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Lived experience: Diverse perspectives on raising a child with autism

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Lived Experience: Diverse Perspectives on Raising a Child with Autism

by

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A dissertation submitted in partial fulfillment
Of the requirements for the degree of
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ABSTRACT

This qualitative study examines the lived experience of culturally diverse caregivers to children with ASD. The study is situated within the theoretical framework of the life-course theory. Specifically, the impact of the transition of diagnosis on the trajectory of the primary caregiver's life-course is explored. Further, coping mechanisms, caregiver burden/satisfaction, diagnosis, and other components which contribute to the larger construct of lived experience are discussed. Participant stories were obtained through the use of interactive interviewing techniques and transcripts were transformed into a cohesive narrative designed to evoke emotion within the reader while preserving the authenticity of the data. Further, the study contributes to a disability-related discourse which challenges the current deficit model and gives a voice to individuals who may have previously been marginalized based on their cultural and disability-related characterizations.

Chapter One

Introduction

Statement of the Problem

In recent years, the prevalence of individuals who have been identified as having Autism Spectrum Disorders (ASD) has increased dramatically. Specifically, between 1997 and 2006, the number of 6 to 21-year-old children classified as having an ASD in public special education programs increased by 528%, from 42,517 to 224,594 (U.S. Department of Education, 2002). Further, the disorder is four times more prevalent in boys than in girls (Autism Society of America, 2008). The prevalence rate of ASD increases at an annual rate of 10%-17% while the annual cost to support the disability is an estimated \$90 billion (Jarbrink & Knapp, 2001). Because of this marked increase in identification, there is a need to promote awareness about the disorder and its implications, as well as investigate the impact of our educational policies on children and families with autism.

One challenging issue faced by school systems today is teacher knowledge. Research indicates that there are many strategies that are considered evidenced based practices. For instance, a large amount of research on ASD focuses on the effectiveness of positive behavior support (Becker-Cottrill, McFarland & Anderson, 2003; Carr et al., 1999; Carr et al., 2002; Cole & Levinson, 2002; Fox, Dunlap, & Cushing, 2002; Lucyshyn et al., 2007; Odom et al., 2003; Turnbull et al., 2002; Wehmeyer, Baker,

Blumberg & Harrison, 2004; Valdivia, 2007) and other evidence based practices such as social stories (Adams, Gouvousis, VanLue, & Waldron, 2004; Barry & Burlew, 2004; Crozier & Tincani, 2007; Gray, 1998; Ivey, Heflin & Alberto, 2004; Kuoch & Mirenda, 2004; Rust & Smith, 2006; Sansosti, Powell-Smith, & Kincaid 2004; Scattone, Tingstrom & Wilczynski, 2006; Smith, 2001) and augmentative and alternative communication (Bondy & Frost, 2002; Bondy & Frost, 2001; Bryan & Gast, 2000; Charlop-Christy, Carpenter, Le, LeBlanc, & Kellet, 2002; Ganz & Simpson, 2004; Hodgdon, 2001; Kravitz, Kamps, Kemmerer & Potucek, 2002; Son, Sigafos, O'Reilly, Lancioni, 2006; Tincani, 2004). Unfortunately, many individuals, including service providers and other professionals in the field, are unaware how to effectively work with individuals with autism and their families (Autism Society of America, 2008) in a manner that empowers, respects, and acknowledges their lived experience (Knox, 2000). This lack of knowledge in evidence based practices on the part of professionals and service providers impacts the family's ability to be actively involved in a collaborative educational process.

While there is evidence documenting the importance of the family component in intervention design (Baird et al., 2000; Beatson & Prelock, 2002; Prelock, Beatson, Bitner, Broder & Ducker, 2003; Wall, 2004; Wolery & Garfinkle, 2002), there is minimal research pertaining to the lived experiences of and the coping mechanisms employed by primary caregivers (Glidden, Billings & Jobe, 2006) of children with ASD . Additionally, culturally diverse families (Harry, 2002) of children with autism (Zhang & Bennett, 2003) have also been under researched. Specifically, the intersection of race, family coping mechanisms, and autism has been overlooked (Dyches, Wilder, Sudweeks,

Obiakor, Algozzine, 2004); as autism is evident across racial and ethnic groups, and its prevalence rate continues to increase (United States Department of Education, 2002), it is critical that future research examine the intersection of these constructs.

The lack of research on coping mechanisms and lived experiences of primary caregivers to individuals with ASD is problematic as it has the potential to provide professionals with the information they need to improve service accessibility for individuals with ASD and their families. The family story has the power to provide first-hand accounts of what it is like to raise a child with ASD, along with the perceived needs of the primary caregiver(s). However, existing family-related literature on ASD is primarily comprised of memoirs written by parents of individuals with ASD (Fleischman, 2004; Green, 2003; Rubin, 2007). In addition to the memoirs of parents with children with ASD, quantitative, mixed-method, and qualitative studies exist that examine and document caregiver burden, satisfaction, coping mechanisms, and well-being of caregivers of children with disabilities, but not ASD specifically. (Banks, 2003; Glidden et al., 2006; Green, 2007; Green, 2003; Leiter, Krauss, Anderson & Wells, 2004; Pruchno, Patrick & Burant, 1997).

There is a need for research to examine the coping strategies, well-being, and caregiver satisfaction/burden experienced by caregivers to individuals with ASD. This differentiation is needed due to the relatively emergent nature of and the uncertainties associated with ASD. How do caregivers cope with this uncertainty? How does the unknown impact the life course of the primary caregiver? Transitions, associated with the life course perspective, are life-changing events that may have an impact on social status, identity, and role involvement (Elder, 1985). The diagnosis of a child with ASD would

serve as a transition for the family of the child, specifically to the life course of the primary caregiver(s). The concept of transitions can be situated in a stress and coping perspective to allow for an examination of the intersection of the timing of the diagnosis, the social context in which the diagnosis occurred, and the challenges associated with the potential stressor, namely the diagnosis (Seltzer, Greenberg, Floyd, Pettee & Hong, 2001).

Knox (2000) suggests that professionals in the field begin to examine the family system through the use of an interpretive approach which views families as experts of their own lived experiences. While the aforementioned concepts of coping styles, caregiver burden/satisfaction, and well-being are significant pieces of the larger concept of lived experience, they are not exhaustive. The current study is grounded in this literature because these components serve as a foundational construct on which to build the larger story of lived experience. Research addressing the coping mechanisms of caregivers to individuals with disabilities illustrates that these mechanisms tend to differ across cultures, and that African-American caregivers typically report higher levels of caregiver satisfaction and lower levels of caregiver burden than their White counterparts (Pruchno, et al., 1997). Further, conceptions of disability tend to differ among cultures (Harry, 2002; Rogers-Adkinson, Ochoa, Delgado, 2003), thus warranting an examination of the intersection of culture and lived experience within the context of this study. However, the goal of the study is not to explore the cultural differences among the families, but to explore the impact of the *diagnosis* transition on primary caregivers of children with autism from diverse backgrounds.

Much of what we know about autism involves history, diagnosis, prevalence, and intervention. Little is known about the impact of the *diagnosis* transition on the life course of the primary caregiver(s). This qualitative study examined the lived experience of diverse primary caregivers of three children diagnosed with ASD through the use of interactive interviewing techniques, thus allowing for serendipitous findings. This has implications for professionals in the field, in that, the larger concept of lived experience will be explored at a depth that may be difficult to attain through traditional quantitative methods (Corbin & Strauss, 1998). Further, the study contributes to a disability-related discourse which challenges the current deficit model and gives a voice to individuals who *may have* previously been marginalized based on their cultural and disability-related characterizations. My professional experience and educational knowledge helped to guide and inform my interpretations rather than serve as a vehicle for me to pass judgment.

Research Questions

This study examined the lived experience of primary caregivers who have raised a child with autism. Primary caregivers of African-American, Hispanic, and Caucasian descent were interviewed in order to obtain three separate accounts, from diverse perspectives, of raising a child with autism. Data was collected through the use of interactive (Ellis, 2004) and responsive (Rubin & Rubin, 2005) interviewing techniques. Additionally, the researcher maintained field notes in order to document environmental, emotional, and personal factors pertinent to the study. The intersection of culture, disability, and lived experience had implications for the goals of this study and contributed to the overall development of the narrative.

What are the lived experiences of diverse families in raising a child with autism?

This is a broad question which is explored the following:

- a. impact of the diagnosis (transition) on the life course of the primary caregiver(s)
- b. coping mechanisms
- c. caregiver burden/satisfaction
- d. well-being
- e. family culture
- f. community experience/participation
- g. service availability/accessibility

Because the methodology used in this study values an authentic account of lived experience, the interview was not limited to the above categories. Rather, the interview protocol was dynamic in nature and continued to emerge and change throughout the course of the study. The meanings of the participant stories were interpreted within the context of the interview, thus making it difficult to specify explicit research strategies prior to the outset of data collection (Patton, 1990).

Qualitative Inquiry

Interactive interviewing is a process which requires the researcher to engage in a collaborative experience with the participant as well as a critical examination and reflection of the self (Ellis, 2004). Further, interactive interviewing emphasizes not only the participant story, but the story of the interaction between researcher and participant. This interaction, in which both parties share their own stories and experiences, is the focus of interactive interviewing. Subsequently, the researcher is not limited to a

predetermined list of questions. Rather, the interview is semi-structured and allows the researcher to probe using open-ended questions in order to achieve a greater depth of understanding of the lived experience. Due to the dynamic nature of this interviewing technique, the interviews reflect participant individuality and do not necessarily address identical topics.

The focus of responsive interviewing (Rubin & Rubin, 2005) is on the depth of understanding attained from the interview experience rather than the breadth of information gathered. Further, this method acknowledges that the experiences, personalities, and feelings of the interviewer and interviewee interact and influence each other. Thus, the researcher must exhibit self-awareness through the examination of any biases or expectations that may exert an unintended influence on the participant. Personal involvement and self-reflection are encouraged as these practices facilitate empathy and improve the overall quality of the interview (Rubin & Rubin). To this end, the personal journey of the researcher is intertwined within the family stories through the use of problematics and metanarrative reflections in order to illustrate the interpretive process of the researcher (Peshkin, 2000).

The family stories are based on the lived experiences of the primary caregiver(s) of the child with autism. The researcher did not seek out the stories of siblings, extended family, or the individual with autism.

While traditional quantitative researchers may perceive the inability to generalize this study to a larger population as a limitation, qualitative research defines generalizability in different terms.

In the context of qualitative inquiry, Ellis (2004) views generalizability as the way in which the story speaks to the reader, while Lincoln and Guba (1985) utilize the term transferability as a means of referring to the way in which the reader applies the findings of the study to new situations; “retrospective generalization” (Eisner, 1991, p. 205) refers to how we continuously modify the way in which we view our past and future experiences based on our interaction with the research findings. Further, Harry (2002) warns against assuming that recipients of special education services are representative of their cultural group and that findings are not necessarily accurate reflections of the larger culture. The goal of this study was not to generalize to the larger cultural group, but rather to gain a deeper understanding of the role disability and culture play in the construction of lived experience for three particular families.

Researcher Identity

In all research the identities of the researcher impact the interpretation of the data (Peshkin, 1988). Researcher qualities have the potential to “filter, skew, shape, block, transform, construe, and misconstrue what transpires from the outset of a research project to its culmination in a written statement” (Peshkin, p. 17). When researchers are aware of these qualities, they are able to disclose this information to the reader along with the potential effect of these qualities on the final product. Harry (1996) posits the notion of “researcher personas” (p. 296) and how these personas guide the way in which she identifies with the families she studies; her *insider* status. This *insider* status, in turn, influences the decisions she makes as a researcher. Thus, it was important for me to identify my own researcher personas and how these personas had the potential to impact the decisions I make as a researcher.

I have both taught individuals with ASD and have a close relationship with a family member diagnosed on the spectrum. Although I have not had the experience of raising a child with ASD, I believe that my previous interactions with families of children with ASD provides a common association between myself and the families I am researching, thus allowing me to view the families as “these” families rather than “those” families (Harry, 1996). These personas had an influence on my interpretations, participant responses, and the nature of the researcher-participant relationship. However, disclosing my multiple researcher identities served as a mechanism for providing as honest a portrayal of the families as possible. Further, I shared and negotiated my interpretations with the research participants, through the use of member checks, in order to ensure that they did not feel as though they were being misrepresented. This triangulation of the data served as a method to enhance the truth value, typically known as internal validity in traditional quantitative research, of the study (Lincoln & Guba, 1985).

The following chapter will provide a review of the literature addressing autism, life course theory, stress and coping in family and disability related discourse, and qualitative research methods utilized over the course of the study.

Chapter Two

Review of Literature

The purpose of this study was to examine the lived experiences of diverse families in raising a child with autism. A brief history and overview of ASD is presented in order to provide a foundational knowledge of the disorder. Narrative inquiry and family perspectives of disability are discussed to illustrate the importance of the family story and its implications for professionals in the field. Further, coping and stress literature pertaining to caregivers of individuals with ASD, along with an explanation of the life course theory are examined to illustrate the need for researching lived experience through a life course perspective. The literature pertinent to this study was reviewed and will first focus on an overview of autism, including prevalence, definition, characteristics, etiology, diagnosis, and treatment. Family issues will also be explored with an examination of coping, stress, well-being, and the use of narrative. A discussion of the life-course theory will conclude the review of literature.

Autism Literature

Prevalence and history. Autism is a neurobiological condition that is typically diagnosed prior to the age of three. In recent years, the number of individuals who have been classified as having autism spectrum disorders (ASD) has increased dramatically. Prevalence rates indicate that 1 in every 150 8-year-old children is diagnosed somewhere on the spectrum. (Center for Disease Control, 2007). Because of this marked increase in

classification, which could be due to changes in identification procedures, the need to promote awareness about the disorder and its implications is recommended (Center for Disease Control, 2007).

The words "autistic" and "autism" are developed from the Greek word "autos" meaning "self." Leo Kanner used the term "autistic" in 1943 to describe 11 children "as having marked differences in their ability to socialize with others and extreme rigidity in their behaviors" (Heflin & Alaimo, 2007, p.49). Kanner described specific characteristics demonstrated by children classified as having "classic Kanner syndrome" (Scheuermann & Webber, 2002). These characteristics included: communication deficits, presence of echolalia, distress in unfamiliar situations, lack of engagement in imaginative play, and the presence of repetitive behaviors (Wall, 2004). Additionally, in 1944, Hans Asperger, of Vienna, Austria, published a seminal paper describing a similar disorder, which became known as Asperger's syndrome. Kanner's (1943) and Asperger's (1944) work were the "first theoretical attempts to explain these complex disorders" (National Alliance for Autism Research, 2005).

Definition and characteristics. There are various definitions of autism which have been presented throughout the years. However, according to Wall (2004), all definitions address the impairments present in social interaction, communication, and imagination skills. These impairments are often coupled with the presence of repetitive behaviors. The DSM-IV (2000) defines autism as a biological/neurological condition that is usually diagnosed before three years of age. Three distinct criteria, which are often referred to as the triad of impairments, are used to diagnose autism. These criteria include: "1) qualitative impairment in social interaction, 2) qualitative impairments in

communication, 3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities” (DSM-IV, 2000, p. 299.00).

Autism is a spectrum disorder, meaning that children diagnosed with autism display a wide range of ability levels. Autism Spectrum Disorder (ASD) refers to the “broad range of subtypes and levels of severity that fall on the spectrum of autism and pervasive developmental disorders” (Simpson et al., 2005, p.1). The primary subgroups on the spectrum include Autistic Disorder, Asperger Syndrome, Rett syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder. While these subtypes have different diagnostic criteria, the triad of impairments is evident on all areas of the spectrum.

Watson, Baranek, & DiLavore (2003) discussed the findings on affective development, sensory processing and attention, praxis and imitation, communication, play, motor features, and stereotyped behaviors in individuals with autism. Their synthesis of research on affective development acknowledged limited facial expressions as a possible symptom of ASD. In the area of sensory processing and attention, symptoms such as hypersensitivity to light and sound, aversion of certain food textures and social touch, and over-focused attention were also reported in individuals with autism. Deficits in comprehension, communicative means (eye contact), communicative intent (pointing), play, and motor development were also noted. However, deficits in motor development were not readily evident until after the third year of age (Watson et al., 2003).

Early indicators of the above characteristics include: lack of babbling or cooing, pointing, or gestures by 12 months of age, no single words by 16 months of age, no 2-

word spontaneous phrases by 24 months of age, any loss of language and/or social skills at any age, does not look at others, does not respond to name, does not show objects, does not engage in symbolic play (Baron-Cohen, Allen, & Gillberg, 1992; NICHD, 2001b; Woods & Wetherby, 2003).

The social characteristics associated with a diagnosis of ASD have particular implications for families. In particular, behavior challenges exhibited by children with ASD have been shown to have a negative impact on stress-levels, emotional well-being, and quality of life of the caregiver (Allik, Larsson, Smedje, 2006; Hastings et al., 2005; Higgins, Bailey, & Pearce, 2005). Subsequently, taking a child with ASD into the community can serve as a source of stress (Hastings). In order to avoid this stress, families may engage in isolationist behavior in order to avoid social situations where stereotypical ASD behaviors may manifest themselves (Autism Society of America, 2008).

Etiology. In the 1950's and 60's, Bruno Bettelheim claimed that "refrigerator mothers" were the cause of their child's autistic tendencies. The detachment and lack of affection shown by these mothers was believed to be the cause of autism in children. This belief was later disproved when Dr. Bernard Rimland and Dr. Eric Schopler began to challenge Bettelheim's claim. In 1964, Rimland demonstrated that Bettelheim's theory was false by establishing autism as a biological condition (National Alliance for Autism Research, 2005).

More recently, autism has been established as a disorder of neurobiological origin (Akshoomoff, Pierce, & Courchesne, 2002). Current research addresses the role of genes (Castermans et al., 2004), vaccines (Bernard, Enayati, Redwood, Roger, & Binstock,

2001; Rimland, 2000; Shaw, 2002) concentration of toxic elements (Fido & Al-Saad, 2005), and differences in brain structure (Herbert, et al., 2005; Vargas, Nascimbene, Zimmerman, & Pardo, 2005) as possible causes of ASD.

In 1977, the first autistic twin study was published, which suggested a genetic basis for the disorder. In the early to mid 1990s, genetic researchers began to link autism to individuals with abnormalities on chromosome 15. In 1998, researchers reported evidence of a link between autism and chromosome 15q and chromosome 7q. By 2001, several researchers had completed genetic screens that have identified several genomic regions containing genes that could be associated with autism (National Alliance for Autism Research, 2005). Currently, there are many theories and hypotheses regarding the etiology of autism spectrum disorders. The vast array of theories and hypotheses regarding the etiology of ASD can have implications for families. Specifically, despite the fact that Bettleheim's claims have been dispelled, families often experience guilt and blame over their child's diagnosis (Kuhn & Carter, 2006; Mercer, Creighton, Holden, & Lewis, 2006). The genetic basis of the disorder has caused some parents to lay blame on themselves for contributing genes which may have led to their child's ASD (Gray, 1995; Mercer et al., 2006), however, little is known as to whether or not parents experience guilt over their parenting skills. This can be problematic in that unresolved feelings of guilt can result in feelings of inadequacy in their role as a parent (Kuhn & Carter, 2006).

Herbert et al. (2005) identified an increase in the amount of white matter present in the brains of individuals with autism. This increase in white matter is said to be associated with connectivity abnormalities typically found in the areas of the brain responsible for higher-order processing skills. Additionally, Vargas et al., (2005)

conducted a post-mortem study where the brains of 11 individuals with autism, aged 5 to 44, were examined. The results revealed inflammation in the same areas of the brain with abnormal white matter growth. However, the study was inconclusive in determining whether or not the inflammation is actually the cause of autism, or if it is a result of something else that causes the disorder.

The mercury present in some vaccinations has been speculated to contribute to the presence of autism (Bernard et al., 2001; Rimland, 2000; Shaw, 2002). According to Bernard the FDA and the American Academy of Pediatrics (AAP) determined that the typical amount of mercury “injected into infants and toddlers via childhood immunizations has exceeded government safety guidelines on an individual and cumulative vaccine basis” (p. 462). Bernard identified similarities among individuals with mercury poisoning and ASD such as: speech and language impairments, sensory deficits, abnormal behaviors, and cognitive impairments. Although parallels have been made between mercury poisoning, vaccines, and the presence of ASD, there is insufficient research to conclusively label mercury poisoning and vaccinations as a cause of autism (Simpson et al., 2005).

Diagnosis. As no specific biological markers have been identified as causes of ASD, diagnosis of the disorder is made based on purely observational measures, which leads to questions regarding the reliability and validity of the diagnosis. Screening tools are used as a means of identifying children who may be at risk for being diagnosed with autism. Screening tools alone do not provide a diagnosis of ASD. Most of these tools employ a parent questionnaire and they must report sensitivity and specificity. The sensitivity of a tool refers to the true positives, or the number of individuals who were

identified as at-risk and then later failed the follow-up testing and/or were diagnosed with ASD. The specificity of a screening tool refers to the true negatives, or those individuals who were identified as no risk and who later passed follow-up testing and/or did not receive an ASD diagnosis. In addition to the parent questionnaire, observations are necessary and typically occur in both clinical and natural settings. Baird et al., (2000) identify the need for both parents and professionals to monitor behavior and opposed the idea of a single screening. Continuous monitoring paints a more comprehensive picture of the child's behavior and decreases the likelihood of misidentification.

Family Literature

Overview. According to the Autism Society of America (ASA) (2008), autism impacts individuals from all racial, ethnic, and social boundaries; the disorder can affect any family or child. In addition, approximately 1.5 million people in the United States today are living with the effects of ASD (ASA). Unfortunately, despite the increasing prevalence rates, many professionals in the field are still unaware of how to effectively collaborate with individuals with ASD and their families (ASA). Further, there is an overall lack of awareness about the disorder and its implications for those affected.

The increase in the number of individuals diagnosed with autism illustrates the need for increased awareness about the disorder and collaboration among parents, teachers, and professionals. Parents and professionals report several barriers to the development of a collaborative partnership among stakeholders. In particular, language, ethnicity, parent education level, and others have been identified as barriers (Dunlap, 1999; Turnbull, Turnbull, Erwin, & Soodak, 2006; Yap & Enoki, 1994) Further, research has reported that parents often times feel as though they have little or no involvement in

their child's educational programming (Osher, Osher, & Blau, 2005; Spann, Kohler, & Soenksen, 2003). In addition, service delivery models for community agencies do not always take into account the increasing diversity in regards to ability/disability, language, religion, family dynamics, socio-economic status, and ethnicity (Harry, 2008; Lynch & Hanson, 1998; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007).

Current literature on the topic of autism and other disabilities identifies the need to address the family component, cultural and linguistic diversity, and service accessibility (Dyches, et al., 2004; Harry, 2008; Zionts, Zionts, Harrison, & Bellinger, 2003; Zionts & Zionts, 2003). Dyches contends that as ASD often coexists with mental retardation and a lack of functional speech, parents are faced with challenges that far exceed those associated with an ASD diagnosis. In particular, research should address the intersection of these challenges with family characteristics. An exploration of this intersection has the potential to yield information related to levels of stress in the home and the ability of the caregiver to effectively instruct their child in the areas in which challenges are experienced (National Research Council, 2001).

Wolery & Garfinkle (2002) discuss an under-reporting of children's family structure, ethnicity, and race. Family and cultural dynamics impact the way in which caregivers perceive their experience raising a child with ASD. Specifically, information addressing "familial appraisal of autism within a cultural context" (Dyches et al., 2004) is not readily available. As family is the most basic unit of cultural identity, perceptions of disability and accessibility of services across cultures must be examined (Dyches). In addition to perceptions of disability, family adaptation to disability within a multicultural context is an area which has been largely ignored. While The Resiliency Model of Family

Stress, Adjustment, and Adaptation (McCubbin, McCubbin, Thompson, & Thompson, 1998) addresses multicultural constructs, research utilizing this framework has yet to make the distinction between ASD and other developmental disabilities (Dyches). This is problematic, in that, ASD is considered to be a more debilitating disorder than many others (Randall & Parker, 1999) and places more stress on families than other disabilities (Weiss, 2002). Subsequently, there is a need for research which seeks to examine the intersection of race, family adaptation, and ASD (Dyches).

Although the literature provides caregiver accounts of living with a child with autism (Abbeduto, et al., 2004; Boyd, 2002; Gray, 2006; Green, 2003; Greenberg, Krauss, Seltzer, Chou, & Hong, 2004; Magana & Smith, 2006; Rubin, 2007; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2007), many of these accounts utilize quantitative methods to examine caregiver coping mechanisms (Abbeduto; Smith et al., 2007), well-being (Abbeduto; Greenberg et al., 2004; Magana & Smith 2006; Smith), and stress levels (Boyd) without acknowledging the larger construct of lived experience. Additionally, they fail to provide accounts from diverse perspectives (Dyches, et al, 2004; Zionts & Zionts, 2003). In fact, much of the research in the field of ASD completely disregards or minimizes race (Connors & Donellan, 1998).

Qualitative research does exist which examines caregiver lived experience. For instance, in *Finding Marisa: A Mother's Story* (Rubin, 2007), a mother of a daughter with autism provides a first hand account of her day-to-day experiences. However, this account is told from the perspective of the mother, who has a graduate degree in special education. Further, the account does not situate the story within the larger body of literature on lived experience (i.e. coping, stress, well-being) nor does it attempt to

provide systematic analysis, recommendations or conclusions (Rapin, 2007). Green (2003) examines the stigma associated with having a child with a disability, including autism. However, a mixed methods approach is used where stigma is both quantified, through a regression analysis, and qualified, through the use of interactive interviews and narrative. Further, the study was limited to mothers of children with varied disabilities, not autism exclusively, and 81% of participants self-identified as Caucasian, thus indicating a need for additional research which examines autism (Dyches et al., 2004; Zions & Zions, 2003), lived experience, and culture (Dyches; Harry, 2008) from purely qualitative measures. Parents of children with ASD have also used the internet as a venue for self-publishing their narratives. Fleischmann (2004) analyzed these narratives and discovered that many parents described the diagnosis of ASD as a *turning point* in their lives. In addition, while several narratives addressed the challenges associated with raising a child with ASD, the majority of the narratives also expressed the experience, and associated changes parents have endured, as positive. Research indicates that exchanging narratives facilitates the coping process and a change in perception for parents (Huws, Jones, & Ingledeu, 2001). Subsequently, the change in perception can lead to a more positive view of the diagnosis (Fleischman). This indicates a need for further narrative exploration of caregiver lived experience related to raising a child with autism (Fleischman).

Process. “The loss of the idealized child is like a grieving process. It takes a long time, it never ends, it is constantly changing and it is a journey...Having a child with special needs transforms raising a child into an unanticipated and unpredictable journey. From hearing the diagnosis to embracing the disability, a life altering experience occurs” (O’Neil, 2008, p.1).

Critical to the larger construct of lived experience is the process caregivers and families go through following the diagnosis of a child with a disability. Specifically, life course theory emphasizes the importance of time, context, process, and meaning on individual development and family life (Bengtson & Allen 1993). The social context in which the diagnosis occurs, along with the prior experiences of the caregiver, impacts the way in which the diagnosis is received by the caregiver. Kubler-Ross (1969) outlines stages of mourning that families experience following the diagnosis of a child with a disability. However, Seligman & Darling (1997) caution that this progression should be viewed as a guide rather than a prescription for family behavior as families are complex in nature and the impact of a diagnosis is unpredictable. Further, this is one commonly applied construction of the process families go through in learning and living with a diagnosis of disability or illness. This process has been applied not only to disability-related literature, but also literature which addresses death and dying (Zell, 2003). The stages include (1) Denial; (2) Bargaining; (3) Anger; (4) Depression; (5) Acceptance

Denial is thought to serve as a buffer for the parent who is experiencing grief, in effect, denial allows the parent the opportunity to gather the inner strength necessary to acknowledge, accept and manage the diagnosis (Kricos, 1999). Parents report feelings of numbness, confusion, and helplessness (Seligman & Darling, 1997) Denial is reinforced through the deficit-based perspective, which emphasizes the negative effects of the disability, used by many professionals (Ho & Keiley, 2003). Further, this deficit-based perspective not only inhibits parents' ability to accept the diagnosis but also hinders the development of collaborative relationships with service providers.

The bargaining phase involves parents engaging in activities, such as donating their time to a worthy cause, turning to religion, and seeking out all possible therapeutic options in an exchange for an improvement in their child's condition (Ho & Keiley 2003; Seligman & Darling, 1997). When these options fail to result in an improvement in their child's condition, parents may experience anger, the next stage in the mourning process, regarding their child's diagnosis. This anger is often projected onto spouses for lack of support and failing to create a child without a disability, professionals for failing to heal the child, and God for allowing the situation to occur (Seligman & Darling). Anger can be exacerbated guilt on the part of the parents, lack of support from school and/or community, and an unavailability of services (Ho & Keiley; Seligman & Darling).

Depression and acceptance are the final two stages caregivers experience when faced with raising a child with a disability. Once the anger has subsided, parents can fall into a depressive state upon realization of the chronic nature of their child's disability. When parents are able to discuss their child's shortcomings with relative ease, achieve a balance between encouraging independence and showing love, collaborate with professionals to identify realistic goals and objectives, pursue personal interests not related to their child, discipline without undue guilt, and abandon overprotective/overly harsh behavior towards their child, then acceptance has been achieved (Hornby, 1994).

While these phases provide a framework for understanding the process of coping with the diagnosis of a child with a disability, the way in which families experience and progress through these phases is not universal and is impacted by factors such as culture, family structure, and lived experience (Seligman & Darling 1997).

In an effort to move away from models outlining linear stages of mourning, such as Kubler-Ross' (1969), Vincent (1990) developed the following model which “emphasizes a more continuous movement towards advocacy and acceptance” (Ho & Keiley, 2003, p. 242). The stages include:

1. Questioning if the diagnosis is correct
2. Exploring how family members and children make meaning of the diagnosis
3. Investigating who can help and how much
4. Optimizing the potential of treatment
5. Becoming an advocate for families of children with disabilities

Vincent's (1990) model is representative of a collaborative-resource perspective, in the way that it explores the demands placed on families following a diagnosis and the resources available to assist in meeting these demands. Additionally, the model facilitates the development of a collaborative partnership between families and service providers where available and appropriate resources are the focus (Ho & Keiley, 2003).

Another model representative of the collaborative-resource perspective is the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1994). The FAAR model includes two phases, adaptation and adjustment. The model maintains that the ability of parents to cope with their child's disability changes over time and is impacted by different transitions, or crises, within both the life cycle of the parent (divorce) and the life-cycle of the child (entering school). The adjustment phase is defined as a period of stability within the family, whereas the adaptation phase is the family's response to the crisis or transition. In order to achieve feelings of adjustment, the family must adapt or change to meet the demands imposed by the crisis (Patterson, 2000). Accessibility of resources, the social and historical context in which the crisis occurs, and the timing of the crisis or transition within the life course also has implications for how

well a family is able to adjust (Seltzer & Greenberg, 1999; Wethington, Cooper & Holmes, 1997).

Coping/stress and caregiver burden/satisfaction. Caring for a child with ASD can be a challenging task due to the many stressors that are experienced by the primary caregiver. Namely, stressors include: the day to day stress arising from care giving, a lack of caregiver confidence in their ability to handle the child's behavior, the absence of support services, and the realization that there is no cure for ASD (Twoy, Connelly, & Novak, 2007).

These stressors make coping mechanisms essential for caregivers who are faced with the challenge of raising a child with ASD (Twoy, et al., 2007). Research has shown that caregivers of children with ASD have a higher level of stress (Duarte, Bordin, Yazigi, Mooney, 2005) than caregivers of children with intellectual disabilities other than ASD (Olsson & Hwang, 2001). Further, caregivers of children with ASD experience higher levels of stress than caregivers of children with Down Syndrome and typically developing children (Bouma & Schweitzer, 1990; Dumas, Wolf, Fisman, & Culligan, 1991; Fisman, Wolf, & Nah, 1989, Holroyd & MacArthur, 1976; Wolf, Noh, Fisman, & Speechley, 1989). Also, higher levels of stress were evident in caregivers of children with ASD than caregivers of children with cystic fibrosis (Bouma & Schweitzer). Studies looking at differences between mothers and fathers of children with ASD suggest that mothers tend to exhibit higher levels of stress than fathers (Hastings, 2003; Hastings et al., 2005). Additionally, fathers have been found to use less problem-focused coping strategies than mothers (Essex, Seltzer, & Krauss, 1999; Hastings & Johnson, 2001). The majority of research has examined stress levels of the mother while little emphasis has

been placed on paternal stress and coping (Quinn, 1999; Katz, 2002; King, King & Rosenbaum, 1996). Thus, there is a need to examine stress and coping from a dualistic perspective.

In addition to findings on caregiver stress levels, research indicates that caregivers of children with ASD report lower levels of marital satisfaction (Fisman et al., 1989; Wolf et al., 1989; Rodrigue, Morgan, & Geffken, 1990, 1992), higher levels of depressive symptoms (Fisman; Wolf; Rodrigue, et al., 1990, 1992), less parenting competence and less family adaptability (Rodrigue) than caregivers to children with Down syndrome and caregivers of typically developing children.

Green (2007) found that mothers of children with disabilities reported socio-cultural constraints rather than emotional distress in raising their children with disabilities. However, despite the socio-cultural constraints, mothers perceived valuable benefits to having a child with a disability; these perceived benefits are decreased by the impact of perceived stigma on the emotional distress of the mother. Gray (2002), concurred that the perception of stigma by the caregiver may contribute to the overall stress and depression experienced by the caregiver, caregiver self-efficacy has also been shown to contribute to levels of anxiety and depression (Hastings & Brown, 2002). Lastly, parents of children with ASD are more likely to perceive that their child had a more difficult temperament than parents of children with mental retardation and parents of typically developing children (Kasari & Sigman, 1997). These increased levels of stress, depressive symptoms, marital dissatisfaction, and anxiety emphasize the importance of coping strategies to minimize the impact of the stressors.

Although research exists which examines the lived experience of primary caregivers and the coping mechanisms they employ when faced with raising a child with ASD, this literature fails to examine these constructs through purely qualitative methods. Current literature in the area of stress, coping and well-being has assessed levels of stress and well-being and methods of coping through the use of survey instruments. The Resiliency Model of Family Stress, Adjustment, and Adaptation is frequently used and is designed to measure a family's ability to adjust and adapt to stressors (McCubbin & McCubbin, 1989). The Resiliency Model includes five propositions which include:

1. The pileup of family demands (stressors, strains, transitions) is related to family adaptation, and this is a negative relationship;
2. Family typologies based on specific strengths of the family system (cohesion, adaptability, family hardiness, family time and routines) are related to family adaptation, and this is a positive relationship;
3. The family resources are related to family adaptation, and this is a positive relationship;
4. The family's positive appraisal of the situation is related to family adaptation, and this is a positive relationship; and finally
5. The range and depth of the family's repertoire of coping and problem-solving strategies when employed to manage a crisis situation are related to the level of family adaptation, and this is a positive relationship (McCubbin, 1993, p. 55).

While this model has been shown to effectively illustrate family coping and adaptation methods, it does not achieve a level of depth that can be attained through the use of qualitative interviewing techniques such as interactive interviewing. More

specifically, information regarding changes in coping mechanisms over the life course is not readily available and little research has been conducted with focuses specifically on caregivers of children with ASD (Gray, 2006).

Many studies examining coping strategies and stress levels of parents of children with ASD required participants to respond to instruments utilizing Likert scale questions (Abedduto, et al., 2004; Greenberg, et al., 2004; Magana & Smith, 2006; Orsmond, Seltzer, Greenberg, & Krauss, 2006; Smith et al., 2008; Tway et al., 2007). Results of current research, both quantitative and qualitative, revealed that caregivers of children with ASD employed varied coping strategies such as positive reframing of potentially traumatic situations (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings et al, 2005; Hastings & Johnson, 2001; Tway), seeking support from family and friends (Gray, 2006; Tway), families facing similar situations (Gray; Tway), spiritual beliefs (Gray; Hastings; Tway), and agencies and programs (Gray; Tway). Strategies used by caregivers were categorized as either internal or external strategies. Internal coping strategies came from within the family: communication, relationship, and cognitive, whereas external strategies came from outside resources: community, social contacts, spiritual support.

Hastings et al. (2005) further characterized coping strategies utilized by caregivers of children with ASD into four dimensions:

1. Active avoidance coping: self-blame, use of drugs/alcohol to cope, giving up, distractions to avoid the stressor
2. Problem-focused coping: seeking social and emotional support from others, identifying potential strategies
3. Positive coping: humor, positive reframing, acceptance

4. Religious/denial coping: comfort in religious beliefs, prayer, meditation, refusal to believe what has happened

Caregivers utilizing active avoidance strategies were found to display higher levels of stress and increased mental health problems. Additionally, results from the study suggested that positive reframing of stressful life events, such as the diagnosis of a child with ASD, was related to lower levels of depression in both mothers and fathers of children with ASD. Longitudinal study results indicated that the total number of coping strategies used by caregivers decreased over time and there was a shift towards more emotion-focused means of coping (Gray, 2006).

Research also revealed that coping strategies appear to differ across cultures and gender. Specifically, non-English speakers were found to rely more heavily on spiritual support than do their English-speaking counterparts and Asian-Americans relied on reframing whereas Caucasians relied more so on passive appraisal, or avoidance of problems (Troy et al., 2007).

Research on African-American and Latino(a) caregivers is limited; research that is available is dated and is rarely specific to raising a child with ASD. However, research on Latino caregivers with a child with a disability, not specific to ASD indicates a high level of need for both family (Magana & Smith, 2006; Skinner, Bailey, Correa, & Rodriguez, 1999) and formal supports (Skinner et al., 1999). Literature addressing the coping strategies of African-American families included three key factors, religious connectedness, culture/ethnicity, and family structure and functions, which influence the “interpretations, coping resources, and adjustments of African-American families with children with disabilities” (Rogers-Dulan & Blacher, 1995). Further, greater resilience

and acceptance has been documented among ethnic minority families when compared to European American families and mothers (Harry, 2002). These findings warrant additional research addressing coping mechanisms within the context of family, disability, and ethnicity (Harry). Findings also indicate the need for face-to-face, qualitative research addressing the both coping strategies and caregiver burden/satisfaction (Arzubiaga, Artiles, King, & Harris-Murri, 2008).

Narrative.

“The people who come to see us bring their stories. They hope they can tell them well enough so that we understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember that what we hear is *their story*” (Coles, 1989, p. 7).

Narrative inquiry is much more than the simple telling of stories (Clandinin, Pushor, Orr, 2007). Rather, narrative is a complex methodology which incorporates interpretation, art, literary practices, and the goal of capturing the lived experience of others. This methodology offers insight into the complexity of human life and the way in which an individual’s role, such as that of a caregiver to a child with ASD, can be understood within the larger context of their lived experience (Liamputtong & Ezzy, 2005). Specifically, narrative allows us to understand the impact of raising a child with ASD on the life course of the caregiver (Krauss, Seltzer & Jacobson, 2005). According to Ellis (2004), the goal of this qualitative form of research is to create a sense of social awareness and empathy. Further, researchers seek to evoke “emotional experience in readers, give voice to stories and groups of people traditionally left out of social scientific inquiry, produce writing of high literary/artistic quality, and improve the readers’, participants’, and authors’ lives” (p. 30).

Disability narratives have played a significant role in contributing to the dialogue about disability and lived experience. Specifically, self-published narratives of parents with children with autism are evident in both print and internet arenas. Analyses of these narratives indicate that telling one's story is part of the coping process that many parents go through when dealing with an ASD diagnosis. Further, constructing a new story allows caregivers to positively reframe the ASD diagnosis (Fleischman, 2004). Positive reframing can subsequently lead to lower levels of depression and improved well-being (Gray, 2006). Disability narratives have also given a voice to those individuals who have previously been left out of the literature because of their association with disability. Additionally, they provide an authentic account of what it is like to live with a disability or care for someone who has a disability. Traditional quantitative studies are limited in that they are unable capture the "richness, complexity, and depth" (Morris, 1991, p.82) as qualitative approaches can. Quantitative researchers see themselves as separate from the researched and strive to obtain results which can be generalized to larger populations. Narrative inquiry does not share these values. Rather, the narrative approach to inquiry emphasizes the importance of building relationships with those we study, attempting to see the world through their eyes, and re-presenting the experience in a manner which is true to their everyday lives (Ellis, 2004). To ensure the research participants' voice is accurately re-presented, many qualitative researchers negotiate, through member checks, their research texts with their participants (Pushor & Murphy, 2004). These negotiations often facilitate additional dialogue between the researcher and participants and create conditions for further thought and interaction with the text (Clandinin et al., 2007). Additionally, the actual process of creating a story is especially critical for those

individuals experiencing high levels of stress or transition, such as those associated with an ASD diagnosis, in that an individual's ability to cope is influenced by the stories they tell about themselves (Gergen, 1988; Sarbin, 1986 as cited in Fleischman, 2004).

Narrative inquiry does not attempt to control nor operationalize the contexts in which the research is conducted. Instead, narrative researchers acknowledge that researcher bias and experience, research contexts, the lived experience of participants, along with additional factors, play a role in the telling and interpretation of the story (Clandinin et al., 2007). This acknowledgement of researcher presence in the story creates a multi-layered account, thus adding to the depth and richness of the text. The concept of "life-story meshing" (Bruner, 2004, p. 699) is an important part of this process. Essentially, in order for the storyteller and the listener to connect over story, they must share a "deep structure about the nature of a life" (p. 699), otherwise one party may feel disconnected from what the other is saying.

"The remembering makes it now. And sometimes remembering will lead to a story, which makes it forever. That's what stories are for. Stories are for joining the past to the future. Stories are for those late hours in the night when you can't remember how you got from where you are. Stories are for eternity, when memory is erased, when there is nothing to remember except the story." (O'Brien, 1990, p. 128).

The sociology of storytelling posits that lived experience is constructed through the stories an individual tells about their lives. Storytelling is more than a way to inform others about our lives. Rather, stories assist in identifying purpose and meaning in our lives as well as in the construction of our identity (Berger & Quinney, 2004). A good story is one which resonates with some part of our life. It brings us to the realization that our stories are worth telling and gives us the courage to do so (Coles, 1989). Expressing

oneself through autoethnographic writing, allowing one's vulnerability to infiltrate the page, has a dualistic purpose. It not only facilitates the process of self-exploration and discovery but it encourages the reader to express his or her feelings and compare their life experiences with those of the storyteller (Ellis, 2002). "Good autoethnography works toward a *communitas*, where we might speak together of our experiences, and commonality of spirit, companionship in our sorrow, balm for our wounds, and solace in reaching out to those in need as well" (Ellis, 1998).

The idea of *reflexivity*, as posited by Bruner (1990), is an essential component in the process of interpreting our life stories. Specifically, reflexivity involves reflecting on the past within the context of the present, however, it is important to note that "neither the past nor the present stays fixed in the face of this reflexivity" (Bruner, 1990, p. 109). The ways in which we reflect on past experience, as well as the cultural context in which this reflection takes place, serves as a mechanism for continuous interpretation of our storied lives. Thus, certain stories may be more or less meaningful depending on the context in which they are reviewed (Bruner). Essentially, we become the narratives through which we tell about our lives (Bruner, 2004). The way in which we tell our life stories is guided by the various processes associated with the culture with which we identify. More specifically, these processes "structure perceptual experience, to organize memory, to segment and purpose-build the very "events" of a life" (Bruner, 2004, p. 694). Essentially, the act of self-telling our life story is interpretive in nature; it is these interpretations which contribute to the continuous renegotiation of our life as we see it.

This act of self-telling can be referred to as the autobiographical method (Bruner, 1995). However, it is cautioned that autobiography cannot be used as a means of referring

to “life as lived” (p. 161). Rather, autobiography is the act of constructing or creating a life; an interpretive process. The autobiographical process involves combining *witness*, *interpretation*, and *stance* while at the same time maintaining a semblance of truth and negotiability, or the acceptance of the autobiographer’s life into the larger “community of lives” (p. 169). *Witness* refers to the life events that one has experienced, either first hand or as an observer. The goal is to portray experience as “facts” (p. 167). *Interpretation* involves situating the facts within the larger context of experience in order to provide them with a “wider significance” (p. 167). *Stance* refers to one’s view of the Self and plays a role in balancing the interplay between *witness* and *interpretation* (Bruner). The result is a life construction that is a product of the culture with which we identify.

The validity and reliability or “truth” of research involving storytelling has been questioned by positivists, however, it is the extent to which the story is able to “evoke the vividness of lived experience” (Berger & Quinney, 2004, p. 1) on which qualitative forms of research base the measure of truth. Bruner (1990) refers to validity as an “interpretive concept” (p. 108) in that it is subjective in nature. Catalytic validity (Lather, 1986) assists in helping study participants, as well as researchers, in understanding their experiences so that they feel empowered to transform their lives. Further, catalytic validity requires the researcher to fully examine biases, associations, and self-interests and the role they play in interpretation (Cohen, Manion, & Morrison, 2000).

Life Course Theory

The life course theory looks at the life course of individuals through a historic, social, and cultural context where life course is defined as a “sequence of socially defined events and roles that the individual enacts over time” (Giele & Elder 1998, p. 22). In life

course theory, transitions (Elder, 1985) or *turning points* (Clausen, 1995) are viewed as events that have the capacity to alter the trajectory of the life course. The diagnosis of a child with ASD would classify as a transition or turning point. Further, the timing of this event combined with socio-historical conditions and geographic location provides a framework for further examining the ways in which the diagnosis of a child with ASD impacts the primary caregiver's adult development (Seltzer et al., 2001). Research on stress and coping illustrates that caregivers of children with disabilities tend to modify the ways in which they cope over time (Gray, 2006). However, the social context in which the transition occurred cannot be ignored. It is only within the last 33 years that a "climate of support" (Seltzer, p. 266) has been provided for caregivers of children with disabilities. Specifically, prior to changes in legislation, shifting attitudes regarding disability, and improved services, the social context in which families of children with special needs lived was not conducive to the provision of a climate of support.

For instance, it is only with the enactment federal legislation such PL 94-142 *Education for All Handicapped Children Act* in 1975 that supports have been readily available to individuals with disabilities. Consequently, the passage of this legislation altered the previous social context in which individuals with disabilities did not have access to the services mandated by the passage of PL 94-142. Thus, caregivers raising a child with ASD prior to the enactment of this legislation may have had more difficulty coping and managing the day-to-day challenges of the disability as supports were not readily available. Specifically, caregivers in more recent studies (Seltzer et al., 2001) reported a more positive life course adaptation than caregivers who did not have access to the service provisions mandated by PL 94-142.

Life course theory emphasizes the interplay of *trajectories* and transitions within the social context in which the individual resides. Specifically, the timing of the roles to which the caregiver must adapt is critical to the impact the transition has on the trajectory of the life course. Research indicates that caregivers of children with ASD must continuously adapt and change roles in order to meet their child's changing needs throughout the life course (Bristol & Schopler, 1984; Gray, 2006). Specifically, the family stress proceeds developmentally with early stressors including managing the significant needs of the child and chronic fatigue from constant supervision. These early stressors are transformed into new stressors, such as the permanency of the condition and community acceptance, as the child moves through the developmental phases of early childhood, adolescence, and adulthood. Specifically, levels of stress intensify as the child enters adolescence (Seltzer, Krauss, Orsmond, Vestal, 2001). The transitions associated with the progression of a child with ASD from adolescence to adulthood influence the roles caregivers must take on; the timing, duration, and sequencing of these roles can thus impact the overall trajectory of the life course (Macmillan & Copher, 2005).

Much of the research conducted within the framework of a life course perspective examines chronic disease and the aging process (Anstey, 2008; Dupre, 2008; Sayer & Cooper, 1997; Shlomo & Kuh, 2002). Most often, the long term-effects of a chronic disease and its impact on the life course of the patient, from birth to death, has been examined, along with the concept of successful aging, or the ability to effectively adapt to transitions in the life course. Less frequently, the life-course approach has been used as a framework for examining criminal offenders (Hanks & Carr 2007; Laub, Sampson, & Sweeten, 2006; Nagin, Farrington & Moffitt, 1995) and the evolution of deviance and

criminal activity along with turning points within the life course which may have led to criminal behaviors. While this research does not address the concept of disability within the life course, this research does provide a frame of reference for the current study. Particularly, findings from the aforementioned studies indicate that behaviors, attitudes, and roles vary over the life-course and are dependent on various factors such as age, social contexts, and life events, or turning points, which can alter the trajectory of the life course.

However, little research has been conducted which examines *how* and *why* stress and coping changes over time (Gray, 2006; Hastings et al., 2005; Seltzer et al., 2001). Additionally, little research addresses the change in the life course of the primary caregiver. What were their goals prior to the transition of diagnosis of a child with ASD? How have these goals changed since the transition? Moreover, the life-course perspective views significant events, such as the birth of a child and the diagnosis of a child with a disability as a transition which impacts the trajectory of the caregiver's life-course.

Chapter 3 will outline the methods used to examine the lived experience of diverse caregivers of individuals with autism in the current study.

Chapter Three

Methods

The purpose of this study was to examine the lived experiences of diverse primary caregivers in raising a child with ASD. The study was situated within the theoretical framework of the life-course theory posited by Elder (1985). Specifically, effects of the transition in the life-course that caregivers experience when a child is diagnosed with ASD were examined along with caregiver burden/satisfaction, coping mechanisms, and other constructs which contribute to the larger concept of lived experience. This study utilized a narrative methodology with interactive interviewing techniques; in particular, the interviews were treated as narratives.

In addition to examining the lived experiences of primary caregivers of children with ASD, I explored my own experiences from a dualistic perspective: as a family member of an individual with ASD and as a researcher of others' lived experience in raising a child with ASD. Richardson (2001) acknowledges the importance of "getting personal" (p. 31) in research. Writing-stories (Richardson, 1997) explore the intersection of the personal and political and allow us explore our own worlds in a way that allows us to feel a "connectedness to others" (Richardson, 2001, p. 36).

"Writing about your life in writing stories can be a sacrament. By this I mean two things: experiencing the flow of writing and experiencing a connectedness to others. The sense of time and place as separate is undermined, re-understood as deeply related. As you write, you can feel yourself connected to others; the meaning you construct about your life connects you to others, making communion-community-possible" (p. 36-37).

In order to attain this feeling of connectedness to study participants, I included my own story and journey with autism as part of the current study. Richardson (2001) also notes that “writing is a method of discovery” (p. 35), we write in order to learn something. My aim for the study was to simultaneously discover what it is like for three caregivers who are currently raising a child with ASD and how my own experiences as a family member of an individual with ASD impacted my interpretations of participant stories. It is important to acknowledge that this research study was important to me as an individual, therefore, it was essential that my voice not be silenced in order to achieve the “objectivity” which is sought after in traditional quantitative research. In this study, my writing story served to nurture my own individuality (Richardson) while, at the same time, further my understanding of both my life and participant lives.

The life stories, or personal narratives (Riessman, 2002) told by the participants revolved around a specific event in their lives, namely, the diagnosis of a child with ASD. Narrative is a form of “retrospective meaning making” (Chase, 2005, p. 656) where individuals make sense of prior actions and events. Subsequently, interview data was transformed into a cohesive narrative which “expresses emotions, thoughts, and interpretations” (Chase, p. 656) from both participant and researcher perspectives. In this particular study, the terms *narratives* and *stories* were used interchangeably.

The use of interactive interviewing (Ellis, 2004) and responsive interviewing (Rubin & Rubin, 2005) techniques were used in order to facilitate a multi-layered account of lived experiences. Interactive interviewing emphasizes not only the participant story, but the story of the interaction between researcher and participant (Gubrium & Holstein, 2002). Both parties bring their own stories and experiences to the table and it is the

intertwining and negotiation of these stories that is the focus of interactive interviewing. For example, in a study conducted by Kiesinger (1998), interactive interviewing is used to “reflexively connect our experiences that use Abbie’s life story to challenge and deepen my understanding of my own life, and my own experiences to heighten my comprehension of hers” (p. 2).

The focus of responsive interviewing (Rubin & Rubin, 2005) is on the depth of understanding attained from the interview experience rather than the breadth of information gathered. This method acknowledges that the experiences, personalities, and feelings of the interviewer and interviewee interact and influence each other. Thus, the researcher must have sufficient self-awareness to recognize any biases or expectations that may exert an unintended influence on the participant. Personal involvement and self-reflection are encouraged as these practices facilitate empathy and improve the overall quality of the interview (Rubin & Rubin, 2005). The personal journey of the researcher should be intertwined within the family stories through the use of problematics and metanarrative reflections with the goal of illustrating the interpretive process of the researcher (Peshkin, 2000).

To this end, I intertwined my story with the participant stories in a manner that allowed me to connect my experiences with participant experiences, thus heightening the understanding of both storied lives, or narratives. While I have never had the experience of raising a child with ASD, I do have a family member who is diagnosed with Asperger’s Syndrome, which is one of the conditions subsumed under the umbrella term of ASD. Further, I have worked extensively with students with ASD in my professional role as an educator. While these experiences do not mirror the experiences of the

participants, they did influence the interactions between myself and study participants, in that we share a common association with disability. Additionally, my previous experiences also influenced my interpretation of the participants' lived experiences; this impact was explored through the use of metanarrative reflection (Peshkin, 2000) which is interwoven with the participant stories to create a multi-layered account.

In interactive interviewing, the researcher is not limited to a predetermined list of questions (Wood, 2001). Rather, the interview is semi-structured and allows the researcher to probe using open-ended questions in order to achieve a greater depth of understanding of the lived experience. Further, by clarifying, prompting, and questioning the participant, the researcher encourages the participant to disclose the knowledge resulting from their lived experience (Wood) of raising a child with ASD. Participant disclosure assisted me in determining how and when to use the topics identified on the interview protocol, thus making the interviews themselves conversational in nature. A proper interactive interview facilitates the development of participant as researcher (Wood). Specifically, the participant is able to make connections and identify themes within the telling of their lived experience. The semi-structured nature of the interview allowed for differentiation in the content of participant stories. Specifically, participants were not restricted to the categories set forth in the interview protocol and had the freedom to address topics that I may not have initially anticipated. Due to the dynamic nature of this interviewing technique, the interviews reflect participant individuality and do not necessarily address identical topics. In order to facilitate the interactive nature of the interviews, I initially provided participants with a tape recorder that they could use to document their experiences and feelings without the need for the researcher to be present.

The intended purpose was to establish a foundational relationship between the researcher and participant in that I would have used the information on the tape as a building block for subsequent conversations. However, as none of the study participants indicated an interest in using the tape recorder, I had to come up with an additional strategy to facilitate the interactive nature of the interviews. Specifically, I disclosed portions of my family story during the interviews in an effort to relate our experiences. This act of sharing initiated a commonality between the participants and myself. Additionally, I noticed that study participants often inquired about my family story during the course of the interview. This dialogue allowed for interaction between both parties, thus assisting in the development of a multi-layered account where the interaction between the researcher and participants is evident throughout the participant stories.

Table 1 outlines Wood’s (2001) procedures for conducting the interactive interview:

Table 1

Interactive Interviewing Procedures

Step	Description
Starting the interview	Explain the purpose of the interview Assure participant of anonymity Explain that the researcher is trying to learn from the participant Obtain participant permission before tape recording or taking notes

Letting the informant lead	Find the balance between keeping the interview focused on the topic, but allow the participant to define the content of the discussion
Probing	<p>Stimulate the participant to provide more information without injecting yourself too much into the interaction</p> <p>Remember that sometimes the best way to probe is to remain silent and wait for the participant to continue.</p>

The interactive nature of the interviews is consistent with Lather’s (1986) concept of reciprocity, which implies a “give and take” between the researcher and study participants. A status shift between the researcher and researched should be evident, specifically, the researcher should transform from stranger to friend over the course of the study. Reciprocity facilitates the empowerment of the researched and contributes to the overall construction of meaning. In order to attain full reciprocity, Lather suggests that interviews be conducted in a manner that is interactive. Specifically, researcher self-disclosure is essential. Additionally, sequential interviews should take place in order to “facilitate collaboration and a deeper probing of research issues” (p. 266). Participants should also have a role in the negotiation of meaning. In this study, member checks provided participants with the opportunity to negotiate the researcher’s initial

interpretation of the interview transcriptions. Namely, participants were provided with both interview transcripts and the story created by the researcher which emerged from the transcripts. Participants were then encouraged to add, subtract or modify the story in a manner that they believed to be consistent with their lived experience.

The interviews were conducted face-to-face, in the participants' homes, in order to facilitate rapport development and a positive relationship between myself and the study participants. This relationship provided the foundation necessary for the depth of personal disclosure I was hoping to achieve through this study.

Respondents included primary caregivers from three families; one family of African-American descent, another of Caucasian descent, and one family of Hispanic descent. The family of Caucasian descent is my family story. Including the story of my family and their experiences in raising a child with ASD served to enhance the trustworthiness of the study. Specifically, the act of experiencing the emotionality associated with having a family member diagnosed on the spectrum contributed to the overall development of the narrative. This association is not something I have ever fully explored nor understood. Therefore, engaging my family and myself in the cathartic process allowed me, as both family member and researcher, to experience disability in a manner which was previously unknown.

Current literature on ASD emphasizes the need for research on families from diverse cultural backgrounds (Dyches et al., 2004; Magana & Smith, 2006). While the current study did not seek to generalize to the cultures represented in the study, inclusion of diverse participants provided preliminary data which will be used as part of a future research agenda addressing culturally diverse families of children with ASD.

Data consist of demographic information and interview transcripts from each of the three in-depth interviews conducted with the three primary caregivers selected for participation in the study. Interviews were audio-taped and conducted in English at a mutually agreed upon time and setting, in the families' homes. The interviews were transcribed by an outside source. However, the transcriptions were reviewed for accuracy by both researcher and study participants. The first interview served as a rapport building discussion in an effort to establish a foundation of trust between the participants and me; the concept of lived experience was addressed along with an explanation of interactive and responsive interviewing. The areas that I hoped to address during the course of the interview were discussed. Respondents were invited to add to or subtract from these areas of interest so that their interview was tailored to reflect their individual lived experience. Additionally, each participant was provided with a tape recorder so that they could begin the process of telling their stories without the pressure of having a researcher present. However, when a subsequent date was scheduled to pick up the participant recorders, all participants indicated that they would rather speak directly to me than into the recorder.

The second interview involved documenting the primary caregivers' stories about raising a child with ASD. Specifically, the interview protocol provided in Appendix B served as a fluid and dynamic tool on which to base the interviews. Participants were asked to detail their lived experience in raising a child with ASD. I asked participants to begin by telling me "their story" as it related to raising a child with autism. Based on the information provided by the participants, I asked clarification questions as needed. Additionally, if participants did not initially address the categories outlined in the

interview protocol, I addressed them during follow-up questioning which occurred at the end of the second interview.

The final interview allowed time for member checks. Specifically, study participants were asked to authenticate the transcript data, as this process serves to enhance the credibility of the study (Lincoln & Guba, 1985). None of the participants noted any inaccuracies within the transcriptions, however, two of the three indicated an interest in viewing the final “story” once it had been completed. In addition to the audio taping of the interview content, I utilized field notes to document any environmental factors which I thought may be pertinent during the data analysis phase of the study. These factors were used in to assist in the development of the setting and their impact on the overall tone of the interview.

However, this protocol was breached during one of the interviews. When I arrived at the home of the caregiver of Hispanic decent, she appeared disappointed that she would not be able to share her story with me on that particular day. As we had spoken on the phone several times prior to the initial meeting and because I did not want to damage the initial connection that we shared, I made the decision to move forward with the interview on the first face-to face meeting. I did, however, meet with her on several subsequent occasions to review both transcripts and the story itself.

The study addressed the following research questions:

1. What are the lived experiences of diverse primary caregivers in raising a child with ASD?
 - a. What impact did the transition of diagnosis have on the life-course of the primary caregiver?

- b. What coping mechanisms are employed by the primary caregivers
 - i. Do these mechanisms differ across respondents?
- c. To what extent does the respondent experience caregiver burden/satisfaction?
 - i. Do feelings of caregiver burden/satisfaction differ across respondents?

Participants

Participants included persons, male and female, who are primary caregivers in the process of raising their child with ASD. The caregiver from each of the three selected families self-identified with one of the following ethnicities: 1) African-American 2) Caucasian 3) Hispanic, with each ethnicity being represented. Families from each of the aforementioned cultures were selected due to the dearth of current research addressing the lived experiences of diverse caregivers and their experiences in raising a child with ASD (Dyches, et al., 2004; Magana & Smith, 2006). Again, while this study did not seek to generalize to the larger cultural populations, the examination of the lived experience of culturally diverse caregivers will provide preliminary data for future research agendas designed to specifically investigate the relationship between culture and lived experience. While females are the predominant gender represented in studies examining stress, coping mechanisms, and burden/satisfaction of caregivers to individuals with disabilities, particularly in earlier works (Quinn, 1999; Katz, 2002; King et al., 1996), this study did not limit participants on the basis of gender. However, the majority of individuals who responded to recruitment efforts were female. The sole representation of the male gender

occurs in my family story as it was the preference of my family members that they be interviewed as a cohesive unit.

As the researcher's primary language is English, all caregivers selected for participation spoke English fluently as translations of interview data can be difficult and have the potential to result in inaccuracy (Halai, 2007; Corbin & Strauss, 1998;). In particular, words that carry significant meaning in one culture often lose this meaning when translated into another language and culture (Halai).

Upon Institutional Review Board approval, study participants were recruited through networks at the university where I hold a position. Specifically, the director of a program designed enhance the physical activity for students with developmental disabilities and a mentor teacher in a local school district, served as my primary means of recruitment. I provided them with recruitment brochures (Appendix C) which described the study in user-friendly terms. Caregivers were asked to communicate their interest in participating through the network and/or directly to me by phone or email. Only two responses were received, one from a mother who self-identifies as African-American and one from a mother who self-identifies as Hispanic, as such, there was not a need to contact participants not selected for participation as all interested parties were included in the study. The Caucasian family selected for participation was my own family.

Demographic information was collected prior to the interview, through the use of a self-reported questionnaire (See Appendix A), and included: a) marital status b) ethnicity c) SES d) family structure e) age f) education level g) occupation.

Purposive sampling, a nonprobability method, was employed as there was a "clear rationale or criteria for selecting the participants" (Champion, 2002, para.8). Specifically,

this study was looking for caregivers of children with ASD and who self-identify with one of the following cultures: African-American, Caucasian, or Hispanic. More importantly, selected participants were able and willing to share their experience with me through interactive interviews.

Variables

Due to the design of this study, there was no need to manipulate an independent variable nor examine the relationship between an independent variable and a dependent variable. However, there were several variables within the context of the study which had an influence on the results. These variables included: participant gender, SES, participant-researcher rapport, family dynamics, and researcher and participant biases. Because the aim of this study was to examine the lived experience of diverse families from a narrative perspective, the aforementioned variables were not controlled as their presence helped to define and inform the family story as well as make a contribution to the overall dynamic and authenticity of the data. However, participant ethnicity and language were controlled to an extent, as criteria for inclusion indicated that participants should self-identify with one of three ethnicities as well as speak English fluently.

Instruments

I developed a dynamic interview protocol, which is provided in Appendix B, to include components of lived experience. Although this instrument was developed in advance, it simply served as a guiding mechanism for the interviews. The protocol was not provided to study participants prior to the interviews as the categories addressed on the protocol might have had a limiting effect on the type of information participants chose to disclose during the interview sessions. However, the content of the interview

was not limited to the categories included in the protocol; it was dynamic in the sense that I used probing questions tailored to the level of disclosure provided by the respondents. Subsequently, the individual respondents' experiences and individuality are reflected in the transcription and tend to deviate from the originally developed protocol as I did not want to stifle nor limit the respondent's story. The following categories were included in the protocol and served as a foundation on which to build a discourse on the lived experiences of raising a child with autism. A more detailed protocol can be found in Appendix B.

1. diagnosis
2. coping mechanisms
3. caregiver burden/satisfaction
4. family culture
5. service availability/accessibility
6. school experience
7. community experience/participation

Data Analysis

Narrative inquiry is much more than the simple telling of stories (Clandinin et al., 2007). Rather, narrative is a complex methodology which incorporates interpretation, art, literary practices, and the goal of capturing the lived experience of others. According to Ellis (2004), the goal of this qualitative form of research is to create a sense of social awareness and empathy. Further, researchers seek to evoke "emotional experience in readers, give voice to stories and groups of people traditionally left out of social scientific inquiry, produce writing of high literary/artistic quality, and improve the readers',

participants', and authors' lives" (p. 30). The current study utilized a narrative inquiry methodology to explore the lived experiences of primary caregivers of children with ASD. The data obtained was explored and analyzed through the following methods.

Frank (1995) describes the distinction between thinking *with* a story, and thinking *about* a story. The first can be termed narrative analysis, whereas the latter is referred to as analysis of narrative (Bochner, 2006). Thinking *with* a story requires the researcher to engage in self-reflection and identify the different ways in which the story is representative of or has an effect on his/her experience as an individual. Further, thinking *about* a story involves critically analyzing the content of the story in order to identify the larger themes and patterns within the stories themselves (Ellis, 2004).

In this study, a combination of both narrative analysis and thematic analysis of narrative was utilized. Specifically, during the narrative analysis phase, I provided insight into the ways in which the stories influenced me and my future directions as a researcher, as well as my experience as a family member of an individual with ASD. These experiences were interwoven into the participant stories in a manner that simultaneously provides the reader with insight into my lived experience as well as the lived experience of the study participants. Field notes and problematics (Peshkin, 2000) facilitated the interweaving of the professional story with the family story. Specifically, the italicized portions of the participant narratives are illustrative of my reactions towards and my interpretations of the participant stories. The non italicized portions represent the storied life of the participant. Kiesinger (1998) emphasizes the importance of telling a good story, which involves writing an "evocative, believable account" (p. 15) that speaks to "not only to the minds of readers but to their hearts, emotions, bodies, and interior selves"

(p. 15). I had to negotiate narrative and historical truths in order to achieve a balance between story and accuracy of story elements including “time, place, mood, tone, and character” (Kiesinger, p. 15). While the goal of the study was to accurately portray the lived experience of study participants, a story which is engaging to the reader was also necessary. This required me, as the researcher, to make decisions regarding inclusion and exclusion of interview related dialogue within the final narrative. The selected dialogue components are the ones which contribute to the overall ebb and flow of the constructed narrative, while at the same time, preserved the authenticity of participant lived experience.

In the second phase of data analysis, participant stories were analyzed in order to identify common themes through a thematic analysis of content (Ellis, 2004; Polkinghorne, 1995). Thematic analysis involves identifying, analyzing and reporting themes within the data. Specifically, the researcher plays an active role in identifying patterns/themes, selecting those which are of interest to the researcher and the larger study and finally reporting these patterns/themes to the readers. (Taylor & Ussher, 2001). Identified themes then served as a basis for constructing and organizing the larger narrative work which was designed to “illuminate the content and hold” (Ellis, p. 196) within the stories of the study participants. However, the main focus of the analysis was the story of the participants combined with my own personal journey within the experience. Therefore, the primary mode of representation was narrative analysis.

The story is layered with traditional analysis in order to gain a deeper understanding of autism and lived experience. Initially, the interview data was transcribed verbatim from the audio tape recordings. Additionally, field notes were used

to identify changes in voice tone, emotion, and demeanor that may have occurred during the interview process. These changes were noted in the margin of the transcripts.

There Are Survivors (Ellis, 1993) is an exemplary piece in which the author shares her experience coping with the passing of her brother in a tragic airplane crash. Ellis shares her experience in a storied format, drawing the reader into her pain and loss. It is only after the story has been told that she begins to undertake a traditional form of analysis where she connects “lived experience to research in sociology of emotions to engage readers in topics that are usually overlooked by social scientists” (p. 724). After the participant stories were told and my story was interwoven through the use of metanarrative reflection, I connected the lived experience to research on the life-course, caregiving, ASD, and other pertinent literature that served to guide the interview protocol. This layer involved a thematic analysis of narrative, namely the stories were analyzed and discussed within relevant literature. This traditional analysis comes at the end and is separate from the story, as the goal was to provide the reader with an evocative account of lived experience, not an analysis of the experience; the story takes precedence over the traditional form of analysis.

In the thematic analysis phase of the study, I immersed myself within both the interview transcriptions and the narratives which were developed from the transcriptions. Through continuous readings and negotiation of the narratives, emergent themes and the themes set forth in the interview protocol were identified, the latter which were informed by literature in the field. As the nature of the study allowed for serendipitous findings, themes were not limited to those set forth in the protocol. Connecting the lived

experience of raising a child with autism to literature in the field provided the reader with a deeper understanding of current issues facing caregivers and families.

Validity

In qualitative research, the concept of trustworthiness, which encompasses credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985) have replaced the traditional terms of internal and external validity and reliability. Specifically, the credibility of the study is determined by the researcher and the reader (Hoepfl, 1997). The reader must be confident in the researcher's ability to respond to the research environment and study participants (Patton, 1990); this study intertwines researcher reflections, or problematics (Peshkin, 2000), within the participant story. Through the use of problematics, I was able to illustrate my responses to and interpretation of the environment and respondents. The italicized portions of the text represent my reaction to the participant; it is an internal reaction and was not communicated to the study participants. During member checks, the italics were removed and study participants only had access to the dialogue that was created from the interview transcriptions. Verbatim transcriptions were also provided to participants. The use of problematics, along with member checks, and maintenance of descriptive field notes, which are viewed as a lens for establishing validity, contributed to the overall triangulation of the data (Creswell & Miller, 2000; Eisner, 1991). Triangulation of the data demonstrates that researcher interpretations are consistent with data collected during the interviews with study participants, thus enhancing the credibility of the study (Lincoln & Guba, 1985).

Traditional quantitative researchers may perceive the inability to generalize this study to a larger population as a limitation, qualitative research utilizes the concept of transferability. Transferability addresses the degree to which the findings allow us to view our experiences in a new way (Eisner, 1991). Further, Ellis (2004) defines generalizability as the way in which the story speaks to the reader “about their experience or about the lives of others they know or unfamiliar lives” (p. 361). This study sought to represent the lived experiences of respondents through a storied format with the goal of evoking an emotional response within the reader, thus meeting the criteria of transferability set forth for qualitative research.

Limitations and Researcher Identity

While I have never had the experience of raising a child with ASD, I have worked extensively with students with ASD and have a family member who is diagnosed with Asperger’s Syndrome. These experiences present a source of researcher subjectivity. However, instead of viewing these previous experiences as a limitation of the study, they were viewed rather as a means of entrée into the lives of study participants as they provide a common ground on which to begin the exploration of lived experience. The use of metanarrative reflections illustrated my subjectivity as a researcher and the ways in which it impacted interpretation of the data. This self-disclosure, or researcher reflexivity, contributed to the validity of the study (Creswell & Miller, 2000). Further, incorporating my own family story illustrated my vulnerability as a researcher, thus contributing to the overall reflexivity of the story.

Harry (1996) posits the notion of “researcher personas” (p. 296) and how these personas guide the way in which she identifies with the families she studies; her *insider*

status. This *insider* status, in turn, influences the decisions she makes as a researcher. Thus, it was important for me to identify my own researcher personas and the potential of these personas to effect the decisions I made as a researcher. While I have never had the experience of raising a child with autism, I have had multiple experiences interacting with individuals with autism, including a family member, who is diagnosed with Asperger's Syndrome. I acknowledged the potential bias as a result of these experiences and accepted the role these biases may have played in the interpretive piece of the study. In order to fully disclose these biases, I incorporated my own family story so that the reader may easily attain entrée into my lived experience as the researcher of this study. Further, my identification with a Caucasian race/ethnicity also presented an issue of bias as study participants embodied both similar and differing cultural backgrounds. In interpreting the participant interviews, it was imperative that I acknowledged my own biases and how these biases may have influenced the interpretations (Harry). In order to limit the bias in the overall narrative, study participants were provided with the opportunity to examine my interpretations for accuracy. No inaccuracies were noted and all participants indicated their satisfaction with the way in which their story was portrayed.

At this point I feel as though a more thorough description of my "family member" diagnosed on the spectrum is warranted. Tanya, by definition, would not be considered my family member. However, I had an extensive relationship with her brother and the rest of her family for a period of seven years which spanned through college and graduate school. I started dating Cameron when I was 20 years old. We met in college, fell in love and spent every waking moment together. His family was my family and my family was

his family. We were all together on the holidays, we went on vacations, his mom would call me “just to check in.” This was my family for seven years, they were everything to me and they still hold a special place in my heart despite the fact that the relationship between Cameron and myself dissolved a little over a year ago. This group of people represents everything a “family member” means to me. They have been there for me in good times and bad, they have seen me at my worst and at my best and they have never judged. Cameron’s sister, Tanya, is someone with whom I grew very close during those seven years and we still maintain a phone/email relationship today. Tanya is diagnosed with Asperger’s Syndrome. We always had a special bond because, according to her, “I got her.” Despite the fact that I “got” Tanya, I came to realize that I did not “get” her family’s experience. I often reprimanded Cameron for the way he spoke to his sister and held back feelings of anger towards other family members when I felt as though they did not treat Tanya in a way that was, according to my training, appropriate. After a major blowout between Cameron and I over the treatment of his sister, I decided I wanted to learn more about what raising Tanya was like for his parents. I was convinced that they would “take my side” and Cameron would see they error of his ways. What I anticipated learning could not have been further from the truth. I had very little knowledge about what it was actually like for Cameron and family. What I learned changed me in a way that I will never forget. It inspired me to seek out the stories of families, to really hear what they have to say and to do so without making judgments. They are my true inspiration for this study and the reason why I decided to include their story and my journey within the current study. Pseudonyms have been used throughout in order to

protect the identity of the interview participants. Additionally, the names of schools and identifying locations have been changed.

Prologue

My passion and dedication to the education of individuals with exceptional needs grew out of my own experiences within the educational system. This may lead you to believe that my experiences in school were so positive that I decided I wanted to give back what I had been given. That is only partly true. Truthfully, it is primarily the negative experiences which my family and I were subjected to that continue to resonate in my memory today. Had it not been for a supportive teacher I had in high school and the constant encouragement from my family, I wonder if I would be where I am today.

I was in first grade; it was Easter time. I remember because we were coloring Easter Bunnies as part of an art activity. I decided to color my bunny white because, at the time, I had a bunny at home named Abby who was an albino. I proudly brought my completed worksheet up to my teacher who looked at it, then looked at me and shook her head. “Heather, look at Stephen’s bunny, how brightly it is colored. Why are you so lazy?” She added injury to insult by tearing up my picture in front of me and handing me a new blank worksheet with the instructions to make it look “more like Stephen’s.” I will never forget the embarrassment and shame that I felt at that moment. This is when my self-confidence began to deteriorate.

Over the years, my mother was brought in for countless meetings after I had (unsuccessfully) been tested for gifted not once, not twice, but three times. “She just does not have the capacity to succeed at this level,” they would tell her. Middle school was a

little easier because of the fact that my teachers pretty much left me alone. My parents were over the moon when they found out that I had been accepted to the IB program at the local high school, and not wanting to disappoint them, I decided to attend the program. I became involved in numerous extracurricular activities including track and cheerleading. Once again, my academics began to suffer and my mom was summoned for a conference. All of my teachers were there, along with the IB Principal and guidance counselor. I listened while, one by one, the teachers spoke of my failings, my lack of potential, and alternative options for my final year of high school. "I have seen absolutely no growth," I think you should begin considering community college options," "she is just not cut out for the rigorous nature of the program." I watched tears fill my mom's eyes and I felt ashamed, embarrassed, and unintelligent. Then it was Mr. Walsh's turn to speak. He looked at me, looked at my mom and then faced all of the teachers. "You are all wrong about Heather. I see tremendous potential in her and I believe that she can successfully complete this program." Somehow, he managed to convince everyone to give me another chance. I will never forget how much his words meant to me, inspired me to become something better, to show those other teachers exactly what I was capable of. It was at that moment that I made the decision to become a teacher.

I excelled in my undergraduate and Master's studies while receiving positive evaluations from supervisors during my field placements. I knew special education was my true calling when I volunteered in an Elementary classroom where students with exceptionalities were included for part of the day. I enrolled in the special education elective courses during the last semester of my undergraduate work and chose the special education track for my Master's degree. During my student teaching I worked with

students with a wide range of disabilities including students on the Autism Spectrum. I loved coming to school each day and challenging myself to develop new and creative ways to present the material so my students would understand and retain the information. After graduating with my Master's degree, I began working at an elementary school as a special education teacher. I loved my job but soon realized that I was often perceived as the "time-out room" by teachers who were frustrated by their students' behavior. Many teachers saw the students in special education as "Heather's kids" despite the fact that "my" students were included for more than 70% of their day in the general education classroom. I soon became frustrated with my characterization as the "disciplinarian" and approached my Principal to discuss the possibility of conducting a training with the general education teachers. My goals were to address effective strategies to use in the classroom as well as my role as the school special education teacher. I was quickly rebuffed with the explanation that there was no time for such a training and that she would be sure to clarify my role at the next faculty meeting. This clarification never manifested and I came to the realization that many of the general education teachers were not adequately prepared to work with students with special needs.

It was this realization that inspired me to pursue a Ph.D. in the area of Special Education. I thought that if I could effectively prepare teacher candidates to collaborate with general educators and other multidisciplinary team members that I would, in turn, be improving outcomes for more students. The decision to leave the classroom was a difficult one for me but knowing that I would still be making a difference in their lives eased my anxiety and quelled my hesitation.

I enrolled in the Doctoral Program in the summer of 2005. At this point, I had been dating my college boyfriend, Cameron for five years. His sister, Tanya is diagnosed with Asperger's and I frequently used my new found classification as a doctoral student and special education teacher to legitimize my "knowledge" about individuals on the autism spectrum. I reprimanded Cameron for the way he spoke to his sister. I constantly reminded him that she was not "severe" as she was diagnosed with Asperger's. This led to many altercations and frustration on both ends. I was frustrated that he was not listening to me and did not understand the autism spectrum. He was frustrated because I did not understand his experience as a brother of an individual with an Autism Spectrum Disorder (ASD). The constant misunderstandings inspired me to seek out the experiences of his parents. I was certain that they would corroborate my perspective and Cameron would be proven wrong. My prediction was further from the truth than I ever could have imagined.

Chapter Four

Donna and Marty's Story

Donna and Marty Kurtis are Caucasian parents in their late-fifties, have been married for almost forty years and have four children who range in age from thirty-two to twenty-seven. Cameron, my former partner is the youngest at twenty-seven, followed closely by his sister, Julie, who is twenty-nine. Tanya is thirty and Brad is the oldest at thirty-two. Donna and Marty both come from Irish Catholic backgrounds and have lived in the same house since before Brad was born. It has undergone several extensive remodels making it look much newer than its thirty-six plus years. Donna runs a manufactured home resale company which is lucrative considering the central Florida town in which they live. Marty recently retired from an executive position at a manufactured home company but still participates as part owner of a senior living and golf course/country club community. Their combined household income is well over \$100,000.00 per year and now that their children are grown and out of the home, they spend the majority of their time traveling and vacationing. Their community is a tight knit one and many of their relatives live within 20 minutes of one another. Everyone comes together on holidays and the average attendance at family functions ranges anywhere from 40-70 people. For the seven years I was a part of this family, I attended these family functions and grew very close to many of the extended family as well. Everyone knew who I was and I always felt as though I was one of the Kurtis', Donna

and Marty reinforced this feeling by including me and telling me that I “was part of the family.” No one ever expected mine and Cameron’s relationship to dissolve and many were shocked and, according to Donna, “devastated” when it did. I still maintain a relationship with the family, particularly Donna, Tanya, and Brad’s wife, Anna. Donna recently finished treatment for breast cancer and I feel as though our relationship grew stronger during that time despite the fact that Cameron and I were no longer a couple. The following story begins about six years into the relationship between Cameron and myself and ends in January of this year.

“I seriously can’t believe you! By saying that, you totally negated everything my family has gone through with her. I know you are way smarter than I am when it comes to this, but you didn’t live with it so don’t say things like that when you don’t have a clue!”

Oh God! How am I going to calm him down? I didn’t mean to upset him this badly.

“Cameron, please calm down. I wasn’t intentionally trying to negate your experience. I was just trying to point out that in the grand scheme of things, Tanya is not severe, and for you to say that she is, gives people who don’t know her a completely different perception of who she really is. When you say someone has severe autism, people automatically see a person who flaps their arms or rocks in a corner and has little or no verbal language. I just didn’t want Phil (my friend’s husband) to think Tanya was something she isn’t.”

“I’m just sick and tired of having to defend my family to you. We have been through so much more with Tanya than you will ever know. To us, she is severe, period.”

“But Cameron, I’m just trying to make you understand...”

“I understand just fine, I know what we’ve been through and I see it as pretty severe, regardless of what you think. End of discussion.”

Should I press him further? How can I make him understand that Tanya does not have severe autism. She has Asperger’s syndrome, which is not considered a severe diagnosis in the grand scheme of Autism Spectrum Disorder (ASD).

“OK, conversation over, I just don’t want you to be upset with me. I hope you know that my intention was not to contradict what you were saying; I was just trying to clarify it a bit so Phil had a better understanding of who Tanya was. From now on, I’ll stay out of it.”

“Good, are you ready to go?”

My stomach churns as I think back to how angry Cameron, my boyfriend of six years, was with me at that particular moment. Never in our relationship had I seen so much defensiveness in his eyes. He was defending his family, defending what they had gone through with Tanya. I tried to use my experiences working with students with autism and my knowledge of the disability to help Cameron understand where Tanya fell on the continuum of Autism Spectrum Disorder (ASD). However, that is not what he wanted to hear. I wonder if our problems in communication about this issue will have a negative impact on our relationship in the future.

The argument I had with Cameron spurred me to request an interview with his parents. I wanted to hear their side of the story and try to understand why Cameron was so defensive when it came to Tanya. I knew I could not continue to walk on eggshells whenever Tanya’s disability came up in conversation. My hope was that Cameron’s

parents would provide me with inside knowledge, and a different perspective, about what it was like to raise a child with autism. Although I was apprehensive about approaching them with such a sensitive topic, it was easier than I anticipated. They were more than willing to sit down with me and tell me whatever I wanted to know. I expected a very structured interview where I asked the questions, and his parents answered them. This was not at all the case. I listened while they told me stories of raising a child with a disability. The talking and telling of stories changed my perceptions and allowed me to become an insider to the experiences of a family I thought I knew. The following account portrays one family and their lived experiences of raising a child with autism.

I take a deep breath in an effort to ease my anxiety as I pull into the driveway of a house I have visited on countless occasions during my six year relationship with Cameron. I have never spoken this formally with the family about Tanya's disability and I am anxious to hear what they will share with me.

This family was met early on with the challenge of raising a child with Asperger's syndrome, combined with a physical disability, Attention Deficit Hyperactivity Disorder (ADHD), and characteristics of Obsessive Compulsive Disorder (OCD). Despite the fact that these disabilities were staggered in their diagnoses, their manifestation was present from birth.

Tanya was born in 1977 with a physical disability, which presented itself during delivery. She was born in the front breached position with her feet over her shoulders, pushing forward on her ears. Due to the birthing position, Tanya was diagnosed with a physical disability. She began wearing polio braces, to stretch her Achilles tendon, when

she was 3 months old. At 16 months old, she could barely sit up or walk, but, according to Cameron's mother, "Tanya could talk for days!"

I had to smile when Tanya's mother, Donna, was telling me about her uncanny ability to talk. Tanya still has this ability and it amuses me that it was developed so early in life. I specifically remember the unique experience I had sharing a hotel room with Tanya during Jennifer's, her younger sister, wedding. She sat outside the bathroom and talked to me through the door while I was showering and putting on my makeup. She must have talked non-stop for a good forty-five minutes. She was telling me how excited she was about being the Maid of Honor in the wedding. It was a moment of pride for her and I was happy that this responsibility made her feel important.

My thoughts are interrupted by Donna's voice, who has continued her story of Tanya's early years. "Tanya's preschool years focused on the physical aspect of her disability. She was a toe-walker and would often run around the house on her tip toes."

"I can't even tell you how many times she fell flat on her face," Cameron's father, Marty, offers, laughing.

It is pretty funny, I think to myself. I can just see Tanya now, running across the slick wooden floor in the living room, red curls flying, and then boom! Flat on her face. What a sight!

"Her Achilles was really short, which is why she was a toe-walker, actually, she still is a toe-walker, but it's much better than it used to be," Donna says smiling.

I can detect the slightest moisture in the corner of her left eye. I hope they are still feeling OK about sharing this experience with me.

“When did you start to notice that there was more than just a physical disability going on?” I inquire.

Donna continues her story, with Marty watching her closely and sporadically nodding his head in agreement. “Well, when Tanya went to elementary school, we began to notice her having trouble with math, and more severe problems with her social behavior. She could read anything, but she couldn’t do the math. She just couldn’t grasp the concepts; even the concrete concepts were difficult for her. We worked with her at home, hired tutors, but the math just didn’t seem to stick. I think it was around third or fourth grade that she started being pulled out of the classroom to go to a special class for math. I think they called it SLD.”

“So, was Tanya diagnosed as having a Specific Learning Disability?” I ask, trying to put the pieces together in my head.

“No, she wasn’t diagnosed as SLD, but she still attended the special math class for the extra help.”

I remember that in special education, when a student is diagnosed with one disability and is receiving services for that disability, they are also eligible to receive additional special education services, such as academic remediation.

I attempt to clarify for myself by relating Tanya’s school experience to my own experience as a teacher. “Oh, I see, I had a student who was diagnosed as having a Speech/Language disorder, but I still served him academically because of his initial special education eligibility.”

Donna nods her head in understanding. “I remember the special ed. teacher explaining it to us something like that. Since she was already receiving special education services, she could be placed in the SLD math class.”

“We went through so many diagnoses because as she got older. She had so many different symptoms associated with so many different disabilities. She had a lot of the symptoms of Obsessive Compulsive Disorder.”

Marty interrupts, “She still does, but they are not as severe as they used to be, thank God.”

Donna agrees with her husband and continues her story without the slightest bit of hesitation. “I couldn’t go anywhere unless I told her where I was going. Even then she would run to the door, look out, and make sure I was getting into the car like I said I was. When she was younger, she wouldn’t let me out of her sight. If for some reason she couldn’t find me, she would have a complete meltdown.”

“Tanya was also diagnosed with ADHD. She was put on Ritalin, then Adderall, and now she is taking Dexedrine. I was against the medication at first, but once I saw that it gave her some kind of relief, I accepted it. As she got older, the behavior problems became more severe and we were so frustrated because she never fit into any disability category. She was acting out so much, especially in middle school, and more so in high school. She was always in trouble for getting into fights with other kids. The other kids teased her and she would go after them. She also started stealing. Our town is small so everyone was aware of what was going on. Let’s just say we owed people a lot of favors when it came to Tanya.” Donna lets out a nervous chuckle and continues.

“The parents of the kids she was fighting with or stealing from would call the house. I would have to calm them down, apologize, and convince them not to call the police or go to the school principal to get Tanya suspended.”

I cannot believe what I am hearing. It was evident to me that Tanya had a disability, illustrated by her difficulty with social situations. I have observed this aspect of her disability first hand, but never knew about these behavior problems. Not being privy to this information makes me feel as though I have been an outsider for the past six years. I am finally beginning to understand why Cameron always becomes so defensive when it comes to Tanya. I have been spreading my so-called “knowledge” and didn’t have the slightest clue about what went on.

“I finally got to a breaking point where something else had to happen. I was at my wits end. I had four children and I felt as if I was neglecting three of them. It wasn’t fair to them. Our doctor in Tampa recommended that we take Tanya to a specialist in Boston who studied children who had both ADHD and Asperger’s. This was the first time we had ever heard of Asperger’s and we were excited about the possibility of finally finding a place where Tanya fit, so we made the decision to take her to the specialist in Boston.”

I am amazed at the detail with which Donna tells the story, she remembers the doctors’ names, the dates, and descriptions. It’s almost as if she is in a trance as she is telling the story; so focused. I have so many questions, but I do not want to interrupt her.

“We flew up to Boston and met with the specialist during Tanya’s sophomore year in high school. He sat with her while we watched through the double-sided mirror. He did a bunch of tests on her, and showed us this checklist of Asperger’s symptoms at

the end of the testing. Tanya had all of them! We just felt tremendously relieved to have finally found a place where Tanya fit.

“But we were scared. They didn’t give us a lot of hope for where these kids would be in ten to twelve years,” Marty adds.

“But,” Donna continues, “We were so excited to share the information with Tanya’s teachers. We thought now that we had an accurate diagnosis Tanya would get the services she needed. Unfortunately, no one really knew anything about Asperger’s because it was a relatively new concept for our small town. Tanya fell back into the same old routine of acting out. She was so unhappy because she didn’t have any friends and her siblings did. She would make friends for a little while, but they would only be her friends until the money ran out, then they were gone. We talked to Tanya’s psychiatrist about her lack of friends, and she explained to us that Tanya was an outsider. So she tended to attract other outsiders. It was at that time that she recommended sending Tanya to a special school, away from here.”

From the strained look on Donna’s face and the way her brow is furrowing, I can tell that this was a difficult decision for her and Marty to make.

“How did you react to that suggestion?” I ask.

“At first I was totally against it. I was afraid of what people would think if I just up and sent her away. I look back and realize that I should not have cared about what anyone else thought. I finally came to the realization that I needed to do this, it was best for everyone--for us, for our other children, and for Tanya.”

“That must have been a hard decision for you two to make. How did Tanya respond to the decision?”

“It was a very tough decision. We both lost a lot of sleep over it,” Donna says, looking over at Marty, who finally sees an opportunity to add his two cents.

“We went to visit three different schools--one in Boston, one in Pennsylvania, and one in Vermont. We decided on the one in Vermont because of the different things they offered. There were two staff members for every student. The academic programs were very structured, which is exactly what Tanya needed, and the living arrangements were *really* nice. The price was a little expensive, but we wanted what was best for Tanya, and fortunately, we had the means to do it.”

But what about the families who do not have the means to do it? What do they do? Are they not also entitled to “the best?” It is unfortunate that SES impacts the quality of services that are available to children with ASD.

“Tanya didn’t see it as fortunate,” Donna continues. “She had a complete meltdown. She didn’t want to go at first, but after we took her up there for a visit and an interview, she was more receptive to the idea. We had to go through an application process, complete with interviews, which I thought of as a formality. Tanya was so worried about not being accepted into the school. That was really interesting to me, because I didn’t think there was any way they *wouldn’t* take her. Tanya just wanted to be accepted somewhere. She had been an outsider for so long. She just wanted to find a place where people would like her for who she was, not for how much money she had on a particular day or what kind of gifts she gave.

I hope my face isn’t giving away the sorrow I am feeling right now. I wonder if Tanya realized that she was an ‘outsider.’ Were her feelings hurt by her so-called friends, or did her deficit in social skills mask her ability to perceive their shallowness?

“Tanya started attending Ridge Valley in Vermont her junior year of high school. She wasn’t allowed to talk to us for the first two weeks she was there. It was part of the program, but it was really hard for her, and us. The director of the school would check-in to let us know how she was doing, but we weren’t able to talk to Tanya until the end of her second week. Even then, the length of the conversation was limited to ten minutes.”

“Did Tanya’s behavior improve with her being in a different, more structured environment?” *Before Donna has the chance to answer, I anticipate what she is going to say. I’m sure it must have. Look at Tanya now. She rarely acts out anymore, she lives on her own. Sure, her ability to read and respond to social cues is still questionable, but overall, it seems as though she has made a marked improvement.*

“No, it got worse.”

“Really?” I ask, flabbergasted.

“Oh God! It was horrible. She would have a best friend one day and the next day they would be in these terrible fights. Not the cutesy fights either, physical fights. She was stealing phone cards and running up bills on our credit card. Tanya had no concept of what was right and wrong with guys. She disappeared at a hockey game with some guy and they couldn’t find her. At one point, they called us and said that she wasn’t going to be able to stay because they couldn’t keep her safe. So we hired a support system-- graduate students to help look after her while she was at Ridge Valley.”

“When she went to Champlain for college, we had to do the same thing. We hired grad students in special education and psychology, who needed extra money, to essentially baby sit Tanya.”

“So did Tanya graduate from college?”

“No, we had to bring her home, it just got so bad. The inappropriate behavior..”

“She maybe passed like ten hours, that’s it,” Marty interjects.

“So we made the decision to bring her back here. But we couldn’t live with her, not anymore. It was just so unfair to Cameron. He was the only one still at home.”

“His buddies would come over here and Tanya would flirt with them. I mean it was bad!” Marty exclaims, his eyebrows raised.

“She was obsessed with the computer and online. She would get online and run up credit cards that she wasn’t supposed to. Heather, we have paid \$2500 phone bills, twice. \$2500 in one month! \$800 another time, some guy from Winter Haven, somehow she charged his credit card for all these phone calls she was making to Vermont. It was all we could do to stop him from pressing charges. We have to get behind her and clean up the mess and she just does not know the consequences. She doesn’t realize; it’s just not there.”

Why wouldn’t Cameron tell me any of this? It is understandable that he would want to protect his family, but had I known this, it is possible that a lot of our communication issues could have been avoided. No, do not place the blame on him, our challenges have been just as much my fault. I should not have made judgments.

“Tanya actually got hurt in Vermont. She went someplace, to a bar, some guy beat her up, took her money and left her on the side of the road. Then she comes home and beats up Cameron. She threw the phone at him and hit him in the head with it. I told her that I had had it. I took her and told her that we were going to move her into an apartment. I couldn’t have her hurting Cameron. I think it was easier because she had

already been away for a few years. It was probably the most peaceful time of our life. I know that sounds horrible, but for our other children, it was necessary.”

I admire Donna and Marty’s vulnerability right now, their willingness to share this experience with me. It hits me that I, like Tanya, have been an outsider. Not in the same sense, but an outsider nonetheless. I question my previous interactions with Cameron, and regret some of the comments I have made about his insensitivity towards his sister. It would have been nice if I had tried harder to see where he was coming from instead of forcing my educational jargon onto him without acknowledging his lived experience.

“Is the apartment you moved her into the same apartment she lives in now?”

“Oh no! We’ve been through apartments too,” Donna says, shaking her head. “She was asked to leave the first complex she moved into because she was harassing a police officer who lived in the apartment below her. Tanya would feed the officer’s cat and the lady asked her to stop, but Tanya continued to feed it. Tanya would always go down to the officer’s apartment to talk and try to make friends with the lady, but the lady didn’t want to be friends. Tanya has a hard time reading social cues, so she kept persisting and the lady ended up reporting her to the office. She also had loud parties and got into trouble for that as well, so they finally asked her to leave.”

“In between all of this, Tanya held at least 30 jobs, I’m serious, at least 30, if not more. She worked herself through the entire mall over there: Burdines, Belk, Best Buy, Kmart, Home Depot. It’s always co-workers; she just can’t get along with them. You know when it’s coming. She would start to complain about someone hating her and she would have meltdowns all the time. You know, throw temper tantrums, scream at us for

no apparent reason, and accuse us of trying to control her life.” Donna sighs in exasperation.

Marty continues, “It was around that time that she decided to run off with one of those magazine selling groups. It was essentially a cult. They brainwashed her into going on the road with them to sell magazines.”

“She called to tell us she had lost her job. She got into it with one of her managers at Kmart and started screaming at him. She actually got banned from the store! We begged her not to go, but she left anyway. She called and told us to come and pick up Nikki (the family dog) because she was leaving. We went over to get Nikki and she was gone. The place was filthy. We didn’t hear from her for two weeks.”

I can see the strained look on Donna’s face as she re-tells this experience.

It is difficult imagine the feeling of having a child run off and leave. I speak to my parents every day. The thought of going two weeks without talking to them is absolutely unfathomable to me. As a parent, I think that not hearing from your child, especially one who has a disability, for two weeks would be agonizing.

“She finally called the day before Father’s Day to say that they were leaving the state. She wanted to go out to dinner with the family for Father’s Day before they left. I told her that these were things she wasn’t going to be able to do anymore if she was going to be gone all the time. She wouldn’t be able to do all the things with the family that she was used to. I told her ‘I don’t know how you feel about it, but it really breaks your mom’s and my hearts.’ That really seemed to bother her and she asked us to come and get her,” Marty sighs, as if preparing for the final blow.

“We went to pick her up; she had to sneak out so she could come and meet us. At that point we had to appeal to a different side of her. How are you going to get your teeth cleaned? How are you going to get your prescriptions filled? All of the things that she thought we controlled because we didn’t want her to have a life, she realized we did because we *wanted* her to have a life. She really broke down then. I just remember how filthy she was when we picked her up. She was at some nasty motel where she had been sleeping on the floor. We took her to a nearby restaurant to eat and she started telling us about how they would eat at gas stations. If she didn’t get any cash from her magazine sales, she had to sleep on the dirty floor of a motel. It was just terrible. Tanya decided that she wanted to come home. After we were finished eating I went up to the motel room to get Tanya’s things. One of the girls threatened me. She said that Tanya wasn’t going anywhere, and I said ‘oh yes she is. I am her mother and she is leaving right now.’ I was just so afraid! Then Marty came to the door and got Tanya’s things, but I was just so scared. We got into the car and tried to leave, but they stood right in front of the car so we couldn’t.”

“And I got out of the car and almost hurt somebody. I took out my phone and threatened to call the police.” Marty says, making a fist with his hands.

“The manager of the group came out and said ‘oh no, no, Tanya can go.’ They had her Nintendo, her games, her wallet, her money, her watch, but they said it was locked in the room. They promised to meet us the next morning and give it to us. Of course, we never heard from them again. Right after that incident, 20/20 had a special on those kids saying that they were all abandoned, or outsiders, that did not have any place to go. That’s just one of our roads with Tanya.”

“Sometimes we just have to sit back and say we shouldn’t feel sorry for ourselves, we should feel sorry for her. Having the diagnosis really helped with that. Just to know that there were other people out there, who were like her, was really comforting.” Donna lets out a sigh of relief, as if she is reliving the experience as we are talking, thankful that her daughter is safe.

“I definitely have less patience with her now though. I just feel like I don’t know how to deal with her sometimes, it’s so frustrating. If she’s angry at us, she will call the house ten and twelve times just to yell at us for trying to control her.”

Debra’s short, tight words illustrate the frustration she feels because of Tanya’s actions.

Cameron used to tell me about Tanya’s obsessive calling, but I always reprimanded him for his insensitivity. “She can’t help it,” I would say. “It’s not her fault, it is part of the disability. You should try to be a little more understanding.” In retrospect, I realize that, as an outsider, it was not my place to reprimand him. He has lived with Tanya day in and day out. All of my interactions with her have been brief and meltdown-free; my experiences are insignificant in comparison to Cameron and his family’s lived experience with Tanya. Who am I to make judgments about an experience I know so little about?

“It’s even more frustrating because she never forgets the things she thinks we do wrong. But when it comes to her acting out, she forgets about it immediately. If we are still upset with her two hours after the incident, she doesn’t understand what she did wrong. She thinks it’s over and done with.”

“Looking back on the past 29 years of Tanya’s life, things have definitely been difficult, but at the same time, we really don’t know any other life. Taking Tanya to her therapy sessions, we look around and see the others, who are usually much worse than Tanya, and we think well, maybe it’s not that bad.”

I can tell the interview is coming to an end as Marty and Donna begin exchanging stories with each other about recent incidents they have encountered with Tanya. The love in their eyes for each other is apparent. They have shared the experience of raising a child with autism and their marriage appears stronger than ever. Marty and Donna’s communication is open and honest and I sense a genuine connection between them. Memoirs written by parents of individuals with autism continuously reference the spouse as a participating partner of the marital unit. Spouses work together to advocate for their child and the services to which they are entitled (Boushey, 2001; Welteroth, 2001). This collaboration is what has strengthened Marty and Donna’s marriage as well as their ability to communicate effectively. I hope that my relationship with Cameron can overcome our current communication obstacles and we can come out on the other side with as much love and admiration for each other as his parents have for one another.

“Thank you so much for talking with me about this, I learned so much about your experiences. I definitely have a newfound appreciation for you all,” I say smiling.

“Well, thank you, but I’m not sure if we handled everything the way we should have. We just did the best we could,” Donna says.

I raise myself up off of the navy leather sofa and walk into the family room where Cameron is laying on the couch watching TV.

“So, babe, how did the interview go?” Cameron asks with a hint of sarcasm in his voice.

“It was very enlightening for me,” I reply honestly. “I had no idea how many serious incidents your family has gone through with Tanya. I have a completely different understanding and appreciation for you and your family.” I search Cameron’s face for some kind of sign to continue. He nods his head in agreement and wraps his arms around my waist.

“I’m glad that you were able to hear it from my parents. I don’t think you ever really *heard* me when I would try to talk to you about Tanya.”

“I know, and I’m sorry. I thought you were just being a typical younger brother; that you were reacting to Tanya with more frustration than understanding. I never wanted to discredit what you and your family have gone through. All I know is what I’ve learned through my course work and my own personal experiences in the schools. I realize now that my experiences are completely different from you and your family’s experiences. I had no right to make judgments.”

Cameron smiles and nods his head and I know all is forgiven. He was initially a bit resistant to my suggestion for an interview with his parents, perhaps he was embarrassed or maybe he was trying to protect his sister, I am not sure which. Either way, he appears relieved that I know and even more pleased that I admitted the error of my ways. I believe that this interview will allow me to see Cameron and his family in a different light. I mentioned initially that I have often become upset with the family about a tone of voice, action, or comment towards Tanya, it is my hope that my newfound knowledge of the family story impact the way in which I respond to such situations in the

future. Part of being a professional is to listen to parents, however, their stories fall on deaf ears if we are consistently placing value judgments on what we hear.

In listening to Donna and Marty's story, I am humbled. I did not know as much as I thought I did. I saw myself as an insider, privy to the cutting edge research, educational terminology, and rich with experience. It turns out I was just the opposite. I was an outsider when it came to this family's lived experiences, just as Tanya is seen as an outsider by many others because of her disability.

In order to fully understand and appreciate the story of Cameron's family, I had to "unlearn" (Merzer et al., 2001) what my previous experiences had taught me. Putting my judgments aside, I learned the importance of the family story and the impact it can have on the professional story. In order to fully understand where parents and family members of children with autism are coming from, we must negotiate the way in which our professional story influences our interpretation of the family story. As professionals, we are outsiders as we are not privy to the lived experiences of the family. When families make the decision to share this lived experience with us, it is imperative that we listen without making judgment. Taking the time to validate interpretations and honor other's lived experience is essential in future communicative interactions. This newfound knowledge will guide my future research with diverse families and their lived experiences in raising a child with autism.

The second interview with Donna came after the relationship between Cameron and myself had dissolved. However, when it came time to make the phone call to Donna, I felt very little apprehension about contacting her for a subsequent interview. We had exchanged cards back and forth a number of times within the past few months but I had

not actually seen her since before I moved to California in August 2008. I made the initial contact with Cameron because I wanted to make sure he was OK with me contacting his mother. "I know they would love to hear from you," he said through the phone. "My mom asks about you all the time. I think they ask about you more than they ask about me!" he says jokingly. We exchange pleasantries for a few minutes more and make plans to meet up when we are both back in Florida at the end of the month. I feel nostalgic as I pick up the phone to call Donna.

"Hello?"

"Hi, Donna! It's Heather, how are you?"

"Hi, Heather! It is so wonderful to hear from you. Cameron told me that you might be calling. How are things in California? Are you loving it?"

"I am still adjusting, but overall I am doing well. How are *you* doing?"

"Oh, you know, just trying to keep my spirits up and think positively. I am in remission though so we are keeping our fingers crossed."

"That's wonderful!" I say enthusiastically. "I have thought about you a lot over the past few months and I am so happy to hear that you are doing well."

"Thanks sweetie, the gifts and cards you sent me really helped keep my spirits up."

"Well, good," I say with a smile "that was the intention."

We both laugh and talk for a few more minutes about life in general and my new career in California.

“The dissertation is coming along but I was wondering if you might be willing to do another interview with me? You guys are the inspiration for my study and I would love to speak with you further about your experiences if you are up for it.”

“On one condition,” Donna says. It is difficult to tell if she is joking or being serious.

“And what is that?” I ask anxiously.

“Well...Cameron told me that you would be back at the end of the month and we would love to see you. Do you think you could come and visit us at the house? I will let you interview me to your hearts content,” she laughs. My stomach does a flip and I feel a little emotional. That house has so many memories for me, all wonderful, all missed. The thought of going back almost brings me to tears.

“I would love to come and see you at the house,” I say without hesitation

“Great! It will be so wonderful to see you and catch up. How about the first Saturday you are here? We could do around 11am or so and then have lunch.”

“That sounds perfect,” I say smiling. Donna sounds truly excited to see me. I am looking forward to the visit as well but feel a little uncertain as to what the dynamic will be like once we are all under the same roof again. Will it be conducive to the interview? Will I hold back from them? Will they hold back from me?

As I turn onto the Kurtis' street I am reminded of all the times we spent together during the seven years Cameron and I were together. Driving to the house today seems different, feels different. I am struggling to hold back tears as the memories come flooding back. I take a few deep breaths and manage to compose myself before I pull into the familiar driveway. I look up and see Cameron coming out of the house towards me.

He opens my car door and gives me a hug. “You look great!” he says genuinely. “As do you,” I say, giving his signature khaki shorts, t-shirt and flip flops a once over. “Come on in, my mom is the only one here but she is excited to see you, she has been talking about you all morning.” I smile and some of my initial fear begins to subside. Just walking into the house brings back familiarity, the smell of the Creamy Nutmeg Wallflowers to which Donna is addicted, the pristine kitchen with what look like my favorite peanut butter oatmeal cookies on the counter, and the glass jar of peanut M&Ms which sit on the family room table. Donna once told me that she fills it up every time I come over because she knows they are my favorite.

“Heather!” Donna exclaims, pulling me close. Her embrace is long and hard, bringing me close to tears again. She puts her hands on my shoulders and looks at me, taking me in, her eyes moist as well. “You look gorgeous, I love the dark hair, California suits you.”

“Thank you. You look amazing as well. It is *so* good to see you,” I say, giving her another hug.

“It has been way too long.” Cameron takes this as his cue to exit and mumbles something about going to wash the car. I get the feeling that the interaction between Donna and myself may have made him uncomfortable by reminding him of what “was.”

“Help yourself to some M&Ms, I put them out just for you....and, I made your favorite cookies,” she says with a wink.

“I already scoped them out,” I say laughing while simultaneously taking a handful of M&Ms. Donna and I walk into the family room and take a seat on the same navy leather sofa where the first interview took place. I ask permission before turning on the

tape recorder and Donna just gives me a smile and says “of course, you know you don’t have to ask.” I place the tape recorder on the antiques coffee table and face her. “We talked before about your experiences with Tanya and you gave me some amazing insight into what it is like to raise a child with Autism. You are the true inspiration for my dissertation and I just want you to know that.”

Donna smiles and tilts her head, “well, we see you as an inspiration as well. Look how far you have come these past seven years, we are so proud of you.”

“Thank you,” I say lowering my eyes. One of the biggest strains on mine and Cameron’s relationship was the fact that I went back to school. I went from being an elementary school teacher with nights and weekends off to a full-time doctoral student where finding time to do laundry was next to impossible. I know that Donna is aware of this fact so hearing her say that she and the family are proud of me is really meaningful.

“That really means a lot to me. This dissertation is the final hurdle so I am really looking forward to being done.”

“I can imagine!” Donna laughs. “So, what can I tell you Heather?”

“Well, last time we spoke a lot about the experiences you have had with Tanya and the overall process you have gone through. Today I would like to know a bit more about how those experiences impacted you as a person. How did your life change as a result of having a child with a disability?”

“It definitely changed in a lot of ways. I was working full-time at Shady Brooke (the family’s community and golf course) right up until Tanya was born. I had planned to take a couple of months off to transition Brad to the new baby. Things did not really go as planned. As I mentioned before, Tanya was born with a physical disability so we

constantly going back and forth to the doctor. Trying to find a babysitter who we felt comfortable with was next to impossible so Marty and I made the decision that I would stop working, at least for the time being.”

“How did that make you feel?”

“Honestly, I was OK with it at first but then I started to feel,” Donna pauses and searches for the right word, “trapped.” She says almost inaudibly. “I know that is wrong on so many levels but that is the honest truth. I felt trapped in my own home.”

For some reason this admission does not surprise me. Donna has always been someone who is constantly on the go. Whether it was work, shopping, going on trips, organizing a family function, playing Bunko with the girls, or sewing new cheerleading outfits for the local squad, she was always involved in something. Imagining her “trapped” at home with two small children is very difficult for me as it does not represent the Donna with whom I am familiar.

“Just going to the grocery store was a challenge. I felt as though all of a sudden I had all of this responsibility and no time for myself. I got pregnant with Julie when Tanya was one and a half so that added to the burden as well. Cameron came not long after and before I knew it, I had four children all under the age of six. It was an absolute madhouse here, I felt incompetent more often than not and I broke down and cried on a regular basis. I never did anything with just myself and the children because I felt as though I could not handle them all. Tanya was such a handful. Had it not been for her disability, I think things would have been a lot easier. The other three children were very well behaved and looked after one another. Tanya was different, she absolutely consumed me.”

Raising four children with typical development would be a challenge! Adding a child with a disability into the mix must have really been difficult for Donna, especially since they were all born in such a short period of time. I think it is sad that Donna looks back and sees parenthood as a burden and wonder what could have been done differently in order to alleviate that for her. When I think about becoming a parent, the term burden is something that is furthest from my mind and I begin to wonder if it was Tanya herself which Donna considered the burden or the actual task of parenting four small children. Was Tanya able to sense that she was a burden? How might this have impacted her?

“I felt as though I was spending all of my time with her and no time with my other children. I became almost resentful. This is probably not painting the best picture of me right now, is it?” she looks at me questioningly.

“This is *your* story Donna, there is no right or wrong, good or bad. You are being honest about what you felt, that does not make you a bad person, it makes you human.”

“Thank you for saying that, sometimes I feel as though I did not do right by Tanya, but I also feel as if I did the best I could considering the circumstances,” I nod my head in agreement as Donna continues her story. “We did not have a whole lot of family support because everyone around here was having kids around that time so they were all busy with their own. Our parents were living in Michigan at the time so they were not around. The only people we had to count on were each other. Marty was wonderful. He offered to quit working and stay home with the children because he saw how miserable I was. You don’t even know how badly I wanted to take him up on that offer,” she says with her fists clenched. “I was just so tired and drained. In the end I decided it did not

make sense for Marty to give up his income because he made so much more than I did. The fact that he offered is what stands out in my mind though.”

It is easy for me to visualize this unselfishness on Marty's part as I have witnessed it first hand many times. He is the quiet strength of the family, always ensuring that everyone is taken care of and happy. He takes his role as a husband and father very seriously and his love is unconditional.

“Once Tanya started school at four years old, I got a little bit of reprieve. Julie and Cameron were still at home and I was finally able to give them the attention they deserved while Tanya and Brad were at school. It was not the ideal situation but at least they got something, I felt as though I had been neglecting them since they were born.”

All through college, Cameron and Julie received care packages, cards with cash, and other extravagant gifts. After we graduated, Donna would frequently “treat” Cameron and I and Julie and her boyfriend to vacations, dinners, and concerts. I wonder if this is her way of trying to make up for the guilt she feels about neglecting them during the early years of their life.

“So, I would say that, overall, Tanya has impacted my life in a very significant way. Not all of it has been bad but it has definitely been a challenging road for the whole family. We thought twice about going on vacations because we didn't want to have to deal with any of Tanya's meltdowns away from home. Going out to dinner was difficult and a lot of times we left Tanya with a babysitter while we took the other three children. They needed time with us too, and at home, Tanya took the majority of our attention.”

I am not really sure how I feel about this confession. I understand the need to give all children attention but how must Tanya have felt being left at home with the

babysitter? Perhaps this is what Donna and Marty needed to do in order to feel as though they were doing right by all of their children. I do not know what it was like for them, perhaps this form of avoidance was a form of coping for the family.

“I didn’t really go back to work until we sent Tanya to Ridge Valley either so that was difficult for me. The decision to send her away was difficult but we felt it was the best for her, our other kids, and us! Marty and I went over it and over it and over it again until we were finally OK with our decision. Tanya completely lost it when we told her but after we visited the place she was more open to it. This was not until high school though. I don’t even know how we did it for so long, we were at our wits end with her. We were feeling guilty about not paying enough attention to Cameron and Jessica, Brad was already in college. The years she was gone were so peaceful. I know that sounds horrible but it is the honest to God truth. The stress level in the house went *way* down and we felt as though we had our lives back. I started working part-time again and my mood really improved. Looking back I think I may have been a little depressed during those years because I always felt that despite everything I did, I was a failure.”

My heart swells, I have never seen Donna this vulnerable before. Openly admitting that she felt as though she was a failure as a parent is not something I ever would have imagined her saying. I know that Donna has always been hard on herself, especially when it comes to family functions. The house has to be pristine, remodel after remodel has taken place in order to make it perfectly presentable. Food must be beautifully presented, there is always way too much of everything. She literally breaks her back to please everyone. It must have been very traumatizing for her to constantly feel as though she was failing as a mother.

“I think that you are a great mother, and I cannot imagine you ever being a failure,” I say in an effort to comfort her. “It must have been tough for you but I am sure that you did the absolute best you could, your best is all you can do.”

“I finally realized that somewhere down the line,” Donna says smiling. It has definitely not been an easy road. Sometimes I still feel as though I am micromanaging Tanya’s life. But, I know if I don’t, she will not take the responsibility. I make her dentist, doctor, and hair appointments. I manage her finances, pay all of her bills, fill her prescriptions, and keep track of her oil changes and things like that. She just can’t be trusted to take care of those things. She gets so mad at me when I remind her to do certain things, like take her medicine, but when I don’t remind her, she forgets. It’s like a no-win situation. I worry about what will happen when Marty and I are not around. What will she do? I don’t want the other kids to be left with the burden and I have tried to teach Tanya how to take care of these things, but she just doesn’t get it. That is a big worry of ours, what will happen after we are gone. Tanya has a Godmother and Godfather but they are older as well so that is not a permanent solution.”

Donna appears stressed and her voice becomes strained. I understand her concerns as I have seen how Tanya lives. Even though she lives on her own, her place is frequently in disarray and she is unable to find important things. She has challenges with money management and relies on her parents to take care of various facets of her life.

“We will figure it out at some point, it just weighs on us. We want everyone to be taken care of. So, anyway, I am not sure what else I can tell you. You mentioned the impact on my life and it has been huge. There has been stress, there has been resentment, there has been lack of sleep! You never know what you are going to get with Tanya. I

love her to death but it really has been difficult. I did not think that I would be 56 years old and still managing my 31 year old daughter's life. It is a big responsibility but I have adapted to it. I used to feel guilty about going out of town and on vacation with Marty because I was worried about Tanya. You know we have a lot of family in the area and they have really stepped up; telling us that they would keep an eye on her while we are gone, call to check in with her, that kind of thing. The other kids all live out of the state so we can't rely on them to look after her. So having the family step up to the plate has also given us a break. Definitely not the life I envisioned but I would never change anything. Tanya is a great kid, she has her little idiosyncrasies, but we love her anyway," Donna smiles and sighs simultaneously. We talk for a few more minutes about Tanya and then move into the kitchen where Donna has prepared finger sandwiches, veggies and dip, and of course, my favorite peanut butter and oatmeal cookies. Cameron magically reappears from washing the car, as if on cue, and we all sit at the bar and munch on the snacks. We talk for another hour or so, Cameron's new sales job in Kansas City, my life in California and the exciting news that both Brad's wife and Julie are expecting. Not wanting to overstay my welcome, I start to get up.

Donna looks up. "You are leaving already?"

"I don't want to monopolize your *entire* afternoon, just part of it," I say with a smile.

"Well, it was great to see you, we really miss you, Heather." I sneak a peek at Cameron through the corner of my eye and he is looking at the ground.

"I miss you guys too, let's not be strangers."

“You could never be a stranger to us, please keep us updated on how you are doing.”

“Consider it done,” I say moving towards Donna for a goodbye hug. We embrace and I can feel the emotion building in my throat. She walks me to the door and hugs me again. Cameron follows me to the car and opens my door for me. We exchange goodbyes and he leans in to give me a hug. I feel the emotion rise again and it takes every ounce of self-control I have not to cry. We hold onto each other for awhile, almost as if we are afraid to let go. I pull away first, afraid that I will not be able to hold back the tears if I hold onto him any longer.

“Drive safe, text me when you get home,” he says gruffly.

“Will do,” I manage. He closes the car door and I immediately reach for my sunglasses before he can see the tears that are about spill out of my eyes. As I pull out of the driveway and begin my journey home, I know in my heart that our relationship is truly over.

I have since spoken with Donna several times but the conversations with Cameron have been few and far between. We are both trying to move on with our lives and the best way to do that is to minimize our contact. At this point there is still too much emotion involved for us to maintain a friendship but I like to think that someday this will be possible.

As I am in California, I emailed Donna the completed story, minus the italicized portions, to obtain her thoughts and approval. She indicated that she “loved the story” and “hopes that it will help other parents who have been dealing with some of the same

issues.” She also reiterated that reading the story gave her a newfound appreciation for what she has been through and the knowledge she has gained throughout the “process.”

“You know, talking about everything I have been through with Tanya helped me to realize that maybe I did not do such a bad job after all. I mean, look at how far she has come. I think sometimes I forget about all the progress we have made since day one, thank you for helping me to remember.”

Chapter Five

Sandra's Story

Sandra was referred to me by a colleague at Sonoma State University that I enlisted for assistance with my recruitment efforts. Sandra indicated her interest in participating to my colleague and I was then forwarded her contact information. After exchanging a few brief emails, Sandra and I connected by phone. She told me a little about her son, Justin, who is 15 years old and was diagnosed with Pervasive Developmental Disorder at the age of four. We talked briefly about the study, I explained the anticipated time commitment, she confirmed her willingness to participate and we set up a mutually agreeable time for our first meeting. The phone calls and emails were very businesslike and I felt a little apprehensive about the first meeting with Sandra. On the phone she told me that she was fine with the interviews because she was so used to talking to the psychologists and doctors about Justin. This raised a red flag for me because I do not want my caregivers to see me in the same light as they see a psychologist or a doctor. My purpose is not to provide them with clinical information or answers but rather explore their experience and the associated emotion of the experience. I struggled with how I could communicate this without appearing overbearing or presumptuous. Because of her previous interactions with the doctors, I was afraid that she might not be willing to share the emotionality of her experience that I was hoping to achieve through this study.

Sandra self-identifies as African-American and lives in a small town in Northern California where the population is 3,764; with 92% identifying as Caucasian and only 0.5% identifying African-American. The town can be classified as predominantly middle class as 70% of the families report a household income between \$30,000 and \$149,999. Sandra's family falls within the upper range with a household combined household income of over \$100,000 as self-reported through the demographics information sheet given to participants at the outset of the study. She completed some college and works full-time as a manager of a national chain retail store. She lives in a 4 bedroom house with her oldest son, Darren, her younger son Justin, and her husband Paul. Sandra is the oldest of 4 children. Her brother in-law and one of her sisters live on the property in an adjacent house.

As I pull into the long driveway at 11:00am on a Monday morning, I notice a beautifully landscaped garden and walkway that leads to the main entrance of the house. Sandra emerges through the open garage door before I manage to get out of the car. She greets me with a hesitant smile and an extended hand.

“Hi Sandra, it's great to finally put a face with a name,” I say enthusiastically.

“Nice to meet you as well, why don't we go inside?”

As I step into the house I notice that it is a lot larger than it looks from the outside. It is tidy and I notice that the Christmas tree is still standing and decorated in the room off of the kitchen, despite the fact that it is now the end of January. Sandra leads me to the kitchen table and motions for me to sit. She takes the seat opposite of me.

“So, here I am, what can I tell you?” she asks.

“Well, as I mentioned on the phone, I was hoping that this meeting could serve as a rapport building session, you know, give us an opportunity to get to know one another and become comfortable with each other. Sometimes reliving the experience can be an emotional thing because all of the memories are brought back to the surface...”

Sandra nods her head in agreement. “It is kind of an emotional thing, actually, if you look back on some of it. I can remember a couple of moments where I was pretty emotional, but it’s not all bad. If you don’t mind me asking, what is your motivation for this?”

“I don’t mind at all! I taught Special Education at the Elementary level for a number of years and I always sort of gravitated towards children with autism. I found them incredibly interesting, that is probably what started my interest in autism as a disability. As for my interest in families, I have a family member that is diagnosed with Asperger’s Syndrome. I always thought I knew everything there was to know until I actually sat down with her parents and listened to what they had to say. I felt as though I had all of this knowledge because of my experience in the classroom. I came to find out that I knew virtually nothing about what it was like for families of children with autism.”

“Parent experiences can be totally different,” Sandra says slowly.

“Yes, I found that sitting down with my family members and asking them about their experiences really opened my eyes to the differences in perception between families and professionals in the field and allowed me to understand what we can do to help families more. I think a lot of times families feel as though...”

“No one understands,” Sandra interjects.

“Yes, exactly. So, that is why I am doing this, because I learned so much from my family members.”

Sandra smiles, “that’s cool,” she says. “I was really excited when Elaine asked me if I wanted to participate, I think it is important for people to understand what it is like for us and if I can help someone in the process, well then that makes it even better.”

I feel relieved as Sandra begins to open up. I believe telling my story made her feel more comfortable showing a little vulnerability, which I can tell is not an easy thing for her to do.

“Well, I am really excited that you are willing to participate as well. I am looking forward to learning more about Justin and what it has been like for you as his primary caregiver. I do have a tape recorder that I will leave for you so that you can talk openly about your thoughts and feelings without the pressure of having an interviewer present. I would like to pick it up before our next meeting so that I can get more of a feel for your story. Is that OK with you?”

“That sounds great. I am not sure if I will use it, I really do not feel any pressure to talk about Justin, it is kind of nice to have someone who wants to listen. Maybe I will try and get my husband or sister to talk about their experiences.”

“However you would like to use the tape recorder is fine with me, you have free reign. When would you like me to pick it up?”

“How about a week from today? I have off on Mondays and 11:00am is a good time for me, is that OK with you?”

“That works for me as well. I will give you a call the day before to confirm. You have my contact information, right?”

“Yes, right here!” she waves a yellow legal pad

“Great! Please call me if anything comes up, questions, concerns, whatever. It was really wonderful meeting you Sandra and I am very much looking forward to hearing more about your experiences.”

“Thanks, Heather. I will give you a call if anything changes, if not, I will see you next week.”

I stand to leave and Sandra walks me to the door. She tells me more about her garden and how much she used to love working on it on the weekends. “No time anymore,” she says, shaking her head. “I finally had to break down and hire someone to take care of it, such a shame.” I nod my head in agreement and comment again about how beautiful it looks. She smiles and continues walking towards my car. We shake hands again and exchange goodbyes. I get into the car feeling a bit better about the upcoming interviews. Sandra began to open up about her experiences and I saw the pain in her eyes when she mentioned that raising a child with autism is an emotional process. However, I also feel as if she is somewhat guarded, which is completely understandable considering that this is our first meeting. However, I am unsure as how to begin breaking down the walls that seem to surround her.

When I arrive at Sandra’s house the following Monday, she meets me outside and greets me with a familiar smile. “Hi, Heather. It’s great to see you again! I have to tell you that after we spoke last time, I started thinking about what it had really been like for me these past 11 years.”

“That’s great!” I say with a smile. “Did you use the tape recorder to record your thoughts?”

Sandra looks a little bit embarrassed. “No, I didn’t. I would rather talk to someone than something. It is really nice just to have someone to listen to you.”

I feel my heart do a little dance in my chest. I am truly flattered that Sandra would rather speak with me than to the tape recorder. I am also fraught with the realization that this could be a common feeling among parents to children with a disability. Do families just want someone to listen to them? Hear them? Acknowledge their experience?

“Well, that is what I am here for!”

“I know this was just going to be a short meeting so that you could pick up the tape recorder but do you have time to do the second interview today?” Sandra asks nervously.

I actually had not been planning on a two hour interview today but it would break my heart to say no to her. She appears anxious, hopeful, almost desperate, to talk to me. She fidgets while awaiting my response and looks down at her shoes.

“Of course! I have all the time in the world,” I say with a smile.

“Really?” Sandra asks skeptically.

“Absolutely! I set Mondays aside as my research days so I have nothing scheduled for today.”

Her face lights up, “great, well come on in then and we can get started.” I follow her into the house and take the same seat at the table from last week. Sandra surprises me when she decides to sit next to me, as she sat across from me last Monday. I turn my chair to face her and she looks expectantly at me for direction. “Why don’t you start by telling me what you thought about after our first meeting.”

“I started thinking about how it all started. Just before Justin started elementary school, he was going to preschool. And the preschool teacher kept saying, “I don’t think he can hear”. And I’d say, “yes he can hear. He can hear just fine”. And she kept saying “no, I don’t think he can hear.” So finally I said, “okay.” I had already taken him for all his checkups and stuff. And I knew he could hear, but I went to the doctor anyway.

I can hear the frustration building in Sandra’s voice as she speaks, it seems as if she is reliving the moment in her mind, remembering how she felt, her hand slaps the table with emphasis as she says “he can hear!”

She sighs and continues. “So we took him to the doctor, and that’s when everything started. The doctor said, “whoops!” I think he was a little bit embarrassed that he did not catch it right away, because we went to all the checkups and he always told us that everything seemed normal. He ended up referring us to a psychologist because he was not able to make the diagnosis himself. Everything started to change after that day. We ended up getting the diagnosis about 7 or so months after we were initially referred. It was such a pain, going here, waiting, going there and waiting more. I was not really sure what the diagnosis was supposed to do. I knew it meant he would get some extra support in school but I didn’t know what it meant for us as a family.”

I wonder why diagnosing agencies do not initially provide parents with access to or contact information for resources to which they are entitled. It seems as if these “services” are only available to those who actively seek them out or have prior knowledge that they are available; I am reminded of a “secret society” where only a select group of individuals are granted entrée. How is this fair?

“We told my family and my mother pushed me to go for support. I probably would have never, ever done it. Both of us are working parents. We live fairly comfortably. So going for support was not something I wanted to do.”

I feel a little bit caught off guard by Sandra’s hesitation about pursuing services. Perhaps it is my professional experience which has ingrained in me the importance of early intervention that makes me feel this way. However, I know that family coping styles are different, perhaps this was Sandra’s way of initially coping with the diagnosis.

“I have a sister who is kind of slow, she will be 50 this year, and my mother said that she wished she had of gone and gotten services for her. But when we were growing up, that wasn’t something you did. The family was poor. We did whatever we did to survive. My dad worked, my mom worked.”

I begin thinking about the role of culture and poverty plays in the rate at which caregivers to children with disabilities seek out services. Is it a lack of awareness about the availability of services? Or is it a cultural or socioeconomic construct which prevents certain families from taking advantage of the services to which they are entitled?

“My mom never had any support for my sister so she was really insistent. She kept telling me that I needed to go and see what kinds of services were available. She actually sent my sister with me to make sure that I did, can you believe that?” Sandra laughs. So I probably would have never, ever done it had it not been for my mom making me go. I don’t even know how we ended up getting a referral to the services. But somehow somebody knew and they pushed me. That whole thing is kind of a blur for me.”

Sandra looks visibly drained at the memory. She sighs deeply and I think about Tanya, my family member with Asperger's. The detail at which Donna retold the story of diagnosis and the services they sought out was incredible, everything down to the very last detail. I wonder if Sandra's lost memories are a product of her need to maintain an unbreakable exterior during the process. Coping mechanisms vary from person to person and perhaps blocking the experience from her memory was Sandra's form of coping with the diagnosis.

“Once you get the ball rolling though, the services are available to you. But, I am not very good at going after them. I made it work all of this time without the extra services so I figured, you know, what is the point? Some of the services I got by accident, just by asking a question. Sometimes we would get a new social worker and she would blurt something out. I found out that missed out on child daycare the whole time. From the time that Justin started school until last year, we didn't have daycare support. I paid for all of his daycare. And then it comes out that we were supposed to have daycare.

I find myself becoming frustrated. How can this happen? Luckily, Sandra had the means to pay for Justin's daycare, but what about those families who do not have the means? What happens to them? I understand that parents should be advocating for their children. However, how can we, as professionals, expect them to advocate effectively when they are not aware of what is available? We are the ones who are at fault, not the parents.

I thought to myself, oh my God, are you guys going to throw me all that money back? Of course, they didn't but it's all right, you know, if he were normal I would pay for daycare anyway.”

It takes every ounce of self-awareness and control to not visibly cringe at the sound of the word “normal.” My experience as a professional comes at me like a pair of oncoming high beams, I wish I could shut my eyes until it passes...It is not fair of me to react like this. I immediately feel guilty as I become aware of how any change in my demeanor has the potential to change the entire dynamic of the interview, I can see how disconnect between the professional story and the family story can occur.

“I feel really lucky because I had a lot of family support, my family support more so than Paul’s family. His mom helped out a little bit when she was alive, but for the most part, my family did most of the daycare. If we wanted to go out or something, because my folks didn’t really understand that, then his mother would babysit. My parents don’t really understand relaxation. Sometimes Paul and I really just needed some time for ourselves, you know, to go out to dinner or whatever. When I asked my parents to watch the boys while we went out, they told me no. They just weren’t going for it. My mom and dad didn’t understand. They raised seven kids. They never went anywhere. They still don’t do anything. They didn’t grow up that way, they’d say I wasn’t a good parent if I did that,” Sandra laughs nervously. I get the impression that her parents’ words impacted her more than she is letting on. To them it was the stupidest thing on earth, so I had to find somebody else to babysit for time away from the kids.” Sandra shakes her head, looking a little flustered. She pauses briefly, as if trying to figure out where she wants to go with her story.

“So, anyway, back to how it all started. Justin’s pediatrician sent us to a child psychologist for testing to find out really what was wrong. I remember getting the report and I remember my husband saying, oh, he’s not mentally retarded. Because that’s what’s

on the report, mental retardation, PDD autism, and it starts going on into more clinical descriptions of what's going on. I just remember him saying, more than once, my son's not retarded."

I am immediately reminded of my previous interview with Adriana, the mother to a Hispanic boy with autism. Her husband also had a difficult time accepting that his son may be different. Perhaps it is different for fathers; denial as a form of coping with the loss of an idealized son.

"I would also say that there were a couple of moments where I think my family did not understand. For a long time, my dad said, "there is nothing wrong with that boy. He's normal, you guys are just messing him up." My dad was in denial for a long time. He would say that we were not disciplining him enough. But now he gets it, he gets that Justin is different. I still think that Paul's family truly does not understand that Justin is autistic. They just do not seem to get it. And I really was kind of numb more than anything about the whole situation."

Numbness...A feeling unlike any other. A defense mechanism to block the pain of what is really happening. Not allowing yourself to feel, to experience the emotion of the situation. This was my experience when my uncle passed away. I had to remain strong for everyone else in my family as I felt the most removed from the situation. I did not allow myself to feel the pain of loss until I returned home and expressed my emotion through story. I wonder if the story Sandra is telling will be therapeutic to her in the same way it was to me. In a sense, we have both experienced loss of a family member.

After the numbness passed, I realized that we needed to do *something*, we have this diagnosis and we have to deal with it, for Justin's sake, but I didn't know where to go

next. It was getting close to the time where Justin would start school, so I filled out some of the paperwork and included that he had been diagnosed with autism and PDD autism, but the school in Miller Lake did not have special classes. They were not prepared to deal with someone like Justin so they told us not to send him to school. They wanted to have him tested in order to find out where to place him. So, I thought to myself, here we go again!” Sandra rolls her eyes and throws her hands up in the air, indicating her frustration with the process.

“We had to go through more psychologist tests, more doctor visits, more waiting. I could tell Justin was getting annoyed with the whole thing. First they send somebody to the house to talk to the family. They decide that they want to test him; then the school decides that they want to test him too. Poor Justin! By the time we got to the psychologist in Sonoma, Justin just did not want to take any more tests, he was so upset. They give the same tests, over and over, just different versions. And I thought, man, I don’t blame you. He’s just sitting here, and everybody’s looking at him, making him do the same thing, walk this way, do this, look at this, do that. I could see him getting irritated by the whole thing, and I felt for him in that sense.

This seems to be a common occurrence in the process associated with diagnosis. Test, after test, after test. I understand wanting to ensure an accurate diagnosis but it seems almost cruel to subject a child to such a process. Is there an easier way that maintains accuracy but is also less burdensome for the child and the parents?

“He didn’t end up starting school until the middle of the year in January because they couldn’t place him in Miller Creek. There was no special class. So Justin ended up going to a different school for Kindergarten. We definitely had some concerns about him

going to school. We thought that he wouldn't understand or wouldn't be part of what was going on, or that he would get left alone. He did not have a lot of verbal skills at the time so communicating with him was difficult. That was really his issue. He didn't know how to say things. Everything was going really well until one day they lost him. I completely lost it! Sandra shrieks, with her eyes wide and fists clenched. Apparently, he was standing by the flagpole waiting for the bus, but nobody knew where he was. They found him eventually, but what really bothers me is that they turned around and told us that they didn't know where he was. I remember telling the teacher, "now I'm worried about the school system. You know that Justin is special, he starts off in your class, then he goes to the other class, and then he goes back to your class. Shouldn't you be watching him? You are supposed to be taking care of *my* child! This is supposed to be a safe environment and you are going to stand here and tell me that you didn't know where he was?"

Sandra seems angry and I can tell that talking about the school personnel lost her son is bringing old emotions to the surface. You send your child to school, a place that is supposed to be safe, a place where you assume they are being looked after. To have that kind of faith broken must be very difficult. I am left with a feeling of unsettlement.

"It's like Darren, my older son, told me last semester. "I got a 'C' in class at the JC." And I said, "well, that's really good. I'm proud of you." But then he proceeds to tell me how he got the C. He said that he never went to class and barely finished his assignments but that the teacher liked him so he was *nice enough* to give him a 'C' when he really should have failed. So, I was like – don't tell me all that. That's information I don't need to know. If I had just known that you had gotten the 'C' I would have been all right. So, if I had just known that Justin got on the bus and came home that day, I would

have never known that he was standing by the flagpole and nobody could find him, and that they didn't know where he was at the time. That is when I lost all faith. I actually told the teacher "okay, now I have no faith in you people."

Fear...that is what I detect in Sandra's voice. She is reliving the experience while telling the story and it is having an emotional impact on her. Looking back on my years in the classroom, I wonder what I would have done in this situation. I think, for ethical reasons and to appease my own conscience, I would have confessed to the parent as well. However, as I try to envision myself as a parent, I am left feeling a bit perplexed. On one hand, I would absolutely want to know of the school's error so that I could take steps to ensure it never happened again. Additionally, I would have the option to remove my child from an environment I felt was not safe. However, the loss of faith in the school system, a place that is supposed to do right by our children, would be a difficult thing to handle as well. It seems like a double-edged sword.

"Right after that little incident, we had the opportunity to transfer Justin to a different school. It was the best thing we ever did! He was able to have the same teacher from first grade all the way until sixth grade, at the same school. There were ups and downs as far as the class size but overall, Justin did really well there because it was a nice, structured environment. I think what I learned from that experience was that the teacher could be on your side, but they're bound by what they can say. As we grew more familiar with the teachers, they would say more stuff to you off-record about services and what kinds of things you can ask for. I really am not one of those people who was digging, digging, digging all the time trying to find out what was out there. I always thought that if everything was okay, I've accepted that he's autistic and that he's only

going to be able to do this much, then I don't really need to search for anything else. I didn't know what was out there could help him any more than what we were already doing”

I have seen this all too often in the public schools...teachers who want to tell parents about available services or technology that would really improve the student's outcomes. However, due to current budget crises and the fact that schools have pay for those additional things, parents are often left unaware. Many community organizations offer services free of charge to parents, to this end, I believe that teachers, schools and community organizations should develop partnerships so that everyone is on the same page as to what services are available to which students. This information could then be communicated to parents rather than leaving them in the dark.

“After sixth grade there was Junior High and in this area there are about 15-16 elementary schools that converge into one junior high. It was very different from what Justin had in his special day class. They went through a slew of teachers in those two years so the classroom management was just not there. Everything became distracting to Justin, which made him a distraction to the class. He just could not handle all of the noise and commotion. The school called an IEP meeting within the first few weeks of the year to tell us that this may not be the right environment for him. They really did not have a lot of options for Justin at that school so the Occupational Therapist (OT) decided to take him under her wing. Every time the classroom teachers would have a problem with Justin, they would just ship him off to her room.”

This is all too familiar to me. During one of my years teaching special education at the elementary level, I would frequently serve as the unofficial “time-out room” for

many students with disabilities who were included in the general education classroom. While I did not mind having the students in my room, I felt as if many of the teachers were abusing the “time-out room” because they simply did not want to deal with certain students. This frustrated me, but at least I knew that if the students were with me, there would be some kind of learning taking place.

“One day, she called me and asked me to come down so that I could observe Justin in his classroom; she said she was really worried about him. This, by far, was the most heart wrenching hour ever-- in all the whole process that we’ve gone through.” Sandra takes a deep breath, closes her eyes, as if visualizing the experience in her mind, and continues.

“Poor Justin! I swear, he had his backpack, which he always carries with him. It was like he was on the outside looking in, just on the edge of everything but not a part of it. It reminded me of my sister, who’s a little bit slow, in high school. I was a senior, she was a sophomore. She used to hang out with me all the time. And I’d say to her, “you know what, you need to get your own friends.” Here I am, this is my payback”, Sandra sighs wistfully and I notice the remorse in both her voice and her eyes.

“You need to get your own friends. You can’t hang out with my friends and me because in a year we’ll be gone.” I said that to her! “You need to get your own friends. I don’t want you to hang out with us at lunch anymore.” I used to watch her do the same thing Justin was doing that day. She’d go get lunch. She’d go sit somewhere. Then she’d go kind of sit next to a couple people and sort of talk to them. When they did not talk to her, she just walked around the campus the whole lunch break. Well, that’s what Justin did on this lunch break, and I was so upset! It was like oh my God, I can’t believe this!

He's not really part of a group, but he's in and out. And he seemed to be happy, but you could tell that he really wasn't. Because if you're not part, my feeling is, if you're not part, then you're not really. And so we spent the whole lunch hour watching him just kind of float in and out. That was a big eye opener for me. I had seen it before, and I thought to myself, oh man, this is not good."

The visual of Justin wandering around during lunch breaks my heart and I can see that Sandra is becoming emotional as well. Donna, my family member, also commented on Tanya's "outsider" status and how she always felt as if Tanya was struggling to find her niche in life, a place where she belonged and was accepted for who she was. It can be difficult for children with disabilities to develop and maintain meaningful and lasting friendships and as a result, they "float" through school never really belonging to a certain group or clique. The guilt Sandra feels is apparent by the comment she made about Justin's "outsider" status being payback for the way she treated her younger sister. I see the remorse in her eyes and can tell that this memory still haunts her.

"We spent the rest of the year working on Justin's ability to verbalize more. But the year just was a bust. He didn't learn anything really. I think a lot of that was because he went through three or four different placements that year. I finally I broke down and cried at the last meeting. The school told me that they really did not know which placement was best for Justin but that the placement they were offering was his last and only choice."

"Did that make you feel as if they were just trying to pass Justin along, as if they did not want the responsibility of dealing with him?"

“That is *exactly* how it made me feel! I could tell they just did not want him at all based on what happened in the last two years, not the great five years before that, but the last two years. They really didn’t give me a choice. And I sat there, and I cried.”

Even as I write this now, my eyes fill with tears and my heart swells with emotion for Sandra and all of the other families who have experienced similar interactions with the school system. How agonizing it must be to feel as if your child, your own flesh and blood, is not welcome – unwanted, especially in a place where they are supposed to be building a future. What kind of hope does this give to parents?

“I finally realized that maybe they were right, maybe this was not the best placement for him. There was another time I went to observe Justin and he started banging his head on the door! And I’m like, what is that? I’d never, ever seen that behavior. I mean, he’s got teenage tendencies. He likes girls. He got taken advantage of by a bunch of girls in junior high, because he was in love. “But they’re my friends, mom.” “Okay, your friends don’t take your money Justin.” He just wanted to be liked. He did whatever they wanted so the other kids would like him. But when I came into that class and he was banging his head on the door, I thought to myself, that’s not my kid! That’s not how he is at home.”

I am reminded of my family member, Tanya, who is diagnosed with Asperger’s Syndrome. Her mother told me a very similar story about Tanya and how she would do almost anything to feel as though she belonged, to become an insider, a part of something. She was taken advantage of several times by people who pretended to be her friends so that they could get something from her. I feel sick at the memory. As a teacher, I can now see where some of the animosity between parents and teachers can begin. I

have spoken with parents on several occasions regarding their child's behavior and thought they were in complete denial because they refused to accept that their child "could do such a thing." Looking back, inviting the parent to come and observe so they could see first hand is a logical suggestion. This could help to bridge the gap between home and school and facilitate the development of a positive collaboration between parents and teachers.

“After junior high, he ended up going to a high school down in Glen Park. There were two classes at the school that we could choose from. We interviewed one of the teachers and all she talked about was vocational curriculum. I was really thrown off by that. Justin was only 14 years old and she was already talking about teaching him how to get a job. I felt as though that was all she thought he could do with his life. That's not what I want. I really want for him to continue reading and writing and math, the basic skills that you get in school. Now, I get it”, Sandra says matter of factly. “He's not going to be a scholar or anything like that, but he should be able to reach his full potential in the academic areas. I did not like that there was so much of a focus on life skills. I wanted it to be more on education.”

I smile as I listen to the passion and determination in Sandra's voice. She understands that Justin may have limitations but she does not allow these challenges to get in the way of her dreams and aspirations for her son. I find it truly admirable and silently applaud her for advocating for her son.

“Then something incredible happened, oh my God, if you believe in God or a higher power. Someone must have been looking after Justin and the family.” Sandra clasps her hands together and smiles, the excitement in her voice is evident. “Our cousin

Mike, who had been teaching kids with developmental disabilities for a lot of years, was offered the job as the teacher in Justin's class. I thought, here we go! We get a great teacher-- finally! The classroom makeup is not the greatest but Mike always makes sure that instead of going to the church to help clean or whatever other activity they are doing for their vocational work, Justin stays in the classroom and he does math, reading, or practices writing. In fact, we just had the IEP this month and Justin met all of his goals!"

Sandra is elated at the fact that Justin has met all of his goals. She is practically beaming from ear to ear with pride for her son. One of my favorite memories of teaching elementary school special education was being able to tell the parents that their child was making progress and had successfully mastered their IEP goals. The looks of relief, happiness, and even surprise is indescribable. I often left those meetings with tears of happiness because the parents themselves were so emotional. Letting parents know that you believe in their child is sometimes all it takes to instill a renewed feeling of hope.

"There is one problem with the program though, and I have voiced this concern to Mike as well. The kids have virtually no social interaction. They have their own program, they are on their own bus, they do not integrate with the regular school, the kids just kind of sit off to the side, you know. We started off the school year trying to get them into PE, at least, but there was no room for the special ed. kids in PE, none of the teachers were willing to take them. Mike tried, but being a new teacher at the school and not knowing anyone made it – he was trying but he was never able to get anybody to take them. I think it is really important for Justin to have some social interaction with the rest of the school so we made sure to include it on the IEP for next year. Justin is going to take a regular class, either math, or music, or computers or something."

“Overall, school has been interesting. It has been a journey, learning all of the ins and outs. I guess if I had put my mind to it a little bit more, I would probably be more savvy about getting things for him. Some things you just stumble upon and it turns out to be a really good thing. In my opinion, that’s better than being in somebody’s face all the time. Some parents are really aggressive about that. I’ve never been that way in life anyway, so it doesn’t fit my personality. But I think we’ve done all right for him overall, he’s doing okay.”

“What about *you* Sandra? How do you feel about this journey has impacted *you*?”

“I have definitely had my moments where I cry and wonder why. But I just tell myself, this is the way it was supposed to be. And he’s special. He’s special where he is now. The students in the class look up to him, and they love him. He’s the leader of the class, even though that’s probably not the best place for him to be. I keep saying there should be a world for in-between-ers. Because he can’t be in the real world over there at Miller Lake, but he’s a little too much for where he is now. But, you know, where he is now, he’s pretty happy. That is what is important to me, that is what makes me happy. As a parent, you want what is best for your kids and I feel as though we have done the best we can. I have never felt like Justin’s disability was a burden or anything like that. I love him to death. He’s just the cutest.”

“Did your career path change at all during the course of this experience? Do you think Justin’s diagnosis impacted that for you in any way?”

“I always had a goal of being a retail store manager and the year Justin got diagnosed was the year I was promoted. So, no, I think I am where I would have been anyway. I think that I am way farther than I ever thought I would be. I really didn’t have

a goal of having kids, and I had two of them,” she laughs. I always thought I wanted to be a store manager, I just didn’t know it would be at the store I am at today. I was an Assistant Manager there for 10 years. As far as Justin’s impact, well in retail, a lot of times you can work around some of the things you have to do for your kids. It’s like a perfect job. So, I don’t ever want to be anything other than a store manager. That’s where my head is, so career-wise, I’m okay.”

“Is there anything else you would like to share about your experience?”

“I think it is really important for parents to understand that sometimes they need help. I got plenty of support from my family with babysitting and stuff like that, but it is the normal, everyday type stuff...cleaning, gardening, you know maintaining the house that can really become a burden. So, I think that parents should just ask for help and get support, because it is not an easy road - and the support, it makes a big difference.”

“Thank you so much for sharing your story with me Sandra, it was really powerful and I admire you for how strong and resilient you are.”

“It was great to talk about it actually. I was a little nervous at first because I had this idea that it would be like talking to the psychologists all over again. But it really is nice to talk about it and have someone listen to and understand everything that we have been through. Will I be able to see the final product?”

“Of course, I will call you once everything has been transcribed and we can meet up to review everything, you know, make sure it is accurate. Then, I will write it up and share it with you.”

“How exciting!” Sandra stands and reaches out her arms. I hug her back and thank her again for her willingness to speak with me. We exchange our goodbyes and

make arrangements for a follow-up visit. As I get into the car I begin thinking about the story that was just shared with me. I am deeply touched and impacted by Sandra's willingness to share her experience with me and it makes me wonder how many caregivers just want to be heard, understood, and respected.

Our final meeting to conduct member checks occurred approximately two weeks after the final interview. Instead of going to Sandra's house, we met for coffee at a local café. Sandra's reaction to the story was something I never expected, it brought tears to her eyes. "You know, I have never had anyone to talk to about this and I am so thankful that you were there to listen. I read this and I think, wow, this is *my* experience, this is what *I* went through, this is my *story*. And you know what, it's not half bad," she laughs. It makes me see things from a totally different perspective. When we first received the diagnosis I was unsure and confused and now I feel strong. I feel like as a parent, I have done good."

Chapter Six

Adriana's Story

Adriana is a 36 year old mother of two who was born in Mexico. She moved to the United States when she was 9 years old. She speaks both Spanish and English fluently, although English is her second language. She has a college degree and currently works as an Esthetician in the Day Spa that she owns, she also works part-time in a doctor's office doing skin care. Her husband is Caucasian and works as a business executive in San Francisco. Their combined household income exceeds \$100,000.00.

I found Adriana with the help of a teacher who currently works with our University credential candidates. I was having trouble locating a caregiver of Hispanic decent who was also fluent in English so I contacted her to inquire as to whether she had anyone in mind. She said that she had the "perfect" person for me but would need to ask if she were interested in participating. I heard back from Lisa in a matter of hours with Adriana's contact information. As it was later in the afternoon, I decided to wait until the following day to initiate contact with Adriana. I arrived home around 8pm that night to find the message indicator blinking at me. I pressed the button and was met with an unfamiliar voice. "Hi Heather, this is Adriana. Lisa gave your contact information because you are doing interviews with parents of kids with autism. I would *love* to connect with you so *please* give me a call back at your earliest convenience. I can't wait to talk to you sweetie!" By the time the message ended, I was grinning from ear to ear.

Adriana sounded so excited to speak with me and that made me even more eager to speak with her. There was something about the tone of her voice that immediately put me at ease and gave me a good feeling about the interview. My hand reached for the receiver to dial but I stopped myself as I realized that it was after 8pm and she had a 6 year old child. I certainly did not want to start off on the wrong foot by calling too late in the evening so I replaced the receiver with full intentions of calling her first thing in the morning...well, maybe not *first* thing, but as early as would be polite.

“Hi, is this Adriana?”

“Yes it is.”

“This is Heather, Lisa gave me your...”

“Oh hi sweetie! It is so great to hear from you! Lisa told me all about the interviews that you are doing and I think that it is so great. I would love to connect with you and tell you all about my son Cruz. Does anytime this week work for you?”

“Absolutely! I am free Thursday after 3pm and Friday all day. Is there a particular time that works best with your schedule?”

“11:00am on Friday would be perfect.”

“That works for me as well, I would be happy to come to your home if you are comfortable with that.”

“Oh, absolutely! That would be wonderful, then you can see Cruz’s room and his environment and everything!”

I almost cannot believe the conversation that I am having. Adriana seems so open, so willing, so excited to share her experience. I have not even met her and I can already tell that she is a very dynamic individual.

“That sounds wonderful. I am really looking forward to meeting you Adriana!”

“Same here, sweetie. You take care and let me know if anything changes.”

We exchange our goodbyes and I realize that I did not even tell her anything about the study, its purpose, nor the structure of the interviews. I wonder if I should call her back but then decide that I will explain everything to her when I meet her on Friday.

Friday comes with great anticipation. I am like a kid who is anxiously awaiting a trip to Disney World. I cannot believe how excited I am to sit down with Adriana. I am not nervous as I was with Cameron’s parents, nor am I hesitant as I was prior to meeting Sandra. I feel as if I am going to meet up with an old girlfriend who I have not seen in ages. My GPS chirps and brings me out of my daydream, “arriving at destination, on right.” I look to my right and see a handsome single story house with a wrought iron entry gate. The gate opens as I pull into the driveway and down the incline which leads to the house. The house is definitely under construction as there are dirt mounds and piles of rock which looked to have been pulled up in order to make room for a large landscaping project.

I look to the left and I see Adriana walking towards me, smiling and waving. She is absolutely stunning, one of the most beautiful women I have ever seen. She stands about 5’4, has shoulder length black hair, brown eyes, and dressed impeccably in black pants and a matching blouse. I get out of the car and walk over to meet her. She reaches out and hugs me. “It is so wonderful to finally meet you Heather, I was so excited to talk with you about my son and your work. I think what you are doing is really special and I admire you so much. Please, come on in and pardon the mess. We are in the process of redecorating. It will be lovely once it is all finished.” She goes onto tell me about the

plans she has for the garden area and how the concrete room that greets you upon entering the house is going to be transformed into a formal dining room which overlooks the garden. “Right now, though, the boys love to skateboard across it!” she laughs. I smile warmly at her and tell her what a lovely home she has and how wonderful it is to meet her acquaintance. She leads me over to an oversized dining room table where she sits down at the head of the table and motions for me to sit to her immediate left. “Can I get you some water or lemonade?” she asks, getting up. I politely decline and she sits back down. I thank her again for taking the time to speak with me and take out my informed consent documents to explain the purpose of the study to her along with the format of the interviews.

“So today is just kind of like a meet and greet?” she asks a bit disappointed.

“That is what the intent was,” I say, wishing I would have explained the interview structure that day on the phone. “I was also going to leave this tape recorder with you so that you could have the freedom to talk about your thoughts and experiences without the pressure of an interviewer present.”

She looks at me and smiles, “sweetie, I would much, much, *much* rather talk to you than that tape recorder. I think you are a beautiful person, I just get this amazing vibe from you, like we were meant to meet or something.” I feel my cheeks turn red at her compliment and tell her how excited I was to meet her after we spoke on the phone.

“I felt as though I was having a conversation with one of my girlfriends!” I say candidly.

She smiles, “I was just so excited to tell you everything today, it has been a long time since anyone has wanted to hear about my life with Cruz.” I think for a moment and

wonder how critical it is that I follow the initial interview schedule protocol that was set forth.

I look back to Adriana and say “well, if you feel comfortable enough, I would be willing to do the interview today.” I really hope I do not get in trouble for breaching protocol, I just could not bear the thought of disappointing her.

“Really?” she asks as her face lights up.

“Absolutely,” I say without hesitation. I feel the need to go with my gut on this one. Adriana seems so genuine and I felt comfortable with her from the moment we met. I can always schedule another interview should this one leave gaps.

“So, where should I start? I guess at the beginning right?” she says, laughing.

“That would be great! Do you mind if I turn the tape recorder on now?” I ask.

“Oh sure, that way you won’t miss anything! So, my son Cruz was diagnosed with PDD, which is Pervasive Disorder Development and I had no idea what that was. They said that he was showing some signs of autism but they were not so blown, and that he also had a speech delay. I wanted to learn more about it so I just went on the web and I started researching what that meant.”

Adriana is very animated while she is talking, practically bubbling over with excitement. I wonder if she has ever had the opportunity to talk about her son in this way. She seems so open and honest, almost as if the story has been building inside of her and she has finally been given the opportunity to let it out.

“It has been three years since he has been diagnosed. He is six now and we started the process when he was three. Since then, it has been quite the journey, we are doing a lot of alternative medicine which is really working; it is just so positive. The medical

industry, they just want to diagnose and they want to give you medication and say “OK, go away, you are fine.” But with autism, what we have found out is that their body is so toxic and their system does not break down toxins like normal kids.”

Adriana’s knowledge is incredible. She went searching for answers to her son’s disability and refused to accept the medically based treatment at face value. I find this very brave, as I do not know if I would have the courage to utilize alternative medicine for fear of further impacting my child.

“The doctor gave Cruz ADHD medication and that is even more toxic so I decided to do alternative medicine. Lots of vitamins and supplements and most recently, the hyperbaric oxygen chamber, have you heard of that?”

“No!” I say completely enthralled. “Tell me about it!”

“Well, we have it tonight and I go all the way over the hill to St. Curie. It looks like a tablet and it is what divers use when they go out in the deep sea. When they come back they put them in this oxygen chamber and it stimulates cell production. In kids with autism it has an impact on the pressure in the brain and it kick starts all of the functions that are not connecting properly. It also promotes healthy white cells so it speeds up the process of healing. So that is what we have been doing and it has been amazing!” The excitement in her voice continues to grow as she talks about the impact that the oxygen chamber has had on Cruz. “It has just been so amazing, you know he has some little characteristics. He jumps and flaps his hands and makes little noises but after being in the chamber for 30 minutes, he was just so calm. He laid his head on the pillow, and was just really relaxed. So after the 50 minute session we got out and, no joke, he did not jump-he did not do any of his hand flapping for 3 whole days. It was just incredible.”

“I guess I should have started at the very beginning!” she laughs.

“I don’t mind at all, you can start wherever you want,” I say with a smile. I am truly captivated by her story.

“So, when Cruz was born, I had no symptoms. I had a perfect, healthy pregnancy, he was developing perfectly. But, when he was born, her had thrush. They called it *candida*. I did not know what that was at the time so they told me it was thrush and they gave me this purple-violet medication. I had to do a little swab of it in his mouth and that was supposed to get rid of the bacteria. We did that for about a month and finally it went away. But, what we found out recently is that when a child is born with that, it tends to be internal and you need to be treated with antibiotics. Well, the doctors didn’t do that,” she says shaking her head. “I believe it started there and I think that the *candida* broke down his immune systems because that is what it does. But there were no signs, I mean, he walked early and he even talked at 5 months, he would point, everything developed normally. He was such a good baby, he slept through the night, he didn’t cry. What I did notice though was at about 2 years and 2 months he had his vaccines. MMR, chicken pox and something else, there were 4 shots. So, I brought him home afterwards and he was like “Owie!” and rubbing his thighs. So, I took his pants off and he had hives the size of tennis balls, they just started crawling all over the body.” I gasp audbly. “I know!” Adriana says, a worried look in her eyes. “I called the doctor and they told me that he must be having a reaction to the vaccines and that I should give him Benadryl. I was so scared because the hives were just crawling up his body so I decided to take him to the hospital. Benadryl was not going to do it. I rushed him in and they were like “ooh this is a

really bad reaction” so they gave him a shot to reverse it. After that, I noticed that everything stopped.”

This is not first time I have heard a parent indicate that their child was going through typical development until they received their MMR vaccines. While my professional experience reminds me that studies have shown that vaccines do not cause autism, I find myself questioning the extent to which I believe these studies. Perhaps the vaccines trigger something else within the body that has been dormant up until that point? I do not understand how everything can just stop after a vaccine has been given but yet not be related to the onset. Parents know their children, they know when something is wrong, Adriana is convinced that Cruz’s development came to a standstill after the administration of the vaccine. I feel torn between science and experience.

“He started going backwards, he did not want to talk anymore, he wasn’t happy.” The tone of Adriana’s voice changes and is now somber as she retells the story. “He started getting rashes all over his body, just out of the blue. Just all of these weird things. He started preschool when he turned three and even though his speech went backwards, he was still able to communicate. I said to my husband something is wrong, something is not right. But my husband kept saying that he was just a late speaker. Everybody would tell me, even his pediatrician, told me “he has big brother to do all the talking, he will develop, the younger child always speaks later because they have the older sibling to do all the talking.”

How frustrating it must have been for Adriana to be continuously rebuffed. My mother has always told me that a mother’s instinct is the best kind; it seems as though this rings true for Adriana.

“So, I let it go for the time being and took him to preschool. I told the teacher about Cruz and where he was at, what I thought and about a month into school, she came to me and said “you know Adriana, I really think that your son might have autism.” And I did not know what autism was, it was the first time I had ever heard of it. At first, I was a little hurt by the teacher.” Adriana’s brow furrows and she leans in towards me to emphasize her feelings. “I was like how dare she say that my son have autism because I was just so protective. I guess I always thought that kids with autism were like Rainman or what you see at the state hospital. I never knew what that word meant.”

I admire Adriana’s candidness and think about how much unawareness there is about the disorder. Many people hear the word autism and respond exactly as Adriana did. I hope that these stories will contribute to the efforts designed to increase awareness about the diversity of the disorder and the different ways in which it can manifest itself.

“I came home and I was all freaked out. I was like Oh my God. She is a teacher. To be honest, part of me knew that what she was saying was true. I looked it up on the web and there was a little bit of information, but not like it is now. I called his pediatrician and told him what the preschool teacher had said. The pediatrician said “Oh no! He is not. Do you want me to write her a letter?” I told him no because I did not want to start any kind of fight, but I wanted to know what was wrong. So I asked if I could bring Cruz in for an overview. The doctor said that he would have to send me to a behavior specialist and that it would take a long time. I told him to get the process started because I did not want to wait any longer. In the meantime, he continued to go to preschool and that helped. But, he was not progressing like the other kids. He entered preschool at 3 years old and by the time I got him enrolled in a special day class with the

county he was 3 years, 8 months. So, it took 8 months to go through the process because I had to get him diagnosed through the regional center and then Sonoma county. Let me tell you, it was quite the process. Dealing with insurance has been a complete nightmare!”

Why? Why is the process so long and tedious? I understand the importance of ensuring an accurate diagnosis but it seems as if the system makes parents jump through hoops in order to receive services for their children. We stress the importance of early intervention but when a diagnosis takes 8 months to secure, how is that helpful to the child or the family?

“But, the program that he is now is great, he loves it! The atmosphere just seems really calming for him. He is doing amazing. He is talking- saying three words sentences. He is pretty independent and bright in other areas, but in speech, that is where he was affected. He currently speaks at about a 4 year old level, and he is 6. But, for a while there, he was 5 and talking at a 2 year old level so he has really made a lot of progress.”

Adriana just radiates positivity. She smiles as she tells me how much progress Cruz has made and it is obvious that she is very proud of her son. I believe that the experience is what you make of it. Adriana chooses to focus on the positive, which in turn, creates a perception that minimizes the negative impact of the disability. Disability has typically been viewed through a deficit based lens and I appreciate Adriana’s determination to focus on the positive.

“I think a lot of it has to do with the alternative medicine that we use. I had blood, stool and urine tests done and it turned out that he was really lacking in vitamins. He lacked in B12, magnesium, and especially Vitamin A. Instead of making 80% of vitamin

A like our bodies normally do, he was only making 10%-- and vitamin A acts as an antioxidant so his body was not breaking down the toxins. The buildup made it really difficult for him to concentrate. He felt uncomfortable in his own body, his sensory skills were off. But, since I have started the vitamins, he is like a new kid. He sleeps through the night. I know it sounds like I am complaining about all of this but it has just been such a blessing to me to have a child like Cruz because I totally see a different side of disability now.”

Adriana is so sincere in her words and I can tell she really does see having a child with autism as a blessing. Her love for him is evident in the way she talks about him, her eyes light up, she becomes animated. She has truly embraced the experience. I often wish that Cameron’s family would have seen Tanya in the same way that Adriana sees Cruz. I wonder if their perception of Tanya negatively impacted the amount of caregiver burden that Donna experienced.

“It has just really blessed us in a lot of ways. His older brother, Raul who is 9, is really great with him. I sat him down and explained to him that his brother was special and now he just really takes care of him. We were at this function, at a book fair, and one of the kids came up to Raul and was like “hey, what’s up with your brother? Is he stupid?” I did not say anything because I wanted to see how he would respond. Raul looked at that kid and said “my brother is not stupid. You know, he rides a motorcycle, and it is a gas operated one, do you ride a motorcycle?” and it just broke my heart. I had to turn around because I almost started to cry.”

I feel the tears well up in my eyes and I hold them back. I look down at my notebook to avoid her gaze. I often wished that Cameron would exude the same kind of

brotherly love for Tracy-and maybe he did in his own way. It was never something to which I was privy but I would like to think he would stand up for in the same situation.

“He is just such a blessing to us. You know, God does not give us more than we can handle. Of course, I have my days and I think, can I find hope today? Am I on the right track? Am I doing something to his body that I should not be doing? But I am just the kind of person that tries everything. I read up on the latest research, that is how I found out about the hyperbaric oxygen chamber.”

“Overall, in terms of our family, I just really feel like it has been such a blessing.

This is the third or fourth time Adriana has used the term ‘blessing.’ I am inspired by her positivity but wonder if deep down this is some sort of defense mechanism. I do not want to negate her experience but yet I find myself questioning her overzealousness. On the other hand, Adriana’s ability to positively reframe the experience could certainly contribute to her current perception of the presence of the disability as a blessing.

“Sometimes it can be hard if we go to Chuck E Cheese or a birthday party. I know that it is hard on him, but I take him anyway because I feel that he needs to be exposed to that, he needs to do everything that normal kids do. It can be tough though, when we go to birthday parties the moms will kind of stare at you and then start staring at Cruz. They ask “what is going on with your son?” and at first, I felt-- not embarrassed, never embarrassed-- but I didn’t want to talk about it because it hurt too much and I did not want to make him look bad. But then I figured the more I didn’t talk about it, the worse it was. So, I found that talking about it is easier because a lot of people do not know what autism is and once I explained it, they were more receptive.” Adriana continues talking about the importance of not hiding the disability, indicating that she is unashamed of her

son and his disability despite some of the negative reaction she experienced within the community. “Cruz has been invited to so many more parties and functions now that people know so I am glad I got over the hurt and was able to tell people his story.”

Adriana goes on to talk about her more recent experiences with parents and how blessed she feels to have the life she has been given. The love she has for her family is evident and I can tell that the relationship she has with her husband is one of mutual respect and love.

“And my husband, he is just amazing.” Adriana’s face lights up at the mention of her husband. “He is my backbone and he is just so supportive, my in-laws are wonderful as well. We all work together, you know. We are very close-knit. If I find new research or something I make copies and share it with everyone.” Adriana’s tone becomes more serious. “My family has been kind of interesting though. You know, I have to translate everything for my mom because she only speaks Spanish. At first I was kind of apprehensive to let her talk to Cruz in Spanish because of his speech delay and the school said that I should just speak to him in English so that he doesn’t get confused. But, I thought about it and I was like, no! This is his culture and he is young and he will absorb it and he will learn it. I think it has been great for him too, he does not speak a lot in Spanish, but he understands it all.”

I can tell that Adriana feels strongly about her Mexican heritage and her desire to expose Cruz to it despite the recommendation of the school is inspiring. I feel a bit disconcerted that the school would discourage a second language being spoken, it seems as if they are responding from more of a deficit model where the focus is on what Cruz is

unable to do rather than his potential. Adriana clearly sees her son's potential and capitalizes on it at every opportunity.

“Everyone in our family is just so great, and I know there are a lot of women out there who do not have that support and my heart goes out to them because it is hard.

“I could imagine in a relationship too, that it could be difficult between a husband and a wife, especially for a man. Just recently, I asked Cruz, do you want to play baseball?” And he said “yeah!” I was really excited because sports were always kind of a challenge. So I took him to the T-ball program at the Boys and Girls club but it was too much for him. I noticed that he kind of started backing away and was wrapping himself around my leg. I think just paying attention to your child-- that is just huge because they will tell you what they are feeling. And I knew right then that this was not the right place for him.”

It is amazing to me how Adriana is so in-tune with her son. She clearly has a special bond with him and understands him in a way that no one else does. I find my mind wandering back to Cameron's family and how different their interactions with Tanya were. Donna seems to share that same kind of bond with Julie, Cameron's older sister and I often felt as though Tanya was left out of many of their mother-daughter activities. I question whether or not the bond between Adriana and Cruz contributed to Adriana's ability to positively reframe her role as a caregiver to a child with ASD. Could the lack of this bond be part of the reason for the burden Donna felt towards her role as a caregiver?

“So then I researched the Special Olympics and my husband had a *really* hard time with that. He said “no, Cruz does not belong there.” And I said, “honey it's not

about belonging, it's about what's easier for him and what is right for Cruz. I know you want to say he is good at sports, but the other program is a little bit too much stimulation for him and he is not absorbing it, he is shutting down because its freaking him out." So we talked about it and he just felt strongly that Cruz did not belong there. We went back and forth for awhile—we would talk about it and then not talk about it. We did that for about a month before I just decided to make the appointment and go," she laughs mischievously. "I had the kids all dressed up, Cruz had his baseball glove and we were basically walking out the door. My husband stopped and asked me where I was going. I told him we were going to sign-ups and he said "sign-ups for what?" I said "T-ball for Cruz." I could tell he was a little upset because his face got a little red and he said "I thought we decided we weren't going to do that" and I said no, "you decided we were not going to do that, I did not. You are welcome to come but you have 5 minutes to get ready." He started mumbling about this and that and I told he did not *have* to go," she smiles again and winks. "I told him that I was going because I really wanted to see what they offered. Finally he gave in and told me to wait while he got ready. Let's just say it was a very quiet drive all the way to Santa Rosa.

What tenacity! Adriana truly is a strong woman who wants what is best for her son. It is also apparent that she understands her husband and how he might react to the situation. She did not want to disrespect his opinion as she gave him the option to come along, knowing that he would take the bait.

"When we got there, it was the coolest thing. It was a great experience for my older son because life is not about everyone looking the same and learning the same. Cruz comes up and they do the tryouts and he hits it, he is really coordinated when it

comes to sports. I noticed that while I was filling out the paperwork, my husband was just sitting there, looking around. I think, as a man, it is a lot harder for them to think, Ok here is my boy, but he is not going to be a star player. I think it is harder for them than it is for moms. The most incredible thing happened next, the coach, who has Down Syndrome, comes up to my husband and says “well you look very sporty, would you like to coach?” A smile appears on Adriana’s face and she giggles like a school girl. “The look on my husband’s face was classic! He had no choice but to say yes! It was so perfect! He agreed to be the Assistant Coach and thank God it all worked that way because I think it really helped him see it in a different light.”

Looking back, I wish I would have sought out more male participants. Adriana’s perspective is interesting and it makes me think about the different ways the diagnosis of a child with a disability can impact a man and a woman differently. I also wonder if having a son with a disability impacts fathers more than having a daughter with a disability would. Is the same true for mothers or is it reversed?

“I think in a relationship, in a marriage, I can see where that would be tough, especially in Latin families. For me, because my husband is American, I have a little more balance. But if my husband was Mexican, I think it would be really hard because they are very macho. Their kids have to be perfect, they have to act perfect and being out of line means big problems. It is really interesting, in a Latin couple, in a Mexican couple, the husband is a little bit more aggressive and they do not believe in all of the alternative medicines, they just believe in going to the doctor. So the vitamins and outside services I have gotten for Cruz would not fly if I had a Mexican husband. I have a cousin down south who is struggling with the same, her little boy is 4 and they came to Sonoma

to visit us. And because I have been working with Cruz, I was able to pick up on little characteristics. So, I said to her, I don't mean to get into your life but I really think you should have your little boy tested because I think he is showing signs of what Cruz has. And she says, "oh no, he is nothing like Cruz." I said, "I am not telling you to hurt your feelings but I am just saying that the earlier you catch it, the better because it will take time to get him in the right classes."

"Her husband came to me later and said "oh, no, he is not retarded!" And I said, I am not saying he is retarded, he is far from that but maybe you should do some research on autistic kids because they are brilliant. You might have an inventor on your hands- and I was trying to make it more positive."

How hurtful that must have been for Adriana. I find it admirable that, despite his cruel words, Adriana was still able to shed positive light on the situation. Had I been placed in this situation, I am not sure I could have shown as much class and grace as Adriana was able to do. My first instinct would have been to defend my child, likely leading to an intense verbal altercation. Adriana's capacity to remain calm and collected is illustrative of her acceptance of and devotion to her role as a caregiver to a child with ASD.

"Still, they have not done anything and their little guy can barely talk and they keep saying "oh, you know he just turned 4." Well, at 4 you should be almost reading. The way they are handling it, just makes me feel that I am so fortunate because my husband is very supportive and he is totally into researching the web, let's search for this vitamin, let's see what this does. I am very fortunate to have that because I think if it was

a Mexican father, I would not be able to do those things. It is just interesting to see that dynamic.”

“How did it make you feel, their reaction towards you?” I ask cautiously, anticipating this could be an emotional memory for her

“I felt like they were judging me and I think they thought that Cruz was not smart. They looked down on me, felt sorry for me. The way he came to me when he said, “you know, he’s not retarded,” it took everything I had to stay calm. But then I thought this man does not know much, he is not educated, so I had to forgive his words-- he just doesn’t know. We had a family reunion not long after and I have an aunt, who is very good with Cruz, always loving on him. But she came to me and said, “well, did you drink when you were pregnant?” And I said “no, Thalia, you know I don’t drink.” As a mother you already kind of blame yourself. I have thought to myself, did I eat too much fish? Did I eat something with mercury in it? You just kind of blame yourself for things. Maybe he ate something when he was young that was toxic and you think about all of that. She was telling me that “studies say that if you drink when you are pregnant that...” and I said, “yes, I know the studies but I did not drink and right now nobody really knows where it is coming from.”

I can tell that Adriana has come to terms with her Aunt’s accusations. Her calm demeanor is indicative of a woman who has endured much, but has persevered and learned to accept and cope with the harsh comments to which she has been subjected.

“And now, you know, autism is becoming really prominent in the Mexican channels and I will get calls from my family members in Mexico telling me that the doctors down there are curing it. But I told them that this can’t be cured-- you can heal

the children by teaching them differently and using supplements. But I just think they are very far from knowing what the truth is. Right now, we are just trying to put the pieces together and that has been difficult. We know it is genetic in nature so we both feel guilty, we just want to know how it happened. I can't even begin to tell you about all the directions I have gone in, just to try and put the pieces together so we can say ok, this is the route we are going to take. Ever since we got the diagnosis, we have been trying to figure out which way was best.”

It is not the harsh comments of others that continue to haunt Adriana, but rather the self-blame and guilt that she harbors for somehow contributing to her son's condition. She looks as if she is trying to hold back tears at this point. I want to reach out and touch her hand-let her know that this is not her fault, neither her nor her husband are to blame. Maybe her continued search for the newest treatments is her way of making up for her feelings of guilt.

“Can you tell me a little bit more about how you felt when you received the diagnosis? Were you relieved? Were you scared?”

“You know, I felt upset because I will tell you how they told me. It took 8 months to get this appointment and we were so hopeful! We figured that we would go in and they would help us and we would have all these new amazing things to do to help Cruz. So we go there and they took us into a room and took Cruz into another room. We were able to see through the mirror as they were testing him. It was very bizarre, it was almost like he knew that I was behind the mirror because he kept looking toward it and asking for me. It was a very stressful situation which lasted for about 2 hours. They came out and I asked them what they thought because I was really excited and my husband was very excited

too. So, basically they said “well, what we are going to tell you, you are not going to like.” And I said, “OK, well, it cannot be any worse then what we have been dealing with.” The doctor said “we think that your son is partly mentally retarded and he also has autism, which is blocking his speech. What you need to do is focus on every day life for him, don’t ever expect him to go to college.” “That is what they told me.”

Adriana’s face begins to crumple and her eyes begin to fill with tears. This time I am unable to hold mine back as well. What devastating, crushing words! Adriana wipes a tear from her eye, takes my hand, takes a deep breath and continues.

“I looked at the doctor and I said OK, so this is the hope you are giving parents? I am very confused. We come to you for hope. Is this what you are telling parents? Because if it is then the hope you provide is disgusting and disappointing. We just took 4 hours out of our schedule to come here, to get help, and this is what you have to tell me? You know, what a thing to say to a mom- your son is never going to go to college. I mean, they did not have to say it like that. So, I said to the doctors, you know what? We are going to prove you wrong. I am going to write a letter and send it to your superiors because you all should not shatter parents like this. You are lucky that I am a strong woman and I know that my son is going to be OK. He may not become a doctor, but you know what, he is going to be fine. So, your words? They mean nothing to me.”

The tears in Adriana’s eyes continue to fall but her tone is one of anger. I am so impacted by this revelation that I am having difficulty composing myself. I envision Adriana and her husband receiving this news from so-called professionals, dressed in their white coats. How must that have felt? I try to put myself in her position but I am not a mother so I cannot even begin to fathom what it must have been like for her in that

room. She came into the office excited to get help for her son, she was hopeful. She leaves crushed, the hope that she once had vanished. How is that right? How is that OK? It is no wonder there is a disconnect between parents and professionals in the field. Parents want hope, is it so hard to give it to them?

“Then, of course, the pediatrician told me that I was taking it all the wrong way and I said, no, “you need to learn to talk nicer to parents.” And I felt like I wanted to cry because, I mean, how horrible! So then I asked them, “what makes you think that he is mentally retarded?” They told me that when they asked him certain questions he just did not want to answer. I said, “no, I saw what you did and you did not even make an effort to connect with him. Maybe if you would have gotten down on the floor and played ball with him and tried to make a connection, then he would have been more receptive to your questions. You know, he is in this room, trapped, with four adults, how do you think he feels?” And you know what they told me? They said “well, we’re the professionals.” I said, “yes, I understand that you are supposed to be professionals but you were not very professional today.”

I am completely at a loss for words. My throat stings with emotion. I am brought back to a time in high school when I struggled with academics. A conference was called with my mother and all of my teachers. We sat in a circle in one of the teacher’s classrooms, one by one, they looked at me and looked at my mom and told her that I was not cut out for the advanced program, that they had seen no growth, that I should seriously considering going to the JC as college would be a struggle for me. I cried, my mom cried. We left feeling devoid of hope. The “professionals” gave us no suggestions, no strategies that I could use to improve, they simply wrote me off, much like the medical

professionals did with Cruz. As I proved my “professionals” wrong, I am confident that Adriana and Cruz will do the same.

“I grabbed the kids and my husband and told them that I did not need their help anymore. It was really sad. When we left both me and my husband were just really quiet, we didn’t even say a word to each other. Even today, I just get so upset because I knew what my husband was thinking. I knew better and I told him that Cruz would be fine. The most important thing is that Cruz has our support, we believe in him and that is all that matters. I think that it is the hardest part. A lot of people rely on the medical side and when that goes bad, you don’t know where to go. That is why what I think you’re doing is so amazing. You are going to tell the stories and people will learn that there is hope. You are just such a blessing and there was a reason we were supposed to meet because what you are doing really is huge.” I can feel the lump in my throat begin to rise again.

“What you’re doing as a mother is huge too. You maintain hope and continue advocating for your son despite what the professionals told you. They gave you no hope because they view disability through a deficit model. You turned around and made your own hope, you challenged them and look how far you have come. What you are doing, as a mother, as an advocate, is truly amazing and *I feel blessed to have met you.*”

“Well, I am glad to have met someone like you because dealing with the doctors, going through that process was definitely the most hurtful thing that I have had to endure; but you know, you live and you learn and you get stronger. Every time I feel weak, I think of that and I tell myself that I can do this, for Cruz, he’s my baby. I always tell my husband, I may not cure Cruz, but I am going to heal him- this is going to be the year.”

The meeting designed to serve as a time to complete member checks was a bit on the unusual side. I had gone skiing in Tahoe over the weekend and failed to acknowledge the impact that the glare of the sun off the snow can have on exposed skin. This resulted in second degree burns to my face which left my skin red, blistered, and cracked. It was so bad that it was a struggle for me to go out in public because of my feelings of insecurity. I remembered that Adriana worked as an Esthetician and gave her a call to see if she could help me. She scheduled an appointment for me the next day and her day spa. In an effort to kill two birds with one stone, I brought the completed story with me so she could review it. In between facial exfoliations, peels, and rinses that she performed on my face she was able to look over the story. “Wow, you made me sound so fabulous!” she exclaimed. “That is because you *are* fabulous,” I told her, “I didn’t do anything, it was all your words.”

‘I really appreciate this Heather, this story represents everything that our family has been through. I really do view our life as a blessing and I would not change it for anything,’ she says with conviction.

“I know you wouldn’t. You were so positive in everything you said, it was truly inspiring.”

“Aww! Thank you, I just hope that my story will help other parents. Finding hope is the hardest part, especially when it can be shattered so easily. I want parents to read this and say, OK, if she can find hope, so can I.”

Adriana and I continue to communicate on a regular basis. She shared Cruz’s latest IEP with me and asked if I would consider working one on one with him every week. I agreed and we are currently in the process of negotiating a schedule. Adriana is

truly a dynamic person and the participant I feel as though I connected with the most. I truly admire her positivity and determination and look forward to maintaining a continuous relationship with her and her family.

Chapter Seven

Discussion

Overview

This study involved examining the lived experiences of three caregivers to children with ASD. All three caregivers were college educated, married, and had combined household incomes of over \$100,000 per year. Despite these commonalities and association with disability, the caregiver experiences were diverse in nature. This diversity can be attributed to a number of factors. The difference in the ages of the caregivers is significant: Donna is 56 years old, Sandra is 43 year old and Adriana is 36 years old. This generation gap indicates differences in the social and historical contexts in which participant experiences took place, thus influencing the impact of the diagnosis transition on the trajectory of the caregiver life-course (Bristol & Schopler, 1994; Gray 2006). Additionally, the ages of the children with ASD were also significantly different, with the oldest child, Tanya, being 25 years older than the youngest child, Cruz. As such, caregivers have differing levels of experience when it comes to raising a child with ASD. While Donna has raised a child with ASD for 31 years, Adriana has only had 6 years of experience. The diversity in participant experiences can be further explained by factors such as cultural differences, researcher-participant relationship, and the way in which I re-presented participant experiences in a narrative structure. The aim of the study was to

answer the following question: What are the lived experiences of diverse caregivers in raising a child with ASD? Subsumed under the larger construct of lived experience were elements such as coping mechanisms, caregiver burden/satisfaction, experiences with the school system, impact of the diagnosis on the life-course of the caregiver, community reaction, and service accessibility. These elements are representative of the themes which emerged across participant stories and are situated within the context of the life-course theory (Elder, 1985) which examines the impact that transitions, such as the diagnosis of a child with ASD, can have on the trajectory of the life course of the caregiver. Closely related to the life-course theory is the Family Adjustment and Adaptation Response (FAAR) model (Patterson & Garwick, 1994). Specifically, the FAAR model includes two phases, adaptation and adjustment. The model maintains that the ability of parents to cope with their child's disability changes over time and is impacted by different transitions, or crises, within both the life cycle of the parent and the life-cycle of the child. The accessibility of resources, the social and historical context in which the crisis occurs, and the timing of the crisis or transition within the life course also has implications for how well a family is able to adjust (Seltzer & Greenberg, 1999; Wethington, Cooper & Holmes, 1997). Also related to the life-course theory are Kubler-Ross' (1969) stages of mourning, which outline the process some caregivers go through in order to attain acceptance of their child's diagnosis of ASD, and The Resiliency Model of Family Stress, Adjustment, and Adaptation which is frequently used to measure a family's ability to adjust and adapt to stressors (McCubbin & McCubbin, 1989). The following analysis will situate participant stories within the aforementioned bodies of literature.

Over the course of this study, I came to the realization that storying ones lived experience is a very personal act which requires extensive self-reflection. It is the act of self-reflection on the part of the caregivers which contributed to the diversity of the stories. The way in which they storied their lived experience impacted the way in which I, as both a researcher and family member of an individual with ASD, interpreted and re-presented this experience. The caregivers who chose to share their stories with me communicated their experiences to me in a way which was meaningful to them and I, in turn, created a cohesive narrative whose aim was to capture the emotion associated with these experiences while preserving the authenticity of the experience itself.

Donna's story conveys the experiences associated with raising a daughter with Asperger's syndrome. She communicates the challenges and emotions she has experienced while trying to simultaneously raise three additional children and longing for a life where she can return to work and some kind of normalcy. It is only after Tanya is sent to a specialized school for individuals with disabilities in Vermont that, according to Donna, a sense of peacefulness returned to the home. While Donna continues to look after Tanya's finances and other aspects of her daily life despite the fact that Tanya is now in her early thirties she feels as though she has adapted to the day to day demands. However, she is still burdened when she wonders about what will happen to Tanya when she and Marty are not around to look after her anymore.

While Donna's story focuses more on Tanya's behavior challenges and the impact raising a child with Asperger's had on her life, the focus of Sandra's story is on the trials and tribulations she endured while navigating the educational system. She emphasizes the importance of family and acknowledges how much they have supported her with raising

Justin. Sandra is a strong advocate for Justin's independence and encourages him to participate in day to day activities with typically developing peers. Although she refers to Justin as "special," she does not allow the disability to consume either one of them. Sandra also considers the overall impact of Justin's ASD diagnosis on the trajectory of her life-course to be very minimal as she maintains that, career-wise, she is farther today than she thought she would be.

Adriana's story emphasizes the importance of sustaining hope despite the adversity that is associated with raising a child with ASD. She is continuously searching for the next treatment so that she can "heal" her son. Like Sandra, Adriana emphasizes the important role that her family plays in her life but also references the stigma and guilt she sometimes experiences as a mother to a child with ASD. Adriana realizes that staying positive is what is best for her and her family; this use of positive reframing (Hastings et al., 2005) minimizes the impact of the diagnosis transition on the trajectory of her life-course.

Despite the diversity of participant stories, common themes emerged, many of which relate back to the literature on stress, coping, and well-being. Specifically, while all caregivers utilized coping mechanisms to adjust and adapt to the experience of raising a child with ASD, the coping mechanisms employed were diverse in nature. This diversity impacted the extent to which caregivers were able to adapt to the transition of a diagnosis of ASD and the impact of this transition on the trajectory of their life course.

Additionally, all caregivers experienced the different stages of mourning (Kubler-Ross, 1969). However, the way in which they progressed through these stages of mourning was inconsistent across participant stories. Further, not all caregivers

progressed through all stages of the mourning process. Specific details of this process for each individual caregiver will be provided within the individual analyses.

Experiences with professionals in the field, community reaction to their child's disability, availability of services, and challenges associated with navigating the system were also addressed within participant stories. While all caregivers maintained that the process associated with the diagnosis was tedious in nature, the caregivers' interactions with professionals were dissimilar. While Donna's story focused on more positive interactions with service providers, Sandra and Adriana's emphasis was on the negative aspects of these interactions. Subsequently, this had an impact on the rate and frequency at which caregivers accessed services. Two of the three caregivers utilized language indicative of feelings of stigma and isolation associated with raising a child with ASD.

The following pages will examine these themes, and others, within the context of current literature in the field in order to provide the reader with a deeper understanding of autism and the lived experience of study participants. Each participant story is analyzed separately in order to highlight the individuality of the experiences. Excerpts and examples from participant stories serve to connect the larger body of literature to the larger narrative work.

Donna. Much of the language in Donna's story highlights the challenges associated with raising a child with a disability whereas feelings of hope and optimism are sparse. Her story is replete with different situations in which "meltdowns" occurred and where they were forced to "get behind her and clean up the mess." This indicates that perhaps Donna has not fully adjusted to the transition of raising a child with a disability.

If situated within the life-course theory, the transition of Tanya's diagnosis impacted Donna in a way that significantly altered the trajectory of her life course.

The life-course theory posits that the social and historical contexts in which the transition occurs, which in this case is Tanya's diagnosis, influences the impact of the transition on the trajectory of the life-course (Elder, 1985). When Donna received the initial diagnosis of physical disability she was a mother with a small child who was used to working a full-time job outside of the home. Once subsequent diagnoses, such as ADHD and OCD, were received, Donna was a mother of 4 young children with little outside family support. The context in which the transition occurred is one that is not necessarily conducive to adaptation because additional stressors were constantly being added (McCubbin & McCubbin, 1989): the birth of four children within a six year period, transitioning the children into school, receiving updated diagnoses, continuous stress related to Tanya's inappropriate behavior both in the home and community. All of these stressors combined would make it difficult for Donna to fully adjust to the diagnosis transition.

Further, Tanya did not actually receive an Asperger's diagnosis until her Sophomore year of high school. That means for fifteen years, Donna was living in uncertainty about Tanya's condition. Tanya was diagnosed with a physical disability, Attention Deficit Hyperactivity Disorder (ADHD), and Obsessive Compulsive Disorder (OCD), however, none of these diagnoses fully explained the characteristics and behaviors Tanya exhibited. Once they finally received a diagnosis, Donna indicated that they felt "relieved" to finally find a place where Tanya "fit." However, this relief was coupled with fear as they did not receive much hope for where Tanya would be in the

future. This is also considered a transition within Donna's life course, however, the lack of hope associated with this transition made it difficult to adapt and accept (Patterson & Garwick, 1994) the new Asperger's diagnosis. Right after the diagnosis, another transition took place, throwing the balance off yet again. The decision was made to send Tanya away for school. The transition of Tanya leaving home for the first time evoked feelings of guilt and shame, "I was afraid of what people would think if I just up and sent her away." These feelings could also inhibit Donna's ability to adjust. This lack of adjustment could thus influence the way in which Donna perceives herself as a mother and negatively impact her feelings of self-efficacy (Hastings & Brown, 2002).

Donna's coping styles emphasize the use of internal strategies with her husband serving as her main form of support. Very few external coping strategies were observed as Donna did not actively seek out spiritual support nor support from social networks. In a sense, she engaged in what can somewhat be characterized as isolationist behavior. This is consistent with literature on ASD which indicates that parents often times engage in isolationist behavior in order to avoid social situations where challenging behaviors, on the part of the child, may manifest themselves (Autism Society of America, 2008). In addition to feelings of isolation, caregivers to children with disabilities often feel stigmatized because of their child's disability (Green, 2003). Donna felt stigmatized by the community because of Tanya's inappropriate behaviors and refrained from leaving the house: "I felt trapped." This supports Goffman's (1963) theory of courtesy stigma where a person acquires a stigma based on their close association with another person with a stigma, which in this case, is Tanya.

Donna's coping strategies can be further characterized according to the dimensions set forth by Hastings et al.,(2005). Specifically, Donna engages in active avoidance coping (Hastings) as she frequently blames herself for her inadequate parenting skills. Caregivers utilizing active avoidance strategies such as self-blame, use of drugs/alcohol to cope, giving up or avoiding the stressor all together, were found to display higher levels of stress than caregivers who employed more positive coping strategies. This is also consistent with literature indicating that Caucasian caregivers rely more heavily on passive appraisal, or avoidance of problems, as means of coping (Twyo et al., 2007).

Kubler-Ross (1969) identified five stage of mourning which parents of children with disabilities go through after receiving a diagnosis: 1) Denial 2) Bargaining 3) Anger 4) Depression 5) Acceptance. However, it is important to note that not all parents will progress through the stages at the same rate; some stages may be skipped altogether. Donna's story focused on the stages of anger and depression. Particularly in the second interview, she expressed feelings of inadequacy as a parent and feelings of depression. "Looking back I think I may have been a little depressed during those years because I always felt that despite everything I did, I was a failure." Having family support is a coping mechanism that has been found to be effective in dealing with day to day stressors (Gray, 2006). However, Donna reported that most of her family lived in Michigan and those who did live nearby did not understand how to take care of Tanya. The burden was left upon her and her alone. This lack of family support could explain why she experienced feels of anger and depression.

Additionally, research indicates that caregiver self-efficacy has been shown to contribute to levels of anxiety and depression (Hastings & Brown, 2002). Donna refers to herself as a “failure” indicating that her level of self-efficacy is relatively low, thus potentially contributing to the depression she feels. The stress that Tanya placed on her was so intense that she felt as if she were “neglecting her other children.” While Donna has learned to live with and cope with Tanya’s disability, I question whether or not she has truly achieved acceptance. I am left with the feeling that she is still somewhat resentful as her story focuses primarily of the challenges associated with raising a child with ASD and ends without much of a resolution. However, one of the conditions of acceptance is that the caregiver is able to attain a balance between encouraging independence and showing love (Kubler-Ross, 1969). I believe Donna has mastered this. Tanya lives alone, drives a car and holds a job, of which are indicative of encouraging independence. Donna shows love in her own way, taking care of prescriptions, managing Tanya’s financials, and generally being there for her. I think sometimes she is just overwhelmed with the responsibility and may find it difficult to develop and maintain the same kind of emotional relationships with Tanya that she has with Cameron and Julie. However, this lack of emotionality in no way indicates a lack of love. “Tanya is a great kid, she has her little idiosyncrasies, but we love her anyway.” Perhaps the feelings of resentment and anger that Donna harbors deep inside influence the way in which she is able to connect with Tanya on a more emotional level.

The act of telling one’s story has been described as part of the coping process as it allows caregivers to positively reframe the experience associated with the diagnosis of ASD, thus contributing to lower levels of depression and improved well-being (Gray,

2006). While Donna's story is not necessarily indicative of positive reframing, her final email to me illustrated that perhaps she is beginning to focus on more positive aspects of the experience. She indicated that she "thoroughly enjoyed" talking about her experience and that the act of telling her story gave her a "newfound appreciation" for what she has been through.

Sandra. Sandra maintained an air of strength and composure throughout the interview process which supports research documenting increased resilience and acceptance among families considered to be ethnic minorities (Harry, 2002). This resilience could be attributed to her use of both internal and external coping strategies. Specifically, Sandra relied heavily on her family for support and acknowledged the importance of having a life outside of her role as a caregiver both of which are subsumed under the dimension of problem-focused coping strategies (Hastings et al., 2005). Sandra's reliance on family support influenced her ability to adjust to the transition of having a child diagnosed with ASD.

The transition of the diagnosis within Sandra's life-course only minimally impacted the overall trajectory of her life-course. She indicated that despite being faced with the challenge of raising a child with ASD, she feels as though she is in the place she would have been if Justin had not been born with a disability, in fact, she feels as though she is "much farther" than she thought she would be.

While there was a period of adjustment following the transition, Sandra's utilized a repertoire of coping and problem-solving strategies in order to move into a phase of adaptation. In her story, she acknowledged that one of the most important things for her to realize was that she needed help. Her family was there to assist with the care giving

aspects, but the burden of maintaining the home was one which weighed heavily on her. The number of demands placed on a family (stressors, strains, transitions) has a negative impact on the caregiver's ability to adapt and adjust (McCubbin, 1993). Sandra acknowledged the potential impact of these demands and sought help in order to alleviate some of the burden, thus facilitating the process of adaptation and adjustment (McCubbin & McCubbin, 1989).

Justin's school experience proved to be frustrating for Sandra. She was constantly met with adversity from the teachers and administrators over the course of Justin's schooling. The constant transitions associated with moving from school to school, classroom to classroom was difficult for both of them. Sandra was left feeling as though no one wanted Justin in their school or classroom because of his disability. Sandra openly admitted that she was not the most savvy at advocating for Justin because she was unaware of many of the services that were available to him. This is consistent with literature addressing service accessibility in that ethnic minorities typically access services at a much lower rate than their Caucasian counterparts (Balcazar, Keys, & Balcazar, 2001). Further, it is suggested that a lack of awareness of available services accounts for the discrepancy in the rate at which these services are accessed (Harry, 2002). Much of what she learned fell into her lap through conversations with other parents, teachers, and social workers. School was "a journey, learning all of the ins and outs," and was a significant stressor for Sandra. Talking about her and Justin's experiences in school is what evoked the most emotion from Sandra. However once she was able to learn the "ins and outs," she was able to adjust and adapt to future school related transitions in a more effective manner.

Denial was the first step in the process Sandra went through in learning to accept and live with the transition of an ASD diagnosis. She reported feeling “numb”, which, according to Seligman & Darling (1997), is indicative of denial. Sandra also reports that many of her family members experienced denial with the initial diagnosis, including her husband and father. During the denial phase, Sandra was able to gather the inner strength necessary to acknowledge, accept, and manage the diagnosis. The story she tells does not indicate a progression through the stages of bargaining, anger, or depression before moving into the stage of acceptance. Sandra’s story indicates that she has achieved full acceptance based on criteria set forth by Hornby (1994). She is able to discuss Justin’s challenges with relative ease, effectively collaborate with professionals to identify realistic goals and objectives for her son, and abandon overprotective behavior towards Justin. He is permitted to drive the family truck when they go out together and he also has the freedom to make plans with his friends outside of the home, away from her supervision.

Sandra is resilient and it is this resiliency which has facilitated the successful adaptation to and acceptance (McCubbin & McCubbin, 1993) of her role as a caregiver to a child with ASD. The act of storying her lived experience, like Donna, impacted her in a way that allowed her to positively reframe her experience. This reframing convinced her that she has succeeded as a parent and is giving Justin the best life she can. “I feel like as a parent, I have done good.”

Adriana. The language Adriana uses when telling her story is very positive. She continuously refers to her son as a “blessing” and that she feels “blessed” to have been met with the experience of raising a child with ASD. These references to spiritual support

are consistent with literature addressing coping mechanisms. Specifically, non-English speakers are more likely to rely on religious coping mechanisms than their English-speaking counterparts (Troy et al., 2007). While Adriana does speak English, it is not her first language. Further, while this does not qualify her solely as a non-English speaker, it is indicative of her linguistic diversity, which has been shown to play a role in coping mechanisms employed.

The notion of hope is omnipresent and her quest to “heal” her son never wavers. Adriana relentlessly seeks out alternative forms of medicine to facilitate the healing process in her son’s body. Research suggests that Latino caregivers of children with ASD seek out non-traditional treatment options more so than their non-Latino counterparts (Levy et al., 2003). This is interesting as Adriana posits that Mexican families “just believe in going to the doctor.” Further, “the vitamins and outside services I have gotten for Cruz would not fly if I had a Mexican husband.” However, only one such study (Levy et al.) indicated this preference towards non traditional methods, thus indicating a need for additional research in this area.

Adriana is the only caregiver in the study to speculate on the cause of Cruz’s disability. She believes that the MMR vaccine that Cruz received when he was a little over 2 years of age contributed to the onset of autism. Research in this area maintains that mercury, which was present in vaccines until 2001, has been speculated to contribute to the presence of autism (Bernard et al., 2001; Rimland, 2000; Shaw, 2002). However, research is insufficient to conclusively link the mercury present in the MMR vaccine to the onset of autism (Simpson et al., 2005). In 1999, the Public Health Service agencies agreed that, as a precautionary measure, thimerosal, a mercury-containing preservative,

should be reduced or removed from childhood vaccines (CDC, 2008). However, as Cruz only received his vaccines 4 years ago in 2004, the mercury level present in the vaccines he was administered would have been minimal. However, more recent reports have speculated that perhaps thimerosal was not the sole culprit of the alleged toxicity. Aluminum hydroxide is another compound which is present in childhood vaccines; studies indicate that aluminum toxicity can lead to neurological damage and that there is a significant relationship between aluminum and mercury in vaccines and neurodevelopmental delays (Freedom of Information Act, 2000). However, it is important to note that this conclusion was based on a transcript of a closed meeting called to discuss results from a study involving CDC and four HMOs which examined data from Vaccine Safety Datalink. No subsequent studies have been conducted which link mercury and aluminum levels to the onset of autism. This uncertainty continues to haunt Adriana as she reports feelings of guilt for having possibly contributed to her son's diagnosis.

Adriana utilizes a combination of internal and external coping strategies. Specifically, problem-focused coping and positive coping mechanisms are the most frequently used. Problem-focused strategies involve seeking social and emotional support from others as well as identifying potential strategies to improve outcomes (Hastings et al., 2005). In Adriana's case, she references the intense support she receives from both her husband and her in-laws, indicating that they are very "close-knit." She also continuously seeks out new treatments and strategies, such as the use of vitamin supplements and the hyperbaric oxygen chamber, in order to improve her son's outcomes.

Positive coping strategies involve the use of positive reframing (Hastings et al.,

2005). Adriana “believes” in her son and acknowledges that “he is going to be OK,” despite the report she received from the medical professionals. Research indicates that positive reframing of stressful life events, such as the transition of the diagnosis of a child with ASD, is related to lower levels of depression in caregivers (Gray, 2006). Adriana does not use language that implies feelings of burden or depression. Instead, she feels as though “He [Cruz] is just such a blessing to us. You know, God does not give us more than we can handle.” This reference indicates Adriana’s faith in God and utilization of religion as a coping mechanism. She also makes extensive references to the important role that her family plays in her life and describes her husband as her “backbone.” Research on Latino caregivers, and ethnic minorities, with a child with a disability indicates a high level of need for both family (Skinner et al., 1999) as well as an increased level of resilience (Harry, 2002).

Like Sandra, Adriana does not see the transition of a diagnosis of a child with ASD as impacting the overall trajectory of her life course. In looking at the social context in which the diagnosis occurred, Adriana was happily married, secure in her career and enjoying her role as a mother. Once the diagnosis was received, Adriana was able to adapt and adjust to the transition because of the support systems that were in place in her life. Specifically, Adriana’s family typology, which exudes cohesion, has a positive relationship with the family’s ability to adapt to the constant transitions associated with raising a child with a disability (McCubbin, 1993). The flexibility of her career allowed her to both meet the needs of Cruz while maintaining a professional presence within the work place. Adriana’s consistent use of positive and problem-solving coping mechanisms

allowed her minimize the impact of the day to day stressors (Patterson, 2000) associated with raising a child with ASD, thus facilitating her successful adjustment to her role as a caregiver.

I found evidence of progression through all of Kubler-Ross' (1969) stages of mourning. Although Adriana experienced denial, it was only for a short time. She did not want to talk about Cruz's disability because it hurt her too much, and she did not want to portray her son in a negative light. However, once she came to the realization that people were "more receptive" when she talked about his disability, she began to open up, allowing her to move through the phase of denial.

Adriana is very focused on research new treatment methods in order to "heal" her son. Part of the bargaining phase involves parents seeking out all possible therapeutic options in exchange for an improvement in their child's condition (Kubler-Ross, 1969). While Adriana has all but abandoned traditional medicine as a means of treatment for her son, she continues to seek alternative methods which could be indicative of her continued progression through the bargaining phase. Only at one point in time did I find evidence of anger in Adriana's story. The medical professionals had just told her that she should not expect her son to go to college. She fought back with anger and emotion "We are going to prove you wrong." "Your words mean nothing to me." It is this anger that motivated Adriana to seek out alternative forms of medicine that would heal her son and improve his outcomes. Despite the fact that Adriana has accepted her son's disability, it is evident that she intermittently experiences feelings of depression and blame. As a mother, she indicates that she often blames herself and questions her food choices during pregnancy as well as those choices she made in regards to feeding her son once he was born. She

acknowledges the genetic basis of autism and communicates that both she and her husband are trying to “put the pieces together” in an effort to find out how their son developed autism.

Despite the fact that Adriana feels guilt over her son’s condition, she does not allow it to paralyze her. Instead, she focuses her energy on positive thinking and finding hope. Her positive appraisal of the situation has a positive impact on her ability to adjust and adapt (McCubbin, 1993) to her role as a caregiver to a child with ASD.

“You live and you learn and you get stronger. Every time I feel weak, I think of that and I tell myself that I can do this, for Cruz, he’s my baby. I always tell my husband, I may not cure Cruz, but I am going to heal him- this is going to be the year.”

Bringing it Together

The preceding analyses highlight the experiences of three caregivers, from diverse backgrounds, within the context of a larger body of literature. While common themes such as the impact of the diagnosis on the life-course of the caregiver, the use of coping mechanisms, progression through stages of mourning, adaptation and adjustment, and the process associated with navigating “the system,” were identified across participant stories, the way in which these themes manifested themselves within the participant stories is individualistic. I feel it is important to discuss common threads that emerged across participant stories as well as address some concerns associated with the study.

Research indicates that culturally diverse families of children with autism have been under researched (Zhang & Bennett, 2002). Subsequently, the intersection of race, family coping mechanisms, and autism has also been excluded (Dyches et al., 2004). This study initiated a dialogue with caregivers of children with ASD who were culturally

diverse while simultaneously exploring constructs such as coping mechanisms and caregiver burden. This dialogue provides the foundation on which to build a future research agenda which will continue to explore this intersection, but on a larger scale and across additional ethnic groups.

Research indicates that ASD is equally diagnosed across cultures and socioeconomic status (U.S. Department of Education, 2002). While the families in this study are culturally diverse, they all come from relatively affluent backgrounds. Therefore, it is important to note that these stories are not indicative of the larger population of caregivers of children with ASD. Further, even though study participants identified with certain cultural groups, their stories are not representative of the larger cultural group with which they identify; it is their unique and individualized experience. This indicates the need for future research to explore not only across additional ethnic groups but also socioeconomic levels.

Current literature on the topic of autism and other disabilities identifies the need to address the family component, cultural and linguistic diversity, and service accessibility (Dyches, et al., 2004; Harry, 2008; Zionts et al., 2003; Zionts & Zionts, 2003). The county in which the study was conducted is relatively affluent which made locating caregivers with diverse socio-economic statuses difficult. Further, the majority of caregivers of children with ASD, who self-identify as Hispanic, are not fluent speakers of English. Therefore, there are additional issues related to linguistic diversity that have not been addressed in this study. Specifically, language differences have been identified as a barrier to successful collaboration between parents and professionals (Dunlap, 1999; Turnbull et al., 2006; Yap & Enoki, 1994). This is problematic in that families of children

with ASD are being silenced because of their linguistic association. Subsequently, service delivery models for community agencies are unable to provide services which are accessible to families from linguistically diverse backgrounds (Lynch & Hanson, 1998; Thomas et al., 2007).

However, the acknowledgement of these limitations inspires me to set forth a future research agenda which seeks out the stories of those individuals who have been left out of the current study. Specifically, subsequent research should examine the experiences of caregivers who identify as Asian, American-Indian, and multiracial. The experiences of caregivers whose income levels are at the poverty line should also be sought out as I anticipate that their concerns would be very different from the caregivers in this study who had the resources to seek out and obtain supplemental services for their children. Caregivers who are non-fluent in English also have stories to tell and they should have the opportunity to do so despite their linguistic diversity. Future studies should recruit individuals from linguistically diverse backgrounds with the assistance of translators.

In addition to the aforementioned limitations of the study, I felt it important to outline several commonalities which emerged across participant stories and the implications of these commonalities for professionals in the field.

Blame, frustration, and a lack of hope were concepts which consistently emerged across participant stories. This is problematic in a sense that in order to obtain services for their child, caregivers are forced to deal with a process that is tedious and frustrating. Further, once the diagnosis was received, feelings of hope were reportedly shattered by professionals in the field. It is evident that parents already feel some sort of guilt over

their role in the manifestation of the disability and it is important that this guilt not be compounded with subsequent negative experiences. Suggestions for future research include an examination of the system and the process associated with obtaining a diagnosis. This is a difficult enough time for parents, our job as professionals, is to make it as painless as possible and reflecting on what works and what does not work with the current system is an important place to start. In order to do this effectively, future research should be conducted across ethnicities, socioeconomic statuses, family structures, and linguistic associations.

Despite these feelings of blame and frustration, two of the three caregivers consistently referred to the experience of raising a child with ASD as positive. Further, all caregivers reported that the act of telling their story had a positive impact on them. This is consistent with literature indicating that exchanging narratives facilitates the coping process and a change in perception for parents (Huws et al., 2001). This has important implications for the field in that it suggests a need for further exploration of caregiver experiences within a narrative framework (Fleischman, 2004).

Developing an ethic of care (Gilligan, 1982; Noddings, 1984) within medical professionals is another essential element. An ethic of care evolves out of one's interconnectedness with others. It emphasizes the importance of fostering the development of care through interactions with others and maintaining interest and concern in others' well-being. Interest and concern are communicated through genuine attentiveness and compassion towards others (Keller, 1996). This has implications for professionals in the field in that the two of the three caregivers in this study experienced a lack of compassion, attentiveness, and overall concern for their child following the

diagnosis of ASD. Parents come to medical professionals for hope, for direction. It is important that we provide them with the hope they seek while simultaneously providing them with the realities of the diagnosis. Additionally, we should encourage parents to hang onto that hope, no matter how difficult the situation becomes. Educating parents about ASD as a disability, sharing success stories and focusing on the positive will also help parents understand that they are not alone and that they are not to blame for their child's disability.

Researcher Reactions

Donna's story is the most personal to me. My initial reactions to her story are skewed by my desire to protect her and the rest of the family. I was torn between my desire to talk about how much I admire her for her vulnerability and strength, while on the other hand, I wanted to further examine her use of language and the overall tone in which the story was told. I also wanted to remain true to who I am as a researcher but I also felt the need to protect her from any critical analysis that may portray her in a negative light. In the end, I believe I was able to achieve a balance between family member and researcher. This negotiation between my two personas was difficult for me because of the past relationship that we shared. It is important to note that Donna confided in me some of her inner most feelings because of our past relationship; it is this relationship which facilitated the level of disclosure with which I was provided. Had the researcher been a stranger, as I was to the remaining two participants, it is possible that her story would have taken on a different, perhaps more critical, tone.

In realizing this discrepancy, I became more aware of the judgment I was placing on the caregiver stories. While my goal at the outset of the study was to listen to the

caregivers while reserving judgment, I found that this task was next to impossible. My previous experience as an educator influenced the way in which I responded to the participant stories as did my experiences with my own family member who is diagnosed with ASD. My interpretations had the power to emphasize one aspect of a story while deemphasizing another. The negotiation between narrative and historical truth required me to immerse myself within the interview transcripts through repeated readings so that I was able to incorporate elements of the transcriptions which contributed to the ebb and flow of the story while, at the same time, preserving the authenticity of the participants' lived experience.

I feel as though I formed the strongest connection with Adriana. She was open with me from the very beginning. She exuded strength while, at the same time, showing vulnerability and emotionality. Another reason I felt such a strong connection to Adriana is because, despite our differing cultural backgrounds, we are similar in many respects. We are the closest in age, being only eight years apart. Our outward style is similar, as are some of our mannerisms and interests outside the home. I felt as comfortable with her as I feel with some of my best girlfriends. The bond between Adriana and I has grown since the interviews and I am confident that we will maintain a friendship long after. This relationship influenced the way in which I responded to her experiences. I had an overwhelming desire to believe her story and legitimize her actions, much like the desire I had to protect Donna from an overly critical eye.

The relationship between Sandra and myself was slower to progress than those relationships with Donna and Adriana. While I feel as though I was able to connect with her on an emotional level, I was continuously met with the feeling that she was holding

back from me. I cannot fault her for this as I was a complete stranger to her when we first met. I question whether I should have done more to establish rapport with Sandra prior to the main interview. I feel as though my responses to Sandra's experiences, as indicated by the italicized problematics in the results section, were less emotionally involved than were my responses to Adriana and Donna. It was difficult for me to connect with Sandra on that level because of her strong exterior. Upon meeting her, I was a bit uneasy and often pondered how I might begin breaking down her walls. I think that my uneasiness prevented me from connecting with Sandra on a deeper level. This is unsettling to me because I feel as though I did not do justice to Sandra's experience. The richness that is present in the other two caregiver stories far outweighs that of Sandra's story. I am disappointed in myself for failing to make a deeper connection with her. However, in future studies, I believe it will be important for me to allocate more time for rapport building sessions. Developing relationships with caregivers is not something that can be done overnight and some caregivers will be less willing to open up than others.

Individualizing interview time lines would be an effective way to address this limitation.

This study made me aware of the diversity in the experiences of three caregivers to ASD. All the caregivers in this study indicated that having someone listen to them and acknowledge their experience was one of the greatest gifts they could have been given. Showing parents that you are interested in hearing what they have to say opens doors that may have remained otherwise closed. I learned the importance of the family story and the impact it can have on the professional story. In order to fully understand where parents and family members of children with autism are coming from, we must negotiate the way in which our professional story influences our interpretation of the family story.

As professionals, we are outsiders as we are not privy to the lived experiences of the family. When families make the decision to share this lived experience with us, it is imperative that we listen without making judgment. In a study conducted by Blue-Banning, Summers, Frankland, Nelson, & Beegle (2004), parents expressed their desire for professionals to “listen carefully and nonjudgmentally to what the other has to say” (p. 172).

“The first thing is to listen to us ... because we know our kids better than anybody.... I think some of these people have preconceived notions about everything.... So if I tried to say, to tell them [professionals] something, it'd be LISTEN TO ME” (Blue-Banning, et al., 2004, p. 172).

It is crucial that we, as researchers, remember that it is our responsibility to provide a “voice for the various stakeholders-- by listening to their voices and considering their voices within the full context of their experiences” (Sandall, Smith, McLean, and Ramsey, 2002, p. 135).

I have learned the importance of withholding judgment about the lived experiences of others. Creating self-fulfilling assumptions is not a component of effective communication. Mutual respect, trust, and parent empowerment are essential components of collaborative relationships and effective communication between parents and professionals (Blue-Banning, et al., 2004). Taking the time to validate interpretations and honor other’s lived experience is essential in future communicative interactions. This newfound knowledge will guide my future research with diverse families and their lived experiences in raising a child with autism.

Epilogue

This experience has taught me some very important lessons in both my personal

and professional life. First and foremost, I have regained the self-confidence that left me that day in first grade. I realized that I am capable, I am intelligent, and I should not feel ashamed of my past mistakes or perceived “failures.” I have also re-learned the importance of listening, honoring and respecting the stories and experiences of others.

My interactions with the families in this study helped me to understand only a small piece of what it is like to raise a child with ASD. I am humbled by this experience as I realized that I do not really “know” as much as I had originally presumed to know. This new found knowledge will guide my future interactions with not only families to children with disabilities but to all individuals with whom I come in contact. Legitimizing one’s experience is an important part of truly understanding and empowering both the self and the other. We are not put here to judge nor criticize the experiences of those with whom we interact.

The self-reflection in which I engaged throughout this study allowed me to reorganize my previous experiences as student, teacher, and researcher in a way that no longer confines me to a predetermined set of qualifications, but rather serves as a foundation on which to build future experiences. I have come out of this process with a renewed passion for my career and desire to learn more about the experiences of families faced with the challenge of raising a child with ASD. It is my hope that by reading the stories of the caregivers in this study, other family members will be inspired to tell their story, or at least find a renewed sense of hope. I hope that researchers who read this study will be inspired to seek out the stories of those individuals who may have been marginalized not only by their association with disability but by other perceived constraints. I know that my research agenda includes expanding upon this study by

seeking out the stories of fathers, grandparents, siblings, and individuals with disabilities. Further, I hope to seek out the stories of additional ethnicities, socioeconomic statuses, and family structures that are not represented within this study. Stories are powerful entities which have the potential to facilitate social change by increasing awareness and understanding. Communicating the implications of this and future studies to service providers is also one of my priorities.

I successfully defended this dissertation on June 11th, 2009, a day that will live in my memory for the rest of my life. This process has changed me in a way that goes beyond future research agendas and changing perspectives on my style of interaction. I have become more self-assured, more confident, more determined. I feel as though my past negative experiences with teachers and the school system are insignificant in comparison to the pride and passion I feel at this very moment. Thank you to the people in my life, family, friends, and teachers, who never gave up on me, who pushed me to be my very best, and whose encouragement and love I will never forget. This accomplishment is as much yours as it is mine.

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Appendices

Appendix A: Demographic Information

Primary caregivers will be asked to complete the following demographic information sheet:

What is your marital status?

- Single
- Married
- Divorced
- Widowed

What is your race?

- African-American
- Caucasian
- Hispanic/Latino
- Other

What is your age range?

- 18-25
- 26-30
- 31-35
- 36-40
- 41-45
- 46-50
- 51-55
- 56-60
- 61-65
- Over 65

What is your yearly household income?

- Under \$25,000
- \$25,001-\$35,000
- \$35,001-\$45,000
- \$45,001-\$55,000
- \$55,001-\$65,000
- \$65,001-\$75,000
- \$75,001-\$85,000
- \$85,001-\$95,000
- \$95,001-\$100,000
- Over \$100,000

Family Structure

- Both parents living in the home
- Single parent (divorced)
- Single parent (widowed)
- Single parent (never married)
- Extended family living in the home

Education level

- Some high school
- High school graduate
- Some college
- College graduate
- Advanced degree (Master's, Specialist, Doctorate)

Working Status

- Full-time job
- Part-time job
- Not employed at this time

Occupation (Please provide below)

Appendix B: Interview Protocol

Approximately three interviews will be conducted with each of the study participants.

The first interview will serve as a rapport building discussion in an effort to establish a foundation of trust between the interviewer and respondents. Further, the concept of lived experience will be addressed along with an explanation of interactive interviewing.

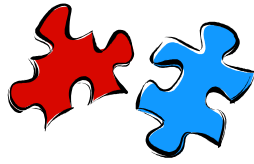
The second interview will involve documenting the primary caregivers' lived experience with raising a child with ASD. The interview protocol will serve as a guide for this semi-structured interview

The third and final interview will allow time for member checks and negotiation of interviewer interpretation. If any inaccuracies arise, the researcher and study participants will negotiate the perceived inaccuracy so that both parties feel they are represented in a manner consistent with their lived experience.

Interview Protocol

1. Caregiver feelings about diagnosis and the impact of diagnosis on their life-course
2. Feelings about caregiver burden and/or caregiver satisfaction experienced in raising their child with ASD
3. Coping mechanisms caregivers have employed
4. Their perception of the impact of living with a child with ASD on other family members (relationships among family members, interactions)
5. Knowledge, availability, and accessibility of services for the family (are there barriers, if so, what are they?)
6. Experience within the school system
7. Experience and interactions within their community
8. Their goals for their child

Appendix C: Recruitment Flyer



ASD Research Opportunity

Would you like to participate in a research study addressing your experience raising a child with ASD?

PURPOSE: The current research study seeks to examine the experience of primary caregivers in raising a child with ASD.

REQUIREMENTS:

- Three (3) interviews with the researcher (1-3 hours in length)
- Permission to audio tape the interviews
- Primary caregivers to a child with ASD
- African-American, Caucasian, or Hispanic decent

NATURE OF THE INTERVIEWS:

The first interview will serve as an opportunity to get to know you and gather preliminary demographic information. During the second interview, you will be asked to tell your story about what it has been like raising a child with ASD. The researcher will ask questions about your experiences as well. The third interview will serve as an opportunity for you to review the interview transcripts and researcher interpretations. Any inconsistencies can be addressed at this time.

CONTACT INFORMATION

If you are interested in participating in this study please provide your contact information below and the research will get in touch with you to answer any questions and provide more information about the study.

NAME _____

PHONE # _____

BEST TIME TO CALL _____

EMAIL (if available) _____

About the Author

Heather Brace is currently a faculty member in the Department of Educational Leadership and Special Education at Sonoma State University in Rohnert Park, CA. While completing her doctoral coursework at the University of South Florida she had the opportunity to serve as Project Coordinator for a U.S. Department of Education Transition to Teaching grant. She also worked as an elementary school teacher of students with special needs in Florida for 4 years. She earned her Master's degree in Special Education in 2003 from the University of Florida.

Her research interests include lived experiences of caregivers to children with ASD, teacher candidate self-efficacy, and effective components of teacher education programs.

She currently resides in Northern California with her 2 Chihuahuas, Bailey and Brody, and her Papillion, Brady.