

THE LOSS OF A DREAM: PARENTS RAISING AN AUTISTIC CHILD

by

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B. A., Arizona State University, 2004

A THESIS

Submitted in partial fulfillment of the requirements for the degree

MASTER OF SCIENCE

Department of Family Studies and Human Services
College of Human Ecology

KANSAS STATE UNIVERSITY
Manhattan, Kansas

2008

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ABSTRACT

This study explored the parents' perspective of having a child with Autism living in the home. Specifically, the researcher was looking to explore the attachment style between the parent and child, as well as the process of the parents' changing their expectations of their child, from the expectation of raising a normal child to raising a child with Autism. In order to understand the experience of both families interviewed, the researcher, through semi-structured, qualitative interviews, interviewed each parent separately. A multiple case study approach was used in order to allow for comparison within each family. Methods for analyzing the data included coding the data, so that the data could be analyzed from the individual interviews and also analyzed based on family response.

For the parents interviewed in the study, four themes emerged that were similar for all parents. These themes included the diagnosis process, the differences in attachment before and after their child was diagnosed, the changing expectations of themselves, each other and their diagnosed child, and the parents' views on getting professional help, such as therapy. Both families shared the experience of confusion during the diagnostic process, especially confusion surrounding the cause and prognosis of Autism. All parents in the study illustrated the attachment injury after their child's diagnosis, in addition to when the child began showing the classic signs of Autism. The study also found that each parent's expectations changed from higher ones of themselves, spouse and diagnosed child to more moderate and low expectations of their spouse and diagnosed child. Last, all parents interviewed expressed that seeking therapy would have helped them deal with the diagnostic process and better cope with having a child with Autism. It is believed by

the researcher that these themes have emerged because of the families' shared experience of raising an Autistic child.

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ACKNOWLEDGEMENTS

I would like to thank Anthony Jurich, Ph. D. for helping me through this process. He has encouraged me to strive to be the best that I can be, and has put in the time, effort and guidance to help ensure that I reached my academic goals.

I would also like to thank Candyce Russell, Ph.D., Sandra Stith, Ph.D., and Susan Raviaro, Ph.D for offering their guidance, expertise and interest in this project.

DEDICATION

To my parents, Ed and Linda Ritchie:

Thank you for the love and support that you have given me throughout my academic career. Both of you have always believed in my abilities and have never doubted that I could achieve my personal and academic goals. You have been there for me through everything, the good times and the bad. You have taught me the value of hard work and have helped mold me into the person that I am today. I want to let you know that I am grateful for everything you have done and couldn't have done any of this without either of you. I love you.

To my grandmother and grandfather, Jerome and Frances Ritchie:

I do not believe that any grandchild could be as fortunate as me to have grandparents that are so wonderful. I am thankful that you are able to be a part of one of the biggest milestones in my life. I want you to know that I appreciate everything that you have done to help me succeed in my personal goals. I love you.

The Berke Family:

I want to thank you for having me in your home and allowing me to work with your beautiful son. I want to acknowledge your family because working with you has inspired me to write this thesis, and even though you could not be a part of this research, other parents could tell their experience of raising a child with Autism. Your family is an amazing one and I want to thank you for giving me the opportunity to get to know all of

you and hold your family in my thoughts and prayers for years to come. Words cannot describe how much I thank you.

The O'Malley Family:

To my second family: I love each and every one of you as if you were a part of my own family. These last four years have been filled with laughter and tears. I have appreciated the opportunity you have given me to get to know you, work in your home, and virtually become a part of your family. Because of you, I have strived to advocate for people with disabilities and their families, which has partly inspired me to do this research. I appreciate your belief in my success and skill of telling the story of other families who have children with disabilities, who were able to be involved in this study. I will never forget you, and couldn't have been as successful as I have been in reaching my goals if it weren't for you. Thank you! I love all of you.

And finally to my major professor, Anthony Jurich, Ph.D. (Tony):

Over the course of my Masters program at K-State, you have not only helped guide me academically, but have also become a colleague and a friend. You have made my experience so pleasurable, that I am saddened to be graduating. Tony, you have a way about you that makes people feel at ease around you and important to the department. Those feelings have really made me feel at home and highly regarded by the MFT faculty. I appreciate all of the discussions we have had about any and everything. You are one of a kind, and I feel so fortunate to have known you and had you as my major professor. Without your guidance, I may not have been where I am today. Thank you!

CHAPTER ONE

Introduction

Although relatively little is known about Autism spectrum disorders (ASDs), research has begun to help families and practitioners understand theories surrounding its etiology and effects on the child diagnosed. The most current research suggests that ASDs could stem from several different sources, including environmental factors, biological factors, vaccinations containing high levels of mercury, and a deficiency in a child's immune and endocrine system (Fombonne, 2003; Hertz-Picciotto, Croen, Hansen, Jones, van de Water & Pessah, 2006). Research has also focused on the coping styles of the primary caregiver of the child, as well as siblings living in the home of the child diagnosed with an ASD. The research indicated that most parents with normally developing children attached to them in a way that forms a secure bond between parent and child, as opposed to parents with a child with an ASD, who often have attachment difficulties. These parents understandably form a more disorganized attachment or standoffish method of caregiving to the child (Naber, Swinkels, Buitelaar, -Kranenburg, van IJzendoorn, Dietz, van Daalen & van England, 2007).

Pauline Boss' (1999) research on ambiguous loss and familial coping found that ambiguity and grief stemmed from the caregivers' inability to find closure from their loss. Boss described this phenomenon as "leaving without goodbye" and "goodbye without leaving". "Leaving without goodbye" is often experienced by family members of loved ones who have been abducted or kidnapped, as well as loved ones who are missing in action or prisoners of war. Boss initially described "goodbye without leaving" in a context where family members of loved ones with Alzheimer's Disease (AD) lose the

relationship they once had with the person with AD. This type of ambiguity can also be applied to the grief that parents experience when their child deteriorates or lacks to develop normally, due to an ASD.

Little research has been done specifically with the parents of a child with an ASD, specifically Autism, and how they have come to terms with their child's disability, over the years, after their child's diagnosis. Pauline Boss' (1999) research on ambiguous loss among the caregivers of Alzheimer's patients has begun to scratch the surface of this concept by exploring the loss of the relationship between the disabled and the caregiver. She also discussed the changing roles and expectations that caregivers have to endure and accept, before they can move out of a "frozen grief" of their loved one's condition and successfully move on with their new situation.

The research questions, that will be asked to the participating families in this study, will not only explore the dynamics between the child diagnosed with Autism and their parents but they will also create a new niche in Pauline Boss' (1999) ambiguous loss theory by applying her concepts to parents' changing expectations and familial roles, as a way of successfully coping with the loss of relationship they have experienced through having a child with an ASD. This research will also look at the family therapy aspect of the expression of true emotions by focusing on the parent's experience through the use of Sue Johnson's approach to emotionally-focused family therapy.

These questions will be achieved by performing a dual case study. This study will allow the researcher to interview two sets of parents with children who have been diagnosed with an ASD. The families' stories of their personal experiences will help further the research within the area of parent's process of coping with their child's

disability, while bridging the similarities in Pauline Boss' (1999) theory of ambiguous loss with family members of loved ones with AD and families with loved ones with an ASD. In addition, through conducting the semi-structured interviews with parents of children diagnosed with an ASD, I hope to explore parental expectations of themselves, their child who is diagnosed with an ASD, other members of the family and the community in which they reside.

Glossary of Terms

Attachment- the affectional bond that is formed between two or more individuals (e.g. parent and child).

Attachment Styles :

Dependant Attachment Style- a style of attachment where an individual cannot effectively detach from their caregiver. In many cases, the infant will show signs of distress, by crying hysterically and/ or not eating, when their caregiver leaves their presence. In adolescence and adulthood, the individual may engage in many relationships that are codependent.

Disorganized Attachment Style- a style of attachment where an individual does not recognize his or her caregiver in infancy and shows no signs of attachment security and trust toward others in adulthood.

Secure Attachment Style- a style of attachment where an infant feels safe with his or her primary caregiver(s) which leads to the formation of meaningful relationships for the individual throughout childhood, adolescence and adulthood.

Autism Spectrum Disorders (ASD)- Pervasive Developmental Disorders that fall into the Autism spectrum including: Autism, Asperger's Syndrome, and Pervasive Developmental Disorder, not otherwise specified (NOS).

Developmental Disabilities- an organic disability that develops in utero that becomes limiting to an individual before the individual reaches early childhood and continues to debilitate throughout his or her life.

Dual Diagnosis- a term coined when an individual is diagnosed with one or more developmental disabilities.

“High Functioning Autism”- also referred to as Asperger's Syndrome. Asperger's Syndrome is an ASD that produces severe and sustained social impairments but not as severe in the communication area. The impairments seem more subtle in the very young child but become more apparent as the child reaches pre-school and school age. The Asperger child/adult is usually in the normal intelligence range (Diagnostic and statistical manual of mental disorders, 2004).

Mental Retardation (MR)- significantly sub average general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of these areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety. These impairments can range from mild MR to severe MR (Diagnostic and statistical manual of mental disorders, 2004).

Multiple Case Studies- two or more in-depth examinations of an instance of some social phenomenon, such as a village, a family, or a juvenile gang (Babbie, 2004).

Pervasive Developmental Disorders (PDD)- developmental disorders that are characterized by severe and pervasive impairments in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests and activities (Diagnostic and statistical manual of mental disorders, 2004).

Qualitative Research- a method of research that does not produce statistical data. This style of research allows researchers to explore social life in its natural setting, while producing a richer understanding of various social phenomena.

Structured Interview- an organized interview prepared with preset, open-ended questions, usually performed during qualitative research.

“Tactile Stemming”- a compulsive and inappropriate focus on the sense of touch, usually experienced by children with Autism Spectrum Disorders (e.g. repetitive rubbing, hitting, ect.).

“Verbal Stemming”- a compulsive and inappropriate focus of the feeling of one’s vocal cords and sounds that one makes, usually experienced by children with Autism Spectrum Disorders (e.g. repetitive and continual short shouts, groaning and grunting, etc.).

CHAPTER TWO

Review of the Literature

Autism Spectrum Disorders

Autism spectrum disorders (ASDs) fall under the umbrella of Pervasive Developmental Disorders (PDD) found in the Diagnostic Statistical Manual of Mental Disorders (Diagnostic and Statistical Manual of Mental Disorders, 2002). These disorders are relatively newly labeled disabilities that are affecting millions of children worldwide. According to the most recent clinical updates, autism spectrum disorders are estimated to occur in approximately every 6 per 1,000 children (Fombonne, 2003; Yapko, 2004). Furthermore, the U.S. department of education noted the increase of autism spectrum disorders in school aged children, which was approximately 12,000 children diagnosed in the 1992-1993 school year, to 118,000 children educated in the 2003-2004 school year (Yapko, 2004). ASD's, especially Autism, affects many children worldwide, where a majority of these children are boys. Currently the ratio of boys with autism spectrum disorders tower 4:1 over female children.

Epidemiological studies note a significant increase in ASDs but, since the causes of this increase have still not been identified, the findings of current research exploring the incidence, prevalence, and etiology of ASDs are inconsistent with one another. Some theories about the etiology of ASDs that have been researched have linked environmental factors, biological factors, vaccinations containing high levels of mercury, and a deficiency in a child's immune and endocrine system to the development of ASDs (Fombonne, 2003; Hertz-Picciotto, Croen, Hansen, Jones, van de Water & Pessah, 2006). Although research cannot support a direct connection between these proposed etiologies

of ASDs, they can support the facts that ASDs are prevalent and debilitating disorders for anyone who comes in contact with them, including the person diagnosed, the family of the diagnosed, and the children in the child's school system.

Two of the most well-known forms of ASDs are Autism and Asperger's Syndrome. Autism, probably the most recognized of the Pervasive Developmental Disorders, gained popularity in diagnosis during the 80s when a popular film, *Rain Man*, hit mainstream media. Although this film does not accurately capture all of the aspects of Autism, it does demonstrate much of the difficulty people with Autism and their family face on a daily basis.

Autism is marked by an onset of developmental delays by the age of three years old. Some areas of development that are affected are social interaction, communication and behavior, which include the lack of symbolic or imaginative play (Diagnostic and Statistical Manual of Mental Disorders, 2002). A child with Autism may display social impairments by avoiding eye contact with others, exhibiting flat facial expression, failing to develop peer relationships appropriate to his or her developmental level, lacking interests or shared enjoyment with others, and often showing no social or emotional reciprocity.

Some of the communication delays that accompany Autism are: first, a lack in the development or implementation of spoken language; second, the inability to carry a conversation with others; third, the presence of stereotypical or repetitive use of language, called "verbal stemming", and fourth, the absence of varied imaginative or social imitative play, consistent with the child's developmental level. Frequently, the

Autistic child is socially withdrawn and may be described as being in his or her “own world” or isolated from other children.

Junee Waites’ (2003) novel, *Smiling at Shadows: A Mother’s Journey Raising an Autistic Child*, illustrates the communication delays that often accompany Autism. She described that her son failed to develop spoken communication until age six. Instead, he would grunt and yell at a piercing volume until his needs for food, water, or stimulation were met. Waites described that she often had no idea what her son was grunting or yelling for, so she admitted to eventually tuning them out. Waites’ son’s delays of communication are also described as “verbal stemming”.

Waites also described her son’s lack of imaginative play. She recalled that her son used to meticulously line up building blocks in a row that were matched by color and size. She noted that other children, who had played with the same blocks, built houses and log cabins with them. Her son, on the other hand, chose to create a long line of blocks grouped by color or pattern, which would eventually cause his playmates to lose interest in his play and move onto other games or toys. Waites’ son’s communication style is typical of many children diagnosed with an ASD.

In addition, many children with Autism appear to be lost in their own world. I have observed children with Autism, in a learning facility specifically designed for Autistic children, tune out sounds around them and stare straight forward into space. Someone could call their name, typically getting no response from the child. At times, even walking over to the child and tapping him or her on the shoulder may invoke no response from his or her trance-like state. Other behaviors that I have observed include running around a room or classroom uncontrollably, while laughing hysterically, with no

cognizance of others or things around them. I have seen these children literally plow over siblings, other playmates, and objects in their path without looking back or slowing down. Usually an adult has to catch and hold the child so he or she doesn't cause more destruction to the room or hurt the children around them.

Behavioral characteristics that Autistic children display include a preoccupation with a stereotyped activity that is characterized by abnormal intensity of interest, adherence to specific and rudimentary rituals in everyday activities, repetitive motor mannerisms (flapping of the hands, etc.), also called "tactile stemming", and preoccupation with parts of objects (DSM-IV-TR, 2002). Many times these rituals and preoccupation with parts of objects can resemble obsessive compulsiveness because of the anxiety that is caused if the child is pulled away from his or her rituals or preoccupations. However, these rituals are not consistently performed as a part of a normal routine, as usually seen in obsessive compulsive behaviors. For example, an Autistic child may flap his or her hands or jump up and down on their toes purely for the feeling they get from the movement. In addition, this child may also be preoccupied with a random object or toy, such as a model car, and open and close the car's doors until the doors on the car breaks. The child will typically lose interest after the toy breaks and find another toy upon which to focus. Even though many of these characteristics are similar to other Pervasive Developmental Disorders, such as Rett's Disorder and Asperger's Syndrome, they are markedly different and should not be mistaken as the same diagnosis.

Asperger's Syndrome, on the other hand, also known as "high functioning Autism", is a Pervasive Developmental Disorder that is commonly misdiagnosed as Autism (Yapko, 2004; National Institute of Mental Health, 2007). Although many of the diagnostic

requirements are the same for Asperger's Disorder and Autism, there are some major differences between the two. One difference is that Asperger's Disorder only requires, for diagnosis, two areas of impairment in social interaction, one from the criteria of stereotypical behavior and interests and no significant delays in language or cognitive function. Autism, on the other hand, requires at least six total significant impairments in social interaction, communication and behavior, with one or more impairments occurring prior to three years of age, in order to be diagnosed. Another major difference between Asperger's Disorder and Autism is that Asperger's Disorder does not specify when the delays begin, during a child's development, nor do children with Asperger's Disorder have a usual dual diagnosis of Mental Retardation, which is common in conjunction with an Autism diagnosis (DSM-IV-TR, 2002; Yapko, 2004; Naber, Swinkels, Buitelaar, -Kranenburg, van IJzendoorn, Dietz, van Daalen & van England, 2007).

As one can readily see, there has been much confusion in distinguishing the differences between Autism and Asperger's Disorder and because the clinical criteria are so similar. However, their similarities bring about many of the same cognitive and development problems in children. Therefore, these Pervasive Developmental Disorders are grouped into the broad category called Autism Spectrum Disorders(ASDs), until the research catches up with the frequency that these disorders are occurring (Yapko, 2004; Naber, Swinkels, Buitelaar, -Kranenburg, van IJzendoorn, Dietz, van Daalen & van England, 2007).

Studies about Attachment and Parental Coping

The diagnosis of ASDs has been on the steady increase, while relatively little is known about their etiology. It is important not only to continue to perform medical research on its origin, but also to study the effects that a child's diagnosis has on his or her family. Several studies have attempted to describe how the family responds to a child with an ASD. However, most of the research has focused on the attachment that occurs between the parent and child and the coping strategies used by parents of children with an ASD.

The research on the ASD child's ability to connect or attach with his or her parents and the parent's attachment response to the distant child has been a topic of interest since the 90s. All of the research on the parent-child attachment and/or the child's ability to attach to caregivers has been based on John Bowlby's (1969; 1979; 1988) theory of attachment, which will be discussed later within this chapter.

Some research within this area has focused on the similarities between child attachment and adult attachment (Weiss, 1994). This angle seemed to be a practical starting point, as adults base their attachments in adulthood on the type of attachment they had made (or have not made) to a caregiver in infancy (Bowlby, 1979). Research and theory have evened the playing field, concerning child and adult attachment, because they theorized that, if a child had a secure attachment, as he or she grew older, he or she would be able to form secure attachments to others in his or her life (Weiss, 1994; Bowlby, 1979).

This aspect is important when looking at the literature because, up until the mid 90s, little was known about ASDs, not to mention the attachment styles of children with ASDs. It was assumed, during this time, that children with Pervasive Developmental

Disorders attached similarly to typically developing children (Bowlby, 1969). Now research has indicated that not only do children with ASDs attach to their caregivers in a disorganized way, the parents of these children often respond to the child's attachment style in kind (Steele, Steele & Fonagy, 1996).

On average, research showed that most parents tended to attach normally or securely to their infant child who was developing normally (Steele, Steele & Fonagy, 1996).

However, research has also reported that an attachment strain has been specifically noted between parents and their child who has an ASD (Konstantareas & Homatidis, 1992). In other words, parents, who showed their child consistent love and affection, assumed that their child would respond to their touch and voice positively by making grabbing gestures and/or smiling at them when the parent entered a room. When the child's gestures were instead flat affect and non-responsive toward parents who had consistently given love and affection to the child, parents became confused and frustrated, which caused a strain within the relationship they believed they had established with their child.

Konstantareas and Homatidis (1992) interviewed mothers and fathers to understand their perception of their involvement with Autistic, Mentally Delayed, and normal children. They found that, according to the parents in the study, the parents of an Autistic child had less overall interaction with the child on a daily basis than parents of a mentally delayed or a normally developing child. The parents of the autistic children reported that they feared they would overstimulate the child if they were as involved as they would be with a typically developing child. Another explanation that the parents gave for their under- involvement was they mistook the child's inability to initiate contact with the

notion that the child did not need as much contact from their parents (Konstantareas & Homatidis, 1992).

As research on the attachment styles of children with disabilities, specifically ASDs, began to emerge, the data showed that children with Autism and mental retardation tended to have a more disorganized style of attachment than did typically developing children (Naber, Swinkels, Buitelaar, -Kranenburg, van IJzendoorn, Dietz, van Daalen & van England, 2007). According to this research, a disorganized attachment style was characterized by increased anxiety and heart rate when their primary caregiver entered the room. This was found to be caused by the child's feeling of insecurity toward their primary caregiver. Furthermore, the research indicated that children with any form of Mental Retardation (MR), which is often co-morbid with a diagnosis of Autism, were more likely to form a disorganized attachment, in addition to the inability to cope with their anxiety in the face of stress, even when his or her primary caregiver is present than were typically developing children (Naber, Swinkels, Buitelaar, -Kranenburg, van IJzendoorn, Dietz, van Daalen & van England, 2007).

The author explained that this occurs because the child did not understand his or her situation or, for a brief moment, was unable to recognize a caregiver or environment, which caused anxiety and uneasiness within the child. Lastly, this research showed that the severity of the child's ASD determined the degree of the insecure attachment to the child's caregiver. According to Rogers, Ozonoff & Maslin-Cole (1991), these findings were partly in line with the theory of developmental delay. A child's inability to interpret other people's emotional cues or internal states created confusion in a child when they were separated from their primary caregiver. Children with ASDs have consistently

shown their inability to recognize when their caregiver is happy because they usually do not respond in kind to their caregiver by smiling or cooing. Therefore, it is no surprise that the caregiver of a child who has an ASD may become distressed and begin grieving over the changes in relationship they are experiencing with their child, due to the lack of the child's ability to securely attach to them. It is usually at this point, that many parents come to the conclusion that their child is different from a normal developing baby and the dream of having a typical parent-child relationship with their child is lost (Twoy, Connolly & Novak, 2007; Gray, 2006; Boss, 1999).

Twoy, Connolly, and Novak's (2007) recent study explored the various ways that parents adapt to the changes in behaviors and routines their young child, who is diagnosed with an ASD, exhibits. Their study focused on families that had a child with ASD 12 years or younger. Although they found that most families fell within the normal coping range, they discovered several ways that parents cope with an ASD diagnosis. Most parents in the study used the coping strategies of social support, redefining the stressful situation, spiritual involvement, seeking out community resources, and using passive appraisals.

Gray (2006) used semi-structured interviews to explore how parental coping styles of parents, who have a child with an ASD, changed over time. The study consisted of two phases. He initially interviewed 35 parents, whose Autistic children aged between 6 and 8 years old, were enrolled in a treatment center for their disability. Two years later, he followed up with the 20 families who were left from the original interview, in order to see how their situation had changed. Gray initially found that the parents interviewed cited 51 different coping strategies to help them deal with their child's disability.

The number one answer that parents stated in the initial interview were the use of treatment services (e.g., centers specializing in Autism treatment, respite care and private care), as well as the utilization family support. When Gray interviewed the 20 families two years later, he found that the coping strategies utilized by parents had shifted away from treatment services and family support and had moved to other styles of coping, such as using different philosophical perspectives to justify their child's disability, domestic routines, and keeping in contact with other parents with Autistic children. The use of treatment centers was a distant second form of coping, because the parents had learned how to cope emotionally with their child's disability through the use of treatment services, such as family therapy, and accessing early intervention services for their child (Gray, 2006).

Other research, surrounding parental grieving and coping with their child's disability, was stemmed from Pauline Boss's (1999) idea of Ambiguous loss. Ambiguous loss is a theory of loss and coping that gained great popularity for researchers and families who dealt with Alzheimer's disease (AD), soldiers that returned from war with Posttraumatic Stress (PTSD), and other serious mental illness (Blieszner, Shifflett, 1990; Boss, 1999). The main component of ambiguous loss is the belief that some losses can be vague and uncertain, just as the deterioration process found in AD and ASD. Boss argued that the main difference between ambiguous loss and ordinary grieving is that the grieving process is frozen and loved ones cannot completely allow themselves to grieve normally, so that they can achieve detachment in order to attain the normal closure necessary for healing from the perceived loss.

Boss (1999) described two main types of ambiguity found within frozen grief. First, is the idea of “leaving without goodbye” and the second is “goodbye without leaving”. “Leaving without goodbye” is the frozen grief caused by family members’ not being able to say goodbye to their loved ones before they die. The mystery that surrounds the family is whether their family member is deceased or if they are still alive. This type of ambiguity is found in abduction and kidnapping cases, as well as prisoner of war and missing in action situations in war.

The second type of ambiguity that leads to frozen grief is “goodbye without leaving”. Blieszner and Shiflett (1990) discussed the phenomenon of ambiguous loss and AD. Although they did not use the phrase ambiguous loss, they did describe the situation as “coping with nonexistent but non-terminal relationships” (Blieszner and Shiflett, p. 61). The idea here is that AD patients’ caregivers, whose main role was as family members, began having difficulty putting closure to the previous relationship they had with their loved one diagnosed with AD or other forms of dementia. Redefining the relationship was important in the research in order for the caregiver to cope with the loss of an established relationship, even though the ill person was still physically present. It was also important for the family member to reevaluate their relationship roles in order for them to be able to continue to care for their ill family member and his or her changes in personality and/or behaviors.

As we know, most aspects of ASDs are still a mystery at this time. Even the ways that families grieve have not been studied thoroughly. Therefore, Boss’s (1999) idea of the ambiguity of loss and the notion of “goodbye without leaving” can also apply to a child’s deterioration, due to an ASD. O’Brien’s (2007) research continued to explore this

phenomenon within the mysterious realm of ASDs. Her sample included 63 participating mothers whose children (ages between 2 and 13) had been diagnosed with an ASD. She interviewed the mothers of the children, in regards to their identity ambiguity, depressive symptoms and child related parenting stress. O'Brien (2007) found that the mothers in the sample reported alternations between hope and hopelessness. They reported feeling the emotional rollercoaster of feeling in control one minute and, in another, feeling completely helpless. O'Brien's (2007) findings align directly with Boss's (1999) theory of ambiguous loss. Boss (1999) notes that ambivalence, the expression of contradictory feelings in situations where a caregiver is experiencing ambiguous loss, is often common and is a part of the frozen grief phenomenon.

What ASD Studies Have Not Covered

ASD studies have focused mainly on the etiology of the disorder, the behaviors that usually accompany the disorder, and the coping styles of parents and caregivers of children diagnosed with an ASD. Research hasn't adequately explored the phenomenon of the loss of the parental dream of having a normal child. Although Boss' (1999, 2004) ambiguous loss theory has the ability to extend into this area of parents' having to change their expectations of their child, research is currently lacking in this area. I hope to fill in the gap where the research is lacking by interviewing parents of children with Autism and explore how they understand their relationship to their child. In addition, I hope to also learn how those parents' attachment to their child effect their expectations of their child with Autism. Last, I want to ask the parents in the study what has helped or hindered the mourning process of having a child with Autism. In order to achieve this, I will rely on John Bowlby's (1988) theory of attachment between a parent and a child. I will also

attempt to explain this phenomenon by incorporating Bowlby's (1969) theory of attachment and loss and Boss' (1999) theory of ambiguous loss to try to better explain how parents of ASD children mourn the loss of the dream and expectations of having a "normal" child. I will also integrate Sue Johnson's emotionally- focused therapy and other ideas, spawned out of an experiential perspective, concerning the emotions that come into play in the creation of a secure attachment between a parent and a child.

Attachment Theory

John Bowlby's theory of attachment (1969) relates directly to the loss of attachment between a parent and a child. Although he does not focus, in depth, on the parent-child attachment between a parent and a child with a disability, attachment theory does have implications for the style of attachment in the early stages of development, where the attachment changes as the child's disability becomes more evident. This idea of the loss of the normal attachment to a parent sets the stage for exploring parental grieving of not only the attachment injury but also coping with the grief of lost expectations for a "normal" child.

In brief, Bowlby's theory of attachment is based on numerous research studies that focus on animal behavior. He contends that human attachment, although somewhat different, has more similarities to other animals than we may have previously believed. The main reasons why animals, such as primates, attach to their mother are for safety reasons. Some of these safety reasons include protection from predators and the opportunity to learn behaviors vital for survival. Similarly, human infants create an attachment to their primary caregiver, usually the mother, because of similar reasons.

Initially, infants are dependent on their mother for food, shelter, and protection. Within the first year of life, infant children still depend on their mother for food, shelter, and protection, but also to learn social cues vital for survival. Therefore, the child makes his or her needs known, through distinctive cries, to his or her mother in order to ensure his or her own survival. Research has studied this pattern of attachment in children ages 1 month to 18 months old (Bowlby, 1969). Only children who had neonatal trauma or mothers who did not create a secure base with their infant, displayed a different pattern of attachment.

The pattern of attachment that an infant displays toward his or her mother is also important when creating the mother's attachment to the child. Clinging, crying and sucking behaviors in infancy allow the infant to tell the mother that she is needed. As the child becomes older, smiling, reaching, and following behaviors indicate to the mother that the child has formed a bond with her. This give-take relationship between the mother and child is the normal process that creates the secure bond between the two.

If the child has a disability in infancy, he or she may display behaviors that may lead to constant care or to a lack of care by the mother. Some infants with asphyxia, for instance, have cried very little, thus giving the mother the impression that they are not needed by the infant. Mothers, in these cases, may perceive the child's needing little assistance and unknowingly neglect the child's needs by checking on them and holding them less often than the child needs. Other cases, where infants have mental retardation, the child may continually cry, which initiated the mother's constant care and attention. In turn, these children don't effectively learn how to self-soothe, which can lead to separation anxiety in childhood and the inability to form relationships that aren't

codependent in adolescence and adulthood (Bowlby, 1988; Konstantareas & Homatidis, 1992; Waters & Crowell, 1999). In cases where a child is overstimulated by the mother by her constant rubbing, holding, and tending to the infant, whenever he or she cries, the infant learns to rely on his or her mother for soothing and consistently appearing in the child's view. Therefore, the infant becomes used to this style of care and, over time, demands the continual need of his mother. The infant, crying constantly for everything, displays this need, even if he or she is fed, clean, warm, and dry. Both styles of caregiving and attachment can be dangerous to the child in the future because either the mother neglects the child, without knowing the child's needs, or the child receives too much stimulation from the mother, which may create a dependent style of attachment (Bowlby, 1988).

Children with ASDs are difficult to study because most children, including those with ASDs, develop normally in infancy and into their first years of life, where the parent-child attachment is initially established. However, after the child begins to display ASD behaviors, the parent-child attachment changes. The child may no longer display the smiling, reaching, or following behaviors he or she once did. Thus, the child, who once displayed normal attachment behaviors, seems to virtually regress back to a newborn infant's style of attachment, where they grunt or cry when they need something, instead of reaching or calling on a parent for help.

Once their need is fulfilled, children with an ASD will usually ignore or not want any more stimulation from their caregiver. This attachment loss creates confusion for many mothers, who are devoted and loving caregivers to their children. Unfortunately, the

child's attachment to his or her parents rarely improves or changes once the child begins to regress (Waters & Crowell, 1999).

Ambiguous Loss Theory

Ambiguous Loss Theory was developed by Pauline Boss (1999) in order to better explain the phenomenon of loss without definitive closure. She describes ambiguous loss as the incomplete or uncertain loss that surrounds and freezes the grieving process. She discusses two types of loss within this theory. The first kind of loss, being physically absent but psychologically present, occurs when family members are unsure if their loved ones are dead or alive. The second kind of loss that Boss describes is when a loved one is physically present but psychologically absent. Boss illustrates this type of loss by describing the dynamic between caregivers and their loved one with Alzheimer's disease (AD). This kind of loss, although it primarily focused on AD, is relevant to the study of the type of parental grief that surrounds their child's diagnosis of an ASD.

The problem with the second kind of loss, also phrased as "goodbye without leaving" (Boss, 1999), is the overwhelming sense of ambiguity that occurs within the caregiver and other members of the family. For instance, AD patients' spouses frequently find themselves asking the question of whether the AD patient is still their husband or wife, even though the patient doesn't remember them. In this situation the caregiver finds him or herself plagued with the mystery of their loved one's condition and whether the roles in the relationship have changed.

Caregivers of AD patients find the balance between caregiver and spouse difficult. Boss (1999) contends that the role(s) that an AD patient's spouse has to change in order for the relationship to continue into the future or else it will be frozen. The ambiguity

surrounding a family member's diagnosis of AD has to warrant taking on more roles, such as caregiver and spouse. Problems, such as caregiver loss of self, depression, anxiety and burnout, occur frequently when the caregiver does not adapt to their loved one's diagnosis and their changing roles (Boss, 1999).

When a child is diagnosed with an ASD, his or her parents have already established a secure relationship with the child. Therefore, parents find themselves shrouded in uncertainty about the diagnosis, their child's future and their new role in the child's life. Many times parents are caught up in denial and do not change the expectations they had established for the child before his or her diagnosis. For instance, many parents of a child, who has been diagnosed with an ASD, still hold their child to a standard typical for a normally developing child. They may take their child to his or her pediatrician if the child is showing signs of developmental disability, such as delayed crawling, walking, mimicking and talking. These parents have not adapted to their child's diagnosis, thus, many continue to feel hopeless and helpless over their child's condition.

Boss argued that, in any ambiguous loss situation, the hardest hurdle to jump is the unanswered questions in a family's situation. As in AD, ASD research has not caught up with the number of diagnoses that are being made. Therefore, when caregivers try to better understand their loved one's condition, they are frequently let down by their practitioner's inability to answer their pressing questions. Therefore, caregivers naturally try to make their own sense of their situation by placing blame, in order to rationalize the trauma, or keeping up with the status quo, which is the idea that things are how they always were and nothing's going to change.

Only after the caregiver realizes that their situation is not caused by any one reason, they begin to heal by reevaluating their situation. Some choose to continue the growth of the relationship with the understanding that the person they knew is physically present but not psychologically attending, as they were previously. Therefore, they begin the process of accepting the disabled person with their new strengths and limitations. For example, parents of children diagnosed with an ASD may focus on their child's strengths in agility and creativity, while realizing that their child may always be limited in abstract thinking and communication. This step takes the child's parents out of their denial and allows them to reformulate their thinking about their child and their child's future.

In my experience, working in the homes with various families where a child with Autism or Mental Retardation (MR) was present, I have noticed that parents of Autistic children begin the process of changing their expectations of the child later than parents of children with Mental Retardation. I believe that the reason for this is because the Autistic child shows no signs of abnormality in behaviors or actions in infancy, unlike the child with Mental Retardation. Parents of children with Mental Retardation tend to go through some of the symptoms of ambiguous loss but they frequently remain in denial for a shorter period of time, because the child has shown complications consistently since they were born, unlike a child diagnosed with an ASD at two years old, who showed virtually no delay in infancy. The parents of the child diagnosed with an ASD has to let go of the dream that their child could get better and become "normal", which takes a lot of processing and reevaluating role and behavioral changes.

In addition, many parents of children with MR, unlike parents of children with an ASD, had a vague idea that there could be complications with the child when the child

was in utero. Once the child was born and exhibited complications, pediatricians were able to give parents more of the answers they were looking for in order to help explain why the child was born the way that he or she was. Parents of ASD children seem to be blindsided by their child's condition. Many parents may feel as though they are in a situation where they've been "dooped" by nature because they thought they initially had a happy, healthy baby. Only after a couple of years do they start to see those dreaded signs commonly associated with an ASD. Many parents become drowned in guilt because they feel as though they did something wrong or that they have been bad parents because their child started regressing. Once the child is diagnosed, parents still have many unanswered questions surrounding the etiology of the disorder and the breadth to which the disorder will affect the child. This mystery, surrounding the diagnosis and attachment, makes Boss' (1999) ambiguous loss theory an important part of this research.

Experiencing Emotions

Several family therapists have relied on emotions to help unlock the vitality of a family system. Pioneers in this field include Carl Whitaker, Virginia Satir, and Sue Johnson (Nichols & Schwartz, 2004). The main premise in the experiential approach to therapy is the idea that unblocking emotional expression can help family members who are experiencing grief, loss, and conflict, get in touch with their real feelings. Once family members become in tune with their true feelings, whether those feelings are hopes, desires, or dreams, family members are better able to create positive change within the family dynamic and move forward from the trauma they have experienced (Nichols and Schwartz, 2004). For example, parents of children diagnosed with an ASD can gain acceptance of their child's disorder, through experiential therapy, by exploring the true

feelings, such as fear and guilt, that denial is protecting. Only once parents, who are plagued with denial, have uncovered their true feelings surrounding their child's diagnosis can they begin to move forward with their life.

This idea of experiencing emotions is also related to attachment theory. Greenberg and Johnson (1988) initiated the idea that emotion organizes the attachment responses and serves as a communicative foundation in relationships. For example, if a mother who has a child with an ASD slowly begins to recognize that her child is withdrawing and not continuing to attach to her, she may become hurt but may respond to this experienced hurt by becoming angry. This anger can become a natural defensive response to the mother's hurt because no mother would want to bear the thought of her child's rejecting her. Furthermore, a mother might feel a better sense of control by being angry, instead of experiencing her true feeling of hurt. Therefore, in order to protect herself from getting hurt more in the future, she may choose to spend less time with the child instead of seeking help for her grief.

Greenberg and Johnson argued that, in cases like this, the mother, who is in need of the attachment with her child, may also be afraid of exposing that need and may, in turn, push away the loved ones to whom they long so much to be connected (Nichols and Schwartz, 2004). The idea of getting this mother to let down her defensive fears so that her deep and genuine emotions can emerge is the main premise of emotion-focused experiential theory. The safe, therapeutic environment can help parents similar to this mother feel less vulnerable and supported as she lets down her defensive barrier and gets to the core of her feelings.

Many parents find themselves becoming stuck in their protective emotions. They frequently neglect their true feelings in order to protect others from becoming upset or to protect themselves from vulnerability. This phenomenon is described as the “white knight” mentality. This occurs when caregivers remain in denial and suppress their feelings in order to appear to others that they are remaining strong in a hard situation. The belief is that, if they remain strong during the hard times, those around them will adopt that attitude and the family’s support system will be ready to support them. Experiential family therapy is founded on the premise that the cause and effect of family problems is emotional suppression (Nichols and Schwartz, 2004). Family members must first explore their true emotions before they can forge a genuine emotional connection with the rest of their family.

Continual emotional suppression tends to explain the repeated absence of both parents in studies that focus on families who have children with an ASD. Often, couples who experience a traumatic event, such as having a child with a devastating disability will become distant with one another and may eventually disengage or even divorce. Emotionally-focused experiential theory asks the question as to whether family members are communicating on a superficial level about how they may be feeling about their current situation. Therefore, they do not get to their true feelings about the fears they have for their child and the disappointment they feel because their child cannot fulfill the dreams they had made for them.

This can cause problems for the family of the child with an ASD and the child diagnosed with an ASD, because parents rarely remain flexible under this experienced pressure. Many parents will begin to resent their situation, causing them to argue and

neglect the needs of their child, thereby creating a tense living environment for all family members. Other parents experiencing this pressure may choose to over-protect their child diagnosed with an ASD, causing the child to become dependent on them. Over the course of time, parents learn to rely on their child's need for them, creating an unhealthy, codependent relationship between parent and child.

Only after every person in the affected family can admit to themselves how they feel about their current situation can they express it openly, without fear, to other family members, so that all can move forward with their lives. This communication between family members promotes interaction which, often times, leads to a sense of connectedness between family members during the midst of their situation. From that connectedness, acceptance of others' feelings toward the situation begins to flourish, creating the new ground for accepting the family's current circumstances.

Summary

Autism Spectrum Disorders (ASD) are still very new to clinicians, the medical community, and academia. Therefore, there are still many questions, regarding the disorder's etiology and treatment. Parents of children with an ASD find themselves in a whirlwind of confusion as to how their child developed the disorder, how to get effective help for their child, and what the future holds for their most precious asset. It is extremely important that more research be conducted so that these questions can be answered, because the prevalence of ASDs are currently occurring at the alarming rate of 6 per 1000 (Fombonne, 2003; Yapko, 2004).

Research, which has focused on the family of children diagnosed with ASD, has explored the parent-child attachment style, parental coping, and just recently parental

ambiguous loss. The research indicated that children with ASDs do not form a secure attachment to their parents. Therefore, parents instinctively spent less time with their child than they would had their child been “typical” in their development. Research has also indicated that parents of children with other disabilities (not including ASDs) did not exhibit spending significantly less time with their child than did parents of normal children.

Bowlby’s (1969) attachment theory, Pauline Boss’ (1999) theory of ambiguous loss, and Sue Johnson’s (1988) emotionally-focused experiential theory attempt to explain the phenomena by stating that, when the normal attachment process is interrupted by trauma, causing an attachment injury between parent and child, the parent will harbor the primary emotions of hurt and fear that they have “lost” the relationship with their child and, instead, display withdrawal, anxiety, and symptoms of depression (Nichols and Schwartz, 2004). Boss (1999) explained that this process is called frozen grief because the parents are caught in a negative cycle of trying to grieve for the loss of their “normal” child, while the child who exists in their lives is still present. This creates a confusing dynamic for parents, causing them to push away their true emotions and focus on the here and now, disregarding the importance of reestablishing their role as a parent of a child with a disability.

Although this research focuses on parental grieving, it does not address how parents cope with the loss of their own dreams and expectations for their children. Current research has touched on the issue of how parents go to extremes of either denial of their child’s disability or completely rearrange their life (Boss, 1999). In order to answer this question, I hope to interview parents of children diagnosed with Autism and explore the

dynamic of the changing dreams and expectations they have for their child who has been diagnosed with Autism.

CHAPTER THREE

Methodology

The purpose of this study was to explore the “loss of the dream” that parents experienced when they discover that their child had a debilitating Autism Spectrum Disorder (ASD). Specifically, this study illustrated how parents of children, who were diagnosed with an ASD, changed their expectations of the child and his or her abilities and the acceptance of their changing roles, from parents, to parents of a child with a disability, over the course of time. This was done by using a qualitative research approach.

Qualitative research helps describe a phenomenon in its natural setting (Babbie, 2004). The observer, or interviewer in this case, captured the dynamics of parental expectations and gained a fuller understanding of the changes that occurred in parental roles over time. Other methods of research, including quantitative research, limited the scope of the reader and did not fully capture all of the dynamics that occurred in a natural setting such as a home. The type of qualitative research that was used in this research is called a “multiple case study”.

A multiple case study is commonly used when a researcher wants to “extend the case study to several subjects who can be classified together into a distinctive unit or group within the larger society” (Grosf & Sardy, 1985, p.113). Although a single case study would be beneficial to this research, a multiple case study could better capture the different, changing dynamics that parents of children with an ASD child experienced over time. In addition, the nature of the research warranted the two distinct perspectives of the two families’ interviewed to show parents’ initial reaction to their child’s diagnosis

and the acceptance of their child's disability over time. The benefit of multiple case study research included its ability to allow the researcher to compare or distinguish between the perspectives of the participants in the study (Yin, 1989). Structured interviews were used in the research in order to capture each parents' perspectives about their situation and track their changes in attitudes, expectations, and behaviors, when trying to cope with their child's diagnosis.

Qualitative Methods

Qualitative field research was most useful to this study because it enabled the researcher to observe social life in its natural habitat (Babbie, 2004). This type of research produced a better understanding of the dynamics that occurred within each family, because the researcher could ask the family open-ended questions concerning their situation that helped paint a better picture of that family's experience. Qualitative research was also useful in exploring phenomena about which there was little or no research or when research that exists in an area paints a "hodgepodge" picture of its findings, rather than a cogent, integrated picture. Although a qualitative style of research was appropriate for this study, it was important to note that this type of research posed both strengths and weaknesses. As already mentioned, one strength of this style of research was the ability for the researcher to pick up on subtle nuances in attitudes and behaviors during the interview (Babbie, 2004). Another strength of this style of research was the researcher's use of open ended questions, which allowed the participants to relay information they perceived to be important to them, giving the researcher a more in-depth understanding of how the respondent viewed his or her world or situation (Patton, 1990). The main weakness of qualitative research was the difficulty that researchers face when

trying to analyze the responses of the participants of the study. Responses were more subjective and idiosyncratic, which made the interpretation of the data difficult, due to the absence of standardized responses. Because of this, qualitative research methods have focused less on generalizing to the larger population and focused more on the specific phenomenon being studied (Patton, 1990; Babbie, 2004).

Role of Researcher

When performing any research study, especially qualitative interviewing, there was a potential risk for researcher bias. The researcher's main role was to interview the families in the study, process the information given, and report the findings in a fashion that was not biased. However, the risk of researcher bias could occur when the researcher subtly words questions in the interview that allow the participant to detect the researcher's views on the topic of discussion. This, in turn, could persuade the participants to agree with the researcher by up playing or down playing an event, according to how the participants believed the researcher wanted them to answer.

However, it is important to note that the researcher did have some bias in the study and is pointing them out here, so that she could avoid structuring her interview questions in a way that were skewed toward her bias rather than balanced, non biased questions. One bias that the researcher had was that she believed that both parents in the study would have similar experiences to one another. This bias was based on her previous experience of working in the home of children with Autism and saw the parents of these children's day to day life as parent and caregiver. Another bias that the researcher performing the interview had was that she believed that the parents of the Autistic children in the study would express having a hard time coming to terms with their child's disability, because

of the attachment they created with the child when they were an infant. This bias stems from the researcher's experience talking to parents of Autistic children about the initial diagnosis and hearing the parents describe the crushing reality that something was truly wrong with their child and there was no "cure" for their child's problem.

Although it was impossible to completely eliminate researcher bias in this qualitative study, the researcher has taken measures to help balance her study so that it was not skewed toward her personal biases. First, the researcher explained her biases to her committee before the research began, and some interview questions were eliminated or reworded in order to prevent leading the parents to answer in a specific way during the interview. Another way that the researcher took her own biases in to consideration while performing the research was to review the transcript of the interviews in a biased mindset and have another, non biased person from the research committee review the transcript and compare the two reviews to see if the emerging themes of the study are similar.

It is important to know who the researcher was for this study. The researcher was a biracial (Native American and Caucasian) female born in a Southeastern town. She was an only child in a middle class family. The researcher received her bachelor's degree in Sociology, with emphasis in the family and community health, from Arizona State University. While working on her bachelor's degree, the researcher spent time working with individuals with dual diagnoses (individuals who have been diagnosed with two or more developmental disabilities) as well as individuals with Autism. The researcher's experience, working in a variety of settings with individuals with disabilities, has allowed her to observe individuals and their family interaction in the clinical, group home, and familial home settings. This experience has allowed the researcher to learn more about

individuals with disabilities and their families. The researcher is currently attending a university in the Midwest, where she is working on her master's degree in marriage and family therapy. During her masters program studies, she has worked with many families who have one or more family members with disabilities, including mental illness, mental retardation (MR), and ASDs.

Procedure

Selection of Participants

Participants for the study included two middle class, two-parent families, who had a child diagnosed with an ASD, specifically Autism. The criterion for the first family was that they had a child with Autism who was eight years or younger, with the child having been diagnosed between the ages of two and three. The criterion for the second family was that they had a child diagnosed with Autism who was 18 years of age or older, with the child diagnosed between the ages of two and three. The reason why two families with a child of different age ranges were picked for the study was because the researcher showed themed similarities between the families, regardless of the age of the individual diagnosed with Autism and the experience of that individual's parents. In addition, the researcher also relayed helpful information and resources to the parents of the younger child, who was less informed about their options, regarding the care of a child with a disability, social supports, and other general information that may be helpful to them, based on the information given to the researcher by the parents of the older child with Autism.

The selection of the participants was derived from the researcher's previous knowledge of these families in the study area. Her active involvement in the community allowed her

to meet numerous families who had children with Autism. The two families chosen for the multiple case study specifically met the criteria of having a child with a Autism that was aged eight or younger or over the age of 18 years old. The children must have been diagnosed between the ages of two and three and still live with their custodial family. The participating families were asked by the researcher if they were interested in participating in this research study. The researcher produced a letter and mailed it to the families asked to participate in the research. Both families agreed to participate.

Informed Consent Form

After the letter (Appendix B) that explained the research was mailed to the families who were asked to participate in the study, the researcher scheduled a meeting with each family, where only the parents of the Autistic child were asked to attend. During the meetings, the families were briefed on the research being conducted and were also presented the informed consent form (Appendix A).

Demographic Information Sheet

After each parent in the study signed the informed consent sheet given to them by the researcher, the parents were also presented with a demographics information sheet (Appendix C). The purpose of this sheet was to provide the researcher with additional information about the family. In addition, the demographic information was also used as a point of reference for the researcher, so that differences between each family could be better understood during the data analysis.

Semi- structured Interview

The main purpose of a semi-structured interview (Appendix D) was to present the family with a set of pre-formed questions by the researcher so that the family's interview

process was organized. The style of the interview questions were open-ended, so that each parent interviewed could elaborate on points which they felt were important, as well as keeping the interview conversational in nature (Yin, 1989). It was important for the parents being interviewed to be able to describe their experience to the researcher, because, in essence, they are the experts of their own life and are the individuals who are best able to report their experiences (Darlington & Scott, 2002). Semi-structured interviews also allowed the researcher to ask each parent separately the same set of open-ended questions, so that the data could be compared during data analysis.

Debriefing

After the families were interviewed, the researcher took the time to debrief the families on the experience of being interviewed about this difficult topic. The researcher assessed whether the family endured significant stress by being interviewed for the research. Phrases such as “this is too much for me” and “ I forgot how difficult this was to talk about”, etcetera, cued the researcher to help the family de-stress from the situation by speaking with them longer about their current feelings toward their situation and the interview process. Lastly, if the family was in need of a therapist to help them cope with their feelings, the researcher referred them to a therapist in their area. It is important to note that none of the parents in the study asked to be referred to a therapist during the debriefing process.

In addition, the researcher asked the family if they would be interested in knowing the results of the study. If the parents declined, the researcher gave the family the contact information of her major professor where the information would be stored for future review if they desired. On the other hand, if the parents expressed that they wanted to see

the results, the researcher assured them that they would be contacted after the research was completed to discuss how they would like the results to be shared with them in writing (e.g. the researcher giving the family the results section via mail). Last, the parents involved in the study were assured that their privacy and confidentiality would be upheld by the changing of names in the study, destruction of multiple pieces of demographic data collected from the family, and the audiotapes used in the interview after the transcription was completed. Last, the interview responses were kept under lock and key in case the participants of the study wanted to access them after the study was completed.

Data Analysis

The analysis of the semi-structured interviews was done using qualitative data analysis. Qualitative analysis allowed the researcher to take non-quantitative data, such as semi-structured interviews, recovered by the researcher, and analyze them through coding, and memoing (Babbie, 2004). However, the first step after the researcher interviewed the participants was to transcribe the interviews from the original audio recording of the semi-structured interview to word form, so that the researcher could have the interview on paper as a resource to revisit before she began coding.

Coding, also known as classifying or categorizing individual pieces of data, coupled with a method for information retrieval, is the key process of qualitative data analysis (Babbie, 2004). Coding provides the researcher with a system to find information in transcripts so that, when they were needed in the write up, they were easily retrieved. In addition, coding also has another important purpose to the researcher because it allowed her to organize her data so that she could discover and explore patterns within the data

that pointed to theoretical understandings, such as Pauline Boss' (1999) theory of ambiguous loss, John Bowlby's (1969, 1979, 1988) theory of attachment and Susan Johnson's theory of emotionally- focused family therapy. Strauss and Corbin (1990) contend that coding is an important part of data analysis because it allowed the researcher to name and categorize the data by breaking it down into discrete parts. From there, the researcher was able to compare the data for similarities and differences and develop more questions about the phenomena that were reflected in the data (Strauss and Corbin, 1990).

Another step of qualitative data analysis, specifically coding, is a method called "memoing". Memoing involves the researcher's writing memos to herself in order to describe or define concepts found in the data (Babbie, 2004). The kind of memoing that was used in this research project was sorting memos and integrating memos. Sorting memos was important in this research because it presented key themes found in the data. Sorting memos were also used as an attempt to discover and create reason among the data gathered, by bringing together sets of related material that the researcher had coded (Babbie, 2004).Integrating memos' purpose was to tie together all of the sorting memos in order for the researcher to bring together the whole research project. These memos allowed the researcher to tell a coherent and complete story, while casting it in a theoretical context (Babbie, 2004). After the results were written the transcripts, memoes and audiotapes used for the interview were destroyed.

CHAPTER FOUR

Results

This chapter provides the reader with the themes found within the transcript of the semi-structured interviews with the mothers and fathers of the two families interviewed, who have a child in their family diagnosed with Autism. Each interview was conducted separately with both mothers and fathers from the two families in the study. The family with the child, who is eight years old or younger, will be described as mother #1 and father #1 or grouped as family #1 in this and the next chapter. The parents of the child who is older than 18 years of age will be described as mother #2 and father #2 or grouped as family #2 in this and the next chapter.

This chapter will explore these themes in-depth, while giving the reader a clearer idea of these parents' experience of raising an Autistic child. However, before the themes are described, I will give the reader a more in- depth background of both families who were interviewed for this study. It is important to note that the real names of the parents and children in this study have been changed to protect their privacy.

Overall Description of Families

All of the families included in the interview process were asked to fill out a demographic sheet (Appendix C). From the demographics sheet, information was gathered about each family. All of the parents in the study were of Caucasian decent. None of the parents reported being church going people, but reported their religious affiliation as "Christian". The ages of the parents range from 33-58. All of the parents were high school graduates and obtained at least an associates degree. The range of income for the two families was between 30,000 and over 50,000 per year.

Mary: Mother #1 and Dave: Father #1

Mary, 33 and Dave, 34, resided in the Midwest and lived a middleclass lifestyle. They married in 1998. The couple had three children together named Jenny, 10, Brody, 8 and Nathan, 5. Mary and Dave moved to the town where they currently resided two years ago from another town in the West. They were still unsure what resources were available in their area that would help them with their son, Nathan's new Autism diagnosis. Mary and David wanted to be a part of this study, because they wanted to express their views on Autism and the diagnosis process, in addition to sharing their experience with other families who have Autistic children, as well as the professionals working with families living with Autism. Table #1 displays the members of Mary and Dave's family during the time of the study.

Carla: Mother #2 and John: Father #2

Carla, 55 and John, 58, lived in a Midwest town and lived an upper middleclass lifestyle. They married in 1984. The couple had one son, Matthew, who was 21 at the time of the study. It is important to note that Carla and John lived in the town where they currently reside for over 20 years. They are highly respected residents of the city and have been advocates for people with disabilities since the mid 90s, by donating their own money, raising money, and promoting awareness of disabilities in their community. Carla and John were interested in participating in this study because they wanted to share their experience of raising a child with Autism with other families who may be going through the same issues. Table #1 displays the members of Carla and John's family during the time of the study.

Table 1. Identification of Family Members

Family #1	Family #2
Mother #1 “ Mary”	Mother #2 “ Carla”
Father #1 “ Dave”	Father #2 “John”
Child #1 “ Jenny”	Child #1 “ Matthew”
Child #2 “ Brody”	
Child #3 “ Nathan”	
Child with disability= child #3 “ Nathan” Diagnosis = Autism Age= 5	Child with disability= child #1 “Matthew” Diagnosis= Autism Age= 21

Family #1: Experience of having a child with Autism

Mary and Dave described their life as hectic after the birth of their son, Nathan. When describing how life was before Nathan was born, Mary stated, “after my first two kids, I thought my life was running as planned”. She described how both Dave and she worked outside of the home, had good and affordable childcare, and bought their first home. After Nathan was born, Mary and Dave found that their financial situation changed very much because of Nathan’s medical bills. Mary had to quit working outside of the home and take care of Nathan, because she couldn’t handle working a full-time job, afford childcare for an infant with special needs, and take care of her toddler and school aged daughter, in addition to tending the family’s home.

Although Mary and Dave described their current situation as running as smoothly as possible, the couple still continued to have stressors surrounding Nathan’s Autism diagnosis. Dave discussed the frustration he has felt since the day Nathan was diagnosed.

He stated, “your natural response is to look for answers for what’s happening to your kid”. Dave expressed that the professionals who should have known the answers weren’t answering all of the questions he had regarding his son. He explained that he went on a “quest” for answers himself by searching online. Eventually, he began looking for someone to blame for Nathan’s condition, because the people who should have known about Autism, didn’t know anything about its causes or prognosis.

Dave and Mary both described, in their interview, that the lack of information about Nathan’s diagnosis caused problems with their connection with him. Dave explained that, after Nathan was diagnosed, he exhibited righteous anger or anger that he believed to be justified, due to his son’s diagnosis, as a way of coping with his situation. In the interview, Dave said that he blamed everyone especially Mary, for Nathan having Autism. He described how he turned “inward” and began feeling sorry for himself, instead of worrying about what Nathan and the rest of the family needed. Although Dave’s relationship with Mary is strong today, he admitted he doesn’t have the same connection to Nathan as he does to his other son Brody, because they do more things together than Nathan and him. Mary also described a sense of disconnect from Nathan. She explained that, although she felt the immediate need to protect him after the diagnosis, she noticed Nathan’s becoming emotionally distant from her. She wanted to distance herself from him to avoid being hurt. In her interview she stated, “Nate wasn’t a happy baby... I felt like my efforts to connect with him and be his protector were in vain...I know now that it’s part of the disorder, so I’m more used to it now; although, it still hurts at times”. Even though Mary and Dave discussed their perceived disconnect from their son, both parents agree that their relationship with Nathan had improved and

continued to get better, because they were learning more about him and were beginning to understand his personality more as he got older.

Mary described that she had been frustrated, not only because of the lack of information and awareness of Autism but by the kind of support she had received for her son. She stated that , “I just want the professionals to give me professional answers to my questions and be sympathetic to my frustrations and suggest things that may help”, instead of the professionals who she described, who expected her to know exactly what avenues to take to get help for her son. Dave also felt the lack of support from several medical professionals in the community where the family resided. He described the ignorance of many professionals in the medical community concerning Autism. He said, “ I think having to jump through hoops to get Nate into regular daycares, doctors, dentists, you know, has been frustrating. It seems as though Nate is set a part anyway because he’s different”. Dave continued to express his frustrations during the interview by saying, “ ...your telling me that we have to pay “X” dollars more for childcare, because your daycare isn’t equipped for Autism; and we have to drive two hours to the dentist because, your dentist doesn’t treat kids with disabilities ?”. Mary also mentioned the high cost of treating a child with Autism and the lack of daycares’ ability to mainstream children with disabilities into regular daycare programs. She stated that finding an appropriate place for Autistic toddlers that balance education and childcare was very expensive.

Even though the couple hadn’t had the best experience working with daycares and medical professionals in their community, they believed that individual and/or family therapy would have been beneficial to them if they had sought it. Dave stated that at least

he should seek therapy, because he wanted to get a hold of his anger and become closer with his son Nathan. Mary felt that therapy would be beneficial to her if the therapist could be sympathetic to her frustrations and make suggestions that may help Nathan, instead of giving stringent orders on how to solve specific problems she may be encountering with him.

The couple did mention that, even though having Nathan in their family had created additional stressors in their family life, he had also brought strength and spontaneity to the family. Mary stated that, “one thing our family is really good at is pulling together and getting things done”. Dave added that, “Nate has brought a lot of spontaneity to our family. He’s brought that part back in me”. Both Mary and Dave agreed that having Nathan in their family had made their marriage stronger and considered them a “good team”. Mary mentioned that the family did need to work on structuring their environment so that the family’s everyday routines become predictable for Nathan. She believed this will be good for him, because she had heard from numerous sources, such as online websites, about Autism and members of the medical community, that organization and structure are very important to individuals with Autism. She also wanted her family to begin planning activities that would be as stimulating for Nathan as they are for her other children, so she wanted the family to begin thinking of ideas.

Family #2: Experience of having a child with Autism

Carla and John believed that, after Matthew was born, they both had to change their expectations. John said that after Matthew was born, “I had to re-evaluate my priorities”, meaning that he knew he couldn’t work all of the time when he had an infant at home. Carla felt as though she just wanted John to be able to provide for the family. She didn’t

care whether or not he became a big executive for a large corporation. Carla also described that she cut her work back to take care of Matthew because, “having a business and a baby doesn’t always jive...”.

The couple’s expectation of Matthew also changed. The two agreed that education was the most important thing they wanted for their child. After the couple learned that Matthew was Autistic, Carla and John were unsure what to expect from their son. Autism was not a popular diagnosis in the 80s. The couple did not know what this disorder would mean for their only son. Dave described that, after Mathew’s diagnosis, he, “was concerned about what that would mean for his future...we didn’t know if he was going to be institutionalized or something”. Only after the couple realized that Matthew, “wasn’t an ultra hard kid to handle”, they began to learn more about his personality, what he was good at, and where he needed support.

After Matthew’s diagnosis, the couple discussed the feelings of hopelessness for their son. They were certain that he was going to be institutionalized, so both Carla and John distanced themselves emotionally to avoid being hurt in the future. During the interview, Carla stated that she was embarrassed to write Matthew off so quickly but she was very scared and didn’t know if the child she knew would continue to digress to a point she couldn’t care for him anymore. John explained that one of the reasons why he distanced himself from Matthew was because, “...you’re looking at this beautiful child, and everyone’s saying in a sense, ‘be scared, be very scared. He’s got this thing that’s going to make him a different person all together. Who you think you know now, is not who he’ll be in the near future’. That’s scary as hell to be told as a parent”. In this statement, John was referring to his perception of how the medical community explained Autism,

which caused more fear and concern; thus, causing John and Carla to want to detach themselves from their son.

At the time of the study, Carla and John described their relationship with Matthew as rewarding. She described Matthew as, “an amazing young man, who has so many talents that, unfortunately, are mostly seen by John and I”. She also described how John and Matthew often do things together, such as go to college sports games, fishing, and camping. Both Carla and John were proud that Matthew had progressed as he had and had come into his own in the community through participating in Special Olympics and volunteer work. Carla and John said that they just want Matthew to be as good as he could be so that he could be as independent as he wants to be in the future. Carla expressed in her interview that she couldn't imagine Matthew's being any different than who he is, and she cherishes the time she has with him, because it goes so fast.

Despite Carla and John's initial opinion of the medical professionals who first misdiagnosed Matthew with mental retardation, and the professionals afterward, who scared the couple, because of the lack of information about Autism; Carla and John admitted that Matthew was in individual therapy for several years. They believed that this therapy has been one of the biggest supports for the whole family. John described that Matthew's therapist, “offered a lot and support and reassurance for me. She would remind me that Matt would be okay, he just has a different way of learning things, which may take longer than other kids. She'd also give me ideas to keep Matt “constructively busy”, so that he's learning but not easily bored”. The couple relayed that not only did therapy help Matt become comfortable with himself and not dwell on his differences but it saved Carla and John from seeking treatment for themselves. Carla believed that

because, “Matt likes who he is and is ok, John and I are ok. That’s saved us from having to get therapy. It’s a strange thought but, because Matt had therapy all of those years, we didn’t need it”. Carla does admit that therapy would have also been helpful to John and her during the time emotions were running high, between Matthew’s different diagnoses.

Emerging Themes

Some interesting themes emerged from the parents interviewed. Some of these themes overarched both sets of parents interviewed, which encouraged the researcher to conclude that both sets of parents experienced many of the same circumstances, solely because they were raising a child with Autism. The themes focused on (1) the diagnosis process, (2) the attachment to their child before and after diagnosis, (3) their changes in expectations of themselves, each other, and their diagnosed child, and (4) their views on getting professional help, such as therapy. Other themes found, after analyzing the transcribed interviews, are family specific, meaning that they materialized directly from the experience of the parents of the younger child or distinctively from the parents of the older child. These themes included: (1) the parents’ current acceptance of their child (strengths and limitations), and (2) the use of a support system.

Diagnosis, Attachment, Expectations, and Therapy: Themes shared by Families #1 and 2

After reviewing the transcripts of the structured interviews given to family #1 and family #2, some themes emerged that were similar for both sets of parents. All of the parents expressed the confusion surrounding their child’s diagnosis process. It is well known by many parents, who have a child with a disability, that, commonly, a second or third opinion is needed before a diagnosis of a specific disability should be accepted. For many of these parents, they had to learn by going to different professionals and get

conflicting diagnoses for their child. Both sets of parents interviewed experienced a similar experience that many other parents of children with disabilities face. Different professionals who had contact with their child gave them conflicting opinions.

Family #1 initially went to their son's pediatrician after Mary (mother #1) noticed her son was delayed. The pediatrician told her that, "some kids do things slower than others". Only after they enrolled their son into an early preschool program and the teachers in the program noticed their son's significant delay were they referred to a child psychologist and received a diagnosis of Autism. Family #2 went through a similar experience with their son. Carla (mother #2) noticed delay in her son and she and her husband took him to their pediatrician. He informed the couple that Matthew was "retarded". However, Carla knew about retardation and noticed that, unlike children who are mentally retarded, her son wasn't progressing at all. Her friend, who taught special education, told her to take her son to the Menninger Institute. At the Menninger Institute, Carla and her husband John (father #2) were given Matthew's formal Autism diagnosis.

Even after the parents in the study got second opinions from professionals in the field of child psychology, the frustration of the diagnosis process wasn't over. Both sets of parents were looking for answers about Autism. They usually left appointments more confused about Autism than when they walked in. The parents interviewed attribute this confusion to the professionals' not understanding Autism or having current information about the disorder.

As Carla stated in her interview, "it doesn't help new families who are inflicted with this to get a diagnosis, then not get any answers from who's supposed to know best about this....there's no excuse for not knowing [current information]". Mary also expressed her

frustrations about healthcare and mental health professionals' lack of answers in this statement, "I just want professionals to give me professional answers to my questions and be sympathetic to my frustrations and suggest things that may help in raising a healthy, productive, Autistic child. That's all".

Another theme that both family #1 and #2 shared was the changing relationship with their diagnosed child. Before their child's diagnosis, all of the parents interviewed expressed that they were closer to their child before diagnosis, than directly after diagnosis. Some of the reasons given for this disconnect from their child was righteous anger or anger that is believed to be justified, fear, and the lack of emotional connection felt between parent and child. Father #1 stated that he thought, "Man! What happened?...Honestly, I was looking for someone to blame....I wasn't thinking of Natey and his future....so really, I guess my relationship with him lessened because I was so caught up in my own fight that I pushed him away". Mother # 2 described the fear she felt after Matthew's diagnosis that caused her to initially push him away. She portrayed this process of disconnect by saying, "At first, I was thinking, well, I guess we're going to have to have another one (child) so that we can be normal parents...I guess then I just wanted anything to put what was happening to Matt behind me. I didn't want to hear it, didn't want to deal with it...". Last, mother #1, explained that she disconnected with her child, because she felt as though he had disconnected from her. She stated that, "he wasn't responding to my touches of love anymore, and would cry and scream with me as he would with a complete stranger. I felt that the love and affection between a mother and son should have been reciprocated....It was so hurtful at the time to think that I'm doing all of this for him, and he could care less".

The last theme that both sets of parents shared was their changes in expectations of themselves, spouse, diagnosed child, and the way that their family functioned as a unit. Each parent expressed that they had to change their expectations of themselves, regarding their career. They also noted that they had to re evaluate their expectations of their diagnosed child, because each parent was still unsure what may be in store for their newly diagnosed child.

All of the parents interviewed for this study expected to be career oriented. The parents in family #1 both expected to work a full-time job, even after they had children. Mary (mother #1) found that she could work full-time until Nathan was born. She realized that “she couldn’t do everything”, so she had to quit her job to take care of Nathan, because he needed so much extra attention. Carla (mother#2) described a similar situation when she stated, “ I knew that having Matt changed everything for us. I mean, he was a real needy baby...I had to eventually stay home to take care of him”. Both of the fathers in the study realized that they had to become the sole provider for the family. They focused on occupations that would bring in the most money, regardless of their college degree. However, both fathers do admitted that, although they expected a more traditional family, where the wife took care of the children and the home, they have had to help around the house more than they did before Nathan and Matthew were born.

In addition, all four parents changed their expectations of their diagnosed children. Mary and Dave (family #1), expect Nathan to be a kid. They weren’t sure what the future would hold for him, and allow him to be “free-spirited, and spontaneous”. According to Dave, Mary and he expected their older children to be “little Einsteins”, who go to college and have successful careers.

Carla and John (family #2) had the same expectations for Matthew when he was younger. They were unsure about how Matthew was going to progress, so their initial expectations for him were very low. Now, Carla and John are reminded by Matthew on a daily basis that he can do a lot of things and can be a successful member of their community. Therefore, their expectations have changed from being low to being relatively high, based on the parents' familiarity with Matthew's abilities.

The last major theme that arose from the interviews of family #1 and family #2 was their view toward getting professional help, specifically therapy. All four parents stated that they believed therapy would have been helpful for them individually and as a family, even though none of the parents in the study received individual or family therapy. The parents expressed that therapy would have helped them cope with their child's diagnosis, express emotions appropriately, and gain information about Autism. These common themes have been represented in Table #2.

Table 2. Representation of Common Themes Among Family #1 and Family #2

	Diagnosis	Attachment	Expectations	Therapy
Mother 1	Confusion, looking for answers, went to multiple doctors	Disconnect after diagnosis: love not reciprocal	From high to low for Nathan, changes in self expectation	Believes therapy would have been beneficial to self and all children; help cope with changes and info gathering
Father 1	Righteous anger , confusion, multiple doctors	Disconnect after diagnosis: felt sorry for self, blaming	From high to low for Nathan, expect more for self, less for spouse	Wishes he would have sought individual and family therapy; help deal with anger, changes and info gathering
Mother 2	Fear, confusion, misdiagnosis, multiple doctors	Disconnect after diagnosis: shame, embarrassment	From high to low then back to high for Matt; self and spouse expectations changed from high to moderate	Matt sought therapy, believed to be beneficial in confidence in himself; believes family therapy would have been beneficial; used therapist for info
Father 2	Fear, misdiagnosis, looking for answers	Disconnect after diagnosis: protecting self from hurt	From high to low then to moderate for Matt; self expectations remained high; for spouse, from high to moderate	Matt sought therapy; believes good support system; thinks family therapy would be beneficial; used therapist for info

Acceptance of Autism and Social Support: Diverging Themes

Although the four parents interviewed had similar experiences having a child diagnosed with Autism and views toward therapy, they do have some differences in themes that may be attributed to the age of their child and how long they have lived with Autism in their family. Mary and Dave (family #1) had not fully come to terms with Nathan's diagnosis. They expressed that they were still unsure what about his future. Their hope for him was that either his brother or sister will care for him after Mary and Dave are deceased. Carla and John (family#2) hoped that their son Matthew was doing well after they are deceased but that he will have learned enough skills that he could live as independently as possible.

Mary and Dave also expressed in their interview that they had difficulty figuring out what their son's strengths and limitations were and how those could either be resolved now or limit him in the future. Dave mentioned that Nathan was a creative child who was talented in art. This strength was not mentioned again by neither David nor Mary within either of the parents' interviews. The parents primarily focused on his limitations, such as his delay in preschool and his continual mannerisms, including the compulsive and inappropriate focus on his sense of touch or the feeling of his vocal cords, which are called tactile and verbal stemming. Mary and Dave stated that, if Nathan weren't Autistic, they would have expected Nathan to finish high school, go to college, be successful in his career and have a family. However, since Nathan was Autistic, they didn't expect much from him, because they were unsure of his capabilities.

Carla and John had a good understanding of who Matthew is as a person and what his strengths and limitations were. For one, they realized that Matthew was very talented in

music. He had learned the piano, guitar, and harp and can read music well. Carla also stated that, “he’s got a memory like a steal trap”, meaning that he remembered things, such as birthdays and important dates that slip her or her husband’s mind on a regular basis. They also understood that, as long as Matt had a schedule of daily events, he did fine on a day-to-day basis. Carla described that, “he likes to come home from his day program, see what we’re having for dinner, and set the meat out to begin thawing... or he’ll make a salad and put it in the fridge for dinner”. Carla and John’s understanding of Matthew’s strengths allowed them to refine the skills that he had, and teach the skills that he needed to know so that he could be even more successful and independent in the future.

Since Carla and John had lived with Matthew in their home, they not only understood where Matthew excelled but what limited him on a daily basis. Many Autistic individuals, including Matthew, become very nervous in new situations. Knowing that about Matthew, Carla and John tried to expose him to various different environments in the community so that he became more comfortable in new surroundings. They also understood that Matthew could only be as good as *he* could be not as good as Carla and John waned him to be. John explained this notion by stating, “I remember looking at him (Matthew) and thinking: I wonder if he’ll be our next president, or a doctor or a lawyer. My aspirations were high...but once we realized he had something wrong with his brain, then expectations changed...I just wanted Matt to be the best he could be with what he was dealing with”. Carla also helped illustrate this point when describing how Matthew sets his own expectations of himself, which continued to show Carla how much he could do. She stated, “frankly I’m still learning, because I’ll still want to help him do things,

that I think may be too much for him, and he tells me he knows how to do it, and to basically, 'back off mom'!".

Another difference between the two families was their utilization of social supports. Mary discussed the feeling that no one understood what she and her family were going through. Therefore, she decided to exclude others, including friends, healthcare and mental health professionals as a part of her family's social support system. She stated that, "my friends have actually distanced themselves from me a bit, because they don't know how to react to Nate on play dates and stuff like that". She also expressed her frustration with professionals, such as psychologists, speech and occupational therapists, because they would tell her they "understand", when Mary feels they don't understand her situation because they don't live with an Autistic child.

The distance she felt between her family and social supports has made her feel as though her "plate is full", because her support came solely from her husband and his parents. Thus, she felt as though they were taking this on alone. She believed that her life had become so hectic that she had trouble starting new things that she knew may benefit Nathan, such as structuring and organizing her household.

Carla and John, on the other hand, had so many social supports in their community. Carla described that, "we are so lucky to have great people that are very involved with Matt. Because of them, Matt has some friends who don't have disabilities, and that has made him well-rounded". Family #2 discussed several different forms of support not only for them but for Matthew. For example, they noted that, when Matthew went to his day program, he would learn skills that are beneficial to him and those skills were carried over and used in the home. When Matthew was at harp lessons, he was stimulating his

brain and his sense of touch. Also visiting his grandparents gave him a sense of satisfaction because he'd help someone else. Not to mention, during this time Carla and John were able to take a well deserved break and recharge their emotional and physical batteries.

However, Carla described how this was not always the case when Matthew was younger. She stated that, "when Matt was younger, I didn't expect anyone to help, because I didn't think anyone would know how to take care of him". John also described how he and Carla didn't ask for help because they both, "didn't know what to expect from support", since they thought no one seemed to know about Autism or how to work with children who were Autistic. Although both sets of parents differed in the way they received support today, it is important to note that Carla and John went through the same feelings of isolation that Mary and Dave were currently experiencing. However, once they began trusting others' ability to help, they opened themselves up to get the support they needed. The themes described are depicted in table #3.

Table 3. Differences Among Family #1 and Family #2 Within Common Themes

Mother #1	Father #1	Mother #2	Father #2
Not sure of Nathan's strengths, but know his weaknesses; unsure for Nathan's future	Limits outweigh Nathan's strengths; foresee other children caring for Nathan in adulthood	Know Matt's strengths and limits; utilize strengths and work on limits; want Matt to be self sufficient in future	Know Matt's strengths and limits; appreciates strengths and helps him with limits; want him to be able to make own choices
Not utilizing supports other than immediate family; feels isolated and no one understands	Not utilizing supports other than immediate family	Many supports in the community; believes supports are beneficial to Matt and self	Many supports in community; believe Matt benefits from support as well as himself

CHAPTER FIVE

Discussion

The parents interviewed for the purpose of the study have some common themes concerning their changing expectations once the child began showing signs of the disability, the initial disconnect in parent-child attachment after diagnosis, and the parents' view on the benefit of therapy. Other themes discussed in Chapter four are themes that were family specific. These themes include the process of getting to know the child with Autism and understanding his strengths and limitations, as well as the parents' utilization of social supports in their community.

It is important to note that the family specific themes were believed to be diverging only because family #1 was at a different place in experiencing Autism than family #2, since family #1 had only lived with Autism in their family for about 3 years, while family #2 had 15 or more years experience with Autism. However, family #2's interview noted that they had similar experiences as family#1 when their child was younger. Therefore, these diverging themes were believed to be directly related to the age of the first child diagnosed in the family and the family's experience with Autism.

Similarities with Existing Literature

A majority of the themes that emerged out of the interviews with families #1 and #2 have significant ties to the existing literature. The parental disconnect from the diagnosed child was strongly connected to Bowlby's (1969) theory of attachment and Boss' (1999) theory of ambiguous loss. In addition, other research that has studied the distancing behaviors, caused by a disorganized attachment style, between parent and child, were covered in the review of literature (Naber, Swinkels, Buitelaar-Kranenburg, van

IJzendoorn, Dietz, van Daalen & van, England, 2007). The parents' positive view toward seeking therapy, during and after their child's the diagnostic process, corresponded with Sue Johnson's experiential emotionally-focused therapy and her ideas about experiencing true emotions, rather than protecting and submerging them. This means that, if the parents sought therapy during and after their child's diagnosis, it would have helped them retain the strong attachment that they felt they had injured with their child, because of feelings of hurt, fear, and anger surrounding the diagnostic process. The theme of parental understandings of their child's strengths and limitations strongly related to Twoy, Connolly and Novak's (2007) and Boss' (1999) research on the ongoing parental adaptation to the changes they experience with their child. The last theme, the utilization of support that surfaced from the interviews, relates to Gray's (2006), research concerning different modes of support families with children who have disabilities use and parental coping styles. However, it is important to note that Gray's (2006) research findings differ from family #1's current use of social supports. These themes will be elaborated upon subsequently.

Attachment Injury and the Literature

All of the parents interviewed explained that, after their child was diagnosed with Autism, there was a perceived attachment injury in the parent-child relationship. The parents' answers in the interview attributed this attachment injury to various reasons including: emotional reactivity and the perception that the child did not reciprocate love. The parents interviewed revealed that emotions played a part in the disconnect with their child after he was diagnosed with Autism. Mother #1, explained that her disconnect came from her observation that Nathan showed signs of discontent with everyone with whom

he came into contact as an infant and toddler, even his mother. She described these feelings as hurtful and had thoughts of “giving up”. Father #1 also described feelings of extreme anger of Nathan’s diagnosis, because of the lack of answers he was getting from the medical community surrounding his diagnosis. He explained that he was on a “quest” for answers, and started becoming closed off to both his wife Mary and his son Nathan. He believed that this caused an attachment injury with Nathan, because he was more focused on himself and his need for answers, than what his son needed during this time. Although Mother #2 was ashamed to say it in the interview, she wanted to avoid everything to do with Matthew’s diagnosis. In her interview, she stated that her initial thoughts were, “we can have another (child), so that we can be parents to a normal child”. Her overwhelming fear and uncertainty encasing Matthew’s diagnosis, caused her to have a mentality like children playing the game “hot potato”, where she would do anything to get away from having to face the problem. She also mentioned that she experienced the problems with being unable to soothe Matthew when he was a baby, as mother #1 stated previously. Last, Father #2 attributed his disconnect from his son, Matthew to the persistent fear and confusion surrounding Matthew’s diagnosis. He explained that he was extremely frightened that his son may be institutionalized, because of their possible inability to care for him.

The literature suggested that the parents’ perceived attachment injuries arose from the frozen grief process contained in Pauline Boss’ (1999) theory of ambiguous loss. She explained that many caregivers, who experience a loss that is vague and uncertain, try to make sense of their impending situation by using blaming behaviors to rationalize the trauma. Fathers #1 and #2 both described blaming behaviors in their interview. Father #1

admitted that he blamed everyone for Nathan's diagnosis, including his own wife. Father #2 used words such as "quack" to describe the medical professionals who initially diagnosed his son with MR. Boss explains this blaming behavior by attributing it to the fathers' need for answers about their child's diagnosis and being let down by the lack of information about Autism. In addition, O' Brien's (2007) research aligned directly with Boss' (1999) theory of ambiguous loss, and explained the "emotional rollercoaster", of feeling in control one minute and, in another, feeling completely hopeless in the situation. The theory noted that the expression of contradictory feelings and emotional reactivity in situations where a caregiver is experiencing ambiguous loss, was often common and is a part of the frozen grief phenomenon and attachment process that occur in the parent-child relationship.

The idea of the lack of return of love from the child, when love was given by the parent, correlates with Bowlby's (1969) theory of attachment and Naber, et al's (2007), research on disorganized attachment style. Both mothers interviewed noted that their son exhibited signs of a disorganized attachment style, with characteristics such as continual crying and the inability to distinguish between a caregiver and a stranger. Research, based on John Bowlby's attachment theory, suggests that, when a child attaches in a disorganized way to the parent, the parent's natural response is to react in kind and form a disorganized attachment with the child (Steele, Steele & Fonagy, 1996). Other research, based from attachment theory, reported that attachment strains have been specifically noted between parents of children with ASDs, over parents with typically developing children (Konstantareas & Homatidid, 1992). The research found that parents, who consistently give love and affection to their child, who does not reciprocate the affection,

become frustrated and confused, causing a strain within the parent-child relationship. The research based on John Bowlby's attachment theories (1969;1979;1988) helped explain why an initial parent-child attachment injury occurred with both families interviewed for this study.

Parental Views on Therapy and the Literature

Families #1 and #2 relayed that, if they had chosen to seek it, therapy would have been beneficial during the time their child was showing signs of changes and after the child's initial diagnosis. Susan Johnson's experiential, emotionally-focused therapy (EFT) would have been helpful to these parents during this time. The main premise of emotionally-focused therapy is uncovering true emotions experienced during times of grief, loss and conflict. The parents interviewed for this study all admit that they experienced an attachment injury after their son began showing signs of Autism and during the diagnostic process.

If the parents had received Susan Johnson's style of therapy, the parents would have been able to deal with their overwhelming emotions surrounding their grief, because the therapist would have been able to help them become "in tune" with their true feelings. This would have allowed the families to create positive change within the family dynamic, which could have helped them move forward from the trauma they had experienced. Therefore, the acceptance of their child's disability would have come faster for both families, rather than the parents harboring anger and blaming behaviors, also called "defensive-fears", that accompany denial.

Families #1 and #2 described their family as "tough" and emphasized the strength within the parental subsystem. Susan Johnson's EFT could also have helped both families

realize that they are a strong unit, without having to take on the “white knight” mentality. As explained in Chapter 2, this mentality occurs when individuals neglect their true feelings in order to protect others and themselves from appearing vulnerable and others around them from becoming upset. Therefore, this mentality allows the individual to appear strong during adversity and their hope is that others around them will adopt the same attitude. Family #1 described that, after Nathan was born, their family became “tough”, and adopted the mantra that they “don’t take any shit from anyone”. Family #2 described that having Matthew has made the parental unit “stronger” than it was before. These descriptions of how families 1 and 2 viewed themselves could have been explored in family therapy using Susan Johnson’s EFT style of therapy, allowing the families to be able to say positive things about how their diagnosed son had affected their life without the feelings coming from protective emotions such as defensive fears and anger.

Parental Understanding of Their Child and the Literature

It was noted, in the results chapter, that family #1 understood their child’s strengths and limitations less than the parents in family #2. This finding was not only expected, because family#1 has had significantly less time to get to know their child, than family#2, but is also a normal part of adapting to the child’s diagnosis (Twoy, et al., 2007;Boss, 1999). Parents #1 and #2 mentioned in their interview that their son Nathan is a creative child who enjoys art. However, they primarily tended to focus on Nathan’s limitations, which included his developmental delays, trouble in preschool, lack of focus, and continual need for stimulation.

Boss(1999), described this phenomena as a normal process that parents go through when they are experiencing the ambiguity surrounding a loss described as “goodbye

without leaving”. Boss (1999) described that many parents are so caught up in the ambiguity that they fail to change their expectations that they had for their child that they established before his or her diagnosis. She continues by saying that, since the parents have not adapted to their child’s diagnosis, they tend to focus on his or her limitations and feelings of helplessness become stronger over their child’s condition.

The parents interviewed in family#2 described that, although there was a lot of confusion surrounding their son Matthew’s diagnostic process; they had adapted to his diagnosis over time and now know who he is as a person. They focused on Matthew’s strengths of learning several musical instruments, his great memory, and involvement in community organizations, rather than dwelling on his limitations. Family #2 realized that Matthew does have limitations but they chose to be proactive and help define his limitations so that he can improve on them. Boss (1999) described that family #2 realized that their son’s diagnosis wasn’t caused by any one reason and had begun to heal over the years by reevaluating their situation. Therefore, family#2 began the process of accepting Matthew with his new strengths and limitations and have reformulated their thinking about who he is and his future.

Family #2 noted in their interview that getting Matthew into therapy helped them with the process of understanding Matthew and his strengths and limitations. They explained that the therapist helped them understand normal progress for Matthew, gave them praise and support, and also helped Matthew become comfortable with himself. Mother #2 stated that, “Matthew is ok with who he is, so John and I are ok”. Family #2 understood now that their son is a happy, loving person with many talents, who continues to amaze them everyday.

Differences from the Existing Literature

Family#1 and #2 differed from one another and Gray's(2006) research in the utilization of social supports. Family #1 expressed that they did not trust many medical professionals to be straightforward with them. This was based out of the "hush-hush" experience the family had, surrounding their son's diagnostic process and their son's inaccessibility to the care he needed. Furthermore, mother #1 mentioned that her friends in the family's community have distanced themselves from her, because they don't know how to deal with Nathan and his behaviors on play-dates and outings. She described that she began going to church in order to feel accepted again. She explained that she stopped attending services because the members of the church wanted to reassure her that God was in control of Nathan's situation, not her. Mary expressed that statements, such as these, frustrated her because she felt that all of her work with Nathan was in vain and anything she tried to do for him wouldn't make a difference in helping him develop cognitively and socially. She continued to illustrate this point by saying that Nathan's own father didn't really even know how to handle stressful situations with Nathan, so he just passed him back off for her to handle. This had caused her to feel isolated and overwhelmed with her situation.

Nathan's father described his frustrations and mistrust with medical professionals in the community where they reside. He stated in his interview that it was difficult to find daycare, doctors, and even dentists in town who will see Nathan, because the professionals say that they aren't equipped to handle Autism. Therefore, the family has kept Nathan at home during the day and has driven over two hours just to see a dentist. They did not utilize social supports outside of the home because they wanted to avoid

being let down by professionals in the community. They had continued to take on everything by themselves.

Family #2 realized now that everything has come “full circle”, in their process of adapting to their son’s diagnosis. Mother #2 described that, although Matthew was initially misdiagnosed by his pediatrician, even after he was formally diagnosed, they couldn’t get answers about his diagnosis. It had all been a learning experience for her family. She and her husband eventually understood that their son needed help or he was not going to progress, regardless of the lack of information about Autism. Family#2 had to set their overwhelming need, to protect their son from people outside of the family aside and decided to seek emotional, speech, and occupational therapy for Matthew, which turned out to be a great experience for everyone in the family.

The literature shows that a majority of families, who have children with disabilities, rely heavily in the beginning on treatment centers, respite care, private care, and family support (Gray 2006). Over time, Gray (2006) found that the use of support changed to adopting a philosophical perspective to justify their child’s disability, such as adopting religious meanings to explain their child’s disability, maintaining domestic routines, and keeping in contact with other parents of Autistic children. The use of treatment centers was a distant second use of social supports, because Gray explained that many of these parents sought treatment to help them cope early on, such as family therapy and early intervention services for their child.

Family #1 relied heavily on family support. Their lack of trust in medical professionals and treatment, other than family therapy at this time, had caused them to choose not to seek support outside of the home. Family #2 had always used treatment services for

Matthew, because they harbored an overwhelming sense of guilt surrounding his diagnosis. Mother #2 stated in her interview that, “I didn’t want him to blame me for his Autism”. The family had also relied on family support and continued to do so today. Instead of seeking early intervention services and therapy, Matthew has attended a day program specifically designed for adult individuals with disabilities. Father #2 described that the reason why the family had not ventured far from their original treatment plan for Matthew. He stated, “if it worked for Matt, we kept it up, and if it didn’t, we stopped it”. By this, he meant that they have learned what has worked for their son over the years and what hasn’t, simply by trial and error.

Limitations

The main limitation in this study was the difference of income between family #1 and family #2. Although both families fall within the middle class socioeconomic status, family #1’s income is significantly less than the other family interviewed for the study. In addition, family#1 has three children in the family to support versus one child in family#2. This limitation may have made it more difficult for family#1 to seek treatment for themselves and their child, such as early intervention services and therapy for the issues that they discussed earlier in the chapter. Therefore, this may have been a reason why their actions did not support Gray’s (2006) research findings on family’s utilization of support.

Another potential limitation to the study is the depth of the interviews with the participating parents in the study. It was the researcher’s goal to obtain a richer description of the parents’ experience of raising an Autistic child. However, the interviews were unable to capture the researcher’s desired richness due to the length of

the interviews with the parents and the environment where the interviews were conducted. If the interviews were longer than an hour in length for each parent, the researcher could have asked more questions and explored more of the parents' responses in depth. However, given the participants' availability to participate in the study, the interviews were conducted in the participants' home, usually at a time when all of the family members were present in the participants' home. Therefore, a longer interview for each parent would have been burdensome to the participant, making the interview rushed.

Implications for Clinicians

The findings of this study do provide suggestions for clinicians who work with families who have Autistic children. Suggestions for healthcare professionals and therapists will be discussed in this section.

Healthcare Professionals

All of the parents in the study discussed the confusion, lack of information, and number of healthcare professionals visited during their child's diagnosis process. The parents attributed this confusion of the process to the healthcare professional's lack of knowledge on Autism. Every parent interviewed stated that the doctors who diagnosed their child could not explain anything about Autism, other than that it's a debilitating disease that would seriously affect their child for the rest of his life. The parents explained that the doctors' lack of knowledge created mistrust in medical professionals after their child's diagnosis. Therefore, they felt hopeless and alone.

According to the parents interviewed, having current information about Autism for newly diagnosed families would have been extremely helpful. Instead of the parents having to research Autism themselves in order to find answers, a packet about Autism,

available at the doctor's office that provides current information on the disorder, would have helped ease the anxiety during the diagnostic process. The interviews also provided insight to the problems with accessibility to healthcare professionals for their child with Autism. They discussed issues about trying to find medical treatment and childcare that were equipped to handle Autistic children. One family stated that they have to drive two hours to take their son to the dentist and pay an exorbitant amount of money if they wanted to enter their child into an Autism capable preschool. It is important for healthcare professionals to make their services accessible to everyone, including individuals with disabilities. When these services are too expensive or not available to families, the children do not receive the proper care they would have received if they were a normally developing child. Therefore, the child falls farther behind.

Mental Health Clinicians

Even though all of the parents interviewed in the study agreed that therapy would have been beneficial for them, if they had chosen to seek it, they had concerns about the therapeutic process. Mother #1 stated that she did not want to see a professional who assumes she knows what she 's doing as a mother of an Autistic child. Instead she expressed that she wants a therapist to offer suggestions and listen to frustrations. Father #2 wanted mental health professionals to follow through on what they promise to their clients. He knew that many mental health professionals aren't as knowledgeable about disabilities as they profess to be. He wanted mental health clinicians to have the latest information on disabilities, so that they can provide counseling, refer families to the appropriate social supports, and answer questions parents may have about their child's disability.

As the families stated, it is important for mental health clinicians to continue to update themselves on the research being published about disabilities. In addition, it is imperative that therapists, who work with children who have disabilities, to learn and understand enough about the disabilities in the DSM-IV, so that they can adequately explain a child's diagnosis to his or her parents. Furthermore, information packets on disabilities, such as Autism, should be available for clients to take with them. Within those packets, websites that offer information about the disability, names and telephone numbers to available, and accessible community supports for both the parent and child, and information about the grieving process should be included.

Taking an authoritative stance or an all-knowing approach in therapy seems to be a turn-off for the parents interviewed in the study. Instead, acting as a sympathetic listener to parents' frustrations and a cheerleader for successes that occur in the family's life appear to be a reason why parents would choose to seek therapy. Once the parent and therapist establish a good therapeutic relationship, the therapist may begin to make helpful suggestions or explore causes of problems and reason for successes with the parents, if they are open to it. Taking time with the parent of an Autistic child within the therapeutic realm creates a calming in their often, chaotic world. Parental tension should lessen as they enter the therapy room. They should look forward to speaking with the therapist on a weekly basis and leave feeling less tension and more hopeful about their situation.

Implications for Researchers

Because this study is exploratory in nature, it provides a foundation for further research. First, it would be interesting to interview parents of children of other impairing

disabilities, such as MR or cerebral palsy, to see how their experiences compare to the experience of parents with Autistic children. This would allow the researcher to incorporate more literature into the study to help explain the trends that may occur and gain more insight on the experience of parents, in general, who have children with debilitating disabilities.

Second, it would be helpful if multiple case studies on the same subject could be opened up to more families with children diagnosed with Autism. This would allow the emerging themes found in this research to be confirmed or refuted by the other families included in a larger scale multiple case study. Therefore, it would be easier to generalize the themes found to a larger population and open up even more possibilities for future research by possibly providing additional themes.

Last, it may be beneficial to consider a follow-up interview years later with family #1, so that the researcher could gain the family's changing perspective, as a family who has lived with Autism as family #2 has in the study. This would allow the researcher to compare an older family#1's experience with family #2 from this study and confirm or invalidate the themes that emerged specifically because family#2 had lived with Autism longer and had a better understanding of the disorder.

Conclusion

After conducting the research, analyzing the findings, and relating the findings back to the existing literature, it is believed that the parents in the study had common themes and reactions to the changes in their lives, mainly because their children were Autistic. Both families expressed the confusion that surrounded the diagnostic process and the initial, negative emotions surrounding their child and the impending situation. In addition, the

families described distancing behaviors as a protection against feeling hurt by their child or feeling like a failure as a parent.

Another commonality between family#1 and #2 was that they both initially felt isolated from the rest of the world; because they perceived that no one would be able to help them with their child. In addition, both families interviewed for the study believe that therapy could have helped them gain more information on Autism and offer critical emotional support for the stressful time all of the parents endured during their child's diagnostic process. Last, the unity that both families described in the research could be attributed to having to remain strong during the tough times but was also credited by each parent to their Autistic child. Each parent interviewed noted that having a child with Autism in their family has not only made their family stronger but more adaptable to change.

Role of Researcher

In addition to gathering and analyzing information for the purposes of the study, it is important to illustrate the effects of this study on the researcher. The researcher, an advocate for individuals with disabilities and an individual who has worked with many people with disabilities and their families for the last 8 years in her community, has seen the issues that the parents in the study experienced on a daily basis. The researcher repeatedly found herself remembering the struggles of the many parents of children with disabilities, with whom she had worked over the course of her college career. Listening to the parents' interview about their struggles with finding appropriate health and childcare invoked a lot of memories regarding the barriers that every parent with whom she worked with had experienced. These memories caused the researcher to empathize with the

participants of the study, who had feelings similar to the many parents with whom she had worked, of, “why me, why my child?”. She also related to the feeling of being on an emotional rollercoaster with the parents interviewed, because she had experienced the feelings of continual triumph and letdown when she worked with children diagnosed with Autism. It is believed that, from this study and from the researcher’s own experience working with the parents of children with disabilities and their children, these parents’ stories of raising a child with a disability and these stories’ similarities are important and merit further research.

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Appendix A
Parent Informed Consent

KANSAS STATE UNIVERSITY
INFORMED CONSENT TEMPLATE

PROJECT TITLE: A parents' perspective of having a child with Autism

PRINCIPAL INVESTIGATOR: Tony Jurich, PhD

CO-INVESTIGATOR: Tiffany Ritchie

CONTACT AND PHONE FOR ANY PROBLEMS/QUESTIONS:

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(785) 532-1488
jurich@ksu.edu

Tiffany Ritchie
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IRB CHAIR CONTACT/PHONE INFORMATION:

Rick Scheidt, Chair
Committee on Research Involving Human Subjects
203 Fairchild Hall
Kansas State University
Manhattan, KS 66502
(785) 532-3224

PURPOSE OF PROJECT: The purpose of this research project is to interview the parents of children diagnosed with Autism. By interviewing these parents, the researcher hopes to gain an understanding about their experience and how they have coped with their child's disability.

PROCEDURES TO BE USED: The researcher will interview the parents of the child diagnosed with Autism. Questions may include those that ask about the family, what it was like for the parents after the child's diagnosis, and what it is like living with a child with Autism now. All questions will be asked in a manner that is respectful in nature.

ALTERNATIVE PROCEDURES OR TREATMENTS, IF ANY, THAT MIGHT BE ADVANTAGEOUS TO SUBJECT: None

LENGTH OF STUDY: Each interview is expected to last about one hour.

RISKS ANTICIPATED: None anticipated

BENEFITS ANTICIPATED: Parents will be able to relay their experience, to the researcher, of having a child with Autism in the home. This may be beneficial to the

parents in the study because they will be able to speak openly about their experience, which many parents with Autistic children aren't able to do.

EXTENT OF CONFIDENTIALITY: The responses of the participants will be kept confidential and will remain in the possession of the interviewer. The interview will be audio-taped and later transcribed. After the transcription process, the audio tapes will be destroyed in order to maintain the participants' privacy. The confidentiality of the participants will be maintained by the researcher by changing names within the write-up of this research. Furthermore, paperwork signed by the participants will be kept separately and securely from the research write up in the office of Tony Jurich, PhD at Kansas State University and will be destroyed upon the completion of this research project.

IS COMPENSATION OR MEDICAL TREATMENT AVAILABLE IF INJURY OCCURS: (in cases where more than minimal risk is involved) N/A

PARENTAL APPROVAL FOR MINORS: No minors will be interviewed

I understand that this project is research, and that my participation is completely voluntary. I also understand that, if I decide to participate in this study, I may withdraw my consent at any time, and stop participating at any time without explanation, penalty, or loss of benefits, or academic standing to which I may otherwise be entitled.

I verify that my signature below indicates that I have read and understand this consent form signed and kept by the participant.

Father's Name: _____ **Date:** _____

Father's Signature: _____ **Date:** _____

Mother's Name: _____ **Date:** _____

Mother's Signature: _____ **Date:** _____

Witness to Signature: (project staff) _____ **Date:** _____

Appendix B

Letter to Potential Participants

Date

KSU LETTERHEAD

Dear Parents:

My name is Tiffany Ritchie, a masters student in Marriage and Family Therapy at Kansas State University. I am currently working on a research project in order to obtain my masters of Science degree in this field.

You probably recognize my name, because I am an active member of the community advocating for individuals with disabilities. I have a strong interest to interview parents in this community whose child has been diagnosed with Autism. I am interested in hearing about the experience of being a parent of a child who has been diagnosed with Autism and applying this experience to my research.

This is a unique opportunity for you as a parent to relay your experience to a future practitioner so that I can include it in my research, as well as providing an educational piece for other practitioners in the community to learn how to better serve you in the future.

Your participation in this research project would be greatly appreciated. To participate in this study, please send the enclosed stamped envelope, addressed to the Family Center, with the bottom portion of this letter within thirty (30) days of the above date. If you choose to participate, you will not be required to come to the family center for the interview in order to maintain your confidentiality.

Sincerely,

Tiffany Ritchie, B.S.

Anthony P. Jurich, PhD

RESEARCH STUDY PARTICIPATION FORM

_____ Yes, I would like to participate in your research project regarding Autism in the family. Please contact me to set up a time that is convenient for me to be interviewed.

Contact information: I can be reached at this phone number _____

_____ No, I am not interested in participating in this research.

Appendix C

Demographics Information Sheet

Demographics Information

Individual Information

Mother

Age: _____

Occupation: _____

Education: number of years completed _____

highest degree completed _____

Race/ Ethnicity:

_____ African American

_____ Asian

_____ Native American

_____ Caucasian (white)

_____ Hispanic/Latino

_____ Pacific Islander

_____ Other _____

Father

Age: _____

Occupation: _____

Education: number of years completed _____

highest degree completed _____

Race/ Ethnicity:

_____ African American

_____ Asian

_____ Native American

_____ Caucasian (white)

_____ Hispanic/Latino

_____ Pacific Islander

_____ Other _____

Marital Status:

_____ Married (number of years _____)

_____ Separated (year separated _____)

_____ Divorced (year divorced _____)

_____ Other (please explain)

Child with disability

Age: _____

Description of disability:

Grade in school: _____

Special services available to child:

Child Race/ Ethnicity:

_____ African American

_____ Asian

_____ Native American

_____ Caucasian (white)

_____ Hispanic/Latino

_____ Pacific Islander

_____ Other _____

Family Information

Estimated Family Income:

_____ Below \$ 10,000

_____ \$10,001- \$20,000

_____ \$ 20,001- \$30,000

_____ \$ 30,001-\$40,000

_____ \$ 40,001-\$50,000

_____ \$50,000 or more

Religious Affiliation:

_____ Protestant

_____ Catholic

_____ Jewish

_____ LDS

_____ Islam

_____ Hindu

_____ Buddhism

_____ Agnostic

_____ Other _____

Appendix D

Semi- Structured Interview Questions

Interview Questions:

1. Before you had children, what had you envisioned your family to look like?
 - a. For yourself?
 - b. Your spouse?
 - c. Your child (ren)?
2. What were the expectations that you had for yourself, your spouse, and children, after you had children?
3. How do you feel now about your current situation?
4. How would you describe _____ to others?
5. When did you realize _____ was different than other children?
6. What were your thoughts when those signs began emerging?
7. do you believe that those signs you saw strengthened or lessened your attachment to _____?
8. How do you think having _____ in your family has impacted who you are as a family?
9. What do you believe your family's strengths are?
10. Where do you believe are growth areas for your family?
11. (For younger children): What are your hopes for _____?
What are your fears for _____?
12. (For older children): What were your hopes for _____?
What were your fears for _____?
13. What do you expect for _____'s future?
14. How would those expectations be different for _____ if he didn't have Autism?
15. Where did you receive the most support in dealing with the challenges of having a child with Autism after your child was diagnosed?
16. What were your expectations of the support you were/ are receiving then/now?
- 17.(For older children): Where do you receive the most support now? What changed?

18. Was anything unhelpful to you/ your family?

19. Does your family use a therapist?

20. If so, for individual therapy, family therapy or both?

21. What advice would you give to other families who have a child with Autism?

22. What advice would you give to professionals who work with families who have children with Autism?