful, particularly doctors who did not have similar views regarding theories on the cause and development of ASDs, and doctors who did not believe the mothers when they initially described the issues they were seeing in their children. One mother discussed the impact of a developmental pediatrician who described her son as “completely unintelligible

and...[was] basically saying what his potential was.” She further discussed how overwhelmed she felt when she had to sit in a small exam room with her son and several doctors. Insurance companies were referred to as “not on your side,” and named as something that had been “hurtful” by one parent. Working with governmental organizations and attempting to access resources, particularly the Autism Scholarship Program in Ohio were further cited as “hurtful” or “difficult to deal with.” She described the process of accessing resources as “a process where you have to get hurt one time to figure out what to do the next time. And it’s sad that it’s hurting your child, that’s what’s difficult about it.” One mother discussed the public education system as particularly hurtful to parents and their children, stating that the public schools “wine and dine you and promise you the stars and moons and the minute you walk out the door, your child is in the special needs room 99 percent of the time.” Finally, one mother stated that the things she found most hurtful were the “things that you internally think about.” She felt one of the most hurtful things for parents was “always seeing the other side,” or always seeing parents with typically developing children, and that the thoughts and comparisons she made were always the most hurtful, rather than anything said or done by other people.

**Question 5: How have others’ beliefs about autism impacted your relationship with your child?**

This question was asked to get a sense of whether parents felt they were impacted by external factors, such as other people, the medical model of disability, and current and past theories of autism, and whether these factors impacted the ways in which they were able to feel close to or relate to their child. This question was confusing for several

parents, who asked for clarification on who the “others” might be, asked for clarification on the question, or did not initially answer the question in their answer. However, once the question was clarified, each parent answered the question to some degree. Four of the mothers initially said that they did not feel that societal or other peoples’ perceptions of autism impacted their relationships with their children. One mother indicated that when physicians underestimated her son’s abilities, or attempted to outguess his potential, it got her “fired up,” but did not necessarily “change [her] path,” stating “It’s my way of being able to come around and say ‘ha, told you so’ ... Kind of like my ‘in your face’ moment.” Another woman felt she had managed to avoid a lot of the problems that may arise in this area because she did not describe her child as having autism to other people, but rather, chose to say that her son had “developmental delays” or “speech issues.”

The mothers of the two oldest children, whose children had been diagnosed for the longest period of time, stated that they did feel that they had been influenced by other people’s perceptions of, and reactions to, autism and that this had impacted their relationship with their child. One mother stated that she felt other people’s reactions had changed her relationship with her daughter, because “there are times when I wish she was more neurotypical.”

The final mother, whose son had been diagnosed for seven years, stated that she felt she was much more influenced by other peoples’ ideas and perceptions of autism when her son was newly diagnosed, and that the varying theories about autism had a large part to do with this. In particular, she said that in the beginning she accepted what doctors told her and underestimated her son’s potential. She felt that if the doctor who diagnosed her son had “offered suggestions of early intervention and hope and ideas, it

would have greatly changed the course even of [B]’s life...” However, she indicated that it was only over time that she was able to recognize the impact these people had on her and her perceptions of autism, and her perceptions of son, in particular.

**Question 6: What do you want others to know about your relationship with your child?**

When the parents were asked what they would like other people to know about their relationship with their child, several parents suggested that their relationship was similar to that of a parent and a neurotypical child. Several parents also suggested that they would like people to know how “loving” and affectionate their child can be. One mother described her son as a “tender hearted little man,” another questioned whether her son would be as loving if he did not have autism, and a third mentioned the “deep connection” and respect she and her son have with one another.

One mother focused on the fact that she wanted other people to know that “just because [they] don’t see some of the typical things that other kids have, it doesn’t mean they’re not in there,” and in particular stated that “laughing” was something her son was able to “achieve,” that he was “loving,” and that he knew more than was readily apparent. Two mothers focused on their interactions with their children in parenting them, and wished people recognized that they are implementing necessary parenting techniques, and have to interact with their children differently than parents of typically developing children.

**Question 7: What have people said about you and your child that you never want to hear again?**

One mother said that she never wanted someone to call her daughter “retarded” again, stating, “[D’s] not retarded. She’s not stupid. She’s not an idiot. She’s weird...she’s fine with that because, you know, I’m weird.”

Another mother stated that she disliked when people made comments about how “lucky” her son was to have her as a mother, and felt that these comments gave her “too much credit” and made her feel like they were saying she “deserved a medal” for parenting her son. A third mother disclosed that, when she was choosing not to disclose her son’s diagnosis to friends and family, people assumed that she was not meeting her son’s needs, and that there was a silence around the issue because people were “afraid to ask.” Similarly, a theme that emerged in several parents’ answers was the wish that family members and friends would trust that the parents know what they are doing in their choices for their children. Several mothers also stated that family and friends denying their child’s problem, or disagreeing with the family’s theories on autism, was particularly hurtful and something they did not want to hear again.

**Question 8: Is there anything else I should have asked you about your relationship with your child? If so, what?**

At this point in the interview, one mother described her child as a flower, stating that he has a “different rate of blossoming.” While some children have a few big, beautiful petals, she described her son as having “lots of little petals, millions of little petals,” and hoped that one day he would be a “beautiful flower with lots and lots of little petals.”

Another mother wanted to emphasize how well she and her daughter get along, and how they have similar interests and are able to talk about books together. One mother wished

to reiterate that she did not want to change her son, stating that she worried that if her son did not have PDD, his personality would be different, and that she “can’t wish for that.”

Another mother elaborated on how having a child with an ASD has affected the other relationships within her family, particularly her relationship with her husband. One mother also touched on the judgment she feels from other people when she mentions that she and her husband are thinking about having another child, in part because they want their son to grow up in a social environment. She also mentioned the financial strain of having a child with an ASD, the difficulty of insurance companies, and the challenge of finding a balance between investing in expensive therapies and prioritizing finances.

## **CHAPTER 5**

### **Discussion**

#### **General Discussion Regarding the Process of the Interview**

One of the most prominent features of the interviews conducted for this study was the level of deep sharing and storytelling engaged in by the participants. More than half of the participants became emotional during the interview when sharing their stories. Following the interview, after the tape had been turned off, the researcher engaged the participants in a brief discussion as a means of both debriefing from the interview, providing closure, and obtaining feedback about the interview process. Several participants shared during this time, as well as during the interview, that the topics discussed during the course of the interview were not topics they thought about often, and not things they had the opportunity, or even necessarily the desire, to discuss.

Green (2003), states that mothers need other mothers to talk to about child rearing. Perhaps because of this avoidance of the topic, the uniqueness inherent in the interview process, and various other personal and social factors at play, all of the parents interviewed tended to initially deny or downplay what seemed to the interviewer to be the most poignant and important answers and stories shared. The process of the sharing of these stories was almost certainly more powerful than can be portrayed through the transcriptions and analysis included here. The emotionality of the experience, the sense of power felt in the room when thoughts were clarified and deep, life-altering stories



were told, and the joy and love that was so apparent when the mothers spoke of their relationships with their children, is unable to be depicted.

Similarly, in terms of the process of the interview, the points at which the mothers became emotional was interesting and spoke to deeper processes involved in societal perceptions, conversations they have been able to have, and stories that have not been tapped or have been unable to be told. For example, this excerpt from one interview speaks to the aspects of parenting a child with an ASD that are often deeply meaningful and important to parents, but are often overlooked and ignored, or perhaps even devalued, due to the pervasiveness of the medical, deficit driven model.

Participant # 3: ...the way society is...it's always focused on the deficiencies.

And so you tend to focus on that so much that sometimes you overlook the good things.”

Researcher: Absolutely. Tell me about some of the good things.

P: Umm (starts crying)...you're making me cry. [laughs]

R: It's okay, take your time.

P: Um...ack. He's an amazing kid. He's super smart. He's very engineering...

The participant proceeded to relate several stories about her son in terms of his strengths, his unique abilities, and his sense of humor through a mixture of laughter and tears. Several other mothers demonstrated the ways in which they may have internalized the tendencies of society to devalue or downplay the achievements of their children and the ways they relate to them. One mother became tearful when discussing the connection she has with her son, stating “we have such a deep connection and...a common respect for one another. And we connect so deeply that words, they're not needed. ...[B]ecause [B]

is so sensorial, you know having a child come up and smell your cheek to identify who you are...?” She shrugged, as if at a loss for words, then laughed saying “I’m kind of embarrassed people are going to hear that. But it’s awesome.”

An example from another mother demonstrated more ambivalence in this arena. She discussed how her child knows more than he initially appears to understand, and has more “typical” abilities than are readily apparent. Finally, she said, “I mean, he just learned to point to mom and dad, but I wouldn’t tell my friends that. I mean, it’s just irrelevant, I guess.” While it was clear that she was excited about her son’s new ability, it was equally apparent that she did not feel this was an acceptable topic of conversation, or that it would be valued if shared and, as such, she discounted it as “irrelevant.”

Although both mothers and fathers were recruited for this study, only mothers responded and, as such, only a female perspective can be assumed and interpreted from these results. While these results are not surprising, it is important to note the impact of gender on the responses. It should also be noted that because only mothers participated in this study, and most of the research on parenting children with special needs focuses on the impact and needs of mothers, this does not mean that fathers do not experience the same need for storytelling and sharing of experiences, or that fathers do not experience deep and meaningful relationships with their children with ASDs. Rather, it seems that this may speak to the gender roles and stereotypes pervasive in our patriarchal society. In particular, while it is not generally “acceptable” for mothers to discuss their experiences parenting children with disabilities, it is likely further unacceptable and outside of the norm for fathers to share such stories and engage in dialogues surrounding parenting in general, and parenting children with disabilities in particular.

Finally, the researcher's identity as a young woman who is not a parent, much less the parent of a child with an ASD, came up with each of the participants with whom she did not have a prior relationship either before or after the interview. While each of the participants seemed open to the process of the interview, one mother in particular seemed hesitant or suspicious of the researcher's ideas about ASDs and, seemingly, about the model of disability from which she was operating. Near the beginning of the interview she stated, "I hate labeling. So even when you asked...what his label is (on the Demographic Information form), I just really think it's ridiculous because anywhere on the autism spectrum you can label a child with Asperger's or PDD and they can be so vastly different." The researcher agreed with her and continued to listen to her feelings about labeling and diagnosis. Finally, the researcher attempted to put the participant's uneasiness to rest by stating, "Diagnosis can be a very fine line, especially on the PDD spectrum, and then you do wonder: what good is it going to do anyway?" This response made the participant laugh and seem to relax, such that much of the defensiveness and nervousness that was apparent in the beginning of the interview began to dissipate.

### **Medical and Minority Model Interpretations**

As discussed in the literature above, the medical model continues to be the most prominent conceptualization of disability for medical professionals and for society at large. Through the interviews for this study, it became apparent that the parents included in the interviews had run up against and internalized the medical model to a large extent. The most prominent way in which this was apparent was in the parents' desire to "cure" their child of autism.

However, the mothers also seemed to have an inherent understanding of the minority model that was exemplified in several ways. Most of the mothers, for example, demonstrated a resistance to the idea of “labeling” their children and treating all individuals with the same “label” regardless of their individual characteristics. One mother discussed how she felt people were “label happy” in the United States. Another mother stated, “I think the label is really an injustice because every kid shows so many different unique things that I really don’t like to use it...I just don’t like putting people in a box like that. ...I mean, I think as a parent you know better than anybody else what’s wrong with your child.”

In addition, one mother discussed how she felt when the director of her son’s school treated him as though he was more than the label of autism, stating, “...[she] was the first one who gave [B] the freedom to be a child without a label.” She also discussed her resistance to the medical model, the desire to make her child “normal,” and his first teacher’s attempts to hide him from typically developing children. Although her son was able to participate in the classroom activities, the teacher wanted him to repeat kindergarten, rather than move into the first grade class. She stated:

the teacher told me, the 1<sup>st</sup> grade teacher, told me that she observed him flapping his arms in front of the copy machine and that he would distract the other students in the classroom, and they are all paying for private education...and I thought, you are one sorry Sally, aren’t ya? Not to teach how to...respect one another and embrace diversity. You’re sending a really horrible signal. And I think you’re underestimating those children.

In this, the mother's strength and belief in her child becomes apparent, as well as the way in which she was able to reject the medical model and resist the notion that her child was less than the other children, or that he and his behavior needed to be hidden.

Several parents also alluded to the idea of "theories" of autism and referenced professionals or concepts that indicated which theory they personally believed in. One mother described her frustration with the increasing number of theories and treatments, and the difficulties discerning which would be most beneficial for her child. She stated:

[E]verybody has a pathway to nowhere, it seems. Empty promises. Throwing lots and lots of money at it. All of those things contribute towards the reality of the situation. And you have to go through years of that. I mean, that's not months I think for most of us, that's years of going through it, figuring it out, how you're going to stop trying to fix the child and live harmoniously. When you figure that out, when you stop obsessing over how to fix it and start learning how to live with it, then all of a sudden things change and they become beautiful.

This mother, whose child had been diagnosed for the longest period of time, acknowledged a level of acceptance and identity formation surrounding disability of her child and of his ASD that was not seen as explicitly in the other interviews. In particular, the other mothers seemed to be much more focused on "curing" their child's ASD and working towards normalcy through the variety of therapies they attempted. One mother stated:

it's not like if you have a child that's born with Down syndrome...you can't fix that. But with autism, there's a lot that you can do. ...So I think that puts a little more guilt on the parents...it just always falls back like a guilt trip that you didn't

do good enough. With other diagnoses, you can't change them. But I've seen it. I've seen it. I've seen lots of kids change, so you can change it.

In a similar vein, several mothers discussed the difficulties of choosing which therapies would be worth attempting, which ones they deemed not worthwhile, and which therapies were unable to be tried due to being out of their price range, too far to drive, etc. "I don't want to leave any stones unturned," one mother said, "but I need to be careful about which stones I try turning over because, are they going to make me more miserable?" The pressure on parents—and particularly on mothers—to try various therapies and “reverse” their child’s diagnosis appeared pervasive and affected all of the mothers interviewed to an extent

...the problem with this diagnosis is, is—it's somewhat fixable, if you know what I mean, and it's all, I mean, everything is in my hands with him. ...So if you don't make the strides that you think your child is going to make then [pause] it's going to be your fault. You know?

The variability within the autism spectrum, and within the various diagnoses comprising the spectrum, was also a theme mentioned by parents. One mother discussed her hesitance to use the label of “autistic” to describe her daughter, but also acknowledged that the concept of the spectrum, and her actual diagnosis of PDD-NOS would not be understood. Several mothers stated that when people heard the word “autism,” they pictured “the kids on the TV who are...(imitated head banging/rocking behavior)” or “Rainman.” To attempt to explain the concept of the spectrum, one mother stated that she described her daughter as “slightly autistic.”

**Researcher:** What sort of response do you get when you say things like that?

**Interviewee:** It's sort of an "OHHHhhhhh." Like they KNOW something. You kinda want to go, "what do you mean OHHHhhh?" ... There was this boy that, when [D] was in 7<sup>th</sup> and 8<sup>th</sup> grade, she went to a school that had two autistic boys. They were very nonverbal, very, you know...(imitates head-banging behavior) and [people] expect that's what autism's like. And it is. And then there's C. And they don't understand that. They don't understand that even though she reads constantly, way above her grade level...[pause] and she's got a typical IQ. And, but, she acts like an 8-year-old and they don't understand that. Why can't she behave herself? You know? Why can't...when she's wearing a skirt...why can't she keep her legs together? Why...there are no easy answers.

### **Attachment**

Many parents, in various ways, acknowledged the loving relationship they experience with their child. Although the parents described their relationships in different ways and acknowledged experiencing the attachment bond differently than parents with typically developing children, the affective bond felt by the parent, and the attachment expressed through affect by the child, was apparent in the parents' responses.

For example, one mother stated that her son had "special little things that he does to tell [her] 'I think you're special'...." In particular, she stated:

Like he just loves, like especially when he's tired or when he's just gotten up in the morning, he'll lay on the bed and look right into my eyes and hold my hands and look right into me, or grab my head and move it towards his so he can look right at me. And he'll just do really soft stroking, like this, that are just really sweet, really gentle, he's saying "I really like you, this feels good, let's snuggle

some more.” But...those are things that I view as him saying “we’re super close, you really know me.”

The above response underscores the idea that using traditional methods to measure attachment of children with ASDs is inadequate. Similarly, other parents’ responses indicated that the current socially constructed meaning of attachment—both for the parent and for the child—is inadequate in adequately describing the affective bonds between children with ASDs and their families.

### **Gender**

Gender appeared to be a significant factor that was acknowledged by many of the mothers interviewed, many of whom indicated that the responses provided by their husbands would be significantly different than their own. One mother stated explicitly, “my husband would give you a completely different interview because he’s so much more laid back, he doesn’t worry about any of this, but that too is just a woman thing I think.” Most of the mothers indicated that it was primarily their responsibility to find the therapies and treatments they wished to try for their child and while they described their husbands as supportive, they did not indicate that they had a significant role in this process. The mother above further stated:

...the day I got his diagnosis, I locked myself in the basement for about a week, online, just to read and research as much as I can because, like I said before, I feel that his improvement or whatever you want to say, is in my hands. Nobody else is going to do it but me. And that is one of my biggest fears. I tell my husband all the time, I tease him that he better learn some of this stuff because if I’m not here...somebody better do it.



Another mother stated, “it’s probably all almost up to me. If it costs money, I run it by [my husband] and talk to him about it, but if I push hard enough, he will do whatever I talk about enough and make it happen. So, [pause] it’s pretty much just me.”

Two of the mothers mentioned mother and author Jenny McCarthy with disdain, stating that they “don’t like to give Jenny McCarthy any props” and even that it was “embarrassing” to be quoting her. However, they both borrowed the phrase that McCarthy made popular through the title of her book, stating that mothers of children with autism are “mother warriors.” In describing the hurtfulness of the education system, one mother stated:

... You’re a warrior at home. You’re a warrior at school. You’re a...you’re...it’s just...it’s ridiculous that we have to fight so hard. We’re exhausted anyway trying to figure out why this happened, what did we do, and then the one place that you feel you should get a little relief is that your education system would at least be on your side. It’s exhausting.

However, even while the parents work towards a “cure” and towards “normalcy,” they also state that they would not want to change their child. “I guess...I worry that if he didn’t have PDD that his personality would be different, and I love his personality, he’s caring, he’s got a loving personality. And I just worry that he would be different, so I can’t wish for that.” Another mother ended her interview by stating that she had wanted to ask other parents what they had planned for their life and for their child prior to their child’s diagnosis, or what their trip to Italy would have looked like had they not been detoured to Holland. When the researcher turned this question back to her, she stated,

“...thank god I missed the boat to Italy...Thank goodness I was detoured to Holland. Because they have windmills and they spin, and [B] loves them.”

Given the history of the understanding of disability in terms of the models described, and the history of ASDs in particular, it seems that mothers still seem to experience a significant amount of guilt, and perhaps blame for their children’s disabilities. The guilt appeared on several levels: many mothers compared their child’s level of functioning, or the “severity” or number of maladaptive behaviors demonstrated, and reported feeling “guilty” over the relative functioning of their child. Others reported guilt in terms of why their child was diagnosed, their inability to get their child diagnosed sooner, not intervening sooner, or their child’s lack of progress. In the quote above regarding Jenny McCarthy, the mother reported parents are frequently exhausted from trying to understand what caused their child’s ASD, and what they as mothers may have done to cause it. The mothers’ theories about autism and its causes played a major role in their understanding and conceptualization of what caused their child’s disability, as well as what their role may have been in causing it.

Finally, one mother explicitly raised the difficulty of maintaining her marriage while parenting a child with an ASD. When talking about her husband, she stated:

I think you either accept what it is or some people just go their separate ways because they can’t figure out how to deal with their relationship with the other person and their child. So I think that’s a really difficult piece. But then the other side, who knows your child or would love your child like his father. ...that’s probably why a lot of moms have to work hard at their relationships because you know that person knows everything about the child, and accepts everything about

them, and it's harder for their little world when you take that apart. That's why I think you work harder to try to keep everything together.

### **Conclusion and Clinical Implications**

The purpose of this study was to provide parents of children with ASDs a space to describe their relationship with their child as they live and experience the relationship, outside of societal constructions of disability, family, and relationship. Consistent with other studies published in recent years, the mothers interviewed expressed significant concern and anxiety surrounding such factors as marital relationships, their child's progress, finances, and the reactions of society to their child's disability. As Landsman (2005) noted, all of the mothers evidenced an inherent understanding of the minority model of their disability at some point during the interview. However, this understanding was muted by the script of the dominant medical paradigm indicating that acceptance and celebration of the child, without the constant push towards normalcy, was a reflection of bad parenting and, in particular, bad mothering.

As described by authors Tunali and Power (2002) and Cashin (2004), the mothers in this study described a redefinition process by which they came to accept and embrace their "real life." However, while the prior researchers described this process as a means of coping with uncontrollable and chronic stress or a way of reducing cognitive dissonance, the mothers in this study described their redefinition of daily life as a way of coming to embrace and accept their child in a world that views having a child with a disability as a burden (Cashin, 2004; Tunali & Power, 2002). In particular, one mother stated that having a child with an ASD:

...definitely does take you away from most of [your] dreams...[but]...you completely readjust and you find...it still never changes. It never ever changes. Your relationship with your child...everything around you and the language and EVERYTHING changes and your scenery and the opportunities you have. But the relationship that your family builds is still there, it's always the same.

The process of describing, clarifying, defining, and explaining their child, their family life, and their experiences parenting a child with an ASD was an emotional experience for many of the parents. However, the emotionality of the experience did not come from the difficulties and strain of raising a child with a disability. Rather, the emotion stemmed from relaying stories of beautiful and valuable moments with their child, and from the experience of reflecting on the impact of society and the devaluation of their child and their family life. The redefinition described by the mothers brought them to an emotional place outside of societal constraints in which they could recognize that disability did not mean that they were “not going to have a life full of riches and wonderful memories and experiences.” Differences were noted between parents whose children had been diagnosed for longer periods of time, and parents who had newly diagnosed children, particularly in that parents who were farther away from the initial diagnosis appeared to be further along in the “redefinition” process, as well as more accepting of minority model ideals in general.

When asked what else they would like people to know about their relationship with their child, the mothers' responses were profound. In particular, they stated that just because the “typical” things her child was typical of were not readily apparent did not mean that he was not capable of them, and that he knows more than people think.

Another mother reiterated that her family life and relationship with her child was “not that much different than typical.” A third mother stated she wanted people to know “autism doesn’t LOOK like anything. People with autism, you know, when they’re sleeping, they look just like neurotypical children.”

The clinical implications of this study are important for professionals to consider, particularly those involved in delivering the diagnosis of autism to families, or involved in the ongoing treatment of children with ASDs. In particular, professionals should listen for the point parents are at in the “redefinition” process, and acknowledge that “redefinition” of family life and relationship is not necessarily linked to “coping” with the “burden” of parenting a child with an ASD. Rather, “redefinition” is linked to the fact that mothers need to experience living with a child with a disability in a society that does not represent their reality, or value their children in the manner that they accept and value them. Further, parents are frequently attempting to reconcile the difference between the medical model mindset promoted by society and professionals, while they are living in a world in which their love for their child can at times transcend the desire for a “cure,” for a miracle treatment, or for a way in which to make their child “typical.” Their relationship, even when the child is nonverbal, is unique, and recognized as “something beautiful.”

In spite of this, the very real stressors of having a child with an ASD that have been noted in other studies are equally apparent in this study. The origins of these stressors, however, rather than stemming from the child, are often more linked to society, lack of resources, and lack of support. The painful experiences named by the mothers in this study indicate that professionals have a long way to go in terms of truly providing

family-centered, competent care. While societal change is certainly needed, it seems that much of the necessary change may need to begin with professionals and the manner in which they provide treatment and diagnosis, conduct research, and publicize information.

### **Limitations**

The primary limitations of this study relate to the sample of participants gathered. First, the researcher was familiar with three of the participants through various extracurricular activities. Each of the parents responded to the recruitment material of their own accord and were not selected or otherwise targeted as ideal respondents. However, it is unknown the extent to which the prior relationship may have influenced the parents' response, or the researchers' knowledge of the participant could have influenced interpretation in spite of the fact that several precautions were taken to maintain objectivity. An additional limitation could be that five of the six parents were part of the same parent-run organization. While Roads to Recovery does not promote any particular views of autism, or require participants to agree with any common viewpoints, the parents involved at Roads to Recovery are naturally a select group that is likely more invested in working with their children, as evidenced by the fact that they sought out a means of alternative education where they need to play an active participatory role. Further, because of the expense of the school, and the fact that many of the families at Roads to Recovery are recipients of the Ohio Autism Scholarship Program, the researcher estimated that the families utilizing this organization likely all fell within the middle to upper-middle SES bracket, which was verified by the parents' self-report on the Demographic Information form.

Research indicates that there are significant disparities in terms of the information available and resources available to parents of children with disabilities based on factors such as ethnicity and socioeconomic status. Age of diagnosis, accuracy of diagnosis, and ease of obtaining diagnosis and treatment are also often influenced by these factors. This discrepancy was apparent in this study; however, because of the small number of participants and the exploratory nature of the study, this aspect of the experience of parenting a child with an ASD was unable to be explored. However, the discrepancy, which is consistent with national trends, was noted.

Further, the identity of the researcher as a young woman who had not had the experience of parenting in general, or parenting a child with an ASD in particular, may have an impact on the openness of the participants, on the trust level of the participants, or on the understanding and interpretations made by the researcher. Green (2003) discusses the benefits of the researcher identifying as a member of the group being interviewed, stating that as a member of the marginalized group being studied, she was unable to position herself as an “objective observer,” and would disclose this to the participants, stating “the mothers would need to know that we are ‘insiders’ in order to be at ease in telling their stories” (p. 3). This researcher was asked by several participants either before or after the interview if she had a child on the spectrum, and while it did not appear that this significantly impacted any of the participants’ responses, it is possible that a researcher identifying as an “insider” would have elicited different responses due to her personal experience and understanding of the issues being discussed.

## **Future Research**

As evidenced by the results of this study discussed above, parents of children with ASDs seem to carry a mixture of medical model and minority model understanding and viewpoints in regards to their children. While some research has been done on the models most ascribed to by parents, and some information is available in regards to the hesitance mothers demonstrate in ascribing to and advocating for the development of the minority model (Ong-Dean, 2005), little in-depth information is available on specific factors influencing the internalization of the medical model of disability. For example, it may be beneficial to conduct research exploring the impact of the age of the child at diagnosis on the parents' tendency to accept versus reject the medical model. Further research on the effect of the manner in which the diagnosis is given, and the resources provided to the parents after diagnosis on the parents tendency to move towards or away from a minority model understanding of their child's disability. A longitudinal study on parents' internalization of the minority model after diagnosis may be beneficial in determining the ways in which mental health and medical professionals can encourage parents to broaden their understanding of disability and develop alternative perspectives about their children's place and role in their family and in society.

Most of the research conducted on parenting children with ASDs centers on the experience of parents. While this study attempted to move outside of that trend by recruiting "parents," only mothers actually responded to and engaged in the study. As discussed above, this potentially speaks to several factors related to gender, gender roles, and the roles of women as parents and caregivers. However, fathers reportedly continue to be involved in their children's lives and develop meaningful relationships with their



children with ASDs that are often different, as cited by the participants of this study, than the relationships between mothers and child. Further research on the relationships between fathers and their children with ASD, as well as further exploration of the impact of society's tendency to negate the importance of "story-telling" and discussing issues related to parenting for men in particular may be an advantageous direction of study.

## Appendix A

### Consent Form

Reconstructing Autism:  
A Phenomenological Study of the Relationship between Parents and their Children  
Diagnosed with an Autism Spectrum Disorder

This consent form is to certify my willingness to participate in this research study.

Laura Elizabeth Solomon, a doctoral student in the School of Professional Psychology at Wright State University in Dayton, OH, is conducting a research study to determine how parents of children with an autism spectrum disorder describe their relationship with their child. I am being asked to participate in this study because I am the parent of a child diagnosed with an autism spectrum disorder.

My participation in this study will involve engaging in a one hour, open-ended interview with the primary investigator, Laura Solomon. This interview will be audio taped. Following the interview, the tape will be transcribed such that all identifying information about me and my child will be removed, and the tape will be destroyed.

During the course of the interview, I will be read some information and then asked to answer questions about my relationship with my child. I will also be asked some questions about my family's demographics, such as my child's age, ethnicity, and diagnosis. This information will not be used in any way to identify me or my family. Information that I provide will be kept strictly confidential and all responses I provide will not be associated with my identity in any way.

It is possible that my participation in this study may elicit mild psychological distress related to the disclosure of information of a personal and potentially difficult nature. If I experience psychological distress that is intolerable or beyond what I expect, I may choose to contact a mental health professional to address my concerns by asking my primary care physician for a referral.

There will be no direct benefit to me from participating in this study. However, the information that I provide may help health professionals to better understand the experiences of parenting a child with an autism spectrum disorder, and the effect of society's perception of autism on families. My participation or non-participation in this study will in no way impact my standing with Roads to Recovery or Dayton United Against Autism.

Any information about me obtained from this study will be kept strictly confidential and I will not be identified in any report or publication. **PARTICIPATION IN THIS RESEARCH IS VOLUNTARY.** I am free to decline to be in this study, or to withdraw from it at any point. Further, I can choose not to answer any question during the course of the interview, for any reason, with no repercussions.

If I have questions about this research study, I can contact the researcher, Laura Solomon at [solomon.17@wright.edu](mailto:solomon.17@wright.edu), or Dr. Julie Williams, faculty advisor, at 937-775-3407 or [julie.williams@wright.edu](mailto:julie.williams@wright.edu). If I have general questions about giving consent or my rights as a research participant, I can call the Wright State University Institutional Review Board at 937-775-4462. If I would like a copy of the group (not individual) results of this study, I can contact Laura Solomon at the email address provided above. Estimated completion time of the study is January 2011 for those interested in obtaining a copy of the results.

I have read and understand the above statements, and by signing on the line below, I indicate my consent to participate in this study.

---

Signature

---

Date

## Appendix B

### Demographic Information Sheet

Thank you for your participation in this study. The purpose of this study is to examine the relationship between parents and their child diagnosed with an autism spectrum disorder. The information collected in this study is strictly confidential and will not be used to identify you in any report or dissertation. Participation in this study is voluntary; therefore, you are free to decline to be in this study at any time.

1.) Gender of parent (check one):

Male: \_\_\_\_\_

Female: \_\_\_\_\_

Other: \_\_\_\_\_

2.) Ethnicity of parents (provide in space below):

3.) Within your family, would you identify yourself the primary caregiver for your child?

Yes \_\_\_\_\_

No \_\_\_\_\_

4.) Socioeconomic Status (SES)

a. Lower SES \_\_\_\_\_

b. Middle SES \_\_\_\_\_

c. Upper SES \_\_\_\_\_

5.) Child's gender:

Male: \_\_\_\_\_

Female: \_\_\_\_\_

Other: \_\_\_\_\_

6.) Child's ethnicity:

7.) Child's current age:

8.) What is your child's diagnosis? (i.e. Autism, PDD-NOS, etc):

9.) How old was your child when he/she was diagnosed?:

10.) Does your child have any other diagnoses? If so, specify below:

11.) Do you have other children?

Yes \_\_\_\_\_

No \_\_\_\_\_

12.) If yes, what are the ages of your other children? (provide in space below):

13.) Do all of your children currently live at home? (provide in space below):

## Appendix C

### Interview Protocol

Thank you for your participation in this study. Your responses are appreciated and valued. The purpose of this study is to gain a greater understanding of how parents of children with an autism spectrum disorder view their relationship with their child.

While a great deal of research has been conducted on children with autism spectrum disorders, and some research has been done on their families, the voice of parents in this research is sorely missing. Emily Perl Kingsley wrote a poem you may be familiar with called “Welcome to Holland” about her experience parenting a child with special needs. I am going to read you Kingsley’s poem, and then ask you some questions about your personal experience parenting a child on the autism spectrum.

Welcome to Holland

Emily Perl Kingsley

Copyright 1987

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It’s like this...

When you’re going to have a baby, it’s like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It’s all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, “Welcome to Holland.”

“Holland?!” you say. What do you mean, Holland? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.”

But there’s been a change in the flight plan. They’ve landed in Holland and there you must stay.

The important thing is that they haven’t taken you to some horrible, disgusting, filthy place, full of pestilence, famine, and disease. It’s just a different place.

So you must go out and buy a new guidebook. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever, go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

### **Interview Questions**

- 1.) What is your understanding of the mother's message in this poem?
- 2.) In what way does this poem represent your experience?
- 3.) In what way does this poem NOT represent your experience?
- 4.) Who and what has been most helpful? And most hurtful?
- 5.) How have others' beliefs about autism impacted your relationship with your child?
- 6.) What do you want others to know about your relationship with your child?
- 7.) What have people said about you and your child that you never want to hear again?
- 8.) Is there anything else I should have asked about your relationship with your child? If so, what?



## **Appendix D**

### **Roads to Recovery Recruitment Letter**

TO: Roads to Recovery

Are you the parent and primary caregiver of a child diagnosed with an autism spectrum disorder?

Would you be willing to discuss your experience parenting a child on the autism spectrum?

If so, please consider participating in the following research study:

Laura Solomon, a doctoral student in the School of Professional Psychology at Wright State University in Dayton, OH, is conducting a research study on the relationship between parents and their children with autism as they view their relationship. This research is being conducted under the supervision and advisement of Dr. Julie Williams, faculty advisor.

The first 8-10 eligible volunteers will be asked to complete a brief demographic information sheet and engage in an in-person interview with Laura Solomon. It is estimated that the entire process will take approximately one hour. If you are willing to participate, please contact Laura Solomon at (301) 788-7721 or [solomon.17@wright.edu](mailto:solomon.17@wright.edu).

For further information about this research study, please contact Laura Solomon, at 301-788-7721 or [solomon.17@wright.edu](mailto:solomon.17@wright.edu), or Dr. Julie Williams, faculty advisor, at [julie.williams@wright.edu](mailto:julie.williams@wright.edu).

## **Appendix E**

### **Dayton United Against Autism Network Recruitment Letter**

TO: Dayton United Against Autism Network

Are you the parent and primary caregiver of a child diagnosed with an autism spectrum disorder?

Would you be willing to discuss your experience parenting a child on the autism spectrum?

If so, please consider participating in the following research study:

Laura Solomon, a doctoral student in the School of Professional Psychology at Wright State University in Dayton, OH, is conducting a research study on the relationship between parents and their children with autism as they view their relationship. This research is being conducted under the supervision and advisement of Dr. Julie Williams, faculty advisor.

The first 8-10 eligible volunteers will be asked to complete a brief demographic information sheet and engage in an in-person interview with Laura Solomon. It is estimated that the entire process will take approximately one hour. If you are willing to participate, please contact Laura Solomon at (301) 788-7721 or [solomon.17@wright.edu](mailto:solomon.17@wright.edu).

For further information about this research study, please contact Laura Solomon, at 301-788-7721 or [solomon.17@wright.edu](mailto:solomon.17@wright.edu), or Dr. Julie Williams, faculty advisor, at [julie.williams@wright.edu](mailto:julie.williams@wright.edu).

## Appendix F

### Interview ID # 01

**1.) What is your understanding of your mother's message in this poem?**

Um well it would basically be that she thought she was going to have the life that many many people have but when she figured out that she wasn't she decided that she just wanted to accept her real life and that there was beauty in it.

**2.) In what way does this poem represent your experience?**

Um I don't know sometimes I think about it as maybe that is the path that I'm on and sometimes I think that maybe I'm going to have another child someday and I'll be able to experience some of that other world, but I'm not sure if that's going to happen, so um I'd say 90% of that poem represents what I feel. I don't know why I say the 10% doesn't describe me, but I thought it was very moving and extremely real of how it does feel.

**3.) So that 10%....that goes into my next question. In what way does the poem not represent your experience?**

Well I don't really think about...I mean the part that strikes me is that I didn't have all these plans, I didn't have any plans, I just knew what type of child I would have liked to be, so I just had in my head an idea of how I would have played with my child. Like, I didn't have grandiose ideas of how I was going to dress them or different things like that, but I guess it would be imagining...I don't even try and imagine because it's not possible. I didn't have anything planned. I mean, I was excited about being pregnant and I was happy about it, but I still feel like we can experience a lot of the same things just in a different way.

**Can you talk more about what that different way is?**

Well, um, our focuses aren't on hanging out with other kids or birthday parties or shopping or do you like this shirt or do you like this one better, or I really really want a new bike. It's more about going to the water park, seeing how many parks we can visit this summer, are we going to go to King's Island a zillion times. I try to think about the way he likes to experience life and I try to have fun with it in different ways.

**4.) Great, thank you. In your experience, who and what has been most helpful?**

Probably my husband is most helpful. Someone to talk to. Definitely not parents of children of typical kids, I don't think they're helpful because they think they understand and they don't. I find parents of other children with autism about 50% helpful, whereas my husband is 95% helpful, because he knows [A] through and through whereas another parent has the same experiences but they're obviously different but it's hard to...and each child is so different that they tell you a story about how, you know, so and so didn't talk till he was three either, but it's really not the experience you're having and you don't know what yours is going to end up like, but your husband is someone who knows every detail, so...

**So having someone who is going on this journey with you**

This exact journey...yes and not parents, I mean grandparents, like my parents, I mean I think they're very welcoming and loving but since they don't live at our house it's not the same for them. I would say that a parent of another child would be more helpful than a grandparent.

**Okay. In your experience who and what has been most hurtful?**

I don't think anything has been real hurtful to me. I get real annoyed with parents of typical kids who tell stories about their kids and complain that you know people say things like "my child talks too much he never shuts up." I'm like oh my god [laughs]. It's really annoying to hear that, I can't stand when people say that. Or they just complain about their kids you know "[X] is really having a bad day today" or "her sister won't stop playing" and I think "but that's all typical stuff" and it's normal and fine and it's just not the same, it's not what I go through. So that's hurtful to hear stories about complaining about typical kids. That's very hurtful. [pause] For us, we haven't had a lot of meetings with developmental pediatricians, we just kind of stay away from that because we feel like staying home and working on his goals is better than going to someone and having them say "well you've come this far and here's where I suggest you go next," we already know what to do, it's just kind of inherent. As a parent, you just figure that out on your own. Other people like regular pediatricians, um, I haven't really found any that I like. And [A] has had a lot because of his bone marrow transplant, but I'd say our current one is very...he rushes us a lot, he did praise me the other time because actually I didn't give him antibiotics. He said he had a double ear infection which he had never had before, and he suggested that it could be very painful at his age and we might want to try the antibiotics, but I didn't want to, so we went home and he got better on his own and when we went back at the 2 week appointment to check, he looked and said it was gone. He said "how did you do on the antibiotics" and I said "I didn't give them to him" and he said "I'm proud of you." We had had a big discussion about why he really

wanted me to give them to him before I left, but he's...I don't know , I had picked him out because he was on the DAFEAT website for being really open and doing a good job, but I don't feel that I have had the same experience. Any other pediatrician has been real pushy and encouraged me to get [A] more shots and things that I don't necessarily feel comfortable with at this point, so...it's an up and down relationship with the medical field. That's all I can think of, is there anyone else you want to know about, I can try to think about more examples...

**5.) That's okay, this was very helpful. My next question is how have others' beliefs about autism impacted your relationship with [A]?**

When you say others, who could those others be?

**Any of those people you mentioned before...parents of typically developing children, medical professionals, society in general, grandparents, other family members...?**

Okay, read the question again?

**How have others' beliefs about autism impacted your relationship with your child?**

Um...I don't know that they really have. It's more of a personal relationship. My husband has had some issues with his friends saying stuff like "well if you just played with him more, I don't think you're spending enough time on your hands and knees working with him" and he's been really hurt and hasn't spoken to the person who said that, but I haven't had anyone make any big mistakes like that with me or give me advice that's not warranted...say the question one more time?

[laughs]

**How have others' beliefs about autism impacted your relationship with your child? So you mentioned before too like other parents of typically developing children not really understanding what you're going through. Has that impacted the way you view your relationship with [A] at all, or how you think about your relationship or**

Well I mean, I think that my relationship in order to keep both of us happy is harder to manage than a typical relationship with their child, but the way I view it, I don't think it's changed it. You can obviously say I'm jealous of their relationship with their child, but I don't think it changes the way I view my own relationship with him. I mean "maybe I should act more like them," no....I mean, I can explain how I view my relationship with him.

**Okay, why don't you tell me about that?**

Well, I think that he certainly has special little things that he does to tell me I think you're special, I think you're great and when I respond to those with just being with him at that point, then I think that shows it the most.

**Can you give me an example?**

Like he just loves, like especially when he's tired or when he's just gotten up in the morning, he'll lay on the bed and look right into my eyes and hold my hands and look right into me, or grab my head and move it towards his so he can look right at me. And he'll just do really soft, stroking like this that are just really sweet, really gentle, he's saying "I really like you this feels good let's snuggle some more." But...those are things that I view as him saying "we're super close, you really know me"...I don't know where I was going with that. I would say

that I view our relationship as probably 15% of that type of thing and then the rest is me figuring out what should we do now, should we go have fun and not worry about all this learning stuff, or what can I do to make his life on another path to help him find another goal or do better at this. So I have a hard time figuring out how much time should we spend playing and how much time should we spend working. I think, well he does plenty of work and I guess it would be the way I set it up as I'm pretty much...I guess sometimes I think well what else, what other therapy can I do with him to make him feel...well not feel better, but feel...succeed. Should I go down to Cincinnati Children's and do, what do they call it, Therapeutic listening, because someone told me about a month ago that she went, four years ago when she knew this little boy who had autism she went with his mom down to Cincinnati Children's and they did Therapeutic Listening and he hadn't said a word and after that was over, he started talking. [laughs] I mean, you just hear random stories and you're like "oh, well maybe I'll be able to try that, but you know, I don't want to leave any stones unturned but I need to be careful about which stones I try turning over because are they going to make me more miserable. I mean, am I going to go down to Lebanon and do Therapy Learning Center? Everyone around me is doing it right now and they're seeing changes, but the changes that they're telling me don't make any sense to be because those aren't real changes, and those people have a younger child than me, but still, it's something that other people are doing that other people have done and I feel like I have to try. But then there's other things like Oxygen Therapy that other people



try that I would never try and don't plan on ever trying. I want to make sure that as a mother I try enough things to make sure he has every chance that he can.

**It sounds like that's a lot of pressure as a parent to try to make all those decisions, to try to figure out what's going to help and what's not, and what might help another child**

And what's just going to put more stress on him. I mean, do we need to drive to Lebanon for two weeks straight, two times a day, and do an hour session and then wait two hours, stay in Lebanon, and then do another 30 minutes and then go home, but you have to come back every day for 2 weeks or you ruin the therapy. So I mean, they're just, there are a lot of things that are available. And speaking of, there was another thing that I considered doing that sounded stressful for both him and I but I don't remember...I was about to say it. Anyway, I view a lot of our relationship as me figuring out what his course or his path is, for the next couple months and are we happy with where we're at or is there something else we need to change. Do we wanna try something called [unintelligible] that some parents have tried and reported as wonderful, but you know, it's 90\$ every other month. Is it something we want to get our hopes up about and then nothing happens? I don't want to go to Piqua. I like the planning part of my life when it's not helping [A] figure out where he's going with his path and more focused...that's the better part for me to do with him just having fun and enjoying his...I think that's going to build his lifelong relationships, what he thinks about other people and I want him to think "people are great and I'm going to have a great time and I love it here." I love it when he gets out of the car and he looks

around and you can tell he knows he's been there before and he's ready to go in. You can tell by the pace of his walk whether he's pumped up about that place or whether he's like "oh great we're back here." Where did I take him the other day where he got out of the car and walked in really slow like "oh man, there's nothing in here for me." It wasn't the health food store but it was something...Walgreens. He was like "oh god!" [laughs] I'm like well we have to go in here. But when we go to the Kettering Rec, he bolts towards the door. Or like the Beavercreek Y last night, he's like "oh, I'm here" and you can see him perk up in his seat and look like "yep, this is familiar good territory!" [laughs]

**That's great. I can tell you must get excited too when you see him excited and happy like that. All those decisions that you said you need to make...who helps you with making those decisions?**

Not a lot of people. I would say, actually, it's probably all almost up to me. If it costs money, I run it by [husband] and talk to him about it, but if I push hard enough, he will do whatever I talk about enough and make it happen. So...but it's pretty much just me. I mean, I might ask another parent, but if it feels good in my gut, I just do it.

**Do you find asking other parents helpful?**

I used to, in the beginning. But as he's gotten older, I've found that, you know, as your child gets older you think he's going to be um...you don't really know when you're newly diagnosed how....maybe if he would have been different or succeeded and done really really well with VB or ABA when he started it, but he's on a slower path, so I don't necessarily think other parents are super helpful.

I mean, they definitely can give you a lot of feedback of “I tried that and here’s what happened to me” or “I really liked it” or “I thought it was a waste of money,” I mean, I definitely listen to all that input, but um, you know I have several friends who have done a lot of supplement stuff, DAN doctor related, and we did that for a really long time without any success and we took a year break and now we’re going to start again. I mean, to me, some kids just, their bodies just aren’t ready at certain times, so we’ll see what happens.

**6.) Okay, thank you. What do you want other people to know about your relationship with [A]?**

Um...I’m not really into telling a lot of people about my relationship with [A]. I’ve always been a real quiet person, I don’t talk a lot with them about that, but I guess if I was forced to tell people, um...I would say...well just because you don’t see some of the typical things that other kids have, it doesn’t mean that they’re not in there. A lot of those qualities do exist, they’re just harder to find and harder to see and a lot less often. Like laughing. I mean, he definitely has that and his dad is excellent at helping him achieve that. He definitely is loving, even though he might not show that out in public, it’s more of an early morning/nighttime thing like I was explaining earlier. Um... [pause]. Other things I want them to know. Well, I’d say he definitely knows a lot more than they would think that he knows. But just because we don’t sit there and bring food and show him a bunch of cards and work on goals in front of them, I mean [A] probably pretty much couldn’t handle that I mean, he’s got enough of that going on throughout the week, but it is something that he can do, but we don’t

work on it, I mean, he just learned to point to mom and dad, but I wouldn't tell my friends that. I mean, it's just irrelevant I guess.

**Is it something you would talk to other parents of children with autism about, more so than parents of a typically developing child, or is it something you don't talk about to others at all?**

I don't talk a lot about it. One time, I felt like he had a really super good day and so I wrote like a little letter about it and posted it on his list serve but I'm just not a real open person. I do keep like a little journal that I write in at night and say "[A] did this and this today and this and this is really cute, and this is the first time I ever saw him do this." But whenever something really big happens on a certain day, or even something smaller that I want to have written down, I write it, but I think it's more for myself. I don't really show it to anybody. I definitely don't show it to anybody.

**Is that how you've always been or has that developed more since...**

Oh yeah, I've always been that way.

**Okay. Is there anything else you want to add for this question?**

What was the question?

**What do you want others to know about your relationship?**

Well, I guess fun for us is different than fun for others and um...

**How is fun different?**

Well, I think that another might must just be like...they have fun taking their kid to Chik-Fil-A and have fun eating out, but that's like...[A] are you using your fork, [A] are you staying in your seat, [A] are you waving hello to this person and

goodbye, are you going to pee your pants, are you....whatever. So, I don't worry about those things when we're doing a fun fun activity like going to the park or the water park or Kings Island or going roller skating. I mean, we definitely take our potty breaks and do whatever, but a typical easy day when somebody would go to the mall and have a play date, he doesn't really care about mall playground equipment. So that might be fun for them, but it's not fun for me, it's stressful. Now I'm done. [laughs]

**7.) Okay, great. What have people said about you and your child that you never want to hear again?**

I don't think anything. I can't really think of any examples. I mean, [name], my step-mom, sent me a card for mother's day that said that next to her mom, she thought I was the best mom in the world.

**Awww**

But I mean, people don't really talk about us I don't think, or at least say anything directly to me. [laughs].

**Okay, how about more broadly in regards to people's perception of autism. Is there anything about autism that you don't want to hear again? You gave the example before of what your husband's friend said to him. That seems like one pretty extreme example. Can you think of anything else? And maybe there isn't, that's okay too.**

I don't know, I have some pretty good friends. I mean, some of them if there's just me and 4 of them, they might start talking about kid stories and things. For example, my friend and I with 3 other girls went out and she started talking about

her little boy, and I can't remember what she said, but she called me later and said "I heard myself say typical," and I don't remember the exact thing that she said, but she just wanted to say like "I felt like what I said I used the wrong word and I might have used the word normal and I didn't really mean it. " She tried to say that she was sorry and that she didn't really mean it. But I don't really talk to that many people. When they start talking about that stuff, I don't say, "Well [A] is this this and this and whatever" I just be real quiet and don't talk and hope the conversation ends soon so I don't have to hear too much of it. But she was actually out of the group, she was saying the most nice things and was more careful out of anyone there, and she was the only one to call and say "are you okay, I'm sorry." But it wasn't even really that big a deal, it's just I was annoyed that they were saying "man I hate it when this happens" and "man I hate it when this happens" and it's almost like they forget that, you know, none of that stuff happens to me and I wish it did.

**Right.**

So I don't know. I mean, she said "I was thinking about it because my sister just had a baby with special needs and I'm starting to learn to be more observant and try to be understanding of her feelings, so I just wanted to call and say that."

**When you said that she was more careful, what do you mean by careful? Or what do you maybe wish the others had done to be more careful?**

I don't know, it's so hard to remember the exact thing. It's just tiny stuff. Like complaining about their kids and silly stuff I think she was talking about like man it's hard because her other little boy...her 3 year old was allergic to eggs and milk

and this and that and she was complaining that it's hard to find something and she always has to bring a cupcake to the party and..You know, but to me, bringing a special cupcake to the party is something that I've been doing for a long time plus 8 thousand other special items. So to only have that one other little thing to do extra would be fabulous. [laughs]. I don't know, I just sense that she was trying not to...she must have noticed that I wasn't saying anything but nobody else seemed to notice that. There really wasn't anything hurtful said, it's just annoying to hear them complaining it was just little things, and nobody said anything like "Man, I can't wait till [A] can do such and such with my child, he feels so uncomfortable when [A] goes up to him and doesn't say anything."

**Right. Is there anything you would say to them? If there weren't going to be any repercussions, and you could say anything you wanted. Is there something you would want to add into that conversation?**

Well I don't know that me saying something like "you shouldn't complain about your kids, it's fabulous that they talk a lot" or "it's wonderful that they're playing with their sibling in that way" or "at least they're getting up in the middle of the night to go potty...it's better than still being in a pull-up. That's the stuff they were complaining about "My child gets me up twice a night and I have to walk her to the bathroom because she's afraid of the dark and I wish she would just get up and go to the bathroom." I mean, I don't know that me saying "well do you know what happens to me every night; this is what happens at my house." I don't know if that would make them feel any better or worse about themselves or what

lesson that would teach them, unless they were in my shoes, it wouldn't benefit them. I don't think they would, it wouldn't do anything for them.

**Would it do anything for you to do that? To have that conversation?**

I have had that conversation with one of my friends in that big group of five, but she lives so far away, I see her a lot less and I think she is real sensitive about it since I had the conversation with her, but I just don't see her as much anymore cause she lives further away. But she's always been more, I don't know, I guess she's always just been more sensitive, and that's why I had the conversation with her to begin with.

**8.) Absolutely, her being open to begin with would make that conversation easier. Okay, my last question is just is there anything else I should have asked you about your relationship with [A]?**

Anything else...hmmm...no. I don't think so.

[Tape ended]

After tape ended:

Participant described her child as a flower, stating that he has a "different rate of blossoming," and whereas some children have just a couple big, beautiful petals, he has "lots of little petals, millions of little petals," and that one day, he's going to be a "beautiful flower with lots and lots of little petals."

She also reiterated that she would like people to know that her son does do things that are normal, other people just don't see them.



## **Interview ID # 02**

### **1.) What is your understanding of the mother's message in this poem?**

I have heard that poem before...and oh man...if only more people felt that way. I mean, obviously the mother's message means that she's seeing her child's worth and sometimes when you're raising a child with disabilities they teach you far more than you would ever expect and with that you view the world differently than you would have if they didn't have the disability and the message is a message of hope and a message that disability doesn't mean you're not going to have a life full of riches and wonderful memories and experiences, but that's probably, I'm assuming that this mother is pretty seasoned because you're not going to get that sort of perspective in my opinion from a parent of a child who is newly diagnosed. It takes time to be able to relate to that poem.

### **2.) In what way does this poem represent your experience?**

Um, well, it's pretty obvious. I mean you go to college, you're working professionally, and you think you're going to have a different life. But for me I wake up with [B] and I almost feel guilty because I do know a lot of parents who struggle on a daily basis. I mean, from the moment they wake up until the time they go to bed, the struggle, their kids are pretty behavioral, and [B] is a pretty happy guy and I know that I'm blessed. Plus, now, that he's 9 years old, I guess I relate to it b/c I see the wonderful things that he brings because he is who he is.

### **What are some of those wonderful things?**

Oh his sense of humor. I mean...mostly his sense of humor you know. I mean, walking into Wal-Mart, or not Wal-Mart but Sam's Club and he sees himself on

the surveillance camera and he's jumping and waving his arms and looking at himself in the TV and he's cracking up and I'm cracking up and, yes, is this socially inappropriate, it is! But I don't really care because I think it's hysterical and I think it's about finding the humor and the quirkiness and the funny things and um...I think it's absolutely fascinating to find out how very intelligent he is. Beyond all this stuff, beyond all the things you might see, the social behaviors, the quirkiness and all that, if you can look beyond that it's extraordinary to figure out how their minds work.

**Absolutely. Is there something in particular that helps you to look beyond those things?**

Honestly, I think parents have to go through the seasons. You just have to do it, you can't save anybody, and I think because you go through the whole rescue my child from autism process, the doctors with the...everybody has a pathway to nowhere, it seems. Empty promises. Throwing lots and lots of money at it. All of those things contribute towards the reality of the situation. And you have to go through years of that. I mean, that's not months I think for most of us that's years of going through it, figuring it out, how you're going to stop trying to fixing the child and live harmoniously. When you figure that out, when you stop obsessing over how to fix it and start learning how to live with it, then all of a sudden things change and they become beautiful.

**Do you think every parent gets there?**

No. I do not think every parent gets there. Unfortunately, I don't think every parent gets there. And that's okay, you know, because every child is different,

and I can't say that maybe I would have gotten there if [B] wasn't who he is. It makes a difference depending on the child, obviously.

**Is there anything else you can think of that moves parents in that direction?**

I don't know, I would suppose for some.... support groups. Things like that where can have a voice and work with people who have been there and I would say that...I was never that kind of person, I'm not a support group type person, um, I think I'd rather throw one than attend one you know. I think it's really important and there are people who can't live without it and it's extremely healthy for them. I just am really blessed to have a healthy marriage and you know a lot of parents are divided over this and without that support group and a place to help them figure out how to navigate their way through, they wouldn't they just wouldn't be able to get there. So...I hope that answers your question.

**3.) It does, thank you. In what way does the poem not represent your experience?**

Oh geeze. I don't know, it's pretty spot on. I would have to dig to find an answer to that, but I think that regardless of whether you have a child with a disability or not, you do buy all the books and you do go to the classes and it's hysterical in hindsight I think for most parents because there is no recipe. All these books, all these recipes on how to parent. Once you've been there and done it you see how ridiculous it is. For whom are they writing that book about? They're all so unbelievably different, every single child, regardless of whether or not they've been, whether or not they've have a label slapped on them because that's really how I feel about it. We're label happy in this country so you know I just think...I

think it's a beautiful poem and it speaks to me in volumes because it's so parallel to the way I feel. So I can't think of a way that I disagree with any of it.

**4.) Okay, that's fine too. In your experience parenting [B], who and what has been most helpful?**

Oh my goodness. Well my husband. All of his tutors. I can't...I just really have been lucky to have a great team of tutors since [B] was about 2 ½ or 3 years old. They've been a huge part of his life and without them, he wouldn't be where he is today. And without them, I would be insane because you have to have respite. You have to have...because there's a lot of behind the scenes work so it doesn't stop with the tutoring sessions, there's a lot that goes into it. When you're supposedly having respite, you're thinking about okay what do I need to do, okay I need to go to the health food store and get this supplement or this diet thing and so I think the tutors are a huge and important piece and in my case my spouse and my daughter. We really have no other support.

**Who and what has been most hurtful?**

Uhhh. Wow. Hurtful. I need to think about that. Um...probably the grandparents.

**Can you say more about that?**

I'm just trying to think if I want to say it, I don't want to be offensive.

**Okay, that's alright too, we can move on.**

Um...well...I think...it's in a sense it's not anything vicious, it's just when you're not knowledgeable about something you're a little apprehensive to be around it. So, but that goes for both of my children, that's not just for my son, but I do think

that's the most hurtful is that they just sort of don't even know who my kids are. So I think that's very hurtful and I think they doubt [B]'s intelligence and his ability because they don't spend any time with him although they're 10 minutes away. They would rather write a check and support the cause than get their hands dirty and take him out for ice cream or you know...the other day my dad said "oh look, he turned the volume up all by himself" and I wanted just to crack up because I wanted to say "yeah he reads and he does multiplication and division and...okay...but you're impressed that he turned the volume up on the computer by himself." You know what I mean? So I'm like wow, okay, they really have no idea at all. And I think also it's very hurtful when obviously I'm very, I'm a strong vaccine about why so many children have autism and, I think, well for 90% of the people I know it's vaccine related and I really, it's hurtful when my family, obviously there's a freedom of speech, but when my family knows how strongly I believe that there was a turning point, a definite turning point with [B] and through his immune system being suppressed with antibiotic use—obnoxious antibiotic use—and then the environmental trigger of vaccines, and then the blood work that I have that says he was toxic at 2...it's just it's hurtful when they have to tell me every story that is on Fox News that some expert is claiming that there's absolutely no link. It's ignorance behind not knowing the truth. Or even not being able to entertain that there might be an environmental trigger and I'm not saying that everybody doesn't have the right to their opinion, but when you know how it's affecting your grandchild, it's probably better to say "well I disagree with her, but I'm not going to upset her by saying anything out loud about it." Agree

to disagree sort of approach would be most pleasant. And I think if they had to live my life every single day, not only that, but see what I do with the other families and interview them and there hasn't been a family yet that I've interviewed that hasn't brought up the fact that they think vaccines play a role. Every single one of them. I don't know one yet who has said differently. That, I think, fuels my fire because it's a criminal act in my opinion and I just wish the family would be more supportive. And I understand. I mean, the media's a powerful thing, but unless they really dove in and did their own research and can come up with a strong argument, I would be really entertained, that would be great for me. I'm not afraid of the opposition. But at least be informed. Don't take it just because you heard it on Fox News and you believed it.

**Right, and I would imagine this is all compounded for you by the fact that they don't really have a relationship with [B], and their knowledge of [B]'s functioning and what he can do, what he can't do, how autism has affected him, is so limited.**

That's exactly right and I think also they don't live my life where I have been to conferences all over the world. I tend to believe parents before I believe any doctor to be honest with you. Because what I used to think was my story when my child was 2, I found that isn't my story. We all have the same story. My child had lots of ear infections, lots of antibiotic use, I don't think it's any one vaccine, I think it's an accumulation of neurotoxins, and people blame it on the MMR because you've had so many by the time you're 15-18 months. I should write a book, "Don't Blame it on the MMR." [laughs] I mean, I think it's a faulty

vaccine, but I don't think that's the bullet, the full bullet. So I think just, it's hurtful, it's very hurtful having to advocate for your child and the only other thing I want to say Laura is that it's, when you're talking about hurtfulness, I think the whole education system is extremely hurtful to parents. Having to babysit your IEP in public schools. They wine and dine you and promise you the stars and moons and the minute you walk out the door, your child is in the special needs room 99% of the time and its...it's just respite. Glorified babysitting if you will. And unless you're me, who knows that every single word on the IEP counts. Everything, the way you write the IEP, it has to be effective. People, parents go in there and they assume that the school's on their side. And of course, that would be the way that you hope that it should be, right? But then you find out through the seasons like I spoke about that...and I hate to use the term "warrior" because I don't like to give Jenny McCarthy any props [laughs] that's kind of embarrassing, but it's just the terminology...that's exactly it. You're a warrior at home. You're a warrior at school. You're a...you're...it's just...it's ridiculous that we have to fight so hard. We're exhausted anyway trying to figure out why this happened, what did we do, and then the one place that you feel should get a little relief is that your education system would at least be on your side. It's exhausting. And it's hurtful because the child should come first. The child should always be first. And I think it's why I just decided that public school is not for my kids. That's why I truly believe that Montessori has been wonderful. It has at least at the core given me some relief because of the fact that they respect my child and they'll follow him and he tells them where to go next. Whereas in

the public school system, it's just extremely hurtful for them to look at the child as an object and they feel that there's one methodology that they should use for all of them. Well that just shows you, that is just not going to be a solution to this problem. Because the kids are so different, you can't just say "oh, the teaching methodology is going to be..." you can't do that, so it is hurtful that they don't listen, they don't want to listen to the parent at all, they have their own plan and we're supposed to shut up and fall in line.

**I heard you say, too, that at the Montessori school they demonstrated respect for the child. Has your experience in public school been that they do not respect the child as well as the parent?**

In my experience, and I'm sure there are hopefully some people out there who will tell you otherwise, but I haven't met one yet. I know they're out there, but I just haven't met one yet. But yeah, I don't think that, I don't think it's purposeful, I don't think they go in thinking that they're going to disrespect the child, but through their actions it's pretty clear that there isn't respect for the parent nor the child. This is a job, you go in, you clock in, okay, follow the formula. We're going to do Touch Math, we're going to writing, we're going to do...I mean it's 10 minute workstation increments. I don't think it's a purposeful thing that they're doing, but I think if you stop and think about the child's day and think about how you're treated and think about your IEP meeting, it's pretty clear that there's not a whole lot of respect for the child nor the parent.

**Right, it sounds like it all just adds up.**



It all adds up. But again, all of these special educators, they have good hearts.

They chose the profession for a reason, and you know, it's primarily coming from the administration with financial restraints and all of that and it just gets muddled along the way with...just like the rest of the world, money is always the root of the evil for anything, right? You know. There's always a reason why, they do what they can do and they're just kind of a mold, do you get what I'm saying?

**It sounds like you can see the reasons why things are this way, but it's still hurtful when they can't be flexible for people who maybe are "outside of the box."**

That's exactly right. And that's okay. I mean, it's you know, it's okay. Some people survive that way even have to have that. So it's just all in what you're looking for I guess.

**And it sounds like being able to figure out what you need as a parent, and go out and look for it?**

Right, I mean, come on Laura, some people just want to drop their kid off. Most of them. [laughs] I mean, they want to drop their kid off and that's it. They don't want to be any more involved than that. You know, that's the interesting thing about parents of kids with autism. They might be parents who would drop their kids off, had it not been for this disability coming into their lives that makes them need to get in there.

**It really changes things.**

It changes things and it makes them more invested. Maybe by force, it's a heck of a boot camp to be involved in, but it certainly does, it certainly does. It's

interesting that came up because I think that's spot on. A lot of these parents that I know would have definitely been the type. Heck, maybe me too, you never know.

**You never know.**

Although I discovered Montessori before [B] was born. G [older daughter] was at Montessori. So maybe not. But the majority of the parents that I know wouldn't have been as involved in their child's needs educationally if it wasn't for autism rearing its ugly head.

**5.) Right. You know, we've kind of touched on this already, but maybe we can discuss it a little more. How have others' beliefs about autism impacted your relationship with your child?**

Ummm...significantly. Um...there are so many different opinions out there.

Reread the question, I want to make sure I answer it properly.

**Okay. How have others' beliefs about autism impacted your relationship with your child?**

Well...it's really interesting, I'm just thinking back over the years, trying to think back to the beginning, they impacted me much more significantly than today.

**In what way?**

Well, you know, when the doctors first diagnose, or loosely diagnose in my case, their beliefs about autism were so uh...[laughs]...oh what do I want to say....they just weren't very evolved b/c they didn't really know what was going on. They didn't, at that point, I mean obviously there was a huge rise in autism and they were still figuring it out and I guess they really didn't have very high expectations

for [B]. And that impacted me because I didn't set the bar high enough. So I think that if I would have had a diagnosing doc who offered suggestions of early intervention and hope and ideas it would have greatly changed the course even of [B]'s life, even though he had a mom who got in there and said "whatever," you know, I mean I remember [B] being diagnosed and the diagnosing doc giving me this packet which was a joke. It was so outdated, it was COFEAT, it was a COFEAT packet, so it wasn't even a packet she created, it was a packet she got from another organization, and the websites hadn't been updated for a couple years, most of the phone numbers were disconnected, it was really NOT helpful and I thought, now, thinking about it, I think "god how do those parents who are absolutely not proactive in any way, how do they...I don't...you know what I mean? No wonder they drop their kid off.

**Right.**

And then, the pediatrician, who refused to send me to get diagnosed, who was telling me that my child was just a boy and developed slower, oh my god I've heard that a million times now too, that's not just my story. "Oh boys just develop slower," I'm like "he doesn't look at me anymore!" That impacted me because of the fact that they did not believe me. And I could have got in there earlier! So again, disrespect for the parent. If they would have listened to me. That was very hurtful to [B]'s development. Not to immediately refer me to the pediatric developmental specialist. So, but then again, there are people who have had positive impacts on me. As interesting as the director of the school is that

[B]'s attending right now, I loved when she said, "Well let's not talk about labels. He was sent through my front door, now let's figure it out."

**That's awesome.**

So, she was admitting, hey, I don't have the answer. But at the school, public school, they said "oh here's what we're going to do, we're going to do ear aerobics, and then we're going to do, you know, touch math, and then we're going to do, you know they had a recipe. So I liked her honesty of you know, I don't know, but let's figure this out together.

**She saw beyond "okay, this is a kid with autism, and this is the prescribed program we're going to do" and was saying "okay, let's not just look at that, let's look at who he is in our school."**

Right, and how he might be able to contribute to the community. Because she was already seeing his ability and not his disability, as cliché as that has become, it's the truth. And, um, so that was extremely powerful to me. And also she was the first one who gave my son freedom.

**In what way?**

Before that, you know the recipe was that you have to have them, you know, the only thing they suggest, is because they're too lazy to figure out other ways, everybody's always like "oh, do applied behavior analysis." Well, thank goodness they found that, because now they have something they can throw at people when they diagnose them. This is what you should do. But there are other things! These are people, these are individuals. And we did it, and I don't regret it, you know we did that, but I'm just saying ...it's a very regimented program. It

teaches compliance in a way that is a little bit medieval, you know what I mean.

[laughs]

**Yeah, a little bit.**

And again, this is my perspective, and I'm not saying that this isn't the right thing for another family. Maybe that child absolutely needs to have it in that format.

And I'm saying this director was the first one who gave [B] the freedom to be a child without a label.

**How old was he at that time? Because it sounds like your experience with her is really the first time...**

It was, he was in first grade. But he had been in Montessori two years before that at a different school. But they...all Montessori's are different. At that Montessori he did great. But when he was going to go into first grade they didn't want him to, not b/c of his behavior, he never had behaviors in 2 years, he got along fine. No problems. But the teacher told me, the 1<sup>st</sup> grade teacher told me that she observed him flapping his arms in front of the copy machine and that he would distract the other students in the classroom. And that they are all paying for private education.

**Wow.**

And I thought, you are one sorry Sally, aren't' ya? Not to teach how to, I mean, she's going to influence these other children's lives and she can...instead of teaching how to respect one another and embrace diversity, you're sending a really horrible signal. And I think you're underestimating those children.

**Absolutely, in their acceptance of [B] if they were provided the proper modeling?**

Mmm hmmm, and I wondered if she even knew who Maria Montessori was, she had to tell me about her education at Xavier, and I thought “well that’s good but, did you know Maria Montessori supposedly taught the unteachable?” I mean, that’s the core of her existence? You know, people get lost, they get lost when they don’t...along the way when they start seeing how valuable they are and they can’t be humbled more. But she was the first one who gave [B] freedom, and what a gift that is. She impacted me greatly and she’s certainly not a perfect person and either am I, but um, she taught me a lot.

**6.) That’s wonderful. What do you want other people to know about your relationship with [B]?**

Umm...I would say that probably we have such a deep connection. And...um...a common respect for one another. And we connect so deeply that words, they’re not needed. It doesn’t matter. You know, I can’t imagine my life without him. Even on days where he drives me crazy, it’s more because I’m exhausted than because of anything he’s done. So I guess just that we appreciate one another and I think that I would want people to know that he is... that our relationship is probably deeper than any relationship any parent could have with a typically developing child.

**What makes you say that?**

Words get in the way. You know, when you have a child that's chatty chat chat chat, I mean, they are, because [B] is so sensorial, you know, having a child come up and smell your cheek to identify who you are...?

**It's a completely different way of connecting.**

[laughs] I'm kind of embarrassed people are going to hear that. But it's awesome. Umm...just being in the car and driving and having him reach over just to touch my arm. It's much deeper than words. I think human touch, or that whole sensorial experience, that he shares with people he's close to, it's just a deeper connection than words can provide.

**7.) Right, absolutely, thank you. What have people said about you and your child that you never want to hear again?**

[laughs] Oh god...umm...I don't know, I don't think I have anything like that. I mean, I don't think I have heard anything about [B] and I that I would never want to hear again. Something that's a little bit agitating to me, but I'm going to hear it again, and it doesn't bother me THAT much, but one irritating thing is "oh, [B] is so lucky to have you as a mom. So lucky. What would he do if he didn't have you?" That gives way too much credit to me. I mean, how about him! He's the one doing all the work, you know? That's too much credit for me

**It leaves out that you feel lucky to have him as a kid?**

Yeah! Almost like I'm doing...almost like "what a good person you are to be there for your child. To advocate for him, and make sure his needs are met, put up with him all day, he's so lucky to have you." That's so...annoying.

**It makes it sound like he's a burden that you have to put up with.**

Yeah, or that I deserve a medal for it.

**Right. I can absolutely see why...**

You see what I'm saying? It's frustrating. And it is, it's I just...yeah. That's just really unnecessary, and again, ignorance, and shows me you don't really get it.

I'm his parent. Of course I'm going to be there for him. And I'm there for my daughter, too, there's no difference. And you're not saying "oh she's so lucky to have you as a mom!" So I don't know, there's nothing else, there's really nothing else that I can think of. I mean again, it's really not about words, it's about, I mean, I can do without people looking at us. That's extremely annoying. And I get it! I mean, I get it. because I'd probably be one of those people staring if I didn't have a kid...but not staring out of "ugh" but staring out of "wow, what's going on and how can I save them?" [laughs] Because I have the disease to please and I'd be like is there anything they need, what can I do for them? [laughs] So you know...

**8.) Okay, my last question is: Is there anything else I should have asked about your relationship with your child?**

Um...not really. But I think that probably a good, what I'm always curious about is, that I never have the courage to ask, is "well what life did you have planned?"

**That's a good question.**

"What were your expectations before autism came along?" Or "what are you going to miss the most because of autism?" And you hear some parents that say my son isn't going to play sports, which isn't true, you know, they do, but, or my son's not going to get married, or my son's not going to go to the dance. Or he's



not going to form friendships or be hanging out with his buddies at our house. So, I guess that would be the one question that I would have...

**Asking what your trip to Italy would have looked like?**

What would your trip to Italy have looked like...mmm hmm, exactly.

**So what would your trip to Italy have looked like?**

Well now, at this stage of the game, now that he's 9, my answer is going to be different than when he was 2. But now I'm thinking, "thank god I missed the boat to Italy." Because Italy's not really all it's cracked up to be. There's dirty water in Venice. [laughs] And you know, it's very...it's either very expensive or very...poverty...it's one or the other. And...it's too busy in a lot of places. So my answer would probably be "thank god I missed that. Thank goodness I was detoured to Holland." Because they have windmills and they spin, and [B] loves them. [laughs]

**That's awesome, I love that. Thank you so much.**

**Interview ID # 03**

**1.) What is your understanding of the mother's message in this poem?**

Hmm... Well it made me a little emotional.

**It's okay, take your time.**

[crying] Well, let's see. I think that...it's hard to be different...and it's hard when you have your mind set on the way something's supposed to be.

**Absolutely**

[crying] But...I think it's...you get to a point, I don't want to say acceptance, because I don't think you ever really accept what is, I think you always work towards what could be. But you get to the point where you realize you can't change certain things and the hardest part is trying not to constantly defend your child. Because there's nothing said, but people don't understand, so that can be really difficult. Like I find myself explaining a lot for him. Or even the other day, I told my mom this, we were at the playground and—when he was younger, he would go up the slide and he would just stand at the top and then he would just sit there and he wouldn't let the other kids go down. Well he would do that for a while and the kids didn't understand what he was doing, and so I would go up there and would say “hey it's your turn now” and he would go down, but it was awkward. So I stopped letting him go because it just got to the point that I'm like it's just not productive and what is he doing and it was just weird. But he's grown so far the past couple years that the other day, we were at the park and he asked me if he could go up there, and I said no, and told him no, and finally I was like okay, go, and, surprisingly, he just went along with the kids. It just completely

changed. So what I realized is, sometimes, I protect him from situations that he's actually able to handle. And so it's a hard line because you don't want to be that person in public that you have to explain to strangers or to people what's going on, but then you also want to try to protect your child from what other people think. So, but it's strange because sometimes you have to let it go, and let it be and let him figure it out for himself, and that's a hard thing for parents. With my 2 year old, I do that all the time, because I have the confidence that he can maneuver situations. You know?

**Right**

But the only person in that situation where he was watching the kids go down that was bothered was me. It wasn't him. He didn't care. So I think that's the internal struggle that you deal with you know? It's your knowledge of what's different rather than their knowledge of what's different. Does that make sense?

**Yes, absolutely. What about the other kids at the park, or the parents at the park?**

Um, well a lot of times the kids will try to talk to him, and he's not very responsive to people he doesn't know. He's more responsive to adults than to children and so sometimes kids will talk to him and ask him questions and I'll have to answer for him. Just because they'll come to him, and sometimes he will answer, but he's just generally not interested in people he doesn't know very well. So....and parents don't generally get involved, especially they see that something is different, I think that's just generally an awkwardness that they don't choose to really engage in, but kids don't understand those social graces, so they will ask

and I'll just say, you know, "he's shy." I hate labeling. So even when you asked you know what his label is, I just really think it's ridiculous because anywhere on the autism spectrum you can label a child with Asperger's or PDD and they can be so vastly different

**Absolutely**

And so I think the label is really an injustice because every kid shows so many different unique things that I don't really like to use it. Like so many of my friends have the autism charm and autism this and autism that, well I support the cause and I do what I can for research and I support it I just I don't like putting people in a box like that. You know? So I just try not to use those kinds of things, unless I absolutely have to. I mean, we didn't get a label for [C] because it just wasn't absolutely necessary and we found funding through [?] and other places and without having to get a psychological evaluation. I mean, I think as a parent you know better than anybody else what's wrong with your child.

**Absolutely**

So, having my child diagnosed wasn't really, I mean, having somebody else tell me what I already knew really didn't seem like it made sense.

**Right. Have you met any resistance to that from medical professionals, other parents...?**

Umm...no! The only purpose we had in getting diagnosed was to get services like occupational therapy and speech therapy. In school, I mean, he's been tested and he's on an IEP and he has social deficiencies and articulation deficiencies but, um, academically, he's right on track. So while he does test below average, it's in

terms of interactions, socialization, understanding communication and things like that between people. So the only time we've been met with resistance has been when went on the scholarship and we had to have some sort of formal letter and we got that through our DAN doctor who just said you know, I've been treating this child for pervasive developmental disorder, and so we've never, and like I said, I think he's kind of more towards the Asperger's with a little bit less speech, because cognitively he's very smart, he's very on track. He does interact with other kids, he does give me eye contact, he follows directions, and he's just not...he's not as talkative as an Asperger would be. But I've also met some kids who are diagnosed with Asperger's who don't have a lot of speech, so...

**Diagnosis can be a very fine line, especially on the PDD spectrum, and then you do wonder, what good is it going to do anyway?**

[laughs] Exactly.

**2.) In what way does the poem represent your experience?**

I think that...I think that in the beginning you kind of fight that you can change things. And I think you fight so hard and I think a lot of parents go through where they think that the more that they do, the faster that the product is going to come. And so you kind of dive into it head first and try to work as hard as you can and it can be really consuming. But I think what you realize eventually is that yeah you have to do all those things and yeah it's important to be proactive and to work with your child but sometimes the more you push, the harder it's going to be to get where you've got to go. I mean, I think I learned this, we were doing occupational therapy one day and doing all the sensory diet stuff and just trying to

work hard, work hard, work hard, to the point where I just realized...he's past that, you know, he's still a kid, so, I think for my husband it was a little harder for him to come to grips with what is. For a long time he just kept saying you know "oh he's just two" or "he's just three" or "I know a lot of kids parents who say they didn't talk until they were four," so he was more in denial I think than I was. But I always had hoped that by the time he was five from early intervention that he would be able to integrate back into the classroom. Well, he is, but we still have things that we work on. It's kind of always an uphill battle, but the fight changes all the time. So maybe some days you're fighting this and you master this and the next day you're fighting this and this but you master this battle and now you've got a new problem. So I think it's a little bit different from, it's hard to keep, if I didn't have a younger one who was typical, it would be hard to keep friends with a lot of typical parents because they just don't understand. You know, [C]'s on a special diet because he has food allergies and he was tested, I was aware that some parents treat children with a special diet without testing, but we did all the tests and he has allergies, so he's on a special diet and he gets biomedical interventions, so, it's hard for people to understand why we're doing those things. It's hard for some people to, I have a friend who has a son that I think is 4 months older than [C], I think, they were young together, you know when they were one, and typical children, unless they are very unique, tend not to want to play with somebody that doesn't want to play with them. So it's hard to perpetuate that relationship because you know we get together and [C] is off playing by himself and the other little boy wants to play with him and is like "he

won't play with me," and so it's just a constant struggle. So, I think that's where it's difficult. Sometimes you take comfort in the other parents who have children with special needs, because you don't ever need to explain anything. There's a lot more understanding and acceptance. But, for [C], b/c he's so high functioning, it's better for him to be around kids who are typical b/c he's a modeler. So you have to find the right type of kids and you have to find the right type of parents. So it's kind of a struggle in that sense and everything has to be more planned than for a typical child. So like if we want to go out to dinner, typically [C] is not so regimented that if we change anything the days ruined, I mean, he's pretty good about that kind of stuff. But you know we have to plan his meal, and we have to plan this to make sure we go...so it's just a very much more aware process. Kind of like having a diabetic child. It's just a lot more that goes into it. So I have friends that will say "I'm going to go do this, and do this, and then do this" and I'm like "that's great, but at a certain point, he's done." It's just too much for him. Or they'll say "we're going to go to the water park" but [C] doesn't like to get splashed a lot, and he's getting better at it, but it's kinda hard to work with that because we're going to pay \$35 and he's not going to want to do 50% of those things. Those are the kinds of things that make it a little bit more difficult.

**3.) Absolutely, I can certainly see that. In what way does the poem not represent your experience?**

Um...let's see. I think sometimes it's easy to concentrate on the things that aren't there. And I think sometimes it's harder to see all the good things. So, the way

society is, and you know, school, it's always focused on the deficiencies. And so you tend to focus on that so much that sometimes you overlook the good things.

**Absolutely. Tell me about some of the good things.**

Um...you're making me cry. [laughs]

**It's okay, take your time.**

Um...ack, he's an amazing kid. He's super smart. He's very engineering.

He's...it's very interesting, I read an article not too long ago that was about a study being done that said that children whose father was an engineer, whose grandfather was an engineer, had a predisposition to autistic tendencies because of the way their brains function.

**Interesting**

But he's very much a self taught kid. He loves video games, he loves computers, and for a 5 year old, he's way beyond his age. And he's a self...he'll pick up the remote control and fiddle with it until he knows how to do things where a lot of kids would kind of be lost. Those kinds of things I mean he has an amazing memory. It's ridiculous. He's very, he loves cars, they're a big deal to him. Last summer, my sister in law and her daughter came from Switzerland, my husband is Swiss, and they drove a Dodge Caliber. 2 days ago, we were driving down the road and we saw the same car, and he says "look, that looks like Amy's."

**Wow!**

I was like wow, how did you remember that? I mean, things like that, or if he likes a book we'll read it twice and then he knows every single word. For the entire book. I mean, there's things about him that his brain just functions so



differently. He's also, compared to my other child, for him, he was always very calculated. Like if he were going on the jungle gym, he would be holding onto the rail, and would be very cautious, and very calculating, not doing things that are dangerous. And my other one, will get up and jump off the same thing three times, no matter how many times he cracks his head. So there's really interesting differences between the two of them that are just really I don't know. It's just really unique to him, even as a little boy, not a lot of little boys are like that. Um, and things that he likes to do, he can concentrate for a long period of time. Not with things he doesn't like to do, obviously, but...it's...I mean, he's got a little sense of humor, it's kind of a dry sense of humor. But it's there, and I think that's funny too that he likes to try to make jokes.

**Can you give me an example?**

Um, let's see, what did he say to me the other day? He knows that his grandma really hates balloons, and when he pops balloons it makes her really scared. So he walked up to her and said "Gigi, I'm going to pop the balloon and you're going to get scared!" and started laughing. Or, he's funny, you know, he's 5, so he's really into toots and bodily functions and stuff. So you know, he tooted the other day and goes, "Miko tooted!" And Miko's our cat, and you know, so it's just stuff like that where he gets it, and he thinks it's funny. And some things are just so typical, and then other things are...I see him so much more on level with my 2 year old. I mean, it's hard for me in particular, and I feel really blessed that he is high functioning and typical in a lot of areas, and I mean, a lot of parents especially parents at Roads, their kids are not high functioning and are nonverbal,

and so I always try to keep that perspective and appreciate that an where I am, but it's difficult for me because I hold him to a different standard. Because he's so close to being typical, it's more frustrating for me when he's not typical. Does that make sense?

**Yes**

So I just see him being a certain way for a day or two and then he kind of regresses or goes back or has a bad day, it's twice as hard because I know he's capable of being like that. So that's when I wonder is it easier this way when I know that those things can happen, or is it easier when you know this is where we're going, this is where we're at. Obviously, in the long run it's easier where I am, but it's also more frustrating because you constantly have that pressure on him to be at that best, you know?

**Right, sure, and it's like where then do you set the benchmark, how do you know where to**

Right and he's 5 and you know, 5 year olds have bad days. And that's really hard for me because he's my first and my younger one is you know...younger, so I don't have anything to compare it to. So sometimes it helps me to talk to my typically developing kids...parents of typically developing kids because they'll tell me something that's normal, and I think it's part of the spectrum. And you know, they're saying "my kids drive me up the wall and they whine and cry and" you know what I mean? You're like okay, I've got to kind of shift my perspective because then it's like I need to figure out where it is.

**So you're saying that it is helpful to talk to those friends to get that perspective, and I heard you say before that sometimes it's also not so helpful**

It is but it's not. I think I'm a very open person as it is. I have two really good girl friends whose kids are generally around the same age, so...it's hard to make new friends. And those friends I've had since...well one since [C] was really young and once since before I even met my husband and before we had kids, so I think for them they've known him for so long and it's obvious to them and to us that there was something a little bit different and in those cases, I am a very open person and I will ask a lot of questions because I mean, there's no way out except through, I mean, let's just call a spade a spade. The more you try to brush under the rug...some people are awkward and they don't know how to be, so the more you are open about it, the more they understand. So for my typical, you know my friends with typical children, sometimes I do, I tell them things and then they're like you know, that's normal. And then sometimes I try to stop myself because they'll tell me about problems with their child and it'll be like "Oh, Tucker's going to soccer practice and he doesn't want to play, and it's a really big deal because his dad really wants him to be involved in team sports" and I'm sitting there thinking...wow...and this is your biggest problem? But you know you don't always want to trump somebody on the hardships of life, so, I listen and just keep it in the back of my head, like, you know, this is a big deal to them and I need to respect that because different things are a big deal. So that's kind of the hard part, you don't want to be that person that's like "seriously? Look at my life." You know? So you try to be...try to know that people are going to deal

with things in different ways, you know, just like my other friends who have children who are more involved, I try to be really careful when I explain about things that are wrong with my kid because to them, things that are wrong with my kid are things that their kids are kind of working towards. So it's kind of a delicate balance to be able to accept everybody and all their children at the same stages while being respectful of it.

**4.) Absolutely, kind of related to that is my next question: who and what has been most helpful for you?**

Huh, my mom used to work with special needs, but she worked with severely...with IQ levels below a certain level. When schools went to inclusion, she worked with the kids that didn't go to public school, she worked with kids who were 19-22, so that's transitioning out into the community. So she has been really helpful in terms of in the beginning, knowing where kind of, when things were wrong and I think you know, when it first came, you know, I kept thinking he was going to grow out of certain things and she had to be the one to say, like you know, "something's not right." Because even one of my best friends who was helping me watch him at the time, there's certain things you can't...you know it's hard to cross those lines. So she had to be the one to be like you really should take him in, you should get this figured out, what's going on and things like that, so she's been extremely helpful because they have a very special bond. When I first [unintelligible] I had to work down here, and we used to live in Cleveland and he had to commute, and he wasn't a citizen yet he was still in the process. So we didn't know how things were going to end up or if he was going

to keep his job or not, and so we lived with my mom for a couple years when [C] was just born, and she was kind of the other parent. So they have a really unique bond and whenever I lose my patience with him or am at my wits end, she always is the one to even me out. So that's been amazing, to have family that's supportive, that's just accepting. I don't know how we'd get through without that. But beyond that, um...I have a girl that works that is a mom out at Roads, and she has been just really supportive. [crying] I never, people kept telling me I should join support groups and I'm like "oh great, we'll sit around in a woe is me group" and I know not all of them are like that, but after I joined Roads...it's not a group that's focused on what's wrong with our child and what's different, we're all focused on educating our child and on moving forward and helping the community and doing things. So this other mom who programs with my son, she kinda took me under her wing and helped me decide to go out of public school, helped me to set up the program, and get through all these things and take more charge of my son's education and where it was going and I don't think I would have been able to do this process without her. She's gone through it, and she's gone through all the hoops and all this stuff. And also my...the DAN doctor that we have we've kind of gone back and forth. For some kids the biomedical treatment doesn't really work, and I know some people really don't like the DAN doctors, but she's been really helpful ...but...as a parent I think you have to know that this is a very new science so it's kind of a trial and error type thing. So even though there there's definitely [unintelligible], it's not like a doctor who says okay you've got strep throat here's penicillin, and it makes it better. It's kind of

like this is what we think will help, if it doesn't work, we'll take a step back. So it's kind of like it's a little trial and error type, but it's helpful to have somebody really listen to what's going on in his life. So like, a couple months ago she had him on this medicine and although it was really helping him in some ways, it started making him really behavioral. And he's not that kind of kid usually, like behavioral to the point that it was really disrupting the family. My 2 year old was starting to model his behavior, and it was very bad behavior, you know, throw yourself on the ground, yelling, angry, things like that. So I talked to the DAN doctor and told her what's going on and, you know we have to have that dialogue and we have to have that back and forth and problem being, it's really expensive. So that's the hard part of autism. There's a huge expense to it to do it the right way. To treat it the right way. To get the therapy you need in the right way. We are not lower class, thank god, you know, a lot of people are eligible for state funding, and you know, a lot of kids with autism are on the waiver because they're below a certain level and they're never going to go to college and they're never going to do these things. Well, in order to be on waiver you have to sign away all your child's tuition money that you save, and I'm not ready to give up on that yet. So you have to kind of get to that place where you're navigating on your own a little bit. So the DAN doctor has been helpful, more to make me a more responsible parent in terms of reading up on what we're doing. Instead of being that parent that, I mean, when he was little he got all his vaccinations. And I'm not one of the parents that thinks vaccines cause autism, but I think they aggravate certain predispositions to you know, some of these issues. Before I would just

take him to the doctor and say ok you're right you're right you're right. And I think the more that you kind of go through the process, you have to realize that you need to be more responsible. You know, I feed my kids organic food, I do research on things, and I try to be more [unintelligible] because I realize that sometimes what's supposedly in the best interest is not always in the best interest of the kids. Um I think that the supports are there in terms of the biomedical community type thing but you have to be educated. Educate yourself about it. And I always wonder to myself, what do parents do who work during the week, who don't have any money, don't have any support, what ...their kids I'm sure could take leaps and bounds from it but they just don't have any resources. And that's what really sad.

**Having access to resources and being able to take advantage of the resources is so key.**

Yes! Well even the autism scholarship fund from Ohio is a really great thing, but you have to put your own money into it first...and that's 5 or 6 thousand dollars. You know, occupational therapy even if your insurance will cover it can still be 100 bucks a session. How do you get those? I mean, that's just really tough for me to think about.

**Yes, me too. I know the financial strain is really hard on all parents, though, and figuring out how...**

You know, it's not how you do it, it's you don't give yourself an option not to do it. So there is no other option and you just make it work.

**Good point, that does seem to be true. Um, as a follow-up to my last question, who and what has been most hurtful?**

Um, I don't think that people in general are hurtful, but you know, things are difficult. Insurance companies are not on your side. That is a challenge. Because it's hard to know that things could help your child and you can't get them. So the biomedical treatments, that's all out of pocket because insurance companies don't acknowledge those things. So we have to get things like he had Candida, yeast, and things like that and they don't see that as an actual problem. So then that's out of pocket. So that's been difficult. It's been difficult with some scholarship through Ohio because if things aren't specifically stated in specific terms, then you have a really hard time, and it's hard when you are writing your IEP the specific things you're going to need and the materials to put out on the form. So things like that have been really hurtful, I mean not hurtful, but difficult to deal with. It's unfortunate, but it's a process where you have to get hurt one time to figure out what to do the next time. And it's sad that it's hurting your child, that's what's difficult about it. So you've got to learn, it's a learning curve that goes on. And I think the things that are most hurtful, I was talking to my mom the other day, things that you internally think about. So I've thought a couple times, you know, he's five, he could be playing soccer, and things like that are difficult, so it's more coming to grips with the fact that you know, like it said, this is what you picture, and this is what is. Not that what is is horrible, it's just different.

[crying]

**Right, sure.**



So you've got to realign at some point. But you know, I think not every kid would have wanted to do that. And I think maybe it's strange to think, but at some point in your life, your kids are not going to live up to what you thought they were going to be, no matter what it is. It just happened to me a little bit sooner. So some think their kid will be a doctor and he turns out to be a mechanic. So I think it's just there's certain things that...they are who they are. You aren't going to change who they are. And you can help them through things that are difficult. Like, [C], he could sit in the corner all day by himself playing video games and doing things that are self-contained. So you have to do the difficult thing, take him out of the corner, which isn't always the funnest thing to do, but it's the right thing to do for him. I think that most parents would say the hardest thing is always seeing the other side.

**Right, like you were saying, too, at 5 you're thinking he would have been playing soccer, but there are always going to be different milestones, there's always something down the pike, so at 10 you might have the same reaction of well at 10, I imagined he would be doing this. So it's not like that pain ever goes away, like the poem said. But like you said and like the poem said, realizing that where he is is a beautiful thing, too...**

Right and I think too looking...I'm really lucky that he has interests that are not...some people with Asperger's have interests that are you know, strange. Like I knew a kid that was obsessed with cats, and every type of cat and cats cats cats and, you know, the things he's interested in are functional. So cars. And not like he was when he would just spin the wheels on it, completely not any sort of

use. But you know, the type of cars, he likes to design cars on video games, he likes to look at the cars and he...you know, things like that, or the video games or the computer, I mean those are things like, you can build on those. So if it was something like...well he does actually have an obsession that is not functional and strange and that is vacuum cleaners, although, that's another mechanical device, with wheels and things like that. So I feel like he has this tendency towards these things and I kind of feel like we can work on those. So that's kind of easier. So many he's just not that kind of kid that will play sports or whatever, I mean, my husband wasn't that type of kid, he was into video games and computers. So when I think of it that way I'm like okay, maybe he's just going that way. I think it's easier and harder at the same time having a second one, because I see a child going through the typical milestones and I think to myself "oh my gosh if I would have known that I would have definitely known there was something wrong earlier. What he's doing is miles ahead of where [C] was. But then there's other stuff that's not that I'm like "Are you kidding me" the common sense stuff, like, you just hit your head against the wall you're going to do it again? So some of the things are like yeah, I see back and forth the differences, but I don't know, I know a lot of parents who have children on the spectrum who have older children and then stop with the child with autism. We when we had our second one, we just we were trying...we just found out there were some issues with [C], but we also didn't want to not have him have siblings, because I think, well right now is a prime time for sibling rivalry, they're 3 years apart, um, and a lot of their social graces are on the same level which I think is difficult, I think eventually that

[younger son] is going to be his best influence with social skills and pulling him back into the real world. So even though it's a bit difficult, I think that down the line it's going to be really good. They have a lot of problem and [C] has issues because he's very self-focused, I mean he doesn't really understand why sharing is a good thing. Thinking about others feelings is hard for him because it's very abstract, and hurting someone's feelings is hard because he doesn't know why. Well you know I want it...I mean, it's hard lots of times because he can be really mean to his younger brother, and I know some of that is typical but some of it is just not social. So I think over time though when [younger son] is able to verbalize more instead of...screaming and yelling...that it will be a little bit easier. I think...you know. It's kind of hard for me to accept that the younger one is going to have to take the role of the bigger one, but...que sera sera, you know, that's going to definitely be part of the process.

**5.) Sure, that can be a hard one to watch unfold and to accept sometimes. How have others' beliefs about autism impacted your relationship with [C]?**

Um...I don't really use the term autism a lot when I explain him. If I say, talk to people about him I'll say "he's got developmental delays" or "he's got some speech issues" but I think there's such a negative perception of autism that people automatically go to, like, "Rainman." I think that not using those labels is helpful because they can make their own judgments when they meet my kid. Like, we were trying to switch schools, and I was calling Montessori schools which is what he does, and as soon as I say something like "he's on the spectrum" it's automatically "oh we don't deal with that." You know, so stuff like that is crappy

because they didn't even meet my kid. They don't even know my kid. They don't even know what he's capable of and that he is where he is. And so, that was the first time I'd ever felt that because he'd always been in the range where he was not too different, but a lot of parents at Roads had to deal with that a lot earlier, which is just heartbreaking I'm sure to have somebody judge their kid because of that. Or without even knowing them. But I think that the public is just not educated. And there really is just no reason for that anymore. If they don't have to be, I mean, everybody now knows somebody with a child with autism and I know that it's something people are becoming more aware of, but I think that it's something that they don't understand...the varying degrees of autism. And I heard too that they're taking Asperger's out of the spectrum. I think the varying degrees people need to be aware of. Just like, if you want to call intelligence varying degrees of whatever, there are varying degrees of that and academic success. So I think that that's been a challenge for me. And some people what they will argue is shame and no, I'm not ashamed, I just don't think that accurately represents my child, and so I'm going to not...it's kind of like when you would say to somebody "that girl over there is really rude," before I'd even know you then I would think that. So I kind of let people think what they think and I use the label when I have to. When it means that I'll get more services, or when he can get more money for things that he needs, because that unfortunately is the way that society functions at this point.

**Right. Do you think that by not using the label, that you've managed to avoid a lot of the stigma then?**

I think that...yes. And that's a really awful thing to say, because if [C] wasn't as high functioning as he is, then I couldn't have gotten away with not using it. But because [C] is at that point, I can say, well he's a little eccentric, and people know there's something different about him. But if you were to have gone to his classroom at the end of the year, you probably wouldn't have been able to pick him out all the time. And so, I tend to not use the label because I don't like the way people objectify the kids like that. And if I don't have to use it, I don't want to. And if I didn't have to use it to describe other kids that are autistic, I wouldn't use it for them either because I think right now...people want to put everybody into these little boxes so they can understand exactly what they are without having to put any work into it. And so, I think that's just a tragedy. I think that's what I've learned; I mean, I even have trouble in terms of kids who are lower functioning in terms of verbal...nonverbal. I sometimes ask their parents "do you think they understand that" because I don't know. I don't know. And I'm not trying to be rude, but sometimes people ask me the same thing "did he get it?" and I'm like I don't know, maybe not. But I think it's all about understanding, and when you put that label on, you don't take the time to understand. You don't get to know each child, when you put the label on, you don't get to know the person, you don't have to spend that kind of time.

**They already think they know, they think they have an idea of**

It's like oh, we'll put you right in that pile and that's your personality and who you are and that's it. And then you miss all the really cool things about who they are and what they're good at, as well as where they have more difficulty.

**6.) Right, thank you. What would you like others to know about your relationship with [C]?**

Um...I don't really know. I guess I don't find it that much different than a typical...although I can see people thinking that I'm firmer or I don't want to say mean, but I guess strong. I have to raise my voice sometimes I have to talk loud sometimes. Sometimes I have to grab him because physically, he needs that input to say look at me. You know, stop. And I don't know if people see that as like "oh my god," but there are different ways that I have to parent him that are different than I would with my second son. And I mean, he's a boy and they're both boys, but with [C], sometimes, he can't rationalize. You can't sit him down and say "no [C], this was wrong because of this, this, and this and if you do this then you..." he lost you three sentences ago, so you don't have that. You have to find other ways to get your point across. Sometimes, unfortunately, that is grabbing him and putting him and saying this is not acceptable, but there's a different way you have to do it. And it's not every parent that does that, even with children with autism, but with him that unfortunately is what you have to do. If you try to have a conversation and he doesn't want to hear you, then he'll argue with you, he's that typical, he'll do that. So there are certain things that are different, um, I think that with mothers of children with autism, and I don't agree with everything that Jenny McCarthy says, but I do agree that mothers in particular, and some dads, I mean I've met some dads, but you have to a literally, you have to be literally mother warriors. You are going out every day and fighting against everything and a lot of uphill battles just to do what's best for

your kid. And I absolutely commend every mother of children with autism because it is constantly an uphill battle. And some parents choose not to take that battle, so the ones that are taking it are...are being the parent they never knew they could be because they have to. One of my friends said to me "oh you're so amazing and you're so this and you're such a good mother," and I hear that and I'm like "you would do the same thing in this situation, you just don't know it." You just would never know it until you are here. I'm doing what every other mother would do in this situation, well, not every other mother, but every mother who wants their child to succeed and will do anything. And I think even if you don't have the resources if you're a mother who has that same feeling, you'll figure out as much as you can. You're going to find and uncover anything that you can. And I think that a lot of mothers are of children with autism are researchers, and they will go out and find whatever they can and they'll uncover every rock and they'll do absolutely everything they can think of, especially if things aren't working. It's not like you know, physical therapy, that you say "do this for 6 months and then you'll be done, you'll be alright" because there's no end. And sometimes you get to a stalemate and you have to figure out what do we do, and because all of this is so new, there's no clear-cut path. You know so a lot of times we're saying I've heard about this new therapy and I've read about it and I've seen it work so what do we have to lose, so let's try this. The downside of this is that there are always people who are looking to take your money. Unfortunately people will do anything to make their children better. So if somebody says to you, if you give me 1000\$ I can cure your child, sometimes

people will do it. But I think what I've realized over the years is that there is no cure. There is no magic pill and even if there was, I would...I don't...I mean, what is normal? That's another thing I started to realize, the idea of normal is relative too, whoever said what's normal is normal? I have to have realistic expectations for my son, and the small milestones are big event. So as long as they're moving forward and not moving backwards, that's positive. But I've had to convince my husband a lot of times, like when we took him out of public school he was like "what what are you thinking" but it's...it's like that in a lot of relationships where you have to say this is what I think and I think this would be good and let me have the [unintelligible]. Or even though we did the DAN doctor, I showed him the blood work and said okay we have to change his whole diet and our life is going to be in disarray, but it has to be convincing. I think in the end, I would never make a decision that I would hurt a child and in certain situations you think to yourself...this can't hurt, right? So I give it a try. I think why some people fail is that they won't commit to it a full 100%. I think a lot of parents say "oh we're going to try this diet" but they do it for a bit and they don't see anything, so they go back. I think that's the danger of a lot of these therapies, if you are going to commit to something, then you are going to commit to it for a longer period of time, a year, two years, because if you think in the short term...you're never going to see the effects and your life is going to constantly be in upheaval. And even still, there is no guarantee that you will see effects and that's the thing, if somebody said to me, go as hard as you can and in the end, it will all pay off. It's one of those things where...if you're rehabbing an injury you



know that in the end, you will be where you want to be and the hard part of this is you can do everything in your possible power and you still may not see what you thought was going to be there. It's hard sometimes to keep going. [crying] But then you see your kid do something that you couldn't imagine and you have this renewed sense of...of purpose and you're like "alright! let's go." And I think if you would have seen my son last year as compared to where he is this year, it's amazing it's an amazing change and it hasn't been a smooth growth, but along the way you get this sense that you're doing the right thing and so you just keep trekking along. And I think too, I was just thinking about this, between mothers and sons or children and fathers and children is really different. I think a mother is always going to play the maternal role and fathers get [unintelligible] really easily. So I have to constantly remind him, he always, and I'll do the same thing, but he's always comparing him to typical and saying "This is typical" and talking to him like he's typical and I'm like no, he still has all these issues. So it's a hard line for him in particular because he can't always tell if he's misbehaving or if he doesn't understand. So recently he said he thought he was misbehaving, and I was like no, he doesn't understand and yelling at him isn't going to help. It's not like a purposeful I'm not going to do what you want me to do, it's either I don't know or can't do what you're telling me to do. You know?

**Right, he's not willfully misbehaving.**

Right and so I think the mother and child and father and child relationship is really different.

**Would you say that's true for typically developing children too, or is it...?**

I don't know, I really can't speak on what I don't know and my younger one isn't old enough yet to notice anything. I do know that when it comes to disciplining, because he's so young, my husband still treats him like a baby. So he's always...he won't put him on the step or swat him on the butt, he'll just use redirecting. And with [C], it's disciplining. Because I think my husband still sees it as an intentional act. And so that's been...I try not to get involved because I don't want to try to teach my husband how to parent, but I do want him not...how do you punish somebody for something they can't control? You know? So it's a hard line, because he thinks that he's able...and sometimes he is, that's the hard thing. Sometimes he plays that, because he can. And he's very smart in that way and it sounds bad, but he can be very manipulative. He pushes his teachers and therapists and he figures out how hard he can push and where he can push and what...and that's what hard. You have all those things that are so typical that typical kids would be doing those same things, but without the capability to sit down and say "this is why you can't do that," and so you have to become more creative about certain things. And it actually kind of helps with having a second child, because I think we bombard kids with so much language, they don't understand. So you learn to be very simplistic in the way you interact with your kids and I think with the second one it kind of helped because you have a better understanding of how their minds kind of work, you know?

**7.) Sure, the way you communicate with your other son just carries over because it's what you're used to, that makes sense. What have people said about you and your child that you never want to hear again?**

Hmm...I don't think I've ever heard anything, at least not to my face. But people have said to me that I...and this is my father in law said to me that I was blowing this out of proportion, that he'll grow out of it and that you're and it was almost like a you're creating something where there's not and that bothers me. Number one, it's obviously not in his nature to accept the fact that somebody's different. But it's just...I mean...why on earth would I want to create a problem where there's not one? And sometimes people like I have other friends a cohort in my [unintelligible] and they say "everything you're saying just sounds like a typical 5 year old." Kind of like...yeah, I guess you could see that if you didn't see some of those things. so I think that's difficult because [C] is so much at that grey area that people kind of think that you're creating something where there's not. But I guess in general people don't like to think that there's something wrong with children. So they'll try to suspend that aspect, you know, they'll say "oh you're just over reacting" or "you're an overprotective mother" you know what I mean? Things like that where you're like "oh I wish I was," but it's to make them feel better. I think too that I've never heard anything about me as a parent, but I think sometimes they see my child as misbehaving instead of dealing with things that he can't deal with and they think that's bad parenting. And I mean, it's, I see parents dress their kids in shirts that say "I'm not misbehaving, I'm autistic" and again I don't ever, I would never put my child in that t-shirt but at the same time I don't...it makes sense because people see it as a lack of parenting skills when really there's nothing you can do in certain aspects because you don't you can never see things coming. And I think that's what some of the difficult is with [C],

because you can have the perfect day, and something can go horribly wrong and the whole day will be off. And it can be something as small as like he got his hair wet, and now for the rest of the day he's in a bad mood, stuff like that so people interpret those things as poor parenting skills and that's difficult. Or if you have a typical kid and you're in a store and he has a tantrum, it's just like...sometimes removing him from a situation like you would a typical kid isn't the best option because it teaches him that he can do that and then we'll leave. So I think that's some of the hard things, that people judge your parenting based on that.

Like...how typical they act.

**8.) Sure, I can definitely see that. My last question is just is there anything else I should have asked you about your relationship with [C]?**

Umm...I think that for me in particular it's been a little bit of a struggle for me. He's a lot more like my husband in his personality. So with my younger one, even though he's two, he can be really stubborn, we're a lot more alike. He's a lot more social, a lot more outgoing; our personalities are very similar so there's kind of that draw towards people who are more like you. Don't get me wrong, I love both my children to death, but it's hard sometimes to understand my older son because he's not like me. So that I think is another interesting twist to the relationship is you have these hurdles to come where you have these special needs, but then you have the obvious hurdles...not hurdle, but whatever it is you deal with as parents when your child is more like the other parent, your husband or wife...you know, it's already hard to work with to deal with that in the way you work or function, and then you have another piece of it and it can be difficult

to because I think sometimes I try to downplay how much...I'm very lucky that he's a very loving child. He's a cuddler and a lover and I don't know what I would do if he was a child with autism who does not like that. I probably would...well I would have had to deal with it by now. I think sometimes because he's so independent and so on his own, I think sometimes I downplay how much he needs me. Does that make sense? And he is very interesting in that the little one, I'll pretend to be upset and that very much upsets my older one. He does not want to see his mom upset whatsoever. So things like that, he doesn't see that...he sees me being upset and he doesn't want that. Or if my husband and I get into an argument, it very much upsets him that that's going on. Where, people tell me with other children they might internalize, he can't, so he's very expressive about it. And so, some of those things get kind of difficult and I find myself, too, I find the dynamic we didn't touch on is how having a child like this affects the other relationships in the family. Like between the husband and wife, because this is never something my husband planned for either. He never had kids, he never dealt with kids, and then to have a child who has special needs is even a step farther away. So I think a lot of times it's up to the mother to step in and defend, but it's hard to constantly play that mediator. It puts you and that other person at odds when you're trying to say, like if I said to you, if I was critiquing your parenting style. You know, and that's very personal and then it's like well you're just running the show and you're trying to do everything and I'm not trying to, all I'm trying to do is to get you to understand and to take a step back, but in order to do that you have to analyze yourself and that's not really

easy for everybody to do. As a mom, I don't want to say...it sounds really bad, but you're forced to have to do that. It's your role in the family. But dads don't really have to do that as much. It's harder for them to take a step back. Not all dads, but a lot of type A personalities, manly men, and you know it's hard for them to look at themselves and say what am I doing or what could I be doing better. Because those are the ones that are going through the whole process, and you know you get to learn because they're going through it all too. And as moms, you constantly have to adapt where I think dads are kind of used to you know, being on the well I don't want to say on the outside, but they're kind of the ones that generally roll with the punches and it's just easier for them to say "it's them" then for them to say "it's me." Or if I say something about relationships if I say "well [C] was really bad today" and he says "well he's always bad." You know it's just like ugh, it hurts me when you say that about my child. To him, it's just an observation, it is what is. To me, that's mean. He just doesn't get it. It's stuff like that, and so, that's the hard part is navigating those inter-relationships...or intra...inside your family. It's kind of like when my youngest grows up, I mean, he already knows something's different. But having that conversation, too, and you know, how do you not be resentful of the sibling? [crying] So figuring how to navigate that, that's the most difficult. And then you have to really work hard not to be resentful towards your son, and that's a really awful thing to say, but it's really easy to be that you. You have to remember to understand, and you have to be more emotionally involved to understand not to resent, does that make sense? And it's not their fault, that's not what I'm saying, but you start to resent the

behavior and their actions and then it's hard to be a parent because you have anger. You know what I mean? So I think it all, I think it, you have to have a really great support system, somebody to vent to, and somebody to talk to to be able to deal with that. Because nobody wants to feel that way about their kid.

**Absolutely, but what I'm hearing you say is that your relationship with your kid doesn't just affect you and [C], it affects you and your other son, it affects you and your husband...**

Right and observing things too. It's hard for me too like if my husband's outside and I hear craziness going on, for me not to get involved is difficult. And I don't want to step in and step on his toes but at the same time, I don't want their interactions to be negative. I don't want it to be a negative thing for [C]. It's hard to have that line of keeping my distance and letting him deal with it to stepping in to protect my son. So that's difficult because most parents will just say if the kid just walks out the kid doesn't want to be with them and it's just that the kid doesn't want to be with them. But with [C] it's different because he just doesn't get it. He doesn't get why he's angry. And there's this point where my husband would yell at him, and then my son would just say to me "I don't want Daddy to get angry. I don't want Daddy to yell." And that's what he saw was just that anger, and that's...how do you approach him and say "this is your son's perception at this point."

**Right.**

And he'll be like "oh he doesn't know..." and I'm like "he's five, and he might not know, but that's really how he feels." And so, it's a hard—and then you feel

like you're attacking him as a parent—so you get into this whole dynamic so that's a hard weight. And I think that's why a lot of parents of children with disabilities or disorder or issues, they have problems. Because you have enough pressures as a couple, and then you add in the very unnatural issue and it kind of complicates things in a different way. And the thing is that if [C] was typically developing, then we wouldn't have half as many fights as we do. But, you know it is what it is you can't change things. So I think you either accept what it is or some people just go their separate ways because they can't figure out how to deal with their relationship with the other person and their child. So I think that's a really difficult piece. But then the other side, who knows your child or would love your child like his father. That's another thing, and that's probably why a lot of moms have to work hard at their relationships because you know that person knows everything about their child and accepts everything about them and it's harder for their little world when you take that apart. That's why I think you work harder to try to keep everything together.

**Sure, absolutely.**

So yeah, that's all I would add...I think I'm done.



**Interview ID # 04**

**1.) What is your understanding of the mother's message in this poem?**

I read that for the first time when I was pregnant with [younger son] because I had been diagnosed...I found out he was going to be a dwarf while I was still pregnant with him. And even though you don't you get what you want, you still got something beautiful, you know? Even if it wasn't what you were expecting. It's still something that you need to pay attention to and not get yourself bogged down in "what if," you know?

**2.) Yes, absolutely. In what way does this poem represent your experience?**

[long pause] Well you have to learn a whole new language. You know, I can't treat [D] the same way I would treat [middle son] and the same way I would treat [youngest son]. I have to learn a whole different way of relating to her. And you know, it's not an ugly thing, it's a beautiful thing. She's such a sweet, innocent person. [laughs] And she's herself. She can't be anything else.

**3.) Sure. I notice when you talk about [D], you get a really big smile. [nods] In what way does the poem not represent your experience?**

[long pause] Well from my understanding, the woman who wrote the poem, she had a child with Down syndrome. So everyone who looked at that child knew that her child had a disability. Whereas with [D], if you look at her, you can't tell. So people don't know that I'm in Holland. You know? And they don't always, people don't always understand that.

**What sort of implications, or what sort of differences does that make for you? People not recognizing that you're in Holland.**

It doesn't make a lot of difference, but there are times when people, you know, they get frustrated with [D], and they get angry with her because she doesn't do what they expect her to do. Or they expect her to act the same way as everybody else. They don't make special accommodations for her being different, whereas if she was in a wheelchair, or if she had Down syndrome, and she had physical, outward...like [youngest son] being a dwarf, they look at [youngest son], they KNOW he needs special accommodations. And he gets them, you know? I think that's a big thing, people don't understand that she needs to be treated differently.

**What have you had to do to navigate that?**

It's so hard because she...her IQ tests out at 99, so it's a perfectly normal, average IQ. So it's hard to get people, especially people at school. Now her individual teachers at school, they know, because they've been around her. Other people, especially other students, think that if she's in a regular class she should be able to blah blah blah. It's frustrating for her and frustrating for me.

**[D] is older now, so how is she dealing with that? You said that she's 18 now, right?**

Yes. She...she deals with it pretty well now. You know, it still gets to her when people call her retarded or dumb. But if somebody says "you're weird" she says thank you. [laughs] You know?

**[laughs] Good for her!**

And, or, if somebody says "you're crazy" she says "I'm not crazy, I'm weird."

[laughs]

**That's great.**

So she takes it a lot better than she used to, when she was in like 5<sup>th</sup> or 6<sup>th</sup> grade, she'd always come home crying.

**I'm sure. She...**

But all the teachers love her. And some of the students will stand up for her. Not as many as when she was in 7<sup>th</sup> or 8<sup>th</sup> grade, but um...she has her advocates at school, so she does take it a lot better. And now that she is getting older and she's starting to understand a little bit more what people see when they see her...although today she was in her fairy costume riding her bike over to her grandmothers...[laughs]

**Was she?**

Yes. I think that's great.

**4.) Absolutely. In parenting [D], who and what has been most helpful?**

[long pause] Just knowing that there are people, like people at her schools. Counselors. Psychiatrists. Knowing that there are people who understand what we're going through. If I had to do it alone, I think I'd pull all my hair out. I don't think I could deal with it by myself.

**In what ways have those people been helpful?**

I think in a lot of ways just knowing that I'm accountable. So like when we go to the psychiatrist, and he says "well how's [D] doing?" I don't have to say "well she was so horrible that I just had to beat her senseless." [laughs] I have a reason to treat her well. That sounded really bad. [laughs]

**I'd imagine there are times when it is really frustrating.**

Yes, there are times, there are times when it is so frustrating [whispering].

**Absolutely.**

[whispering] There are times when she doesn't take her medication and she goes through the house going "woof...woof...woof!" And she just keeps doing it and doing it until I'm like, "you didn't take your medicine, did you?" "Nooooo [mumbling]."

**So they help you by holding you accountable.**

Yeah. Most of my information comes from the internet. But...I don't get a lot of information from those people, but I just know that there is somebody that I can...that knows how [D] is that I can sit down and say "[D] is not in a good mood today" and they're like "okay, we know what to do."

**Okay.**

Luckily at high school, she's had the same language arts teacher and the same math teacher and the same art teacher every year.

**And has that helped her?**

That's helped so much.

**Having some consistency?**

Yes. She has 6 classes a day, but having those same 3 teachers every year has been a big step of consistency for her.

**How about any other people...other parents of children with special needs, family members...has anyone else been helpful?**

Well I don't really I don't really have anybody I hang with that has children with special needs. I mean, I do have friends that have children with special needs...but I don't really talk a lot with them or their kids have different special

needs or whatever. And I would say...I would say my mom is very supportive but I spend more time telling my mom stuff about [D]. And my grandmother...oh God my grandmother...you know, she's on the internet finding stuff about autism and about how to *cure* autism and giving stuff saying "I thought you might could use this about [D]." I'm like "thank you grandma."

**Yeah.**

What else do you say? It leaves you thinking about it...thanks grandma.

**Would you consider that hurtful?**

It's my grandmother. She's 83 years old; she's had a small stroke. From anybody else, I would. But from my grandmother, no. She cares. And you know like if it was my uncle, yeah I would consider it very hurtful. But because it's my grandma...psh.

**Okay, sure. That's actually going into my next question: who and what has been most hurtful?**

Other kids. Other kids. Hearing what other kids say about her, to her. She doesn't have a lot of friends. She's 18, she acts like an 8 year old, you know there's not a lot of kids that are comfortable with that. She looks like a 12 year old. And a lot of parents aren't comfortable with that either.

**What has let you know that they aren't comfortable?**

Well, either their face does. Or they say "she's 18? She doesn't act 18. She doesn't look 18." So you have to say "well she's slightly autistic," because they don't understand autism spectrum, they don't understand...so I say slightly autistic.

**What sort of response do you get when you say things like that?**

It's sort of an "OHHHhhhhh." Like they KNOW something. You kinda want to go "what do you mean OHHhhhh?"

**Like "what did that mean to you?"**

Yeah, exactly. But um, because she doesn't look like she has a disability, it's harder for people to understand what autistic means. Because they're used to see the kids on the TV who are [imitates head banging/rocking behavior].

**Right.**

There was this boy that...when [D] was in 7<sup>th</sup> and 8<sup>th</sup> grade she went to a school that had 2 autistic boys. They were very nonverbal, very, you know ... [imitates head banging behavior] and they expect that that's what autism's like. And it is. And then there's [D]. And they don't understand that. They don't understand that even though she reads constantly...way above her grade level... [pause]

**...and she's got a typical IQ**

She's got a typical IQ. And...but she acts like an 8 year old and they don't understand that. Why can't she behave herself? You know? Why can't...when she's wearing a skirt...you know, why can't she keep her legs together?

Why...there are no easy answers.

**No, definitely not. From what you were saying before, it sounds like you've been able to see even in your own family the difference between someone who has a visible disability and someone who has an invisible disability. So you really have that comparison of some of the differences in attitudes and...**

Yeah, yeah. And having like...having my 3 kids, [D] and [youngest son] are biracial, and then my middle child is so white he's clear...actually we think he might be 1/8<sup>th</sup> Mexican but we're not sure. But on his father's side. But I've been asked a couple times if [D] and [youngest son] were adopted. The first time it happened [youngest son] was about a year old and we were in Trotwood at Burger King, and this lady, a white lady, comes over to us and says "oh they're so cute are they adopted?" And I said no. They're mine. And she made this face and she said "oh...well that's alright now a days."

**Oh wow.**

And...you know... that's when you just kinda go... [pause]

**Wow. That must be so hurtful.**

Yeah, that's *really* hurtful. You know, we're in the middle of Trotwood and she comes up and just drops something like that. Yeah, I've been asked if I was babysitting when I have all 3 of them with me. And usually it's just a curious question because they don't expect a family to be...different. Families are supposed to look like families.

**Right...and you've got both race and disability playing in as factors, so that really...**

Yeah, yeah, and [middle son] is the only one that doesn't have a disability.

Well...for now. When he gets older it may become an issue. He's got a neurological condition called neurofibromatosis. It's when...like with our nerves they grow from the skin down in, and people with neurofibromatosis, sometimes their nerves grow up. And it causes little painful neurofibromas.

**Wow, you've certainly got your hands full, don't you?**

Yeah, he's got a couple learning disabilities that we have to deal with at school that are related to neurofibromatosis.

**You must be a busy woman!**

Yeah

**5.) I'm sure! My next question is how have others' beliefs about autism affected your relationship with [D]?**

There have been people who, like, I was closer to them when the kids were younger, but as the kids got older, they see how [D] acts and it's partly how [D] acts and partly how I relate to her that they kinda pulled back. So, when they thought [D] was "normal" – I put that in quotation marks, tape recorder—[laughs] –when they thought [D] was quote "normal" they were fine with their kids playing and everything and then when their kids got interested in other stuff and [D] wasn't, you know, they pulled back. And so... you know...

**Mmm hmm. You said, too, that sometimes it was how you related to her that made people pull back as well?**

Well like if I...if [D]...especially when she was about 10 or 11, she would get nervous and would crawl under the table and she would hide there. And people would say "pull her out and give her a swat on the butt" or "make her go do something" or whatever. Or like when we were swimming, they'd say "just put her in the water" because I'm not doing what they would do with their neurotypical child. But you know...

**But you knew that [D] was different, and you had to parent her differently.**



Right. Exactly.

**Do you think that changed your relationship with [D] at all? The way you saw her, the way you interacted with her...**

At times. There are times when I wish she was more neurotypical.

**Sure.**

I mean, if I can be honest.

**Absolutely, of course there are.**

I mean, yeah, there are times. But if they came out with a miracle cure for it, I wouldn't do it. She's so sweet and beautiful and innocent. You know...I think my biggest problem with [D] is that she has acne, and she doesn't like the feel of lotion and she never would let me put the acne cream on her. We had some of the biggest fights about that. Because I mean, before she had the acne her skin was so beautiful, and she was so beautiful and you could see her face. And now with the acne, that's all you can see when you look at her is the acne. And for about 2 weeks she would let me put the acne cream on her and it cleared up and she was so beautiful. But then she just, she didn't like the feel of it and I had to stop. And that was our biggest...so when I look at her I just think I want that acne gone.

**Sure, but it's a real sensory issue for her it sounds like.**

Right. I even tried doing it while she was asleep but it didn't work. [laughs]

**[laughs] Wow, you really tried everything didn't you?**

I did! She was so beautiful. I mean, she's still beautiful, but her skin was so beautiful.

**Right. Does it bother her?**

A little bit. People say stuff. Pizza face and [unintelligible]...stuff like that.

Yeah, but...yeah.

**6.) Okay. My next question is what do you want people to know about your relationship with your child?**

Hmm... That's a good question. Wow. [pause] I don't know, mainly just that she IS my child. However, I treat her in...most likely what's best for her. Like, I took her swimming when she was about 6. Or no, my sister took her swimming when she was about 6. And she was terrified to go in the water. So I picked her up...I had to go pick her up literally, I went to the pool and saw what was going on and thought "we need to do this." So I went and put on my swimsuit and I got in the water with her and she was crazy she was SCREAMING. I said "come one lets just put your toes in the water." And she was screaming, five or ten minutes she was screaming. But then she liked it on her toes. So I took a couple steps out and she started screaming even worse. But then she finally calmed down and I kept going until her whole body was in the water, well, up to her neck, and I put her down and she was FINE with the water. I took her back in the shallow end and she just played the rest of the day. But I had to be the mean one to push her into the water to get her to do something that I knew she was going to like.

**Right, but I'm sure people were looking at you like "what are you doing?"**

Right. And even my mom will do that. Like I'll be trying to get [D] to do something or try something or whatever and...by pushing her to do it...my mom will be like "just leave her alone leave her alone" and I have to be like "mom, I've

got to.” Cause I know how to get [D] to do something, especially if I know she’s going to like it. Like pineapple. I had to do that with pineapple. “Just try a little tiny piece of it, come on [D], just try it, open your mouth...open...open your mouth. Try a little bit” and before you know it she says “I LIKE IT!” “See, I knew you would. [laughs]

**Right. [laughs] But I can imagine other people don’t understand that process that you know you need to go through. So it sounds like you would like people to know that you know what’s best for her...that you ARE her mother, and you’re acting with her best interest in mind because you KNOW her.**

And I’m not going to do anything to hurt her. Well, other than maybe try to pry her mouth open. The other day we went to the air force museum. And we were going to go in the room with the big rocket. And [D] started crying because she didn’t want to go in there. And there was this lady that we kept bumping into, a couple, and they were from Nigeria. And she said “why is my friend crying?” And I said “well she’s scared,” you know, I didn’t want to explain the whole autism thing, and she said “oh...don’t be scared, if they were going to fall, they wouldn’t let us in here” or I forget how she said it, but it was really cool. And she said “don’t cry my friend” and gave [D] a little pin in the shape of Nigeria with the Nigerian flag on it and she pinned it on [D].

**Awww**

Yeah, and it just helped [D] calm down and it was okay. It was very cool.

**That is really cool. What a wonderful experience.**

Yeah.

**You know, you mentioned before that when you say the word autism, people think of someone who is much more severely affected than [D]. Is there anything you would like people to know in regards to autism, or her diagnosis, or what autism looks like for her?**

Well first of all, I want people to realize that autism doesn't LOOK like anything. People with autism, you know, when they're sleeping, they look just like neurotypical children. You know? They look exactly the same. And there are, you know, there, just because somebody looks normal—that was in quotation marks, too—that, just because somebody looks a certain way doesn't mean they're going to act a certain way. And you know that with [D], she's just like a giant puppy. Treat her nice and she'll treat you nice. But yeah...I think people should know that autism doesn't look like anything.

**Sure, and it's so different for everyone.**

Even people that have the same diagnosis of PDD-NOS as [D], it manifests in so many different ways.

**Absolutely. And it's pretty unusual for you, too, to have a girl with an autism spectrum disorder, isn't it? Because the majority, 3 out of 4, are boys, from what I last read.**

Right. It was really hard for us to get the diagnosis. The doctors just wanted to say "oh she's just shy" or "it's just anxiety" and I'm like NO, NO, it's more than that. But I was lucky that I have a friend who has a son with high functioning autism, because I recognized in him behaviors that [D] has, although he was a

little more severe, but I recognized in him the behaviors, like the self-comforting, like [D] will do like this [hand flapping] or like this [rocking/hand movements] but I recognized—well I think that was the most important thing was seeing him so I could recognize it.

**But it sounds like it really took you recognizing it and kind of diagnosing it yourself and going and essentially asking for the formal diagnosis.**

Yeah...we didn't get a formal diagnosis till she was 12 years.

**Wow...how frustrating, because I'm sure this really affected school and pretty much every area of her life.**

Yeah, I feel f we were to have gotten a diagnosis sooner, we would have gotten so much more. Like social training. There are programs for the younger kids. And by the time she was 12, most of the kids in those programs were 5 and 6 and she's considered too old for that type of thing. So, you know...what can you do.

**7.) Yes, that's true that there are many more services for younger children. My next question is what have you heard about you and your child that you never want to hear again?**

Well, about [D], I hate it when people call her retarded. Because she's not retarded.

**Right. Absolutely not.**

[pause]

**That's a big one. Especially for her now that she's older and she understands it so much more now, too.**

Yeah, okay, now if it was like an 83 year old person and she said you know, “awww, is she retarded?” I could cope with that. But when it’s “is she retarded??” You know, the tone. Like there’s a difference. Like [youngest son], he hates being called a “midget.” He considers that a cuss word. You know, he doesn’t like that word. But if somebody comes up and asks him “are you a midget?” in a curious sort of way, he’ll answer “no, I’m a dwarf.” But, it’s all in the tone. But yeah, [D]’s not retarded. She’s not stupid. She’s not an idiot. She’s weird. [laughs]

**And it sounds like she’s okay with self-identifying as “weird.” She’s okay with that.**

Well yeah. She’s fine with that because, you know, I’m weird. [laughs] But I guess you will know that by now.

**8.) [laughs] Well it sounds like you are both proud in your “weirdness” together...that’s excellent. My last question is just whether there is anything else I should have asked you about your relationship with [D].**

Well, we get along together really well. Like, she’ll come to me and she’ll ask me questions about anything like “mom, why does a butterfly...” you know.

She’ll just come to me and ask me anything. We share a lot of the same interests and stuff, we read a lot of the same books, but she’s really into vampires where I’m just like eh, okay, whatever. But we share a lot of the same interests, and we get along. Sometimes it looks like we really don’t get along, because [D] has a tendency to she tends to go into herself when she’s doing things, but we do share a lot of the same interests and we get along really well.

**That's great, that's really important.**

It is, it is. Yeah. We have really good discussions and good talks...a lot about books, or just about whatever. We have good talks.

**You know, as I hear you talking about her, I hear a lot of respect in the way you talk about her, in spite of the fact that you also say that she still also acts a lot like a child, and that there is a lot you still need to do for her. I mean, in terms of you talking about reading the same books, and having these discussions—I just hear a lot of respect in the way you talk about her.**

Yeah, well, I'm like that with all 3 of my kids. People have told me...[youngest son]'s father told me, I really like [youngest son]'s accent.

**Accent?**

Yeah, that's what I said, probably with the same look on my face. Accent? He said "yeah, he speaks all proper like you do." [laughs] I mean, when my kids were little, especially [D], my grandmother told me to talk to them like they knew what I was talking about, she said "don't talk to them like they're little. So even when she was like 3 days old, I'd say you know "okay, we're going to change your diaper" but I've always, I've always treated my children as if they're equals that don't know everything. And so you know, I say things and I talk to them, and you know, some people are like "I'm an adult, you're a child. I know what's best for you and I'm going to do that." I think that's helped a lot, especially with [D], because she forgets a lot, so to be able to remind her respectfully is important. Well she forgets a lot except for with the Twilight Series...that she remembers everything. [laughs]

**[laughs] Well, you know...sometimes we need to choose what's important to remember!**

Yeah. [D]'s things right now is [unintelligible]

**Which is?**

It's vampires. It's a series of books by [unintelligible]...they made it into the TV series "True Blood."

**Oh, okay.**

I haven't seen the show, we don't get cable.

**I've never seen it, but I've heard of it.**

We don't get cable because [middle child] would be like, glued to it.

Constantly..."BUT THERE'S SOMETHING ELSE ON!" No. So we don't get cable. But, she really likes the books. She's read each one of those books, there's 10 books so far, and she's read each one at least 3 or 4 times. They're on the computer, so she reads them on the computer. Twilight books, she's read them all several times. Vampire Academy...she's really into vampires.

**Like so many other teenage girls right now!**

Exactly, exactly! Yeah...she's into Twilight and [unintelligible]

**Yeah, I've purposely stayed out of all of that [laughs]. Okay, that's all my questions, unless you have anything else to add?**

I don't....I don't think so.



**Interview ID # 05**

**1.) What is your understanding of the mother's message in this poem?**

Um...I guess um basically just in general you know when you have a baby you do you think kinda of like what you did, you think well I played baseball so they're gonna play baseball and they're going to be better than me, stuff like that. And you do, you kind of plan out your kids life before they're even born. And um, yeah, then when you get a diagnosis, it definitely does take you away from most of those dreams that you think...But you have to find, then you...but in my son's...when I first got a diagnosis in some ways, so many things didn't matter anymore. And that's probably a good thing, like the silly little things that people care so much about. It's like... [pause]

**Can you give me an example?**

Like for, just the simple fact that we had bought just a piece of land, that we should have already built on by now. It's just like in a nicer neighborhood and you just think, "Oh we're going to build a nicer house." It might happen, it might not, but it's way off track now. So [laughs] it's just like...lots of money. And it's just like I tell my husband, you know, it doesn't matter. As long as we're with our kids, I really don't care anymore. You kind of lose that...like... [crying]

**You kind of lose that, it changes your priorities.**

Yeah [crying]

**And at the same time, the loss of that is really painful, just like it says in the poem, but at the same time I hear you saying that you change your priorities and you have to readjust.**

Yeah, you completely readjust and you find...it still never changes. It never ever changes your relationship with your child. I don't, I mean, I have a 5 year old; I don't feel any relationship change with my son at all. Everything around you...kinda like the poem, I mean you're not different but everything around you and the language and EVERYTHING changes and your scenery and the opportunities you have. But the relationship that your family builds is still there, it's always the same. It's like I said, it's...in a good way, I'm a really organized kind of up-tight person and even just having 1 child and definitely having a second one it lets you almost kinda let loose the things that don't matter.

**So have you seen a change in yourself?**

Oh gosh yeah. Definitely way more relaxed. You know, I still have a lot of stress, but honestly, most of the stress is money. If I had, like we all say, you read all these famous people doing things and if somebody just gave me a hundred grand and I could just set it up it would be perfect. You know, not just for me, for his program and I didn't have to worry about how to fund it, there would be no difference, I think it would be almost like normal life.

**But the stress of figuring out how to pay for everything is really what puts a lot of strain on you.**

Yeah, and like I said, you know, I don't know. I mean, there's definitely times where...I'm never sad for myself, I get sad for him. I'm never sad for myself though. [crying] Because I mean, our relationship never changes.

**Sad for him in what way?**

Um...I just hope that he doesn't...I don't know yet. He's not old enough yet.

**He's still pretty young.**

And my husband disagrees on this, because he's very happy...he's so happy.

But...kids are cruel.

**They are.**

[crying]

**Or they certainly can be.**

[Laughs—crying]

**Is it okay if we go on to the next question?**

That's okay, don't worry, I'm a sensitive mess anyway. [laughs]

**Don't worry, this can be a really tough conversation to have, and you aren't the first person who has gotten emotional, you definitely aren't. I really appreciate you being willing to meet with me and have this conversation today.**

[laughs]

**2.) In what way does this poem represent your experience?**

Um...again, touching on what I just said. I mean, I'm a labor and delivery nurse, so I know that whole, the preparation. It's sad to think, you know I even think now after my son's diagnosis, I think now because I know the numbers and I know so many moms come in and I deliver so many babies, it's like, one of these babies that I've delivered in the last month...and it's just sad to see, they don't even know it's coming, you know what I mean?

**Right**

It's almost different if you get like...I don't know. And the problem I think with this diagnosis is, is--it's somewhat fixable if you know what I mean, and it's all, I mean, everything is in my hands with him. And like I said, I think the thing with the money; it's frustrating, because if I had so much money I could do so much more. So you don't make the strides that you think your child is going to make then...it's going to be your fault. You know? [crying]

**It sounds like it's incredibly hard never knowing what's going to work, or what's going to be enough—**

Right, it's not like if you have a child that's born with Down syndrome that you can know ahead and prepare, and you can't fix that. But with autism, there's a lot that you can do. I've already seen it. So I think that puts a little more guilt on the parents, especially people who can't afford to do things. Or you know, don't know the services. Or some people when they get diagnosed you just get handed a packet and they don't even explain it. And then it ends up being too late or just...it just always falls back like a guilt trip that you didn't do good enough. With other diagnoses, you can't change them. But I've seen it. I've seen it. I've seen lots of kids change, so you can change it.

**Right, and yet you never know either what that possible end point is**

Yeah!

**So it's almost like you never know what you're working towards. There's so much uncertainty. What do you do or how do you cope with all that pressure on you and that potential guilt trip being there?**

Oh gosh. You know, I'm so busy I never have time to stop and think about it. Like, my husband would give you a completely different interview because he's so much more laid back, he doesn't worry about any of this, but that too is just a woman thing I think. And being a nurse, I mean, it's just a caretaker personality. But I don't know, I'll just say I just can't worry about it. But like, at night or when I get that moment. But pretty much I go from like 8 until 11:00 every night. Which is a good thing to keep yourself busy. So...yeah. I don't know. I don't do anything you know, other than that to help me.

**3.) Okay. In what way does the poem not represent your experience?**

Um...I would say that it does. I would say that it describes it pretty well.

**Okay.**

Yeah, I can't think of anything.

**4.) Okay, that's fine. In your experience parenting your child, who and what has been most helpful?**

Um...parenting them as just a parent?

**However you want to interpret it.**

Well...I don't know, I just don't know.

**In your journey so far parenting [E], who and what has been most helpful?**

My path so far has been...is the day I got his diagnosis, I locked myself in the basement for about a week, online, just to read and research as much as I can because like I said before, I feel that his improvement or whatever you want to say, is in my hands. Nobody else is going to do it but me. And that is one of my biggest fears. I tell my husband all the time, I tease him that he better learn some

of this stuff because if I'm not here...somebody better do it. [laughs]. I threaten him, so...you just need to learn and prepare and find as many network people as you can, because even years later, you can be like really? Wow I didn't even know that, it's amazing what you learn and what you learn from other people that will help sometimes. And when it's your child you want to do everything. And you wish you had that at the very beginning, you know, it would be about a book this big, but...you know...

**Who are some of those other people that you're learning from?**

Um...of course just things that I've read. Physicians. Well, physicians on our side, I should say.

**What do you mean by physicians on our side?**

Um, there's some doctors that don't think they can um, you know, get better, just that it's not going to work. And I have doctors on both sides of that spectrum. And that's fine. But so from the doctors and research and statistics and reading and um...families at Roads, we get together every now and then for our fundraisers and we talk, you know, talk back and forth about well what's this therapy and how does this work. One of the other mothers and I talk about every other day, every day, just about every day life...just about life in general. Um, but that helps. You learn things, you learn what really worked for their child and its possible it might work for yours too or help your child.

**Absolutely. So other parents are helpful. Doctors are helpful when they're on your side.**

Yeah, when they're on your side, when they'll listen to you.

**Sure. In your experience, who and what has been most hurtful?**

Umm... [long pause]. I'm going to cry a lot on this one, you might want to skip it and come back.

**Skip it and come back? Okay, that's fine.**

Yeah.

**5.) Okay, how have others' beliefs about autism impacted your relationship with your child?**

I wouldn't really say much of any.

**Okay. Would you say that other people's perceptions of autism...like you mentioned before that the physicians who aren't on your side believe that children with autism can't improve...would you say that that has had an impact on how you view your son, on the goals you set for him...**

Well...it gets me fired up a little bit. It may not make me change my path. It's my way of being able to come around and say "ha, told you so," kind of thing.

That's happened more than once already, probably twice, with physicians. And it's just nice for them to be able to say "oh wow, what a difference." Kind of like, my in my face moment. [laughs]

**Absolutely!**

Kinda like "what were you saying again? Well look at him now."

**"In your face moment"...I really like that. What would you like other people to know about your relationship with your son?**

I guess that it's like...probably any other child except for, gosh I don't know, because, since the day he was born until today because he was a boy, and we

don't have any boys in my family, and I'm very close with my daughter too, but I think it's just that opposite sex thing. So...I'm so protective of him, like way before...and we just had this special bond. And I've just never been around boys. I would think, for the average 3.5 year old, my son and I are much closer than most parent and child, especially boys, because a lot of boys are really wild and really ornery. And now that my son is hyper, but he's SO sweet and huggy and kissy and just cuddles and is so loving. So...and he's not doing it...he's not going and doing that 3.5 year old just being ornery per se, he'd almost rather be with us, so I think that we're closer than a lot of families I've seen.

**What sort of things does he do that demonstrates that, that lets you know that?**

Oh he, he just always want to be close by, or anytime he gets tired he comes up and he constantly wants attention and wants to play and he's a big kisser he's a kisser and a hugger and um...and he always just kind of checks in with me. Even if he's uncomfortable he always just kind of checks in with me like "oh, I'm cool, I can do this." So um...yeah, and he actually listens really well, so if he does get, when he does do something wrong and I tell him you know, "that was wrong," he says "I's sowwwwy" and it's so cute and he'll come over and give me a hug like he's just a tender hearted little man.

**6.) That's what it sounds like. Thank you. Is there anything that people have said about you and your child that you never want to hear again?**

Umm...no...not about me I wouldn't say. No.

**About your family, or about autism in general even?**



Well, I think that there are some people that don't, and I don't tell them, and some even family, I don't tell them...I don't tell them a lot of what I'm doing because they think I'm wasting my time. I don't even go there with some family members. And then other family members will come and say "wow" I mean, "you guys are doing a really great job with whatever you're doing" um but then there's other family members that are pretty close family members and I just don't even discuss it because they think I'm thinking too high, that my goals are too high

**That [E] won't be able to achieve those things**

Yeah, and they're constantly like, "well you're going to be doing this for blah blah blah," so I just don't even talk about it. I don't want to talk about it. I don't talk about it a lot. I mean, every now and again. I just don't talk about it a lot. Occasionally

**You mean with extended family or in**

Yeah, well, I talk about it with my mother-in-law. But that's about it. Extended family, we don't talk about it. I mean, he's not doing any outlandish behaviors where maybe the other kids are questioning. Then I can see us having to talk about it a lot then. But truly a lot of people just think he's speech delayed.

Because he does talk. And when we have birthday parties, he's right in there with all the other kids; you can't pick him out, other than his speech delay. So, but, I can see where it would get...but not in my situation, or not a lot.

**Right. So you're saying family members you don't talk to a lot in regards to his diagnosis...is there anyone who is a safe person to talk to?**

Well...my good friends, I do.

**Are these parents with children with special needs?**

No. Nope, I have probably about 3 friends, but 1 best friend I talk to all the time. She's a social worker though so she's nice to talk to. And actually, I guess her brother, he's like 30 now, but he does have, I don't know...whatever the correct term is, he's mentally retarded or whatever. But she's just one of my best friends from childhood. But a lot of my friends, again, I don't discuss it. If they had a question of course I would answer it, but like I said, he fits in there and I don't think I need to bring it up every time I'm around people because that would give them a purpose to sit there and stare at him and there's people that I don't know, they just think he's speech delayed, like extended friends and stuff. Just really my close knit family knows and I talk to them about it. [E] lot of my acquaintances they don't know. And like I said, he can fit in, he's just more hyper, but he's really social. And then again, I don't want people to say he can't do this, because that's what makes me mad. Or that they think he has a label, because you know when somebody has a label they're going to stare and observe them and try to figure it out. Yeah. Nobody's ever asked me about it.

**Okay, thank you. Is it okay if we go back to the question before, or would you like to skip it, because that's okay, too.**

Sure, we've reached the end? I can't remember how it was worded, but something about something that made me the most mad?

**Mmm hmm. Who and what has been most hurtful?**

Um...I think maybe his first developmental pediatrician, his first observation paper she wrote on him, some of the terms that she used fired me up pretty good. Um...basically calling him completely unintelligible and um...just some other terms basically saying what his potential was, and of course what to do and stuff, but just words, such as constantly words like unintelligible stuff like that. It was a different story a year later. But that was kind of my first moment of “huh...how’d you like that?”

**Your first “in your face moment?”**

Yeah! “What did you say about unintelligible?” The second time we came in...he was diagnosed at 2 years 3 months, and we went back when he was 2 years and 10 months, and...he knew his alphabet.

**Wow...wow!**

Yeah! I was like...”what did you say about him being, like...” it was basically the summary of it was that this child is completely unintelligible and has no clue what’s going on around him. Um...you know, with other stuff. I guess it was very unfair and biased. We were in a room this size with three doctors. I’m like, he’s 2!

**That’s definitely overwhelming for anyone.**

Yeah, he doesn’t want to talk to you number one, he’s overwhelmed, and number two, he’s already a little behind, so, that was part of the...while reading over her report. I can remember crying. [crying]

**Well sure, of course**

But then we went back the next year and they were so much nicer.

**I'm impressed that you even went back the next year!**

Yeah, well, I know, but there's only one developmental pediatrician in town.

So...

**I see, well that certainly limits you then, because it sounds like that's someone you feel like you need.**

Right.

**It sounds like you have had a lot of people from the very beginning saying that the goals that you have for him, and what you see him as being able to do, they don't see him as being able to do.**

Definitely, yeah.

**What keeps you able to keep setting that bar higher?**

Um...I guess just him. You know, it's almost like my child instinct. Like when a parent tells you you can't do something you're like "okay," and though it might not be the way you're supposed to do it or the length of time that you're supposed to do it. But you're going to find a way how to sneak your way around it. It's pretty much, you don't ever give up on your kids, you're never going to give up on them. [crying]. It's that unconditional love and like I said, I do for him what I hope someone would do for me if I were in that situation. Because he's not unintelligible, he's VERY smart, he is really smart. [crying]

**You know, that's a theme I hear from a lot of parents is "I wish people knew how smart my kid really is."**

Yeah!

**That's something I've heard from a lot of parents, and that's something that always amazes me with these kids as well.**

Yeah, you know they might do it differently, or sometimes you're listening to them and they do a little quirky thing in the middle. Well other people focus more on that than on getting back to what that child is really saying. Like my daughter who's 5, she knew her ABCs by the time she was 3, I guess, and I literally could sit down with him and he just...I'm like...wow...he knew that before my daughter! I mean, she was 4 by the time that she could write and recognize...and he just picks things up and recognizes and knows things, I mean, most 2.5 year olds don't know their ABCs.

**Right!**

[Laugh]. You know, his numbers, he counted to 20 by that time of the second appointment, too. It's like wow. But yeah, a lot of people still see...but there may be other things. But that's the thing I want to give him, I want to give him a voice because the more he talks, the more he can express and that's how people recognize...in general the population sees, well if he can't talk in a normal sentence, there's something wrong with him. But...but he talks. He can say his ABCs. He does talk now, more. But if you don't hear it then it's not happening almost.

**Right, and people have a hard time looking, like you said, beyond those other things. I liked the way you said they might do something quirky in the middle and that distracts people from what they're saying.**

They can't look outside the box.

**Right, exactly, it's hard for a lot of people, and even medical professionals, they have a hard time seeing outside of that and seeing what it is the parent is really able to see. So then it comes back to the parent saying "well he can do this and it's really awesome!"**

The doctors on your side...on the autism side...or on the parent's side, I should say, they will actually get down and play and have them do things. Whereas with the developmental and with my regular pediatrician they want to talk to him and have him give them all the answers, and if he can't do that then well, he can't do it. Whereas the other doctors will demonstrate, or say let's do this, or they just know how to go about it. It's not just black and white. Which, it's just it's different people. Because in general most people, they can just click right in and get it.

**So they're able to go in and find different ways of getting the response they want, they're able to think outside the box. Because a lot of times these kids respond differently and show you they know things in other ways.**

Yeah, like you might have to ask the question a little bit differently because they don't know what one particular word means, so they just completely ignore it. So you're like "hey you!" and then you just have to ask it another way and they get it and they respond and you're like "oh, okay, I'll remember that I have to ask it this way."

**Right, exactly. Okay, my last question is just is there anything else I should have asked, or anything else you want to tell me about your child or your relationship with him?**

Um...I don't think so. I think we hit all the emotions. [laughs]

**Okay, well thank you very much!**

**Interview ID # 06**

**1.) What is your understanding of the mother's message in this poem?**

I think she's just saying that it's not what she expected, and it's different, but it's okay. And what she said at the end, like you said, that it's not so terrible, it's not so bad, you just have to adapt your life around it and adjust and it becomes second nature, it's what you're used to.

**2.) Absolutely, thank you. In what way does the poem represent your experience?**

Well, I think [pause] I think that the poem seems like it's from birth, and most autistic kids aren't diagnosed till later. But, um, so I think, you do think everything's okay, and then it's not. And not that everything isn't okay, it just isn't what you expected.

**3.) Right, that's a good point. In what way does the poem not represent your experience?**

Maybe just like I said, that it's not right away, because you think things are good. It's not that they're not good...

**Right, like you said, things aren't what you expected...it's not until later that you find out you're in Holland rather than in Italy.**

[laughs] Right.

**4.) In your experience being a parent of a child with autism, who and what has been most helpful?**



I think we had an interview at the [unintelligible] school and that was not helpful, and then we had an interview with [mother of child with autism] at Roads...do you know [mother]?

**Yep**

Yeah, she's great, she was so helpful, I mean when you go to the doctor you get like this book of stuff and it's so overwhelming and she like, you know, basically told me, went through all the stuff and told me "this is all the stuff you need to get done first." The scholarship, you know, and so she was a big help. And also, Clark County was a big help, he was signed up for "Help Me Grow" and up until he was 3, we had a really good person that helped us like with food allergies and giving me the information that I needed, and helping me know that I could take advantage of the preschool program through the school. So, um, but yes, [mother] helped me by really laying out "this is what you need to focus on first" and that was really helpful.

**It sounds like what you found helpful was having people able to help you access resources and find your way in the beginning.**

Yes and family too. Family has been pretty supportive, so that helps.

**In what way have they been supportive?**

Um...[crying]

**It's okay.**

Sometimes my parents take [F] and that's good, because it's good for him to have the one on one. But then sometimes they take both, and that's hard because they're 20 months apart. But actually, they just went through [unintelligible]

therapy, and he's doing really great, he's been going to church and we were gone for a couple days and they took them to a parade, and he sat there and my dad told him to go get candy and he went and got candy and sat back down. But like last summer he was a big runner, and this summer he's doing much better. My other son is going through the terrible twos right now, so actually [F] is usually a lot easier than he is. But, I have a sister-in-law who tries to research stuff and find stuff and help and really, the family tries to get down on his level and talk to him because that's really his major thing, his major thing is his speech delay. I think that THAT'S what's frustrating for him. That's mainly what it is, because we understand him most of the time, but when we don't, you know, it's frustrating.

**For both of you, I'm sure.**

Yeah. So I think that answers your question.

**Yes, thank you. In your experience who and what has been most hurtful?**

I don't think...well, I think maybe when there's been times when I went out in public and like there might have been times where I you know, opened up a bag of chips or he opened up a bag of chips so I could keep shopping and the lady at the counter just rolled her eyes at me because I had opened up the bag of chips, but I didn't want him to have a fit, so sometimes I open up things in the store and I pay for it, so I'm like what's the big deal, but she just looked at me like "I can't believe you're doing that." And then I've had a couple people give looks because when [F] gets frustrated, he'll hit and I've had a couple look at me like "oh you're just going to let him hit you like that?" And he's doing it out of frustration, and sometimes I do put him in timeout or spank him, but if I do that every time, you

know, it's like you have to tell him "no, don't hit" but people don't understand that. And people just think, you know, you're letting him hit you, and I'm like you don't understand so I think that it's other people...I don't know.

**It sounds like other people's judgment, and the fact that they judge without knowing...**

Yeah, and it's not their fault, you know, they don't know. And I mean, some of my friends, they don't know, they don't really know a lot about it, but they're good with him, so they can't really discuss it... And some people especially in the beginning didn't want to ask a lot of questions, because in the beginning I didn't really want to talk about it.

**Sure.**

But a lot of people...I think people are always afraid to ask.

**Has that changed for you? The not wanting to talk about it**

Yes, actually. I think I still worry about you know, we have a while till kindergarten, but I still worry about him being labeled. It's not, I don't know I always look at things more positively than I probably should. The thing that makes him PDD is his speech and his communication, and if his speech gets better and his communication, well his communication has already improved through ABA, but those two things, I mean, if he starts to talk, what if he's doing really well by kindergarten? I just don't want him to be labeled and not just being labeled but not need services he would have originally needed and so I think that's something I still struggle with. So I don't mind people knowing so much, but I think that's why I didn't want people to know, because I was a teacher. I

know how they don't mean to that, but once you're labeled, you're labeled and there's nothing wrong with being labeled autistic, but there's so many kids that are kind of losing that diagnosis that I at least want to wait until kindergarten to see how he's doing. And then, you know, if we need to go on with it then then I'm fine with that. But so many people that I talk to, you just hear stories about how when kids turn 4 they really start talking, and 4 just seems like such a pivotal time, so, you know, I'm just really optimistic and waiting for that.

**Sure, absolutely. Would you say that reactions and interactions with medical professionals have been helpful or hurtful, or maybe both?**

Um...I don't know. I think his developmental doctor, she has an autistic son, and I think the only thing that's frustrating with that is that she doesn't think shots...she thinks shots are good, and I don't agree with that. And it's frustrating because she has a son and she thinks there's absolutely no link between vaccines and kids, so, and we're in a study right now in Columbus, it's a genetic study, and I think it's genetic and it's caused by shots and environment triggers and some kids can't handle it and some kids can. But, I stopped giving him shots, and [younger son] won't get them until he's older and his body is able to better handle them. I'm frustrated with the pediatricians who, I mean, everybody who makes you think that it's okay for you to give your child, your newborn, a shot in the hospital and weeks later get more and more and more, that's too many things in their system at such a young age, whether they're autistic or not. I get frustrated with that, because when you're pregnant with your first child and you don't know any better, you think "oh, it's okay, everybody else is doing it, that's what the

doctors say, they're saying it's okay." And then I get frustrated with the doctors the pediatricians who think that the rise in autism has nothing to do with the amount of shots they get. And you trust these doctors to help you and it's really frustrating. That's the hard part with some parents I think because they're, you know, some people hear that you're not vaccinating and they're like "what!!!" and I'm like, well, you're not infected by a child. And my pediatrician isn't crazy about it, but he understands, he understands that I don't want my children to get shots, but he doesn't like it. And when [F] was, before, at 18 months, I told my doctor he was talking—[F] walked at 10 months, he started talking at about a year, he would say "thank you" you know, two words, he was coming right along, and I said I think he has a hearing problem, he's ignoring people, and I just got "he's fine, he's fine." And I came back and was like "he's not fine! I want a hearing test" and he said "oh well you know best." I was like "well, last time you told me...you know" So I was frustrated with that, and then you get frustrated because you have to wait 3 months for a hearing test, and you know, wait 3 more months to get him in once he qualified for speech, so it's a total of like 6 months. We did tubes, because we thought tubes were the problem, and the tubes probably did help him, but after the tubes, that delayed things, because after the tubes we're like "well, he's still not talking." So there's a bunch of stuff that seems to get in your way where I think a lot more people need to be more proactive and be more aware.

**Right, sure, especially because of the importance of early intervention and**

Yeah, cause all that stuff just slows you down and I've talked at the hospital and they're great, we get speech thereapy and we're starting OT there, but you know, its ridiculous that it takes that long to get in.

**Right, I'm sure waiting lists and everything are long, too. It all just seems to add up, like you said.**

Right

**5.) How have others' beliefs about autism impacted your relationship with your child?**

What do you mean?

**Um...how have others' ideas about autism, what autism is, what they think kids with autism look like, maybe even your own ideas about autism before you really knew about it, has it affected the way you thought about [F], or...**

Not really because I think that...well I mean at first yeah, my husband and I were like, well, you know, is he going to be able to go to college, because that's one thing that you want to see, but then you realize every child's different, but then you have early intervention and you don't really know how things can affect your son and I think that I'm always looking for new stuff, listening and talking to other parents to try to see what's the latest new thing you can do to try to help.

Um, but, I think that the thing about autism is that children do look typical looking, and you just don't know because one child can talk and one child can't.

So you don't know where you're going to be with it. You know?

**And then I remember you talking before too about how situations like the one at the grocery store come up, and he looks typical, so people are going to assume it's a parenting issue or...**

Right, you know, there was a stage where he was hitting me in the face and I was putting him in time out quite a bit but he's gotten better. I try not to treat him differently, but in a way you do and you can't help it.

**Right, and sometimes you might have to.**

Right, but um you know so far I don't think my younger son...well...he's got the type of personality that if he needs more attention, he lets you know. [laughs]

But for kids its just what they're used to. And I think that could be, and it's hard to tell where he's going to be in the next couple years, but I have the feeling he's going to be more severe, which is going to be harder. Um, so. I think that will affect him [younger son] more if he is going to be more severe, which is kind of...well right now it's just the way his brother is...

**6.) Right. What would you like other people to know about your relationship with your child?**

I don't know, I guess just that he is so loving. I always wonder if he didn't have it if he would be as loving as he is. I mean, I think he would, but I don't know if that's a characteristic that he has that would...but he's very loving. I think that, my husband and I, and his little brother, I think we have a good relationship with him. He's very happy. I don't know, I enjoy being with him. I guess that some parents, well, every parent needs a break, but I guess that I just want to do as much with him as I can and not push him off on somebody else or send him off

somewhere. I mean, I'll send him to camps and stuff, but, I think there are a lot of parents that take their kids to gymnastics with us or whatever and there will be like an aide or someone out with them, and I'm out there with my child. And I know it's exhausting for the parent and that's like their break or whatever, but I want to be out there with my child. And like I said, maybe it's just harder on them than it is on me, I don't know. But that's one thing is that we're close and I want to keep it that way. I think it's important that we have another child, and I think it's good that they're close because I think that relationship with [F] is really helpful. And [younger son] talks really well for his age and I think that's good, I think that helps [F]. And we want to have another one, we're going to have another one. And I go back and forth wondering, well, is that going to take away from [F]? But I think you know, it will be good, I think it helps. I think it's good for him to have siblings and a big family.

**You said before how loving [F] is, how does he demonstrate that or how do you know that?**

Sometimes he'll come up and give us a pinch on the cheeks, just really gently pinch. And he'll come up and just want me to hold him, or he'll come up and just lay on the couch with us. So I mean, a lot of times I'll do it, but sometimes he'll initiate it, which is good. Now he doesn't initiate it with his brother as much, but I think that will come with more time. So you know, I'll tell him to give his brother a kiss or a hug or sometimes they'll be rolling around on the couch and we've been trying to get him to kind of practice with his brother, so we'll tell him



to put his arm around him, you know. But I think it'll come. But I think he initiates it with us just as much as we do with him.

**7.) Great. What have people said about you and your child that you never want to hear again?**

I don't think I...I do know that when we weren't telling people right away, I know people, friends were concerned that we weren't meeting our child's needs. And I know it was because they were concerned that they noticed his speech delay, so they were concerned that we weren't meeting the needs of our child, but I'm like "you have NO idea." I mean it's like, our child's in speech therapy, we're waiting for OT, we're doing ABA, it's like you have NO clue. We went to a neurologist just to see what they could do, and we're going to try to go to a gastrologist, and we're taking him to a sensory [unintelligible] therapy in Lebanon. We are going to a chiropractor in Finley, I mean, you have NO clue and that's part of the, and I wish they would have told me, but just...don't judge me. If I don't want to tell people right now, I don't want to tell people and I'm sorry that you're our friends, but that's none of your business. And I understand that they're trying to say you need help and they...I guess not telling them is my fault, but the bottom line is that they don't know what we're doing. And a lot of people, I mean a lot of people don't ask, so they don't understand, so they don't know, they're afraid to ask. If they would ask...

**It sounds like the silence around the issue can be a problem**

Yeah, and I know my brother-in-law, my husband's twin, he has a hard time. [F] will be clincing to me and he will take him and try to play with him in another

room, and I try to make him understand that it's okay if he's clinging to me, and you know it's okay if he's sitting on my lap, I don't mind. But he will try to play with him or take him away from me, and I have had to tell my husband to go in the other room and get [F] from his brother, and I told my sister in law that either he needs to try to understand how to deal with [F] in that it's going to be a little bit different, but I think he needs to try to have a better relationship, and I said you know it's great that you want to play with him and stuff but you can't just grab him when he's not doing anything wrong and take him in the other room because he doesn't understand. [F] will be screaming, and he's scared, because he doesn't understand you know? He didn't want to go in the other room. I talked to my sister-in-law about it, so she could talk to him, because I was like he's [unintelligible], and she said "well he doesn't spend enough time with [F] to know," and I was like well, I think it's...I think he's trying to figure it out a little bit better. I think that's the hard part for people is that I do treat him like a typical child, but he's not, and you have to do things differently. And like I said, I don't put him in time out every time he hits me because he's frustrated because he can't talk. So I think people just don't understand.

**8.) Absolutely. My last question is just is there anything else I should have asked you about your relationship with [F]?**

Well, sometimes when we talk about having another child people are like "really? Are you sure you should be thinking about having another child? You know, you already have a son..." And I'm like, you know, by the time we get around to having another child, [F] will be almost in kindergarten, and it's like...it's not

your decision. I've been torn because [younger son] will sometimes just want his attention so badly and he doesn't understand, so he'll just be like "[F], [F], [F], [F], [F]" you know, I think that if he had someone...he needs somebody to connect with in a different way. And him and [F] will eventually be able to connect that way...but I also worry that if we have a third, that the younger 2 will go off and leave [F] by himself. So we're going to have to teach them not to do that, and that's what I do with cousins, I have to remind them that even though [F]'s quiet and off to himself, that they don't leave him out. So I've been torn, but people are saying...I'm trying to raise my child in an environment that is social because I think that will be best for him, and that's MY decision. So, and I've waited because [F] and [younger son] are 20 months apart, and [F] has needed more time, but he'll be older. But yeah, I think that's hard.

Hmm...anything else? I guess just that I worry that if he didn't have PDD that his personality would be different, and I love his personality, he's caring, he's got a loving personality. And I just worry that he would be different, so I can't wish for that.

**Sure, it sounds like it's who he is and that's part of your family.**

Right, and I wouldn't want to change that. I guess the other thing is the financial burden. You know, it's hard. We were going through the bills last night and we have like so many different Children's [hospital] bills. And we had them all laid out and were trying to figure out how much we still owe and what we've paid and what we still owe, and we've changed insurances, so it's so hard to tell what's the old insurance and what's the new one and what they stopped covering...so I've

got all these bills that I need to sit down and, I mean, you can't...you've got to pay these off a little bit at a time, because you've got the other bills, we've got the DAN doctor over here and...you just need to find a balance. And we're one of those people that's always going to owe because you've got to find a balance and you can't pay it all.

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