# THE RECONSTRUCTED SELF:
# UNDERSTANDING THE PRIVATE AND PUBLIC IDENTITY OF A MOTHER OF A CHILD WITH AUTISM

By

Danielle Rene'e Tessen

RECOMMENDED:

Ross M. Imbler, M.A

Karen M Taylor
Karen M. Taylor, Ph.D.

Jean A Richey
Jean A. Richey, Ph.D.
Advisory Committee Chair

Peter A. DeCaro, Ph.D.
Chair, Department of Communication

APPROVED:

Todd Sherman
Todd L. Sherman, M.F.A.
Dean, College of Liberal Arts

John C Eichelberger
John C. Eichelberger, Ph.D.
Dean of the Graduate School

4/25/14
Date

# THE RECONSTRUCTED SELF:
# UNDERSTANDING THE PRIVATE AND PUBLIC IDENTITY OF A MOTHER OF A CHILD WITH AUTISM

A

THESIS

Presented to the Faculty
of the University of Alaska Fairbanks

in Partial Fulfillment of the Requirements
for the Degree of

MASTER OF ARTS

By

Danielle Rene'e Tessen, B.A.

Fairbanks, Alaska

May 2014

# Abstract

The puzzle pattern of the autism awareness ribbon signifies the mystery of life on the spectrum. The spectrum is characterized by the wide range of possible diagnoses of autism. One family out of every 68 is affected by autism. Each shape and color of the puzzle illustrates the diversity of experience for each family and person living with autism. Therefore, the people living the everyday life of autism provide an insightful understanding of how the puzzle pieces fit together. The central focus of this research was the lived experience of the interviewees. Nine mothers of children diagnosed with autism were interviewed. Five themes emerged once the interviews were conducted: (a) public scrutiny, (b) family and friend responses, (c) mother versus society, (d) guilt and stress, and (e) advocacy and networking. Each of these themes represents the stories of mothers who live with children on the spectrum. Each story shared provides the reader with a deeper understanding of mothers' experiences who live with children on the spectrum.

# Table of Contents

## List of Figures

Page

## List of Tables

# List of Appendices

# Acknowledgements

Primarily, I would like to thank my thesis chair, Dr. Jean Richey, who has been my mentor for the past seven years. The true love I feel when I walk into her office has guided me throughout this experience. Jean, you are forever engraved into my heart and soul.

I would also like to thank Dr. Karen Taylor, a member of my committee. Her happiness about life and theories was a breath of fresh air during this process. She strongly encouraged me to participate in the autism community.

My committee member, Ross Imbler, M.A., motivated me to push myself to a higher standard. The humor I perceived in his editing comments was very much appreciated. Through his words of encouragement I believed in my abilities to achieve this level of education.

Each of the relationships in the communication department has shaped my life in a way unimaginable. To my fellow graduate students, we will forever have this memory to share. Each of you has opened my mind and heart to the wonderful world we live in.

To my husband Craig Tessen, your love and support have made my achievements possible. I am more in love with you today because of your reassurance and faith which encouraged me to believe in myself. We survived graduate school together. Now, we know we can make it through anything.

I am beyond thankful for the family support I have received during this journey. To my mother Karen, and bro Kyle, thank you for providing words of encouragement during my entire college career. To my wonderful aunties, Kim and Shanda, I am fortunante to have you both who make me feel so unbelievably special.

To my papa Hubbard, thank you for making me feel the pride my father would have had for me through your support during my undergraduate and graduate career. I am blessed beyond measure to have the Birklid, Hubbard, and Tessen love behind me.

Finally, I would like to dedicate this thesis to my Grandma Glenda Hubbard, the person who first inspired me to push myself to become the woman I am today.

# Chapter 1

# Introduction

*“Intelligence without ambition is a bird without wings." Salvador Dali*

## 1.1 Introducing the Study

I grew up in a big family in a small town and always loved connecting with new people through sharing my family name. I enjoyed being around my family and always looked up to my mom, grandparents, aunts, uncles, and many cousins. After taking a class on interpersonal relationships, I was thrilled to be able to study something that I could directly relate to my life. As I learned about identity construction, I began to realize a big part of my identity involved my connection to my family. I often tried to take the traits I loved from each of them and adapt their qualities to construct myself. My eyes were opened in my undergraduate studies regarding the importance each relationship has on a person. I was overwhelmed by the power people have in each other’s life and soon realized the significance each relationship has on one’s development of self. This is one of the many reasons I fell in love with the field of communication.

During my undergraduate years I enjoyed applying a sociological approach to communication to explore differences people face in day-to-day life. I became fascinated by women and gender studies, which often centralizes embedded power differentials as conditions ripe for social change. The study of critical theory led me directly to another area of social challenge, people with disabilities. Advocacy for people with disabilities became the central focus of my research interest. When I blended women’s studies with social change, my focus shifted over time to an understanding of how a mother advocates for her child when that child has a disability. For me, it then seemed a natural progression to include sociological and communication perspectives. A burning question of mine led me to explore how a mother reconstructs her identity in the face of raising a child diagnosed with autism.

The development of a person's self-identity is continuously being co-constructed throughout daily interactions. During these interactions a person creates a perceived identity through the construction of self. Typically one's identity evolves as a person travels through the many life roles. A young girl begins life as a daughter then becomes a sister who goes to school as a student. Then, she gets a job and is an employee which helps pay her way through college until she is a graduate after which, she will become a career woman. Additionally she may then become a wife who has a child subsequently becoming a mother and then a grandmother. Each role has an expected amount of growth, but what happens when an individual has to quickly reconstruct who they are? What if one of these roles is drastically changed because of an unexpected life-changing event? Every family encounters struggles, but what if the burdens of the family struggle are placed on the mother's shoulders?

### 1.2 Stating the Purpose

A woman's life is forever changed when she becomes a mother who raises her child. In the case with a child who has autism, the diagnosis may come a year or two after the child is born, leaving the mother with unanswered questions in understanding her child's cognitive state. This can be a time of great uncertainty for mothers. The public self-identity of the mother is reconstructed into a new role she may not yet know how to fulfill. The private self-identity will experience change during this time as well. The purpose of this study is to understand the private and public self-identity reconstruction of a mother once she has a biological child diagnosed with autism.

### 1.3 Providing a Rationale

This study is important to me because understanding the experiences of these mothers creates an opportunity for the provision of necessary services. The study will offer understanding of the experience of a mother when her child is diagnosed with autism. Therefore, the understanding or knowledge gained will provide awareness of how to create change and deliver resources for these mothers.

My research will potentially give insight to the mother's conception of self when she has a biological child who is diagnosed with autism.  A woman's experiential knowledge of self as a mother with a child diagnosed with autism may act as a recommendation to others in a similar situation. An understanding of their experience will help create a framework for a more in-depth understanding of identity reconstruction.

# Chapter 2

# Literature Review

*"Autism is not a disability, it is a different ability." Stuart Duncan*

To gain an understanding of a mother's experience a thorough review of literature on autism, identity, and co-culture theory was essential. As the researcher I must note that throughout this study I will be referring to autism by name, the spectrum, or condition. The conscious use of these terms is to deflect the negative connotation that arises when words such as retarded or disorder are used. I will also not use the word normal when discussing neurotypical people (Janzen & Zenko, 2012, p. 22). The word neurotypical is used to replace normal to lessen the stigma of difference. The use of ethical language dissembles the power structure rather than reinforcing the difference through the use of *othering* (Miller, 1982). Ethical language signifies there is a difference, although it does not give a negative implication of a *power* difference. As a communication scholar, I will not refer to autism in the negative connotation because I understand the power of words and choose to take a stand throughout this study.

## 2.1 Autism

*The Diagnostic and Statistical Manual of Mental Disorders 5th edition* (DSM-5) is valuable for this study because it is the guide used by professionals when diagnosing mental disorders (American Psychiatric Association, 2013b). The diagnostic criteria for autism spectrum disorder in the *DSM–5* (2013b) are organized into four criteria:

(a) Persistent deficits in social communication and social interaction across multiple contexts . . .

(b) Restricted, repetitive patterns of behavior, interest, or activities . . .

(c) Symptoms must be present in the early developmental period . . .

(d) Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning . . .

An in-depth representation of the spectrum and examples of the traits are listed at the end of the study (Appendix A).

The definition of autism spectrum disorder (ASD) changed from the DSM-IV to the DSM-5 edition. The new definition is all encompassing of four previously separate disorders. ASD now includes "autistic disorder (autism), Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder" (American Psychiatric Association, 2013a, website). The new definition is a representation of the ever-changing understanding of ASD.

**2.1.1 Myths of Causation.** Leo Kanner named autism in 1943 in his first journal article explaining the new "syndrome" that had never before been documented (Kanner, 1943, p. 242). Around the same time Hans Asperger, an Austrian psychiatrist, worked on diagnosing children with autism traits, but named it Asperger's after himself. These two men are considered the pioneers of autism (Lyons, 2007, p. 2022). Kanner and Asperger gave a name to autism and Asperger's, but they were unable to discover the cause. Theories began emerging to explain the mystery behind cause of the observed behavior. However 70 years after the documentation of the condition there is still no exact known cause. Research has deconstructed the many myths about what causes autism, although numerous myths continue to remain.

**2.1.2 Mother Blaming.** Bettelheim coined the term “refrigerator mother” in the late 1950’s (Simpson, Hanley, & Quinn, 2003). The refrigerator mother theory was published in his 1967 book *The Empty Fortress: Infantile Autism and the Birth of the Self*. He pulled from Kanner’s early discovery that children with autism have highly intellectual parents (Stace, 2010, p.68). The myth that a cold, frigid mother was the reason for a child’s autism was widely believed after Bettelheim (1967) published his theory. The result of having a child with autism was understood to be due to the mother’s inadequate parenting, and the blame was placed solely on her.

In contrast to mother blaming, Sousa (2011) conducted research of memoirs from mothers of children with autism to explore whether the refrigerator mothers myth still lived on. Sousa’s research showed that currently mothers are viewed as warrior heroes rather than refrigerator mothers (Sousa, p. 239). They are expected to devote time, energy, and resources to overcome their children’s disability and to go above and beyond the call of duty to fight the battle against their children’s intellectual disability. The mother is no longer perceived as causing the disability. Consequently, she is expected to help advocate for her child. She must know the medical terminology and research the best possible therapies for her child. She must also possess the many skillsets, which require a vast amount of money, time, and education (p. 239). Although mothers are no longer perceived as refrigerator mothers, today they are expected to take on the many roles essential to providing for their children.

**2.1.3 Vaccinations.** Wakefield et al. (1998) published an article stating there is a positive correlation between vaccinations and regressive autism. The authors claimed they discovered “behavioral regression and loss of communication” (p. 640) in association with vaccinations. It would later be exposed that Wakefield et al. fabricated data to produce an elaborate fraud. Medical licenses were lost and the article was retracted, although the damage was already done. For instance, Rosenberg, Law, Anderson, Samango-Sprouse, & Law (2013) conducted an online survey of families who have a child on the spectrum and their opinion of vaccinations. Rosenberg et al. researched how families with a higher education still believe vaccination to be the leading cause of autism (p. 873). The belief that vaccinations are the cause for autism is still a strong myth in the community, although there is plenty of research that discredits this common belief (DeStefano & Chen, 2001; Miller & Reynolds, 2009).

**2.1.4 Mother's Experience.** Smith, Hong, Mailick, Greenberg, Almeida, & Bishop (2010) proclaim there is a need for family support services for mothers with children on the spectrum (p. 177). In order to understand the experience of these mothers, Smith et al. examined daily accounts of parenting a child with autism (p. 167). They proclaim that the daily stressors that build up over time cause mothers to feel burnt out. Therefore, family services would be beneficial in helping mothers with children on the spectrum to be effective caregivers.

In addition to family services, Ekas and Whitman (2011) found that mothers who have a child on the spectrum experience "elevated levels of distress" (p. 1202). This claim does not mean these mothers are unhappy, but rather that they must adapt to stress successfully in order to have a positive daily experience. Mothers raising a child on the spectrum experience the common stress of daily life; moreover, they also have the stress that comes with raising that child. They found when mothers experience stress in multiple areas, "they are immediately mobilized to seek out support and resources to cope and seek relief" (p. 1210). Ekas and Whitman assert the experience of a mother who has a child with autism is a different experience due to the dissimilar areas of stress. They emphasize that stress becomes less of a challenge when there is a strong support network for the mother.

A study conducted by Rogers, Magill-Evans, and Rempel (2013) examined another aspect that can be challenging when raising a child on the spectrum: feeding. Many children with autism have a hard time eating, which often causes a mother's concern for her child's nutrition. Rogers et al. conducted interviews where four themes emerged. The authors explored the issue through the mother's perspective to understand how they coped with the difficultly of feeding. The results indicated four core feeding issues: "(a) recognition of feeding challenges, (b) defining the . . . challenges, (c) seeking support for validation of the feeding challenges, and (d) staging their approach" (p. 23). Roger et al. suggested that parents need help understanding how to adapt to their child's unique way of eating. Families could work with professionals to help them make decisions on feeding their children (p. 31). The network created to ensure the child receives healthy nutrition can lower the mother's worry on her child's health.

When a mother has a child with autism there will be many different phases she experiences while raising that child. Taylor and Seltzer (2011) examined the relationship between a mother and her child with autism though focusing at the stage in life when the child exits high school. A child diagnosed with autism obtains a vast amount of services during his or her education. Those services terminate when secondary school is completed. The amount of pressure placed on the mother to help her child's transition creates heightened stress in her life (p. 1398). Due to all the changes made at this time the mother-child relationship enters a time of high risk (p.1406). The changes can be hard on mothers due to expectations they have for their child. These expectations are based on where the child is on the spectrum and the life the mother wants for her child, who is now an adult. Granted the transition is experienced differently no matter where the child is located on the spectrum. There is also added pressure from the family that impacts the mother's stress during this transitional time.

**2.1.5 Father's Experience.** Kayfitz, Gragg, and Orr (2010) conducted a study including fathers and mothers in examining positive experiences of having a child with autism. They wanted to include fathers because they are not highly represented in the current literature. The inclusion allowed the researchers to take a look at parenting dynamics. Kayfitz, Gragg, and Orr's findings display mothers experiencing positive feelings about their child at an earlier time than fathers. Fathers were found to be less accepting than mothers in the beginning of the child's diagnosis, and fathers take longer to see their child in a positive light. The survey also showed how mothers view autism:

> Mothers reported more sensitivity and awareness of people with disabilities, greater acceptance of things in life, stronger bonds between family members, greater beliefs in the purpose of all people, and a larger circle of friends than did fathers (p. 342).

The inclusion of fathers in this study allows for a better understanding of the mother's experience when the two are raising a child together. The way a father experiences having a child with autism can greatly affect a mother.

Donaldson, Elder, Self, and Christie (2011) conducted a study on a father's perception of his role during in-home training. Through interviews with fathers in the Elder's Father-Directed In-Home Training (FDIT) they were able to learn about overlapping experiences. Donaldson et al. discovered five different themes: "(a) sharing time, (b) having a close relationship, (c) accepting the diagnosis, (d) concerns of and hope for the future, and (e) benefits of the [FDIT] program" (p. 202-204). Fathers who are involved with programs, such as the FDIT, are able to learn techniques in adapting to their child's needs.

Vacca (2013) conducted a study to examine fathers' involvement. The author examined the barriers that typically inhibit a father's involvement with their child. Vacca discusses the barrier like tactics fathers take part in. These tactics are activities such as being busy with their career, having family related obligations, or their personal feelings. Although it is important for fathers to be a part of their child's life for many reasons, when they are involved fathers reported having higher self-esteem, feeling better as a parent, and also reported having a higher level of satisfaction within their marriage (p. 88). Understanding how fathers' experience having a child with autism helps researchers gain a greater understanding of the family dynamic.

## 2.2 Identity

The epistemology of constructionism viewed through a communication lens places value on interaction and relationships (Richey & Brown, 2007, p. 147). A psychological approach to an identity construction focuses on the behavioral actions and examines the cognitive state in researching a person's self-concept. Self-concept is an interpretation people make about themselves (Christiansen, 1999, p. 548). The difference between a psychological approach and a communication approach is in regard to the actual identity process of construction. The value of a relational approach provides insight to how women reconstruct their identities after having children. A relational perspective on identity construction examines what a women experiences daily after taking on the role as mother. The constructionism framework offers a greater insight as to why the identity construction process may be different when the child is diagnosed with autism.

Miller (1982) presents the unpublished work of George Herbert Mead from the early 1900's. Despite his work using a sociological viewpoint, it still remains foundational to communication work today. Mead began the conversation of the self as being socially constructed in social surroundings. He viewed the self as the "soul and body" (p. 164). The soul and body live together through experience, and the "emergence of the self" develops through the social process (p.165). Mead's study of symbolic interaction (Blumer, 1986), social psychology, and the nature of self (Morris, 2009) comprise an understanding of identity being constructed through interaction. Mead's original ideas continue to apply when studying identity.

In contrast to a social self-perspective, Miller, Potts, Fung, Hoogstra, & Mintz (1990) use Goffman's dramaturgical model of the self to explore the value of stories in the identity development process. Miller et al. examined the social construction of self in childhood through narrative practices. When a person tells a story about his or her self, their identity is continuously being constructed throughout the story. These stories then become internalized and construct the identity of self. Miller et al. were most interested in studying this at the beginning of one's life as a child in order to examine how it becomes important during the process of self-construction. Narrative practices were examined because they are universally common across different cultures (p. 292). Telling stories about the child in the child's presence occurs very often which makes it important to study (p. 296). The telling of stories about children is an important part of the construction process because the child internalizes the story and takes on the identity found in the story. This can be seen as reinforcing the notion of a self-fulfilling prophecy. They also examined the effect when a child tells a story occurring of a personal experience and the caregiver intervenes during the story to either correct the story or add to it (p. 299). The intervening process demonstrates to the child how to correctly interpret the event or past experiences. Miller et al. focus on the importance of storytelling and the notion of co-constructing one's identity with the caregiver through storytelling. The research findings reinforce that identity is a process which cannot be fully achieved without others.

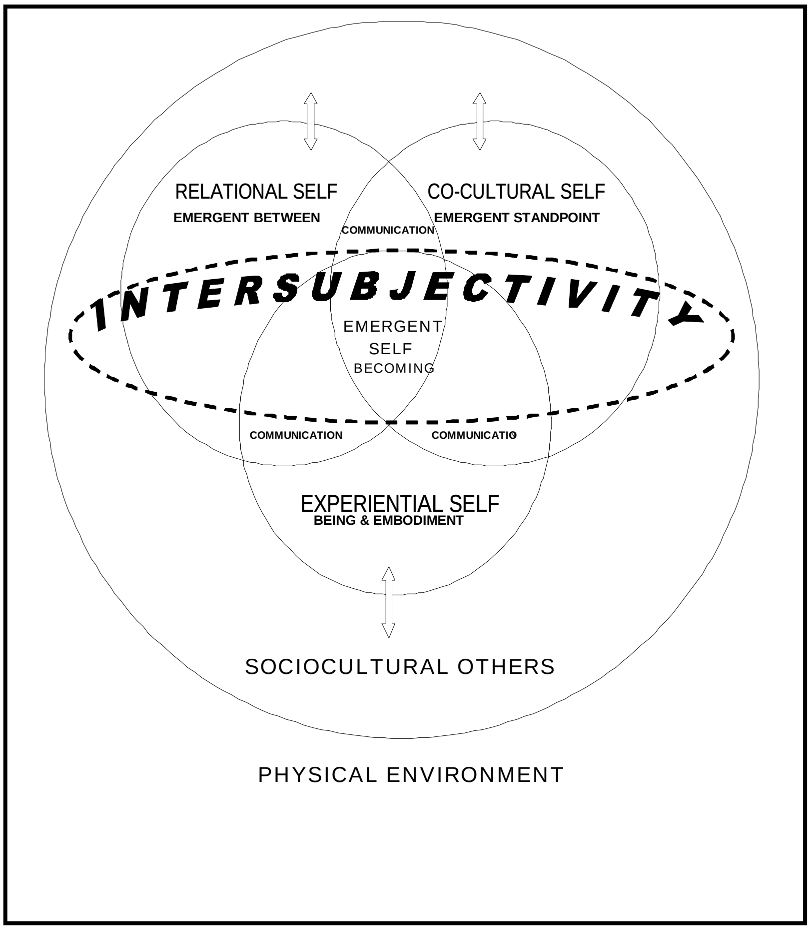
Carbaugh (1996) examines the question, "who am I" by looking at different factors contributing to a person's identity. Carbaugh defines the common understanding of identity as biological, psychology, cultural, and social structure (p. 24). Carbaugh examines these entities through a communicative approach drawing from symbolic interaction. He explores the private and public self through five common American cultural contexts: (a) public leisure (p. 39), (b) work (p. 63), wedding and marriages (p. 89), gender and the "talk show" (p. 123), and community's land-use controversy (p. 157). These scenes examine how a person's identity adapts to their surroundings. The change in identity based on one's surrounding demonstrates the difference between one's private and public identity. An identity change based on the surroundings completes how people construct their identity based on surroundings.  Later, Carbaugh and Brockmeier (2001) examine narrative identity construction to continue the idea of identity being a combination of factors. One must examine multiple aspects of identity due to its adaptive nature. To explore people's identities, their narratives must be taken into consideration (p. 15).

Gergen (1993) examines the construction of self through his many published works. Gergen views reality as a co-construction achieved through interactions. Gergen and Kaye (1992) explore the use of therapy in narrative meaning. With an emphasis on a constructionist orientation, Gergen and Kaye examine how to reconstruct one's viewpoint in order to create new meaning within the therapeutic setting (p. 258). This reconstruction represents the significance of interaction and its effect on a person's self-identity. A person can have her or his narrative, but that narrative also becomes reconstructed through interactions with others. Continuing with this idea, Gergen (2009) explains the many elements making up social construction. Gergen explores the relational self through the constructionist standpoint. It is within relationships that people construct words and meaning (p. 3). These relationships are where the process of "jointly constructing meaning" takes place (p. 120). Gergen's work on social construction continues to adapt its application to be directly applied to everyday life. Nevertheless his work does not create a manual of the social world, rather an invitation to understanding social construction.

Richey and Brown (2007) take the elements of prior ideas from Mead's social self and Gergen's work on identity to develop the emergent self-model (Figure 2.1). The emergent self-model places a strong value on a person's experiences, relationships, and cultural self. First, the *experiential or existential self* is the self-experienced during an interactive moment. Second, the *relational self* is constructed through interactions within a person's relationships. Lastly, the *cultural self* places value on one's standpoint within society and one's co-cultural affiliations (p. 147).

Adopting the emergent self-model displays how social construction works within each person’s “natural and social world” (p. 152). To look at identity construction as occurring through the experiential self, relational self, and cultural self allows for a deeper understanding of the elements behind the identity construction process.

Once a woman has a child and begins to experience life as a mother, her identity will reconstruct to the new role. As a mother adjusts to her new role, she will interact with new people throughout her journey. The interactions will construct her relational self as she connects through her social networks. The new relationships will mold the mother to fit into the cultural expectation of the *good mother* role. Identity construction is an ongoing process affected by a mother’s daily interaction. Therefore, identity reconstruction relies on building relationships (Richey & Brown, 2007). When a child is diagnosed with autism, the mother connects with like others to find her way throughout this new world. As she meets new people, she will rely on the relational self to construct her new role. If she experiences disapproval, it will affect her view of herself as a mother. The mother’s experiential self, relational self, and cultural self will experience identity reconstruction to fit into her new role, a biological mother of child diagnosed with autism.



The Emergent Self: Modeling the Social Construction of Identity

(Richey & Brown, 2007)

Figure 2.1

**2.2.1 Identity and Mother.** Collett (2005) conducted a study pertaining to the social construction of mothers and how mothers shape their impressions of other mothers. Collett posits that a woman becomes a mother by giving birth, but it is not until she plays the socially defined role that is visible to society that she truly takes on being a mother as her identity (p. 328). Through the interview process Collett reveals the importance of social construction and how one may use impression management to fulfill a positive social role. The self-presentation of playing the role as a good mother gives the opportunity to appear as the mother they aspire to become, while also building their identity as a mother (p.330). In her research, Collett found that appearance is a large piece in constructing one's identity. Dressing a child in clean new clothes revealed to be a direct reflection on the mother's self-presentation rather than the child's (p.343). Collett's research demonstrated that women who do not have the resources to dress their children in nice new clothes and who continue to compare themselves to those who do, develop a negative feeling toward their identity as a mother.

Heisler and Ellis (2008) conducted a study to examine if mothers' need to publicly portray a "good mother" appearance in society to feel as if they are in fact acting as a good mother (p. 447). The researchers adapted Goffman's (1967) research on facework to examine how mothers portray their image. Goffman's (1955) idea of facework is based on interactions with others through verbal and nonverbal acts. Heisler and Ellis (2008) found the most common theme throughout their study was: *motherhood is my priority* (p. 455). This finding represents how a mother places her child's needs above her own needs. Heisler and Ellis also detected a mother's need to show they are being a "good mother." Three themes emerged from this idea: (a) interactions with children, (b) children and their accomplishments, (c) sacrificing personal needs versus balance (p. 463). These findings suggest mothers establish the identity as a "good mother" through interactions with others. The findings show the importance of others in a mother's construction of self during the "actor and observer" interaction (p. 463). The identity of becoming a mother occurs over time through interactions with other people.

**2.2.2 Identity and Disability.** A study conducted by Canary (2008) explored how individuals construct disability and ability within the family setting. The study relies on the idea of co-constructing knowledge and how it creates one’s identity. The construction of self begins at a young age in children. Canary states that children with special needs are no exception to this process (p.440). The purpose of the study was to examine communication by interviewing four families who have a child with a special need. Canary wanted to observe how the notion of ability and disability are used within the family setting throughout daily interactions. Canary’s findings suggest that parents need to have more information on their child’s disability to understand what living with that disability means for daily living. Having the correct explanation of the child’s ability, inability, and behavior can give the parents a foundation upon which to create their home (p.454). Gaining more knowledge can give the family the opportunity to build a child’s ability rather than just focusing on his or her disability.

Duggan, Bradshaw, and Altman (2010) studied the communication process involved when medical students ask about a patient’s disability. They found it was often up to the patient to be a self-advocate about his or her disability. This is due to medical students not receiving the proper training on how to deal with the social side of the medical issue. The students who did not have experience with people with a disability often found it hard for them to ask about the patient’s disability.  This opened the door for future education for the medical students regarding how to effectively communicate when interacting with a person who has a disability. Reluctance to breach the topic afterword relates to lack of exposure with people who have a disability.

## 2.3 Theoretical Perspective

In society, people continuously network with one another throughout daily interactions. These groups that form in society through networking consist of people from all different backgrounds. Consequently, these experiences are in association with the group to which the person is connected. A representation from each of the groups allows a greater understanding to how groups interact (Orbe, 1998b, p. 20). The dominant society consists of a small group of powerful people. The dominant group is primarily Anglo, economically affluent, Christian, heterosexual (Kramarae, 2005, p. 56). The rest of society encompasses many different marginalized groups. Marginalized groups are on the outer regions of the dominant society. In order for society to function properly, the groups must be able to interact effectively day to day. The combination of Kramarae's muted group theory, Harding's standpoint theory, and Orbe's co-culture theory constructs a foundation in understanding how different groups interact daily.

**2.3.1 Muted Group, Standpoint, & Co-Culture Theory.** Kramarae (2005) suggests that marginalized groups have plenty to say although they have "relatively little power to say it" (p. 55). Muted group theory is based on the voice of the marginalized being silenced. Therefore, the dominant groups are heard and continue to enforce common language practices. However, it is the experience of the muted people or group that gives a better understanding to how society functions. Both muted group and standpoint theory overlap with the idea of societal hierarchies (p. 58). Standpoint theory functions complementarily with muted group by examining how people label themselves through language.

A more in depth examination of Kramarae's foundational ideas began with standpoint theory. Harding (1991) centralizes the social world as a stratified hierarchy. Each person enters into social life from her or his own unique social standpoint. A person's standpoint, or perspective on understanding the world, is unique as the person is unique, but is also predicated on social factors. Standpoint theory explains how a person understands the world. Marginalized people develop a greater understanding of society because of the multiple perspectives from which they must negotiate. The different perspectives of people come from different social entities. A person's race, ethnicity, sex, gender, sexual orientation, and class are all social entities, or intersections, that contribute to one's standpoint (Crenshaw, 1993). These different aspects of a person's standpoint affect one's ontological and epistemological orientations, creating many different standpoints within society. Through a social constructionist lens these social entities organize the structure of society. A person's reality and identity are created through social interactions and intersections, their standpoint is connected to the social identity and affects the way in which one views the world around them. As a result, each person's world and reality looks different depending on their social standing in the world (Orbe & Kinefuchi, 2008).

Viewing women as a marginalized group focuses on the differences between women and men. This separation is created from cultural expectations on how society views the role of women. The social construction of gender identity places women as the marginalized group. This viewpoint underscores women as disadvantaged in comparison to men who are privileged in the gender difference. Harding and O'Barr (1987) explains that "biology does not explain the shape of society, rather society explains the shape of biology" (p. 125). Harding argues women's roles in society are viewed as less dominant due to the roles in which society places them.

Co-culture theory (Orbe, 1998b) builds on both Kramarae's muted group theory and Harding's standpoint theory. Through adoption of the key components of muted group and standpoint theory, co-culture theory develops these two foundational theories. For example, Orbe (2005) explores how marginalized groups communicate with the dominant society through the mechanisms of a silenced group member (p. 65). Orbe's co-culture theory strengthens muted group theory through examination of how the interactions occur:

> How existing power dynamics create a muted group framework but how individual and small collectives worked together to negotiate their muted group status . . . to shed light on the various ways in which persons reinforce, manage, alter, and overcome a societal position that renders them outside the centers of power. (Orbe, 2005, p. 65)

Orbe (1998a) presented the co-cultural communication theoretical model (Table 2.1) to describe how people "within oppressive dominant structures" communicate (p. 1). The mindful terminology change from muted groups to co-culture was made to shed a positive light on the topic and to "avoid the negative or inferior connotations of past descriptions" (p. 2).  The change to co-culture emphasizes the notion that no culture is superior to another.

| | Separation | Accommodation | Assimilation |
|---|---|---|---|
| Nonassertive | Avoiding<br>Maintaining Interpersonal Barriers | Increasing Visibility<br>Dispelling Stereotypes | Emphasizing Commonalities<br>Developing Positive Face<br>Censoring Self<br>Averting Controversy |
| Assertive | Communicating Self<br>Intragroup Networking<br>Exemplying Strengths<br>Embracing Stereotypes | Communicating Self<br>Intragroup Networking<br>Utilizing Liaisons<br>Educating Others | Extensive Preparation<br>Overcompensating<br>Manipulating Stereotypes<br>Bargaining |
| Aggressive | Attacking<br>Sabotaging Others | Confronting<br>Gaining Advantage | Dissociating, Mirroring<br>Strategic Distancing<br>Ridiculing Self |

Co-culture Communication Orientations

Table 2.1

Orbe (1998a) organizes co-culture interaction into, (a) communication practices, and (b) communication orientations. The twofold categorization allows for the definition of specific communication behaviors “from the standpoint(s) of co-cultural group members” (p. 8). These two factors allow for a greater understanding of interaction without making one group superior to the other. As seen in table 2.1, Orbe’s range of orientations consists of specific behaviors that represent a person’s communication style (e.g., nonassertive, assertive, and aggressive) and approach (e.g., assimilation, accommodation, and separation). For example the application of Orbe’s (1998) model to a mother who uses an assertive communication style and an accommodation approach will result in intragroup networking with other mothers who have children with autism. The assertive style and accommodation approach also results in the mother educating others about her child's needs while also creating new relationships. The table gives an understanding to how a mother's communication approach and style constructs her actions.

Part (a) of Orbe's (1998a) twofold categorization of culture interaction, communication practices, consist of six influential factors: (a) preferred outcomes, (b) field of experience, (c) abilities, (d) situational context, (e) perceived costs and (f) rewards (Orbe, 1998a, p 8-14). Preferred outcomes are based on the desired result of the interaction. Orbe states there are three primary paths a person in a non-dominant position will take in order to achieve a preferred outcome: assimilation, accommodation, and separation (p. 10). The communication practice field of experience affects a person's interaction process due to past experiences. Throughout life co-culture members experience the different ways to interact with dominant society. Over time a person builds her or his bank of knowledge to draw upon when they interact with dominant group members. The communication practice abilities pull from a person's ability to "use other co-culture communicative practices" (p. 11). This communication practice builds on the ability to use certain communication styles. In addition to communication style the situational context a gives meaning to the interaction. Power relations shift throughout the day resulting in different communication practices during the day. The shift involves the surrounding members of each co-culture at the time of interaction as well. The perceived costs and rewards in an interaction is a communication practice choice used to weigh the pros and cons. The combination of the six universal influences provides a full picture of Orbe's co-cultural theory.

Communication practices, part (b) of Orbe's (1998a) twofold categorization, combine preferred outcomes with communication approaches to classify nine main co-cultural communication orientations (p. 15). These nine classifications include: (a) nonassertive assimilation, (b) assertive assimilation, (c) aggressive assimilation, (d) nonassertive accommodation, (e) assertive accommodation, (f) aggressive accommodation, (g) nonassertive separation, (h) assertive separation, (i) aggressive separation (p 15-19). Each provides a unique way co-cultures choose to interact with dominant structures and a greater understanding of how co-cultures interact with dominant structures. The communication practices in association with the co-cultural orientations construct a framework in order to research co-cultural relationships. Orbe (1998a) states there is no correct way for a co-culture to communicate with dominant society (p. 19). As such, a framework such as co-culture allows for the study of interaction without privileging a hierarchical difference.

The different communication methods used when interacting with dominant society provide insight to a co-cultural member's experience. The gaining of knowledge on co-cultural experiences provides insight to society. Gaining valuable knowledge on how co-cultures experience the world allows for a better understanding of how society functions.

## 2.4 Summary and Conclusion of Literature Review

To be adequately educated, it is imperative for the researcher to conduct an in-depth investigation in order to understand both the history behind their topic and current research being conducted on their topic. Through examination of autism, identity, and co-cultural theory I was able to further my understanding about a mother's experience of raising a child diagnosed with autism. My need to gain an understanding of autism was a critical prerequisite for learning about the lived experience of the mothers. Researching identity construction furthered my knowledge base on the re-construction phase that occurs when a woman becomes a mother, and then a mother of a child on the spectrum. Lastly, applying a communication approach with co-cultural theory builds a foundation for understanding their experience through a theoretical approach.

## 2.5 Research Questions

Using the overarching theme of social construction, I conducted a literature review on autism, identity construction, and theories related to networking. Staying true to a constructionism epistemology I was able to narrow my focus to the lived experience of a mother when she has a child diagnosed with autism. I examined past literature that explores the impact felt by these mothers based on societal norms, and how it affects their self-identity. In doing so I developed the following research questions:

**RQ1:** What are the lived experiences of mothers who have a child diagnosed with autism?

**RQ2:** (How) Does having a child diagnosed with autism affect the private and public self-identity/lived experience of the mother?

# Chapter 3

# Research Methodology

*"If you judge people, you have no time to love them." Mother Teresa*

To better understand the scope of the research conducted it is essential to discuss the framework used by the researcher in the study. When exploring the experiences of mothers whose children have autism, particular frameworks are chosen to best shed light onto their lived experiences. The following is an exploration of the methods used in conducting research for studying the experience of a mother who has a child diagnosed with autism.

## 3.1 Methods

**3.1.1 Conversational Interviews and Procedures.** Kvale (1996) provides potent insight on the interview process with the question: "If you want to know how people understand their world and life, why not talk with them?" (p. 1). It is through conversations that people are able to learn about the life experience of others. Conversations allow people to gain an understanding of another person's view of the world. This technique can be used as a research method to uncover the lived experience of a person, though conducting an interview requires more than simple conversation. In order to interview effectively, the researcher must have the conversational skills and knowledge on the methodology backing the approach. The researcher must have the ability to gain trust and credibility with the interviewee through careful questioning and listening. The researcher must also be able to follow up on answers and seek to clarify the interviewee's statements in order to understand the experience of the interviewee. Conversational interviews are a "craftsmanship" that require learning the correct skillset (Kvale, 1996, p. 104). To gather the experience of the interviewee, the researcher must be “knowledgeable, sensitive, and empathetic of the interviewer” (p.105).

**3.1.2 Research Participants.** Each step throughout this study was in line with the rules and regulations put forth by the Institutional Review Board (IRB). After approval for this study, interviews were conducted with nine adult women who are the biological mothers of a child with autism. The selection criteria for participants were adult women 18 years and older who are the biological mothers of a child diagnosed with autism. The selection specifically excludes adolescents, adoptive, and foster mothers. Participants read the informed consent prior to the interview to understand the parameters of the study’s objective (Appendix B). To help protect confidentiality and anonymity, participant recruitment was conducted using fliers posted at various autism-related venues along with non-autism-related venues around Fairbanks. Participants were assigned a pseudonym to protect their identity, as well as not explicitly stating their job positions. The interview method was conversational and relied on open-ended questions. The interview time ranged from one hour to ninety minutes. The interviews took place in a private setting at the convenience of the interviewee, ranging from an isolated consultation room in the Department of Communication, the interviewee’s home, via Skype, or a private setting in a public venue. Before the interviews, a thick description detailing the setting was recorded and notes were taken throughout the interview. Interviews were digitally-recorded using two audio recorders. Immediate transcription followed the interviews. The transcription process involved assigning a pseudonym to each participant to protect confidentiality and anonymity.  Audio-recordings were deleted directly following the transcription. The transcriptions were kept in a secure location in the Department of

Communication during and after the research. The use of thematic analysis was then conducted on the interview data. The thematic analysis involved a review of transcripts for common ideas and repetition of themes. The most central then became the findings of the study. Discussed with academic research support and theory, the findings were then analyzed.

## 3.2 Epistemological Framework of Constructionism

To better understand the methods, procedures, and participants, it is necessary to now discuss the framework in which the study was conducted. A theoretical framework, or one's epistemological viewpoint, gives structure to a person's interpretation of the world around them. The framework is essentially how a person "knows what they know" (Crotty, 1998, p. 3). The epistemological foundation for this study is constructionism, or as Creswell (2007) states, constructivist (p.63) (some social scientist researchers use this term interchangeably). In constructionism epistemology knowledge is viewed as a co-construction between people through interaction. Unlike the objectivist epistemological standpoint, where the researcher is seeking to discover truth in the world, constructionism provides insight into an individual's experience. The constructionism framework focuses on the meaning constructed in the interaction between people. It is an entity that cannot be discovered on its own out in the world (Crotty, 1998, p. 9).

The epistemological contexture of constructionism views the world through an interaction-based reality. As Creswell (2013) states, researchers are able to study each person's lived experience because "individuals seek understanding of the world in which they live and work" (p. 24). A researcher can gain knowledge through interviews with a person who experiences a phenomenon of interest, such as autism.

The constructionist epistemology views knowledge as being constructed between people, therefore this study collected data through conversational interviews. Conversational interviews were chosen because they allow for a greater understanding of the experience of mothers who raise children with autism. The goal of constructionism is to gain knowledge of a person's interpretation of a situation. Through conversation the researcher examines meaning as being "formed through interaction with others" (p. 25).  The goal of a researcher is to gain insight on the worldview of a person's experience. Van Manen (1990) describes the lived experience as "lifeworld" (p. 182) and "lived meaning" (p. 183), which is the way a person interprets the world around them.  In order to obtain the interviewee's lived experience, the researcher co-creates meaning through interactions. Moreover, according to Kvale and Brinkmann (2009), interviewing is a "process where interviewer and interviewee through their relationship produce knowledge" (p.17). This knowledge allows for the researcher to understand the essence of the interviewee's experience.

### 3.3 Theoretical Perspective of Interpretivism

The theoretical perspective is the researcher's position of understanding "what is" (Crotty, 1998, p. 10). Theoretical perspective is the philosophical stance behind the methodology of a study. Extended from constructionism, the theoretical perspective of interpretivism seeks to understand a person's reality. As stated by Crotty (1998), interpretivism "looks for culturally derived and historically situated interpretations of the social life-world (p. 67). Interpretivist research seeks to understand human behavior individually rather than to generalize. Geertz (2008) describes interpretative perspective as paying attention to all areas of "social scientific interest” in order to capture the correct essence of the experience (p. 22). In turn, gaining an understanding of the phenomena requires consciousness of the framework under which the research is conducted.

The constructionist-interpretive paradigm contains the researcher’s epistemological, ontological, and methodological frameworks (Denzin & Lincoln, 2008, p. 31). In short, one cannot explore the researcher’s packaged knowledge without accepting the chosen method for the research. Each intertwining of knowledge of the researcher directs the chosen method for the research. For this study, the epistemological standpoint of constructionism dictates relativist ontology of there being more than one reality. This understood reality is constructed during the co-creation of meaning through conversation in the natural world (p.32). Therefore, the theoretical framework behind the research predicts the chosen route for the study.

### 3.4 Research Methodology of Phenomenology

Qualitative research methodology places the framework, e.g. constructionst, and the research perspective, (e.g., interpretivism), into practice. Methodology is driven by theoretical framework and perspective. Crotty (1998), states that constructionism and phenomenology are unavoidably “intertwined,” and therefore, the methodological foundation for this research is phenomenology (p. 12). The goal of phenomenology is to capture the “essence” of the phenomenon or experience (Creswell, 2013, p. 82). The objective is not to impose meaning, but to gain understanding through detailed observation. Phenomenology seeks to understand the deeper meaning behind everyday life (Van Manen, 1990, p. 9) in order to capture the essence of the lived experience (Creswell, 2013, p. 105).

Setting aside bias during phenomenological research is achieved through "bracketing" (Creswell, 2007, p. 59). Bracketing benefits the research by taking what participants describe at face value without imposing meaning. In this study I had to bracket in order to establish validity to properly unpack the phenomenon. Zenobia, Chan, Fung, and Chien (2013) suggest the researcher should practice bracketing throughout the entire research process and not just during the data collection and analysis phase (p. 3). As a researcher using bracketing I practiced this method of awareness throughout my research rather than only practicing at the end. I was aware of my preconceived notions from the start and practiced not asking leading questions during the interview phase. Each researcher is a product of his or her own experience, therefore bracketing allows for the phenomenological research to be conducted ethically and without one's own interpretation. Kvale & Brinkmann (2009) describe bracketing as "an attempt to place the common sense and scientific foreknowledge about the phenomena within parentheses in order to arrive at an unprejudiced description of the essence of the phenomena" (p. 27). Bracketing allows for an understanding of the lived experience without the researcher's own bias and interpretation coming into play.

A phenomenological perspective includes a focus on the life world, an openness to the experiences of the subjects, a primacy of precise descriptions, attempts to bracket foreknowledge, and a search for invariant essential meanings in the descriptions (Kvale, 1996, p. 38). To understand the experience of mothers who have a child diagnosed with autism, I must place my own foreknowledge aside in order to examine the mother's experience.

**3.4.1 Objectivity and Researcher as the Research Instrument.** Reflexivity is important in human inquiry because the researchers account for their own role in the social setting. Researcher reflexivity is the process whereby researchers are conscious of their own bias, values, and experiences they bring to the study and make them explicitly known throughout their research (Creswell, 2007, p. 243). As the researcher for a study conducted on autism, it is important for me to represent researcher reflexivity by making my bias, values, and experiences transparent. My constructionist framework inspires my belief in the inclusion of people with disabilities, especially at a young age. I understand the need for early intervention, the importance of therapy, and the need for special education classrooms; however, there is a greater societal gain when people with disabilities are included. When people with disabilities and people who are neurologically typical work together side by side, a positive benefit is experience by both students, and for the greater good of society. The children are able to develop an understanding of themselves and others in the diverse classroom, therefore providing an opportunity for friendships and understanding to blossom.

Another aspect I should make transparent is my involvement with the autism community outside of this study. In October of 2013, I became a board member in Alaska for the Autism Society Association. I value being a board member of an organization focused on autism education, advocacy, services and support. When there is positive action taken in these areas, people in the autism community gain the opportunity for equity. I am aware of the value I place on networking, therefore I actively watch for my bias on this topic throughout this study. Over the years I have also volunteered for a local support group known as Wall Busters. Their mission is to educate and advocate for the removal of the barriers of independence for people with disabilities. By getting to know the members and hearing their testimonies I was able to place a face to the issues experienced in Alaska. My awareness of these beliefs and values constructs creditable researcher reflexivity because I am continuously bracketing my bias.

Objectivity can be evasive to the qualitative researcher. The researcher must describe the event without interpretation in order to achieve objectivity. Thick description adds to the reflexivity process by describing the observable relationships between social practice and systems without interpreting their meaning. Creswell (2007) describes thick description as a way to ensure the researcher is transferring the data correctly (p. 204). Thick description confirms that the researcher is able to connect to the meaning behind the interviewee. When I, the researcher, am able to remove myself, to the best of my ability, through bracketing and thick description I am then gaining shared meaning, or intersubjectivity. Lindlof and Taylor (2011) define intersubjectivity as the way humans share their life world effectively with others (p. 37). When I interviewed the mothers for this study we created meaning together during our interaction. Together we created shared meaning as they explained their experiences of raising children with autism. Intersubjectivity allowed for me, the researcher, to gain a better understanding of their experiences. A full interpretation of the experience is gained when the researcher is able to be removed successfully while creating shared meaning. Practices such as bracketing, researcher reflexivity, and intersubjectivity certify the researcher is able to refrain from the natural human act of interpretation.

Unlike positivist research, interpretivists must represent validation in deep description. One way to show validity is the practice of triangulation. Denzin and Lincoln (2008) define triangulation as a use of multiple methods to gain an understanding of the phenomenon in question (p. 7). This combination of methods, empirical materials, and perspectives lends richness to the inquiry and can lead to a deeper understanding. The "multiple forms of evidence" construct a representation of the experience (Lindlof and Taylor, 2011, p. 274). In this study, my committee contributes multiple perspectives to fulfill a deeper understanding of the phenomena being researched. Each committee member has different experiences and backgrounds that bring forth a diverse perspective.

I practiced a form of triangulation called crystallization, which expands triangulation to include researcher reflexivity by utilizing different viewpoints on the same topic (Denzin & Lincoln, 2008, p. 7). Built on traditional qualitative research methods, Ellingson (2009) describes crystallization as a method for the researcher to show a rich understanding of the human experience. As a metaphor of a crystal, this framework represents the self-reflection of the researcher on his or her research. Crystallization is represented in this study through my process of (a) interviewing mothers who have children with autism, (b) transcription of the interviews, taking notes before, during, and after the interviews, (c) thick description of the data, and saturating myself in the data to find emergent themes as well as (d) inclusion of the diversity of thought among my committee, and (e) reflexivity of my role as the researcher (Ellingson, 2009, p. 10).

**3.4.2 Validity and Reliability.** Kvale (1996) defines validity as "the truth and correctness of a statement" (p. 236). The statement, or data, constructed during interviews must be correct in order to represent the standpoint of the interviewee. Validity in qualitative research represents the researcher's accuracy throughout the research process (Creswell, 2013, p. 201). It is essential to ensure the correctness of the data because it represents the integrity of the study. In order to achieve validity the researcher employs validation strategies. In this study, I followed validation strategies such as multiple and rigorous methods (e.g., interviews, audio recordings, transcriptions, thick description), having others review my procedures (e.g., my committee members, outside source), and awareness of my role as the researcher (e.g., bracketing, researcher reflexivity) (Creswell, 2007, p. 44). Strategies such as these guide the researcher to validity through the use of different sources to expose a hidden theme for the researched phenomena (p. 208). The practice of crystallization ensures that validity is achieved throughout the study.

In qualitative research, reliability cannot be conceived as it is in the positivistic research epistemology. In my study I relied on the interviewee and their credibility as being a mother of a child diagnosed with autism. Qualitative reliability represents the researcher's consistency throughout the research (e.g., displaying researcher reflexivity throughout the entire study) (Creswell, 2013, p. 201). Reliability in qualitative research is represented through the idea of "multiple changing realities" (Lindlof & Taylor, 2011, p. 272). Each person has an experience that is unique to their life and so their experiences are unlike anyone else's. Due to this, replication of the study may not turn out the same as it often does in positivistic research. The researcher must also display trustworthiness throughout the study through consistency. Kvale (1996) defines reliability as the "consistency of the research findings" (p. 235).

**3.4.3 Lived Experience.** Phenomenological research focuses on the lived experience through interview research. Van Manen (1990) conceptualized lived experience as the attempt to understand and interpret what occurs in people's lives through description (p. 25). Interview research constructs the researcher endeavor to understand how individuals navigate the events they experience. Knowledge is co-constructed during the interview process between the researcher and participants. Kvale and Brinkmann (2009) describe interviewing as an "active process" where the researcher and interviewee construct knowledge together (p. 17). The goal of the interview research is the production of new knowledge based on the lived experiences of the research participants. Due to the fact that the validity of qualitative research, including interviews, is often called into question, "the craftsmanship and credibility of the researcher becomes essential" (Kvale & Brinkmann, 2009, p. 248). As a result, when conducting interviews, one of the main goals of the researcher must be eliciting thorough descriptions of lived experience from which conclusions can be drawn.

## 3.5 Methods of Analysis

Thematic analysis was used in organizing the data for this research. I became saturated in the data throughout the process of conducting research. I immersed myself in the research through examination of the data several times for the thematic clusters to emerge. Throughout this process many themes and sub themes were noted. I shared my data with my committee members in order to stay true to the crystallization process due to my level of saturation. The process of recognizing themes was integrated into the research process using a researcher notebook and highlighting significant statements during the transcription. Through the use of color coding, I organized each theme and sub theme to distill major themes. A completed description of this data is in chapter four.

### 3.6 Summary and Conclusion of Methods

While studying the experiences of mothers who have children diagnosed with autism, I implemented particular methodological standpoints to highlight their experiences. The epistemological framework of constructionism set the foundation to view the world through an interaction-based reality. Constructionism then led me to collect data through conversational interviews. While conducting interviews I used the theoretical perspective of interpretivism, which seeks to understand human behavior rather than predict it. My research framework of constructionism and interpretivism then rooted my methodology choice of phenomenology and placed it into practice through the method of conversational interviews. Throughout the entire research process I continuously practiced researcher reflexivity and understood my role as the research instrument.

# Chapter 4

# The Interviews

*"Be brave enough to start a conversation that matters." Margaret Wheatley*

For my research I used conversational interviews to further explore the identity reconstruction that occurs when mothers have children diagnosed with autism. Interview questions guided the conversation to gain an understanding of how mothers experience this phenomenon. As the researcher, I am aware that I am the research tool. This awareness was used to set aside my own beliefs in order to represent each mother's experience in the form in which she shared. The following is a compilation of nine mothers' stories shared to explore their journey in having a child on the spectrum.

## 4.1 Tori's Story

Tori is a 52-year-old Alaska Native mother of a 14-year-old son on the spectrum who was diagnosed at age two. I first spoke with Tori on the phone when she contacted me about my study. I felt an initial connection with her as she spoke in a soft voice and had an easygoing nature about her. We set up a time to meet to discuss her "life on the spectrum," as she called it. I drove to Tori's house at 11 a.m. the following Saturday morning. I was nervous during my drive to her house because Tori was my first interview, however, the nerves all went away once she opened the door and invited me into her home. As she greets me with a big smile all my butterflies drift away. We walk up her stairs and her son, Robert, was running down the hall and being very vocal. Tori looks back at me with a disarming smile: "There is Robert." Robert continues down the hall into his room where he remains for most of the interview, while Tori and I find a seat at the kitchen table. Tori sips her coffee and we go over the consent form and began the conversational interview.

**4.1.1 Before Diagnosis.** Interviewer: Can you describe when you first became aware of your child's autism.

Tori: I knew we were going to have a problem with Robert because I was not supposed to have any more biological children, and so I was a medical student at UAF and one day I was working out and I couldn't breathe, it was two weeks before I was going to have my tubes tied, so I went into the doctor and was freaked out because after a four mile run . . . I could not breathe and the doctor said that sometimes this happens to pregnant women and I was like no no no.

Interviewer: This is when you found out you were pregnant with Robert?

Tori: Yes, and so I went in and found out I was four months pregnant.

Tori continued to explain the transition that occurred from her son having the expected orthopedic issues, to the realization that he may have autism as well:

> They could see he had issues with his leg, and so we went to a clinic in Anchorage for all of my prenatal care and there was all kinds of complications on his leg, it was missing some bones and then there was problems with the placenta and where the placenta attached to the body so we knew he was going to have orthopedic issues. He has a condition called phocomelia, which is an orthopedic anomaly of certain areas, so before he was born we had the genetic mapping done to see if anything else was wrong . . . and everything showed up good. So he had his first major surgery at two weeks before he was one and we had early intervention come and do physical therapy and work with him

> and do minor things. At nine months they documented that he had a vocabulary of 50 words, and I didn't think that was unusual because his brothers started talking at three months, and so he had the first major surgery and when we got home, he didn't talk.

I follow up by inquiring why she thought he wasn’t talking. Tori describes the realization by saying:

> It was like he was deaf, and I was thinking okay he is just zoning on the narcotics from his surgery . . . but then he started doing weird things with his toys at home, he wanted to hear the plastic toys hit the wall or the window, and it was like an obsession for all the toys to be like that, and then someone popped a balloon by him, and it was like he was deaf, he didn’t even flinch or move.

I ask Tori if she thought Robert had a hearing issue, but she elucidates that she was a pre-med major and had taken a lot of psychology classes when she was in college. Her education prior to having Robert informed her about autism: “I was noticing the signs of autism . . . and when the hand flapping and the stemming started, I began freaking out.” I ask what she meant by “freaking out” and Tori describes it as “panic.” Tori digs deeper into her experience by explaining the diagnosis process and her family life during that time:

> It was almost 12 years ago. My grandmother raised me and she was very ill at that time, she was 102, but I knew something was going on with Robert so we had the Children's Hospital from Seattle do a screening. My Grandma died at the end of March, we get this initial screening that he most likely has autism, and my mom died in June, and so I was stuck in this grief mode. Then in

> September of that year before he turned two . . . he got a solid autistic diagnosis, which the doctor was not giving out at all at that time.

**4.1.2 After Diagnosis.** According to Tori, after Robert's diagnosis they "had a lot of things they needed to do, but didn't have anything here [Fairbanks]." Robert had intensive speech therapies, occupational therapies, and physical therapies during this time. Tori reports the staff was "wonderful" and when I ask if therapy was a good experience Tori said "yes." However, during the therapy Robert stopped sleeping at around three years of age, and that his eating habits were becoming an issue. Tori explained, "He was very rigid on his eating and he only wanted bacon, sausage, Oreos, chicken nuggets, and fries." I asked her if the food battle was hard on her, as his mother, and if she wanted to feed him nutritious foods. She smiled and expressed how she handled it: "Well, I did what the pediatrician said not to: I force-fed him baby food . . . and we held him down to give him supplements." I ask if she experienced conflicting issues between what the doctor said and what she believed, as Robert's mother:

> Well no, because my child was going to get the nutrition one way or another and me being a pre-med student I knew how important everything was for him to develop . . . and the best thing was that I knew my meds.

However, Tori mentions the current battle of conflicting treatment beliefs due to a new doctor. She says she has been recording Robert's melt-down behaviors to demonstrate the need for particular treatments. Tori terms her feelings during this time as "being highly neurotic and still grieving over everything." I ask Tori if she feels like she was in survival mode during the first few years of Robert's diagnosis, and her response was, "Yes exactly, it was survival mode."

As we talk about the different services and doctors in Alaska, I wonder how her support network was at this time, so I inquire about her family. Tori has two brothers and a sister, but explains “they didn’t want anything to do with the kids.” I question if it was because of her son’s autism: “I think that is a big part of it.” Following her response I ask Tori to explain her experience in revealing Robert’s autism to her family. Tori addresses a moment when she was sharing her concerns with her grandma before he was officially diagnosed:

> I said, ‘Grandma, Robert's not talking’ . . . and she looked at me in her broken English and said, ‘Maybe he's retarded,’ and that sort of hurt, and she then said, ‘That's okay, one of my children was retarded . . . your uncle was retarded, he didn't talk.’ And it felt like she was saying it's like no big deal.

Although Tori’s uncle passed away before she met him. She was later informed that he wasn’t “retarded” but that he only spoke English because he was always in the hospital with “English-speaking people.” I ask her if the word “retarded” offends: “No, but I don't like labels.”

We continue talking about Tori’s brothers and sister, and Tori enlightens me that she took custody of her niece and nephew. I sat back in my chair in the kitchen and we talk briefly about her experience of raising five children.

**4.1.3 Advocacy.** We shift the conversation to what life looked like once Tori had the diagnosis. Tori was not working during the time of diagnosis, but she did go back part-time when her son was two-years-old, and is currently working full-time. She explains that when Robert started school, “it was horrible . . . I panicked because I knew they had nothing for autism and so I had the occupational therapist and speech therapist go with me to the school district and I created his IEP.” IEP stands for individualized education program which is an agreement created to meet the unique needs of the student. The plan is usually a collaboration between the teachers, administrators, as well as the parents, which is why I ask Tori to clarify her statement of constructing her son's IEP. Tori looks at me and laughs: "I did, I created the IEP and the school was like, 'we've never had a parent do this before." She added later that:

> School became hard because he was having meltdowns, he was kicking, and he learned that all he has to do is have a meltdown, and then my mom will come get me [Robert]. He also would have surgeries for his leg, and we were told that he would never talk again, never be potty trained . . . I had people who would come up to me and say I feel so bad for you, your child will never hug you, kiss you, or whatever."
>
> Interviewer: Does it affect you when people make such comments?
>
> Tori: I had a wonderful mentor and she used to do these parenting classes before I had Robert. I had custody and raised my sister's three children who had post-traumatic stress disorder. She said your children learn from you and whatever reactions you have. So it was educating because I was really confused when a person came up to me at work and said, 'You know I really feel sorry for you,' but she was genuine, and she said that, 'Your child will never kiss you or have eye contact and your child will never get married.'

I investigate how this made her feel as a mother and she responds by illustrating how he kisses her, and that they work really hard on his eye contact and he makes great eye contact now. Tori clarifies that she was "a little sad" about his diagnosis, but remembers a story: "One of my close friends who is a therapist, she introduced me to her husband and he is on the high end of the spectrum so I said, ‘You know I'm not sure about that, it's hectic but . . . ’

We discuss Tori’s active involvement in teaching Robert how to kiss, make eye contact, and other social interaction behaviors. People come up to Tori and give parenting advice. Tori reveals her background and what she thinks about people coming up to her in public places to give her advice:

> We would be in the grocery store. I used to be really painfully shy; I would lose job promotions because I refused to give presentations, and I grew up in a village. English is my second language, I was raised very traditional in our culture and was taught you do not go up to people and tell them what to do - you’re respectful. And I remember being at Safeway and this lady comes rushing up to me and demands to know how my baby broke his leg, and I'm thinking oh my God, then I got angry.

Tori starts to laugh: “I looked at her and as I started to walk away I turned around and said, he broke it skiing.” I laugh along with her humorous response to the stranger. Tori demonstrates another time in the grocery store when Robert had a huge purple cast on his entire leg from a surgery: “. . . he's pretty big for his age and it made it hard just to fit him into the cart, and our routine was to make it through the store without a meltdown, we were on a mission, all of the kids would help, we would get him a snack and we went fast to get through the store.” I reiterated her wording of “team effort” and she continues:

> Yes, a team effort and so it was like, please don't talk to him, and he's just quietly eating his Cheese-Its, and we had a bunch of people behind us, and the cashier turns to Robert and says, ‘HEY, don't you think you are too big to be

> in that cart?' And one of my adopted nieces was like looking at me . . . and the cashier turns to Robert and says, 'hey, I'm talking to you!' And I am looking at her like we need to get out of here before he has a meltdown. I can feel the heat crawling up me, and my other son is bagging groceries, and I just quietly said, 'if you haven't noticed the full-length purple cast on him, he just had surgery and he is nonverbal and autistic, and then the cashier just gave a blank look. But then I had to restrain Robert and remove him while he's biting me and fighting me as I am taking him out of the store.

Tori shares other melt-downs, and even shows me an iPhone video recording of what a meltdown looks like. She recorded it to show the new doctor. I inquire about how she feels when meltdowns arise in public places, and she informs me of her training on how to effectively escort children who have meltdowns. Because of this training, Tori describes herself as being "well prepared" to handle those situations. Tori continues on how she reacts to crowds:

> I was trained by a wonderful person who taught me how to get control of the situation when there's an audience, and that it's not good for any child if they're being violent or having a meltdown, they taught me how to say to the crowd — I have this covered, we do not need an audience so back off.

Tori said she feels confident in taking control of situations when crowds gather. However, she mentions that people in the community often give her parenting advice, and when I ask how she handles those situations, she replies with:

> Well I've got this look down that says*, do not F with me.* You know I will annihilate you. So even at the airports when we are having a meltdown you

> know if they do stare, I am already overwhelmed with the situation and so if they're stopping I'll just turn around and give them the look.

She continues to explain about traveling with Robert for his appointments and how it requires “total focus.”

I shift the direction of our conversation by asking how Tori met her friends who have children on the spectrum. She explains that it was through word-of-mouth and through the therapist: “We all belong to a club that we didn’t want to join, but we have no choice, so we come together.” Tori tells a story about some of the calls she has received, including one a few days prior to the interview. The calls are from families who have just received a diagnosis and obtained Tori’s number from someone to use as a help line. I ask if this is something she does voluntarily: “Well, I felt like the entire therapists and people who were in my home helped me even in the bleakest times, you know? They would be there after-hours helping me with stuff that wasn’t their job duties . . . I had no family and it was a godsend that people would show up.” I inquire about her helping families and she explains how “when we are in crisis we can call each other and I have friends all over the United States who have children on the spectrum.” She continues by saying it is nice knowing that someone is there who can share the same experience. Tori reiterates that it is nice to know that they “just get it” and they are “not judging.” She also shared that “Robert's diagnosis has always been on the extreme side: he hits everything plus orthopedic issues so I would talk to families at Alaska Center for Children and Adults who got newly diagnosed.” She then continues with sharing about a time when a mother called: “she was crying and she told me that she thinks life would be better if her and her son were not alive, and that was hard to hear." I chime in by asking, "How did you react to that?"

> I was like I didn't know what to say for a while, but I did some fast talking – how can you say that? Kids on the spectrum have the ability to achieve anything, does your son talk, yes – then, so what if he wants to wear his rain boots every damn day, and I share how extreme my child is and then once I tell them how extreme Robert is it is like they feel better.

We talk more about how she began networking within the Fairbanks community, and she shares a story about a time she was asked to speak to a group known as Key Coalition. Tori has a fear of public speaking, but she wanted to give the speech and "could not say no" to the lady who asked her to speak. After giving her speech at key coalition, Tori was asked to speak in Juneau to the governors and despite her nervous feeling, she did it. Tori was listening to another mother's testimony in Juneau and became overwhelmed with emotions:

> You know part of our culture is you don't cry, there is a time and a place to cry. If you cry you have to do it in private . . . I'm sitting listening to this lady talking about her son . . . and her son has passed and she had pictures and it was such a heart-wrenching story it took everything in me not to cry. Then I started thinking I'm doing this for my son so I was able to do my speech.

After I congratulate her on overcoming those speaking fears, Tori describes a challenge of her son having autism:

> I think the hardest part about having a child on the spectrum is the isolation. I have connected with new moms, and it is a developmental diagnosis that isolates you . . . we go to restaurants – Robert loves restaurants. We all learn

which places are autism friendly and there so many autism-friendly places out there . . . Fred Meyer used to not be autism-friendly, but they sure are now."

She tells me about some experiences of being kicked out of places because of her son's autism, and we begin to sum up the interview.

**4.1.4 Closing Question.** Interviewer: Do you have any advice for the Fairbanks community in regards to autism?

Tori: One of the things I have been advocating for is a [respite] home for a child with developmental disabilities . . . behavioral health has many rest fit homes and it's just so families can get a break . . . and do things that they can't do. There are a lot of families with children on the spectrum and they need a break . . . there's been children on the spectrum abandoned from their families here in Fairbanks and there is no place to keep these kids till they can transport them to institutions. It's so overwhelming that parents just can't do it anymore you know they just need a break they need a moment and children on the spectrum are placed in institution so often.

Interviewer: So a safe place to go?

Tori: Yes just so we [parents] could even just take the time to sleep, that's the biggest thing if you talk to moms, we all have our coffee and well . . . moms just do it for their child."

By this time Robert was making his way into the living room and was listening to music on the T.V. He was sitting on the couch quietly, and when he made the noise "meow" Tori looks in his direction and without skipping a beat during the interview and said, "Yes Robert, that is the sound a cat makes." I began saying goodbye to Robert as I pack my belongings to leave their home. I was overwhelmed with feelings of compassion for Tori and her son Robert, and as she walked me to the door it only felt natural to hug her as I thanked her for allowing me into her home and sharing her story with me, a complete stranger.

### 4.2 Donna's Story

Donna contacted me via email after seeing my flier and we decided to meet at Barnes and Noble on a Tuesday evening around 6 p.m. Donna is a 32-year-old Caucasian with a seven-year-old boy on the spectrum. Her son, Tim, was diagnosed at age three and a half. She also has a daughter, Caitlynn, who is three-years-old.

I began settling myself with my note pad and two audio recorders, and felt the interviewer nerves begin to kick in. To my luck, they dwindled away quickly as we took part in small chat, and I found myself at ease during the conversation with Donna. We discuss the study and Donna signs the consent form before we officially start the interview.

**4.2.1 Before Diagnosis.** I began the interview by asking Donna how many kids she has:

> I have two children, a son Tim who is six, and a daughter Caitlynn who is three. Tim is diagnosed PDDNOS (Pervasive Developmental Disorder-Not Otherwise Specified), which is the high-functioning autism, but I don't know if that exists anymore with the new DSM, but that was his official diagnosis.

I follow up by asking Donna to take me back to that moment when she thought her son had something going on, or suspected autism. Donna responds by saying, “I never thought anything was wrong with him, I thought he was a difficult baby because he cried a lot.” I interject to clarify that he was her first child, and Donna picked right back up with:

> Yes, so I didn't know if I just didn't have experience, or if he was just one of those babies that was more difficult. Really, now I still don't know if that has anything to do with it but it was probably when he was about two and a half, he still didn't have any language, he had vocabulary, but he did not know how to respond to questions, so that was part of it and so I thought anything to get him into a preschool to be around more kids because at that time he was just in a home daycare with only a few kids. I thought he just needs to be around kids, he was very rigid and things had to be a certain way. But he would blow his top with temper tantrums and so I thought maybe he just needs to be around other kids. He can learn how they act. And so I would take him to these places to check it out and looking around and I would think to myself my son is not like these kids, but in the back of my mind still saying he's fine.

Donna describes how she continued putting those thoughts aside until a mother at her son’s daycare mentioned she noticed something. Donna was “appreciative” about the gesture and she took her son to a service that does screenings. She explains to me that when she pulled up to the building her son had a huge meltdown, so they left. Donna then shares that she waited another six months before she took him back after another lady pulled Donna aside and had asked her if anyone ever talked to her about autism:

> She was like, ‘you seem receptive so I'm going to say it but if you don't want me to say anything I won’t,’ and I was like, ‘no please tell me.’ She said, ‘I have been working with kids for 15 years and I see some kind of signs in your son that he may have autism.’

It was at this point that she decided to take her son to be evaluated. Donna shares about the diagnosis process and said she “was there the whole time” during her son’s evaluation. She characterizes her son as “having a hard time with some of the stuff” which qualified him. Donna explains to me that PDDNOS is high-functioning autism, and her son began seeing a psychologist in town after the diagnosis.

I inquire if she had known about autism before his diagnosis, and she answers that she had heard it, but did not understand it completely: “When I pictured autism I thought of kids who did not look at you, that were not affectionate, that did not hug you, kiss you . . . and he's always been very affectionate like that so it was kind of hard for me to wrap my mind around that.”

She also states that she went online and took an autism detector test, “and he did not match up, but he still identifies a lot with the autism spectrum, so it was kind of weird how it all came about, and it wasn't really on my radar.”

Interviewer: How do you feel about the diagnosis?

Donna: I wasn't looking for anything, so if he had it, he did, if not, whatever it didn't really bother me. It was stressful because he was struggling, but as far as the diagnosis I was thinking you know we have to get one to start somewhere, and then he started the preschool at about three and a half and was in an autism only classroom.

Interviewer: Can you share some traits about your son?

Donna: He's always been affectionate and had the eye contact. The focusing is what's hard. He likes things to be a certain way if he's expecting something to be a certain way and it's not very hard for him, he likes to memorize things and then he will talk to you. But he's repeating a movie and he thinks he is

> having a conversation with you even though he is mimicking a movie line so he does a lot of those behaviors.

Donna continues to share about the diagnostic journey and tells me about the psychologist and Anchorage visits with a neurologist, and begins to shed light on the conflicting diagnosis of autism she faced. I ask her if it is hard having a son on the high-functioning end of the spectrum and she responded, “Yes, we don’t fit in anywhere.” She continues explaining the therapies and the autism-only classroom, but then switches gears by explaining her new view of all the intensive therapies.

> Donna: I started pushing them to back off of him, and put him in a typical classroom because I felt like he was learning behaviors and I thought he follows examples really well he wants to be like the other kids. So, I thought maybe if they put him in the other class he would adapt to the children around him. He could see how these kids are not throwing things, because in his autism class he has a place to go to have a tantrum, so in the typical class they don't have that. And, I was thinking maybe if it's not available. Then, he wouldn’t have meltdowns and tantrums.
>
> Interviewer: Do the schools work well with you?
>
> Donna: They didn't agree with me, and that was fine, but I really had to advocate for that change.

Donna states the school does work with her, although it requires “talking with the teachers quite a bit.” When I ask her if it is exhausting to play the advocate role, Donna responds by saying she was more than happy to do it.

> I felt uncomfortable at certain points . . . I didn't want him pulled out of class to go to speech therapy because I feel like he deserves a childhood and he

> shouldn't have to spend his life being pulled out of class to go to all these therapies. Because, when he grows up I think he’s not going to say I wish my parents would have gotten me more therapy, I think he needs to be with kids right now.

Donna expresses she has been happy with the way the school district has worked with her by saying, “I have been impressed with the school district.”

**4.2.2 After Diagnosis.** After discussing the diagnosis process, we shift to discussing what autism looks like in their home. I ask how her husband has taken the diagnosis.

> Donna: He doesn't really acknowledge the whole thing, or situation. He doesn't deny it, but he isn't really sure how to deal with it. With both of our kids I'm the primary caregiver because he works out of town a lot he relies on me to provide him information he doesn't really seek it out himself. I don't withhold anything, but I feel like he doesn't think about it and I feel like I'm always thinking about something I can do.
>
> Interviewer: Do you have any other support, or anyone to talk with about your son’s autism?
>
> Donna: I have friends from the autism society, and other mothers, but we all don't have time just like anybody else. It would be nice if we had more time to sit down and talk about stuff but we just don't really have the time.

Donna explains to me that she quit her job to take her son to the therapies because the services only run during work hours. She recounts her feelings: “They're not taking the whole family into consideration by only offering services at certain times. I know they have families too, but, it’s hard.” Donna explains she is now back at work and they have cut back on the amount of therapies in which Tim is involved. She explains her decision by telling me the hardship all the therapies place on a family: “We've been going for years, thinking where’s the end date? When do we finally get to have a normal life? And, then once we started cutting it out I realized I had more time and I could go to work it wasn't so much that I wanted to go back to work, so we cut out therapy, but the other way around.” I wonder about Donna’s network, so I ask how it was to tell her family about the diagnosis:

> I don’t think they understand, and that's fine, because I didn't either until it became my life, and started living it. It's not really talked about because it's not really important. It's not something that we sit around and discuss and when it comes up we talk about it. I gave my close family the book, *10 things every child with autism wishes you knew* (Notbohm, 2012). My father doesn't understand that it's not a disciplinary issue, he thinks just yell louder, just old-school . . . which is totally fine . . . I don't need them to go get a PhD, so as long as they love him and try to understand him.

I begin to switch gears and ask Donna if having a child on the spectrum has changed her identity:

> I just think what I've learned is how neat people with disabilities are because the way I was raised they were always in separate classrooms and you never got to know many of them. And, I just think they each have their own cool little thing going on just like anybody else. I don't want him to feel that we are fixing anything because there's nothing wrong with him.

We discuss the method of applying for insurances and how it is difficult to go through the diagnosis every year: “It is stressful every year just wondering if he will get funding and if we will get coverage or not, just wondering if he's going to meet the cutoff, or what if he gets too high-functioning for it." I emphasize the idea of "getting too high-functioning" and inquire about how that impacts Donna:

> Donna: Well it's kind of hard because you don't know. I mean if he was severely autistic, then it is obvious and right in front of you, so you just go with it, but when you are on the fence and half of the people are feeding into the denial and they don't know, and you don't really ever know . . .

Interviewer: I interrupt to ask Donna if the uncertainty is hard on her as his mother.

> Donna: I have never been bummed about it or anything . . . I'm more sad about thinking of things that maybe he will miss out on, but I never went through a grieving. The only thing that's really bothered me is wondering if I did something wrong to make his life more difficult like I worried about his life being harder.
>
> Interviewer: What do you mean did something wrong?
>
> Donna: Like I got dental work when I was pregnant or thinking maybe that I didn't eat good enough.
>
> Interviewer: Have you done research on these concerns?
>
> Donna: No, not too much because part of me doesn't want to know and put that on myself, but another part of me always wonders . . . I just hope that I hadn't done anything. But, at the same time, I don't dwell on it at all, whether he had the diagnosis or not he's still the same kid who we know and love. So I wasn't thinking if he's diagnosed with something than anything would change because he is same kid since the very beginning.

**4.2.3 Advocacy.** Donna talks about her involvement with the Autism Society, and I inquire about the autism community. I ask her if she feels a calling to do so, because she has a child on the spectrum: “Yes, I went back to school and I'm in school and I'm studying special education.” Donna continues about her involvement with the autism community: “Oh, it's completely because of Tim, it was never on my radar before now.”

When I asked Donna if there was anything she wanted to share that I had not touched on, she said:

> Just back to feeling involved in the groups and stuff, I feel like I do not enjoy spending time with parents that dwell and that are on the mission to find the cure. I feel like I identify more with people that are all about acceptance and not trying to change people. Because, I feel like a lot of people with disabilities like who they are and they don't want people to fix them. So, I think I get along better with people who share that and have that same philosophy. And I really don't like the poor me, my life is so hard, I mean it's definitely hard in the beginning, but if that's what all the main focus is on its draining.

**4.2.4 Closing Question.** As we came up on to the hour, I finished the interview with my final question.

> Interviewer: Or, is there any advice that you would tell somebody who's just beginning their journey?
>
> Donna: The only thing I ever say is they’re still the same kid that they were a week ago, before you went to the doctor appointment. Nothing has change except for you have a label now. I just try and remind them that they're still the

same kid that they loved before. I mean your whole life changes, your daily routine changes, but at that time they are still the same child that you love.

Interviewer: Is there anything you know now that you wish you knew in the beginning of your journey?

Donna: What I still kind of struggle with today is wondering if I am doing the wrong thing by pulling him out of therapy. But, I feel pretty confident about it and I know it is not for everybody. But, I do wish that the therapy world would be more accommodating, just have different office hours – so people that would like to keep their life could still do that and still do therapy. Being a parent with somebody with special needs is hard enough and that just adds to the stress and I think it would do a lot for families to lessen the stress.

I thank Donna for sharing her story with me and we part ways as we leave the building.

### 4.3 Heather's Story

Heather is a 35-year-old Caucasian mother of a nine and a half-year-old daughter, Kayla, who was diagnosed when she was a little over three-years-old. Kayla is the oldest out of three children. As I walk up the stone path stairs to Heather's home I notice a large colorful autism ribbon sticker on the front door. Heather welcomes me inside to her home and expresses her excitement about my research. There are beautiful family photos that have been blown up and placed onto canvases hanging all around their entryway and living room. The family feel continues into the kitchen with special sayings hung all around. I settle myself into a comfortable chair at the kitchen table and we go over the consent form. I pull out my recorders and set one by

Heather and another by myself before we begin discussing her experience of raising a daughter on the spectrum.

**4.3.1 Before Diagnosis.** Interviewer: Going back to the beginning, can you describe how you first became aware of Kayla's autism?

Heather**:** That was a really long time ago, and as a parent you tend to just focus on the good. Especially, because of where she is at today.

Interviewer: Did you know anything about autism in the beginning?

Heather: Not at all, I knew nothing nine years ago. It was still *all* boys and didn't talk about girls getting autism. There was just really intense behaviors and we couldn't figure it out. And, I just thought I was a bad parent . . . she was my first child, a girl, and so I brought it up to the pediatrician that I was a little concerned because, well, as soon as she could walk she was on her tip toes. She would cry 15 minutes of every hour, she was crying every day, and she carried around objects. It started with a magnet, one of those division line magnets you put on your fridge for kids and she called it her 'mag.' And then, she went to a watch and she wouldn't let you put it on her, she just wanted to slap them. She called them her 'clocks' . . . And she didn't play with toys and those are some of the warning signs. And, if we were to go back and look at what we know now, we see the signs more clear . . . But it still took me about three months to actually commit to doing an assessment. And I knew the infant coordinator at the time and she was really good at trying to coach me, but knew that she couldn't push me because I was not willing to hear that there was anything wrong with my perfect child.

Heather recounts back to a “really difficult summer” she experienced when her daughter began to fecal paint: “I would put her pajamas on backwards, I would duct tape her diaper, and it was an absolute nightmare. It was one of my absolute worst moments of being a mom, as a human being. It infuriated me because I'm a bit of a germ-a-phobe. I didn't understand why she was doing this.” Around this time Heather read an article from Jenny McCarthy and found “acceptance” and thought, “Okay I am not a crazy parent there really is something going on.” At this time she began pursuing the assessment in diagnosing her daughter.

According to Heather, the assessment process was a bumpy start because at that time there was not a lot of research on females being diagnosed with autism. Alaska had only one doctor doing the diagnosis, and he had “totally ruled her out.”

> Interviewer: Did you ever feel a battle between you and the doctors?
>
> Heather: Yeah, because she was a female, which was his big thing, and she had language. But, she didn't have communication, but she had language. You can have the words but if you don’t know how to use them . . . Kayla had severe echolalia which is it's like they sound like a parrot, you will say, ‘do you want some milk?’ and she would respond, ‘do you want some milk?’ And, the inflection in the voice is the exact same and everything is exact same, it's just like a parrot.
>
> Interviewer: Did you feel like you had to push to get the diagnosis?
>
> Heather: No, I felt like I was fighting to prove that I wasn't crazy because my family didn't understand, my husband’s family didn't understand. I felt like I was fighting for *my not craziness.* Nobody wanted to come to my house; I couldn't do playgroups because behaviors were so out-of-control people just

> looked at me like I was crazy. I was sinking deeper and deeper into the abyss of . . .
>
> Interviewer: Almost like isolation?
>
> Heather: Yes, total isolation.

Heather continues to explain how they received her diagnosis. They looked outside of Alaska because they were having a hard time getting the diagnosis. With family on the East Coast and highly reputable facilities researching and diagnosing autism, Heather and her husband flew across the country to receive answers. Kayla was evaluated by a doctor for a very short period of time. In that time he told Heather the diagnosis:

> So, we went to him and he spent 45 minutes with us total; and about 10 minutes of that he was watching Kayla. When he got done evaluating her he sat down with a piece of paper, drew a big circle, and another circle, and another circle and said, ‘well she has Asperger's, ADHA and she has obsessive compulsive disorder’ and this was like a 10 minute diagnosis. So we were just taking it all in at this point, and I'm grasping for anyone to say she has a diagnosis. I don't care what the diagnosis is, but I know now that I am not crazy; because at this point I felt like I was crazy. So I just wanted the diagnosis. So, when we left there I was relieved . . . I was thinking, ‘thank goodness I'm not crazy finally we have a diagnosis’ and my husband was like, ‘this guy just said that my child has Asperger's.’ And he was in a totally different mindset and we were not on the same page.

Heather and her husband went to a local bookstore and purchased every book the doctor suggested they get. As she began reading the books she realized there was a disconnect in the doctor’s diagnosis and the facts behind what he diagnosed Kayla having. They decided to see another doctor out of Alaska, and this time Kayla received seven different diagnoses. Heather said after this diagnosis, “it was really hard” on her: “I look back at that time and have no idea how I survived.”

**4.3.2 After Diagnosis.** Once they received the current diagnosis of autism, they came back to Alaska. Heather expounds that at this time she felt “totally isolated” and was seeking a “support group to talk with.” The insurances are confusing, and it is hard to try and navigate through the experience of having a child on the spectrum: “but you start talking to people and tell your story enough times; then people start directing you and that’s how I got through it.”

Heather was at home with the kids, and she always planned on staying home to raise them. So, when she received the news about putting her daughter into an early school program it was hard because “she had her at home.” Heather describes:

> Heather: They said you have to get her into a school program, and that felt like a slap in the face to me because I had her at home.
>
> Interviewer: Did you feel any type of guilt when you heard that?
>
> Heather: Oh yeah, yes. I always have a tiny bit of guilt till this day that I stayed in denial for so long. Because I feel like if we would've started even earlier where would we be? But then I have to say, ‘no we are doing great with where we are.’ There is no book that says this is what you do this is how you go through it.

According to Heather, at nine-years-old Kayla has adjusted beautifully to the school structure she is in today, although in the beginning there was a slower adjustment. Heather elucidates how the school worked well with her, and gave her an extra year in pre-school to work on potty-training and other areas that worried Heather. According to Heather, the extra year of pre-school made an astounding difference. We continue our talk about the school district and Heather illustrates the positive experience she has had.

> Heather: I am very involved; but I think that, well, what I've learned is, I ask a lot. So I try and give a lot and so I ask when they need help. I know that, between myself and my child, that we require a lot. So, I'm willing to give and help to offset that time, because I know that it's hard. I also try and make sure I understand the process. And, what an IEP is; and what the requirements are to understand what is required by law.
>
> Interviewer: That is a lot of work on your part to read and understand those policies!
>
> Heather: It’s so dry, but you need to understand what is required by law and the policies because you don’t want to create an issue; because that'll kill your team. You don't want to get anyone in trouble, but you just want to get to their attention. That is one of the key things I ever did is become an active involved parent . . . because I've had a lot of opportunities to show that I'm not a crazy ranting parent; but I'm willing to put in as much work, if not more than someone else. I’m not going to ask for things that are unreasonable. I'm willing to work with people, and so once they see that, you open up more doors, more possibilities, and more respect.

**4.3.3 Advocacy.** Heather: I didn't like going to the stores; it was one of the biggest nightmares of mine; she would scream the whole time; if anybody came near her she would scream. And then people look at you and they are like, ‘make your child stop, your child just needs a spanking’ and giving unsolicited advice.

Interviewer: Did people come up to you often with that kind of advice and tell you what they think you should do?

Heather: Oh yeah, and I actually carried cards that said my child is not misbehaving, here's a website you can go to about autism.

Interviewer: It's almost like you're educating those around you that acted that way.

Heather: Yes, because the looks, the stares, even if someone was just looking at me, I would pull a card out. Kayla would also take off and run. And so, that was always a big fear as well. So, I just stayed home for a long time.

Heather says she took it upon herself to make educational cards to inform people who were giving “parenting advice” for the public to understand the reason behind the tantrums is autism. Since the diagnosis, Heather indicates that she has been a positive figure in the autism community, and created foundational resources for parents today who have a child on the spectrum. She talks about helping with the autism society run and explains a moment that arose one night before the run.

Heather: I don’t know what possessed me the day before the autism walk. Things were so crazy; and we came home; and I was laying on the couch; and she came down and laid on the other couch and she said, ‘It is really nice that there is a team with my name for the walk.’ And so I asked her if she knew why there was a team named Kayla, and she responded, ‘Well the first year I didn’t get to go because I was sick.’ And I said, ‘well, there is a little more to it than that.’ So we kind of sat and talked about it.

Interviewer: What a big moment!

Heather: I think if I wouldn’t have been so exhausted from all the autism walk preparation, I would've reacted a little different. But I was so exhausted I literally couldn't even get off the couch. And it was a very mellow conversation and my husband was sleeping. So I ran upstairs and woke up my husband and said, ‘she knows;’ and there was a part of him that was really sad about that. But honestly it's maybe come up four times since then, and twice of the four times she was talking to her brother about it and talking to one of our providers. But it's not like it's a foreign word in our house.

Interviewer: Not a foreign word when you have the autism ribbon on your front door. What a big moment for you and your family.

Heather: Yeah, it was huge, and she just accepted it so well. When we are in our home we like to talk a lot about differences, the positives, and acceptance and we talk about the different ways people think, and don’t focus on the negative.

At this moment Kayla comes to the kitchen and asks her mom if she can go outside. She then notices me and turns to me and says, “Hi, my name is Kayla.” During her introduction she made completely perfect eye contact and stuck her hand out to shake mine. Heather allows her to go outside, and Kayla grabs an item that she enjoys “twizzling.” In their home, they refer to stimming as twizzling. Kayla goes outside; and Heather looks at me with a smile and says, “I just love her. That was a big moment; I didn’t even have to prompt her to do that.” Heather says that she can tell that Kayla’s introduction was rehearsed, although I was blind to the rehearsal that was behind the interaction. Heather points to Kayla in the backyard and explains the routine behind her twizzling. We watch her together by the window while talking about some of Kayla’s past twizzling moments.

**4.3.4 Closing Question.** I wrap up the interview by asking Heather, “Is there anything you wish you had known in the beginning that you know now?”

> Heather: I wish I'd known more about the early signs, I wish I would have known more . . . if I had understood earlier markers, and things I could be doing if I had an earlier diagnosis. You can do earlier intervention and a lot of it was social interaction . . . I wish our state would adopt an early training requirement, that is done during a child’s wellness check. There are ages and stages that could provide a lot of early intervention for children.
>
> Interviewer: Is it important to get information on autism out in society to you?
>
> Heather: Yes because it is one thing to know about autism, but it is another thing to have your child diagnosed with it. It's because they are children – they are perfect – there is nothing wrong with them. So many people talk so negatively about autism; and there are a lot of difficult times that families face and that individuals face. But sometimes, I just wish I could just see the world in such a pure form the way the she does. I analyze everything and am very critical about my surroundings. And she is just pure and this is what it is. And she can find the beauty, and I think that is just such a gift. It is also really difficult for families to access services; and it's sad to me that there is not funding available to help with organizations like the autism society to get the word out. You can only do so much and I had to put a limit on what I could do.

Heather began rounding up her three children to take them to a friend’s house. We say our goodbyes to one another, and I walk out the front door. Kayla and her younger sister follow me and begin playing in the front yard while Heather gets the car ready. The youngest child proceeds to tell me their afternoon plans, and then they both wave bye to me. I get into my car and wave bye back at the girls who are standing by their autism ribboned front door.

## 4.4 Tanya’s Story

Tanya is a 42-year-old black mother of two boys on the spectrum who were both recently diagnosed. Her oldest son Conner was diagnosed at three-years-old and her youngest son Ben was diagnosed at 23 months. Conner is now four-and-a-half and Ben is two-and-a-half. Tanya and I decide to meet mid-day around 1:00 p.m. at Barnes and Noble. I set up at a table off to the side and reflect on Tanya’s two sons. Both of Tanya’s boys were recently diagnosed within the same year. I set up my recorders, and my phone rings. I saw a woman on her phone as well, so I walk over to the magazines and introduce myself to Tanya. Tanya purchases a cold blended beverage from Starbucks and I continue to prepare for the interview. As she returns to the table we discuss the consent form, and I explain the study. Tanya laughs as I hand her the required sheet of people she can speak with after the interview if needed. And she explains how she already knows most of them. Her laugh is comforting and I feel at ease in her presence. After signing the consent form we begin the interview process.

**4.4.1 Before Diagnosis.** Interviewer: Can you tell me about your boys?

Tanya: My two-year-old’s name is Ben, and Conner is my four-year-old.

Interviewer: Were they both just recently diagnosed?

> Tanya: Conner was diagnosed in November, like right before Thanksgiving, and Ben was diagnosed in June.

> Tanya describes her recent experience of finding out her boys have autism:

> It is a lot more with two, with one you know we are like, we got it, but the good thing is we were aware, and educated on it. So I saw the behaviors and traits in Ben right away, so we were right on it. There are so many different tests you can do, and we did the M-Chat test (Modified Checklist for Autism in Toddlers) and you can do it online and it is easy . . . And if we didn't know then, I am sure we wouldn't have caught it until later on. With Conner, he met all the milestones, the difference was he screamed a little bit, but that was out of frustration. I have worked with kids, I loveee kids, and I am very patient. And I could just tell it was something, so we were seeking to take parenting classes.

I follow up about the parenting classes by asking Tanya if she thought that was the reason behind the behavioral issues. Tanya explains how she and her husband were thinking they needed to go and get the parenting skills to manage all of the screaming. Tanya shares that during that process, someone referred her and her husband to the public health center in Fairbanks, "and that's where they did the M-Chat test."

She illustrates the opposite experience she had with her oldest son, Conner. Tanya's son Conner has hyperlexia, which is the ability to read early even without the proper training. Due to his hyperlexia he was advancing fast and was doing great with the "your baby can read" applications.

Tanya: So we were doing that at 6 months and we were thinking all this stuff was working, and we were not thinking anything abnormal was going on. We just thought he was totally absorbing it and doing so well. So when we went to the doctor she said she has seen a lot of parents who have done the "your baby can read" application, and she has never seen them do this well . . . Conner could have been ADD because he hit all the milestones and everything but he just screams.

Interviewer: Did Conner communicate?

Tanya: Yes, he is also very affectionate, both of them are sociable, like the common things you see for autism, they don't fall into that. And that is the thing I am starting to realize is if you meet one child with autism, you have only met one.

Interviewer: Both your sons were diagnosed in the same year?

Tanya: Yes, and it had not even been a year for Conner when Ben was diagnosed, but Conner has come so far in that short amount of time. We got him in preschool, and had him in there already because of his speech . . . but once he was diagnosed we were able to fully connect him into all the resources.

I ask Tanya if this time was hard on her and her husband, and she shares that is was stressful at times. With her oldest son Conner she explains that she was "in denial because he is so bright." Tanya expresses how she began to realize he was having a hard time comprehending simple tasks: "When I look back I see those little things that I didn't notice in the moment." Tanya describes the realization of her first son's diagnosis as a "hard blow." She also shares with me the disconnect of the diagnosis because they were both hitting milestones. She explains this time as hard “because he was doing typical stuff for his age, and it is hard to tell what things are autism and what isn’t.” Although with her younger son Tanya says it was different:

> With Ben, It’s like I knew, I could see it. It’s funny because I took the M-Chat test for Ben, I have the app on my phone. I have all kinds of apps for autism. So I did that test like 50 times thinking I would get a different answer, and I would even answer slightly different to see if I could get a different answer, so I wasn’t in denial, but I was hoping it wasn’t autism and that it was developmental.

Tanya describes how she found out she was pregnant with Ben after four months from being in a car accident:

> I hit a moose and totaled my truck and walked away by the grace of God with nothing. But my shoulder was hurting a little bit, and I went into the doctor for my shoulder, and that is when they told me I was pregnant. And I was like, WAIT, what? Because Conner wasn’t even two and husband was like, wait what, also. So it was a big shock so I had missed the first trimester, so in the midst of all that I was thinking about that is why something is going on, and I wasn’t not sure if it was a developmental.

Tanya continues to describe both son’s autism traits, and how they are very different with their behaviors on the spectrum. She also explains about the genetic testing she had done while she was pregnant and says “everything came back normal.” We discuss a bit about theories on what causes autism, and how each child is so unique to the diagnosis. The discussion prompts Tanya to share: “I am a strong believer in God and I have a lot of support from friends and family.” She explains that she has two older boys, “one is graduating from college” and the other “is a senior in high school.” She describes her family as “close” and very family-oriented.

We continue to talk about her family. Then, I ask how they reacted to the first diagnosis. Tanya explains how “it was hard on everybody,” and how they just “could not shake it” at first. She sought out counseling and expresses that it helped a lot and helped her come to the understanding of her boys having autism: “But I just kind of came to the realization that we can’t understand why it is things happen. Things happen for a reason, and maybe I’ll never know why, but I do know they are going to do great things.”

Tanya describes how the doctor shared some insightful information with her after she received the diagnosis:

> The Doctor said to me, some people want to know why my kid has this, or how my kid got this, well I can’t answer that question. He said all you do is you don’t label him. You give him the name you gave him when he was born, Conner. You inundate him with everything you can, and you watch him and let him tell you what he can do.

Tanya’s philosophy is that her boys with autism are not different than other kids: “If you think about it, we give our kids everything and we wait and see what and who they will become, and this is the same thing. So why should it be any different.”

Tanya and I discuss how some other family members outside of her immediate family took the diagnosis. Some people did not want her sons to be “labeled” and would sometimes make comments about the age she was when she had the boys: “A few responses that I got that were hard.” At the same time, her “strong Christian family” is supportive of the boys even if they questioned the diagnosis. Tanya also told a story about the daughter she lost prior to her two boys, who she refers to as *Hailey's Legacy*: "It was hard for me to tell them because prior to Conner we had a baby we lost, and she had a rare condition, and it's called trisomy 13." Tanya describes her desire to have another baby:

> I just still wanted another baby, and it took me a year to get pregnant with her, and then it was almost 4 years until I got pregnant with Conner. So everybody was excited about Conner and then we get this [autism] and it was like a blow to the stomach. And then we had the unexpected blessing of Ben, so it was double! And so it was kind of hard, because these are miracle babies because Conner took four years, and Ben was right after. And we survived the car accident when I was pregnant with him, hit the moose and walked away, and he was normal looking and everything, and they are just my miracle babies and we have so much to be thankful for.

**4.4.2 After Diagnosis.** Tanya describes how once they received the diagnosis she sought out support networks by reading blogs and exploring Facebook. We talk about Tanya's friends, other than on the web, and Tanya states that parents who do not have a child on the spectrum often "separate" themselves from those who do.

> Tanya: I find myself educating them, I'm always so defensive of my boys, and my husband is 6'5, so Conner is tall for his age, and when he was two people were expecting him to be doing what a four year old should be doing. And now he is actually four, and people are thinking he should be acting like a six year old, so people don't know him. So I have been protective over Conner for that reason. When he has a meltdown and people are looking, I look at them and say, 'He has autism' even when I do not know who they are. So I had to

> pull myself together, because I cannot explain it to everybody . . . because people are watching and people are just rude.

We continue talking about issues in public settings, such as the grocery store. Tanya has a routine she goes through when she brings her boys to the store, and part of that routine is the bubblegum machine. Although Tanya has a routine, she shared a few times when meltdowns occurred in the stores. A particular time when her husband took their son to Safeway people acted “rude” during one of these episodes:

> Then this guy, probably in his 20s, was with his girlfriend and he was walking behind my husband mimicking Conner screaming . . . But that kid was with his girlfriend and I am sure he was just showing off, but it is just rude . . . then my husband ran into one of his friends, a really good friend, and he grabbed the grocery’s while my husband put Conner in the car.

Tanya explained her husband wanted to go give that man a piece of his mind, but luckily his friend helped the situation from escalating. Tanya then describes how the iPhones and iPads have been so helpful in times like going to the grocery store, or when they travel. The electronics have allowed the boys to stay occupied and content. Tanya explains the amount of preparation it takes to travel and how she deals with people who add to the preparation in a negative way:

> But when I think about isolation, people don’t understand how much work it is for me to even go out. Not only do I have to take care of my kids, but I have to also deal with people, which I shouldn’t have to do that, because they don’t even matter. And I don’t mean that in a bad way. Well my mom said it like this; you are already carrying a lot of weight, like a bag of potatoes. So when

> people do and say things that offend you, all you are doing is adding more weight to your shoulders. More potatoes in your bag.

Tanya continues sharing how other people's advice can come from a good place, but it still hurts sometimes: "It is not like they are pressuring me or telling me what to do, it is like they don't understand what I go through."

> Interviewer: Can you explain a time?
>
> Tanya: A lady from church once said, 'I was thinking about you, and you worry too much' and she said it like that, and she meant well, but it bothered me. And I said 'huh?' And the lady said, 'I was thinking about you and you worry too much, so what if they have low social skills' and you know she said it like that, 'So what if they have little social skills, they are very bright and they are going to do well.
>
> Interviewer: How did that make you feel as a mother?
>
> Tanya: I think they mean well, and it comes from a good place and they don't mean to hurt me. But they are not considerate.

We talk about her boys, and how they both have different traits of autism. To stay positive, Tanya reminds herself that her "kids are healthy, they are not on any medications, and how they are not in pain." Talking with other mothers help her "not to be overwhelmed." Tanya said she was trying to put her head around the big picture in the beginning, and tells me how "you can't do that, you have to take it one step, one breath, one day at a time."

**4.4.3 Advocacy.** Interviewer: Do you know any other parents with children on the spectrum?

Tanya: I have a girlfriend that worked with me and her son is younger than Conner. He was diagnosed as well, and I didn't really know, but we ran into one another in therapy. And it is hard because she just had a baby; and she knew both my boys had autism, and I bet she was thinking of her second baby will. So I find myself being strong for her. I try to talk with people, I find because I am a peace maker and I want to make people happy. And sharing my story is good for me, just as I am sharing my story with you right now. Even like the story I shared about my daughter, I want her story to be told. So I am always talking about it and I am always talking about Conner and Ben because I want people to be educated on it and about them . . . Who would not love them?

Interviewer: Do you enjoy educating others on what you are learning about autism?

Tanya tells me her initial thoughts on what autism was, and now that she understands it more she educates others on it. Tanya said she had never been around anyone with autism before so her understanding was "just the norm" until she had her boys. We agree how it is sometimes hard to explain what autism is, because the spectrum is unique and even her boys have very different behaviors.

**4.4.4 Closing Question.** As we come to the end of the hour, I ask Tanya what advice she would share with a family that had just received a diagnosis: "The only thing I would say is you need a lot of support." She retells me about an article she had just read about a women whose son has Asperger's which had gone undiagnosed, and the lady in the article says she felt so alone for such a long time:

> If there is anything I would say it would be support and education. The people who are working with these kids they love kids and they know what they are doing. And they are telling us what to do. And when Ben had his first therapy, I didn't know they could tell I was taking the diagnoses pretty bad, and I brought Ben back the next day and she came up to me and asked, 'How are you doing?' And I just started crying, and she said, 'I saw it on your face, and it is not that common for parents to have two kids on the spectrum.' And she referred me to another parent and I called her and we talked, but our schedules are so busy, so we just share stories.

Tanya shows me photos of her beautiful boys on her iPhone while I begin to pack up. I was able to see the light in her eyes shine as she talked about both her sons. As we parted ways, I felt truly thankful for Tanya's story.

## 4.5 Katelyn's Story

Katelyn is a 41-year-old Caucasian mother of a seven-year-old son who was diagnosed with autism a few weeks shy of his second birthday. She has five kids and her seven-year-old son with autism is her third. She contacted me via email inquiring about the study. Katelyn and her family had been Alaskan residents when she received her son's autism diagnosis, but they now live in California. Due to her location, we set up a Skype interview time. The Skype method is used so the conversation is face-to-face during the interview process. We have a few connection errors during the interviews, which makes it choppy at times. Despite the connection errors, Katelyn's shares her story with me.

**4.5.1 Before Diagnosis.** Interviewer: How did you first became aware of your son having autism?

Katelyn: Well, it was probably a little different than other people. But, it was right after his first birthday he got a lot of vaccines and he just slid downhill.

Interviewer: What do you mean by slid downhill?

Katelyn: He just quit talking and he was generally not happy. And it took us many many months to go through the diagnoses and all the appointments.

Interviewer: How was this time for you and your family?

Katelyn: Well, it was very stressful, but with him he was born with some birth defects and stuff and so by three months old he had gone through a major reconstructive surgery.

Katelyn explains to me the extent of her son's multiple surgeries in the beginning of his life. She tells me about a major surgery that required a heavy blood transfusion. Katelyn says he received a lot of vaccinations directly after the transfusion because of his young age. She indicates she had never had any problems with vaccines with her other children, however her theory for his autism was due to the vaccines in correlation with the blood transfusions. I inquire if her belief regarding the vaccines caused any tension between her and doctors: "Oh yeah. Yep every doctor is a battle. And with my kids since I have had since him . . . it is a constant fight against them because I want to slow down the vaccine and not get them all in one visit."

We converse about the controversy behind vaccines and Katelyn clarifies the reason her family moved out of Alaska was not to receive better services, but was for her husband's job. We discuss the services she received in Alaska, and she responds with: "So-so." I ask her to elaborate and she continues with: "They kind of treated me like I was stupid, and I didn't advertise that I have been actually working with autistic kids for over 20 years. It was a bit of a blessing that I had got my own [child with a disability].”

I interject to have her clarify about her 20 years of experience, and she responds that she was state certified in intensive early intervention program, “which was the equivalent to the ABA therapy.” Katelyn’s training allowed her to do therapy with her son at home, and I asked if she could describe some of her son’s behaviors:

> Completely nonverbal, he did not have a lot of bad behaviors, like most of his behaviors were because he could not communicate, and he would get frustrated and throw himself on the floor and bang his head on the ground. At this point he knows quite a few words, and I taught him sign language myself so we can get some communication going, tantrums are rarely – maybe once a month. He seems to be doing good and he is a bit of a home body.

I inquire about her interest in working with people with disabilities and children with autism:

> Actually when we moved to Alaska when I was six-years-old and my next door neighbor, one of their children had some kind of development disabilities. I don’t even know what it was, but we became close friends and I kind of protected her, and shielded her from the kids making fun of her. And that was all through my childhood, and she was just like anyone else to me and somehow like a passion was born . . . and then I went to college for human services program there and that is when I got into working with the autistic kids.

**4.5.2 After Diagnosis.** Katelyn and I talk about pre-school in Alaska, and when I ask her if it was a good experience she says that it wasn’t. She explains that it was difficult “because he would tantrum” and he didn’t want to get on the bus. The school spent a lot of time calling Katelyn to come and get him, and she didn’t think they had enough teachers per student to “supervise him properly.” She shares her concerns of him being a “runner” and how “he would just disappear onto the playground and be on the slide, and a couple of times he was in the parking lot and almost got hit by a car.” She further elaborates on her concerns with regards to her son’s helmet: “Even with the helmet he requires a lot of supervision so he doesn’t hurt himself.”

> Interviewer: Was school a stressful time?
>
> Katelyn: It was, and then when they got to the point where he was tantruming and melting down and refusing and they would call me to pick him up, and I told my husband I am not doing it again. I am going to educate myself so I can help him. And I am not putting him through that, and it just turned into a family thing, and now I am homeschooling all my kids.

I ask if Katelyn has a good network and she laughs as she responds with, “I don’t know anybody here in California, so it is just me and my husband, so I am with my kids 24/7 and that’s fine, it works for us.” I follow up by asking if she looks at any blogs or online support and Katelyn said “no,” but she talks about a lady that lives in her community “that has an autistic son.” She explains the difficultly of friendship: “She is real busy with her kids and I am real busy with mine. There is not a lot of socializing.” I ask if this friendship was helpful, even if they didn’t meet often: “Yeah it did actually, she helped point me in the right direction for resources when we first got here, and she let me know that California pays for things like diapers for him, which I didn't know." We talk about services, and I question if she felt like she is the person who can take the best care of her children:

> I do, yeah. I just have a hard time handing over that much responsibility to somebody. And if something happened they would probably feel horrible, and I don't want to put anyone in that situation unless they are very highly trained.

We laugh about the amount of coffee she must drink in a day, and then I ask if her previous training helped in her comfort level of taking care of her son: "Yes, he was born with the birth defects, and having to go through the surgeries, he did almost die during the surgery, it was extremely traumatic during that time on both my husband and I." Katelyn continued by explaining how the doctors wanted to keep doing more surgeries, and that she does not agree with that:

> Well, of course they want to do it because it is a teaching hospital and they would get all that experience and $50,000 but I cannot justify putting him through that when he is autistic and he is not going to lead a perfectly normal life. He is not going to ever go out there and play football, you know, or those kind of things, where we have to worry with his head injury.
>
> Interviewer: How do you feel when you talk about his future?
>
> Katelyn: I plan on taking care of him the rest of my life.
>
> Interviewer: You say that with such ease, how did you come to peace with that?
>
> Katelyn: Yeah, I don't know, I think I kind of just accepted that my son has autism. I know there is no cure, but I know all these different things from the readings I've done, and the kids I have worked with, that certain things works for some and others don't. Basically make a big list and try all of these things.

> We tried anything we could afford, we did neuro-feedback where they put the electrodes on the head, and that actually made a huge difference.

We switch gears and I inquire about how her family took the news of her son having autism.

> Katelyn: My parents were very much shamed for having a retarded son, you know just ridiculous things. I have a sister I haven't seen since shortly after he was born just because it was too much for her. She does not want to be associated with us.
>
> Interviewer: Why do you think they do not want to be associated?
>
> Katelyn: I have often thought about that, trying to figure it out. I don't know if it is because he is an embarrassment to the family? So I can't tell anybody, my parents don't even talk about him to anybody, they talk about their other grandkids but not him. I took a lot of time trying to figure out what their problem was, you know, who could not love that little boy?!

Katelyn shares with me that she and her husband are one another's best friends. She elucidates that her son's surgery was hard on her husband. When I ask if she felt like she had to be strong for her and her family, she responds by saying, "Yeah, yep I did. Exactly." When I follow up asking who was strong for her, she says "herself."

**4.5.3 Advocacy.** Katelyn illustrates a story about a time she was at the store and had a stranger come up to her:

> A couple weeks ago and this elder man in his late 70s came up to me and said, 'Your son shouldn't be riding on the cart.' He will sometimes stand in front of me while I'm pushing the cart, but that is my way of making sure he won't run

> off because he is too big to fit in the cart. So I said, 'Yeah, well he is just fine' while I was getting some vegetables. And my son was holding on the cart and pulling it, and I had the baby inside in the car seat, a newborn, and the guy said, 'David, David I told you get off that cart!' And he didn't know my sons name, he thought it was David, and he was tellin him to get off this cart. So I said to the man, 'You know he doesn't understand you, he has autism.' And he replied, 'Well what is that?' So I said well he has some disabilities and he doesn't talk, and he said, 'Well that's no excuse, you need to train your kids to listen better' and I was thinking there is not point arguing with this man who doesn't get it. And I figure most people like that are ignorant.

Katelyn describes how she is not typically a very social person. I ask if she experienced negative interactions in public often, and she responds by sharing a story to illustrate other interactions:

> I have found surprisingly that I get more compliments from people when we are in a public setting rather than negative. A lot of people have come up and told me how good I am doing with these four kids by myself and how well behaved these kids are.

Katelyn shared that those compliments made her feel good, and she shared another story:

> Yeah, it is nice. That is how I met the lady here who has the autistic son. I was down at the pool with my kids by myself, we have a community pool, and she was actually laying there sun bathing and then she came over after about a half hour and asked me if he had autism and I said, 'Well, yeah, he does actually' and then she said, 'well so does my son,  I am down here right now taking a

> mommy break' and she said her kids were at home with the nanny, then she told me how they have a full time nanny and they have all these therapists that come to the house because they can afford that. But she actually complimented me and said, 'I am just in awe watching you handle these kids by yourself because I can't do it by myself. And I still have to get away a couple of hours a day to have some time to myself.'

Katelyn explains how she enjoys spending her days with her children, and that she does not take "mommy breaks."

**4.5.4 Closing Question.** I finish our Skype interview by asking Katelyn if she can reflect on her journey of having a son diagnosed with autism. I ask her if there is anything she knows now that she wishes she knew then: "Well the thing I wish I did was rush him to the hospital after his vaccines." She also talks about having the vaccines further apart so the children are not getting an overload of viruses. It is clear that she is not against vaccines, but she believes after such a massive blood transfusion the vaccines should have been administered later.

The interview wraps up and we both wave goodbye to our computer cameras. I sign off and reflect back on Katelyn's strength throughout her journey.

### 4.6 Rachel's Story

Rachel is a 47-year-old, mixed ethnicity Caucasian, who has a 14-year-old son, Ian, who was diagnosed with Asperger's at age ten. Rachel and I scheduled to meet on a Saturday around 2:00 p.m. at a local coffee shop. Rachel is my first interview with a mother who has a child diagnosed with Asperger's. As I sit at a table, Rachel spots me and comes over to introduce herself. Rachel asks if I am studying only Asperger's and I respond by telling her the scope of my study. She purchases a big cup of coffee and we discuss the consent form before beginning our conversation.

**4.6.1 Before Diagnosis.** Rachel begins by introducing her two children, her 14-year-old son who is diagnosed with mild Asperger's, and her younger, neurotypical son. I ask Rachel to tell me about the beginning of her journey and what made her suspect that her son had a neurological state:

> Well he had problems pretty much his whole life; he had problems nursing at the very beginning. We put him on formula eventually, and he kept throwing it up so he was diagnosed with reflux and we noticed early on he was doing things that babies are not supposed to do. At six or seven weeks he was laughing in his sleep, and smiling.

We talk about some other triggers Rachel noticed, but she clarifies that his diagnosis did not come until much later on: "Yeah, but I kind of ignored it for a long time; it wasn't until he was in the fourth grade that he was diagnosed." She continues: "They did, however, have him in speech therapy before he was three because he wasn't developing words and he had problems with the usual combination with sounds." Rachel explains how the therapy as a good experience, but mentions that the therapist "did not pick up on the autism connection at this time." I ask if Rachel can describe some of Ian's behaviors: "He focuses in on certain topics for a long period of time. He will read a lot of books related in certain topics, and you don't expect a sixth grader to know that amount of information on a certain topic." We talk about some of the topics he is interested in, and I ask if his struggles are hard on her, as Ian's mother: "Nursing was definitely hard; I of course, blamed myself with him not able to nurse, 'thinking am I not producing enough, is it me?' But then I figured out with my second child it was not my fault." Rachel describes how she took her son to the doctor and he was tested for reflux. I ask how this time was on her, and Rachel says "the stress did not come till later." During this time they had another baby because they wanted their children close in age, the boys are "two years, one month, and one day apart." We dig deeper into the stress that came later by discussing troubles with homework:

> I mean he was taking hours to complete his work and I was thinking maybe ADD and not ADHD because he is very calm. But I thought maybe ADD . . . So we put through the forms for checking for ADD and he came back normal for attention, but the social was below normal, and I was the one that brought up autism at that point because of all the things I had seen before.

Rachel's family does not live in Fairbanks, so they were not aware of his Asperger's until they visited during the holidays. On the trip both her children had homework and she noticed her younger, neurotypical child, would always finish first. Rachel brought her son in to get evaluated without her husband and continuously gave her boys her undivided attention and expresses it was hard on their marriage: "And of course at that time all my attention was on the boys, which is hard on the Dad who wants Mom's attention too." I inquire if Rachel ever felt a pull between the roles between mom and wife and she responded, "I don't think I ever felt it, which was probably the problem. Because I was so focused on the boys."

**4.6.2 After Diagnosis.** When Rachel's son was seven-years-old he received a diagnosis: "I feel like he borderlines in between autism and normal." I inquire if Rachel feels it is harder to borderline between the two groups: "It is because people think he is acting normally but then he will do something a bit odd." I ask Rachel if that is the hardest thing about having a son with Asperger's:

Rachel: I think the hardest thing is when I have one who is neurotypical, he doesn't understand especially when he was younger.

Interviewer: Do you see him becoming protective of his older brother at all?

Rachel: He was earlier than he is now.

Interviewer: Does he now have a full understanding?

Rachel: No he is not open to hearing that, he is a bit sensitive to my son getting all these "privileges" through extra care.

Rachel explained that she is "unsure as to what those privileges are," but explains, "Lately I have been spending a lot of time during homework, helping him read the directions and going through the steps. He won't do homework alone; he has to have someone near him." Rachel does not mind helping her son with homework, although she states that the divorce has "been a blessing" because when her ex-husband has the boys she gets to "have time alone." Rachel does have full custody of her two sons.

Rachel: I have full custody of the boys and it was what I wanted. I felt like by having children I had made a decision, and my decision is not something I want to do at only fifty percent.

Interviewer: It sounds to me being a mother is a huge part of your identity.

Rachel: Yes.

Interviewer: How do you see yourself today as being a mother who has a child with Asperger's? Has it change your identity at all?

Rachel: It has made me more compassionate . . . because I see his differences and I see other people's differences. And they are born the way they are and there is so rhythm to it. You just accept them as they are and where they are.

Interviewer: Have you ever sought out any support groups?

Rachel: The main thing is time; it is hard to get into a support group. That is probably why I am on Facebook because I am able to see other people in similar situation without having to arrange for a babysitter for someone to watch the boys for two hours why I go to a group.

**4.6.3 Advocacy.** Rachel is already an educator within the community, and because of that I ask her if she feels a desire to share her knowledge of Asperger's: "I definitely do that, yes, yeah, since the beginning of every year since fourth grade I walk in and have a meeting with his new teacher and his last year teacher so they can discuss." Rachel said she is involved with the IEP process and has a desire to be a part of that collaborative development. Rachel then shares an experience she had the morning of our interview about being an advocate and talking with people about Asperger's: "I do find myself, even this morning someone came in and they were talking about Asperger's and I turned around and said, 'My son has Asperger's.' Rachel and I talk about her son getting older, and she tells me about how she is shifting her focus for her son to be a self-advocate:

Rachel: Yeah, and now at my sons age I am trying to teach him to be his own advocate.

Interviewer: How is that going?

Rachel: I'll walk him down to the teacher, and tell him to tell the teacher.

Interviewer: So you are still being present in it, but trying to get him to self-advocate for his need more? Is it important for you to have him be able to self-advocate?

> Rachel: It really is, to speak up for himself because I am not going to be able to be there all the time.

**4.6.4 Closing Question.** Interviewer: Is there anything you would share with a parent if they came to you with a son that was just diagnosed with Asperger's?

> Rachel: I would say go ahead and have a meeting with the school to get your child on the right track . . . But I am not sure if other parents would be comfortable with that. You need to speak up for them, until they can speak up for themselves.

Rachel and I begin packing up our things, and I thank her for taking time out of her busy schedule to talk with me.

### 4.7 Samantha's Story

Samantha is a Caucasian mother of four Hispanic/Caucasian children. Her oldest daughter is currently five-and-a-half-years-old and was diagnosed with autism at age three-and-half. This is my second interview with a mother who has a daughter diagnosed with autism. Samantha and I meet at UAF in the Communication Department in the Speaking Center to ensure confidentiality. I go over the scope of the study and we talk about the consent form before beginning.

**4.7.1 Before Diagnosis.** Samantha's husband was deployed during the time of her daughter's diagnosis. Samantha was unable to have contact with him at this time because "it was the end of the Iraq war and they had closed down all communication." I begin the interview asking Samantha if she was alone during the diagnosis process.

> Samantha: I was at that time, and I don't have family here [Fairbanks] or close friends or anything like that. So I did not have the luxury of living in that denial. I know everyone experiences it differently, but I couldn't do it. Even in

> the autism community there are people butting heads, and I had people telling me that my daughter didn’t have autism because she acted differently than their son, so I had to go through that. Thinking I had made friends, but then they doubted my child’s diagnosis. Almost like competitiveness between high-functioning and low-functioning.

Samantha’s experience at this time made her feel like a “second class citizen” because she is the wife of a deployed soldier: “I do think there is a way military doctors speak to spouses because they know our other half is deployed, and I was even told by doctors that I did not have my child’s best interest at heart because I didn’t leave Alaska.” Samantha stayed in Alaska and got her daughter early intervention. She explains that during the time of early intervention, they “were working on her IEP meetings, and her speech, and the diagnosis was mostly just for the ABA therapy and coverage.”

> Interviewer: Did you ever feel pressure to solve you daughter’s autism?
>
> Samantha: Yes, and I think that comes from the guilt that is felt. And if you look at the research it points to environmental and prenatal care, and whose fault is that? That is the mother’s, and either feeling pressure from the dad to fix it, or mom feeling guilty, there are a lot of gluten free diet beliefs, and we didn’t do that. We did more of speech therapy and behavior modifications, and we worked with her at home and I don’t let her use autism as an excuse. So she is still going to say thank you, and I sound like mean mommy, but that is how I am raising my child. I did go to a gluten free workshop and discovered that it is ridiculous.

We deliberate about the many different theories in society about causation and cures which lead us to discussing Samantha's experience of having a female on the spectrum.

> Samantha: Well, people always say, 'That's unusual' but everyone is excited to get to know Katie because for the longest time she was the only girl in her therapy. At her school there is an older girl, but they get so excited that they have another girl. Katie does not have the aggressive behaviors. But she does struggle with impulse control, and she runs away.
>
> Interviewer: How does the word autism look in your home?
>
> Samantha: I know Katie has heard me say it; I try not to say: "She's autistic." That's another one I don't like, because it is a label. I say my daughter who has autism, because that is her diagnosis. But unfortunately even people in the autism field say autistic. It is just one thing that really bothers me, so we don't really say it but we describe it.

In Samantha's home her family practices "compassion and empathy across the board." When Katie's brother and sisters ask why Katie is doing something, Samantha describes those times with" "We explain it, but we don't label it."

**4.7.2 After Diagnosis.** Samantha and I converse about some of the issues she had with the doctors in the beginning of her journey after receiving a diagnosis.

> Samantha: This is something that always bothered me about doctors, because once Katie was diagnosed, I already had three kids. And I see people who have their first diagnosed with autism they don't have any more kids because it is so strenuous on the family. But I already had three kids at that time, and I had doctors telling me that I should not have any more kids.

> Interviewer: They openly said that to you?
>
> Samantha: Yes. Yes. And so I was like why shouldn't I have more kids? I understand the genetic part of it. But they would say the percentage of having a second child with autism, and I would look at them like, 'So.'

The doctors told her to not have any more children due to the statistics of having another with autism. Then Samantha gave me her insight on autism, and how a doctor told her something that impacted her perception of what caused her daughter's autism:

> I believe kids with autism have always been around. They were either the weird kid, or the one with the behavior problem, or the kid who was getting checks after their name in school. That is my philosophy. Of course, in the beginning it is kind of hard to take in, you get the diagnosis and you are shocked. But it is how you move through those patterns of grief, sadness, and guilt. Everyone moves through it at different rates, but I did not have the luxury of staying in my bed and crying about my daughter having autism . . . the doctor told me after she was diagnosed, 'Oh it's not your fault' and it had never occurred to me that I had done something to cause my daughter to have autism, and now I do. It is always in the back of my mind wondering what did I take while I was pregnant, was I too stressed, was I too controlling when she was a baby by teaching her sign language, and I spoke to her in another language, does that matter, those sort of things. But I did not have that luxury because my husband was deployed and I had to get out of bed and I had to continue on with my day.

Samantha’s husband is a great support service for her and she is able to “unload on him.” According to Samantha, outside of their immediate family it is harder.

> Samantha: Well my parents have never accepted anything I do, even with living in Alaska or being in the military, they don’t understand anything I do. They live in this little box. So I have no support from them, they don’t read about it, or Google anything.
>
> Interviewer: Did you ever send them information about autism?
>
> Samantha: I did I actually found these brochures on being a Grandparent of a child with autism, but they don’t talk about it. Because if they don’t talk about it then it does not exist.

**4.7.3 Advocacy.** We talk about Samantha’s impressive educational background and current educational endeavors. Samantha has multiple master’s degrees and is currently working on another master’s degree to become educated on helping the Fairbanks Autism community.

> Samantha: I have found in my classwork, yeah, people can be teachers or get their certifications . . . but you don’t get it until it’s your child. And I don’t mean to sound like I am better than them, but it does affect you in a different way. You see it different, and it hits you to that basic core in that venerable area, where if it is just your job, you may care about it, you may be really good at it, but I can see a difference.

Samantha explains how she became very proactive within the community after her difficult experiences during the diagnosis. She took it upon herself to write letters to everyone she had come into contact with at that time:

> Samantha: I actually ended up writing a four-page letter to the commander of the hospital and aid basically saying this isn't right, this is not how someone should be treated when they are going through this devastating diagnosis. And they don't know what's going on, and they didn't offer support and they just sent me to a web site.

Interviewer: How has your involvement with the autism community affected her identity?

> Samantha: It has opened me up because before I didn't feel a part of the community before, I was really really shy. When you have to advocate for your child at the therapist or in an IEP meeting it was hard. So as I built confidence and passion for helping my child, that changed who I was. And also talking with other parents is very catharsis to me, and I hear the quiver in the voice when someone is experiencing the beginning of the diagnosis.

According to Samantha she has a good network of parents who have children on the spectrum. She states that when she sees another mother in therapy whose child may be having a melt-down it is less stressful because "you don't have to share, because we both know."

Samantha has become very involved in the community after her daughters diagnosis, although she has experienced undignified treatment from people who do not know her educational background and experience with ABA therapy: "I have decided that my autobiography is going to be titled *just a mom* because that is how I was treated this summer, it was just awful." We laugh together over her title choice and then I ask her if she feels pressure to be an active mom.

Samantha: Well, I have to be a perfect mom, because then that guilt comes in. I have to be a perfect mom, because I did that [autism] to my daughter.

Interviewer: Do you truly feel that way?

Samantha: Yes, I did that to her, so now I have to be perfect.

Interviewer: Do you think that is why you are such a strong advocate?

Samantha: Well, there is nothing out there that isn't going to tell me I didn't

**4.7.4 Closing Question.** I finish up the interview by asking if there is anything Samantha wishes she knew at the beginning of her journey, or if there is any advice she would give a parent who has just received a diagnosis.

Samantha: The one thing I tell parents is that it is going to be okay. It is challenging. Your child is the same child the day before the diagnosis. Yes, now you have a reason they are doing x, y, and z, but they are the same child. Okay, your kid was diagnosed with autism, but what if your kid was diagnosed with leukemia at 14, autism is not life threating, yes there are safety issues. But they are still your child. They will struggle, but we all have our struggles. Ours may not be something in the DSM-5 that can be diagnosed, but we all have something. There are things that are going to be challenging for them, but some things will also be easy.

## 4.8 Darcey's Story

Darcey is a 45-year-old Caucasian mother of two sons who are on the spectrum. Her oldest son Greg was diagnosed at age four and is now 11, and her youngest son Nathan was diagnosed at age three and is now eight. Darcey is the second mother in this study with two children who are diagnosed with autism. In Darcey's e-mail, she explained that she "would be proud to take place in the study," and would even do it publicly, although, this study is abiding by IRB protocol and protected the identity of all participants. Her e-mail ended with beautiful message behind why she wants to take part in this study: “You are welcome to contact me. Misconceptions and negative public portrayal of autism are some of my son’s greatest obstacles, none of which is their doing. They are not disabled until they walk out my door.” I respond to Darcey with excitement and we set up a Skype arrangement. I set up to Skype in the Speaking Center in the Communication Department at UAF and began by discussing the consent form with Darcey.

**4.8.1 Before Diagnosis.** Darcey glows with happiness as she displays photos of each of her boys through the screen from her home in Anchorage. She shares that her oldest son Greg was diagnosed in 2006 and her youngest son Nathan was diagnosed in 2008. Darcey disclosed in her e-mail that she is a special education teacher, so I ask her if she was aware of the signs to look for when detecting autism.

> Darcey: Actually no, it is a good story. In my case, because of my skills, not only my education background but also because challenging children require certain skills that come naturally. So it is to no surprise that is what I was blessed with them. And because of my natural skill in that area anyway, I was compensating for Greg without realizing how much I was doing. It wasn’t until their father, my former husband and I, visited his family in the states. One of his uncles was a pediatrician and he sat us down and said, ‘I hear you talking about all these challenges you are having with Greg’ and he got to the point of saying, ‘you know you should consider looking into this more.’ He was telling a story about his older son who was diagnosed with MS, and here he is a pediatrician and he never noticed it either, which is the theory of why

doctors don’t treat their own family members. And so it was the exact same thing with me. I was completely overlooking the fact that I might be looking at a developmental disability, or any issue, you know it is something more than just Greg as an intense challenging child. That was an eye opener, and it took longer to get him into the process, then with Nathan . . . The percentage of siblings, especially the same sex, is really high so you can pretty much accept it, which was the case.

We exchange with small talk about the story, and I ask Darcey how she felt when her son was diagnosed.

Darcey: I did have a four to five month adjustment period at first. It took me a while to decide to follow through with the information I had gotten, and it shouldn’t have bothered me.

Interviewer: Why do you feel like it should not have bothered you?

Darcey: Because as soon as I had more information I didn’t think twice about it. I didn’t think of it as sad or scary, my issue was choosing to get all the information. And now I am one of the parents that says, ‘oh your child was diagnosed as autistic, YAY’ and share the great things about it. But then I was not near as informed on autism as I am now, so it took a while for me to grasp the fact that there are reasons behind the difference my son has compared to others. And there are reasons for all these differences that are going to continue to be compared to my same age friends who have babies, they are going to be completely opposite. Getting my mind around accepting the fact that this is a difference and moving on with it.

**4.8.2 After Diagnosis.** Darcey describes the way her family members received the diagnoses as the “way a lot of other people still react to it.”

> Darcey: People act like it is something they need to be sorry for, like ‘oh I am sorry’ as if your child has an illness or something. But that is part of the misinformation about autism that still persists. I mean you see it in the media that this is something terrible, this is something sad; this is something we need to cure. All this misinformation in the news about there being something wrong here, and yes you get a lot of that.
>
> Interviewer: Do you have close friends that feel that way?
>
> Darcey: As my children have gotten older, my friends with same age children have become less and less involved . . . by choice.
>
> Interviewer: Isolation?
>
> Darcey: Absolutely. And I find that with a lot of families . . . it seems to me that lots and lots of families with autistic children experience isolation, and it is a really big issue. That is one of the things that ties into the idea that there is something to be afraid of here. And because my oldest son, Greg, is particularly challenging to people who don’t know him well, or feel like they have the tools to understand and interact with him, they tend to stay away.

We talk about the idea of isolation, and both agree that is it typically due to lack of understanding, or misinformation, that people have about autism.

> Darcey: It is not a deficient in people, it’s a lack of understanding based on what is out there in the media and such. It is almost as if they feel more disabled than my son, and I don’t even use that word anymore even though autism is considered a disability, it actually is not . . . it is as if people, regular

> neurotypical adults feel disabled when dealing with my children, so they just don't.

Darcey describes how she is aware of the "social code switching" that needs to happen while having play dates. She also expresses her understanding of the difficulties that would happen if she "dropped her children off at a house with neurotypical children." Darcey then explains to me the adult autistic advocates that term themselves as "aliens, and they term themselves that way and say it positively because they think of it as my brain is nothing like your brain." Darcey then compares how both her sons understand interaction exchanges to the story about the adult advocates:

> If you don't speak alien, then we are going to have a hard time. And when you have the younger aliens, who are kids, if you are not accustomed to that different style of relating, there is so much miscommunication and misunderstanding. You know your neurotypical parent is going to expect certain behaviors and a certain level of respect. And you just might not get that, and then you may have a power struggle. Especially, with Greg and the way he interacts, and then it's just downhill from there. Then everyone has a poor experience and it damages the relationship and kind of spirals downwards.

Darcey educates me on her wide knowledge base of popular autism cultural terms as we talk about common autism terminology. Darcey continues to learn more about autism through her home life and culturally:

> I've been through many IEP meetings where I know way more about autism than any of the district representatives, psychologist, and sped teachers in the

> room. And you can guarantee that unless you are autistic or you live with it on the day to day basis, you do not know anything. You just don't. There is a big difference between book and life. That is what adult advocates are pushing for now, they say is, 'not about us without us' because there is too much being passed around about what autism is without actually asking those that are autistic, and that is how they word themselves. That is why you don't hear me using person first language, because it was developed by neurotypical people. Autistic people will say, no, autistic is what I am, and that is how I should be listed.

As an academic I have been taught to always use people first language, so I ask Darcey to explain more behind her choice to not use people first language: "When people try and separate something about you from who you are, it is considered a negative . . . you can't separate autism from the person, and if you try to, then you are saying this is a lesser thing about you, and autistic adults are saying that it is not."

**4.8.3 Advocacy.** Darcey describes a recent presentation she gave on parenting those on the spectrum, and how her home understanding with educational understanding has impacted these presentations. She is currently working on a website to let the Alaska community know about her training on parenting techniques those on the spectrum and wants to be "a voice for autism."

> Darcey: The new parenting techniques is what changed our lives for the positive, and it changed my approach in dealing with my sons. It is the basis of my grasp on autism acceptance and the idea behind *different not less*. Especially, when it comes to challenging intense behavior. That is what it was originally designed for, it has made all the difference in the world . . . the

> parenting techniques I teach is about relationships it is about how you see and how you relate to your children.

Darcey explains to me how before she knew and practiced the new parenting techniques she was having difficulty with her boys:

> Darcey: You couldn’t just say, ‘Greg, do this’ and he would be like yes mom and go and do it. Everything was a struggle . . . all those traditional parenting approaches just made it worse and they made for greater power struggles, they made me *angry mom*, and that makes my relationship with my son is suffer.
>
> Interviewer: Can you describe how you felt before you discovered these new parenting techniques?
>
> Darcey: It was frustrating and it was painful. Because I don’t want to be angry mom, and because working with kids who are challenging is something I was always really good at. I come from a family of teachers, I’ve been working in classrooms and volunteering in classrooms and always loved it because it comes naturally with me. So having my own child perplexed me and no amount of skill I could draw on seemed to be providing us the kind of relationship . . . it was a constant battle for us . . . I was looking at my child as a neurotypical child and wondering, ‘why isn’t he doing these things he should be doing?’ I have my education on autism, and I am learning more and more of the information I need to understand. Trying to relate with him on that shared communication.
>
> Interviewer: Did these parenting techniques change your relationship with your boys?
>
> Darcey: Yes, I was able to feel love and joy again.

The new parenting approach was able to help Darcey communicate with her sons, which changed her "vision and way of seeing things." Darcey describes it as "incredibly empowering" and expresses her desire to help other families understand this approach.

> Darcey: The difference is an autistic child needs to feel like they belong. Because everywhere else they go in the world tells them they are different. The minute they walk out their door. That is if they even feel as if they belong at home, and unfortunately so many don't. They walk out the door and the world makes them feel like they do not belong to it. And that is part of the message that I would like to change, and to be able to provide to other families the same foundation that I have now. That's really a big goal of mine.

Even with all the great training and improvements, Darcey explains to me that there is still isolation. She shares that her sons "do not have a lot of same age friends there really isn't that. And there is a lot of space to be made to do that in the community for autistic families, and I would like to do that, but that is another thing on the list of things to do."

**4.8.4 Closing Question.** I ask Darcey if there is anything throughout her journey that she has learned that she would like to share with a mother who just got the diagnosis that her child has autism.

> Darcey: It would be 'congratulations' rather than, 'I am sorry.' Congratulations you just had a child that is only 2% that are ever born. Something great is meant by this, you just have to figure out what that skill is.

We continue to talk about authors Darcey recommends me to research as well as web sites for me to visit. Darcey's shared with me her wealth of knowledge about autism and an hour out of her day to talk with me about her experience with her boys. We wave goodbye to our cameras and I pack up my lap top to head home.

### 4.9 Hannah's Story

Hannah is a 32-year-old Caucasian women with a four-year-old son, Zach, who was diagnosed at two. Prior to our meeting we decided to meet mid-day at a local book store. As I walk into the book store I hold the entry door open for a woman carrying a baby. Once we both enter the store the lady turns to me and asks if my name is Danielle and introduces herself as Hannah. We settle at a table off to the side and go over the consent form before beginning the interview.

**4.9.1 Before Diagnosis.** I ask Hannah to begin the interview by describing when she first became aware of her son's autism:

> It was a little more obvious than other kids because he has speech issues and he is actually still nonverbal at four. He could speak a few words, and then he lost them. So at that point we were sent to the initial screening to get the work up done. It was kind of early, he was 18-months-old, but even at that early point, it was really hard to think, *there is something wrong with my child.*

Everyone around Hannah at this time was "trying to be encouraging and would say that nothing was wrong." Although Hannah expresses that she had a "slight intuition that something was going on." She decided to take her son in for further evaluation.

> Hannah: After I had met with the doctor we sat in a room with her [parent navigator], and my son was chewing on his shirt. She looked at me and said, 'I have a son who is autistic and I remember when he used to do that sort of thing,' which was really strange for me, and at that point I didn't know much

> about autism and I went to the parking lot and I just sobbed. My husband was with me, and he had a very strong sense of denial, and I think I have handled it better than him because he is his *son.*
>
> Interviewer: Do you ever feel yourself being strong for your husband and your family?
>
> Hannah: I think in the beginning I wouldn't tell him everything. It wasn't like I was keeping things from him, but only sharing what he really needed to know. So in the beginning I think I was, then we saw another doctor a few months later for the complete diagnosis and when we were told for sure that he does have autism. I think my husband was shocked because he was probably thinking we were going to go there and just be told that our son needs extra help. So I think that was harder for him.

**4.9.2 After Diagnosis.** Hannah and I speak about the spectrum and how unique each child is. Hannah then refers to when they received the diagnosis the doctor had told them originally that it was good they began early intervention at the young age. The doctor illustrated that if they do intense therapy now, then by the time the child is ready to go to kindergarten they are usually able to mix into the class just fine: "I think we hung too much of our hopes on that, so now we are at the point where he is 4 and still does not talk, in pre-K, and I hope that my husband realizes that he is probably not going to be in the regular classroom. But I think we had our hopes on a different path."

I asked Hannah if she had a network of mothers either locally or online:

> I tried to get into contact with the Autism society here in Fairbanks, but I found it kind of hard to get a hold of them. I found out they have an office and

> I went there three times and nobody was there, I called left messages, and I emailed them but I couldn't really get ahold of anybody. So I guess I really don't have a good network of people really. Now the most recent thing for me is I am really excited about the classes he is in now.

Pre-school has been a great experience for their family. The teachers work well with him, and they send home daily accomplishment sheets connecting Hannah with what Zach did in school that day. With the support Hannah is receiving through Zach schools, I ask how her experience was telling her family about Zach's autism.

> Hannah: Well it was really interesting, my husband's family lives here, his sister and brother. His sister has three children, one is 6 and then twin 5-year-olds, and they all have special needs. The oldest was diagnosed with autism and the twins were in the special needs pre-k, so there was something already kind of there, some base of knowledge of what autism is, and my son wasn't talking, but my husband told them and I think that was hard for him to do. What is almost harder is when people are trying to convince me that there is nothing wrong, that he is just young, and maybe it was the doctor, and how can they even tell. I eventually want to say to them *this is how it is, and it is not helping me to have you try and convince me otherwise.*

Hannah's parents do not live in Alaska, but she has a great relationship with her family and is able to talk with them weekly. Her step mom is a teacher and understands autism more than others, although her dad listens well: "I talk to my dad a lot and he is really encouraging and is who I vent to when I need it." Her husband's local family support and her own family's long distance support provide a strong network for Hannah. Although getting in touch with the local autism community would be helpful.

> Hannah: I do have my friend who has children on the spectrum, and we talk about those things, and her husband is a great guy also. I have tried to get together to have dinner and it is just hard with the new baby and our husbands' schedules. And also, we almost had them over once, but my husband was kind of overwhelmed with the issues and the feeling of 'I don't not want to talk about it anymore.' You know like being around other people who have kids on the spectrum, and they want to talk about it, and it is kind of interesting because he doesn't always really want to talk about it.

Hannah explains that her view about her son's autism is different than her husband's, although they tend to "balance one another out." Her husband did express that it is hard to walk in the door and not have their son say, "Hi Daddy" because he is nonverbal. She illustrates how her identity has changed since they have had kids when I ask if receiving the diagnosis has impacted her life.

> Hannah: I think I was not as ready as I thought I was to have children. I really struggled with the lack of freedom and I guess I didn't realize how different life is once you are a mom, and I would feel guilty because of these thoughts. I had had this idea in my mind of what I was capable of and I didn't think I was doing that.
>
> Interviewer: Does that guilt come from pressure of your own expectations?
>
> Hannah: Yeah, and I was still going through some of that when he was diagnosed. And that was at 18 months, and this last year or so, I don't want to say come to terms, because that is not exactly what I mean but it is more like I

> realized that I am a mom of a child who has special needs and that is part of my identity now, and I don't think my husband is there yet, let alone feeling like a father of a child with special needs. Like for me I identify with that now, definitely, and I can reflect back more and see that is hard to be a new mom, and I shouldn't have put so much blame on myself, and that it is not my fault, it is not something I could have prevented or changed, so that is a comfort now, and that I can give myself a break.

**4.9.3 Advocacy.** Certain social situations have been difficult for Hannah because her son is nonverbal. She is often in between the thoughts of, *do I tell them he has autism* or just playing it off like Zach does not feel like talking.

> Hannah: I think, well recently I have noticed that one of the issues has been whether or not to tell people. And when we went to take my son to the dentist, and my husband was with me, and they had to take x-rays and clean his teeth, so I was sitting with him, and I said to her, 'Did they tell you he is autistic?' And she said, 'No they didn't' and I was like, 'Okay, well he is just so you know.' And then a couple days later my husband said to me, 'Why do you have to tell everybody? Why is it something you have to announce to people?' And actually, I don't feel like I do that, I feel like I hide it, and I'm not trying to, but I don't want people to feel sorry for us and have pity, it is uncomfortable for me.

Hannah explains another social situation in relation to sharing if her son has autism that occurs often:

> When we are at the grocery store, he does pretty good and doesn't yell, I mean he grabs stuff off the shelf and puts it in the cart, but the thing is that the

> checkers are always trying to get him to talk to them and saying, ‘Hi, how are you doing?’ and so I make an excuse every time and I say, ‘Oh he doesn’t like to talk very much, or he is very tired today, he’s shy’ because he is just sitting there and we are in the checkout line and I’m trying to explain to this person I don’t know . . . I feel bad because I don’t feel bad he is autistic, and I don’t feel shameful. But for convince shake I don’t know this person and I don’t know what exactly to say. And it is kind of weird and I don’t think they want that heavy of an explanation either.

**4.9.4 Closing Question.** As we begin to finish the interview I ask Hannah, “If you could go back to the beginning is there something you wish you knew then?”

> Hannah: You have to just be careful not to wear yourself too thin, which I heard but didn’t listen to, and my background is in library so I went and checked out like twenty books at a time, and I would get stressed out that I didn’t read them, so really you just have to be careful to do one thing at a time.
>
> Interviewer: Which sounds good, but I am sure can be hard to do.
>
> Hannah: Right. Especially when you want to do the best you can for your child, and you think *I can learn how to do all these therapies myself, so I am going to stay up late at night and get certified,* which realistically it is hard to do. But I think you just have to take it a little bit at a time.
>
> I thank Hannah for taking part in the interview, and we begin to pack up our belongings.

# Chapter 5

## Analysis

*"In darkness, the pupil dilates searching for light. In adversity, the heart dilates looking for God." Victor Hugo*

As the researcher, I have been immersed in the data throughout the entire journey of this thesis. Immediately following the interviews I transcribed the conversations and then placed the data into narrative stories, resulting in immersion with each individual interview. During the data collection I kept my researcher journal, bracketed when my biases arose, and practiced thick description so as not to interpret the data at that time. I used the tools of reflexivity to account for my own biases in order to represent the co-researcher's experience, although Gergen and Gergen (1991) explain how the researcher's finger-prints are inevitably all over the research. A narrative analysis followed where I interpreted the thematic structures derived from the interviews.

Five themes emerged in representing the experience of a mother when her child is diagnosed with autism: (a) public scrutiny, (b) family and friend responses, (c) mother versus society, (d) guilt and stress, and (e) advocacy and networking. Through the lens of Orbe's co-cultural theory (1998b) and Richey and Brown's (2007) communication model of the social construction of the emergent self, mothers' identities are constructed through their relationships and cultural influences. Therefore, two overall categories were applied to the five themes to organize the co-researchers' experiences: (a) relational construction of identity and (b) cultural construction of identity. This final chapter is a compilation of the themes that emerged throughout the narrative analysis process, which centralize the experiences of those who may not always be heard.

## 5.1 Relational Construction of Identity

Impacted and constructed through the maintenance of relationships, identity continuously changes over time. Identity reconstruction relies on the continuous building of relationships (Richey & Brown, 2007) and these relationships are always changing and adapting, just as people are continuously changing. Gergen (1994) states that “we achieve understanding of the world and ourselves” through cultural and social “interchanges” shared among people (p. 49**).** Therefore, the identity of a person is obtained through the interactions and relationship they have.

**5.1.1 Public Scrutiny.** Seven of my nine co-researchers experienced negative public scrutiny. Public scrutiny is the examination of a person (e.g., the co-researcher) in a public setting (i.e., people other than family or friends). The stigmatization occurs because social interaction norms are typically different with those who have autism, consequently stigma arises when the norms of social interaction are violated. Those social interaction cues range from eye contact, give and take method of communication, tantrums, and a lack of communication (i.e., the child is nonverbal) (Bellini, 2008). However, the social interaction practices are only considered different because of the social construction of “normal.” Therefore these norms can, and often do, change over time. In relation to the increasing number of people who are diagnosed with autism each year, these social interaction norms are likely to adapt. Therefore, as more people violate the social interaction norms, the social construction of interaction will shift gradually because norms are maintained through communication.

In public settings people usually assume children with autism are neurotypical, and therefore lacking the understanding as to why the child's behavior is other than that of a neurotypical child. These encounters typically occur at places like a local grocery store where people, who the mothers do not know, give their opinion to the mother about their child. Heather illustrates this point when she explains:

> People didn't understand, they judged, they thought it was just a parenting thing, I didn't like going to the stores, and it was one of the biggest nightmares of mine. She would scream the whole time . . . and then people look at you and they are like, 'Make your child stop, your child just needs a spanking' and giving unsolicited advice.

Katelyn shared a similar story about a man coming up to her in the grocery store and how he said, "Your son shouldn't be riding on the cart." The man proceeded to tell her son to get off the cart, although Katelyn prefers her son to be on the cart because she can watch him better. She responded to the man by telling him, "He has some disabilities and he doesn't talk," but the man stated his opinion when he responded, "That is no excuse."

There are times where the interaction oversteps boundaries and the co-researcher has to explain to complete strangers about their child's autism. Tori shares a story about an interaction with a cashier that resulted in her son having a major melt-down:

> The cashier turns to Robert and says, 'HEY! Don't you think are too big to be in a cart?' and Robert doesn't respond so the cashier says, 'Hey I'm talking to you!' . . . I can feel the heat crawling up me . . . and I just quietly said, 'If you haven't noticed the full-length purple cast on him, he just had surgery and he is

> nonverbal and autistic' and then the cashier just gave a blank look. But then I had to restrain Robert and remove him while he's biting me and fighting me as I am taking him out of the store.

Interactions such as Tori's indicate the lack of understanding people have about autism. Tanya also shares how she believes people do not understand autism: "I think they mean well, and it comes from a good place, and they don't mean to hurt me, but they are not considerate." Tanya also gave an example of when her husband brought their son to the store and a young boy was "mimicking her son" which offended her husband. Tanya believes the boy was just showing off in front of his girlfriend and did not understand the reason her son was crying was because he has autism.

There are also times when mothers are not sure if they should explain their children's autism, or play down the social expectancies violation. Hannah's son is nonverbal and when she encounters public situations she is unsure if she should explain about her son's autism, or survive the social interaction by making something up:

> When we are at the grocery store, he does pretty good . . . but the thing is that the checkers are always trying to get him to talk to them and saying, 'Hi, how are you doing?' and so I make an excuse every time and I say, 'Oh, he doesn't like to talk very much, or he is very tired today, he's shy,' because he is just sitting there and we are in the checkout line and I'm trying to explain to this person I don't know . . . But for convenience sake, I don't know this person, and I don't know what exactly to say. And it is kind of weird and I don't think they want that heavy of an explanation either

The public interactions place mothers in situations where they are on the spot. Darcey explains that when she does tell people her two boys have autism, she receives responses not equivalent to the way she feels:

> It is something they need to be sorry for, like ‘Oh, I am sorry,’ as if your child has an illness or something. But that is part of the misinformation about autism that still persists. I mean you see it in the media that this is something terrible; this is something sad; this is something we need to cure all this misinformation in the news about there being something wrong here.

**5.1.2 Family and Friend Responses.** Family members and friends are interpersonal relationships that impact a person’s life. Eckstein, Belongia, & Elliott-Applegate (2000) state that “families can be an important source for encouragement” (p. 406). Therefore, a strong network of family and friends can lead to an encouraging experience for a mother who has a child diagnosed with autism. Family members may not know how to interact with the child due to a lack of information about autism and have a hard time accepting the fact that the child is not neurotypical. These factors can be extremely isolating for the mothers of those children. Six out of the nine co-researchers experienced a lack of involvement from family members and friends or refusal to accept their child as diagnosed with autism.

During the diagnosis process friends and family often try to be encouraging by stating “nothing is wrong.” However this is not the reassurance the mother is often looking for at this time. Hannah describes the diagnosis time: “It was really hard to think, *there is something wrong with my child* . . . And everyone around me was trying to encourage me and say nothing’s wrong.” People may not know what to say when they hear their family or friend’s child has been diagnosed with autism.

Although, denying the child has anything going on is a response most parents do not want to hear, such as Hannah explains:

> What is almost harder is when people are trying to convince me that there is nothing wrong, that he is just young, and maybe it was the doctor . . . I eventually want to say to them this is how it is and it is not helping me to have you try and convince me otherwise.

Acceptance also occurs on a more intimate level in the home with spouses. Sometimes, it is hard for the fathers' to completely wrap their minds around their child having autism. Donna describes how the lack of acceptance looks in her home:

> My husband doesn't really acknowledge the whole thing or situation he doesn't deny it, but he isn't really sure how to deal with it. With both of our kids. I'm the primary caregiver because he works out of town a lot and he relies on me to provide him information. He doesn't really seek it out himself.

Along with acceptance, there are issues with understanding what a diagnosis means. Samantha explains how her family "just doesn't get it" and how she stopped telling stories to her parents because they always respond with, "Oh, that sounds like a typical four year old" or ask, "Is Katie normal yet?" Katelyn also encountered a lack of acceptance of her son's autism with her family. She shares how they received support from people, but it was not from the people she expected:

> We were always very upfront . . . We had a lot of support from people, but at the same time people who I thought would support us the most, actually turned their back on us, which was all our families basically. My parents were very much ashamed for having a retarded grandson, just ridiculous things. I have a

> sister I haven't seen since shortly after he was born just because it was too much for her. She does not want to be associated with us.

Heather's family accepts her daughter's diagnosis, and she even felt relief in being able to share the diagnosis to explain her daughter's behavior. However, Heather's mother who is "calm, cool, and collected" became frazzled while making something for Heather's daughter to "twizzle" (an object to use as stemming or to flap repetitively) one afternoon:

> She was watching the kids for a day, because I needed a break, and I came home and the whole living room was covered in ripped pieces of paper all over. And my mom greeted me at the door and she goes, 'Don't look at the mess, I will clean it up, but I just couldn't get it the right width.'

Heather's mom could not get the stemming object the correct width for her granddaughter to twizzle.  This factor created a unique adaptive situation for her mom.

**5.1.3 Mother Versus Society (School, Doctor, Therapy, and Solving).** Originally known as an actress and T.V personality, Jenny McCarthy is now known as being an advocate for anti-vaccinations in relation to autism. She released her story in 2008 with the New York Times bestselling book *louder than Words: A Mother's Journey in Healing Autism.*  The awareness she brought to autism has been powerful, although with her testimony came the questioning of her son's diagnosis. The scrutiny continued as she released another book, *Healing and Preventing Autism*, which caused even harsher speculation regarding her son having autism. McCarthy (2010) continues to fight these accusations, and in 2014 she went on a talk show to clear the record about her son's autism diagnosis. She even released a Tweet surrounding the idea that her son never had autism: "Stories circulating online, claiming that I said my son Evan may not have autism after all, are blatantly inaccurate and completely ridiculous."

Unfortunately this situation is all too familiar to some mothers who are constantly fighting against the beliefs of society. However, just as Tanya stated, “If you have met a child with autism, you have only met one child with autism.” Due to the spectrum being so unique there is always speculation surrounding how a mother should raise her child. There are numerous theories surrounding the word autism, making each mother’s journey with her child on the spectrum unique. For example, when a mother has a daughter on the spectrum she can experience hardship in receiving a diagnosis. This can be based on the doctor’s biased view about females and autism. Crenshaw (1993) described how “social power works to exclude or marginalize those who are different” (p.1242) by centralizing mothers’ voices who are often muted. The concept of intersectionality is represented in a voice not being heard based on one’s standpoint, or as Samantha shares that society views her as “just a mom.” Each co-researcher explained a journey with the schools, doctors, therapies, and the thought behind solving autism in which they had to fight to be heard.

Two mothers who have daughters on the spectrum experienced the conflict over female diagnosis. Heather explains, “The doctor totally ruled her out . . . because she was a female.” Samantha also experienced difficulty in getting her daughter diagnosed. She believes part of this struggle was because she was the mother of a soldier who was deployed. Although, her experience with the doctor took a step further when she was told to not have any more children because the odds of having another child on the spectrum:

> This is something that always bothered me about doctors, because once Katie was diagnosed, I already had three kids. And I see people who have their first diagnosed with autism, they don't have any more kids because it is so strenuous on the family, but I had already had three kids, and I had doctors telling me that I should not have any more kids.

Katelyn's battle with the doctors is with vaccinations with her children after her son was diagnosed with autism. She is pushing to slow the rate of vaccination because she saw the effect they had on her son: "Every doctor is a battle . . . it is a constant fight against them because I want to slow down the vaccine and not get them all in one visit." She also experienced being treated "like she was stupid" by the doctors, despite her having over "20 years of experience" with children who have autism.

Darcey, Tori, Rachel, Samantha, and Donna all experience sitting in the IEP meetings and knowing more about their child's autism than the people in the meetings. Tori constructed the IEP for her son and she believes she shocked the school when they responded, "We've never had a parent do this before." Rachel also created her son's IEP because at the school he attends they do not have IEPs. Darcey explains how she typically knows more about autism than those in the meeting:

> And you can guarantee that unless you are autistic or you live with an autistic adult or child day to day basis, then you do not know anything. You just don't. There is a big difference between book and life, I don't care who they are but they don't know anything unless they live with or are.

Donna's experience with having a high-functioning child on the spectrum is different based on her advocating dropping services: "At the school his speech therapist stormed out of the IEP meeting when I suggested no more therapy, but she doesn't understand, she's not at home with him."

Living with a child on the spectrum allows for a mother to understand what is best for her child. Unfortunately, a mother's opinion is not always taken into consideration when discussing the child's best interest. The mother's knowledge is based on her daily experience of autism, whereas the doctor views autism in a black and white research standpoint. Although throughout the doctor's career they encounter numerous children on the spectrum, they do not know the unique story behind each child in the same light as the child's mother.

## 5.2 Cultural Construction of Identity

The culture surrounding autism is a tight-knit community where parents often see one another leaving therapies. The Autism Society of Alaska has been relatively new to the Northern most chapters. This represents the growing involvement of the autism community. It was put together by a mother who has a child on the spectrum and was seeking out a network of people with similar experiences as her. Since the induction of the Autism Society there continues to be a growing autism community in Alaska.

**5.2.1 Guilt and Stress.** According to Hodge, Hoffman, Looney, Lopez-Wagner, and Sweeney (2009), "mothers of children diagnosed with autism experience higher levels of stress than mothers of typically developing children" (p. 178). The word autism is surrounded by theories of causation, misinformation, and a lack of total understanding. With the DSM-5 there is a full explanation of what the behaviors of autism look like, yet those behaviors are on a spectrum in which cannot describe each individual child with autism. The co-researchers' children in this study ranged from high-functioning autism with full communication, nonverbal autism, low-functioning autism with multiple other medical conditions, and everything in between. The spectrum makes each mother's experience truly unique, although the question of causation remains in most mothers' minds. Based on the intimate act of carrying a child for nine months, mothers such as Donna sometimes ponder if they did something during their pregnancy that contributed to their child's autism.

> The only thing that's really bothered me is wondering if I did something wrong to make his life more difficult . . . I got dental work when I was pregnant and think maybe I didn't eat good enough . . . I just hope that I hadn't done anything.

Some mothers wonder if it was the vaccinations they gave their child, or as Heather shares if it was because of the denial she experienced:

> I always have a tiny bit of guilt till this day that I stayed in denial for so long. Because I wonder if we would've started even earlier, *where would we be?*

After the birth, some mothers are still questioning if they are making the right choices. Some mothers second guess the choices they are making now, such as taking away therapies, or as Tori explains about wondering if she would have moved outside of Fairbanks to receive better services:

> A lot of guilt I felt for many years was all of the people I knew that have children on the spectrum were going and moving for better services. And a lot of them left their families behind, and I felt guilty thinking: *Should I have done that? Would Robert have better results if I would've traveled?*

Despite the love each mother has for her child, the lack of research on autism causes the guilt and stress to overwhelm them. The guilt is based on wondering what caused their child's autism. As Samantha shares, "Well, I have to be a *perfect mom* . . . because I did that [autism] to my daughter." Not only is guilt felt, but having a child on the spectrum can also be stressful. As Rachel shares: "The house is a mess, the boys get the first priority, teaching gets second. But, I learned early on that I need to keep myself high up on that list because then I am better for them." A mother's identity shifts as she experiences these episodes of guilt. Hannah shares how throughout all these phases of guilt or stress, her identity has changed:

> At first, I think I didn't identify as much as being a mom with a child who has special needs. But, now I have had time to adjust and understand it more, and now I am definitely in a much better place because I am okay with it . . . I realized that I am a mom of a child who has special needs. And that is part of my identity now.

**5.2.2 Advocacy, Networking, Positive View.** Ryan and Cole (2009) proclaim that mothers are highly unrecognized for their role as *advocate* once they have a child on the spectrum. Although for most mothers who have a child on the spectrum this is a role they acquire. Altiere and Klug (2009) also explain how parents who have a child with a disability seek out resources for their children to better their life. Advocating redefines culture through the communication of norms. Thereby, a person with a disability is only stigmatized because society has constructed this belief through daily interactions. Murphy (1990) describes disability as a result of society's construction, and not of the person with the following: "stigmatization is less a by-product of disability than its substance. The greatest impediment to a person's taking full part in this society are not his physical flaws, but rather the tissue of myths, fears, and misunderstandings that society attaches to them" (p. 113). It is through the daily interactions that disability is misrepresented based on society norms. As Darcey demonstrates with her quote, “They are not disabled until they walk out my door.” Advocacy was a profound theme in talking with each of the mothers in this study. All nine of the co-researchers have reached out to the autism community in some way and view disabilities in a positive light.

Tori, Donna, Samantha, Darcey, and Heather are all active in the autism community and have become strong advocates for their children by getting involved. Tori describes it as a “network where we can call each other.” Samantha’s experience during the diagnosis phase frustrated her to the point of writing “five page letters” to each person she came into contact with to inform them on improvements they could make. Her letter spoke volumes and created major opportunities for positive improvements.

Other parents have reached out to the community, such as Tanya who got onto Facebook to connect with other parents. Rachel is also on Facebook connecting with other parents because it is hard to find time to get together. Facebook allows her to network from her home without having to get a babysitter.

All of the mothers expressed a positive view on disabilities. As Donna describes:

> What I've learned is how neat people with disabilities are. Because the way I was raised, they were always in separate classrooms and you never got to know many of them. I just think they each have their own cool little thing going on just like anybody else.

Donna’s viewpoint on disabilities represents how these children with autism are people just like everyone else. There is no need to separate them because of their differences, and rather one should embrace the unique qualities they have. Katelyn has also “accepted that it is autism,” and chooses to see her son as an equal to the rest of her children. As Rachel shared, the positive viewpoint on autism creates more “compassion” for those who are on the spectrum. Other than compassion, it has also pushed mothers to do things they may not have if their child was not on the spectrum. Samantha shared that she was “really shy” and “didn’t feel a part of the community” before she became a strong advocate for her daughter. Samantha shares: “I have to advocate for my child at the therapist, or in an IEP meeting, and I built confidence and passion for helping my child, and that changed who I was.” Samantha also shares that speaking with other parents is a “cathartic” experience in sharing experiences.

## 5.3 Emergent Self

The emergent self is constructed through the experience of self, the cultural identity of self, and the interactions of the relational self (Richey & Brown, 2007). Culture is invisible to its members just as experience is often invisible to the self. Therefore, the experiential self was not applied in the organization of themes. Harding (1991), Kramarae (2005), and Orbe (2005) state that those who are marginalized often do not have the words to express their experience. However, a deeper understanding of the societal structures can be understood through the standpoints of those muted groups who, unfortunately, do not always have the words to express their experience.

## 5.4 Co-Culture

Orbe’s work is complex in delineating subsets of power asymmetry in understanding communication approach and style. An application of Orbe’s approach is represented by co-researcher Heather’s response to public scrutiny. Heather has an assertive style with an accommodating approach specifically when she made information cards to hand out in public settings when she experiences public scrutiny. On the card it read: “my child is not misbehaving, here's a website you can go to learn about autism.” According to Orbe (1998a), this demonstrates Heather’s communication orientation as networking (i.e., sharing knowledge), educating others (i.e., providing an autism website on the card), and communicating self (i.e., it is not a parenting issue, my child is not misbehaving). However, the communication style and approach is continuously changing. Heather represents a communication style that results in educating others when she is in public scrutiny situations.This approach may change when she is talking with a doctor, teacher, or family member. The shift in communication orientations is inevitable throughout our daily interactions based on the different standpoints we encounter.

## 5.5 Reflecting on Public and Private

The theoretical approach of public and private is a binary construction which plays out in the experience of relationship and culture. Originally, the mother’s identity construction was going to be viewed through the lens of the private and public self. Identity was continuously represented as relational and cultural throughout the study. It seemed upon close reflection that the core issues were relegated to relationship and cultural experience in both public and private contexts.

## 5.6 Discussion

Reviewing current literature on autism, identity construction, and co-cultural theory created a foundation for interviewing co-researchers, conducting a thematic analysis in order to shed light onto the emergent themes in which to represent the experience a mother has when her child is diagnosed with autism. There were five themes: (a) public scrutiny, (b) family and friend responses, (c) mother versus society, (d) guilt and stress, and (e) advocacy, networking, and a positive view. Two categories were applied to the five themes to organize the co-researchers' experiences: (a) relational construction of identity and (b) cultural construction of identity. Each of these themes allowed for a greater insight to the experiences a mother has when her child is diagnosed with autism.

The puzzle piece symbol used to represent autism demonstrates the missing puzzle pieces surrounding the autism community. The understanding of autism is not complete due to missing pieces of the puzzle. Over time, there has been research conducted to gain a better understanding of the behaviors of autism, although there are many questions that remain unanswered. Those unanswered questions affect one in 88 families, resulting in a plethora of questions for the autism community. There is an urgent need for more research on autism in order to answer the questions for those families who experience autism. In this study, mothers' experiences of living with children on the spectrum were focused upon to gain a deeper understanding of autism's effect on daily life. Through qualitative research each co-researcher's story was shared to highlight on their experience.

**5.6.1 Future Research and limitations.** In this study, only mothers' experiences were explored. I chose to interview mothers because of the intimate nature of pregnancy which leads to the socially constructed role of a mother acting as the main caregiver. A mother's role is typically a nurturing role and she is the person most involved with her child. Therefore, I wanted to understand the experiences of a mother when her child is diagnosed. Future research should examine the father’s experience as well. Masculine roles in society are different than feminine roles, resulting in a different experience when a father has a child with autism. It would be beneficial to research the steps a father goes through when the diagnosis occurs, how he feels after the diagnosis, and if there is a strong need to fix the child rather than accept the diagnosis. Future studies could also focus on early intervention. Due to autism being extraordinarily unique, each parent’s experience is a different journey based on where their child is on the spectrum. For example, those who are high-functioning often experience a state of uncertainty through the shift between living with autism in the community and passing as a member of the neurotypical community. Some children with autism are nonverbal, so a communication study could examine the effects of being nonverbal. Autism invites infinite possibilities for research. With further research, society can assemble pieces of the puzzle to illustrate the entire picture of autism and gain a better understanding.

### 5.7 Discussion Summary and Conclusion

One is 68 American children are on the spectrum. The number of people diagnosed with autism continues to increase. Therefore, people will often interact with a person who has autism or a person directly related to someone on the spectrum. The conversational interviews conducted in this thesis allowed for potent insight to the identity reconstruction that occurs when mothers have children diagnosed with autism. With the knowledge of the five themes that emerged, a reader can more deeply understand life on the spectrum. Autism awareness is growing exponentially every day through the efforts of mothers who advocate for their children.

# References

Altiere, M., & Klug, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual and Developmental Disability, 34*(2), 142-152.

American Psychiatric Association. (2013a). DSM-5 Implementation and support**.** Retrieved from http://www.dsm5.org/Pages/Default.aspx

American Psychiatric Association. (2013b). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Bellini, S. (2008). *Building social relationships*. Shawnee Mission, KS: Autism Publishing Co.

Bettelheim, B. (1967). *The empty fortress: Infantile autism and the birth of the self.* New York: Free Press.

Blumer, H. (1986). *Symbolic Interactionism: Perspective and Method*. University of California Press.

Canary, H. E. (2008). Negotiating Dis/Ability in families: Constructions and contradictions. *Journal of Applied Communication Research, 36*(4), 437-458. doi:10.1080/00909880802101771

Carbaugh, D. (1996). *Situating selves: The communication of social identities in American Scenes.* New York, Albany: State University of New York Press.

Carbaugh, D., & Brockmeier, J. (2001*). Narrative and identity: Studies in autobiography, self, and culture*. John Benjamins Publishing.

Christiansen, C. (1999). Defining lives: Occupation as identity. *The American Journal of Occupational Therapy, 53*(6), 547-558.

Crenshaw, K. (1993). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Standford Law Review, 43, 1241-1299.*

Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). University of Nebraska, Lincoln: Sage Publications.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process.* Thousand Oaks, CA: Sage Publications.

Collett, J. L. (2005). What kind of mother am I? Impression management and the social construction of motherhood. *Symbolic Interaction, 28*(3), 327-347.

DeStefano, F., & Chen, R. (2001). Autism and measles-mumps-rubella vaccination: Controversy laid to rest? *Central Nervous System, 15*(11). 831-837.

Denzin, N., & Lincoln, Y. (2008). *Strategies of Qualitative Inquiry*. Thousand Oaks, CA: Sage Publications.

Donaldson, S., Elder, J., Self, E., & Christie, M. (2011). Fathers' perceptions of their roles during in-home training for children with autism. *Journal of Child and Adolescent Psychiatric Nursing, 24*. 200-207. doi: 10. 1111/j.1744-6171.2011.00300.x

Duggan, A., Bradshaw, Y. S., & Altman, W. (2010). How do I ask about your disability? An examination of interpersonal communication processes between medical students and patients with disabilities. *Journal of Health Communication, 15*(3), 334-350. doi: 10.1080/10810731003686630

Eckstein, D., Belongia, M., & Elliott-Applegate, G. (2000). The four directions of encouragement within families. *The Family Journal, 8*, 406-415. doi: 10.1177/1066480700084015

Ekas, N., & Whitman, T. (2011). Adaptation to daily stress among mothers of children with an autism spectrum disorder: The role of daily positive affect. *Autism Developmental Disorders, 14*, 1202-1213. doi: 10. 1007/s10803-010-1142-4.

Ellingson, L.L. (2009). *Engaging in crystallization in qualitative research: An introduction.* Thousand Oaks, CA: SAGE Publications.

Gergen, K., Kaye, J. (1992). Beyond narrative in the negotiation of therapeutic meaning. *Therapy as Social Construction.* London, Sage. P. 166-185.

Gergen, K. (1993). *Refiguring self and psychology.* England: Dartmouth Publishing Company.

Gergen, K. (1994). *Realities and relationships: Soundings in social construction.* First Harvard University Press.

Gergen, K. (2009). *An invitation to social construction (2nd ed.).* Thousand Oaks, California: Sage Publications.

Gergen, K.J., & Gergen, M.M. (1991). *From theory to reflexivity in research practice. In F.Steirer*, Research and Reflexivity, Newbury Park: Sage.

Geertz, C. (2008). *Local knowledge: Further essays in interpretive anthropology*. Retrieved from http://www.eblib.com

Goffman, E. (1955). On face-work: an analysis of ritual elements in social interaction. *Journal for the Study of Interpersonal Processes, 18*, 213-231.

Goffman, E. (1967). *On face-work.* Garden City, NY: Anchor Books.

Harding, S. & O'Barr. (1987). *Sex and scientific inquiry*. Chicago : University of Chicago Press.

Harding, S. (1991). *Whose science? Whose knowledge?: Thinking from women's lives*. Cornell University Press, Ithaca, NY, 269-270.

Heisler, J., & Ellis, J. (2008). Motherhood and construction of "mommy identity": Messages about motherhood and face negotiation. *Communication Quarterly, 56*(4), 445-467. doi: 10.1080/01463370802448246

Hodge, D., Hoffman, C., Looney, L., Lopez-Wagner, M., Sweeney, D. (2009). Parenting stress and closeness: Mothers of typically developing children and mothers of child with autism. *Focus on Autism and Other Developmental Disabilities, 24*(3), 178-187. doi:10.1177/1088357609338715

Janzen, J., & Zenko, C. (2012). *Understanding the nature of autism: A guide to the autism spectrum disorders.* San Antonio, TX: Harcourt Assessment.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous child, 2,* 217-250.

Kayfitz, A., Gragg, M., & Orr, R. (2010). Positive experiences of mothers and fathers of children with autism. *Journal of Applied Research in Intellectual Disabilities, 23*, 337-343.

Kramarae, C. (2005). Muted group theory and communication: Asking dangerous questions. *Women and Language, 28*(2), 55-61).

Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing.* Thousand Oaks, CA:  SAGE Publications.

Kvale, S. & Brinkmann, S. (2009*). Interviews: Learning the craft of qualitative research interviewing* (2nd ed.).  Thousand Oaks, CA:  SAGE Publications.

Lindlof, T.R., & Taylor, B.C. (2011). *Qualitative communication research methods* (3rd ed.). Thousand Oaks, CA: SAGE Publications.

Lyons, V. (2007). Asperger (1906–1980) and Kanner (1894–1981), the two pioneers of autism. *Journal of Autism & Developmental Disorders, 37*(10), 2022-2023. doi: 10.1007/s10803-007-0383-3

McCarthy, J. (2008). *Louder than words: A mother's journey in healing autism*. New York, NY: First Plume Printing.

McCarthy, J., & Kartzinel, J. (2010). *Healing and preventing autism.* New York, NY: First Plume Printing.

Miller, D. (1982). *The individual and the social self: Unpublished work of George Herbert Mead.* Chicago and London: The University of Chicago Press.

Miller, P., Potts, R., Fung, H., Hoogstra, L., & Mintz, J. (1990). Narrative practices and the social construction of self in childhood. *American Ethnologist, 17*(2), 292-311. doi:10.1525/ae.1990.17.2.02a00060

Miller, L., & Reynolds. (2009). Autism and vaccination – the current evidence. *Journal for Specialists in Pediatric Nursing, 14*(3), 166-172.

Morris, C. (2009). *Works of Gerorge Herbert Mead: Mind, self, and society from the standpoint of social behaviorist*. University of Chicago Press.

Murphy, R. (1990). *The Different World of the Disabled: The Body Silent*. New York, NY:Norton and Co.

Notbohm, E. (2012). *Ten things every child with autism wishes you knew.* Future Horizons, Inc.

Orbe, M. (1998a). From the standpoint(s) of traditionally muted groups: Explicating a co cultural communication theoretical model. *Communication Theory, 8*(1), 1-26.

Orbe, M. (1998b). *Constructing co-cultural theory: An explication of culture, power, and communication.* Thousand Oaks, CA: Sage.

Orbe, M. (2005). Continuing the legacy of theorizing from the margins: Conceptualization of co cultural theory. *Women & Language, 28*(2), 65-66.

Orbe, M. P. & Kinefuchi, E. (2008). Crash under investigation: Engaging complications of complicity, coherence, and implicate through critical analysis. *Critical Studies in Media Communication*, 25(2), 135-156. doi: 10.1080/15295030802032275

Richey, J. & Brown, J. (2007). Cancer, communication, and the social construction of self. In O'Hair, D., & Kreps, G. (Eds.), *The handbook of communication: Cancer care* (pp. 145-64). Cresskill, NJ: Hampton Press.

Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.). (p.923-943). Thousand Oaks, CA: SAGE Publications.

Rogers, L., Magill-Evans., & Rempel, G. (2013). Mothers' challenges in feeding their children with autism spectrum disorder – managing more than just picky eating. *Developmental & Physical Disability, 24*, 19-33.

Rosenberg, R., Law, K, Anderson, C., Samango-sprouse, C., & Law, P. (2013). Survey of vaccine beliefs and practices among families affected by autism spectrum disorders. *Clinical Pediatrics, 52* (9), 871-874. doi: 10.1177/0009922812438435

Ryan, S., & Cole, K. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities, 22,* 43-53.

Simpson, D., Hanley, J, & Quinn, G. (2003). *Refrigerator Mothers.* United States. Kartemquin films.

Smith, L., Hong, J., Mailick, M., Greenberg, J., Almeida, D., & Bishop, S. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Autism Developmental Disorders, 40*. 167-178. doi: 10. 1007/s10803-009-0844-y

Stace, H. (2010). Student research report, mother blaming; or autism, gender and science. *Women's Studies Journal, 24*(2), 66-70.

Sousa, A. C. (2011). From refrigerator mothers to warrior-heroes: The cultural identity transformation of mothers raising children with intellectual disabilities. *Symbolic Interaction, 34*(2), 220-243. doi: 10.1525/si.2011.34.2.220

Taylor, J., & Seltzer, M. (2011). Changes in the mother-child relationship during the transition to adulthood for youth with autism spectrum disorders. *Autism Developmental Disorders, 41*, 1397-1410. doi: 10. 1007/s10803-010-116-9.

Vacca, J. (2013). The parenting process from the father's perspective: Analysis of perceptions of fathers about raising their child with autism spectrum disorder. *Best Practices in Mental Health, 9*(2), 79-93.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.

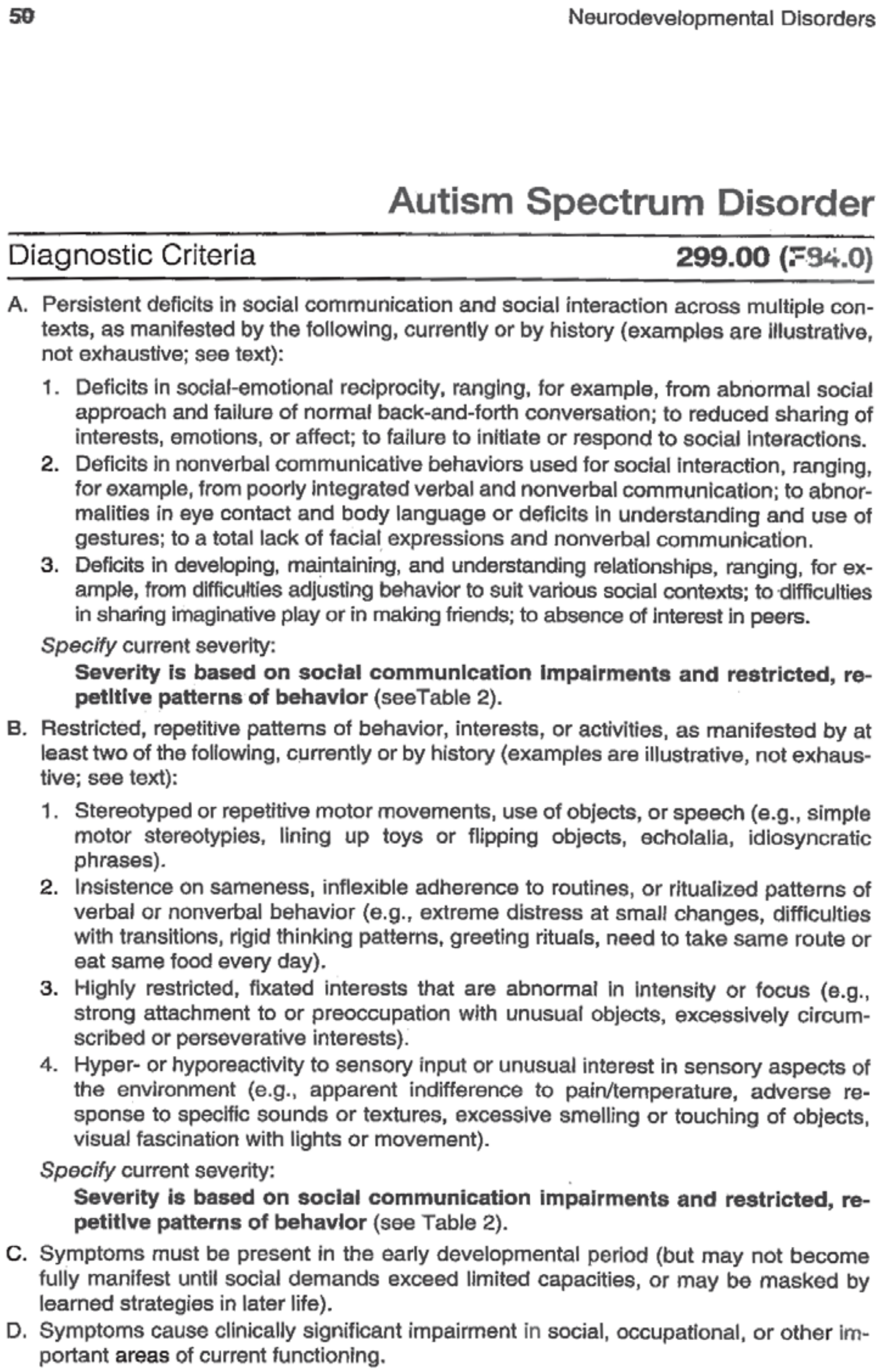
Wakefield, A.J., Murch, S. H., Anthony, A., Linnell, J., Casson, D. M., Malik, M., Walker-Smith, J.A. (1998). Ileal-lymphiod-nodular hyperplasia, non-specific colitis, and pervasive development disorder in children. *The Lancet, 351*, 637-641.

Zenobia C.Y. Chan, Z., Fung, Y., and Chien, W. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process. *The Qualitative Report, 18*(59) 1-9.

# Appendices

## Appendix A

## DSM-5 Autism Definition



### Autism Spectrum Disorder

**Diagnostic Criteria** **299.00 (F84.0)**

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*Specify* current severity:

**Severity is based on social communication impairments and restricted, repetitive patterns of behavior** (seeTable 2).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

*Specify* current severity:

**Severity is based on social communication impairments and restricted, repetitive patterns of behavior** (see Table 2).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

**Note:** Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

*Specify* if:

**With or without accompanying intellectual impairment**

**With or without accompanying language impairment**

**Associated with a known medical or genetic condition or environmental factor** (**Coding note:** Use additional code to identify the associated medical or genetic condition.)

**Associated with another neurodevelopmental, mental, or behavioral disorder** (**Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

**With catatonia** (refer to the criteria for catatonia associated with another mental disorder, pp. 119–120, for definition) (**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

## Recording Procedures

For autism spectrum disorder that is associated with a known medical or genetic condition or environmental factor, or with another neurodevelopmental, mental, or behavioral disorder, record autism spectrum disorder associated with (name of condition, disorder, or factor) (e.g., autism spectrum disorder associated with Rett syndrome). Severity should be recorded as level of support needed for each of the two psychopathological domains in Table 2 (e.g., "requiring very substantial support for deficits in social communication and requring substantial support for restricted, repetitive behaviors"). Specification of "with accompanying intellectual impairment" or "without accompanying intellectual impairment" should be recorded next. Language impairment specification should be recorded thereafter. If there is accompanying language impairment, the current level of verbal functioning should be recorded (e.g., "with accompanying language impairment—no intelligible speech" or "with accompanying language impairment—phrase speech"). If catatonia is present, record separately "catatonia associated with autism spectrum disorder."

## Specifiers

The severity specifiers (see Table 2) may be used to describe succinctly the current symptomatology (which might fall below level 1), with the recognition that severity may vary by context and fluctuate over time. Severity of social communication difficulties and restricted, repetitive behaviors should be separately rated. The descriptive severity categories should not be used to determine eligibility for and provision of services; these can only be developed at an individual level and through discussion of personal priorities and targets.

Regarding the specifier "with or without accompanying intellectual impairment," understanding the (often uneven) intellectual profile of a child or adult with autism spectrum disorder is necessary for interpreting diagnostic features. Separate estimates of verbal and nonverbal skill are necessary (e.g., using untimed nonverbal tests to assess potential strengths in individuals with limited language).

**TABLE 2 Severity levels for autism spectrum disorder**

| Severity level | Social communication | Restricted, repetitive behaviors |
|---|---|---|
| Level 3<br>"Requiring very substantial support" | Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches. | Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action. |
| Level 2<br>"Requiring substantial support" | Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication. | Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action. |
| Level 1<br>"Requiring support" | Without supports in place, deficits in social communication cause noticeable impairments.<br>Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful. | Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence. |

To use the specifier "with or without accompanying language impairment," the current level of verbal functioning should be assessed and described. Examples of the specific descriptions for "with accompanying language impairment" might include no intelligible speech (nonverbal), single words only, or phrase speech. Language level in individuals "without accompanying language impairment" might be further described by speaks in full sentences or has fluent speech. Since receptive language may lag behind expressive language development in autism spectrum disorder, receptive and expressive language skills should be considered separately.

The specifier "associated with a known medical or genetic condition or environmental factor" should be used when the individual has a known genetic disorder (e.g., Rett syndrome, Fragile X syndrome, Down syndrome), a medical disorder (e.g. epilepsy), or a history of environmental exposure (e.g., valproate, fetal alcohol syndrome, very low birth weight).

Additional neurodevelopmental, mental or behavioral conditions should also be noted (e.g., attention-deficit/hyperactivity disorder; developmental coordination disorder; disruptive behavior, impulse-control, or conduct disorders; anxiety, depressive, or bipolar disorders; tics or Tourette's disorder; self-injury; feeding, elimination, or sleep disorders).

## Diagnostic Features

The essential features of autism spectrum disorder are persistent impairment in reciprocal social communication and social interaction (Criterion A), and restricted, repetitive patterns of behavior, interests, or activities (Criterion B). These symptoms are present from early childhood and limit or impair everyday functioning (Criteria C and D). The stage at which functional impairment becomes obvious will vary according to characteristics of the individual and his or her environment. Core diagnostic features are evident in the developmental period, but intervention, compensation, and current supports may mask difficulties in at least some contexts. Manifestations of the disorder also vary greatly depending on the severity of the autistic condition, developmental level, and chronological age; hence, the term *spectrum*. Autism spectrum disorder encompasses disorders previously referred to as early infantile autism, childhood autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Asperger's disorder.

The impairments in communication and social interaction specified in Criterion A are pervasive and sustained. Diagnoses are most valid and reliable when based on multiple sources of information, including clinician's observations, caregiver history, and, when possible, self-report. Verbal and nonverbal deficits in social communication have varying manifestations, depending on the individual's age, intellectual level, and language ability, as well as other factors such as treatment history and current support. Many individuals have language deficits, ranging from complete lack of speech through language delays, poor comprehension of speech, echoed speech, or stilted and overly literal language. Even when formal language skills (e.g., vocabulary, grammar) are intact, the use of language for reciprocal social communication is impaired in autism spectrum disorder.

Deficits in social-emotional reciprocity (i.e., the ability to engage with others and share thoughts and feelings) are clearly evident in young children with the disorder, who may show little or no initiation of social interaction and no sharing of emotions, along with reduced or absent imitation of others' behavior. What language exists is often one-sided, lacking in social reciprocity, and used to request or label rather than to comment, share feelings, or converse. In adults without intellectual disabilities or language delays, deficits in social-emotional reciprocity may be most apparent in difficulties processing and responding to complex social cues (e.g., when and how to join a conversation, what not to say). Adults who have developed compensation strategies for some social challenges still struggle in novel or unsupported situations and suffer from the effort and anxiety of consciously calculating what is socially intuitive for most individuals.

Deficits in nonverbal communicative behaviors used for social interaction are manifested by absent, reduced, or atypical use of eye contact (relative to cultural norms), gestures, facial expressions, body orientation, or speech intonation. An early feature of autism spectrum disorder is impaired joint attention as manifested by a lack of pointing, showing, or bringing objects to share interest with others, or failure to follow someone's pointing or eye gaze. Individuals may learn a few functional gestures, but their repertoire is smaller than that of others, and they often fail to use expressive gestures spontaneously in communication. Among adults with fluent language, the difficulty in coordinating nonverbal communication with speech may give the impression of odd, wooden, or exaggerated "body language" during interactions. Impairment may be relatively subtle within individual modes (e.g., someone may have relatively good eye contact when speaking) but noticeable in poor integration of eye contact, gesture, body posture, prosody, and facial expression for social communication.

Deficits in developing, maintaining, and understanding relationships should be judged against norms for age, gender, and culture. There may be absent, reduced, or atypical social interest, manifested by rejection of others, passivity, or inappropriate approaches that seem aggressive or disruptive. These difficulties are particularly evident in young children, in whom there is often a lack of shared social play and imagination (e.g., age-appropriate flexible pretend play) and, later, insistence on playing by very fixed rules. Older individuals may struggle to understand what behavior is considered appropriate in one situation but not another (e.g., casual behavior during a job interview), or the different ways that language may be used to communicate (e.g., irony, white lies). There may be an apparent preference for solitary activities or for interacting with much younger or older people. Frequently, there is a desire to establish friendships without a complete or realistic idea of what friendship entails (e.g., one-sided friendships or friendships based solely on shared special interests). Relationships with siblings, co-workers, and caregivers are also important to consider (in terms of reciprocity).

Autism spectrum disorder is also defined by restricted, repetitive patterns of behavior, interests, or activities (as specified in Criterion B), which show a range of manifestations according to age and ability, intervention, and current supports. Stereotyped or repetitive behaviors include simple motor stereotypies (e.g., hand flapping, finger flicking), repetitive use of objects (e.g., spinning coins, lining up toys), and repetitive speech (e.g., echolalia, the delayed or immediate parroting of heard words; use of "you" when referring to self; stereotyped use of words, phrases, or prosodic patterns). Excessive adherence to routines and restricted patterns of behavior may be manifest in resistance to change (e.g., distress at apparently small changes, such as in packaging of a favorite food; insistence on adherence to rules; rigidity of thinking) or ritualized patterns of verbal or nonverbal behavior (e.g., repetitive questioning, pacing a perimeter). Highly restricted, fixated interests in autism spectrum disorder tend to be abnormal in intensity or focus (e.g., a toddler strongly attached to a pan; a child preoccupied with vacuum cleaners; an adult spending hours writing out timetables). Some fascinations and routines may relate to apparent hyper- or hyporeactivity to sensory input, manifested through extreme responses to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects, and sometimes apparent indifference to pain, heat, or cold. Extreme reaction to or rituals involving taste, smell, texture, or appearance of food or excessive food restrictions are common and may be a presenting feature of autism spectrum disorder.

Many adults with autism spectrum disorder without intellectual or language disabilities learn to suppress repetitive behavior in public. Special interests may be a source of pleasure and motivation and provide avenues for education and employment later in life. Diagnostic criteria may be met when restricted, repetitive patterns of behavior, interests, or activities were clearly present during childhood or at some time in the past, even if symptoms are no longer present.

Criterion D requires that the features must cause clinically significant impairment in social, occupational, or other important areas of current functioning. Criterion E specifies that the social communication deficits, although sometimes accompanied by intellectual disability (intellectual developmental disorder), are not in line with the individual's developmental level; impairments exceed difficulties expected on the basis of developmental level.

Standardized behavioral diagnostic instruments with good psychometric properties, including caregiver interviews, questionnaires and clinician observation measures, are available and can improve reliability of diagnosis over time and across clinicians.

## Associated Features Supporting Diagnosis

Many individuals with autism spectrum disorder also have intellectual impairment and/or language impairment (e.g., slow to talk, language comprehension behind production). Even those with average or high intelligence have an uneven profile of abilities. The gap between intellectual and adaptive functional skills is often large. Motor deficits are often present, including odd gait, clumsiness, and other abnormal motor signs (e.g., walking on tiptoes). Self-injury (e.g., head banging, biting the wrist) may occur, and disruptive/challenging behaviors are more common in children and adolescents with autism spectrum disorder than other disorders, including intellectual disability. Adolescents and adults with autism spectrum disorder are prone to anxiety and depression. Some individuals develop catatonic-like motor behavior (slowing and "freezing" mid-action), but these are typically not of the magnitude of a catatonic episode. However, it is possible for individuals with autism spectrum disorder to experience a marked deterioration in motor symptoms and display a full catatonic episode with symptoms such as mutism, posturing, grimacing and waxy flexibility. The risk period for comorbid catatonia appears to be greatest in the adolescent years.

## Prevalence

In recent years, reported frequencies for autism spectrum disorder across U.S. and non-U.S. countries have approached 1% of the population, with similar estimates in child and adult samples. It remains unclear whether higher rates reflect an expansion of the diagnostic criteria of DSM-IV to include subthreshold cases, increased awareness, differences in study methodology, or a true increase in the frequency of autism spectrum disorder.

## Development and Course

The age and pattern of onset also should be noted for autism spectrum disorder. Symptoms are typically recognized during the second year of life (12–24 months of age) but may be seen earlier than 12 months if developmental delays are severe, or noted later than 24 months if symptoms are more subtle. The pattern of onset description might include information about early developmental delays or any losses of social or language skills. In cases where skills have been lost, parents or caregivers may give a history of a gradual or relatively rapid deterioration in social behaviors or language skills. Typically, this would occur between 12 and 24 months of age and is distinguished from the rare instances of developmental regression occurring after at least 2 years of normal development (previously described as childhood disintegrative disorder).

The behavioral features of autism spectrum disorder first become evident in early childhood, with some cases presenting a lack of interest in social interaction in the first year of life. Some children with autism spectrum disorder experience developmental plateaus or regression, with a gradual or relatively rapid deterioration in social behaviors or use of language, often during the first 2 years of life. Such losses are rare in other disorders and may be a useful "red flag" for autism spectrum disorder. Much more unusual and warranting more extensive medical investigation are losses of skills beyond social communication (e.g., loss of self-care, toileting, motor skills) or those occurring after the second birthday (see also Rett syndrome in the section "Differential Diagnosis" for this disorder).

First symptoms of autism spectrum disorder frequently involve delayed language development, often accompanied by lack of social interest or unusual social interactions (e.g., pulling individuals by the hand without any attempt to look at them), odd play patterns (e.g., carrying toys around but never playing with them), and unusual communication patterns (e.g., knowing the alphabet but not responding to own name). Deafness may be suspected but is typically ruled out. During the second year, odd and repetitive behaviors and the absence of typical play become more apparent. Since many typically developing young children have strong preferences and enjoy repetition (e.g., eating the same foods, watching the same video multiple times), distinguishing restricted and repetitive behaviors that are diagnostic of autism spectrum disorder can be difficult in preschoolers. The clinical distinction is based on the type, frequency, and intensity of the behavior (e.g., a child who daily lines up objects for hours and is very distressed if any item is moved).

Autism spectrum disorder is not a degenerative disorder, and it is typical for learning and compensation to continue throughout life. Symptoms are often most marked in early childhood and early school years, with developmental gains typical in later childhood in at least some areas (e.g., increased interest in social interaction). A small proportion of individuals deteriorate behaviorally during adolescence, whereas most others improve. Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naive and vulnerable, have difficulties organizing practical demands without aid, and are prone to anxiety and depression. Many adults report using compensation strategies and coping mechanisms to mask their difficulties in public but suffer from the stress and effort of maintaining a socially acceptable facade. Scarcely anything is known about old age in autism spectrum disorder.

Some individuals come for first diagnosis in adulthood, perhaps prompted by the diagnosis of autism in a child in the family or a breakdown of relations at work or home. Obtaining detailed developmental history in such cases may be difficult, and it is important to consider self-reported difficulties. Where clinical observation suggests criteria are currently met, autism spectrum disorder may be diagnosed, provided there is no evidence of good social and communication skills in childhood. For example, the report (by parents or another relative) that the individual had ordinary and sustained reciprocal friendships and good nonverbal communication skills throughout childhood would rule out a diagnosis of autism spectrum disorder; however, the absence of developmental information in itself should not do so.

Manifestations of the social and communication impairments and restricted/repetitive behaviors that define autism spectrum disorder are clear in the developmental period. In later life, intervention or compensation, as well as current supports, may mask these difficulties in at least some contexts. However, symptoms remain sufficient to cause current impairment in social, occupational, or other important areas of functioning.

## Risk and Prognostic Factors

The best established prognostic factors for individual outcome within autism spectrum disorder are presence or absence of associated intellectual disability and language impairment (e.g., functional language by age 5 years is a good prognostic sign) and additional mental health problems. Epilepsy, as a comorbid diagnosis, is associated with greater intellectual disability and lower verbal ability.

**Environmental.** A variety of nonspecific risk factors, such as advanced parental age, low birth weight, or fetal exposure to valproate, may contribute to risk of autism spectrum disorder.

**Genetic and physiological.** Heritability estimates for autism spectrum disorder have ranged from 37% to higher than 90%, based on twin concordance rates. Currently, as many as 15% of cases of autism spectrum disorder appear to be associated with a known genetic mutation, with different de novo copy number variants or de novo mutations in specific genes associated with the disorder in different families. However, even when an autism spectrum disorder is associated with a known genetic mutation, it does not appear to be fully penetrant. Risk for the remainder of cases appears to be polygenic, with perhaps hundreds of genetic loci making relatively small contributions.

## Culture-Related Diagnostic Issues

Cultural differences will exist in norms for social interaction, nonverbal communication, and relationships, but individuals with autism spectrum disorder are markedly impaired against the norms for their cultural context. Cultural and socioeconomic factors may affect age at recognition or diagnosis; for example, in the United States, late or underdiagnosis of autism spectrum disorder among African American children may occur.

## Gender-Related Diagnostic Issues

Autism spectrum disorder is diagnosed four times more often in males than in females. In clinic samples, females tend to be more likely to show accompanying intellectual disability, suggesting that girls without accompanying intellectual impairments or language delays may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties.

## Functional Consequences of Autism Spectrum Disorder

In young children with autism spectrum disorder, lack of social and communication abilities may hamper learning, especially learning through social interaction or in settings with peers. In the home, insistence on routines and aversion to change, as well as sensory sensitivities, may interfere with eating and sleeping and make routine care (e.g., haircuts, dental work) extremely difficult. Adaptive skills are typically below measured IQ. Extreme difficulties in planning, organization, and coping with change negatively impact academic achievement, even for students with above-average intelligence. During adulthood, these individuals may have difficulties establishing independence because of continued rigidity and difficulty with novelty.

Many individuals with autism spectrum disorder, even without intellectual disability, have poor adult psychosocial functioning as indexed by measures such as independent living and gainful employment. Functional consequences in old age are unknown, but social isolation and communication problems (e.g., reduced help-seeking) are likely to have consequences for health in older adulthood.

## Differential Diagnosis

**Rett syndrome.** Disruption of social interaction may be observed during the regressive phase of Rett syndrome (typically between 1–4 years of age); thus, a substantial proportion of affected young girls may have a presentation that meets diagnostic criteria for autism spectrum disorder. However, after this period, most individuals with Rett syndrome improve their social communication skills, and autistic features are no longer a major area of concern. Consequently, autism spectrum disorder should be considered only when all diagnostic criteria are met.

**Selective mutism.** In selective mutism, early development is not typically disturbed. The affected child usually exhibits appropriate communication skills in certain contexts and settings. Even in settings where the child is mute, social reciprocity is not impaired, are restricted or repetitive patterns of behavior present.

**Language disorders and social (pragmatic) communication disorder.** In some forms of language disorder, there may be problems of communication and some secondary social difficulties. However, specific language disorder is not usually associated with abnormal nonverbal communication, nor with the presence of restricted, repetitive patterns of behavior, interests, or activities.

When an individual shows impairment in social communication and social interactions but does not show restricted and repetitive behavior or interests, criteria for social (pragmatic) communication disorder, instead of autism spectrum disorder, may be met. The diagnosis of autism spectrum disorder supersedes that of social (pragmatic) communication disorder whenever the criteria for autism spectrum disorder are met, and care should be taken to enquire carefully regarding past or current restricted/repetitive behavior.

**Intellectual disability (intellectual developmental disorder) without autism spectrum disorder.** Intellectual disability without autism spectrum disorder may be difficult to differentiate from autism spectrum disorder in very young children. Individuals with intellectual disability who have not developed language or symbolic skills also present a challenge for differential diagnosis, since repetitive behavior often occurs in such individuals as well. A diagnosis of autism spectrum disorder in an individual with intellectual disability is appropriate when social communication and interaction are significantly impaired relative to the developmental level of the individual's nonverbal skills (e.g., fine motor skills, nonverbal problem solving). In contrast, intellectual disability is the appropriate diagnosis when there is no apparent discrepancy between the level of social-communicative skills and other intellectual skills.

**Stereotypic movement disorder.** Motor stereotypies are among the diagnostic characteristics of autism spectrum disorder, so an additional diagnosis of stereotypic movement disorder is not given when such repetitive behaviors are better explained by the presence of autism spectrum disorder. However, when stereotypies cause self-injury and become a focus of treatment, both diagnoses may be appropriate.

**Attention-deficit/hyperactivity disorder.** Abnormalities of attention (overly focused or easily distracted) are common in individuals with autism spectrum disorder, as is hyperactivity. A diagnosis of attention-deficit/hyperactivity disorder (ADHD) should be considered when attentional difficulties or hyperactivity exceeds that typically seen in individuals of comparable mental age.

**Schizophrenia.** Schizophrenia with childhood onset usually develops after a period of normal, or near normal, development. A prodromal state has been described in which social impairment and atypical interests and beliefs occur, which could be confused with the social deficits seen in autism spectrum disorder. Hallucinations and delusions, which are defining features of schizophrenia, are not features of autism spectrum disorder. However, clinicians must take into account the potential for individuals with autism spectrum disorder to be concrete in their interpretation of questions regarding the key features of schizophrenia (e.g., "Do you hear voices when no one is there?" "Yes [on the radio]")

## Comorbidity

Autism spectrum disorder is frequently associated with intellectual impairment and structural language disorder (i.e., an inability to comprehend and construct sentences with proper grammar), which should be noted under the relevant specifiers when applicable. Many individuals with autism spectrum disorder have psychiatric symptoms that do not form part of the diagnostic criteria for the disorder (about 70% of individuals with autism spectrum disorder may have one comorbid mental disorder, and 40% may have two or more comorbid mental disorders). When criteria for both ADHD and autism spectrum disorder are met, both diagnoses should be given. This same principle applies to concurrent diagnoses of autism spectrum disorder and developmental coordination disorder, anxiety disorders, depressive disorders, and other comorbid diagnoses. Among individuals who are nonverbal or have language deficits, observable signs such as changes in sleep or eating and increases in challenging behavior should trigger an evaluation for anxiety or depression. Specific learning difficulties (literacy and numeracy) are common, as is developmental coordination disorder. Medical conditions commonly associated with autism spectrum disorder should be noted under the "associated with a known medical/genetic or environmental/acquired condition" specifier. Such medical conditions include epilepsy, sleep problems, and constipation. Avoidant-restrictive food intake disorder is a fairly frequent presenting feature of autism spectrum disorder, and extreme and narrow food preferences may persist.

# Attention-Deficit/Hyperactivity Disorder

## Attention-Deficit/Hyperactivity Disorder

### Diagnostic Criteria

A. A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, as characterized by (1) and/or (2):

1. **Inattention:** Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:

   **Note:** The symptoms are not solely a manifestation of oppositional behavior, defiance, hostility, or failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required.

   a. Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities (e.g., overlooks or misses details, work is inaccurate).
   b. Often has difficulty sustaining attention in tasks or play activities (e.g., has difficulty remaining focused during lectures, conversations, or lengthy reading).
   c. Often does not seem to listen when spoken to directly (e.g., mind seems elsewhere, even in the absence of any obvious distraction).
   d. Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g., starts tasks but quickly loses focus and is easily sidetracked).
   e. Often has difficulty organizing tasks and activities (e.g., difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganized work; has poor time management; fails to meet deadlines).
   f. Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (e.g., schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers).
   g. Often loses things necessary for tasks or activities (e.g., school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones).
   h. Is often easily distracted by extraneous stimuli (for older adolescents and adults, may include unrelated thoughts).
   i. Is often forgetful in daily activities (e.g., doing chores, running errands; for older adolescents and adults, returning calls, paying bills, keeping appointments).

# Appendix B

## Consent to Participate in Research

The Reconstructed Self: Understanding the public and private identity of a mother of a child diagnosed with autism

IRB #(460350-1)

Date Approved July 2013

**Description of the Study:**

You are being asked to take part in a research study about mothers who have a child with autism. The goal of this study is to understand the private and public experience of having a child with autism. The results of this study, which come from the ten interviews in this study, will be published in a thesis. You are being asked to take part in this study because you are a woman over the age of 18 who is the birth mother of a child with autism. Please read this form carefully. You are invited to ask any questions you may have now or at any time during your participation.

If you decide to take part, you will be asked to participate in an hour length interview to share your experiences.

**Risks and Benefits of Being in the Study**:

The risks to you if you take part in this study are minor because your confidentiality will be protected. I see minimal risk of emotional harm resulting from this study. However, if any of the interview process causes you discomfort, you may withdraw from the study with no penalty. You may also choose not to answer any question that is asked and continue with the interview without penalty. A list of agencies that provide emotional support has been included here for your convenience if you would like to talk with anyone.

**Example Benefit Statements:**

There is no direct benefit to this study, although telling about your experiences with a child with autism can sometimes be personally beneficial. There is no compensation beyond our "Thanks!"

**Confidentiality**:

- Any information obtained about you from the research will be kept confidential and the data will be kept stored for five years in a secure location at the University of Alaska Fairbanks.
- Any information with your name attached will not be shared with anyone outside the research team.
- We will protect your confidentiality by coding your information with a number so no one can trace your answers to your name.
- We will properly secure paperwork and store research records in locked cabinets, with limited access.
- The data derived from this study may be used in reports, presentations, and publications but you will not be individually identified.

**Voluntary Nature of the Study**:

- Your decision to take part in the study is voluntary. You are free to choose whether or not to take part in the study. If you decide to take part in the study you can stop at any time or change your mind and ask to be removed from the study. Whether or not you choose to participate, there will be no penalty for withdrawing.

**Contacts and Questions:**

If you have questions now, feel free to ask now. If you have questions later, you may contact

Graduate Student: Danielle Tessen (907-474-1876) or Dr. Jean Richey (907-474-7405)

503 Gruening Bldg., Department of Communication

University of Alaska Fairbanks

If you have questions or concerns about your rights as a research participant, you can contact the UAF Office of Research Integrity at 474-7800 (Fairbanks area) or 1-866-876-7800 (toll-free outside the Fairbanks area) or fyirb@uaf.edu.

**Statement of Consent**:

- I understand the procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been provided a copy of this form and a list of agencies providing emotional support.

____________________________

Signature of Participant & Date

_______________________________

Signature of Person Obtaining Consent & Date

If you would like to hear about the results found in this study please leave your contact information. You do not have to share any of the information below if you do not wish.

___________________________

Email address

___________________________

Phone number

A list of resource for emotional support is provided for your convenience if you wish to talk to someone after the interview.

## Fairbanks Healthcare Providers

Access Alaska
526 Gaffney Rd #100
Fairbanks, AK 99701
(907) 479-7940

Autism Society of Alaska
526 Gaffney Rd #100
Fairbanks, AK 99701
(907) 378-3434
Susan Tanori
susant_stonesoupgroup@live.com

Fairbanks Memorial Hospital
1650 Cowles St.
Fairbanks, AK 99701
Social Service Dept: Out Patient Care
458-5239