ANOTHER BATTLE, ANOTHER HURDLE: HOW PARENTS CREATE MEANING FROM RAISING A CHILD WITH AUTISM

by

Debra Webb Basalik

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Approved by:

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Dr. Christine S. Davis

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Dr. Amy Peterman

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Dr. Ashli Q. Stokes

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Dr. Teresa Scheid

ABSTRACT

DEBRA WEBB BASALIK. Another battle, another hurdle: how parents create meaning
from raising a child with autism
(Under the direction of DR. CHRISTINE S. DAVIS)

The prevalence of autism spectrum disorders (ASD) is increasing (CDC, 2016). Research studies have focused on either medical treatments and therapeutic interventions for this disorder, or the trauma of the diagnostic process. Scholarship, however, currently does not examine how parents reconstruct their role identity to address these changes. Additionally, few studies address how parents create meaning from the experience of raising a child with ASD. This study attempts to bridge the communicative and psychological scholarship on meaning-making as it relates to this experience using the lenses of systems theory and social constructivism. Eight case families participated in in-depth interviews, field observations, and a focus group to discuss the changes to their role identity and to reflect on issues related to meaning-making and the impact ASD has on their lives. Data revealed five themes in the reconstruction of the parenting role: accommodating, advocating, balancing family needs, managing behaviors, and grieving. A contextual theme of changing demands was evident across these five themes, reflecting the wide-range of behaviors and comorbidities associated with the disorder. These changing demands resulted in nearly constant assessment of participant enactment of the reconstructed parent role. Successful adjustment to these revised roles was not evident, and parents constructed both positive and negative meanings to accommodate these changes. Limitations and future directions are also discussed.

DEDICATION

This dissertation is dedicated to my wonderful husband, Evan Basalik. Without your love and support, both emotional and financial, my dream would not be a reality. Thanks for being there when I needed you, and for knowing when to stay away. You have been my champion through this entire process and I can never express just how lucky I feel to have my best friend in my corner. I am so grateful we are on this journey together. Thee, thee, thee.

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Chapter 1: Introduction

Personal Narrative

I wait outside for my child's special needs classroom to exit the school. The staff at this school understands the need for parents to check in with them at the end of each school day, as many of their students are non-verbal. I look over at the other parents waiting under the awning. I recognize the mother of one of the students in my son's class. She is holding a sleeping toddler on her hip. She periodically hikes him, looking as haggard as I feel. *Must be having a bad day*, I think to myself.

"Hey, how're you doing?" I ask, trying to be a sympathetic ear. "You look wiped. Everybody at your house ok?"

"Oh, yeah, we're ok," she answers unconvincingly, taking one hand from her sleeping child and brushing her hair back from her face. "Eli's just been a terror lately," she shrugs.

"I know how that feels," I reply, smiling wryly at her comment. "My guy would try the patience of a saint."

"Wouldn't they all," she sighs.

I reach over and pat the sleepy baby on the back and smile. "Anything I can do?" I ask, trying to provide some support to a fellow parent.

She shakes her head. "Not unless you have a magic pill that can make him sleep."

"You must mean Eli, since this little one looks down for the count," I shake my head and laugh. "If I had a magic pill, I'd have used it on Zach by now. He's basically nocturnal."

“Yeah, so’s Eli,” she replies, looking toward the school doors and readjusting the sleeping toddler in her arms. “With this one at home, sleeping while he’s at school is impossible. I’d kill for a nap.”

“I assume you’ve tried all the standbys. Melatonin? Benadryl? Clonidine?” I ask, trying to be helpful.

“Yeah, nothing works,” she hikes her sleeping toddler up higher and pulls down the child’s shirt. “Sometimes it feels like I’m being punished.” She stares out at the busy school parking lot, her eyes unfocused.

I stare at her, confusion likely apparent on my face. “Punished. Because Eli doesn’t sleep?”

“I know it sounds crazy, but surely I must’ve done something wrong for life to be this hard,” she glances back at me. “Don’t you ever feel that way?”

I look away as I ponder her question, not sure what to say. The painted blue doors swing open and our attention turns to the children emerging from the school, holding hands with teachers and assistants. Before I can form an answer to her question, she walks toward her son and our conversation is over.

I collect my son from his teacher, get details about his day, and proceed to load him into our family car. As I buckle him into his seat, I look at him more closely than usual, ruffling his dark curls and kissing him on the cheek. *Do I feel punished because my son has autism?* I wonder.

Purpose of Research

Transitioning into parenthood is a major life event, changing a person’s life in complex and meaningful ways. An individual’s perception of personal identity evolves to accommodate this transition, incorporating cultural and societal beliefs into their embodiment of the parent role. When child demands require the parent role to deviate from cultural norms, as in the case of autism spectrum disorder (ASD), adults may experience distress as they attempt to incorporate these changes into their enactment of the parent role identity. Finding meaning in the experience of parenting a child with an ASD may facilitate this process, and reduce parental distress or it may add to their negative attribution of the situation. The purpose of this qualitative research study, therefore, was to determine how an ASD diagnosis changes parental identity and how parents create meaning from the experience of raising a child with ASD.

Overview

The Centers for Disease Control and Prevention (CDC) (2016) define autism spectrum disorders (ASD) as “a developmental disability that can cause significant social, communication, and behavioral challenges.” The spectrum of disorders is characterized by (1) persistent deficits in social communication and interactions, (2) restricted or repetitive patterns of behaviors, interests, or activities, (3) early childhood manifestation of symptoms, and (4) the inexplicability of these characteristics by other disorders (Diagnostics and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association (APA), 2013). The presentation of these symptoms can vary widely and comorbidities are common (Matson & Nebel-Schwalm, 2007). Common comorbidities include intellectual impairment, aggressive behaviors, attention deficit disorders, anxiety disorders, mood disorders, epilepsy, gastrointestinal disturbances, and poor sleep patterns (APA, 2013; Mannion, Leader & Healy, 2013). Functionally, ASD and its comorbidities can have a significant impact on a child’s daily life.

Raising a child can be stressful. When this task is compounded by a developmental disability, the impact can be substantial. Research indicates that raising a child with any type of developmental disability can result in heightened stress levels in parents (Fonseca, Navaré, & Canavarro, 2015; Miodrag, Burke, Tanner-Smith, & Hodapp, 2015). Raising a child with ASD, however, can be especially taxing. Both mothers and fathers of children with ASD have been found to have much higher stress levels than parent of children with other developmental disabilities (Hayes & Watson, 2013; Paynter, Riley, Beamish, Davies, & Milford, 2013). Severity of impairment (Tobin & Glenwick, 2006) and problem behaviours (Walsh, Mulder, & Tudor, 2013) have both been associated with increased risk of stress among parents of children with ASD.

Becoming a parent requires the assumption of a new identity. No longer is an adult responsible solely for their own welfare. Responsibility for another human being is time consuming and an integral component in a parent's thoughts, actions, and behaviors. Identity, including parental identity, is created through interactions with others (Gergen, 1991). Each society has tacit expectations for the role of a parent, and the ability of an adult to meet these expectations is an important component in both personal and societal appraisals. Goffman (1963) notes that individuals who do not meet social expectations are subject to stigmatization. Goffman refers to individuals bearing the stigma of deviancy as having "spoiled identities." Thus, when an individual is unable to meet the identity standards of a role or social identity, they may be viewed as having spoiled identities. Raising a child that has atypical behaviors and communication challenges may well lead others to believe that parents are not fulfilling the social expectations of their role as a parent.

The application of the construct of meaning-making to the parenting children with autism is relatively new. An ASD diagnosis not only has a significant impact on the parent role, but also impacts how a parent views both the world and the self, or their global meaning-making system. Attitudes, beliefs, and expectations change. Parental interactions with the world change. Unexpected challenges and difficult demands must be faced, and parents must construct new ways of addressing these new demands. This situational meaning-making process can lead to changes in a parent's global meaning-making system. According to Dewey (1933), it is only when life and its events have both meaning and consequence that control of the events is possible. Experiences and events generate and enhance meaning, while providing rationalization and interpretation for them (Chen, 2001; Park, 2010). Parental meaning-making, then, allows parents to adjust to the changing demands of their new roles. When a parent encounters a highly stressful or traumatic event, such as the diagnosis of a child with an ASD, meaning-making becomes a coping mechanism for managing that experience (Steger, Kashdan, Sullivan, & Lorentz, 2008).

This research study examines both global meaning-making and situational meaning-making from a social constructivist view; that is, how parents construct meaning from the parenting role and the ASD diagnosis. Both circumstances result in a multiplicity of adaptations in an individual's life. This single occurrence changes the manner an individual views disability, parenthood, advocacy, stigmatization, and personal worldviews. Parents must adapt to these changes while concurrently managing them. The process of creating meaning from this process can potentially aid in this adaptation.

Through the use of detailed interviews, observations, and focus groups, this qualitative research study endeavors to gain a better understanding of how parental identity is altered in the context of raising a child with ASD. The study also examines how parents create meaning from this experience. This investigation focuses on parents of children between the ages of 10 and 17, as these parents have likely been adapting and managing the changes to their parenting role for several number of years. Other research in this area has focused on parents of young children or parents of the newly diagnosed. (Dabrowska & Pisula, 2010; Moh & Magiati, 2012). As the diagnostic process and initial adaptations to the diagnosis is likely associated with a unique set of stressors, this study undertook to understand parental identity and meaning-making of parents whose children have been diagnosed for at least five years.

Chapter 2. Literature Review

Autism

The US Department of Health and Human Services (USDHHS) (2014) defines autism spectrum disorders (ASD) as a "broad group of developmental disorders characterized by impaired social interactions, problems with verbal and nonverbal communication, repetitive behaviors, or severely limited activities and interests." The concept of a spectrum is used to characterize this disorder as manifestations of behaviors and symptoms can be extremely broad; that is, individuals can range from mildly to severely impaired. Currently, there is no cure for ASD, but intensive and early interventions have been shown to improve symptoms of the disorder (Itzhak & Zachor, 2011).

Autism was first diagnosed as a mental disorder in 1911 by Eugen Bleuler (1912). Bleuler characterized autism as a withdrawal from reality in those suffering from schizophrenia. In the 1940's, Kanner and Asperger described young patients with high levels of intelligence, a preference for being alone, and an obsessive need for sameness (Baker, 2013). For many years, the disorder's association to schizophrenia was maintained. It was not until the 1970's that autism was identified as a separate disorder. The first formal definition for the disorder appeared in the Diagnostic and Statistical Manual (DSM) III which characterized the disorder as a lack of responsiveness to others, gross communication delays, and unusual reactions to environmental stimuli (Baker, 2013). Later versions of the DSM categorized four individual disorders as comprising the autism spectrum: Autistic disorder, Asperger syndrome, Rett syndrome, and pervasive developmental delay-not otherwise specified (PDD-NOS). In the most recent version of the manual, DSM-V, ASD was characterized as both persistent difficulties in reciprocal social interactions and restricted or repetitive patterns of behaviour (Baker, 2013).

Prevalence. The most recent statistics from the CDC (2016) estimates that 1 in 68, or 1.5%, of all children born in the U.S. has ASD. This prevalence rate represents a 30% increase over 2008, and a more than 60% increase over 2004 (CDC, 2016). The disorder is also more common among boys than girls, with of 1 in 42 boys diagnosed with ASD compared to 1 in 189 girls. The disorder is found across nationalities, ethnicities, and socioeconomic levels (Kaiser, Giarelli, & Pinto Martin, 2012; Kopetz & Endowed, 2012). Onset of the disorder usually occurs prior to age two, but diagnosis may occur later if symptoms are mild. ASD is second only to mental retardation as the most commonly diagnosed mental disability (Bhasin, et al., 2006).

The diagnosis of ASD can be particularly difficult as the symptoms of the disorder can vary substantially (Dave & Fernandez, 2015; Matson & Nebel-Schwalm, 2007) and comorbidities are common. There are currently no biological markers for this disorder, and symptom presentation can overlap substantially with other mental disorders, such as mental retardation or attention deficit disorder (ADD) (Dave & Fernandez, 2015). Diagnosis is currently made utilizing presenting behavior, a developmental history (Bent, Barbaro, & Dissanayake, 2017), and the completion of an ASD screening checklist (Bradstreet, Juechter, Kamphaus, Kerns, & Robins, 2017). Thus, an accurate diagnosis can require significant time. This is concerning as current research suggests that early interventions may have a positive impact on the defining characteristics of the disorder (Dawson, et al., 2009; Wong, et al., 2015).

Impact on families. There are considerable challenges associated with raising a child with a mental health disorder, such as ASD. These challenges and demands can vary significantly, depending on symptom presentation, functional impairment, and family resources (Lee, 2009; Lilley, 2013). Hinshaw (2005) classifies these challenges into two separate categories. The first is that of objective burdens which includes the financial costs, housing issues, and logistical treatment negotiations required to care for a child with ASD.

The objective burdens of caring for a child with ASD can be substantial for parents. Some early interventions have demonstrated improvements in social interactions and a reduction in atypical behaviors for those diagnosed with ASD. Children diagnosed with ASD routinely require multiple therapeutic and medical interventions to address the core symptoms of the disorder. The likely success of these interventions, however, often depends upon the severity of symptoms, and a parent's ability to secure services (Kohlbeck, et al., 2014). These interventions also require long hours of intensive one-on-one interactions with trained therapists over a period of years. Thus, parents of children with ASD spend more time both coordinating and accompanying children to therapeutic appointments than parents of children with physical health demands (Barry & Busch, 2007; Gould, 2004; Porterfield, 2002). Additionally, children with ASD often have significant impairments in their daily living skills, such as bathing or cooking (Perry, et al., 2009). Parents may have to spend more time assisting their children in these domains than parents of typically developing children.

An ASD diagnosis can have a serious financial impact on families. Multiple interventions such as speech therapy, occupational therapy, or behavioral therapy, are often required to treat the disorder. Private health insurance is often less generous in covering these services than for other medical needs (Barry & Busch, 2007; Kohlboeck, et al., 2014). The unpredictable symptoms and behaviors of ASD may also play havoc on parental employment. Parents, especially mothers, are significantly more likely to reduce work hours or to quit working completely to care for their child compared to families of children with other special health care needs (Barry & Busch, 2007; Gould, 2004; Porterfield, 2002). Research indicates that the incremental cost of raising a child with ASD, compared to a typically developing child, is upwards of three million dollars over the child's lifetime (Ganz, 2007). Thus, significant investments of both finances and time are often required by these parents.

The subjective burdens of raising a child diagnosed with ASD can also be significant. These subjective burdens can impact both parental physical and emotional health. Parents of children with ASD report higher levels of stress than parents of both typically developing children and children with other disabilities (Ehrlich, 2012; Hayes & Watson, 2013; Paynter, Riley, Beamish, Davies, & Milford, 2013). This increased stress puts caregivers at an increased risk for negative mental health outcomes, including psychological distress, lower wellbeing, and poorer marital adjustment (Rivard, Terroux, Parent-Boursier, & Mercier, 2014).

A recent study indicates the higher levels of parent-reported child behavioral problems in children with autism and ADHD are positively associated with atypical cortisol patterns and a reduced waking cortisol response (Lovell, Moss, & Wetherell, 2015). As parents often provide caregiving for their children with ASDs for many years, there may be a cumulative negative effect associated with this stress response (Rezende, Coimbra, Costallat, & Coimbra, 2010). In general, parents providing care to children with ASD report lower self-rated health and a higher number of chronic health conditions than parents of children with physical disabilities or children with no special health care needs (Miodrag, Burke, Tanner-Smith, & Hodapp, 2015; Zehner & Walker, 2014). This is not surprising as research indicates parents providing care for children with ASD have heavier caregiving duties and are more likely to experience emotional and psychological distress than parents of typically developing children (Pottie & Ingram, 2008).

Stigma and ASD. Stigma occurs when an individual is perceived to deviate from current social norms in either attributes or behaviors. This perception of deviance results in a diminished or tainted social identity for the bearer, leading to social rejection. This social rejection may take the form of discriminatory acts, attitudes, beliefs, or actions directed toward the person who is stigmatized (US Department of Health and Human Services [USDHHS], 2001). Goffman (1963) explains an individual's relationship with stigma in three ways: (1) the stigmatized are those who bear the undesirable attribute, (2) the normal, or stigmatizer, are those individuals who do not bear the undesirable attribute, and (3) the wise normal is an individual privy to the life experiences of the stigmatized. Goffman (1963) further notes that these relationships with stigma are contingent upon the individual and social contexts.

The aberrant behaviors commonly associated with ASD can be disconcerting to people unfamiliar with the disorder. Parents and other caregivers may receive uncomfortable stares, unsolicited advice, hostile comments, or insensitive behaviors from others when their child's behavior does not conform to social norms (Green, 2004; O'Driscoll, Heary, Hennessey, & McKeague, 2012; Walker, Coleman, Lee, Squire, &

Friesen, 2008). These social judgments can leave parents and caregivers feeling humiliated and socially isolated (Farrugia, 2009). Parental judgment is not limited to strangers or acquaintances. Parents may also be judged by family members and friends, who may not have a clear understanding of the challenges required to care for a child with ASD (Green, 2003). These negative judgments, by family, friends and acquaintances, indicate that parents of children with ASD may experience stigmatization due to their close association with the diagnosed child.

Research has shown a significant relationship between a child's ASD diagnosis and parental stigmatization. Indeed, studies have indicated that parents of children with ASD are more stigmatized than those with other physical or mental disabilities (Green, 2003; Green, 2004; Green, Davis, Karshmer, Marsh, & Straight, 2005). The physical appearance of children with ASD does not lend itself to the quick conclusion that a child is disabled. Therefore, when a child with ASD displays stereotypically inappropriate behaviors, such as a "meltdown," the behavior may be attributed to poor parenting rather than due to a diagnosable disorder (Gray, 2002). These parents experience both courtesy stigma, due to their child's diagnosis, and the stigma of being a bad parent (Farrugia, 2009). In such circumstances, parents and caregivers have exhibited embarrassment, guilt, and shame (Green, 2003; Thibodeau & Finley, 2017). The consequences of parental stigmatization can be serious, with parents withdrawing both themselves and their children from social interactions, which could lead to increased social isolation (Green, 2003). This isolation comes at a cost. This secreting away is associated with increased personal distress and loneliness for those in the stigmatized group and for those connected to them (Weiner, et al., 1988).

Identity

Identity construction and the self are highly researched constructs across a variety of disciplines, including psychology and communication studies. Identity is a representation of the self in terms of the social roles one holds and performs (Stryker & Serpe, 1994; Thoits, 1986). These roles are positions within a social framework that incorporate behavioral expectations, along with rights and obligations, such as a mother, husband, employee, or friend. Role identities answer such existential questions as “Who am I?” and “How do I behave”? The formation of the self is a product of social interaction, as individuals learn who they are through their interactions with others. As individuals interact in a myriad of groups and situations, they assume different roles for different contexts. Thus, the self is not an independent entity, but is rather a multi-faceted construct is created from the roles one assumes in society (Hogg, Terry, & White, 1995; Stryker & Burke, 2000). This review will now describe three theories of identity development that focus on transitions in identity, such as those of parenting and parenting a child with ASD.

Erikson’s Theory of Identity Development. Erikson extended Freud’s stages of psychosexual development by placing greater weight on the social context of identity development. His model encompasses the entirety of the human life cycle, focusing less on the sexual nature of humans and emphasizing psychosocial development (Côté & Levine, 2002). His theory states that humans pass through eight stages of development across the lifespan. In each of these eight stages, individuals face and master new challenges, conflicts, or crises (Crain, 1999). Progression through these stages helps to solidify individual identity, which synthesizes career, sexual preferences, family obligations, religious philosophies, hobbies, political beliefs, and one's choice of peer groups. These various components create a stable identity a person projects to others (Erikson, 1980; Schwartz, 2009).

Erikson's theory proposes that individuals develop an identity through the experience of specific psychological conflicts, each of which contribute to a major element of personality. While most identity formation work occurs during adolescence, it is considered to be a lifelong process (Erikson, 1980) as these experiences continue throughout the lifespan. By focusing on the social as well as the psychological, Erikson's theory serves as a framework of identity development via conflict resolution in the context of social relationships. Erikson's theory is of particular relevance to this research, as it demonstrates that an individual's worldview is generally developed prior to parenthood. Further, Erikson noted that crises of identity, such as a traumatic event, have the potential to alter the individual's worldview.

Social Construction of Identity. As a theory, social constructionism focuses on the social, reciprocal, and complex interactions between people (Shotter, 1992). Social constructionists propose that individuals construct meanings as they interact with each other. That is, personal understanding, significance, and meaning are not created individually, but are created in interactions with others (Gergen, 1991) through the use of language (Leeds-Hurwitz, 2009). Thus, a parent learns what it means to be a parent through their interactions with other parents, peers, teachers, physicians, and family members. Within each interaction, an individual presents a version of the self. This presentation may be an accurate depiction of an individual's personal version of reality, or, it may be an artificial presentation designed to influence the perceptions others (Clarke, 2008).

Social constructionism postulates that identity is temporal in nature and is dependent on being able to link experiences across time (Gergen & Gergen, 1987; 1997). Relating past events and experiences to both present situations and future plans is an important function of identity. Thus, when an individual becomes a parent, they incorporate all of their past experiences of parenting into that identity, as well, incorporating it into their current and future roles. Since identity is created through the interaction with others, self-narratives allow individuals to reappraise past events and anticipate future ones. Thus, identity is a project that is continuously under reflection and reconstruction (Giddens, 1991). It is within this project that individuals create, maintain, and revise their personal narratives. Although it can be reappraised, self-identity cannot be significantly altered. Giddens (1991) proposes that an individual's identity is created through the ability to sustain a particular self-narrative. That is, self-identities must continually integrate new experiences and events into their existing identity, and reconcile those into a coherent biography of the self (Giddens, 1991). Thus, parents of children with ASD must integrate the experience raising a child with ASD into their personal identities.

Identity Control Theory. Developed by Burke (2006), identity control theory (ICT) provides a framework for understanding how individual identities change. ICT focuses on the nature of an individual's identity and the relationship between that identity, its performance, and the social structure in which it is embedded. ICT emphasizes the meaning that is ascribed to particular identities, such as what it means to be a parent. The behaviors and meanings assigned to a particular identity are dependent upon an individual's social structure (Owens, 2000). Parents in one social structure have different identity standards than those in others.

Burke (1991) regarded identities as control systems, and suggests that each system is made up of four components: an identity standard, input (or perceptions), comparator, and output (or discrepancy). The identity standard sets the criterion for the meaning of a particular identity in a particular context. Individuals act in such a way to confirm their identities through their behaviors such that the behaviors conform to the identity standard. Input, or perceptions, consists of the perceived meanings ascribed to our behaviors by ourselves and by others. This information is generally garnered through the form of feedback (Burke, 2006). Input can be received from other children, parents, teachers, or other family members. The third component of ICT is the comparator, which serves to evaluate the perceived meanings to the identity standard. The final component of the system is the output, the discrepancy between the perceived meanings of an identity and the identity standard (Burke, 2006). If the output indicates no discrepancy, individuals will continue to perform the identity in the same manner. If the output indicates a discrepancy exists, individuals will change their behavior to better comply with the standard. This evaluation occurs over and over such that individuals are constantly evaluating their behaviors against a particular identity standard.

An illustration of how ICT is intended to work is as follows. A parent's identity standard may include ensuring a child has play dates with other children. However, a child with autism may have a difficult time with social interactions and may have a meltdown when asked to share their toys. Other parents may cast disapproving looks at the parent of the child with ASD (input). The parent uses this information to determine that their child is not conforming to social standards of behavior (comparator). The parent may then believe that they are not being a good parent, as their child does not act appropriately during play dates (output). Since there is a discrepancy between the standard and the output, a parent may change their behavior to address this discrepancy, such as cancelling future play dates.

According to ICT, the primary outcome of a discrepancy between identity standards, the perceived meanings of others, and the self is a change in behavior to eliminate the discrepancy. However, if the discrepancies persist over time due to contextual changes, the identity standard may shift to align with the altered context (Cast, Stets, & Burke, 1999). This is referred to as identity verification. An example of this process is the shifting identity standard for a parent as a child ages. Identity standards may require parents of infants to meet physical and nurturing needs, while the standard for parents of school age children may require parents to provide discipline as well. The identity verification process is associated with emotional outcomes that guide the process (Burke, 2006). When discrepancies between the standard and perceptions are low, individuals are happy and content. If the discrepancy between perceptions is large, an individual may be distressed or angry. For example, a parent may be unhappy if a teacher’s perception of their behavior is different than their own identity standard. This theory is an important element of this research as it highlights the existence of social expectations for the roles of parents and for parents of children with autism. It is against these roles standards that parents are judged by society and the self.

Disrupted/spoiled identity. ICT posits when an individual is unable to meet the identity standard for a role, they may attempt to change their behavior to reduce the discrepancy. Goffman (1963) referred to the expected role of an individual as their "virtual social identity" and their performed, or accurate, behaviors as their "actual social identity." When the virtual identity and actual identity are incongruent, the individual is subject to stigmatization, or disapproval and censure, from others in society and are perceived as inferior. Goffman (1963) labeled this perceived inferiority as a "spoiled identity." The result of this "spoiled identity" is a change in the social reactions to the non-conforming individual. According to Goffman (1963), individuals are subject to stigmatization when they are discredited or discreditable. Discredited individuals are those who are stigmatized due to obvious non-conformities, such as skin color or physical handicap. Discreditable individuals are those who have non-conformities that are not easily identifiable, such as sexual orientation or mental illness. A model of Goffman's theory can be found in Appendix A.

Goffman (1963) posited that discreditable individuals, like those with chronic illnesses, spend substantial effort in hiding their "spoiled identity." Bury (1982) describes chronic illness as a critical experience "where the structures of everyday life and the forms of knowledge which underpin them are disrupted" (p. 169). Bury and Wood (1979) argue that although chronic illness affects a person's abilities, they are often able to adapt temporarily and meet everyday demands. Individuals with chronic illnesses may attempt to meet the identity standard of a role, then strategically withdrawal from social interaction when symptoms are apparent. These disruptions affect not only the individual, but their families and wider social networks, as the illness may disturb the social norms of reciprocity and social support (Bury, 1982). The illness may impact the future plans of the individual, or their families, causing a “biographical disruption” in their lives, resulting in altered expectations and relationships.

Goffman (1963) notes that stigmatization can extend beyond the individual bearing the undesirable attribute to persons who associate with them, or “wise-normals.” Being the parent of a stigmatized child certainly qualifies for this designation. Research regarding the impact of perceived stigma on family members of those bearing undesirable attributes indicates that, like the stigmatized individual, family members experience increased distress and isolation (Birenbaum, 1992; Green 2003; Green, 2004; Green, Davis, Karshmer, Marsh, & Straight, 2005). Further, parents of children with ASD often feel blamed by others for their child’s differences (Green, et al., 2005). Interactions with others, therefore, can be detrimental to a parent’s sense of personal identity as identity is constructed through the interaction with others (Gergen, 1991; Goffman, 1963).

Bury’s (1982) example of chronic illness as a biographical disruption would certainly apply to ASD. Extrapolating even further, the caring of a child with autism can be easily conceptualized as a biographical disruption for a parent. As ASD has no known cure, parents must alter their planned futures in order to accommodate the care of their affected child. Parents often reduce working hours in order to provide care and access treatment. A parent may even quit work to meet these objective burdens.

Parental identity. Becoming a parent is one of the most significant role transitions a person can experience (Feeney, et al., 2001). Traditionally, it implies taking on the care and responsibility of other human beings. The role of a parent has expanded beyond this basic premise in recent decades. Despite dual income families, the amount of time parents spend with their children has increased significantly (Gauthier Smeeding, & Furstenberg, 2004). The type of activities expected of a parent has also increased, as parenting now incorporates a variety of tasks that previously were not considered fundamental to the parental role (Douglas & Michaels, 2004). Care of a child is now considered to be a form of emotional work (Gittins, 1998) in which a happy, well-adjusted child is the final product of the endeavor (Reay, Bignold, Ball, & Cribb, 1998). These role expansions are also now part of a larger public debate (Freely, 2000) and include such issues as feeding, discipline, time management, healthcare, and physical activity (Bristow, 2009; Gillies, 2008). Thus, the identity standard for the parent role has become both more complex and time consuming than in previous generations.

As noted previously, identities are constructed in concert with others through social interactions (Burke & Reitzes, 1991). It is not surprising, therefore, that parental identity is developed in concert with children, spouses, grandparents, teachers, friends, and peers. Stryker (1980) hypothesizes that the commitment one has to an identity can be ascertained through the extent to which an individual has relationships with others associated with that identity. Parents who are strongly committed to that role identity, therefore, would have many relationships with others as a parent, such as teachers, peer parents, parent organizations, pediatric healthcare providers, etc. Individuals gauge their role performance as parents through the success of their child and feedback gained through social interactions while in the parent role (Beck & Beck-Gernsheim, 1995).

When a child has ASD, a parent’s ability to conform to the identity standard set forth by society is difficult. Challenging or aberrant behaviors may be attributed to parental inadequacies, For instance, negative externalizing behaviors in children are often attributed to poor parental acceptance or discipline (Patterson, 1982; Van Leeuwen & Vermulst, 2004), overly permissive parenting (Wolfe, Jaffe, & Crooks, 2006), unrealistic parental expectations (Chang, Schwartz, Dodge, & McBride-Chang, 2003), the parent-child relationship (Reitz, Deković, & Meijer, 2006), the parent-grandparent relationship (Belsky, Jaffee, Sligo, Woodward, & Silva, 2005), and parent tobacco use (Brion, et al., 2010). However, externalizing and aberrant behaviors are common symptoms of ASD. As these behaviors are outside the cultural norm, the child's behavior may be blamed on poor parenting practices rather than an autism diagnosis.

Blaming parents for a child's mental health disorder is not a new occurrence. Historically, cold, unresponsive, and faulty parenting practices have been blamed for autism, schizophrenia, ADHD, and depression (Bettleheim, 1967). Studies (Birenbaum, 1970) describe parents' daily struggles with negative public reaction to their children's ASD and the negative emotional and psychological impact of these occurrences. Parents experience both courtesy stigma and the stigma of being a bad parent (Farrugia, 2009). To protect their role identity, parents may limit social interactions for themselves and their children.

Meaning-Making

This review has detailed the negative impact of a child's autism diagnosis on a parent or caregiver, and the mechanisms through which that diagnosis may impact parental identity. One way in which parents can incorporate a child's ASD diagnosis into their identity is to create meaning from the experience. Finding meaning is of paramount importance in human life (Frankl, 1963). It is only when life and its events have both meaning and consequence that control of the events is possible (Dewey, 1933). Thus, meaning-making is the cognitive process by which an individual's worldview and actions are defined. Experiences and events generate and enhance meaning, while providing rationalization and interpretation for them (Chen, 2001).

Meaning-making is often utilized when examining past experiences or occurrences (Park, 2010). When an individual encounters a highly stressful or traumatic event, such as the diagnosis of a child with ASD, meaning-making becomes a coping mechanism for managing that experience (Steger, Kashdan, Sullivan, & Lorentz, 2008). These traumatic events challenge the individual's perceptions regarding their identity and their worldview (Horowitz, 1975) and fundamental beliefs like justice, fairness and control (Janoff-Bulman & Morgan, 1994). As worldviews and belief systems provide a sense of purpose, self-esteem, and predictability, experiences that challenge them can result in significant stress and a compelling need to integrate them into one's worldviews or to revise one's worldview accordingly.

Certainly, having a child diagnosed with autism can be considered a significant or traumatic event in a parent's life. A parent's sense of fairness, control, and belief systems are likely challenged as a result, requiring parents to integrate the experience into their worldview and their personal identity. Thus, understanding how meaning is created from traumatic events an important foundation for this research.

Meaning-making model. Baumeister (1991) defines meaning-making as a mental representation of possible associations between events, things, occurrences and relationships. When an individual encounters a highly stressful or traumatic event, meaning-making becomes a coping mechanism for managing that experience (Steger, Kashdan, Sullivan, & Lorentz, 2008). Park and Folkman (1997) developed a model of meaning-making that is based on these principles, which entails seven steps. These steps assume (1) individuals have a set of cognitions or beliefs that are used to interpret their experiences and the world, (2) individuals evaluate events and experiences based on these cognitions, (3) individuals experience stress when events or experiences do not match their cognitions or beliefs, (4) individuals undertake meaning-making in order to alleviate the stress associated with this discrepancy, (5) individuals create meaning in many different ways, (6) individuals reduce the discrepancy between their cognitions and the meaning of the experience though meaning-making, and (7) individuals who are able to ascribe meaning to the discrepancy adjust better to the stressful event (Collie & Long, 2005; Greenberg, 1995; Henry, et al., 2010; Jim, Richardson, Golden-Kreutz, & Andersen, 2006; Park, 2010; Skaggs & Baron, 2006).

Global Meaning. Park and Folkman (1997) describe individual worldviews as global meaning systems that incorporate beliefs, goals, and subjective feelings. These global beliefs consist of broad views of justice, predictability, control, and personal identities (Reker & Wong, 1988). These global beliefs mold an individual's core schemas through which their personal experiences are appraised (Janoff-Bulman & Frantz, 1997). These worldviews may be based on religious beliefs or personal philosophies. Researchers assume that global meaning is formed early in life and is modified based upon individual experience and events (Austin & Vancouver, 1996; Park & Folkman, 1997). Global meaning has a significant influence on an individual's thoughts, actions, and emotional reactions (Klinger, 1998; Park & Folkman, 1997).

Situational Meaning. Park and Folkman (1997) define this construct as the meaning ascribed to a particular event in a particular context. Situational meaning is initiated in concert with stressful events that impact an individual's sense of global meaning. Meaning-making attempts to restore the sense of the world as meaningful and one's life or identity as worthwhile (Michael & Snyder, 2005). Common themes in meaning-making in response to a stressful event include: (1) perceptions of having made sense of the event, (2) acceptance of the stressful event, (3) causal understanding of the event, or the reason for the event, (4) perceptions of positive growth or life changes as a result of the event, (5) changes of identity, or integration of the event into one's identity, (6) reappraised meaning of the event as less catastrophic or dire, (7) changed global beliefs to accommodate the experience, (8) changed global goals due to the experience, and (9) restoration, or changes in, the sense of meaning in life (Park, 2013). Making-meaning is generally perceived to be a positive outcome of attempting to reduce the discrepancy between an individual's worldview and a stressful experience or event. Further, the extent to which the discrepancy is reduced has been linked to better adjustment to stressful events (Currier, Holland, & Neimeyer, 2006; Michael & Snyder, 2005). Park's and Folkman's model is easily adapted to research examining parental meaning-making in the context of parenting a child with ASD. Parental global meaning systems are challenged when stressful events occur. In response to these stressors, parents attempt to address this challenge by creating meaning from the experience.

Posttraumatic growth. The concept of meaning-making in response to a traumatic event has been expanded upon by Tedeschi and Calhoun (2004) in the form of posttraumatic growth (PTG). The PTG model acknowledges that serious events place a significant demand on an individual's adaptive resources and threatens a person's worldview (Calhoun & Tedeschi, 2006). When a stressful event occurs, individuals attempt to create meaning from the experience to restore a personal sense of global meaning. The PTG model does not suggest that this restoration indicates a return to the earlier identity or worldview, but rather one's worldview and identity evolve through a psychological adjustment in thinking and relating to the world. This evolution is highly individualized and meaningful (Linley & Joseph, 2004). The PTG model, however, only encapsulates the degree to which *positive* psychological changes occur as a direct result of the stressor. The negative consequences of the event are not assessed.

The PTG model identifies five components of positive growth, including: (1) an increased sense of personal strength, (2) increased depth in personal relationships, (3) increased appreciation of life, (4) increased spirituality, and (5) openness to new opportunities as a result of the negative event (Tedeschi & Calhoun, 2004) Researchers hypothesize that PTG is related to meaning-making in that it requires reappraisal of the event and creates causal relationships between the event and personal growth (Pals & McAdams, 2004; Parks, 2010). It is important to note that the traumatic event itself does not promote growth in an individual, but rather it is the individual's attempt to integrate the event in their worldview through reappraisal and meaning-making that is essential to growth (Tedeschi & Calhoun, 2004).

As the PTG model focuses on the positive meanings that individuals create after a stressful event, research examining the association between posttraumatic growth and posttraumatic distress have been mixed (Frazier, Conlon, Glaser, 2001; Laufer & Solomon, 2006; Tedeschi & Calhoun, 1996). Some studies show a positive relationship between PTG and distress (Blix, Hansen, Birkeland, Nissen, & Heir, 2013; Nishi, Matsuoka, & Kim, 2010), while others indicate a curvilinear relationship between PTG and distress (Tsai, El-Gabalawy, Sledge, Southwick, & Pietrzak, 2015; Shakespeare-Finch, & Lurie-Beck, 2014). Some researchers posit that posttraumatic growth is not an indication of decreased distress as the two constructs are essentially different (Cordova, et al., 2007; Powell, Rosner, Butollo, Tedeschi & Calhoun, 2003).

While many traumatic events can result in high levels of stress, the diagnosis and rearing of a child with ASD may be more severe as the experience may last for years. Thus, the application of PTG to this research is easily conceptualized. Parental meaning-making in the context of parenting a child with an EBD may be impacted by both the duration their caretaking responsibilities and the disorder's severity. Consequently, the ability to achieve positive meaning-making, or PTG, may also be impacted by these variables.

Significance of Research

This qualitative research study contributes to the literature exploring identity construction and meaning making among parent of children ASD. Approximately 1 in 68, or 1.5%, of children are diagnosed with ASD each year (CDC, 2016). Each of these children has a parent or caregiver who is instrumental in the child's receipt of necessary medical, educational, and psychological interventions in addition to the normal responsibilities associated with parenting. Thus, it is apparent that a child's ASD diagnosis can be a life changing event for a parent that can impact parental goals, beliefs, and attitudes.

The diagnosis of ASD is often accompanied by stigmatizing attitudes for both the child and the parent. For parents, this stigmatization may be derived from a suspected contribution to the child's diagnosis or due to perceived inadequacies in managing the diagnosis. The parental identity, therefore, is tainted due to the parent's and child's inability to conform to societal standards of behavior. Parents may isolate themselves and their child to minimize this stigmatization, increasing the subjective burden associated with caring for these children.

How parents manage this degraded identity and re-create meaning as a result of their child's diagnosis is important to understand. As mentioned in the opening narrative, parents construct meanings in response to the stress associated with parenting a child with ASD. Whether these meanings are positive or negative may provide an indication of parental wellness, caregiver resilience and potential psychopathologies.

Much of the research on meaning-making and parenting has focused on creating meaning from traumatic events, such as the death of a child (Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Keesee, Currier & Neimeyer, 2008; Meert, et al., 2015), a child's rare disease diagnosis (Helm, 2015), or a child's chronic illness (Cadell, et al., 2014; Fonseca, Nazaré, & Canavarro, 2015). Despite the high prevalence of ASD (CDC, 2016) and an increasing social awareness of the disorder, stigma toward individuals with autism remains significant (Gillespie-Lynch, et al., 2015; Gray, 2002). Both children with ASD and their families are impacted by stigma (Broady, Stoyles, & Morse, 2017; Mukolo, Heflinger, & Wallston, 2010). In addition to managing the increased responsibilities associated with caring for the child with ASD, families must also cope with social rejection and isolation, misunderstanding, and sense of loss (Godres, Ozgul, Owen, & Foley Evans, 2005; MacGregor, 1994; Richardson, Cobham, McDermott, & Murray, 2013). Furthermore, these parents must also deal with the need to reframe their parental role expectations, personal identity, and attempt to find meaning in the process of raising a child with autism. Given the critical nature of parental involvement in child outcomes, the paucity of research on this topic is disconcerting. There is a significant need to understand how parents create meaning from a child's ASD diagnosis in order to provide support for struggling families. This study, therefore, will address this gap in the meaning-making literature

Chapter 3. Theoretical Framework

This research will be informed by several theoretical perspectives, including systems theory (especially family systems theory), social constructionism, and narrative theory.

Systems Theory

Like other organisms, humans exist within an environment composed of various systems that interact with each other and the individual to influence development and behavior (Bronfenbrenner, 1979, 1989). According to Bronfenbrenner (1979), humans are embedded within four environmental systems that both influence, and are influenced by, human interactions. These systems include the microsystem, exosystem, macrosystem, and chronosystem. A fifth system, the mesosystem, links the developing individual to the various microsystems (Sigelman & Rider, 2006). A final evolution of the theory acknowledges the importance of personal characteristics that influence an individual's interactions (Bronfenbrenner & Morris, 1998).

Karl Weick's (1979) applied General Systems Theory to the areas of social psychology and organizational theory. Intended to help understand how organizations function, his theory focuses on communication structures within organizations. He posits that the more complex or vague an organizational problem is, the more likely persons within the organization will need assistance from others to cope with, and respond to, these equivocal problems. Indeed, Weick suggests that organizations evolved expressly as systems for resolving ambiguity (or equivocality) and reducing the uncertainty of life (Weick, 1979). The applications of Weick's work extends beyond organizational systems. He suggests that all individuals are led to make sense of their environments when they encounter equivocality and uncertainty (Weick, 1979). A child's ASD diagnosis would certainly apply in this context. According to Weick (1979), equivocality is lessened through the following actions: (1) labeling of experiences, (2) deciding what information to act upon, and (3) deciding what information to disregard.

Family Systems Theory. There are a myriad of interactional environments that influence an individual's behavior and knowledge. Arguably, the family is the most universal of these environments (Bochner, 1976). Bateson and colleagues (Bateson, Jackson, Haley, & Weakland, 1956) and Bowen (1966) extrapolate the concepts of systems theory to family therapy. Both researchers presented their initial hypotheses while working with schizophrenic patients and their families in the 1950's and 1960's. While parts of their work are considered to be outdated, their conception of family systems continues to be relevant. Bateson and his colleagues (1956) propose that communication is never delivered solely on one level, but is subject to tone, movement, and context, and these various layers may be conflicting. At the conclusion of their research, the team suggests that examination of the layers of communication within a family may be useful in therapeutic situations. Examination of the multiple layers of family communication, especially in varying contexts contributes to the understanding of how families manage deal with the stress of raising a child with ASD and how meaning is created from the experience.

Bowen's (1974) contribution to family systems theory also originated through his work with families of schizophrenic patients, He hypothesizes that each family is a unit, or system, and any change in the functioning of that system, be it social, emotional, medical, or psychological, is predictably and automatically compensated for by changes in the other members of the family unit (Bowen, 1974). According to Hoffman (1981), however, family members are not always aware of these changes. Unlike conventional psychotherapies, family systems look beyond the individual, to the system as a whole, to understand the systemic contexts that result in certain behaviors.

Bowen (1974) postulates that family systems are comprised of eight theoretical elements including: (1) the “triangle”, or three-person relationship system, (2) the differentiation of self, (3) nuclear family emotional systems, (4) the family projection process, (5) the multigenerational transmission process, (6) emotional cutoff, (7) sibling position, and (8) societal emotional process. Bowen (1974) posits that the “triangle”, or three-person relationship system, is the smallest stable relationship system. He surmises that two-person relationships are relatively unstable, as they tolerate little tension before entangling a third person. The shifting nature of these tensions between the three members of the triangle prevent resolution (Kerr, 2013).

The “differentiation of self” (Bowen, 1974, p. 117) is an important factor in the creation of identity. Families play a significant role in how its members think, feel and behave; however, individuals vary in their susceptibility to this coercion. A child with ASD may exert significant influence on how other family members behave. However, family systems also vary in their demand for conformity (Kerr, 2013). The less developed a family member’s sense of self, the more impact the family system will have on that member’s functioning. Low differentiation of self also impacts a member’s effectiveness in influencing other members of the family system.

Bowen’s (1974) concept of nuclear family emotional systems, the third in his theory, recognizes that problems among family members usually arise during periods of heightened tensions. He suggests that heightened tensions increase one or more of the four primary relationship patterns in a family system; (1) marital conflict, (2) dysfunction in one spouse, (3) impairment of one or more children, and (4) emotional distance. These basic relationship patterns dictate where family tensions rest; that is, the more anxiety felt by one member of the family system, the less others in the system must absorb. As a result, some members of a family system maintain their functioning at the expense of others in the system (Kerr, 2013). In the case of a family raising a child with ASD, treatment and interventions to improve functioning of the child may occur at the expense of other family members.

The fourth concept of Bowen’s theory is that of the family projection process (Bowen, 1974) which describes the primary way in which parents transmit their emotional problems to their children. Kerr (2013) explicates the concept as a three-step process: (1) the parent focuses attention on a child out of fear that something is wrong, (2) the parent interprets the child’s behavior as confirming the fear, and (3) the parent treats the child as if something is genuinely wrong with the child. This pattern of behavior can shape a child’s development and impact their own self-concept. For example, if a parent perceives a child is lonely, they may spend an inordinate amount of time with that child in an attempt to “fix” the problem. However, the child then becomes dependent upon that attention and may grow dependent upon the parent to prevent further loneliness. Children less involved in the family projection process may have a more mature and reality based relationship with their parents (Kerr, 2013).

The fifth concept of Bowen’s family systems theory is that of the multigenerational transmission process (Bowen, 1974). This concept implies that multigenerational family influences relationship patterns, noted previously, and symptomology that develop within a family system (Kerr & Bowen, 1988). These influences can originate through early learning experiences within the family of origin (Klever, 2009). When a relationship pattern, such as marital conflict, dysfunctional spouse, or child focus, is present within the family of origin for one family member, that family member is more likely to repeat that relationship pattern in their nuclear family (Klever, 2009).

The sixth concept of Bowen's family systems theory is that of emotional cutoff (Bowen, 1974). This concept describes family members handling unresolved tensions with other system members, such as parents or siblings, by cutting off contact with those members (Kerr, 2013). The same ends may be achieved by the relocation of a family member, resulting in little physical contact with other family members, or by refusing to discuss sensitive issues while remaining in physical contact with the family system. This concept, however, does not eliminate the issue and problems within the system remain unresolved (Kerr, 2013).

The seventh concept of family systems theory is that of sibling position (Bowen, 1974) which he derives from Toman's work (Kerr, 2013). Toman's (1962) research on the position of children within a family indicates that individuals holding the family position in their families of origin have similar characteristics. While no position is lauded as better (or worse) than others, Toman (1962) notes that these positions can influence interactions in new developing nuclear families and that these positions could be complementary or detrimental to the construction of new family systems. For example, his work indicates that spousal sibling position is associated with the likelihood of divorce (Toman, 1962).

The eighth and final concept of Bowen's Family Systems theory is that of societal emotional process (Bowen, 1974) which describes how the societal emotional process controls behavior on a broader cultural level. Bowen (1974) notes parallels between societal and familial functioning while treating juvenile offenders and their families. He hypothesizes that the court system begins to function as the parents of the offenders and that the absence of sufficient or adequate parenting is a result of anxiety driven regression (Kerr, 2013) in functioning. Thus, increased crime rates, growth of divorce, polarization between racial and ethnic groups and less focus on personal responsibility are all symptomatic of societal regression (Kerr, 2013).

Bateson and Bowen's theory of family systems and their interactions has played an important role in the development of family and marital counseling (Horn & Hicks, 2002; Nichols & Schwartz, 2001; Hoffman, 1981). Although intended primarily for therapeutic interventions, Bowen's theory has been integrated into non-clinical studies of family dynamics (Broderick, 1993; Day, 2003).

In order to understand how parents create meaning from the experience of raising a child with ASD, it is important to observe family communications *in situ*. The demands each family member places on the other, how those demands are managed, and the tensions they create, can all play a significant role in determining how well parents and a family adjust to the increased demands associated with parenting a child with a mental illness. While each of Bowen's theoretical concepts is an important component in of family systems, this research will focus primarily on those elements that emerge from data collected in this research.

Social Constructionism

Social constructionism is a theory of knowledge that examines the jointly constructed understandings of the world (Leeds-Hurwitz, 2009). This theory assumes that meaning, in all of its forms, is not created independently, but is generated in coordination with others. The primary components of social constructionism include: (1) the premise that humans explain their experiences by creating a model of the social world and how it operates and (2) that language serves as the principal system through which meaning is constructed (Leeds-Hurwitz, 2009). Thus, humans use language and other forms of communication to create shared meanings about the world, the self, and others. As individuals in a society interact, they come to share meanings for specific actions and experiences, and consequently, come to understand these experiences in a similar way (Mead & Morris, 1962).

Individuals live and comprehend their lives through the lens of the socially constructed realities they find meaningful, and through which they interpret their experiences (Gergen, 1985; Hoffman, 1990). New meanings are continually being formed as a result of human interaction. Meanings exist and evolve as part of the narratives that individuals communicate about the self and others (Gergen & Kaye, 1992). Individuals act, and react, based on their constructions about the world.

Social constructionism is an important element in the research of meaning-making. As parents of children with ASD interact within multiple contexts, the meanings assigned to interactions are all evaluated through a socially constructed lens. For example, an interchange that is considered benign by many individuals may be stigmatizing through the lens of a parent raising a child with autism. Further, a parent's reality may evolve as a result of this experience. Perhaps parents whose reality once included perfect grades from their child, may evolve to one in which merely passing grades are an achievement. Thus, understanding parental realities is an important element in understanding how meaning is created within the experience of raising a child with an ASD.

Family Systems, Social Constructionism, and Dialectical Processes. Janet Yerby (1995) combines family systems theory with the communication theories of social constructionism and dialectical processes. Social constructionism was summarized earlier in this review. Dialectical processes, the basis of Relational Dialectics Theory (RDT), refer to the contradictions that arise among a variety of opposing forces when individuals relate (Baxter & Montgomery, 1996). An example of these opposing forces is the desire to be open and honest in an exchange, and the desire to be guarded and secretive in sharing personal information. RDT is a method in which to improve understanding of these communicative tensions between opposing systems of meaning. In terms of communication theory, RDT allows researchers to better understand how these contradictory meanings, or opposing forces, are negotiated in relationships.

Yerby (1995) uses the foundation of Family Systems Theory and integrates both the social constructionist and dialectical processes view into study of familial interactions. By adding the dialectical viewpoint, Yerby (1995) suggests that a better understanding of the family process can be obtained by focusing on how meaning is constructed through communication as family systems function within the dichotomy of their existence. Yerby (1995) further posits that such a model would have the following characteristics: assumes family processes are ever evolving rather than circular, examines the dialectic between the family and the individual, recognizes potential for bias (gender and cultural) in the construction of the family process, presumes that family meaning is co-constructed through conversation, and acknowledges that knowledge of systems is a reflexive process that includes both the knower and the participant. Yerby (1995) proposes the integration of social constructionism and dialectical processes into the family system allows for an exploration of what family members do in the generation of meaning, which is "to is construct and co-construct narratives" (p. 360).

Yerby's (1995) evolution of Family Systems Theory is clearly applicable to this research. As parents learn to manage the responsibilities associated with a child's ASD diagnosis, multiple tensions, identities, and family processes are likely to be created, negotiated and re-created. Inclusion of this theory will aid in understanding how parents create meaning within the experience of raising a child with autism.

Narrative Theory

Narrative theory posits that individuals shape their identities by integrating their personal experiences into a cohesive, developing story of the self (McAdams & McLean, 2013). This developing story is utilized by the individual to provide a sense of self. The creation of the story, incorporating who we are, where we have been, and where we are going, is one form of meaning-making (Bruner, 1990).

One of the primary benefits of engaging in the process of creating a narrative is to make sense of the unfamiliar (Bruner, 1990). When challenging experiences or events occur, the construction of stories aid in creating an explanation for the occurrence. The details and views that are emphasized in the narrative help create meaning from ambiguity. Many researchers posit that it is precisely at this point, when we encounter a disruptive or unsettling event, that meaning-making occurs (Park, 2010). Other researchers argue that the appraisal of the traumatic event is more important than what actually occurred, as it is the identification of the event as threatening or disruptive that triggers the meaning-making process (McAdams, 1993). Engaging in meaning-making through the narrative process is not only an important component of identity development, but it is also associated with positive outcomes, including greater well-being, better health, and increased maturity (King & Hicks, 2009; Pals, 2006).

As noted previously, meaning and identity are created through interactions with others. We communicate our personal identity to others through stories. Through repeated interactions with others, an individual's stories are processed, edited, reappraised, and subjected to a variety of cultural and social influences (McLean, Pasupathi, & Pals, 2007). McLean and colleagues (2007) propose that the stories one shares with others represent different aspects of an individual's self-concept. These stories can be utilized to influence others, provide perspective, and guide our actions (Singer, 2004). Self-narratives can be used to gain insight into individual behaviors, goals, and attitudes. The reflection and contemplation of life narratives yields schemas that provide causal and temporal logic to an individual's sense of identity (Bluck & Habermas, 2001).

Autoethnography. Autoethnography is a category of qualitative, reflexive and autobiographical writing and research in which the researcher acts as the subject (Ellis & Bochner, 2000; Ellis, 2004). The researcher draws upon their personal experiences, knowledge and intuition to closely examine and critique the framework of a particular social context. Consequently, autoethnography connects the social to the cultural by examining the self within a specific context (Reed-Danahay, 1997).

Researchers utilizing narrative inquiry, engage in personal reflection and examine their own attitudes, principles, and beliefs. In narrative research, therefore, there is value in the researcher articulating their introspection and personal reflections as a means to enrich research. According to Denizen (1997), reflexivity is a fundamental element of the research process as researchers are intimately involved in constructing and interpreting investigative findings. Rather than merely summarizing a personal experience, autoethnographers utilize methodological tools and analysis to examine their personal experiences to validate or question existing research or to question cultural beliefs (Ellis, Adams & Bochner, 2011; Foster, 2006; Denzin, 2006).

As the parent of a child with autism, this researcher is not without pre-existing ideas and conceptions regarding the parenting role, it enactment, and how meaning is constructed from raising a child with ASD. As a component of this research study, the researcher will provide personal insights into the experience of raising a child with autism as a means to enrich the findings from the investigative process.

Chapter 4. Research Questions

Autism now affects 1 in 68 children (CDC, 2016). According to Bowen (1974), when one member of a family system has a change in functioning, it is compensated for by other members of the family system. Thus, not only is the child affected by the diagnosis, but parents and caregivers are also affected. The diagnosis causes parents to manage demands and issues never previously considered. These new challenges likely cause significant reexamination of the parent role by those affected. These suppositions lead to the following research question.

RQ1. How does an ASD diagnosis affect how parents reconstruct the parent role identity.

Identities are constructed in concert with others through social interactions (Burke & Reitzes, 1991). Social expectations of child behavior can affect how others, and the parent, assess parental performance to the identity standard. The externalizing behaviors enacted by many children diagnosed with ASD may lead to negative perceptions regarding parental role performance. This may lead to both the parent, and the child, being stigmatized. This conjecture precipitates the second research question.

RQ2. How do parents construct their ability to meet society's role standards for parenting?

Having a child diagnosed with autism can be considered a traumatic event in a parent's life. A parent's sense of fairness, control, and belief systems are likely challenged and they must integrate the experience into their worldview and their personal identity. In order to successfully adapt to the event, meaning is ascribed to the experience (Park, 2010). This premise leads to the third research question.

RQ3. How do parents construct meaning from the experience of raising a child with ASD?

As the parent of a child with autism, I too must integrate the experience into my worldview in order to successfully adapt to the situation. How I reconstruct the parent role identity, how I assess my personal performance to social standards, and how I create meaning from the experience are all phenomena I share with the participants of this research study. This leads to the final research question.

RQ4. How do the researcher's personal experiences of constructing the parent role identity and creating meaning from raising a child with ASD compare to those of the participants in this research study?

Chapter 5. Methodology

Social constructivism is a powerful model for explaining how knowledge is created or produced (Gordon, 2009). Within this theoretical framework, the meanings about the world and life are multiple and varied and there is not one common reality or truth (Schmidt, 2001). As noted in earlier chapters, social constructivism posits that knowledge and truth are constructed through interactions with others and the world (Morcol, 2001). Consequently, all realities are interpreted based on individual experiences and interactions. Qualitative research methodologies, therefore, provide the means to understand the context of individual lives (Creswell, 2003). In a qualitative study, the researcher seeks to understand an experience through the perceptions of those experiencing it and to assess the reality that is constructed by those individuals (Merriam, 2009). Qualitative research is characterized by the following features: (1) occur in a natural setting, (2) aim to develop a thorough understanding of an experience or phenomenon, (3) ask varied questions designed to gain an in-depth understanding of social context, (4) select participants through non-random methods based on their experiences, (5) bring researchers into close contact with the participants through in-depth interviews and observations, (6) allows the researcher to develop close relationships with participants and to interact in the social contexts in which the participants reside, (7) formation of hypotheses does not occur until data collection has commenced, and may be modified as data collection continues, and (8) reports data in narrative formats (Creswell, 2012). This research study incorporated these key features into the study design.

Collective Case Study Approach

As the primary concern of this exploratory research study was to describe the participants' conceptions of the parenting a child with ASD, case-study research methods were used. A case study is a research methodology that is used to produce an in-depth, multidimensional understanding of a complex issue in a real-life context (Yin, 2009). Case studies capture the complexity of individual cases (Stake, 1995). It also involves the in-depth research of a specific *case,* which could be a location, an individual, a policy, or an event within a bounded system (Creswell, 2012; Green & Thorgood, 2004).

A collective case-study gathers information on a single phenomenon, event, or experience from multiple cases. Merriam (2009) notes that a case study is likely to have a more compelling and valid interpretation when multiple cases are included. Thus, a collective case study uses multiple cases, concurrently or sequentially, to derive an even broader appreciation of an issue.

The phenomenon under investigation in this research study was the experience of raising a child with ASD. As this study was informed by data collected from multiple families, it can be considered as a collective case study (Stake, 1995). This study was bounded by the interpretations of participants that all the parents had in common, which further validates the use of a collective case study research design.

Rationale for method. Case-studies are used to explain, describe, or explore events and phenomena in the natural contexts in which they occur (Yin, 2009). The case study approach lends itself to obtaining information of an explanatory nature, such as *how, what* and *why* (Stake, 1995). The justification for using a collective case study design was to inform the research process by producing "potentially contrasting results for predictable reasons" (Yin, 1994, p. 46). Cases selected for such research studies should have a pre-determined boundary that clarifies the nature and time-period covered by the case study, the relevant social group, the geographical area of interest, the types of data to be collected, and the priorities for data collection and analysis (Yin, 2009). The predetermined boundaries for this research was the experience of raising a child with autism in a two-parent household.

Alternative considered methodologies. Other methodologies that were considered, but not used, for this research study included henomenology, ethnography, and auto-ethnography. Phenomenology was likewise eliminated as it is primarily concerned with the emotions and feelings of multiple individuals to a particular event or experience (Cairns, 2002). Ethnography does allow for in-depth interactive research, but it is primarily concerned with the cultural behaviors within a group (Creswell, 2012). Auto-ethnography was also considered, as I am the parent of a child with ASD. This methodology was ultimately disregarded, as research that contains multiple voices can give a broader understanding of the phenomenon under investigation (Merriam, 2009).

Researcher Subjectivity

Subjectivity, the influence of a researcher's experiences, knowledges, and beliefs, has been viewed as a strength and a weakness of qualitative research. It is perceived by many positivist researchers as the insertion of one's values and beliefs into the research, resulting in a distorted interpretation of the phenomenon under study. Conversely, many relativist researchers consider subjectivity to be a potential asset of qualitative research, resulting in unique interpretations and understanding of an issue. A researcher cannot separate themselves from their research, as it is in the interaction between the researcher and the participant that knowledge is created (Gergen & Kaye, 1992).

Although positivist research claims to be objective and value free, most researchers now acknowledge that no scientific research is free from bias (Worell & Remer, 2002). Peshkin (1988), arguably one of the most influential writers on researcher subjectivity, states his belief that it is critical to the credibility of investigations that researchers “systematically identify their subjectivity throughout the course of their research” (p. 17). The attitudes and beliefs of a researcher cannot easily be removed. Therefore, it is imperative that the researcher acknowledge their own subjectivity and critically reflect upon that subjectivity reflexively throughout the research process (Reinharz, 1997).

I am a parent of a child with ASD. In the interest of full disclosure, I acknowledge my own biases and attitudes regarding parenting, autism, and the relationship between the two. To ensure that this research is multi-vocal, and is interpreted in a manner that ensures the credibility of the research, I maintained a written record of my own perceptions, judgements, and beliefs after each encounter in this research study. In the analysis of this research, I offer my own reflexive interpretations so that readers can make informed decisions regarding the credibility of these findings. These reflexive interpretations can be found in my statement of personal identity in Appendix B.

Validity and Credibility

Social realities are inherently complex, and it is unlikely that any research study, no matter how well designed, can irrefutably explain these realities. One method, however, that can be used to maximize the validity and credibility of qualitative research is that of triangulation Davis, Powell, & Lachlan, 2013). Triangulation refers to the utilization of multiple theories, data sources, research methods, or researchers, in a single research study, in order to converge on a single result or conclusion. Denzin (1970) posited four types of triangulation: (1) collecting data from multiple sources, (2) using multiple observers to collect and interpret data, (3) using more than one theoretical position in interpreting the data, and (4) using more than one research method or data collection technique (Denizen, 1970).

This research study employed several forms of triangulation. The first method of triangulation used was capturing data from multiple sources. This research study included eight different case families, each raising a child with ASD. The second form of triangulation used in this study was using more than one data collection technique. Data was collected through in-depth interviews with parents, multiple field observations, and a focus group. Data from each encounter was transcribed and analyzed using the same analytic methods.

The third form of triangulation used was that of member checks. Member checks are a process of providing study participants with data or research findings and giving them an opportunity to offer feedback on the information (Davis, et al., 2013). In this study, member checks were performed on data collected during focus groups. Feedback on the data from the members was incorporated into the final data analysis. Next, theoretical triangulation was also utilized in this study to interpret the data. Data collected in this research study were examined using multiple theoretical lenses: social constructionism, systems theory, and narrative theory.

The final form of triangulation utilized in this research study was using multiple research methods. The bulk of this research study involved collecting data from case families that were raising a child with ASD. A second form of data collection arose from my personal experiences as the mother of a child with autism. As a component of this research study, I provided autoethnographic accounts of my personal experiences of raising a child with autism. These autoethnographic accounts are used to compare how I construct the parent role identity and how I construct meaning from the experience to those of the case families in this investigation.

Sampling

Recruitment. Participants were recruited from April 2016 through July 2016 (IRB Protocol number 15-12-31) using non-random purposive sampling techniques. Flyers were distributed to ASD support organizations, service providers, case managers, and through connections with stakeholders. After receiving IRB approval, flyers were placed in service provider waiting rooms, as well as given to case managers, therapists, and ASD support organization members. The recruitment flyers (Appendix C) provided a basic description of the research study, including a phone number and email address to contact the primary investigator. Interested individuals contacted the primary investigator through one of these two channels. Potential participants were assessed for eligibility though confirmation that they were at least 18 years of age, had a child with an ASD diagnosis that was between 10 and 17 years old, that they were a member of a two-parent household, and that they were able to speak English.

Informed consent and informed assent. Once eligibility was established, the primary researcher made arrangements to conduct the initial interview at a convenient time and location. At this meeting the participant was provided with an informed consent (see Appendix D). Each aspect of the informed consent was covered with the participant. Parents were advised once again of the time commitment for participation in the study. Parents were also advised that any information gathered during the research study would remain confidential and that no names would be utilized during the study.

Once informed consent was provided, the participant was then asked to sign an informed assent (Appendix E). This form asked parents to acknowledge that, although their child would not be involved in any direct interviews, the child with ASD would be a participant in several field observations. Each aspect of this informed assent was also covered by the researcher. Again, parents were advised that information gathered during these field studies would remain confidential and at no time would any child's name be used during the research study.

A list of resources was provided to each participant (Appendix F). These resources included access to three ASD support organizations, as well as fifteen highly rated websites for parents of children with ASD.

Participants. Twelve people contacted the researcher with interest in participating in this study. One individual's child was over age 17. Two individuals had children that were younger than age 10. Another individual chose not to participate due to the time commitment associated with the research study. A total of eight parents provided informed consent and informed assent and completed the research process.

These eight parents were all female, white, and between the ages of 33 and 48 (mean age = 42.5 years). The ages of the children ranged from 10 to 17 (mean age = 12.4 years). Each of the parent participants had one child diagnosed with ASD. Two of the children had comorbid diagnoses of ADD/ADHD. One child had comorbid diagnoses of anxiety disorder and obsessive compulsive disorder. Another child had comorbid diagnoses of ADD/ADHD and sensory integration disorder. A fifth child had comorbid diagnoses of ADD/ADHD and anxiety disorder. The remaining three children did not have comorbid diagnoses.

Participants were all members of two parent households. Fathers' ages ranged from 32 to 51 (mean age = 43.3 years). Case families had between 1 and 3 children per family (mean number of children = 2.1 children per family). Fifty percent of the participants worked full time, 25% worked part time, and 25% did not work outside the home. One hundred percent of the fathers worked full time. The primary language in each household was English. Detailed demographic information for each case is presented in Table 1.

Data Collection

Data collection in a qualitative case study is meant to capture the ordinary events and social constructions of the participants in naturally occurring settings (Brewer, 2000). Multiple methods of data collection were employed to facilitate relationships between the researcher and the participants which provided an in-depth portrait of the participants and their lived experiences (Bochner & Ellis, 1992). Data collection included multiple sources of information, using several qualitative methods of inquiry. Specifically, data was collected via a focus group, 17 in-depth interviews, and 16 field observations for each case family. To fully understand the context of each case, each participant was asked to complete a confidential demographic questionnaire (Appendix G). This questionnaire included the following information: parent gender, parent age, child gender, child age, child diagnosis, parent educational background, parent race, parent ethnicity, and parent marital status.

Interview protocol. After the informed consent, informed assent, and demographic questionnaires were completed, the initial interview was commenced. The interviews followed a semi-structured outline (Appendix H). This semi-structured approach was more structured than an informal, conversational interview, but still provided a measure of flexibility in its construction (Gall, Gall & Borg, 2003). This type of interview allowed the researcher to ensure some consistency across participants, but still allowed the flexibility of asking probing follow-up questions based on parent responses or observations made by the researcher (Turner, 2010). Each interview was audio recorded by the investigator.

At the end of the first interview session, the initial field observation and second interview were scheduled. One participant required a third interview to complete the entire interview protocol. The seventeen interviews ranged from 41 minutes to 1 hour and 35 minutes (mean = 1 hour and 10 minutes). A total of 17 hours, and 53 minutes of interviews were transcribed for study.

Field observations. Field based observations incorporate the systematic descriptions of events, behaviors, and experiences in the natural setting to be studied (Marshall & Rossman, 1999). Observations allow researchers to describe situations and contexts using the five senses (Erlandson, Harris, Skipper, & Allen, 1993) and enable researchers to learn about the behaviors of individuals under study without the filter of a third party. Field observations also allow researchers to examine non-verbal expressions of emotions and validate patterns of communication (Schmuck, 1997). These observations allow for a holistic understanding of the phenomena under study and increases the validity of the research findings (DeWalt & DeWalt, 2002).

A guide to documenting field observations was used to ensure consistency across the observations (Appendix I). This research incorporated two field observations for each family case in their lived environment. Locations for the observations included the student's schools, local parks, local restaurants, and the participants' homes. Notes were taken during the observation by the researcher, and were immediately transcribed after the observation. The beginning and ending time for each observation was noted. A total of sixteen field observations were made during this study. The observations ranged from 47 minutes to 2 hours and 6 minutes (mean = 1 hour and 14 minutes). A total of 19 hours and 30 minutes were documented for these observations.

Focus group. A third method of data collection was used in this research study. A focus group was conducted and six of the eight participants attended. Focus groups provide detailed insights into how individuals think and provide a deeper understanding of the subject under study (Huston & Rowan, 1998). Group interaction between the participants may encourage group members to make connections to various concepts through discussions that may not occur during an individual interview (Kitzinger, 1995). Focus group moderators should use techniques to maximize the comfort level of the participants, including the ability to guide discussion and to encourage participants to express their views on the topic (Morgan, 1997).

The purpose of this focus group was two-fold. The first reason for the focus group was to elicit data from the research participants that might be triggered by comments made by other research participants. These connections allowed for richer data collection by generating connections between the participants. These new connections were explored with the participants in subsesequent individual interviews.

The second reason for the focus group was to potentially increase the social group of those participanting in this research. Research has shown that parents of children with ASD can become socially isolated due to their child's behaviors and sensory issues By conducting the focus group, these parents were able to make new personal connections and potentially increase their social support group.

The primary investigator served as the moderator for the focus group. Using a topical guide (Appendix J), the moderator posed open ended questions to the group designed to elicit in-depth discussion regarding stigma, attitudes, beliefs, challenges, and meaning-making relative to parenting a child with ASD. The focus group was videotaped and transcribed verbatim to preserve data integrity (Krueger, 1994). Notes were also captured and utilized as data (Krueger & Casey, 2000).

Data Management and Confidentiality

Although the participant became known to the primary researcher through the course of this research study, no personally identifying information was noted during the observations and interviews. All transcriptions were completed by the investigator so the data remained confidential. All recorded transcripts were destroyed immediately after transcription. The transcribed interviews, observations, and focus group were stored on a secure computer using Microsoft Word. Data were password protected at the computer log-in level and folder access level.

Data Analysis

Conceived as a marriage of the concepts of positivism and pragmatism, grounded theory was proposed as a qualitative research method by Glaser and Strauss (1967). This method was developed as a systematic methodology that social scientists could utilize for investigating a wide range of social processes (Charmaz, 2006), and Glaser and Strauss advocated its use as an inductive method of generating theories grounded in data rather than deductively creating theories from testable hypotheses. Soon after its inception, however, application of the theory among researchers has diverged. Known for its rigor and consistency, the theory has been adopted by many positivist researchers (Charmaz, 2006). Conversely, other scholars have moved away from the positivist application of the theory to focus on the interpretive and pragmatist underpinnings of the theory. In particular, Charmaz's (2000) interpretation of grounded theory is that knowledge is co-created by the participants and the researcher, and is viewed through the researcher's perspectives of culture, attitudes, beliefs, and cultures.

Charmaz's (2006) constructivist version of grounded theory was utilized in the analysis of this research. Charmaz (2000) posits that grounded theory can be focused on the mutual construction of knowledge by the researcher and the participant. It also allows the researcher to gain an interpretive understanding of participants' meaning. According to this version, using grounded theory means remaining open to all possible theoretical understandings, developing tentative interpretations of the data through coding, returning to the field to gather additional data and refine codes and categories. Charmaz (2003) posits that multiple realities exist and that data and analysis are created through an interactive process, wherein the researcher and the participant construct a shared reality.

Rather than look for a single concern or theme, researchers should use grounded theory to construct an image that draws from, and reflects, the participant's lives (Charmaz, 2006).

Charmaz (2006) states that coding is the pivotal link between collecting data and potentially developing a theory to explain the data. It is through the process of coding that researchers define what is happening in the data and begin to interpret meaning. Grounded theory coding consists of two primary steps: (1) initial coding, which requires coding each word, line, or segment of data, and (2) secondary, selective coding that identifies the most significant or frequent initial codes for sorting, combining, and organizing (Charmaz, 2006). Initial coding requires a rigorous reading of the data, and the goal during the process is to remain open to all possible theoretical directions indicated by the data collected. Glaser (1978) notes that it is during initial coding that data begins to tell a story of what is problematic. Initial coding requires the use of language that describes action (Charmaz, 2006), and should be completed without preconceived concepts in mind (Glaser, 1978). Initial codes are comparative, conditional, and based on the data (Charmaz, 2006). Secondary coding synthesizes and explains larger sets of data (Charmaz, 2006). Focused coding requires decision making regarding which initial codes make the most analytic sense to categorize the data collected. It is through this sorting and categorizing of initial coding that new perspectives and ideas will begin to emerge

Analysis of this data commenced by following the recommendation of Agar (1980) to read each of the transcripts in their entirety prior to coding. This process allowed the investigator to immerse herself in the details and gain a sense of the interview, focus group, or observation as a whole prior to breaking it into smaller parts

(Creswell, 2012). Each transcript of an interview, focus group, or observation, were read in their entirety to allow the researcher to gain familiarity with the details of the data. The transcripts were then downloaded into NVivo 11 for coding and categorization.

In the initial phase of the data analysis, I created a single-case data summary for each case. The goal of within-case analysis is to describe, understand, and explain an experience in a single bounded context (Miles, Huberman, & Saldana, 2014). The transcripts of interviews and field observations from each case were coded using NVivo 11. Each bound-case was coded individually using constant comparative analysis. After each of the cases were categorized, they were examined for patterns within the case.

After individual case summaries were created, the aggregated data from each case was then coded using NVivo 11. Each line of data was coded into an emergent code or category and examined for themes in determining how parents addressed the three primary research questions: (1) How do parents perceive the responsibilities of a parenting a child with ASD, (2) How do parents perceive their ability to meet society's role standards for parenting, and (3) How do parents create meaning in the context of parenting a child with ASD.This process was repeated to ensure similarities and differences were identified. This phase of categorization resulted in 72 unique categories across the eight cases; however, both within and across these eight cases, no category was reported by all eight participants. It was not unusual for some exemplars, or pieces of data, to contain multiple categories. Thus, some data was categorized under more than one category. At this point, secondary coding of the data began, and categories were consolidated or edited to make the most analytic sense of the data. Consolidation continued until themes emerged across the case families that addressed the three primary research questions.

Chapter 6. Results

This research study primarily follows a case-oriented approach. Collective case-study research considers each case as a separate entity, looking for patterns within each case. After looking at cases individually, the individual cases are then compared to each other (Stake, 1995). The within-case and between-case comparisons in this study are both examined utilizing a social constructivism lens, thus allowing the researcher to develop an understanding of the subjective meaning of each case family's experience (Denizen & Lincoln, 2011; Stake, 1995).

Examination of each case family provides a unique perspective on how that family constructs the parent role and creates meaning from the experience of raising a child with ASD. Within-case summaries produces the following themes: (1) accommodations for child by family (2) assessments of the child's behavior against social norms, (3) behavioral challenges of child, (4) changes in parenting responsibilities and demands, (5) comparisons of the child to typically developing peers or other children with ASD, (6) concerns of balancing family needs (7) expectations of child, (8) expressions of emotional loss, (9) encouragement of child interests, (10) judgments of other parents, (11) management of problem behaviors, (12) meanings created from the experience, (12) perceived judgments of parenting skills, and (13) self-assessments of parent performance. Each single case summary is attached (Tables 2 – 9).

After creating individual case summaries, the data is aggregated to obtain cross-case comparisons. Under the research question regarding parenting responsibilities, five themes emerge: (1) *advocating,* (2) *accommodating*, (3) *balancing family needs*, (4) *managing behaviors,* and (5) *grieving.* For the research question asking how parents construct their ability to meet society's parent role standards, one theme emerges: (1) *assessing*. It is important to note, however, that multiple forms of assessing are identified within this one category including: (1) *assessing the child*, (2) *assessing other parents,* (3) *responding to assessments by others*, and (4) *self-assessing*. Under the final research question regarding meaning-making, four themes emerge: (1) inability to successfully adjust, (2) *gratitude,* (3) *compassion,* and (4) *prioritization*.

Finally, an over-arching pattern emerges from the data across each of the research questions: *changing and ongoing demands*. This theme is noted for all eight (100%) of the case families across the other seven themes. In the rest of this chapter, I provide a detailed description of the themes that emerge through data analysis that are relevant to the three primary research questions and to the research overall. Verbatim quotes from participants were utilized to provide context and to function as examples of the themes described. To protect confidentiality, all personally identifying information was replaced with generic descriptors, such as child or parent, in brackets.

Changing and Ongoing Demands

An overarching theme that emerges from the data is that of *changing and ongoing demands*. This theme is present as a contextual backdrop for each of the other themes, indicating ever changing needs and demands appear as a common factor in each of the three research questions. Data collected in both in-depth interviews and field observations indicates participants feel that *changing and ongoing demands* play a significant role in their assessment of parental responsibilities, their ability to meet role demands, and the meanings they created from the experience. For example, around parental responsibilities, Case Mom 1 notes that the responsibilities for caring for her son are likely to be protracted. She stated,

> The only time when I really think about wishing maybe he was completely normal is when I think of when my husband and I die. His sisters might have to take up for him. I worry about him getting taken advantage of. Could [child] live on his own? Maybe, but he's still the type that would go to preheat the oven for a pizza and four hours later forgot to put the pizza in. He would be a hoarder, a junk food addict. He still requires supervision.

Case Mother 8 reiterates these sentiments more succinctly when she states, "Unlike other parents, our responsibilities don't seem to get any easier as he gets older. And whatever works today, probably won't work tomorrow." Case Mother 6 notes the responsibilities required to raise a child with ASD evolve as the child ages. She states, "We are in a good phase right now. But I have a feeling when puberty really hits and adolescence hits [sic], I have a feeling we'll be looking out for resources again." Across each of the eight case families, participants note that the responsibilities of caring for these children is not consistent, nor is it finite.

Parents also note their ability to meet the role expectations of a parent is impacted by the rapidly changing demands of raising a child on the autism spectrum. For example, Case Mom 4 notes,

> Oftentimes over the past year, I've looked at what I have to do with school and I just have cried several times. I can't do this. What was I thinking? I gave up this very stable government job, and here we are. Sometimes I wake up and think

> what was I thinking? Why did I do this? I know it's for the best, and [spouse] knows that too. But the worries are still there.

Similarly, the worry about meeting one's parenting ability does not diminish over time. For example, Case Mother 8 states,

> We worry a lot about what is going to happen as he gets older and we get older as well. Right now, we're able to manage because he's still relatively young, and because we have state services. But what if we lose those services, through budget cuts or something? Or if we get too old to take care of him at home. I am not sure that I can handle putting him into some kind of home. I mean emotionally. It may be the right thing for him at some point, but that certainly won't make doing it any easier.

As noted by this parent, the worries about meeting the expectations of parenting a child with ASD do not become less as the child ages.

Finally, the meanings parents create from raising a child with ASD appear to be dependent upon the changing and ongoing demands of the situations. For example, Case 2 Mother states,

> Whereas with autism that's always something that you have to be conscious of, the fact that your entire relationship with that child can change in a moment's notice and you have no reason to suspect that it's going to happen, the way that it's going to happen.

This statement epitomizes the impact of the changing and ongoing demands associated with raising a child with ASD has on the parent child relationship. Parents acknowledge that the meanings created from the experience may depend on the daily interactions and issues they experience with their child. For example, Case Mother 6 states,

> But I mean if we just dwelled on the negative that would be a tough place to be and to be there all the time, because this is a daily thing. We have some days where we have breakthroughs in this beautiful day and it's like, oh my gosh. This is our perfect child. This is who he's meant to be. And sometimes that's hard because it's like, oh he could be like this all the time. But he's not. Other days, it's just too hard to think about.

Thus, it is apparent that the changing and ongoing demands of parenting children with ASD can have a significant impact on how parents create meaning from their experiences.

RQ1. How Do Parents Perceive the Responsibilities of Parenting a Child With ASD?

Advocating. Parents are quick to recognize that a key responsibility of raising a child with autism is advocating, whether for the child as an individual, or for the entire population. This was a concept that was immediately noted during the focus group. One mother commented, "You need to know as much as you possibly can so that you can advocate for them when you need to and get them the services and therapies they need." These parents seem to recognize that knowledge and education was a key element in being a successful advocate for their child. Another parent noted, "You have to find that confidence within yourself so you can stand up and advocate for your child. Because if you don't like, if you shy away from confrontation its going to be so difficult." Participants indicated that advocating for an individual child, especially in an academic environment, is a key responsibility of theirs. For example, Case Mother 7 remarks,

> By the end of the school year, we were done. That environment obviously wasn't working. We had him moved to another school. [New school name]. So, he gets about half the day Special Ed now, and half regular classroom. So, he gets a lot of one-on-one help. He needs that. He wasn't getting it before.

By evaluating the learning environment in which her child was engaged, this mother determined that it was not appropriate for her son and advocated that her son be relocated to another school. She considered this relocation to be a significant improvement over the previous arrangement. Other participants commented on similar actions. Case Mother 4 notes,

> They told me at school, even though we had the letter saying he's on the diagnostic waiting list that they weren't going to do anything. They could not help him during the school day. That, to me, I couldn't understand why they wouldn't help us. He was having meltdowns pretty frequently and they didn't want to serve him. They knew he had all these other things going on and was being treated for depression. But they would not service him for it, for anything but his speech. It was so frustrating. That's how I got hooked up with Autism Society. I said, you're not going to help me then I'm going to find some people that will. I finally got his pediatrician to do a diagnosis a year before we even got in to [state funded treatment program].

Other parents note that unless they advocate for their child, other adults had little expectations of them. For example, Case Mother 3 notes,

> Like a kindergarten teacher asked if I realistically expected him to read. As a matter of fact, I do. Now, he loves to read. Other things, I know he can do it, but

> he's not there yet. But that doesn't mean we aren't going to keep fighting to get him there.

This mother also recognizes that it is her responsibility to set expectations with school officials and educators. Thus, advocating in an academic environment appears to be an important facet of the parenting responsibilities for children with ASD.

Other parents recognize that ASD is a widespread problem and advocating for the entire population will also benefit their child. Many of the participants commented on career changes or advocacy roles they had taken on in the wake of their child's diagnosis. For example, Case Mother 1 notes,

> The jobs that I had since he's been diagnosed have all had something to do with special needs. I worked at the therapy clinic. I worked at [support center]. It's like what would I be doing, and would I care the way that I do now? There's a whole world out there that I wouldn't have known existed and wouldn't have cared if it hadn't been handed to me. I really think that's why I want to be involved.

Other parent's note similar involvement in advocating for children with ASD. Case Mother 4 says,

> When I looked at my own family and what we could do, I didn't know what to do. It was such a feeling of hopelessness. Certainly, [local county] has got to have some resources for families like ours. They didn't. We didn't have anything. I reached out to the Autism Society and out there wasn't one here in our county. Now I run the local chapter. Parent's need a place to go.

Similarly, Case Parent 5 advocates for the entire population. Although she feels her time is limited, she attempts to advocate, even in a small way. She comments,

> I wish I could do more to help other families, but we are so busy. I do try to help when the [advocacy group] sends out emails and asks for parents to contact representatives or government reps when some sort of legislation comes up. I figure it's the least I can do, sending an email.

It appears that many parents feel that advocating for children with ASD is an important part of their responsibilities in raising a child with ASD.

Accommodating. As parents consider the responsibilities associated with raising a child with autism, many acknowledge that making accommodations for their child is an important part of their job. These accommodations cut across a wide range of activities or contexts. As might be expected, accommodations are made at each child's school via an Individualized Education Plan (IEP) for academic purposes, but parents often comment on other accommodations that were made for their child's schooling that are outside of this IEP. For example, of the eight families that participated in this research study, one child is enrolled in a private school and three are enrolled in charter schools. These alternative learning environments appear to have been selected to accommodate a child's particular educational needs. For example, Case Mother 6 remarks,

> He is very successful there and the idea behind [school] is really to build up some of the kids' social and emotional skills and keep them on track academically. And they do a nice job with the academics there, but it's really about building up some of those social skills.

Case Mother 5 also indicates that a non-public school was chosen for her child to accommodate some of the family's educational concerns. She states, "We wanted him to go somewhere where all the teachers knew him, and were able to connect with him. That's not easy in a big public school." Thus, accommodations are often made to ensure children with ASD have access to smaller, more personalized academic settings.

Accommodations are also made for the child with ASD in the family home. For example, many of the parents comment on the special diets required for their children. In the focus group, one mother commented, "The diet thing, no gluten, dairy. No nuts. And medications. He's got allergies out the roof. Constantly I'm checking him every day for hives." These dietary restrictions are often necessary due to ASD comorbidities. For other parents, diets are undertaken to address gastrointestinal issues or core symptoms of ASD. As another mother noted,

> He's had like 14 biopsies through the intestinal tract and tested for rare tumors. He's on like 6 medicines a day for it. He's on like a soft food diet. We've gone through the no diary, no soy, no gluten, no nothing and nothing helps."

Case Mother 7 acknowledges on the necessity of accommodating her child's gluten free/casein free diet by providing a bag lunch for her child each day. She says, "Yeah and his diet is so hard and trying to fatten him up. I pack his lunch most days because he can't eat in the cafeteria and that's hard, that's stressful." Similarly, Case Family 8 notes, "We have to cook almost all of his meals because of his special diet." Thus, the family accommodates their child's restricted diet by eliminating dining out. Accommodating a child with ASD's food issues, however, may not be diet related, but rather sensory related, as Case Mother 6 notes.

> He was so particular visually and the way things smelled that he would melt down because he would look at the eggs and they would have white things in them. I don't know if you have ever noticed, but when you make scrambled eggs there are little bits of whatever part of the egg that is white. Again, we would have to develop strategies around it. Anytime we had eggs we had the lights turned out and would eat by candlelight or whatever so that he wouldn't be able to see it.

Parent's also accommodate their child's limited interest in trying new foods by packing their child's school lunch every day. For example, Case Mother 1 notes,

> He has the same thing for lunch every single day, which is white bread with turkey breast and microwave bacon. Turkey and bacon. No mayonnaise. That's his sandwich, which has pretty much been his staple sandwich all through high school. Every day, the same thing.

Accommodations are also made to ensure the child's safety. Case Mother 3 notes, "Oh, he used to run. If you look at my house, there's little boxes by the windows and the door so that alarms would go off. He would open the door and just bolt." Case Mother 5 notes similar accommodations. She states,

> We contacted the [county] sheriff's department and got him a GPS tracker. He wears it all the time in case he runs. The biggest problem is that they [sheriff's department] have to come to the house once a month to change the battery in it.

Likewise, Case Mother 8 notes the need to accommodate the child's safety issues. She said,

> He has to be supervised at all times, so that means that household things are limited to activities that can be stopped quickly. I mean, you can't clean out the

> garage or paint or something, unless someone else is there. He could get into anything while your back is turned.

When parents discuss making accommodations for their children, these are often directed at improving their child's social interactions. In Case Family 1, for example, the child with ASD is currently participating in a job training program at a local home improvement store. To increase the likelihood of her son's success, Case Mother 1 describes an accommodation she made to assist him with social interactions he might encounter during the training program. She says,

> I had made him a cover letter that said, just so you know I am on the autism spectrum, so I might come off as a little quirky or have a hard time making eye contact, and I make some strange faces and do lots of shifting and some awkward hand movements, but once I get to know you and you get to know me, you'll see that I'm really a lot like other people. So, I did something like that because I feel it's helpful to him, and it's helpful to the people that he's going to encounter. Rather than people just wondering there's something weird about this guy.

This type of accommodation is made by the parent to facilitate positive social interactions for their child. Similarly, Case Mother 3 notes,

> I've taken him everywhere with me, meltdowns and all. I used to put him in a little shirt that said "Autism, a work in progress" so that people would stop. Now he won't wear what I want him to wear.

It is apparent that these types of accommodations are made to help other individuals understand the stereotypical behaviors or symptoms of the disorder and to ultimately improve the social interactions experienced by the child with ASD.

Accommodations extend to the parent’s social interactions, as well. These accommodations may be geared toward how a parent socializes. For example, Case Mother 8 states,

> Not only do we have to always be willing to cancel or modify our activities for our son, but it is very difficult for us to go to an uncontrolled environment. We almost always have our few friends over to our house because if we go to their house, one of us just ends up watching [child] the entire time.

These social accommodations not only impact *how* parents socialized, but also *whether* they can socialize at all. Many parents limited their socialization as others did not seem to understand the issues associated with parenting a child with ASD. In the focus group, one mother commented, “And there were some friendships we had to let go because they just didn’t understand.” Other parents limited their socialization due to limited resources for child care.As Case Mother 7 states,

> And even like to come here tonight, I mean, [spouse]’s down at the karate class, so my parents watch [child] after school and during the day when there’s no school, so I can’t keep asking them to watch the kids. I’m pretty much stuck at home a lot. I can’t take him with me wherever I want to go. The ladies meet once a month for dinner; I can’t go because [spouse]’s at class.

Similarly, Case Mother 5 states,

> We’ve never been especially social people, but having [child] has really made that obvious. He has a hard time with crowds, new places, or really stimulating environments, so those are things we really think about before we take him anywhere. Will he be able to handle it? Sometimes it’s easier just not to bother.

Not all accommodations are made to compensate or manage negative behaviors. One characteristic commonly identified with ASD is that of obsessive interests in specific topics or hobbies. Responsibilities for parenting a child with ASD includes being supportive of these obsessive interests. A common interest among many of these children with ASD is playing videogames. For example, Case Mother 1 notes that the family had multiple gaming systems to support their child's videogame habits. She states, "He's got several gaming systems. I think the PlayStation is upstairs and the Wii U is downstairs. He has an Xbox 360 in his room. He has the old-school Game Cube System, and he loves to play that." Similarly, Case Mother 7 notes that her son is also obsessed with videogames. She says, "When he gets out of school he'll come home and play games. He's addicted to videogames. That's about all he'll want to do."

For other parents, being supportive of their child's intense interest means being more physically involved. Case Mother 4 comments, "He loves comic books and all those characters. [Spouse] actually took him to Comic Con last year." Case Mother 3 notes how much her son loves Legos and how she and her husband have supported their son's interest in the toys. She comments,

> He loves them. He probably has hundreds of those kits. After he builds them, he and [dad] have battles with them in the garage. [Spouse] set up a big wooden table in the garage for their battles. It takes up half of the garage.

It appears that moms often support their child's interests by taking their children to purchase the items, taking them to the library, or acquiring additional information about the hobby on-line. Fathers, however, seem to participate more directly in these activities, such as playing videogames or attending hobby related events.

Balancing family needs. When asked about the responsibilities associated with parenting their child with ASD, parents are quick to note that these responsibilities often placed stress on other family demands. Of the eight families participating in this study, seven (88%) have more than one child. These seven families must manage the responsibilities of parenting a child with ASD, as well as the demands of parenting multiple children. Raising a child with ASD does not absolve a parent from other parental responsibilities.

When participants are asked about parenting responsibilities, they frequently mention the difficulties experienced in balancing family demands, especially those between children with ASD and their typically developing siblings. As noted earlier, seven of the eight case families included in this study had more than one child. For example, Case Mother 4 states,

> Whenever [sibling] starts to feel down, she'll say you like [child with ASD] better. You do so much more for him and so on and so forth. I just try and empathize with her that he is special. He has special needs, but she is just as equally precious to me and that it sucks that we have to deal with this, but it's going to make her a better person and us a closer family because of it.

Similarly, Case Mom 6 expresses,

> [Sibling] says things like you guys spend a lot of time with [child with ASD] and you spend a lot of time making special accommodations for him and all that kind of stuff. She said I know I don't have Asperger's but I still need special attention too. It's like okay, thank you for the reminder. She talks about sometimes how it's hard to have a brother like that.

Feelings of guilt for neglecting other children, or for having difficulty balancing responsibilities, is a common sentiment expressed by these seven families. As stated by one mother in the focus group, “Guilt. You know you struggle with that. “ Similary, Case Mother 7 notes,

> With [sibling], I feel like she’s always been on the backburner. She was five months old when he was diagnosed. So, all our focus went to him, and I feel like we neglected her in a lot of ways. I feel guilty about it, of course.

These imbalances not only affect parent-child relationships, but also impact marital relationships. Many of the participants note the difficulties they have in making time for their co-parent. Parents have a difficult time finding care providers who they trust, so they often experience difficulties making time for each other. Case Mother 3 remarks,

> We can’t go without [child] anywhere because we don’t have any family around here. So, if we go on daytrips or something, we can’t go anywhere like on a trip. He did at one time stay with one of his workers overnight, and it was not even worth it. She did fine with him, but it made me throw up because I didn’t know what he was going to do. His routine is so boom-boom-boom.

Other participants express similar issues. Case Mother 5 comments,

> We don’t have any family in the area, and it’s really difficult to find someone you trust to take care of [child]. Or someone willing to stay with a kid that has so many issues. I think we actually went about five years without leaving the house together without him. And when we finally did, I was terrified.

When extended family is unavailable, many families have a difficult time finding care providers they can trust, or that their child with ASD will accept. Case Mother 6 says,

> Gosh that's another thing that's been so hard, babysitters. Especially when he was little. He would just scream and cry at the idea of somebody new. It took several times of having interactions with a new babysitter in order for him to get used to it.

The financial costs associated with raising a child with ASD can also have a significant impact on how well parents can balance their family needs. These costs come from many different sources: medications, therapies, or job loss. Case Mother 4 comments on the costs associated with the diagnostic process. She said, "The problem is that we have a high deductible plan for insurance, and we simply couldn't afford to pay $1000 for him to get diagnosed somewhere. I phoned everywhere." Even when insurance is not an issue, costs can be substantial, as Case Mother 8 remarks, "We are lucky in that we have good health insurance, but we still spend $300 or more each month to cover the doctors that aren't in network or the supplements that aren't covered." Case Mother 1 reiterates this idea. She says,

> There's a lot of deductibles and insurances. Because I was taking him to the therapy clinic before I worked there, sometimes money was tight. It was like I'm not going to use the credit card here. I'll use that on groceries.

The impact of the increased cost is substantial when one parent is unable to work. Of the eight case families, two mothers (25%) did not work outside the home at all, two mothers (25%) worked only part-time, and four mothers 50% of the mothers worked full time outside the home. Of those working outside the home full time, one parent worked for their child’s school, and another worked at an agency that provides assistance to exceptional children. Case Mother 2 comments, “Between the three kids and his autism, I can’t work anymore.” The loss of a second income can also impact the child’s access to treatment. As Case Mother 7 indicates,

> Then I lost my job. We had to pull him out because we couldn’t afford it anymore. So, he wasn’t around children anymore and I thought, okay, he just lost those social skills that he was developing, because he quit talking.

As these comments demonstrate, it is apparent that most of the participants feel that balancing family needs is an integral part of their responsibilities as a parent of a child with ASD.

Managing behaviors. Another important responsibility in raising a child with ASD is managing challenging behaviors that are typical of the disorder. These may include trying to minimize repetitive behaviors (e.g. finger flapping), reduce socially inappropriate behaviors (e.g. undressing in public), or prevent meltdowns. This can be difficult as many of these behaviors can be quite challenging. For example, Case Mother 3 notes, “Like last night the game store just blew his mind. He was doing movie lines, and the hands were going.” Case Mother 4 makes similar observations. She says, “The biggest thing is when he starts scripting, just saying a line from a movie over and over again or from a TV show.” Likewise, Case Mother 8 notes, “[child] doesn’t play in the typical sense. It’s just a lot of stimming, either visually with his electronics or flicking a ribbon or string. Often, it is difficult for parents to assess which behaviors are atypical, as Case Mother 7 observes,

> Because when he jumps on the bed I know that's bad, but yet, hey that's kind of normal, just maybe not for his age. Let's not stifle the normal in him. If there's a little bit of normal in there, let's let him do it. I mean, you know?

Challenging behaviors are not limited to repetitive movements. Many children with ASD exhibit other behavioral extremes. For example, Case Mother 4 reports,

> So, for us just making sure he maintains that and doesn't revert back to the screeching, the growling and being mute like he used to be because that was you know, trying to figure out what was wrong and you'd ask him and he'd growl at you for three days.

A disruption to routine or a change in environment may precipitate extreme behavioral reactions as well. These reactions can include aggression toward other family members. For example, Case Mother 6 remarks,

> When we changed the front door, it looks exactly the same, but it was a change. It was extremely difficult for him. He may have even been physical with me that time. That is extremely rare, but he was pretty frustrated that day and said things like I want to kill you because you changed the door and stuff like that. Screaming, crying, like why did you do this and all that kind of stuff and I want you to change it back.

Similarly, Case Mother 8 notes, "He can be aggressive at times, especially towards me. That wasn't such a problem when he was younger, but now he's almost a 100 lbs." Behavioral extremes, like aggression can also be directed toward siblings. Case Mother 7 recalls, "He'll just whack [sibling] for no reason in particular. "She's bothering me," he says. I tell him, "She's just sitting there. She's not doing anything." These behavioral extremes can also occur when demands are placed on the child. For example, Case Mother 4 reports,

> Week before last, he got into some trouble because a teacher had said do something and apparently, he wasn't moving quick enough for her so he got frustrated and balled up his paper. That's what he does. That's one of his things. She said, "Give me the paper." I don't know if he didn't hear her or it had time to register, but he got up to throw the paper away and she kind of sternly said to him, "[child], give me your paper." So, he turned around and threw the paper at her. They considered suspending him for that.

These behavioral challenges can be very stressful on parents. Case Mother 5 notes, "How can you not cry when your child keeps banging his head and screaming and you don't know why?"

Because of these behavioral challenges, many of the participants indicate that part of their responsibilities of a parent of a child with ASD is to prevent these behaviors. Some parents report incorporating behavioral management systems to help prevent behavioral issues. Case Mother 4 remarks,

> I put him on a pretty strict behavior management system. It was positive based. So, every day we would go over what he did and what he did not do. He would get his points, and he could turn in his points, like a token system, for his reward. It was fine. It was great. It was beautiful. He was on track as long as we were on track with that. If we deviated and didn't do it, you could see his behavior plummet.

Other parents indicate that prevention of extreme behavioral issues can only be accomplished through extensive planning. For example, Case Mother 3 observes,

> I think the biggest thing for us is we moved into more of a pre-emptive kind of thing. We're always thinking. If we go somewhere, do we have this, this, this, and this. So, you're always kind of planning ahead of things when you go. It's just a lot more planning than I ever thought I'd be doing.

Case Mother 5 reports similar tactics at minimizing behavioral issues. She says,

> Going anywhere with [child] seems like a military maneuver. Not only do you have to make sure you have the necessary snacks and fidgets, and his iPad, but you have to circumvent the various land mines. Oh, that store has flashing lights, we should avoid it. Or we try to get to the festival or park early to avoid the crowds.

Preventing these types of behaviors even enters areas such as living arrangements. Case Mother 2 states,

> We needed a 4-bedroom house or something we could turn into a 4-bedroom being as they [child and sibling] can't share. We tried that and [child] has to have his own space or we have a lot of meltdowns.

Some parents incorporate medications into their prevention plans. As Case Mother 3 states,

> The non-stimulants make [child] sleep, and the stimulants make him mean. So, we give him a baby dose [of medication] and it's enough to make him focus but not enough to be mean. He's like this is really not helping, but I'm like it is. It's

> enough not to get suspended. We can maintain through the day and get something done as opposed to nothing. So, I give it.

Other parents, however, are concerned about the effects of the medications and choose not to incorporate them into their child's treatment. As Case Mother 7 comments,

> [Doctor]'s mentioned medication but we've never wanted to do that. I wanted to try and see if he can do without it. It does have side effects and I don't want to make him a zombie or aggressive, or doped. And I don't know what it might do to him. It might be okay, but it might be worse.

As a common symptom of the disorder, children with ASD may have disruptive, disgusting, or dangerous behaviors. In an attempt to minimize these behaviors, parents spend a significant amount of their time attempting to prevent or manage these behaviors.

Grieving. When participants reflect on how raising a child with ASD changed their life, many note the emotional losses that they experience. Several parents express losses associated with their child's deviation from *normality*. For example, Case Mother 1 states,

> I think an autism diagnosis is more something that happened over time. It wasn't just the birth experience and then you knew. It was over time. Most of us when we left the hospital thought we had a normal baby. Everybody is always praying I want the baby to be healthy, but nobody says I want the baby to be normal. [Child] is pretty healthy. He's never had any significant health issues other than the ear infections. He's not normal.

Case Mother 5 voices a similar reaction. She states,

> I feel like I shouldn't even talk about it because it's not the worst-case scenario. At the same time, yeah, but I still had a dream that was crushed. He surprised me, and he's doing a lot of things, but there's still things that happen that aren't going to happen for [child].

Other participants express different types of emotional losses. Case Mother 6 notes,

> You do have these dreams for your children. My husband is the most amazing person I've ever met. He's just everything good people are. He's smart and he's so personable. I just loved the thought of having a son like that; to have somebody just like [spouse], to raise a boy like that. Well, we were just dealt a completely different set of cards. Instead, [child] struggles with almost everything.

This mother recognizes that the dreams of raising a child like her husband is something she will not experience. Participants also recognize that fathers experience these emotional losses as well. Case Mother 3 comments,

> [Spouse] had these grand visions that every guy has, doing things with [child]. He is just now coming to grips with the idea of it, and it's been eight or nine years. Finally, he's just coming to grips with it. That was hard to get over.

Case Mother 7 also acknowledges a similar response from her spouse. She states,

> My husband has had [business] for years, and of course he wants his son to do it, and feels like he can't do it. That's hard. He hoped to pass it onto [child] someday. And it's probably not going to happen. He can't even get him to play ball with him or anything.

Participants acknowledge that the emotional losses are felt in both parents, and are not just the experience of mothers. A significant part of the parent role identity for the participants was that of grieving parent.

Based on this data, it is apparent that parents of children with ASD construct their parenting responsibilities as a major part of their lives. These responsibilities include accommodating the child's special needs and behaviors, balancing the time and financial demands of a family, and managing the behavioral challenges associated with the child's diagnosis. The parenting role is also constructed to incorporate grief for the loss of a typically developing child.

RQ2. How Do Parents Construct their Ability to Meet Society's Role Standard for Parenting?

When parents reflect on their ability to meet society's role standards for parenting, they seem to go through a process of assessment. A significant portion of this assessment includes comparing their child's behavior to social norms, to the child's typically developing peers, and to the child's peers with ASD. In determining their own performance, these participants often evaluate the performance of other parents to assess their own abilities. Conversely, they also considered the opinions of these other parents when evaluating their own competence. Finally, parents seem to evaluate their own performance through a process of self-assessment.

Assessing my child. One way in which study participants evaluate their parental abilities is to assess the performance of their child against a set of standards, or social expectations. If the child is meeting these expectations, then the parent feels as if they are likewise meeting the expectations of a parent of a child with autism. For example, Case Mother 7 remarks,

> He don't [sic] know what to do at any sense, at times. If we don't let him play videogames he wonders around and he'll bug her [sibling]. He won't play with toys like other kids. He won't look at books. He sometimes doesn't know what to do. I'm not sure how to handle it.

In noting that the child has difficulties filling his free time, this mother indicates that she is not meeting the expectations of her role as a parent. Other parents comment on similar behaviors. Case Mother 8 states,

> We do worry about the normal things like the kids getting into arguments with each other or whatever, but it's just so much more intense, or you have to be so much more thoughtful about those kinds of things with [child]. It's very different. It would be a lot less stressful. I don't know what to do sometimes.

This parent recognizes that social norms allow for sibling arguments, but that her child's response to these arguments goes beyond what is considered socially appropriate. She admits she doesn't always know how to meet her parental responsibilities when these arguments occur.

When asked to assess their ability to meet social expectations for parenting a child with ASD, parents often compare their child's behaviors to those of typically developing children. If the child with autism is behaving comparably to a "normal" peer, then the parent feels as if they are meeting social expectations. This assessment is often associated with how children with ASD act in a social environment. For example, Case Mother 6 notes,

> I mean he is sitting here in his pajamas. He hasn't showered. We had a conversation where he didn't look you in the eye the entire time. When you think about a typical parent, if you were parenting a traditional type of child, you would not let any of that have occurred.

Similarly, Case Mother 5 comments, "When he's on the playground, he's not playing like the other kids. I mean, I shouldn't have to tell a twelve-year old not to taste the mulch." Case Mother 1 also notes that her son behaves differently than his typically developing peers. She states,

> He still requires supervision. I told him you're starting to get that dirt tan on your neck. He's a big boy anyway. You've got to get that off. [Child] you stink, go put deodorant on again. He still needs some of that common-sense stuff. There's a lot of similarities to normal kids, but I don't think a typical parent would really be able to understand it.

These differences are often more apparent when the child with ASD interacts with typically developing peers. Case Mother 4 observes, "We can see it when he's with the other kids. He's a little bit more immature than they are. That worries me." Although these participants are aware of the symptomatic differences associated with ASD, they still seem to compare their child's behavior to children without ASD when evaluating their own parenting abilities. Inevitably, children with ASD tend to fare worse than their typically developing peers in these comparisons.

Interestingly, parents also compare their child to other children with ASD when they evaluate their own performance as parents. Case Mother 4 remarks, "One of his best friends is also on the spectrum, but he's very introverted and keeps things in. [Child] is the exact opposite of that. I'm glad that we don't have to worry about that." Similarly, Case Mother 5 comments, "He's so loving and sweet, always giving hugs. So many of his classmates [peers with ASD] can't stand to be touched. I'm glad he's not that way." Other participants compare the severity of the disorder in their child to others with ASD. Case Mother 1 states,

> [Cousin with ASD] was always very much in his own world and not engaged with others. You could have said his name 100 times loud in his face, and he was just very blank, nothing. That was my fear. Oh, my gosh how am I going to deal with that. I'm just grateful [child] is high-functioning.

It appears that many of the participants are concerned that their parenting abilities would not have been sufficient for dealing with children with more severe ASD symptoms.

Assessing other parents. Another pattern was observed when participants were asked about their own parenting abilities. Participants compare their parenting skills to those of other parents of children with ASD. Often, participants criticize other parents when they feel the other parents are not meeting their parental responsibilities. For example, Case Mother1 says,

> I did talk to one mom. She needs to go on medication. She's a mess. She just had another baby on top of everything else. Now she's a bigger mess. I said you need to be on medication and get it together. Your kid needs you. You need to do something.

Case Mother 4 make similar comments about another parent. She says,

> I feel like people [other parents of children with ASD] look to me like, tell me what to do because it looks like you have it all together. When they say, "What do

> you do? You guys are doing a good job." Okay, if you want me to share with you what I'm doing, then take my advice. Instead, they say what would you recommend, well this is what I recommend, then they bitch and complain because it takes you an hour to drive to [agency]. It's annoying.

Indeed, many of the participants seem to have little patience with other parents that don't live up to their constructed social expectations. This includes when parents ask for advice and don't follow up. Case Mother 7 comments,

> She wanted to talk to me and get insights. I called her, left a message. Never called me back. I thought you wanted some help, you wanted to talk about it? And they don't call. You know like, really? You seemed so enthused at first. And then they just don't follow through.

The lack of follow through, as seen by these participants, is taken as evidence that these other parents are not meeting role expectations. Case Mother 5 remarks,

> And here she [other parent of child with ASD] was saying, "I just don't know what I should do." And I'm like, well what have you tried? "Well, we haven't really done anything, you know, up to this point." For me that was shock because it was like, just do something. Anything.

By suggesting that other parents are not meeting their responsibilities, participants seem to be positively assessing their own performance in meeting society's role standards for parenting a child with ASD.

Responding to assessments by others. While participants are busy judging other parents, they also seem to be concerned that others are judging them, even if these opinions are not voiced by others. For example, Case Mother 2 comments, "I am sure that when I go out, people look at us and think, hey lady, get your kids under control." Case Mother 4 also feels as if she is being judged when she when she goes out with her children. She remarks, "Sometimes I feel like I'm constantly being judged. If he misbehaves, it's something I did or didn't do, you know? I guess that's just a little insecurity that I have." These feelings are heightened when the child is acting inappropriately, as Case Mother 5 notes. She says "He's laying [sic] on the floor, screaming and kicking, and I am trying to get him up without losing my cool. And you just know, everyone is looking at you, like get it together." Participants express discomfort and embarrassment when they are unable to get their child to meet expected social behaviors.

Several participants in this study comment on the unsolicited advice they receive from others. These comments are interpreted as negative judgements about how the parent is meeting their responsibilities as parents. Case Mother 7 mentions that she often receives these types of remarks while at church. She says,

> And finally, I said we just have to take him outside and walk around, just kind of outside, and that would calm him down. Just walk him around, away from everybody and everything. We got back in and one of the usher ladies said, "Did you give him a good spanking? Did you wear him out?" I said no. That's what she thought he needed, was just a good whooping because he wouldn't be still.

Several parents at the focus group noted that they receive advice from family. For example, one mother said, "Even family members comment. If you just beat him once or twice, get the belt out and he'll straighten up." Similarly, Case Mother 3 comments that she often received similar opinions from her extended family members. She says, "When

I go visit my dad, I'm like oh wow. He would say [child] just needs to be whipped, and I'm like not really. He thinks that I baby [child]." Case Mother 2 reports a similar experience. She remarks, "So, it's you know, difficult to explain to people, even family members. It's difficult to explain what's going on and you get a lot of judgment from people and you get a lot of that well, he just needs a whooping." Case Mother 6 also receives unsolicited advice from extended family. She notes,

> With my mother, she's like, "If one of you kids had this, I know I'd be trying everything that's presented to me. I would try, and I would do my best to help you all." I said, "Mom, I am. I'm doing all I can do. I know I haven't grasped every straw, but you know."

Case Mother 5 notes that these types of opinions even occur in therapeutic locations, when other parents are likely there for similar therapies. She states,

> We were at speech therapy and he was, you know, they have a nice little setup while you wait, chairs and toys and everything. And [child] is jumping up and down. And every time I tell him, "Chairs are for sitting, chairs are for sitting." Another father was there and he was pretty young. He looked like maybe he was just, I don't know, not very old. And he told me that [child] just needed a good spank. I was stunned.

These participants not only suspect disapproval from others when their child does not conform to appropriate social behaviors, but many of these criticisms are verbalized directly to the parent.

Self-assessing. Perhaps no one is a harsher judge of the participants' parenting abilities than the participants themselves. These parents seem to reflect upon, and assess their own parenting skills frequently. In many instances, these parents question whether they are adequately preparing their child for future expectations. For example, Case Mother 6 comments,

> It's like each little problem area I'm always thinking what should we be doing better? What do I need to be doing right now differently than I have been? I just don't want to miss anything. I don't want to look back and say gosh if only I had been prepared for that. If I thought ahead and planned for that then we would have prevented the big catastrophe.

Participants' self-assessments also seem to center around whether all possible therapies and medications have been tried to help their child improve. This seems to be a self-assessment of parental effort. Case Mother 5 says,

> What if there was one thing you could have done that would have really made a difference? That's what I'm always worried about. What if? That's why I was saying at least try. What if this had made a difference and we didn't do it?

Case Mother 7 expresses similar concerns. She says,

> And we [parents] still make mistakes on the way. And you beat yourself up. Did you do the right thing. Is this right? Is this wrong? Should I stop this? Should I keep going forward? I don't know. Should I give him [child] more therapy?

Case Mother 2 summarizes the feelings quite succinctly, when she states, "I think that parents always worry if they've done enough for their kids, that's the nature of parenting. But with autism, the worries are so much bigger."

Not all parental assessments are negative. Several of the participants comment that they feel they are meeting the expectations of parenting a child with ASD even if others may disagree. Case Mother 1, for example, comments, “My oldest daughter says I worry about his health. The doctor has not said anything about it, but he’s a very big, out of shape boy. I felt like I did everything that I could have done.” Case Mother 3 reiterates this sentiment when she states, “I guess it means I was cut out to do this. I’ve met some people who could not put up with half of the stuff I have. I guess that means I’m doing okay.” Case Mother 4 also assesses her performance as laudable. She reflects,

> I have to take some credit, I’m sorry. That may be a selfish way to look at it. When they told me at the school there was nothing they could do. I was like, screw you, I’m going to show you. And I did.

Responding to demands. A major component of parental self-assessment participants struggle with is their ability, or inability, to respond to changing and ongoing demands. These demands range from the ability to respond to new behaviors and new symptoms to responding to the demands of aging. When reflecting on these intensive demands, Case Mother 8 notes

> Like most parents, very little of the hard work of raising my son will ever get recognized by anybody else, except maybe his grandparents or therapists, but unlike most parents, my responsibilities are going to continue much, much longer, probably the rest of my life.

The notion that ASD will *always* be a factor in the relationship this parent has with their child seems to be an important element how this participant assesses her enactment of the parent role. Case Mother 7 makes a similar observation when she comments, “You need extra patience, extra tolerance, extra everything to try to help them cope and learn how to do things and live. Everything’s a bit harder, everything’s harder, even basic, easy things are harder sometimes." These parents acknowledge a significant part of raising a child with ASD is difficult and unappreciated. Case Mother 4 reiterates this sentiment. She says,

> Autism is a 24/7 job, more than parenting. Parenting is 24/7, put autism on top of it and it can be emotionally and physically exhausting. We just go day by day. We pray for a good day today. We'll worry about tomorrow, tomorrow.

Parents recognize that parenting a child with autism means that physical and emotional demands on the parent will be intense, constant, and largely unappreciated. Further, parents will spend a significant amount of their time evaluating their ability to meet these physical and emotional demands.

In summary, parents use multiple forms of assessment to gauge their enactment of the reconstructed parent role. One form of assessment is evaluating their child though comparisons to social norms, typically developing peers, and peers with ASD. Parents also assess their abilities by comparing them to other parents, especially those not meeting the expectations for parenting a child with ASD. Participants also consider the verbalized, and non-verbalized, opinions of others when assessing their own parental abilities. Finally, the participants evaluated their performance as a parent of a child with ASD through self-assessments and reflection.

RQ3. How Do Parents Construct Meaning in the Context of Parenting a Child with ASD?

Participants were asked several questions to elicit how meaning was created from the experience of raising a child with ASD. These questions included how the parent's life is different because of the experience, what it means to raise a child with ASD, and what advice they would give to a parent of a newly diagnosed child.

Struggling to successfully adjust. As parents consider the meaning they have created from the experience of raising a child with ASD, they frequently note the difficulty they have in doing so. For example, Case Mother 6 notes

> I don't know that this was chosen for me? I mean that does sound a little grandiose to say you know that God chose me to parent this child who is sometimes very challenging but I think, you know, again its reframing it from being too negative and just focusing on all of the hard parts about it.

These comments reveal the mother's difficulty in finding the positive aspects of the experience. Case Mother 8 expresses a similar sentiment. She comments,

> I really can't think of any positives associated with my son's autism. I joke sometimes about how tough it was when the older kids were young and I spent all weekend at a ball tournament or dance competition. I say that I don't really miss that aspect [of parenting a typically developing child]. I guess I make those comments so other people don't feel sorry for me. Or my son. Now I'd be perfectly happy spending an entire day at a dance recital now if it meant my son didn't have autism.

This mother also seems to struggle with identifying the positive aspects of parenting a child on the spectrum. Other parents seem to associate the experience with work or expended effort. For example, Case Mother 4 notes,

> You have to have on your big girl panties all the time. You have to thicken your skin, get out there and do it because nobody else is going to do it for you. You never know what you're going to get. There's never a dull moment.

Even as this parent is describing the experience as an adventure, she acknowledges that it is one replete with effort and disruptions. Case Mother 7 makes a similar observation when she comments

> Everything's a bit harder, everything's harder, even basic easy things are harder sometimes. You just struggle to get through, but you do it. You just make those sacrifices and deal with the lack of sleep and everything else that comes with it. But you love them. All you got to do is love them.

Even as this parent describes the boundless love she has for her child, she recognizes that parenting a child with autism is a difficult task.

Expressing gratitude. Despite the hardships associated with raising a child with ASD, many parents are quick to acknowledge gratitude for the experience. They believe there are benefits associated with raising a child with ASD that a parent of a typically developing child might not experience. Participants acknowledge that without the experience of raising a child with ASD, many of the good things in their life would not have occurred. For example, Case Mother 6 states,

> I think parents often start out in a dark place when their child is first diagnosed. But if they give themselves permission to experience that and then start looking at all the positives that come from it. Because it really does. So many blessings we never would have realized. It adds a ripple effect, and there's, yeah, a lot of

> goodness and a lot of positive experiences that will come from this different journey that we're on.

Case Mother 5 describes how much more appreciative her family is when their child with ASD experiences a success. She says, "Because all those accomplishments are that much more significant. They're our kids and they are accomplishing it. It's just, you're thankful for every single one." Case Mother 4 indicates that raising a child with ASD has allowed her to be more grateful for who her child is, rather than for what he is not. She comments,

> Just being able to let go of whatever expectations we may have had and accepting him for who he is. He's amazing. He's not going to be the football player we thought he would be, but he will be a totally amazing [child]. He still believes in Santa Clause and the tooth fairy. He still likes to cuddle with mommy every night. My mom's like, "You can't do that forever he's in middle school." But, I'm going to take it as long as he'll give it to me and be grateful for it.

Case Mother 1 expresses a similar opinion when she describes an ad she placed in her son's high school year book. She says,

> I put a couple of pictures of him over the years, and I put in there dear [child], you will not be found on the popular pages in this yearbook. You were never voted best this or that. There were no athletic awards or any special academic achievements. Yet you have made us so proud. Even when the grades were low, the praise was always high. Delightful, funny, friendly. These were all words used by your teachers over the years to describe you. So, despite having autism

> and all the obstacles that come with it, you have made us incredibly proud. We are so thankful you are part of our lives.

Participants recognize that while their children with autism may not meet the social expectations that typically developing children meet, there are other rewards. Case Mother 8 shares,

> [child]'s probably never going to do things like sing in the school play or play sports in high school, but he takes just as much joy out of bouncing a ball or swimming. Rather than being frustrated about that, I have learned to just accept that fact and enjoy it with him. He's happy and healthy and I'm just grateful for that.

Expressing compassion. Participants are quick to acknowledge that raising a child with autism has made them more sympathetic to the issues others face. As noted during the focus group by one mother, "There is no jumping to conclusions about other parents' behaviors anymore." Similary, Case Mother 4 reflects,

> It's made me more aware of other people with disabilities. More kind, I guess toward others. I see a parent with an unruly child in public and I automatically think he can have an issue, you know he can have something like I'm dealing with. Made me more aware of other people. Things like that. Hearing other parents' struggles. Definitely, I'm more sympathetic and can understand.

Case Mother 5 reiterates the sentiment that raising a child with ASD has made her more both more aware and more compassionate. She states,

> That's the way I look at it sometimes. I know that growing up I didn't notice any children that had disabilities and I really didn't know about disabilities at all until

> [child] was diagnosed. I mean, there were no disabled children in my neighborhood or school. I probably would've seen a child having a fit in a store and blamed the mom. Now, I always ask if I can help, because I know that could very well be me.

These parents recognize that their own problems and issues have sensitized them to those of others. They also recognize this experience has positively impacted their other children.

Case Mother 6 notes,

> [sibling] is this amazing person and I think because of this incredible degree of empathy and kindness towards others. I really think it stems directly from having to accommodate and acquiesce to her brother sometimes. I mean she just understands. She just gets it. Sometimes we have to put some of our desires aside in order for someone else to be happy.

Case Mother 1 notes that her son's diagnosis impacted her daughter's career choice. She remarks,

> [Sibling] has always been so good with [child]. She was five when he was born and then has since gone into special education really as a result of [child]. When she was in high school, she volunteered at the severe and profound classroom and started Lose the Training Wheels [special needs program] there. She said I want to get involved with this population. It's really made her more sympathetic to other families.

Case Mother 2 concurs with these assessments. She notes, “There’s a whole world out there that I wouldn’t have known existed and wouldn’t have cared if it hadn’t been handed to me.”

Each of these participants recognize that raising a child with ASD has made their entire family more sympathetic and compassionate toward others.

Prioritizing. Participants in this study also remark how raising a child with ASD has helped them to prioritize the important facets of their lives. For example, Case Mother 3 states, “You know, it’s made our whole family slow down and realize what is really important.” Case Mother 2 reiterates these sentiments. She says, “He’s happy. I’m happy. That’s what’s important.” Case Mother 8 also acknowledges how raising a child with ASD had impacted her priorities. She states, “I just realize that so much of that other stuff isn’t important. I don’t obsess over every little thing anymore. So what if my house isn’t clean.” Case Mother 6 expresses a similar opinion. She remarks, “We just don’t worry about that stuff anymore. I don’t work outside the home, but I do a lot of advocacy and volunteer stuff. I feel like that’s more important now.” Thus, these eight participants recognize both the changes their child has had on their lives and how these changes have resulted in changing priorities for the participants and their families.

Summary

In summary, ten themes emerge in response to the three primary research questions asked. Across these three questions, an over-arching contextual theme of changing and ongoing demands is also evident. While there is some variation in specific answers, there is significant overlap in the responses from, and the observations made by, the eight case families. The next chapter includes a discussion of these findings and incorporates elements of the author’s personal narrative of raising a child with ASD.

Chapter 7. Discussion

There's always another battle, another hurdle (Case Mother 4)

The present study provided an examination of a topic that has previously been unexplored in the literature, role-identity and meaning-making in parents of children diagnosed with ASD. This investigation is the first to examine parents' care-taking narratives in such a way to draw attention to parental identity construction in the context of the social expectations of parenting a child with ASD. The study also examines parental meaning-making strategies using identity as a framework for assigning meaning. To accomplish these goals, eight case families participated in in-depth interviews, focus groups, and field observations. A semi-structured interview guide was used to elicit information on how parents conceptualize the role of parenting a child with ASD, how parents perceive their ability to meet that role standard, and how parents create meaning in the context of parent in a child with ASD.

Each of the eight case families were examined as individual systems, or as a "set of objects together with relationships between the objects and between their attributes" (Hall & Fagen, 1956, p. 18). Watzlawick, Bevalas, and Jackson (1967) applied this concept to human systems in which the objects in the system are individual "humans, the attributes are their communicative behaviors" and "relationships tie the systems together" (p. 120). A significant function of this system is to define human relationships to each other (Watzlawick, et al., 1967). The environment in which the system exists is the "set of all objects a change in whose attributes affect the system and also those objects whose attributes are changed by the behavior of the system" (Watzlawick, et al., 1967, p. 121). Thus, in this research study, each case family is an individual system and the objects within the system are the individual members. Changes in the attributes of an individual family member can affect the relationships between the family members. Changes in the environment, such as school or work, can also impact the system and its members. After each of these systems were examined individually, cross-case comparisons were performed to determine thematic patterns in the data.

Within a given system, Watzlawick (1984) argues that there are two realities. First-order realities are measurable and verifiable, such as the physical attributes or characteristics of an object. An ASD diagnosis would constitute a first-order reality. Second-order realities are interpretations of first-order realities (Watzlawick, 1984). This is the realm of meaning, or meaning-making. Thus, a common first-order reality, such as an ASD diagnosis, can result in multiple second-order realities, or meanings developed from the experience.

As noted in Chapter 2, Erikson's Theory of Identity Development (1980) proposes that individuals develop an identity through the experience of specific psychological conflicts, each of which contribute to a major element of personality. The majority of identity work occurs during adolescence, but exposure to a traumatic event has the potential to alter an individual's worldview (Erikson, 1980). Erikson's theory indicates that an individual's global-meaning system incorporates views of the parent role. Traumatic events, such as the diagnosis of a child with ASD, have the potential for altering this global-meaning system and the parental role identity.

Examination of the individual case families supported Watzlawick's (1984) theory of multiple second-order realities. When participants were asked to describe the role of a parent of a child with ASD, it was evident that each participant constructed second-order realities that were unique, but several common themes also emerged: (1) accommodating, (2) advocating, (3) balancing family needs, (4) managing behaviors and (5) grieving. A discussion of the unique reality constructions associated with these five themes follows.

One of the first signs that a family is experiencing distress, such as the onset of a major illness, is the disruption of family routines (Steinglass, 1998). During these periods of upheaval, families must reorganize their daily lives to accommodate the demands associated with the disorder or illness. These accommodations cut across a wide range of family activities and contexts, and often require adjustments to schooling, diet and meal planning, socializing, child safety, parent work, financial planning, and medical and therapeutic interventions. These changes affect all family members. An inability to manage the necessary accommodations can lead to increased stress (Murray, Kelley-Soderholm, & Murray 2007) and negative health consequences (Fiese, 2006) for all family members. When accommodations are manageable, parents can develop coherent meaning systems, or worldviews, that incorporate the disorder (Murray, et al., 2007).

Participants in this research study acknowledged that making these accommodations is a key element of their reconstructed parent role. However, unique symptom presentation, changes in symptom presentation, and communication difficulties are often characteristic of the disorder (Dave & Fernandez, 2015; Matson & Nebel-Schwalm, 2007) and make it difficult for families to determine which accommodations are likely to be effective long-term. Additionally, developmental and environmental changes also contribute to the unpredictable behaviors of children with ASD (Mayes, et al., 2012). Making accommodations, while an important aspect of this parenting role, is often unique to each child and difficult to manage as all family members can be affected. Further, an inability to sustain order and predictability in the household can contribute to poor health outcomes for all family members (Fiese, 2006).

Parents in this research study constructed unique interpretations of the changing demands in the parent role required by their child with ASD and utilized unique accommodations to address the demands. Accommodations identified by study participants were quite broad and included such interventions as medication changes, school accommodations and reassignments, adjusting career demands, travel modifications, altering meal plans, and the household environment. The uniqueness of each family system, symptom presentation, and family resources, dictated the need for different accommodations. These families recognized that accommodations made for the child may not be sufficient, and that any accommodations enacted may need to be revised, revamped, or eliminated in the future.

Advocating was a second theme that emerged when participants described their reconstructions of the parent role. Advocating for children with ASD, or the stigmatized population includes several behaviors: (1) obtaining services or supports, (2) speaking for a child, (3) raising issues, (4) facilitating change, (5) promoting welfare, rights, and well-being, and (6) educating others (Boshoff, Gibbs, Phillips, Wiles, & Porter, 2016). Research has shown that parents engage in these behaviors for the challenge of the endeavor, as well as for the personal benefits reaped for the parent and the child. Boshoff and colleagues (2016) suggest that engagement in advocacy-related activities can serve as a coping mechanism for parents providing a sense of control and by enabling parental empowerment and agency.

Gergen (1991) theorizes that individuals learn who they are through their interactions with others. Accordingly, parents learn what it means to be a parent through their interactions with their child, family members, other parents, teachers, and physicians. Parents assume different identities for different contexts, and it appears that the participants in this study agree that the role of advocate is an important component of their reconstructed parental identity. How that role is performed, however, is unique to each family system. The sense of control and empowerment gained through this activity may aid parents in coping with the intense demands required of a parent of a child with autism. Indeed, every participant in this study mentioned some form of advocacy, either for their individual child (75%) or for the ASD population (50%).

Although each of the case families identified advocacy as an important aspect of parental responsibility in raising a child with ASD, how the role was enacted was unique to each case family. In families where financial issues or time constraints were less of a concern (Case Families 3 and 6), participants advocated on a larger scale. That is, these parents not only advocated on behalf of their own child, but could undertake greater responsibilities through volunteering with support groups or serving as mentors to families with newly diagnosed children. When finances or time constraints were more substantial, families limited their advocacy efforts to their own child. It was also noted that when demands changed or became more significant for the child with ASD, parents would reduce their advocacy efforts to focus on the needs of their own child.

A third element identified by participants in their reconstruction of the parent role was balancing family needs. Parenting a child with ASD can place significant demands on all members of a household and the ability to balance these demands is imperative for both positive mental and physical health outcomes (Sikora, et al., 2013). Although outside the scope of this research study, an examination of the literature indicates that parents utilize multiple methods to meet the needs of all family members, including external supports (MacTavish & Schleien, 2004; Koch & Mayes, 2012), differential parenting (Stoneman, 2005; Stoneman & Rivers, 2008), or increased involvement of siblings in the care of the disabled child (Rodger & Tooth, 2004). Further, the demands of the various children often differ and compete for limited resources (MacTavish & Schleien, 2004; Koch & Mayes, 2012). These demands can place stress on the marital relationship, making it difficult for parents to communicate and provide mutual support (Shtayermmnan, 2013). They can also place a strain on limited financial resources, making it difficult for families to meet the needs of each member (Barry & Busch, 2007; Koch & Mayes, 2012; Kohlboeck, et al., 2014).

Again, the unique demands of each family impacted how the parent role was reconstructed. For example, Case Family 3 is the only family in the research study that had only one child. Balancing family needs did not include ensuring sibling needs were met. However, the mother in Case Family 3 copes with a chronic health condition. Balancing family needs for this family included a focus on parental self-care. In Case Family 6, both parents were highly educated. The mother in this family did not work outside the home, the father was a successful professional, and their two children attended private schools. This family did not include financial concerns as a component of balancing family needs. However, this family did feel that balancing their time between their two children was an important responsibility associated with this first-order reality. Thus, families reconstructed the parent role differently based on the attributes and members of their individual family systems.

Balancing family needs was a difficult task for each of these families. For many, the demands required to ensure the families' needs were met necessitated that one parent quit working. Of the eight case families in this research study, only 50% of the mothers worked full time outside the home. For those mothers who did work outside the home, several mentioned taking jobs with more flexibility, either in their child's school or in an advocacy organization. This flexibility allowed mothers to respond to the changing demands of their unique family systems. Participants, therefore, constructed unique second-order realities regarding career and work to address the first-order reality of an ASD diagnosis.

The fourth component participants identified in their reconstructions of the parent role was managing the behaviors of the child with ASD. Externalizing behaviors that are characteristic of autism can be disconcerting, resulting in hostile comments or insensitive behaviors from (Green, 2004; O'Driscoll, et al., 2012; Walker, et al., 2008). Further, disruptions to routine or exposure to uncomfortable sensory stimuli can result in a "meltdown" leading to extreme behaviors and aggression toward others (Ryan, 2010). A child's behavior in public is perceived as a direct reflection of parental competence (Ryan, 2008) and a disruption to public order (Cloke & Jones, 2005). Thus, the management of these externalizing behaviors is an important component of parenting a child with ASD.

Participants in this study acknowledged the importance of managing repetitive behaviors (75%), aggression (62.5%), and other extreme behaviors (75%) of their children with ASD. However, changes in behaviors were common and the unexpected emergence of new or troubling behaviors was not uncommon among the case families. Depending on the unique demands of each child, and the resources available to each family, multiple forms of behavior management were used to prevent or minimize undesirable, or socially inappropriate, behaviors. Methods to manage behaviors mentioned by participants included: intensive situational planning, behavioral management interventions, minimization of disruptions to routines and the environment, and medications. Participants recognize that the appearance of these behaviors can be distressing to both the child with ASD and to those witnessing the behaviors. The second-order realities constructed by these parents, therefore, included managing their child's aberrant behaviors.

The fifth element participants identified in their reconstructions of the parent role is that of grieving parent. The participants acknowledged that a sense of emotional loss is an unwelcome part of their reconstructed parent identity. The diagnosis of a child with ASD can significantly alter a family system (Cridland, Jones, Stoyles, Caputi, & Magee, 2016). Scholarship in this area indicates that parents may feel disbelief and anxiety (Ludlow, Skelly, & Rohleder, 2012) due to the diagnosis. Parents may also experience feelings of loss and grief due to the impact on parental expectations, shock, and disruption to the family system (O'Brien, 2007). Indeed, high rates of depression are found in mothers of children with ASD (Gatzoyia, et al., 2014).

The participants in this research study identified several emotional losses, including the loss of "normalcy," loss of rites of passage, loss of family traditions and characteristics, and the loss of a predictable future with their families. Six (75%) of the eight mothers in this research study acknowledged the use of antidepressants after their child's diagnosis. Expressions of loss and guilt were common among these participants. These parents constructed second order realities that incorporated the role of grieving parent into their personal identities.

Park and Folkman (1997) noted that there are multiple methods in which individuals construct situational-meanings from a single experience. One of these methods is to change one's identity, or to integrate the stressor into one's existing identity.

A common thread in the construction of second-order realities among the participant families was the concept of change. That is, although a family may have interpreted a second-order reality to accommodate a child's ASD diagnosis, the nature of the disorder requires this process be continually repeated. While these changes may appear insignificant to a parent of a typically developing child, these parents feel that even small changes in the child's environment can precipitate significant difficulties. For example, a new teacher may result in major changes in the child's behaviors, causing major disruptions to the entire family. Similar responses were noted across the case families ranging from schools, teachers, diets, medications, aging, sibling demands, therapeutic changes, routine changes, and environmental changes. Each of these changes precipitated new behaviors from the child with ASD that had had to be interpreted by family members. These interpretations resulted in changes to participant constructions of parental responsibilities.

The similarities in parenting responsibilities identified by the participants is representative of the principle of equifinality, which states that "the same results may spring from different origins, because it is the nature of the organization which is determinate" (Watzlawick, et al., 1967, p. 127). Simply put, equifinality suggests that the same goals or end states may be reached through a variety of different trajectories, even in different systems. Thus, when participants construct the parenting role associated with raising a child with ASD, they seem to describe a multitude of methods to achieve the same end state, the health and well-being of their child.

After the changing responsibilities of parenting a child with ASD are incorporated into the parent role, parents gauge their enactment of this role through feedback. Families are considered to have circular feedback loops "since the behavior of each person affects and is affected by the behavior of each other person" (Watzlawick, et al., 1967, p. 31). When feedback is sufficiently large, behavior change may result to maintain system stability. Hence, this feedback allows members of the system to assess personal competence in meeting the demands required by other members of the system and to make changes in behavior if feedback warrants a change.

The concept of feedback is a key component in Burke's Identity Control Theory (ICT) (1991), which was discussed in Chapter 2. Burke's theory equates identities to control systems composed of four components: an identity standard, input, comparator, and output. The identity standard dictates the appropriate way for an individual to behave. Input consists of the perceived meanings ascribed to our behaviors, which is generally garnered through feedback from ourselves and others (Burke, 2006). The comparator serves to evaluate the perceived meanings to the role standard. The output, or the discrepancy between the perceived meanings of an identity and the identity standard (Burke, 2006), indicate if changes should be made to an individual's behavior.

Discrepancies indicate a need for a change in behavior to conform to the identity standard.

Participants in this research study reported using multiple sources of feedback, or input, to assess their enactment of the parent role. One source of feedback participants used to assess their performance to social expectations was comparing their child's behaviors to social norms or typically developing peers. In these comparisons, the child with ASD inevitably did not perform well and parents interpreted their child's poor performance as their own failure. These findings are not surprising as research has shown that parents of children with mental disorders often experience self-stigma associated with a diminished sense of adequately meeting parental expectations (Eaton, Ohan, Strizke, & Corrigan, 2016). Similarly, participants also received feedback from individuals outside the family system through perceived or voiced assessments. Participants that reported these types of assessments generally indicated that the feedback was negative, indicating that the parent was not meeting the responsibilities of the parenting role. These findings are not surprising as other research has indicated that parents often receive criticism from others regarding their child with ASD's behavior (Gray, 1993; Mak & Kwok, 2010). Unsolicited advice and censure from family members was also a common form of feedback received by participants.

As mentioned in Chapter 2, Goffman (1963) notes that individuals who do not meet social expectations are subject to stigmatization and are considered to have a "spoiled identity" as shown in Appendix A. Thus, when an individual is unable to meet social identity standards, they may be viewed as having spoiled identities and social reaction to these parents may be altered. To manage this spoiled identity, parents may develop strategies to hide or prevent the behaviors that lead to the perception of non-conformance, such as managing the child's aberrant behaviors. Several mothers reported stigmatizing stares and comments from others, indicating that the participant was not meeting the social expectations of their role as a parent. These comments corroborate the findings of Green and colleagues (2005) in which parents of children with ASD often feel blamed by others for their child's differences. This stigmatization can be detrimental to a parent's sense of personal identity as identity is constructed through the interaction with others (Gergen, 1991; Goffman, 1963).

Participants also reported other sources of assessment that were more likely to provide positive feedback regarding their enactment of the parent role. Participants reported comparing their child's ASD symptoms and behaviors to other children with ASD. Inevitably, these were downward comparisons in which the participant's child had less severe symptoms or superior functioning, either socially or academically. Participants also compared their enactment of the parent role to other parents of children with ASD. Again, these were generally downward comparisons in which the other parent's performance was generally considered worse than that of the participant. These downward comparisons are not surprising. Social comparison theory posits that individuals are driven to obtain accurate evaluations of themselves (Festinger, 1954). When accurate, unbiased methods are unavailable, individuals will evaluate themselves through comparisons to other people (Festinger, 1954). As an extension of this theory, Wills (1981) suggested that individuals compare themselves to others whom they consider to be worse off to improve self-regard. Fiske (2011) argued that downward comparisons make individual's feel more contented with their circumstances.

Conversely, upward comparisons can lower self-regard. Thus, when participants compared their child to other children with ASD, they receive feedback that their situation is somehow better than the parents of the other child. Further, when participants made downward comparisons to other parents of children with ASD, they invariably outperform the other parents in relation to meeting the responsibilities of the parenting role. Research among patients with severe or chronic illnesses indicates that downward comparisons may produce an increase in the subjective well-being of the patient (Buunk, Zurriaga, & González, 2006; Hooper, Ryan, & Hassell, 2004). This phenomenon is also found among volunteer caregivers of the terminally ill (Van der Zee, Bakker, & Buunk, 2001) and among parents of children with Duchenne Muscular Dystrophy (Hodges & Dibb, 2010).

Participants also reported that they routinely reflect upon, and assess, their own parenting skills. Self-reflection is a process through which an individual evaluates a significant event or time period to determine meaning. Often, a goal of reflection is to seek closure regarding the experience (Dewey, 1933). Conversely, self-assessment is a process through which individuals study their own performance against an internal standard to improve their own performance. Participants in this study did not consistently seem to reach a conclusion regarding their parenting performance through self-reflection, possibly due to the protracted nature of parenting a child, especially a child with autism. Additionally, self-assessments ranged from unsure of their parenting performance to positive assessments of role enactment. This is not surprising. Research has shown that transient factors, such as motives (Kunda, 1990) and mood (Lerner & Keltner, 2001), can impact self-assessments. Thus, the results of the self-assessments and reflections reported in this study are less interesting than their frequent occurrence. Parents engaged in this process of self-reflection and self-assessment multiple times. Perhaps the rapidly changing and ongoing demands of parenting a child with ASD instigate the need to frequently assess one's performance of the parent role.

Participant's assessment of their enactment of the parenting role is closely related to the second-order realities (Watzlawick, 1984) created by parents in response to the ASD diagnosis. When parents of children with ASD encounter a stressful event in relation to the diagnosis, such as a change in symptoms or behavioral extremes, parents appraise the event. If the initial appraisal indicates a discrepancy with the parents global-meaning system, steps are taken to resolve the discrepancy. In this study, parents modified their constructions of the parenting role to encompass the additional responsibilities associated with the diagnosis. These parents then engage in an almost continuous process of assessment to determine if they are meeting the revised role expectations.

Park and Folkman's model of global and situational-meaning (Park, 2010) clearly describes this process (Appendix K). Initial appraisal occurs when a stressor is encountered. A determination is then made between the meaning attributed to the event and parental global-meaning systems. If discrepancies exist, meaning-making occurs to reduce this discrepancy, through one of several processes including: (1) assimilation or accommodation, (2) automatic or deliberate processing, (3) searching for comprehensibility or significance, and (4) cognitive/emotional processing. Once meanings are constructed, and discrepancies are eliminated, successful adjustment to the stressful event has occurred. It is at this point where the model is no longer adequate to describe the process described by these participants. The frequent appearance of stressful events and the constant need to assess parental performance against social expectations do not suggest that parents ever successfully adjust to parenting a child with ASD. Thus, the changing and ongoing demands of the child's disorder on the family seem to accelerate or complicate the process of evaluating situational-meaning.

Based on the information gathered in this research study, I recommend that Park and Folkman's (Park, 2010) meaning-making model be revised for parents of children with ASD. After a stressful situation is encountered, parents of children with ASD appraise the meaning of the event, and attempt to accommodate this new meaning into their global-meaning systems by adjusting to the discrepancy. Prior to incorporating the meaning ascribed to the event into their global-meaning systems, parents reappraise whether they are performing the new role or expectations successfully, and make changes as necessary to eliminate this discrepancy. Often before adjustment is successful, however, another stressful situation is encountered and parental attention is diverted to manage the new stressor. Successful adjustment appears to be a goal that these parents do not obtain. Positive appraisals are fleeting. An endless cycle of stressful events, initial appraisals, and attempts to create meaning are the norm. A revised model has been constructed to represent this cycle (Appendix L).

Systems, even family systems, prefer to operate in a stable manner, or in homeostasis. Homeostasis is the natural balance or equilibrium within a given system (Ashby, 1962). Homeostasis does not suggest that change does not occur within a system, but rather the system expends effort to maintain stability. Systems that experience constant or unpredictable events spend considerable effort to revert to a homeostatic state. Thus, when families of children with ASD encounter multiple challenging events, significant effort is expended to adapt to the changes and accommodate them. The cost of this effort may be parental time (Barry & Busch, 2007; Gould, 2004; Porterfield, 2002), financial resources (Barry & Busch, 2007; Ganz, 2007), and parental physical (Ehrlich, 2012; Hayes & Watson, 2013) and psychological health (Ingersoll & Hambrick, 2011; Paytner, et al., 2013).

Evidence of parental difficulty in successfully adjusting to a child's ASD diagnosis is apparent in the meanings ascribed to the experience by participants in this research study. As would be expected by the posttraumatic-growth (PTG) model (Tedeschi & Calhoun, 2004), parents did ascribe positive meanings to the process of raising a child with autism, including gratitude for the experience, increased compassion and tolerance of others, and an ease in prioritizing the demands of everyday life. These meaning constructions, however appear to be transitory, rather than permanent. A likely reason for this difference lies in the inherent definition of PTG, growth that occurs *after* a traumatic event. For these parents, the trauma associated with the diagnosis may be over, but other traumas associated with the raising of the child with ASD are not as clearly delineated. There is never a post-ASD moment. Rapid changes in behaviors or symptoms in the child with ASD create ongoing stressors that the family manages each day.

The ongoing demands and stresses of raising a child with autism do not stop after the diagnosis is received. This is clearly only the beginning of a long journey. The ability to create meaning from the experience is difficult, as frequent stressors require frequent appraisals and accommodations to the parenting role. Before parents are fully able to integrate new situational-meanings into their global-meaning systems, new stressors are encountered. Parents have a difficult time evaluating their enactment of the modified parent role, as the role is continually under construction. As succinctly stated by one parent, “There’s always another battle, another hurdle.”.

Limitations

This research study is not without its limitations. One of the most obvious is the lack of diversity in the research sample. Although efforts were made to recruit through multiple channels, no parents of color contacted the researcher to participate. Although qualitative research findings are not intended to represent entire populations or to generalize findings to others beyond the specific criteria set for the particular study (Creswell, 2012), the lack of diversity in this sample may reflect a limitation in how parents of color construct the parent role identity when raising a child with ASD. Further, meanings made from the experience may also be unique to this population. Thus, the lack of diversity in this study may be perceived as a limitation.

Recruitment methods may have contributed to the lack of diversity in this research study. Although flyers were placed in several therapeutic settings, and copies were provided to support agencies, it is conceivable that these agencies catered to a non-diverse population. Certainly, these agencies catered to parents that had sufficient time and resources to utilize the services offered. Research has shown that non-white families have less access to family-centered care for children with ASD (Doshi, Tilford, Ounpraseuth, Kuo, & Payakachat, 2017). Parents of color may have had limited access to either the time or financial ability to access these services. Recruitment through a more unrestricted medium may have resulted in a more diverse sample population.

A second limitation of the study involves triangulation. Although efforts were made to gather data in multiple contexts, using multiple methods, the study is still limited by the data collection and analysis of a solitary researcher. The utilization of multiple researchers, or multiple research analysts, may have elicited a different interpretation of the data. The lens of social constructivism, however, allows that there are multiple realities and these realities are interpreted through individual interactions and experiences (Morcol, 2001). Thus, while incorporating multiple researchers in the analysis of the data may have resulted in a different interpretation, the interpretation offered in this study is equally valid.

Another possible limitation of the research study is the personal nature of identity construction and meaning-making. Rapport, trust, and understanding had to be developed for participants to fully disclose how role identities and meanings are constructed. This can take a significant amount of time (Silverman, 2004), and time constraints on the researcher's part, as well as those of the participant, may have impacted the process.

Finally, while the concepts of meaning-making, especially relative to PTG, were used to inform this research study, quantitative analysis of the concept was not undertaken. The intent of the study was to understand how parent's construct their new role identity and how they create meaning from the experience. While quantitative data might have added an interesting element to this investigation, it was not the primary focus of the study.

Future Directions

Scholars interested in this area of inquiry have a variety of opportunities to build upon this research. Future research efforts could center on applying alternative methodologies to address results that emerged from this investigation. Using a different theoretical lens or framework may also provide insights into the identity construction and meaning-making processes not captured in this investigation. For example, all of the participants in this research were mothers. Thus, the examination of this data through a feminist lens could be meaningful.

Future research could explore the differences in identity construction of fathers as well as mothers, as well as how father's construct meaning from raising a child with ASD. It is apparent from this study, that mothers usually play the role of primary caregiver for their diagnosed child. Perhaps the father's role identity evolves differently, as both cultural and familial expectations for him may vary significantly from those expected of the mother in these family systems. Further, this research focused on identity construction and meaning-making in two parent households. It is likely that single parents construct a unique role identity which corresponds with their status as sole parent. Either research study would extend communication or psychological scholarship in this area of study.

This study generated several common themes across the case families regarding how role identities are constructed and meaning-making is created among parents of children with ASD. A future study could examine these common themes among a larger sample, either through targeted interviews, or through the development of quantitative measures of these elements. By gaining a broader understanding of these findings, interventions could be developed that would help caregivers to cope with the increased demands of raising a child with autism.

Finally, the conclusios drawn from this research indicate that parets of ASD have difficulty creating meaning from the experience due to ongoing disturbances, stressors, and traumas. These occurrences may not be the exclusive domain of parents of children with autism. Parents of children with other physical conditions or mental health disorders may also experience similar disruptions in their lives. It would be beneficial, therefore, to access the applicability of the revised model to parents of children with other chronic physical or mental health disorcers.

Summary

As a significant portion of our identity work is completed in adolescence (Erikson, 1980), it is likely adults enter into parenthood with preconceived ideas about the parent role. Parents learn more about the parent role from their social interactions with others (Gergen, 1991), such as teachers, peers, grandparents, and their children. When a child is diagnosed with ASD, the parent role identity is reconstructed to accommodate this new information. Parents in this study reconstructed this role to include five key elments: advocating, accommodating, balancing family needs, managing behaviors, and grieving.

As parents go about their enactment of the revised parent role, they receive input on whether their performance meets social expectations (Burke, 1991). As noted by parents in this research study, feedback is received in multiple forms of assessment, including assessing the child, assessing other parents, being assessed by others, and self-assessing. These assessments may indicate that the parents need to alter their performance in order to meet social expectations. This is an ongoing cycle that is complicated by the ongoing truamas or stressors due to the ASD diagnosis. If a parent is continually unsuccessful in meeting the social expectations of their role, they may acquire a spoiled identity (Goffman, 1963) and subsequently be stigmatized by others.

This ongoing cycle makes if difficult for parents to successfully reconstruct the parent role and to consistently enact that reconstruction. Thus, it becomes difficult for parents to successfully integrate the experience into their global meaning systems. Parents may create temporary meanings from the experience, including expressing gratitude and compassion, and prioritizing their life goals. However, the constant struggle to deal with demands of the diagnosis seem to render these meanings as impermanent.

Conclusions

Estimates indicate that 1 in 68 children in the U.S. has an autism spectrum disorder and there is currently no cure (CDC, 2016). The rapid growth in the prevalence of the disorder indicates that many families are dealing with the myriad of consequences that accompany raising a child with autism. For this reason, it is important to provide attention to the parents and caregivers of these children as their contribution to their child's well-being may be life-long.

Each of the eight case families included in this study are managing the challenges of raising a child with ASD. The detailed interviews, focus group, and field observations provide a unique insight into the new roles these parents are constructing and how these parents are adjusting to these new roles and creating meaning from the experience. By gaining a better understanding of this process, and its associated challenges, scholars and researchers can focus future efforts on addressing the issues raised in this study and help to provide a better quality of life for these families.

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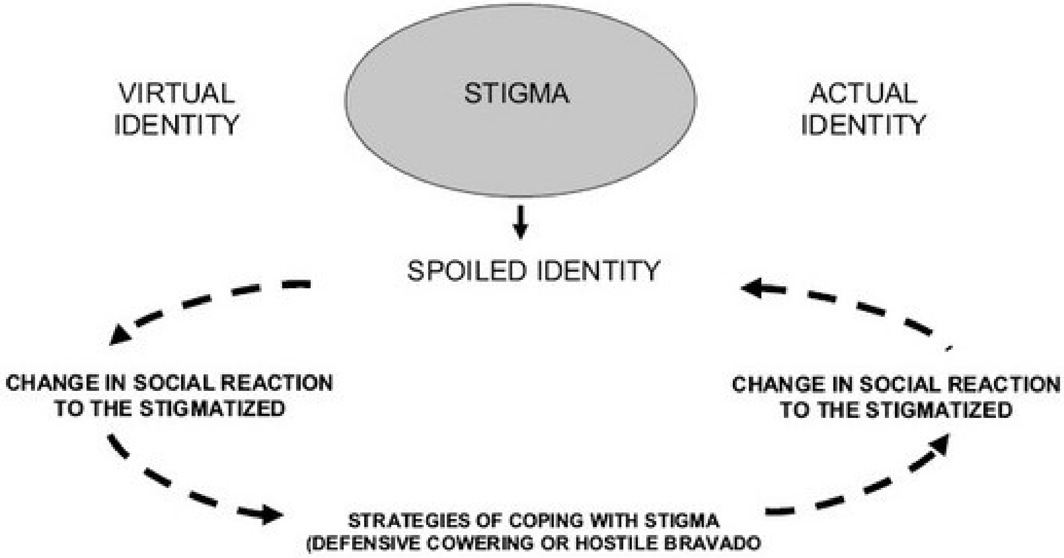
APPENDIX A: Goffman Model of Spoiled Idenity



Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. New York, NY: Simon and Schuster, Inc.

APPENDIX B: Statement of Personal Identity

As stated in Chapter 5, it is important to recognize researcher bias and to acknowledge personal views across the topics presented in this study. Positionality, according to Takacs (2003), is the idea that each individual has unique experiences and beliefs that unsurprisingly affect how human beings see and interpret the world. As a parent of a child with autism, I have my own preconceived expectations, experiences, and beliefs that contributed to my interpretation of the data collected for this research study. Unlike quantitative research, qualitative analysis does not allow the researcher to control for these variables. As a result, it is important for me as the primary researcher to address how my personal experiences and beliefs may have impacted these results.

As mentioned previously, I am the parent of a child with autism. My world-view incorporates beliefs and perceptions regarding the parenting of a child with ASD. Like the participants in this study, I find that these responsibilities change frequently and must be reappraised based on the changing demands of my child's symptoms and the unique circumstances of my family system. A personal narrative describing an instance of identity construction follows.

Personal Narrative: Identity Construction

I know Zach's Client Assistance Program (CAP) case manager has arrived when our two dogs begin barking loudly. "Evan," I shout. "Daniel's here."

I walk back into our designated therapy room (AKA the guest room) to let Zach's ABA (Applied Behavioral Analysis) therapist know that Zach will need to take a break for a few minutes. *I hope this doesn't take too long,* I think. *They just got started.*

By the time Daniel knocks on the door, Zach is bouncing through the house and Evan has kenneled our two ferocious doodles.

"Just a sec," I yell at Daniel through the door, as I fumble the key in the door lock. "This lock is sticking, again." I glance over and inform Evan.

"Something else to fix," he mutters and takes the key from my hand, unlocking the door and opening it wide.

"Come on in," Evan greets Daniel, shaking his hand and stepping aside to allow Daniel entrance into our family living room.

"Hey guys," Daniel says, smiling as he enters out home. "Still locking all the doors with a key?" he asks as he reaches out to shake my hand.

"Yeah, until we can find a better system that will work with these recessed doors," Evan answers. "Zach's had too many near-escapes to stop now."

Zach runs through the house and stops when he sees Daniel.

"Zach, come say hi to Daniel," I prompt, wrapping my arm around Zach's shoulders, pulling him toward me and giving him a sideways hug.

"How're you doing Zach?" Daniel asks holding his hand out to our gorgeous son.

"Zach, Daniel said hello. What do you say?" I prompt him.

"Hi Daniel," Zach mumbles. He slaps Daniel's hand, giving him "five" and squirms away, going back to his ball.

"I'm going to go ahead and take him on back," Kathy, Zach's ABA therapist says, rounding him up and heading back to the therapy room with her arm around our son.

"How's his eye doing?" asks Daniel, pointing to his own eyebrow as we head into our dining room and take seats around the table.

"He gets his stitches out next week," I shudder, pulling out a chair and sitting down. Another doctor's appointment I am dreading.

In addition to having autism, Zach also has ADHD and sensory integration disorder. As a result, he is extremely hyperactive and sensory seeking. He loves watching the world through the windows in our home, and gets excited when he sees something interesting, such as squirrels playing in the trees or a bird on our feeder. Unfortunately, his excitement leads him to over-react and he slaps at the windows or jumps up and down. This has led to more than one broken window.

Up until last week, the biggest problem with this behavior was replacing the glass. Since our home is nearly 100-years old, the windows are quite unique and none are a standard size. Window glass must be individually cut to the appropriate size for each window at the local hardware store. Evan has become quite proficient in replacing the glass Zach has broken due to his excitement.

Last week, however, Zach's enthusiasm led him to bang his head against the window. The result was a long day in the local emergency room and three stitches to Zach's left eyebrow. Replacing the glass each time Zach breaks a window is no longer an option. Preventative action is needed. Barring Zach from the windows is unrealistic, so other options must be considered.

"So, I looked into the grant program for independent living, that I thought you might qualify for," Daniel begins pulling a pamphlet from his crowded nylon briefcase. "The program will pay for modifications to a home to ensure safety if a child is at risk. The only problem is that it is geared toward families that make less than $50,000 a year."

"Well, that lets us out," Evan sighs. This is probably the first time that I'm disappointed Evan has a good job.

"We had someone give us an estimate to replace the widows with something more durable, but that's more than $1000 per window," I mention. With 32 windows in our home, I know this is a prohibitive solution.

"That would require a home improvement loan," Evan adds, discounting that idea. "And that cost doesn't include installation."

"We could always raid the older kids' college funds," I joke, knowing that would never happen. We can't sacrifice their education because Zach slaps the windows.

"I know another family that had a similar problem," Daniel mentions. "They ended-up covering the bottom half of their windows with shutters."

I look over at our windows. "If we cover them up, Zach won't be able to look out. He loves watching the bird feeder and the cars go by the house. I would rather not do that," I comment, shifting in my chair.

Luckily, Evan is a born problem solver. "We could buy sheets of plexiglass or Lexan from the hardware store. I'd just need to find someone who could cut them to fit," he says thinking aloud.

"He could still watch out the windows," I respond, tossing the idea around in my own mind.

"How much do you think that would cost?" asks Daniel. I had almost forgotten he was still here.

“I think we could get the materials for about $100 or so per window,” Evan answers. “But we would still have to find someone who could cut them to fit. That shouldn’t cost too much,” he adds optimistically.

“Assuming that’s possible, how will we install them? Will we need to hire someone, or can we do it ourselves?” I ask Evan. Problem solving with Evan is one of my favorite things in the world. It’s something we have always enjoyed doing together. I just wish it were for a better reason.

“I think we could drill holes in the plexiglass and bolt them directly to the wooden window frames,” Evan answers. “I would probably need a new drill bit, though.”

“And a new drill?” I ask, laughing. Evan loves his tools.

He smiles at me. “Maybe,” he answers.

“That’s still a pretty hefty price,” Daniel intercedes. “Can you guys afford that?”

“Well, we could put it on a credit card,” I respond, but Evan and I hate putting things on credit. It takes so long to pay those things off.

“We could use the money we have put aside for our anniversary trip,” Evan responds tentatively. We have always tried to spend some time alone for our anniversary. A bit of time to reconnect. This year we had planned on going to Jekyll Island for five days.

“We could just spend a night in Charlotte. Go out to dinner, sleep-in at a hotel and order room service,” I reply, knowing that Evan hates the idea of giving up our alone time.

“Are you sure,” he asks hesitantly. “I hate to suggest it.”

“I know, but we are going to be married for a long time. There’s always next year,” I answer. “Besides, if we don’t do something soon, Zach’s going to get hurt even worse.”

I don’t relish giving up my vacation with Evan, but parents are responsible for keeping their kids safe. Sometimes that means sacrificing for them.

As with nearly half of all children with ASD (Anderson, et al., 2012), our son has a tendency to “elope” or run off from caregivers. His “flight” tendencies are a form of sensory seeking. As described in this personal narrative, keeping our son with ASD safe has evolved from keeping a close eye on him to covering the windows of our home with 3/8” plexiglass. His lack of impulse control and hyperactivity necessitates that we continually make accommodations to our home to ensure his safety. We have fenced a large part of our yard to make sure he has a safe place to play. We have placed a locked gate on our porch to prevent his escape. We replaced all the deadbolt locks in the doors of our home with keyed locks. These accommodations have each been enacted in direct response to the changing and ongoing demands required to keep him safe and have necessitated that we balance the demands of his safety with the needs of all our family members.

Similar to the parents in this research study, I recognize that the trauma of my son’s autism did not end with his diagnosis. He is currently 12 years old and has been diagnosed for nearly 10 years. There have been many experiences and changes in our lives as a result of his disorder. Like many of the parents in this research study, we have experienced multiple stressful events that make it difficult to see ourselves as "successfully adjusted" to ASD. The following narrative describes one of our many experiences.

Personal Narrative: Meaning-Making

I roll over in bed and close my eyes again. I hear Zach playing and I wonder if I should go ahead and get up. Its only 6:00 a.m. but he probably is starting to get hungry. As I am steeling myself for the day ahead, I hear Zach's feet running and he's laughing. He sounds like he is out of his room. For safety reasons, we began locking Zach's bedroom door from the outside when we went to bed at night.

"Evan, did you lock Zach's door last night?" I shake Evan anxiously.

Evan rolls over, yawns and looks at me. "Of course," he says. He glances past my head and looks out our bedroom window. "Oh, my God! He's on the roof!" Evan yells sitting straight up in the bed.

One of the unique features of our 100-year old home is that only the center section of the house is two-story. Three sides of the house are surrounded by a single-story roof that is accessible from the second-story windows. The three occupied bedrooms in our house are all on the second floor.

"Jesus Christ!" We jump from the bed, run into the hallway and unlock Zach's bedroom door. Our eyes are immediately drawn to a window that is opened about six inches. Zach's pajama pants lay on the floor in front of the open window. Zach is gleefully splashing in a puddle on the flat roof outside his bedroom window. He is pantless.

"Zachary!" I scream as Evan tries to open the window further. "Get over here right now!"

Zach looks at me and grins. He stands up and runs to the window and looks at Evan and me. “Yay!” he yells, clearly proud of his frightening accomplishment. He then dances across the roof closer to the edge to get a better view of his swing set.

“Open the friggin’ window!” I scream at Evan.

“I’m trying,” he growls back at me. “I think it’s stuck. It won’t open any further. Can you get through, I’m too big!"

I frown at the six-inch gap. “I wish,” I say sarcastically.

“I’ll try the window in our bedroom.” Evan runs from Zach’s bedroom and disappears into ours.

“Zachary,” I plead out the barely open window, trying to remain calm. “Come in and I’ll make you some bacon for breakfast.”

Zachary doesn’t even glance in my direction. He returns to his puddle and splashes and prances through it happily. Suddenly, he runs toward the front of the house as a car motors down our street. He jumps up and down joyfully.

From the corner of my eye, I see our college-aged daughter, Erin, place a foot out of her bedroom window and climb out onto the roof. *At least she has on pajamas,* I think. She darts over to Zach as Evan rounds the corner of the roof in just his boxer shorts. *I’m sure the neighbors are getting an eyeful!* They each grab one of Zach’s hands and lead him to Erin’s open bedroom window.

I run to Erin’s bedroom, grateful it is summer and she was home from school. I grab Zachary as Evan passes him through the window. He is smiling from ear-to-ear.

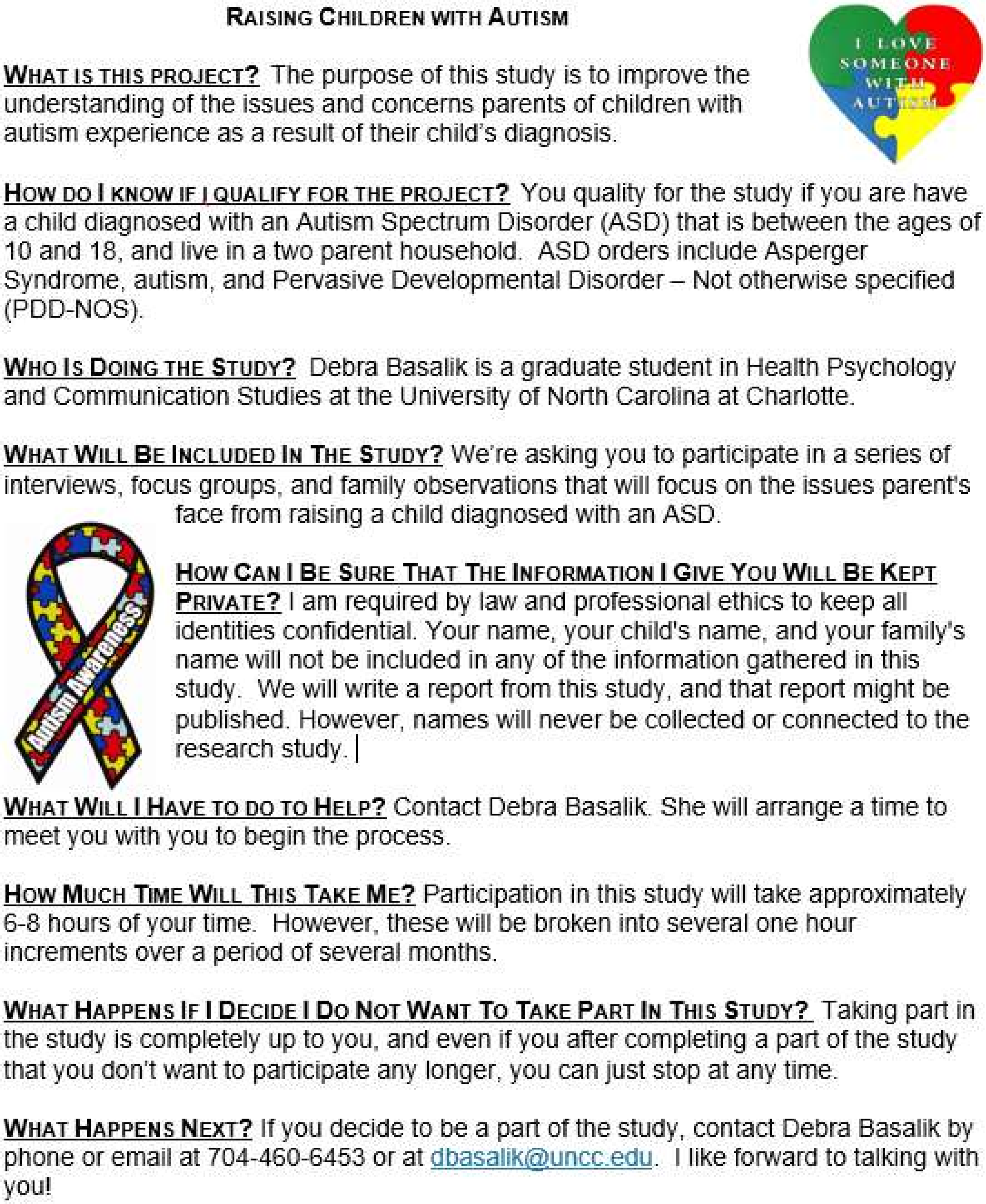
“Zachary,” I sigh as I pull him into a hug, and then grab his shoulders to ensure he is looking at my face. “We don’t climb on the roof. It’s dangerous. You scared mommy and daddy,” I say trying to remain calm and explain why his behavior was unacceptable.

As Evan and Erin crawl back through the bedroom window, Evan takes over the scolding. “Zach, no climbing out the window,” he growls, trying to rein in his temper.

“Sorry,” Zach says smiling. He is clearly not sorry.

I place my hand over my heart and take a deep breath. *This kid is going to be the death of us,* I think. Evan and I may never sleep easy again.

APPENDIX C: RECRUITMENT FLYER



RAISING CHILDREN WITH AUTISM

What is this project? The purpose of this study is to improve the understanding of the issues and concerns parents of children with autism experience as a result of their child's diagnosis.

How do I know if I qualify for the project? You quality for the study if you are have a child diagnosed with an Autism Spectrum Disorder (ASD) that is between the ages of 10 and 18, and live in a two parent household. ASD orders include Asperger Syndrome, autism, and Pervasive Developmental Disorder – Not otherwise specified (PDD-NOS).

Who Is Doing the Study? Debra Basalik is a graduate student in Health Psychology and Communication Studies at the University of North Carolina at Charlotte.

What Will Be Included In The Study? We're asking you to participate in a series of interviews, focus groups, and family observations that will focus on the issues parent's face from raising a child diagnosed with an ASD.

How Can I Be Sure That The Information I Give You Will Be Kept Private? I am required by law and professional ethics to keep all identities confidential. Your name, your child's name, and your family's name will not be included in any of the information gathered in this study. We will write a report from this study, and that report might be published. However, names will never be collected or connected to the research study.

What Will I Have to do to Help? Contact Debra Basalik. She will arrange a time to meet you with you to begin the process.

How Much Time Will This Take Me? Participation in this study will take approximately 6-8 hours of your time. However, these will be broken into several one hour increments over a period of several months.

What Happens If I Decide I Do Not Want To Take Part In This Study? Taking part in the study is completely up to you, and even if you after completing a part of the study that you don't want to participate any longer, you can just stop at any time.

What Happens Next? If you decide to be a part of the study, contact Debra Basalik by phone or email at 704-460-6453 or at dbasalik@uncc.edu. I like forward to talking with you!

APPENDIX D: INFORMED CONSENT

UNCCHARLOTTE

Informed Consent for

How do parents create meaning from raising a child with autism?

You are invited to participate in a research study entitled **"How do parents create meaning from raising a child with autism?"** The purpose of this study is to increase the understanding of how parents perceive changes in the parental role due to a child's autism diagnosis and how a parent's worldview changes to accommodate these perceived changes.

If you choose to participate in this study, you will be asked to participate in several different activities. You will be asked to participate in 3 in-depth interviews regarding your experiences parenting a child with autism. These interviews will take approximately 1 hour each. The interviews will be conducted by the primary researcher, in a location preferred by the participant, and will be audio recorded to ensure clarity. The primary researcher will be responsible for transcribing the audio recordings and at no time will you, your child, or your family's name be included in the transcription process. After the recording is transcribed, the audio recording will be erased.

You will also be asked to participate in 2 focus groups with other parents of children with autism regarding your experiences in raising a child with autism. Each focus group will last 1- 2 hours. The primary researcher will facilitate the focus group and data will be audio recorded to ensure clarity. Again, the primary researcher will be responsible for transcribing the audio recordings and at no time will you, your child, or your family's name be included in the transcription process. After the recording is transcribed, the audio recording will be erased.

Finally, you and your family will be asked to participate in 3 field observations. These field observations will take place in your lived environment, at the location of your choosing (such as at home, on the playground, at church, etc.). These observations will include personal observation and interpretation of witnessed behaviors and experiences by the primary researcher. These observations will focus on the following: interactions between family members, parent communication to the child and about the child, parent care taking of the child, and parent management of child's needs outside the family home. Data collected during these observations will be recorded via researcher notes. At no time will you, your child, or your family's name be included in the researcher's field notes.

There are no known risks to participation in this study. However, there may be risks which are currently unforeseeable. The benefit to your participation in this study is a better understanding of the research process. You may also benefit by meeting other parent's with similar parenting issues. Your participation in this study will allow researchers at UNCC to better understand how the parent role changes and parental meaning occurs in the context of raising a child with autism.

You are a volunteer. The decision to participate in this study is completely up to you. If you decide to be in the study, you may stop at any time. If during any interviews, focus groups, or observations you become uncomfortable, you can stop the interview, leave the focus group, or as the researcher to stop the observation. You will not be treated any differently if you decide not to participate or if you stop once you have started.

UNC Charlotte wants to make sure that you are treated in a fair and respectful manner. Contact the University's Research Compliance Office (704.687.3309) if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact Debra Basalik, Health Psychology/Communication Studies graduate student (704.460.6453) or Dr. Christine Davis, Associate Professor of Communication Studies (704.687.0760).

I have read the information in this consent form. I have had the chance to ask questions about this study, and those questions have been answered to my satisfaction. I am at least 18 years of age and I agree to participate in this research project. I understand that I will receive a copy of this form after it has been signed by me and the Principal Investigator.

Participant Name (PLEASE PRINT)	**Participant Signature**	**DATE**
Investigator Signature	**DATE**	

APPENDIX E: INFORMED ASSENT

UNC CHARLOTTE

Informed Assent for
How do parents create meaning from raising a child with autism?
Parental Permission for Child Participation

Your child is invited to participate in a research study entitled **"How do parents create meaning from raising a child with autism?"** The purpose of this study is to increase the understanding of how parents perceive changes in the parental role due to a child's autism diagnosis and how a parent's worldview changes to accommodate these perceived changes.

As a participant, you will be asked to participate in 2 focus groups and 3 in-depth interviews that focus on your experiences of raising a child with autism spectrum disorder. As such, you may be asked questions that relate directly to your child. However, your child will not be asked to participate in these interviews or focus groups.

If you choose to allow your child to participate in this study, your will child will be asked to participate in 3 field observations. These field observations will take place in your lived environment, at the location of your choosing (such as at home, on the playground, at church, etc.). These observations will include personal observation and interpretation of witnessed behaviors and experiences by the primary researcher. These observations will focus on the following: interactions between family members, parent communication to the child and about the child, parent care taking of the child, and parent management of child's needs outside the family home. At no time will your child be interviewed for this study. Data collected during these observations will be recorded via researcher notes. At no time will your child's name be included in the researcher's field notes.

There are no known risks to your child's participation in this study. However, there may be risks which are currently unforeseeable. The benefits to your child's participation in this study is a better understanding of the research process. Your child's participation in this study will allow researchers at UNCC to better understand how the parent role changes and parental meaning occurs in the context of raising a child with autism.

You and your child are volunteers. Your decision to permit your child to participate in this study is completely up to you. If you decide to allow your child to be included in the study, you may stop at any time. If during any observation your child becomes uncomfortable, you can stop the observation. You will not be treated any differently if you decide not to allow your child to participate or if you stop once your child has started.

UNC Charlotte wants to make sure that you are treated in a fair and respectful manner. Contact the University's Research Compliance Office (704.687.3309) if you have any questions about how you are treated as a study participant. If you have any questions about the project, please contact Debra Basalik, Health Psychology/Communication Studies graduate student (704.460.6453) or Dr. Christine Davis, Associate Professor of Communication Studies (704.687.0760).

I have read the information in this consent form. I have had the chance to ask questions about this study, and those questions have been answered to my satisfaction. I am at least 18 years of age and I agree to participate in this research project. I understand that I will receive a copy of this form after it has been signed by me and the Principal Investigator.

Participant Name (PLEASE PRINT) **Participant Signature** **DATE**

Investigator Signature **DATE**

APPENDIX F: ASD RESOURCES AND SUPPORTS

Autism Society of American

- Phone: (301)657-0881 or 1(800)-3AUTISM (1800)328-8476)
- Mailing Address: Autism Society

  4340 East-West Hwy, Suite 350

  Bethesda, Maryland 20814

  U.S.A.
- Email: info@autism-society.org
- Website: http://www.autism-society.org/

North Carolina Autism Society

- Phone: (*800)442-2762 (NC only) or +1 919-743-0204*
- Mailing Address: *Autism Society of North Carolina, Inc.*

  505 Oberlin Road, Suite 230

  Raleigh, NC 27605, USA
- Email: info@autismsociety-nc.org
- Website: http://www.autismsociety-nc.org/

Autism Speaks

- Phone: (888)288-4762 (Autism Response Team)

- Mailing Address: *Autism Speaks Charlotte Field Office*

  8604 Cliff Cameron Drive, Suite 144

  Charlotte, NC 28269
- Email: familyservices@autismspeaks.org
- Website: https://www.autismspeaks.org/

Highly Rated Websites for Parents

1. www.disabilityscoop.com – Sign up for Disability Scoop's e-mail news to receive the most current updates on developmental disabilities. Disability Scoop's experts have been cited by multiple online news sites, including USA Today and People.com.

2. www.autism.com– The Autism Research Institute focuses on researching the causes of autism, as well as developing safe and effective treatments for those currently affected by the disorder.

3. www.autismweb.com – Managed by parents, AutismWeb includes great insights on different autism teaching methods. The site also provides a forum where parents can go to share their stories, give updates on their children's progress, and share recipes that may be useful for picky eaters.

4. www.ahany.org – The Asperger Syndrome and High Functioning Autism Association website offers some great resources for those with higher functioning autism. AHANY also provides a great list of summer programs and day camps in New York, as well as useful questions to ask when choosing a camp or summer program for your special needs child.

5. www.autismhwy.com -Started by a woman whose son was diagnosed with autism, Autism Highway is both informative and fun. Easy to navigate, Autism Highway provides an extensive list of Autism related events and specialists. In addition, Autism Highway includes many fun games that children are sure to enjoy!

6. www.autismbeacon.com – Also started by the parent of a child with autism, Autism Beacon strives to supply the best resources for autism treatments. Autism Beacon presents a lengthy range of articles on autism, including sensitive topics such as bullying and sexuality.

7. www.autism.healingthresholds.com – Healing Thresholds includes information on many different therapy treatments for children with autism. The site focuses on the top 12 used by parents, but also includes useful information on nearly 100 additional therapies.

8. www.nationalautismassociation.org/family-support/find-a-support-group/ - It is very important for families dealing with autism to have an outlet, such as other parents who are going through the same thing. This site connects them to groups both online and in their area, that can offer that type of support.

9. www.autismnow.org – Autism NOW should be the first place you look for the latest news, research and information on autism.

10. www.myautismteam.com/ - My Autism Team is a social network for parents of kids with autism.

11. www.care.com - Care.com is a great place to find a caregiver.

12. www.autismlearn101.com - This site allows people, including children, with autism to complete online activities geared toward helping them develop vital skills.

13. www.bloomandgrow.com - Being a caregiver can be a rewarding, but also often a difficult and humbling task. This site shares products, strategies and tips for how to help your loved one and cope with the great demands that are put upon you each day.

14. www.autismblogsdirectory.blogspot.com - This site offers a comprehensive list of blogs that are written by and for families dealing with autism. It's easy to get lost in reading their stories when you're supposed to be working, so be careful!

15. www.autisminaction.com – Autism in Action specializes in offering how-to teaching programs that can help your child with virtually any task, from basic self-care to better communication.

APPENDIX G: DEMOGRAPHIC QUESTIONNAIRE

Questions		Parent 1	Parent 2
Gender	Male		
	Female		
Race	American Indian or Native American		
	Asian or Pacific Islander		
	Black or African American		
	Multiracial		
	White or European American		
	Other		
Hispanic	Yes		
	No		
Highest Education Level Completed	Less than High School		
	High School or GED		
	Vocational, Technical, Trade or Business School		
	Some college		
	Associate or Bachelor's Degree		
	Some graduate school		
	Master's Degree or higher		
	Other		
Work Status	Employed Full Time		
	Employed Part Time		
	Stay at home parent/homemaker		
	Other		
	Retired		
	Student		
	Unemployed		
Parent Age	In years		

Questions		Child
Gender	Male	
	Female	
Race	American Indian or Native American	
	Asian or Pacific Islander	
	Black or African American	
	Multiracial	
	White or European American	
	Other	
Hispanic	Yes	
	No	
Current Schooling	Grade level	
	Home schooled	
	Not enrolled in school	
Diagnosis	Asperger Syndrome	
	Autism Spectrum Disorder	
	Pervasive Developmental Disorder- Not Otherwise specified (PDD-NOS)	
	Other	
Child’s Age	In years	

APPENDIX H: SEMI-STRUCTURED INTERVIEW GUIDE

- Please tell me about a typical day with your child?
- Please tell me about some of your daily interactions with regards to your child.
- Please tell me about parenting your child before his/her diagnosis.
- Please tell me about parenting your child after his/her diagnosis.
- Describe some of the responsibilities you have as a parent of a child with ASD. How have these changed over time?
- What's the difference between parenting a child with ASD and a child without ASD?
- Please tell me about a time when you were concerned about your child in a social environment.
- Why do you think your child has an ASD?
- What advice would you give to parent of children that are newly diagnosed with an ASD?
- What are some specific challenges you and your child face?
- What are your biggest concerns for your child? Yourself? Your family?
- How do you think you have changed as a result of your child's diagnosis?
- How has your child's diagnosis affected your life?
- How has your child's diagnosis affected your family's life?
- What expectations do you feel from others as a result of your child's diagnosis?
- What are some positive/negatives of your child's ASD?
- What does it mean to be the parent of a child with an ASD?

APPENDIX I: FIELD OBSERVATION GUIDE

- Identify the context (location, who is present, activities taking place, etc.)

- Description of the surroundings (inside, outside, school, home, etc.)

- Appearance of each participant observed (clothing, age, general demeanor, etc.)

- Verbal behaviors and interactions

    - Who speaks with whom, and for how long
    - Who initiates the conversation
    - Tone of voice
    - Context of interaction

- Physical behavior and gestures

    - What participants are doing/activities performed
    - Who is doing what
    - Who is/is not interacting
    - Personal space

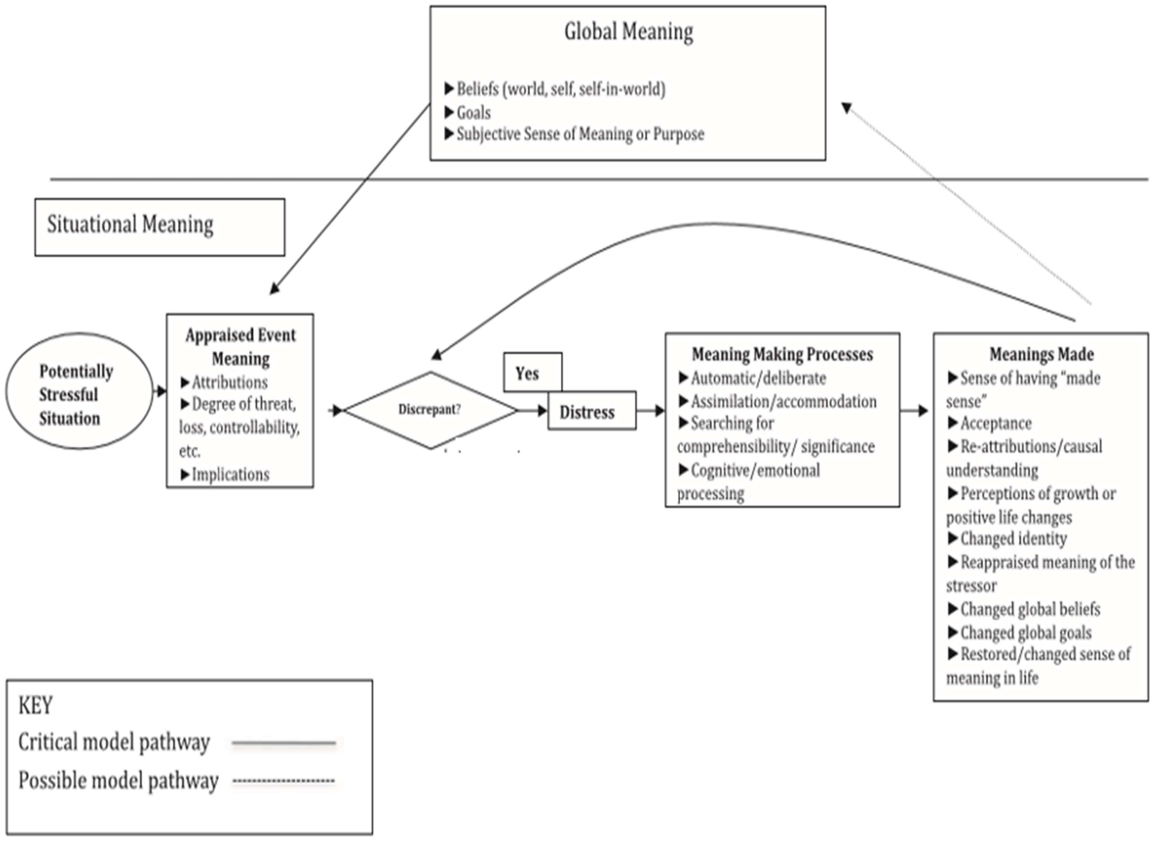
- Traffic patterns

    - Who enters and leaves observation area

APPENDIX J: FOCUS GROUP GUIDE

- Initial introduction (Icebreaker)
- Introductory questions
    - What makes your child special?
    - What does it mean to be a good parent?
- Transition Questions
    - What are some challenges you face as a parent?
    - What expectations do you have of yourself as a parent?
- Key Questions
    - What do you think society expects of you as a parent?
    - What do you think is a parent's role in caring for a child with ASD?
    - What does it mean to be the parent of a child with ASD?
- Ending Questions
    - What advice would you give to a parent whose child is newly diagnosed with an ASD?
    - What is the one thing you wish parents of typically developing kids to know about your or your child?

APPENDIX K: PARK AND FOLKMAN MODEL



Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin, 136*(2), 257-301.

APPENDIX L: REVISED MODEL

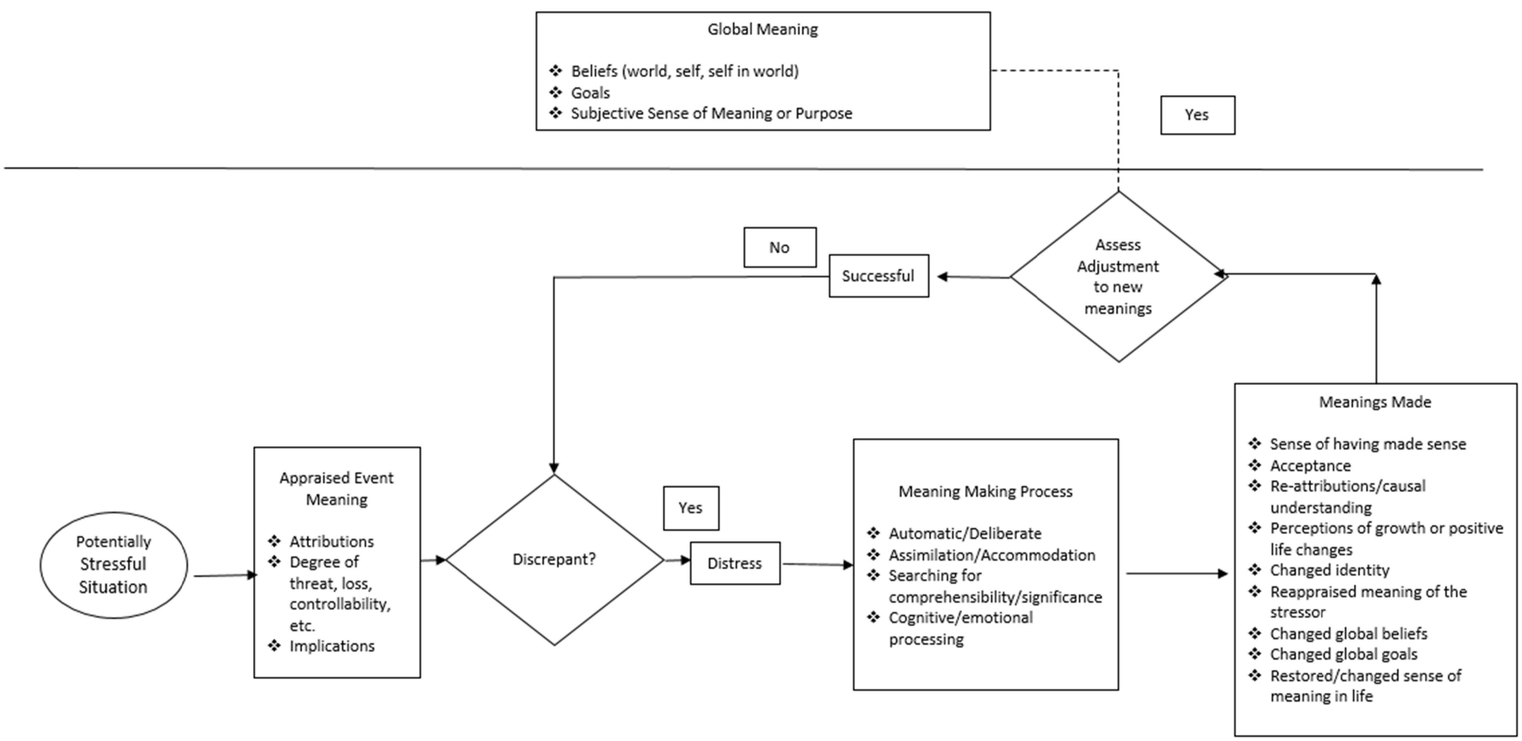


Table 1.
Case Descriptions

		Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7	Case 8
Mother									
	Gender	F	F	F	F	F	F	F	F
	Race	W	W	W	W	W	W	W	W
	Hispanic	N	N	N	N	N	N	N	N
	Highest Education	4	3	7	7	5	7	2	5
	Work Status	1	3	1	1	2	3	1	2
	Age	45	33	38	41	48	46	46	43
Father									
	Gender	M	M	M	M	M	M	M	M
	Race	W	W	W	W	W	W	W	W
	Hispanic	N	N	N	N	N	N	N	N
	Highest Education	4	2	4	4	5	7	2	5
	Work Status	1	1	1	1	1	1	1	1
	Age	46	32	42	42	45	51	45	43
Child									
	Gender	M	M	M	M	M	M	M	M
	Race	W	W	W	W	W	W	W	W
	Hispanic	N	N	N	N	N	N	N	N
	Grade	12	5	6	6	6	7	4	7
	Age	17	11	11	12	12	13	10	13
	Sibling Position	2	1	0	2	3	1	1	2
	Total number of children	3	3	1	2	3	2	2	2
	Diagnosis	ASD ADD	ASD AD DO OCD	ASD ADD SID	ASD DO	ASD ADD AD	ASD	ASD	ASD ADHD

Note: Education level: 1 = Less than HS, 2 = HS, 3 = Vocational, Tech, Trade, or Business School, 4 = Some college, 5 = A.S. or B.S. Degree, 6 = Some graduate school, 7 = Master's Degree or Higher. Work Status: 1 = Employed Full Time, 2 = Employed Part Time, 3 = Stay at home parent, 4 = Other, 5 = Retired, 6 = Student, 7 = Unemployed. Sibling Position: 0 = Only child, 1 = Oldest child, 2= Second Child, 3 = Third Child. Diagnoses: Autism Spectrum Disorder = ASD, Attention Deficit Disorder = ADD, Attention Deficit/Hyperactivity Disorder = ADHD, Anxiety Disorder =AD, Depressive Disorder = DO, Obsessive Compulsive Disorder = OCD, Sensory Integration Disorder = SID

Table 2

Case 1. Data Reduction Summary

Theme	Frequency	Description
Accommodating	11	Child is a high school senior and mother is still making significant accommodations for him.
Assessing	17	Mom still assesses his behavior compared to social norms. These assessments are made academically, physically, and emotionally.
Attributing	26	A common behavior is to speak for child, however, responses are given as [child] thinks this, or believes this.
Challenging	12	Mother still considers many of child's behaviors to be difficult to manage.
Comparing	22	Comparing the child to other children continues from prior to child being diagnosed all the way through childhood.
Expecting	19	Although child has autism, parent still has expectations for the child.
Expressing	11	The experience of emotional loss does not go away as the child ages.
Encouraging	15	Child has special, almost obsessive interests in movies, games, and transformers/power rangers and parent encourages and supports these interests.
Judging	14	Parent has gained quite a bit of experience with ASD and often judges other parents.
Meaning	12	Parent finds meaning in child's successes and her increased tolerance of other children. Parenting a child with ASD requires a lot of effort and recognition of losses.

Table 3
Case 2. Data Reduction Summary

Theme	Frequency	Description
Accommodating	15	Child requires lots of accommodation in everyday life, either due to anxiety or sensory issues.
Assessing	20	Although the child was diagnosed several years earlier, the parent still compares his behavior to approved social norms.
Balancing Family Needs	19	Parent has three children, the oldest has ASD. Parent expresses concerns over the ability to meet each child's needs and spend time with spouse.
Changing	24	The responsibilities associated with raising the child are extremely variable over time.
Comparing	21	Comparing the child to other children continues from prior to child being diagnosed all the way through childhood.
Encouraging	9	Parent encourages child's almost obsessive interests in artistic hobbies, like origami, drawing and making bracelets.
Managing Behaviors	17	Gaining an understanding of child's problems takes quite a bit of effort and investigation.
Meaning	12	Parent finds meaning in the child overcoming current problems and issues.
Self-Assessing	17	As parent raises her child with ASD, she continually questions whether or not she did the best job possible raising the child.

Table 4
Case 3. Data Reduction Summary

Theme	Frequency	Description
Accommodating	16	The child has several behaviors that require the parent to modify the home environment or activities due to safety, sensory, or anxiety issues.
Assessing	15	Child was diagnosed with ASD several years ago, and the parent still compares his behavior to acceptable social norms.
Being Judged	19	Although the child has been diagnosed for several years, the parent still feels judged by others when child does not conform to social norms or expectations.
Changing	15	The parent acknowledges that the responsibilities associated with raising a child with ASD seem to vary over time.
Encouraging	21	Child has an almost obsessive interest in Legos and videogames. The parents encourage these interests.
Expecting	14	Although the child has been diagnosed with ASD, parents still has expectations for the child.
Expressing	12	Although the child was diagnosed with ASD several years ago, the parents still acknowledge emotional losses.
Managing Behaviors	16	Ongoing issues with the child, such as anxiety and sensory needs, require the parent to compensate for those in order to prevent melt-downs or other undesirable behavior.
Meaning	10	Raising a child with ASD has made the parents more compassionate and empathetic toward other kids. Parent also recognize that their life has changed, and will not be reverting to previous expectations.
Self-Assessing	16	Parent frequently assesses the adequacy of her parenting of child

Table 5
Case 4. Data Reduction Summary

Theme	Frequency	Description
Accommodating	22	Parent feels that many of child's behavioral concerns must be managed via through accommodation at home and at school.
Assessing	23	Child was diagnosed with ASD several years ago, and the parent often comments that the child's behavior still does not conform to social norms.
Balancing Family Needs	19	Parent notes that she struggles to adequately balanced her family's needs, especially balancing the needs of her two children.
Changing	23	Parent believes that the challenges associated with raising a child with ASD are intense and variable.
Comparing	18	Parent compares the child's behavior to typically developing kids, even though child was diagnosed several years ago.
Expecting	19	Regardless of diagnosis, parents still have expectations for this child. While accommodations may be made for the child, the behavior is still expected.
Expressing	17	Parent expresses that, although the child was diagnosed several years ago, she and her spouse both still experience emotional losses.
Managing Behaviors	21	Parent notes that child's behavior is very much affected by what the parent does; routine is very important to the child.
Meaning	14	Raising a child with ASD has helped the family reset its priorities. Dealing with the child's issues has also made the family emotionally stronger.
Persisting	17	Parent feels as though much of her son's diagnostic support has only be achieved due to her persistence.

Table 6

Case 5. Data Reduction Summary

Theme	Frequency	Description
Accommodating	15	Parent makes significant accommodations for child to ensure that child is accepted and negative behaviors are minimized.
Assessing	19	Parent routinely compares child's behavior to expected social norms, although child has been diagnosed for several years.
Balancing Family Needs	14	Parent recognizes the difficulty in addressing the needs of the entire family; parent struggles to find time for spouse.
Changing	24	Parent feels that the responsibilities of raising a child with ASD are very demanding and irregular.
Expecting	17	Parent maintains expectations for child, regardless of ASD diagnosis.
Expressing	19	Parent has expressed that the emotional losses associated with the ASD diagnosis have not diminished over time.
Judging	16	Parent feels as though many other parents of children with ASD are very negative, and not supportive; parental experience with this disorder seems to make parent more judgmental of other parents.
Managing Behaviors	20	Parent explains that a significant part of her responsibilities is associated with managing child's challenging behaviors. Medication and therapy are used to address problem behaviors.
Meaning	16	Parent believes that their experience of raising a child with ASD is part of a bigger plan. This seems to empower the parent. Parent also feels that this experience has made them more accepting.
Self-Assessing	19	Parent routinely speculates on whether or not her parenting skills are sufficient for child with ASD.

Table 7

Case 6. Data Reduction Summary

Theme	Frequency	Description
Accommodating	20	Parent recognizes that the entire family participates in making accommodations for their child with ASD, even the younger sister.
Assessing	15	Although child has been diagnosed with ASD for many years, she still compares his behavior to that of expected social norms.
Balancing Family Needs	16	Parent admits to struggling to balance family needs, especially between those of her typically developing daughter and her son with ASD.
Challenging	22	Although the child has been diagnosed with ASD for several years, parent still feels that many of the child's behaviors are very difficult to handle.
Changing	18	Parent feels as though raising the child can be extremely variable; extreme ups and downs.
Expressing	16	Parent notes that she still experiences emotional loss when she thinks that her son will not be like his father. Also, expresses loss when noting that younger daughter acts like older sibling to her brother.
Managing Behaviors	21	Parent notes that significant effort is put into making sure specific behaviors do not occur.
Meaning	17	Raising a child with ASD has helped the family recognize priorities; experience has also made family more compassionate and tolerating.
Self-Assessing	18	Parent continually assesses her performance as a parent and questions whether or not she is doing enough to help prepare the child.

Table 8
Case 7. Data Reduction Summary

Theme	Frequency	Description
Accommodating	22	Parent feels that in order to function in daily life, the family makes significant accommodations for child with ASD, even his younger sister.
Assessing	14	Although child has been diagnosed for many years, the parent still compares the child's behavior to social norms, other children, and younger sister.
Balancing Family Needs	15	Parent feels that they have a hard time balancing the needs of her two children, a son with ASD and his younger sister.
Challenging	14	Although this parent believes her family makes many accommodations for her child with ASD, she still believes many of his behaviors are difficult to handle.
Changing	15	Parent gets frustrated with the frequency of behavioral issues and challenges; the cycle of dealing with new issues is exhausting.
Expressing	14	Parents acknowledge that they still experience a range of emotional losses over child's diagnosis; family will not be able to pass down family business to child with ASD.
Managing Behaviors	18	Parent feels that a significant part of her parenting responsibilities is making sure that her child behaves appropriately. Parent attempts to accomplish this by modifying routines, social interactions, and school issues.
Meaning	15	Parent believes that parenting a child with ASD makes the process more difficult. Parent also believes the process has made her more empathetic.
Self-Assessing	17	Parent continually questions whether or not her parenting skills are sufficient for this child with ASD.

Table 9
Case 8. Data Reduction Summary

Theme	Frequency	Description
Accommodating	17	Parents note that child's ASD requires a significant level of accommodation, beyond the needs of the child's peers.
Assessing	22	Although the child has been diagnosed for many years, the parent still compares his behavior to that of social norms.
Balancing Family Needs	18	Parent worries about the long-term burden of caring for a child with such demanding needs.
Changing	17	The parent recognizes that the demands placed on the family because of ASD are likely going to be long-lasting, varied, and demanding.
Comparing	16	Although the child has been diagnosed for many years, the parent still compares their behavior to that of other children.
Expressing	18	The parent notes that the emotional losses associated with having a child with ASD do not seem to lessen over time.
Managing Behaviors	20	The parent acknowledges that extra effort is required to ensure that situations, places, and people don't trigger negative behaviors in their child.
Meaning	14	Parent notes that the entire family has become better at identifying what is important; acknowledges that other life goals may no longer be possible.
Self-Assessing	17	Parent frequently refers to their capabilities as a parent; questions whether or not they are performing adequately.

Table 10
Cross Case Coding

RQ1: How does an ASD diagnosis affect how parents reconstruct the parent role identity.

1. Advocating
    a. With school system
    b. At school
    c. Changing needs
    d. Parent education
    e. Serving community
    f. Representing entire population
2. Accommodating
    a. Educational needs
    b. Comorbidities
        i. ADD/ADHD
        ii. Anxiety
        iii. Sensory issues
    c. Diet
        i. Allergies
        ii. Gastrointestinal issues
        iii. Sensory issues
        iv. School lunches
    d. Safety
        i. Elopement
        ii. Constant supervision at home
    e. Social interactions
        i. Children’s interactions with others
        ii. Parents inability to socialize
            1. Child care
            2. Constant supervision at other locations
            3. Sensory issues
            4. Dietary concerns
            5. Safety
        iii. Reducing social circle
    f. Special interests
        i. Legos
        ii. Video games
        iii. Comics
        iv. iPad
3. Balancing Family Needs
    a. Other children
        i. Guilt
        ii. Meeting needs
        iii. Relationships between children
    b. Marital relationships

        c. Finances
            i. Insurance
            ii. Costs of therapies
            iii. Inability to work
4. Managing Behaviors
    a. Repetitive behaviors
        i. Finger flapping
        ii. Rocking
        iii. Scripting
    b. Meltdowns
    c. Judging normal behaviors
    d. Bathroom issues
    e. Aggression
        i. Toward parents
        ii. Toward siblings
    f. Preventions
        i. Behavior plans
        ii. Planning
        iii. Medications
            1. Pros
            2. Cons
        iv. Communication
5. Grieving
    a. Loss of normality
    b. Loss of dream
    c. Grieving for spouse

RQ2: How do parents construct their ability to meet society's role standards for parenting?

1. Assessing
    a. Child
        i. Against social norms
        ii. Against typically developing peers
        iii. Against others with ASD
    b. Assessing other parents
        i. Criticize other parents
            1. Other parents not following advice
            2. Complaining
        ii. No follow through
    c. Being assessed by others
        i. Perceived
        ii. Actual
            1. Extended family
            2. Safe spaces
                a. Church
                b. Therapeutic locations

        d. Self-Assessing
            i. Positive
            ii. Negative

RQ3: How do parents construct meaning from the experience of raising a child with ASD?

1. Struggling to adjust
    a. Constant work/struggle
    b. Changing demands
2. Expressing gratitude
    a. Benefits
    b. Blessings
3. Expressing compassion
    a. Others with disabilities
    b. Other parents
    c. Sibling
        i. More compassionate
        ii. Career choice
4. Prioritizing