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## Mothers' experience of having a child diagnosed with an autism spectrum disorder

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Amanda L. Gane  
Mothers' Experiences of  
having a Child Diagnosed  
with an Autism Spectrum  
Disorder

## ABSTRACT

The purpose of this study was to attempt to understand how mothers experience their relationships with their children diagnosed with an autism spectrum disorder (ASD). This qualitative, exploratory study aimed to expand the body of knowledge on mothers who have children with an ASD and their unique experiences. The majority of previous research done in this area has been quantitative and has not considered the individual experiences of this population.

Mothers of children diagnosed with an ASD were recruited from Massachusetts and New Hampshire for this study. Ten mothers with children between the ages of five and nineteen were interviewed face to face regarding their experiences of caring for a child with an ASD. Questions focused on topics such as: (a) Their own perceptions of their experiences, (b) the process of obtaining the diagnosis, (c) the most difficult and most rewarding aspects, and (d) the relationship between themselves and their children.

Findings suggested that being a mother to a child with an ASD is both stressful and rewarding. Participants reported frustrations regarding their treatment by health care professionals and school systems. In addition, they spoke of the multitude of roles they had to play and relayed stories of loss in different areas of their lives as a result of mothering a child diagnosed with an ASD. Suggestions were made for further research on the impact of ASDs on families and how their unique needs can be met.

MOTHERS' EXPERIENCES OF HAVING A CHILD DIAGNOSED WITH AN  
AUTISM SPECTRUM DISORDER

A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Master of Social Work.

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2008

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## CHAPTER I

### INTRODUCTION

The purpose of this study was to explore mothers' experiences of having a child diagnosed with an autism spectrum disorder. Autism has become a term that many people are now familiar with. There are a variety of terms used to describe a set of disorders known as pervasive developmental disorders (American Psychiatric Association, 2000). Some of these include the autisms, autistic disorders and autism spectrum disorders (ASDs). For the purpose of this study, ASD will be used as an umbrella term to refer to autism, Asperger's syndrome and pervasive developmental disorder not otherwise specified (PDD NOS).

Research since the early 1990s has shown a marked increase in the prevalence of children being diagnosed with an ASD (Yazbak, 2003). It appears to be increasing with each year and is the fastest-growing developmental disability in the United States (Autism Society of America, 2007). The term *autism epidemic* has become widely used and describes the seriousness of the increase. Unfortunately, resources are currently inadequate to meet the needs of children diagnosed with autism in the United States (Yazbak, 2003).

Children diagnosed with an ASD are not the only people increasingly being affected by these disorders. Families of these children experience enormous struggles on a daily basis that often go unrecognized. Parenting a child diagnosed with an ASD has been shown to be more stressful than parenting a child with any other disability and

mothers of these children are more likely to suffer from depression than the general population (Mouridsen, Rich, Isager & Nedergaard, 2007). Although it is not always the case, mothers are generally the primary caregivers for their children diagnosed with an ASD (Gray & Holden, 1992), yet their stories generally go untold. Previous research regarding parenting a child with an ASD had generally focused on gathering and reporting quantitative data. This study attempted to give ten mothers a voice and share their stories of loss, frustration, anger, pain and joy. The hope is that this study will create awareness of the needs of mothers of children diagnosed with an ASD and that more research will be done in this area.

Prominent object relations theorist John Bowlby (1980) developed a theory of loss in relation to the death of a loved one. He described a series of stages that a person may go through in the process of mourning this person. Oppenheim, Dolev, Koren-Karie, Sher-Censor, Yirmiya and Salomon (2007) referred to a parent's discovery that their child has autism as a "metaphorical loss of a child" (p. 109). This study explored how a mother of a child diagnosed with an ASD might experience stages of loss similar to those outlined by Bowlby (1980).

This exploratory study investigated the experiences of ten mothers of children diagnosed with an ASD. A review of previous literature will ensue after this brief introduction, followed by the methodology for this research study. After this, the findings will be presented and later discussed in terms of the previous literature and from the perspective of Bowlby's (1980) stages of loss.

The results may be helpful to other mothers of children diagnosed with an ASD as well as for social workers in understanding the unique struggles and needs of these

mothers. This understanding may give social workers a different perspective and guide the way in which they plan treatment when working with mothers of children diagnosed with an ASD.



## CHAPTER II

### LITERATURE REVIEW

This literature review aims to cover a number of areas involving mothers' experiences of their relationships with their children diagnosed with an ASD. To begin with, the review will provide a brief history of the diagnosis and etiology of ASDs. Following this, a discussion of the current diagnostic criteria and etiology for ASDs as well as current statistics in America will be presented. The review will then consider studies involving parents' experiences in relation to having a child diagnosed with an ASD. Finally, a general overview of attachment theory and John Bowlby's model of loss will be provided within the object relation's school of thought.

#### *The History of Autism*

Autism is no longer the rarely diagnosed disorder that it was before the 1990s, but is popularly referred to as the *autism epidemic*. Since the initial definition of autism in 1943, aspects of both the diagnostic criteria and the etiology have altered. Some however have remained strikingly similar. A discussion of the history of the diagnosis and etiology of autism will follow.

#### *History of the Terms Autism and Autism Spectrum*

Austrian born psychiatrist Leo Kanner was the first person to define the term in 1943 and is seen as the father of autism. He used the term *infantile autism* to describe a group of children who demonstrated symptoms similar to those outlined as criteria for the diagnosis of autism in the *Diagnostic and Statistical Manual, fourth edition, text revision*

today (APA, 2000). Up until this point, children with these symptoms had been labeled as schizophrenic or feebleminded (Wolff, 2004).

Kanner moved to the United States in 1924 at the age of 30. He had finished medical school in Austria and qualified as a pediatrician. Kanner had no experience in psychiatry, which was still a relatively new profession that had not earned a significant amount of respect. He worked at a psychiatric hospital in South Dakota for four years before moving to John Hopkins in Baltimore where he soon became a professor. Here he observed patients with serious mental impairments that had been institutionalized over an extended period of time (Grinker, 2007).

In his article, *Autistic Disturbances of Affective Contact*, Kanner (1943) described eleven children demonstrating similar symptoms including abnormal speech, echolalia, obsession with monotony, repetition of certain specific behaviors, concrete thinking and “extreme autistic aloneness” (p. 242). He differentiated infantile autism from childhood schizophrenia and mental retardation stating that the patients in question did not exhibit hallucinations or delusions and were of average to higher intelligence. Kanner’s belief was that early infantile autism was an extremely rare disorder and only occurred in approximately 3 per 10,000 of the population (Kanner, 1943).

At around the same time, a psychiatrist named Hans Asperger was studying a group of children displaying symptoms similar to those observed by Kanner. Asperger was also born in Austria but, unlike Kanner, never made the move to the United States and all his writing was done in German. In his 1944 paper *Autistic Psychopathy in Childhood*, Asperger described four children who were unable to make eye contact and displayed repetitive behavior. Unlike Kanner’s subjects, these children were highly

verbal. Asperger (1944/1991) referred to these children as *autistic psychopaths*. Kanner and Asperger never met (Grinker, 2007).

Following Kanner's (1943) paper, more research was done and in the 1950s, the term autism became widely known. Asperger's work took a lot longer to be recognized. This only occurred in 1981 when Lorna Wing, a British expert on autism, introduced Asperger's work in English. Wing (1981) then changed the term autistic psychopathy into Asperger's syndrome. She described it as a disorder separate to autism, but on the same spectrum (Wing, 1981). Asperger's work was only formally translated into English in 1991. Asperger's syndrome was introduced as a disorder in the DSM-IV under pervasive developmental disorders along with autism (APA, 1994).

#### *The Development of the DSM Diagnosis of Autism*

Although Kanner's article may have had a direct impact on children with autism not being diagnosed as feeble-minded, they were still being diagnosed with childhood schizophrenia until the DSM-III was published (APA, 1980). The original DSM, published in 1952, and DSM-II, published in 1968, were not regarded as scientifically sound and therefore not used within psychiatry as they are today. In the DSM-II, the only mention of autism was part of the criteria for childhood schizophrenia (APA, 1968).

In 1980, the DSM-III was published with five times as many pages as the DSM-II. It was widely used as a reference for diagnosis, and autism was included as a diagnosis for the first time (APA, 1980). In the DSM-III-R, autistic disorder was classified on axis II as a pervasive developmental disorder (PDD) along with PDD not otherwise specified (NOS) (APA, 1987). The DSM-IV included Asperger's disorder for the first time, but it was only in the DSM-IV-TR that Asperger's was viewed as on the autism spectrum along

with autism and PDD NOS. In addition, the classification of PDD was placed on Axis I, there by distinguishing these disorders from Mental Retardation (APA, 1994).

### *History of the Etiology of Autism*

Kanner was practicing and writing during the height of psychoanalysis when psychopathology was seen as having a psychogenic cause. The term *schizophrenogenic mother* was used to explain how schizophrenia was caused by a cold yet controlling mother. With autism and schizophrenia being so closely related, it does not seem unusual that Kanner adopted a similar explanation for the cause of autism. The influence of psychoanalytic thinking is observed in Kanner's (1949) explanation of infantile autism being caused by bad parenting and a lack of maternal warmth. He compared these mothers to refrigerators and the term *refrigerator mother* is still recognized today (Grinker, 2007).

The DSM-II did not include autism as a separate diagnosis. Rather, it was described under childhood schizophrenia as autistic, atypical, withdrawn behavior, failure to develop identity separate from the mother, general unevenness, gross immaturity and inadequacy in development (APA, 1968).

By the 1970s, psychiatry was becoming a more recognized and respected division of the medical profession and more doctors were specializing in it. This enabled more research to be done and mental disorders were being explained from a biological perspective (Grinker, 2007). Even though research has been suggesting a biological cause for autism for more than 30 years, parents often experience strong emotions including guilt in relation to their child's diagnosis of autism. This will be discussed under the section related to parents' experiences in this literature review.

## *Current Diagnosis, Etiology and Prevalence of Autism*

### *DSM-IV-TR Diagnosis of Autism*

Autism is classified as a pervasive developmental disorder that appears before the age of three. In addition, it is a “disorder usually diagnosed in infancy, childhood or adolescence” (APA, 2000, p. 69). The current criteria for the diagnosis of autism according to the DSM-IV-TR includes delays in one or more of these areas: social interaction, language use in social communication and symbolic or imaginative play. There is often a presence of repetitive behaviors such as hand flapping or rocking and preoccupations with particular stereotypical interests. These criteria are extremely similar to those outlined by Kanner (1943). Approximately 75% of people diagnosed with autism have a co-morbid diagnosis of mental retardation (APA, 2000). This is the main point of difference between Kanner’s original and today’s criteria. Kanner (1943) held the belief that people diagnosed with autism were all highly intelligent.

The criteria for Asperger’s in the DSM-IV-TR include impairment in social interactions and restricted and repetitive behaviors, interests or activities (APA, 2000). The main difference between Asperger’s and autism is that with Asperger’s there is no significant delay in language or cognitive development. PDD NOS is a diagnosis given if the child does not meet full criteria for autism or Asperger’s but does display a mixture of the symptoms for both. All three fall under the umbrella term of pervasive developmental disorders or the autism spectrum disorders.

### *Prevalence of Autism and the Spectrum Disorders*

Until recently, autism was believed to be a rare disorder (Gillberg et al., 2006). The DSM-IV-TR (2000) stated that the prevalence is on average 5 per 10,000 of the

general population. The Autism Society of America (ASA) reported that one in 150 babies, is born with autism (ASA, 2007). The U.S. Department of Education announced a 1,700% increase in children receiving special services due to a diagnosis of autism, between 1992 and 2002 (Yazbak, 2003). Males are more likely to be diagnosed with an ASD than females (APA, 2000). There is no information given on other demographic features.

### *Current Etiology of Autism*

Although ASDs are generally believed to have a genetic explanation, there is research addressing other possible causes. These include childhood vaccines (Hornig, Chian & Lipkin, 2004) and more specifically, the Measles Mumps Rubella (MMR) vaccination (Dales, Hammer & Smith, 2001). Improved diagnosis has been linked to the recent alarming increases in incidence (Taylor, 2006).

With the history of autism in mind, the parent's experience of raising a child with this diagnosis will be examined.

### *Parenting a Child with Autism*

ASDs do not only affect the child diagnosed with it, but this diagnosis also has a profound impact on the child's family. The literature shows that parents encounter a number of different experiences and emotions in response to caring for a child with an ASD. This section will outline studies examining parental feelings of anxiety and guilt, struggles with mental health issues, the experience of loss as a reaction to having a child diagnosed with an ASD, and how specifically mothers respond to having a child diagnosed with an ASD.

### *Parental Feelings of Anxiety and Guilt*

Mouridsen et al. (2007) conducted a longitudinal study in Denmark over a 33-year period using a group of 115 parents of children diagnosed with autism and a control group of 330 parents from the general population. The study examined the rates of psychiatric disorders in parents diagnosed with autism in comparison with the general population. Results suggested that parenting a child diagnosed with autism is more stressful than parenting a child with any other disability, including Down syndrome (Mouridsen et al., 2007).

In an exploratory study done in Wales, four parents were interviewed regarding their experiences in the diagnosis of autism (Midence & O'Neill, 1999). These parents had children between the ages of nine and twelve who were diagnosed with autism between the ages of three and seven. They reported that they struggled to understand their children's behavior and were confused as a result. During the period prior to receiving their children's diagnosis of autism, they experienced guilt and anxiety, wondering what they had done wrong. This guilt continued after the diagnosis had been made and the etiology of autism was explained to the parents. Another common experience was difficulty in obtaining the diagnosis, and one parent was accused of being "neurotic" by the pediatrician. Although this was a small sample, it did provide narratives of the parents interviewed.

Grinker (2007) wrote both an anthropological and a personal account of his knowledge of autism. His daughter was diagnosed with autism in 1994, but it took a few years to obtain this diagnosis. Grinker's wife, a psychiatrist herself, was accused of being overanxious by the pediatrician when she first expressed her concerns about their

daughter's behavior. Grinker traveled around the world speaking to parents of children with autism. He discovered that many mothers had similar experiences to his wife's and many had felt like they had been accused of overreacting by pediatricians.

#### *Autism and Parents' Mental Health*

Mourisden et al. (2007) found that depression and alcohol abuse occurred at higher rates in parents of autistic children than in the general population. This study took the differences between mothers' and fathers' experiences into account. The findings showed significantly higher rates of depression in mothers of autistic children than mothers in the general population. In addition it demonstrated that mothers of autistic children were more prone to depression and alcohol use than the fathers of children diagnosed with autism. This study, however, only compared parents who had been hospitalized for a psychiatric disorder and did not take into account parents who may have been dealing with less severe degrees of depression or substance abuse. In addition, it examined the genetic link between children with autism and psychiatric disorders in their parents and did not address what impact having a child with autism had on a parent's mental health.

Gray and Holden (1992) showed similar results to the Mourisden et al. (2007) study. A questionnaire was sent to 172 parents of children with autism examining their psychosocial well-being. They discovered that mothers were more likely to be at home with their children than the fathers and were also significantly more likely to suffer from depression. Unlike Mourisden et al. (2007), this study links the higher rate of depression in mothers to staying at home and being a full time parent of a child diagnosed with autism (Gray & Holden, 1992).



## *Loss*

As stated earlier, Oppenheim et al. (2007) compared the experience of having a child diagnosed with autism to losing a loved one. The strong emotions that parents feel on hearing the diagnosis include shock, despair, anxiety and questions regarding the cause. Ultimately, the hope is that parents will resolve these feelings and come to terms with the diagnosis (Oppenheim et al., 2007). These emotions mirror the emotions that one may feel after losing a loved one and experiencing the different phases of grief and loss outlined by Bowlby (1980).

Oppenheim et al. (2007) looked at two studies (Dolev, 2005; Salomon, Yirmiya, Oppenheim, Koren- Karie, Shulman, & Levi, 2006) that had interviewed parents of autistic children in different age groups. It is not entirely clear how many interviews were evaluated. These interviews included five questions from the Reaction to Diagnosis Interview (RDI), which explored parents' thoughts and feelings regarding their child's diagnosis of autism. The researchers were looking to see how parents demonstrated resolution with regards to their child's diagnosis.

A resolved parent was described as having gone through changes since hearing the diagnosis, accepting the diagnosis while still remaining hopeful and no longer searching for the reasons why their child had autism (Oppenheim et al., 2007). This study looked at a parent's thoughts and feelings surrounding the diagnosis of their child. What it did not address was what other stages of grief parents may have experienced or how they may have moved back and forth between different stages of grief and loss, described by Bowlby (1980).

Parents may not only experience a perceived loss of their child, but may also experience loss in other areas of their lives following a child's diagnosis of autism. An interpretive study was done in Australia looking to explore the experiences of nine parents of children diagnosed with an autism spectrum disorder. Each parent was interviewed separately and the data were then analyzed. Following the data analysis, focus groups with these parents were conducted (Cashin, 2004).

What the researcher discovered was that parenting a child with autism has a profound impact on a parent's sense of self and feeling of competence. The findings suggested that parents of children diagnosed with autism were less spontaneous in their parenting styles, had less social contact with the outside world, felt less able to afford material possessions and concluded that their roles as parents had become the only role they were able to play in their own lives (Cashin, 2004).

What these findings suggest is that the communication and social struggles that an autistic child experiences become part of the parent and they begin to exist together in a "vortex" (Cashin, 2004, p. 164). The difficulty with socialization and rigidity in parenting style mirrors the symptoms of autism that the child is living with and hence they may appear to be living in a vortex together. Living in this vortex with an autistic child leads to anxiety and a feeling of isolation for a parent (Cashin, 2004).

The major strength of Cashin's (2004) study is that it explored parents' experiences using both interviews and focus groups. The findings challenged the hypothesis that rigid socially awkward parents create autistic children, suggesting instead that autism has a significant impact on a parent's sense of self. However, the sample size was small, no issues of race, gender or socioeconomic background were raised and the

method of data collection was not discussed in detail. It is therefore probably not very generalizable.

### *The Role of the Mother*

Both Mourisden et al. (2007) and Gray and Holden (1992) discovered that mothers were generally the ones doing the hands on parenting of their children diagnosed with autism. For this reason, the following reviews focus on mothers and their relationships with their children.

Montes and Halterman (2007) conducted a quantitative study comparing mothers of children with autism to mothers of children who were not diagnosed with autism. A sample of mothers of 61, 772 children between the ages of 4 and 17 were interviewed over the phone. They obtained this large sample from the National Survey of Children's Health, who surveyed approximately 102, 000 parents nationally in 2003 regarding the general health of their children. Montes and Haltermann (2007) restricted their sample to just mothers and asked participants if their child had ever been diagnosed with an ASD. Of this sample, 364 children had been given a diagnosis of an ASD. Stress was measured using items from the Parent Aggravation Scale. The mothers of children with autism reported higher levels of stress and were more likely to struggle with a mental disorder than the mothers of children without the diagnosis of an autism spectrum disorder. However mothers of children with autism reported having close relationships with their children and felt able to cope with the demands of parenting to the same extent as mothers of children without this diagnosis.

Susan Senator is a mother of a child diagnosed with autism. She has written a book as well as spoken at a number of conferences on autism. She described being

devastated after receiving the news that her son had autism and having to go on antidepressants herself. She described a grieving process that she constantly moved through even though she had come to terms with the diagnosis and was celebrating her son's differences (Senator, 2005).

### *Attachment and Loss*

Prior to John Bowlby, psychoanalysts believed that infants needed the mother for the purpose of meeting basic physiological needs. Bowlby was one of the major contributors to the field of attachment, suggesting that infants need the bond with their mothers for development. The mother is an infant's primary attachment through which the child learns how relationships function. This influences the way in which a person develops subsequent attachments with other important figures based on the initial relationship with their mother. Loss of an attachment figure can be devastating (Berzoff, Melano Flanagan & Hertz, 2002).

### *The Process of Attachment*

John Bowlby was one of the first theorists to realize that attachment was a primary need of the infant that if unmet, was detrimental to development (Berzoff et al., 2002). He believed that all relationships that a person forms are based what attachment style they developed as an infant (Bowlby, 1980). Attachment was seen as an innate tendency of the infant developed within the first to third years of life. During this time, the mother and infant form a reciprocal bond. The focus of the infant was a single maternal figure and this bond was seen as essential for normal development (Bowlby, 1958). This bond was formed between mother and child through the infant's use of attachment behaviors.

Bowlby (1958) outlined certain attachment behaviors after observing many infants and listening to accounts of mothers. He described crying, suckling, clinging and smiling as purposeful behaviors used to activate the maternal instinct of the attachment figure. The mother then responded to the child's attachment behaviors by staying close in proximity and being attuned to the need for attachment. Maintaining proximity may be described as the goal of attachment behaviors.

Mary Ainsworth was a student of Bowlby who also contributed to the field of attachment theory. Ainsworth and Bell (1970) defined attachment in the following way:

An affectional tie that one person or animal forms between himself and another specific one—a tie that binds them together in space and endures over time. The behavioral hallmark of attachment is seeking to gain and to maintain a certain degree of proximity to the object of attachment, which ranges from close physical contact under some circumstances to interaction or communication across some distance under other circumstances. (p. 50)

The attachment bond between mother and child generally endures over time and a person may continue to hold an “internal model” of their mother after her death (Ainsworth, 1989, p. 711). This may also be true of other attachment bonds that a person forms throughout their lives. Attachment behaviors change as a person develops, although the style may remain the same (Ainsworth, 1989).

Ainsworth's biggest contribution to the field of attachment theory was that of attachment styles. Through the development of the *strange situation*, secure, anxious/avoidant and anxious/resistant attachment patterns were identified. The child displaying a particular style depended on how the child responded when the mother left the child in a room with a stranger and then later returned (Ainsworth, Blehar, Waters & Wall, 1978).

A child that is securely attached will engage with the stranger while the mother is in the room, but will not engage when the mother leaves. This child will be upset when the mother leaves and happy when the mother returns. A child is able to attach securely if the mother is appropriately attuned to the child's needs (Ainsworth et al., 1978).

A child displaying an anxious/avoidant style is anxious in the presence of a stranger even when the mother is present. This child become extremely upset when the mother leaves and is ambivalent when she returns, wanting to remain close but unresponsive to her displays of affection. This style is seen in children whose mothers are affectionate, but only on their own terms, not necessarily when the child initiates it (Ainsworth et al., 1978).

These attachment styles endure into adulthood and influence the way in which a person forms attachments. For example, a securely attached child will probably go onto have healthy intimate relationships as an adult.

More recent research on attachment postulates that if secure attachment is not achieved in the first few years of life, it can occur at any time throughout a person's life (Siegel, 2001). Siegel described attachment in terms of neurology. He did agree with his predecessors that attachment is an inborn need, but believed that the experiences an infant has will directly shape the system of the brain. This is due to findings that experiences have a direct impact on neural functioning and the brain is able to adapt and grow new neural pathways in response to new experiences.

Whether attachment styles remain consistent throughout life (Ainsworth, 1989) or change through experience (Siegel, 2001), attachment to other important figures may be viewed as an important aspect of life.

### *Autism and Attachment*

Studies have been done on attachment in children diagnosed with autism. Rutgers, Bakermans- Kranenburg, van Ijzendoorn & van Berckelaer- Onnes (2004) conducted a quantitative meta- analysis of 16 studies done on autism and attachment in the Netherlands. What they discovered was that children with autism were less securely attached than those without autism. They did report that in four of the studies done using the strange situation scenario, 53% of children diagnosed with autism demonstrated secure attachment. Another finding was that higher functioning children diagnosed with autism were as securely attached as those without autism (Rutgers et al. 2004)

Hoppes and Harris (1990) compared the perceptions of attachment and maternal gratification of 17 mothers of autistic children and 21 mothers of children with Down syndrome. Open-ended interview questions were used in this study. What became apparent was that perceptions of attachment were closely linked to a sense of gratification from the mothers. The mothers of autistic children reported significantly less attachment responses and a lower sense of maternal gratification than the mothers of children diagnosed with Down syndrome.

### *Attachment and the Decision to Have a Child*

Brazelton and Cramer (1990) stated that a woman's pregnancy mirrors the attachment relationship that she had as a child. When a woman becomes pregnant, she reflects upon all her own prior unmet needs. There may be many different conscious and unconscious motives underlying a woman's wish for a child.

The needs that having a child would meet are identification, omnipotence, oneness with another, mirroring oneself, fulfillment of lost opportunities, renewal of past

relationships and separation from one's own mother. These are all seen as healthy wishes and suggest the complexity of the decision to have a child. The expectations that a new mother has of her child begin before a child is born (Brazelton & Cramer, 1990).

Brazelton and Cramer described a newborn as "embedded in idealizations" (p. 155). The mother fantasizes about creating a perfect relationship with her child, which is a projection of her ideal self. This is described as normal. This projection continues through childhood, where a parent sees the child as part of themselves. Idealization and projection may become complicated if the child displays characteristics that the parent deems *bad* or *flawed* (Brazelton & Cramer, 1990).

All mothers experience disappointment to some degree after realizing that their child is not perfect. The degree of disappointment can be much greater if the child has a birth defect, such as Down syndrome or a cleft palate. The mother may undergo a decrease in self-esteem and mourn the loss of the perfect child (Brazelton & Cramer, 1990). Having a child with a disability may therefore trigger similar emotions to those experienced when losing an attachment figure.

### *Loss*

Bowlby's (1980) book about loss was the third part of a trilogy dedicated to attachment and loss. After focusing on how important attachment relationships are to human beings, he examined the reactions to the loss of such relationships.

Bowlby (1980) developed a four-stage model of mourning through observations of adults who had lost a spouse. The four stages he described were (a) numbing which may then turn to anger, (b) yearning for the lost person, (c) disorganization and despair, (d) reorganization.



In 1980, Bowlby broadened this model to include the loss of a child, studying parents of children diagnosed with a terminal disease. In the first phase, parents displayed disbelief following the moment when they received their child's diagnosis for the first time. He described the parents as "detached" and removed from any emotion (Bowlby, 1980, p. 116). The parents then often become angry, frequently towards the physician giving the diagnosis (Bowlby, 1980).

Following this stage, parents moved into attempting to reverse the outcome, possibly looking for second opinions and information that would refute the doctor's diagnosis. Mothers then often began intense caring activities of the child, ignoring housework, care of her other children and recreational activities. Parents also blamed themselves for their child's illness (Bowlby, 1980).

The phases of disorganization and reorganization occurred following the child's death. Mourning the death either brought parents who were married closer together or it caused the break up of the relationship. Parents reportedly developed a number of different responses including depression and psychosomatic symptoms. Bowlby (1980) described the reorganization stage as a process of "reshaping internal representational models so as to align them with the changes that have occurred in the bereaved's life situation" (p. 94). He described healthy mourning as "in some degree at least, withdrawal of emotional investment in the lost person and that may prepare for making a relationship with a new one" (Bowlby, 1980, p. 25). Some younger parents had another child following the death of a child (Bowlby, 1980).

### *Discussion*

From the above review it is evident that mothers often play the most important role in raising a child with autism. The history suggests that the cause of autism was blamed solely on the mother for at least twenty years. Although it is now known that autism is not caused by parenting styles, parents still feel guilt surrounding their children's diagnosis of autism. Raising a child with autism is shown to be extremely challenging and triggers emotions such as anger, anxiety and intense sadness. Although mothers of children with autism experience strong attachments to their children, they may experience the stages of mourning in response to parenting a child with autism.

## CHAPTER III

### METHODOLOGY

The purpose of this study was to attempt to answer the question of how do mothers experience their relationships with their children diagnosed with an autism spectrum disorder (ASD)? In order to accomplish this, a flexible inductive, exploratory method of research was used. This method was chosen in order to yield subjective perspectives of the participants. A qualitative method was appropriate because of the small number of participants in the study and because the data-gathering method was relatively unstructured (Anastas, 1999). Semi-structured interviews were used to collect data from ten mothers of children diagnosed with an ASD.

#### *Sample*

A non-probability convenience sampling method was utilized in order to obtain participants. This was accomplished by accessing participants through agencies and organizations specializing in autism and Asperger's. This seemed to be the easiest and more effective method of finding mothers of children diagnosed with an ASD, who would consider participating in the study.

The initial criteria for participants to be included in the study were (a) biological mothers, (b) mothers of children diagnosed with autism according to DSM IV criteria, (c) the participant's child should be under the age of 18, (d) the participant's child should have been diagnosed with autism prior to the age of five. These criteria were changed slightly during the sampling stage, due to the difficulty of findings participants meeting

all the above criteria. The criteria were broadened and specified the following (a) biological mothers and mothers who had adopted the child from birth; (b) mothers of children diagnosed with an ASD, including autism, Asperger's and pervasive developmental disorder not otherwise specified (PDD NOS); (c) the participant's child should be age 18 or under; (d) the participant's child should have received the diagnosis in the past two years.

The recruitment procedures included non-probability convenience sampling, the snowball method and word of mouth. Word of mouth was used initially, by approaching a colleague who worked for an agency addressing the needs of families with autism. Through this colleague, five participants were found. Snowballing was then used by asking these participants if they knew of anybody else who might have been interested in participating. This yielded two additional participants. All interested participants were sent a copy of the Recruitment Letter (see Appendix A) as well as the Informed Consent (see Appendix B) to peruse.

Community Resources for People with Autism is an agency serving the entire Western Massachusetts area. This agency was approached and yielded two more participants. The agency offered to advertise for participants in their monthly newsletter. While waiting for the newsletter to be sent out to approximately 800 families, I approached the Asperger's Association of New England and a local autism support group organizer who sent out emails advertising the study to possible participants in New England. Only one participant responded, in New Hampshire. In the meantime, the Community Resources for People with Autism's newsletter had been sent out. I contacted the agency after a week of not receiving any response for possible participants. I

discovered that the advertisement had not been included, in error. By this time, deadlines were approaching and it was decided that ten participants would suffice.

According to the participants who had already been interviewed as well as professionals within the agencies approached, attaining participants appeared to be difficult for a number of possible reasons. These reasons included that mothers who have children with ASD's do not have the luxury of extra time on their hands and that difficulty that mothers had finding people to watch their children while they were being interviewed.

#### *Data Collection*

The design for this study was approved by the Smith College School for Social Work Human Subjects Review Committee (see Appendix C). Informed Consent forms (see Appendix B) signed by the participants at the time of the interviews. The Informed Consent outlined the risks and benefits of participation in the study as well as the purpose and inclusion criteria. Both the participant and I signed the Informed Consent before beginning the interview.

Data were collected using semi-structured interviews that were done face to face. The interviews ranged in length between 30 and 90 minutes. Questions were asked in a semi-structured way in order to explore a relatively unknown subject and to yield rich narrative data from the participants regarding their own personal experiences.

The Interview Guide for this study (see Appendix D) included demographic questions about the participants and their children as well as nine open-ended questions regarding the participants experiences of mothering a child diagnosed with an ASD. Follow-up questions were included if clarity was needed on a particular subject. One

additional question was added following the second interview regarding the actual given diagnosis of the child. This was done as inclusion criteria had been changed to include participants who had children diagnosed with an ASD other than autism. There were no other questions added or changed.

The interview was piloted by one person prior to use with the participants in the study. These data were not reported on in this study. This was done in order to strengthen the reliability of the study. All the interviews were recorded onto a device designed for that purpose. The interviews were then transcribed verbatim. All identifying information was omitted from the transcriptions.

#### *Data Analysis*

Data were coded according to individual questions and patterns in order to make meaning of the participants' experiences. Coding continued until all possible options for themes had been exhausted and all the interviews appeared to have been fully explored. The data was then organized thematically.

## CHAPTER IV

### FINDINGS

This study aimed to explore how a mother is affected by having a child diagnosed with an ASD. This chapter will outline the data collected from interviews with ten mothers of children diagnosed with an ASD.

Nine major themes emerged after transcribing and coding the interviews. Some themes emerged directly from the interview questions while others emerged separately. The demographic data will be presented first, followed by the major themes. The first major theme that appeared was caring for a child diagnosed with an ASD affected career choices of mothers and was seen as hard work. The second theme was the initial diagnosis of an ASD being difficult to obtain from health care professionals. The third was that participants experienced difficulties in getting the schools to meet the needs of their children. The fourth suggested that mothers felt that they had to take on additional roles that they did not always feel comfortable with. The fifth theme that appeared was relationships within the family were impacted both positively and negatively by having a member diagnosed with an ASD. The sixth theme that emerged was that participants described a sense of loss in relation to having a child with an ASD in areas including relationships with their children and others, and finances. In the seventh theme it became apparent that the mental health of some of the participants was affected with increased levels of stress and depression reported. The eighth theme that appeared was the participants attempting to find meaning from their experiences as mothers of children

diagnosed with an ASD. The final theme was participants wanting to share their thoughts and frustrations with people who were not parenting a child with an ASD.

### *Demographic Data*

The sample size for this study was ten. All ten mothers identified as Caucasian. Nine of the participants lived in Massachusetts and one lived in New Hampshire. Ages of mothers at the time of the interview ranged from 32 to 61 years, with a median of age 41 years. Of the ten participants, six were married and four were divorced. Seven of the participants were working at the time of the interview while three reported not working. The participants not working cited their children's special needs as the reason for not being employed at the time. All participants in the study reported having some form of college education ranging from an associates degree to a doctoral degree all-but-dissertation (ABD).

The ages of the children of participants diagnosed with an ASD ranged from 6 to 18 years, with a mean age of 9 ½ years. The approximate ages of participants when their children diagnosed with an autism spectrum disorder were born ranged from 23 to 46 years, with a mean age of 31.8 years. The ages at which the participants' children were diagnosed with an ASD ranged from 1 ½ to 9 years, with a mean age of 3.95 years. Four of the participants' children were diagnosed with autism, three were diagnosed with Asperger's and three were diagnosed with PDD NOS. Nine of the ten children were male and one was female. All the participants children diagnosed with an ASD lived at home with the participants and received special education services.



## *The Impact of ASD's on Time and Careers*

### *"It's Hard Work"*

All ten of the participants described the experience of having a child diagnosed with an ASD as involving hard work. One participant stated, "it does require a lot of extra work and there's a lot of shuffling of time involved." Due to the work involved in caring for their children's needs, some of the participants had chosen a career that related to caring for a child diagnosed with an ASD.

Two of the participants reported making the care of their child diagnosed with an ASD a job in its self. One of the participants stated, "Well I don't really know anything else. It's just more work I guess, but since I just work on the weekends, I feel like I'm just sort of made it my job to, you know, make her have the best life that she possibly can." The other had given up her career in accounting to become a full time advocate for her child.

Of the other eight participants, two had jobs working directly with families who had a child diagnosed with an ASD. Both had begun this work following the diagnosis of their children. One participant gave up her career in politics to undertake a graduate degree specifically in the field of autism because she wanted to learn as much as possible and wanted to help people who were in a similar situation as her. Another participant was working towards a graduate degree in counseling and was hoping to do some work with families with autism. One participant was working towards a degree in special education, one was a teacher at her child's school and one was a professor in a field of science. Only the teacher's and the professor's career choices had not been directly influenced by their children's diagnoses.

*The Diagnosis of an Autism Spectrum Disorder: A Long, Difficult Journey*

*“I Just Knew”*

Seven out of the ten participants reported knowing that their child had a developmental disability before the diagnosis was given. Two of the mothers knew from birth that there was something wrong with their children. One mother stated, “I think that from the time he was born, I knew something was not quite right.” The other five stated that they were not surprised when they were informed of the diagnosis. One participant stated, “It was not a shock for us because we had to pursue the doctors to get the diagnosis.” All of these seven mothers suspected a developmental delay in their children with as ASD because they were comparing the development to that of their other children.

The other three participants reported believing that the symptoms that their children were displaying were normal for an extended period of time, before obtaining the diagnosis. One participant stated, “I thought he was my first child and he was talking and he was good. He was a little hyper, maybe, but other than that I didn’t know any different.” All three of the participants who didn’t suspect that their children had an ASD were first time mothers.

*“Nobody Believed Me”*

Only one of the participants described the process of obtaining the diagnosis for her child as relatively easy, “I will have to refer to the fact that I do have an older child on the spectrum, so I sort of knew some of the signs, so I didn’t have to deal with all of those things (process of obtaining the diagnosis).” She did, however, say that with her older son she had experienced similar difficulties to the other participants in this study.

The other nine participants described an extremely difficult process in getting their children diagnosed with an ASD. One mother was told by a doctor that, “a little more discipline in a stricter household will cure him of his tantrums and disobedience.” Two of the mothers were told that their children had ADHD; one being told that it was ADHD “if anything.” One mother stated, “It was horrible because everyone diagnosed him with something different. I got told that there was nothing wrong with him by countless therapists and doctors. It was a really long process of getting someone to know what was wrong with him.”

Three of the participants described a feeling of relief after finally obtaining the diagnosis. One participant stated, “Since his diagnosis, it has been a relief. I experienced the gates of heaven opening as soon as he got the diagnosis because he could now get so many services. He’s doing so much better.” Another participant stated, “For us personally, it was a relief to have the diagnosis. For a lot of other parents, it’s the beginning of a difficult journey. For us it was the end of the journey and the beginning of treatment.” The remaining participants did not overtly describe the eventual obtaining of the diagnosis as a relief, but did all describe being appreciative of the services that subsequently became available to their children.

### *Playing the School Game*

Another area of struggle for all the participants was dealing with the school systems. One of the major areas requiring hard work for all the participants was getting their children’s needs met by the schools. All the participants spoke about the significant amount of the work, currently or previously, involved in advocating for the needs of their children within the school systems.

Prior to obtaining the ASD diagnosis for her son, one mother described how her son had been expelled from four preschools due to his behavior. The last preschool that he was expelled from told her, “don’t come back because your son is really immature and spoiled and you don’t know how to raise him.”

All the participants spoke about struggles with the school after obtaining the diagnosis. All the children of the participants were or had been receiving special education and had IEP’s. Agreeing on their children’s needs with the school seemed to be the main area of difficulty, as well as understanding how special education services worked. One mother relayed the following story:

Even after we got the diagnosis, the school said things like they didn’t agree with the diagnosis and I felt like saying so when did you become a neurologist? I can play their game and I can fight with people, but I don’t want to. We learned we had to be diplomatic to get what our son needed. We went to mediation for ten or eleven hours which was the longest mediation that our advocate had ever been to. We got the school to finally admit that they were not meeting his needs. So we commuted 45 minutes away for a while to the neighboring school, which is such an amazing school, but then they said we don’t take kids from out of district. So we sold our house and moved closer for the school.

Another mother stated, “There was a real struggle with the school. I had to go on a ten week legislator’s course surrounding special needs just so I would know what to say in the IEP meeting.”

Apart from having to take on a role of advocate, participants also reported having to take on others roles than they never normally would have.

#### *Roles of the Mother with a Child Diagnosed with an ASD*

All the participants spoke of having to take on additional roles than those taken on by mothers of neurotypical children. Two of the participants expressed frustration at

having to take on additional roles that they did not particularly want or feel comfortable with. One mother stated:

I felt displaced and disjointed. I felt like an advocate instead of a mom. Women become displaced in their roles within the family, in the workplace and with extended family members. I had to learn about all the medical stuff and the school stuff and learn about autism. It was exhausting. I was attending autism workshops and support groups, arranging medical testing, speech and language therapy, looking for a neurologist. I just didn't have any time for my own goals.

Another mother stated:

I am the last person that should have been dealt this hand. When I first had him, I said to my husband that I am not going to enjoy this until the kid was seven. I hate all this childhood development stuff, and that's what I have had to learn. People don't want to hear this stuff because it is hard. I am not a psychologist, I am a mother. I am not a teacher or a behavior analyst. I am not skilled at all these graphs and charts, but now I have to do all this stuff.

### *Effects on the Family*

“Autism is a family disorder. It doesn't just affect the child diagnosed with it, it affects the whole family.” Another participant reported, “We had to find ways to fit in with our other child and to do things. That's probably the hardest part is just trying to do things as a family.” All the participants spoke about how having a child diagnosed with an ASD affects the whole family. The areas affected included marital relationships, siblings and the decision to have another child.

### *Marital Relationships*

The demographic information obtained through the interviews showed that four of the ten participants were divorced. All four participants who were divorced cited autism as playing a major role in the breakdown of their marriages. Two of these women had been in relationships following their divorces, and these had also failed due to the demands of their children diagnosed with autism. One of the participants stated:

I didn't realize until he'd been diagnosed for maybe five years, how empty my marriage was, because I had been so busy. I feel like autism has impacted my life in a huge way. I feel like I might have been able to stay married to his dad, but autism had such a huge impact on my marriage.

Another mother stated:

Unfortunately it led to the breakdown of my marriage, through no fault of my son's, but because I had to focus so much of my attention on him and not my husband and he felt like I was ignoring him.

One of the married mothers intimated that her marriage had suffered due to the disorder, "Have you asked mothers about the other half in the support system? Mom's lose a lot more than their sons to this disorder." Another of the married mothers reported that she did not spend enough time with her husband, as he had to get a higher paying job, with much longer hours to support the financial costs of having a child with an ASD.

### *Sibling Relationships*

Only two of the participants' children diagnosed with an ASD were only children. The remaining eight had at least one other sibling. All eight of these made comparisons between their neurotypical children and their children diagnosed with an ASD. All eight reported being affected by the additional time and attention that needed to be given to the child with an ASD in comparison to their other children. One participant reported:

She has a twin sister, who is so much more independent and able to do things on her own. I spend a lot of time just sort of catering to her basic needs while trying to teach her simple tasks that her sister is able to do alone.

Two of the eight participants reported being the most concerned about what the impact would be on the neurotypical sibling. Another mother said:

We have a typical, wonderfully developing four-year-old daughter who is also getting sucked down the vortex with us as we try to find the best way to advantage our son. So there is a real disparity between the attention and time.

The other reported, “We worried about the neurotypical child being the one having to take care of the other one (with an ASD).”

The two participants, whose children with an ASD were only children, compared their children’s degree of independence to other people’s children. One mother reported, “we spend a lot of time with him, a lot more than probably than other parents do it with a 15-year-old.”

#### *The Decision to Have Another Child*

Two of the ten participants stated that their decision to have another child was greatly impacted by having a child with an ASD. One mother stated, “We did eventually decide to have another child, but there was so much anxiety over the second child. And what do we do if we have two kids like this? I don’t think I would take that gamble again.”

#### *Relationships between Mothers and Their Children Diagnosed with an ASD*

All the participants spoke of their relationships with their children as mixed. One participant described it as “hot and cold” while another stated “It’s rocky. He brings me such joy and such anguish, probably within the same 30 seconds.” One participant described it as “a spectrum, just like the disorder.” All the participants described feeling loved by their children, although only two said that their children spontaneously used the words *I love you*.

#### *Communication in the Relationships*

All participants described behaviors rather than words when asked how their children communicated with them. Emotions, especially, were described as being extreme behaviors. One mother stated, “I have to observe emotions in him.” Another

reported that, “He keeps his cards close, he only ever shows emotions through behaviors.” One participant spoke of struggling to figure out what emotion her child was demonstrating: “the most demanding, stressful thing is trying to figure out what the emotion is and how to manage it.”

### *Strong Emotions*

The emotions that the participants most commonly described were anger and frustration. Eight of the ten participants spoke initially of tantrums and aggression when asked how their children communicated emotions. One mother reported that “if anything, he is probably more prone to anger outbursts than anything.” Another spoke of her son as “just hand flapping, screaming and self injuring whenever he is frustrated.”

The other emotion that mothers described was love. Six of the ten mothers portrayed their children as very affectionate, initiating cuddles and kisses. One mother described how her child would push people out of the way to get to her and give her a hug. Three mothers stated that their children could be affectionate, but it did not happen very often. One mother reported that her child was incredibly uncomfortable with affection and “he really doesn’t know how to hug.”

### *“Mommy, I Love You Too”*

As stated earlier, only two of the participants’ children spontaneously said the words *I love you*. One mother related how “There are times when he will come up to you and say I love you too, which isn’t quite right because I didn’t say I love you.” The other said, “I am really lucky. He often tells me that he loves me.” Two of the other participants stated that their children would say that they loved them when prompted. One mother said, “Cartoons are his favorite thing in the world, so if you ask him whether



he loves you or the cartoons more, he will say he loves both the same.” The remaining participants stated that their children show love through their actions: “just because he doesn’t run up and say I love you, doesn’t mean he doesn’t feel it.” Some of the actions that participants described were hugs, smiles and expressing remorse when the child had done something wrong.

*“We Never Know What Is Going to Set Him Off”*

When asked about the most difficult aspects of having a child diagnosed with an ASD, the most common response was not being able to understand their children’s needs due to the communication challenges. Five of the participants spoke of this as being one of the most difficult parts. One mother stated, “ It really is the communication or lack thereof that keeps us wondering what is going on in his head. We can’t define it, so we cant help him through it or explain it in a way that he can understand.” Another mother shared a story:

It was July and I mentioned something about Christmas and he then sat outside in the pouring rain for the whole day waiting for Santa to come and this took us a long time to figure out, because he couldn’t tell us why he was sitting in the rain. My biggest fear is how he is going to be able to cope in the world when he is unable to communicate.

Other common difficulties reported were not being able to get a babysitter, their child’s inflexibility and lack of social interaction. In terms of inflexibility, on mother stated:

He’s extremely inflexible and has to have things his own way. So if I am taking care of his two- year-old brother and he wants a peanut butter sandwich right now, he wants it right now. I have to stop changing a diaper or paying attention to anything else. It’s frustrating because he has three siblings and he has to be the center of my world.

### *The Experience of Loss in Being a Mother to a Child Diagnosed with an ASD*

Two mothers compared having a child diagnosed with autism to someone's dying. One mother said, "They're [mothers] grieving in essentially the same way as death. It's the concept of the dream that has died. My dream is never going to come true and I have to put that to rest somehow. Although when someone dies, they're not parked in your face, everyday making your life hell. The fact is this kid is never going to go to college, this kid will never say I love you mommy and he may never even write his own name."

### *Loss within the Family*

The theme of loss appeared throughout the interviews in terms of marital and family relationships. As discussed earlier, the four participants who had gone through divorces attributed it to having a child diagnosed with an ASD. Worries about neurotypical siblings were also addressed earlier. One participant stated, "I feel like I have been robbed of parenting my neurotypical child."

### *Financial Pressures and Loss of Earnings*

"The financial drawbacks are pretty significant. It costs a lot of money if you are doing all the right things and you can't really work as many hours as a typical family, if you are going to be driving your kid to therapies all over the place." Two other participants echoed this stressor in terms of making sure their children with an ASD was receiving all the necessary services. Another mother stated:

We had our own business for three or four years, so we had a lot of time to spend with the kids, but no money. We ended up having to give it [the business] up and my husband got another job that pays more and I gave up working [so one parent could be at home with the children].

### *The Impact on Friendships*

Three of the ten participants spoke about losing friends as a result of having a child with an ASD. The reasons included not having enough time, and people not understanding the disorder. One mother stated, “I lost so many friends originally, because people couldn’t understand why I was making so much noise [advocating for my son].”

### *Mental Health*

Three of the participants spoke of feelings of guilt, anxiety and depression. One mother stated:

It’s depressing. Most of the days I feel stressed, like I can’t get enough done in the day. I go to therapy regularly and have been for years. It feels hard sometimes, sometimes it feels like I am falling off a cliff and it’s just me here in never never land. It will always define me.

Another stated, “I was really struggling physically and emotionally [after his diagnosis]”.

Mothers did not only speak about the negative impacts of having a child diagnosed with an ASD, they also relayed stories of positive effects of the diagnosis on their lives.

### *Making Meaning out of the Diagnosis*

All the participants spoke of some of the joys related to parenting a child with an ASD.

#### *“My Child Has Taught Me So Much”*

Four of the ten participants spoke of how their child diagnosed with an ASD had taught them new things and made them better people. One mother stated, “I truly believe that he has been brought to me to help me understand the world a little bit better.”

Another stated:

He makes me rethink everyday things, because he has such attention to detail that it makes me discover the joy in all sorts of things. I am teaching him things, but he is also teaching me things, that I would have never expected or experienced without him.

Another mother said, “I am much more of a kind person and I am proud of who I am. My son has been the most influential person in my life. He has made me more tolerant and compassionate.”

*“It’s the Little Things”*

The remaining six participants spoke about finding small things that brought joy to their lives. One stated, “I have to enjoy the moments, stop and smell the roses instead of constantly getting frustrated.” Another stated, “People don’t understand the little joys, but that’s where you have to get them. That’s where the success of the war is, just those little snippets, like sound bites.” Another mother said, “It’s when he smiles, or those moments when he does things when you don’t have to ask.”

*“It’s Hard to Find the Meaning”*

One mother stated that she knew there was a reason that she had been given a child with an ASD, but she just didn’t know what it was yet, “I know there must be a silver lining to this dark cloud and someday, I hope I will find it.”

*What Other People Should Know*

Some of the participants wanted to add that they felt that other people needed more education about ASD’s. One of the mothers stated, “I think my child is perfect. It is the rest of the world that needs to change its perceptions.” Another mother said:

People just don’t kind of understand. They look at me as if I must be the worst mother in the world. You know, the biggest frustration is not my relationship with

him, its what other people think. It's not as stigmatizing as it used to be, but people still don't know what it is like just trying to get through every day.

Another participant said:

I think it is crucial that we need to accept them for who they are. I am often asked if you could take the autism away from your child, would you? I am not sure that I would answer yes. People think I am crazy, but it is who they are.

The next chapter will evaluate these findings from the attachment and loss perspectives as well as discuss their relevance to the field of social work.

## CHAPTER V

### DISCUSSION

This chapter will evaluate the above findings in terms of previous studies and theoretical frameworks discussed in the literature review. Some of these support previous literature while others did not.

#### *The Impact of ASDs on Mothers' Time and Careers*

All the participants in this study reported being the primary care giver for their children diagnosed with an ASD and their career decisions were often based on caring for a child with this diagnosis. Gray and Holden (1992) found that mothers were more likely to be at home taking care of their children diagnosed with an ASD than fathers. The results of this study supported this finding, as the mothers interviewed were the ones who stayed home to care for their child diagnosed with an ASD. However only a small percentage of the participants in the study were able to stay home with their children. The majority maintained careers outside of the home. The difference in findings between this study and Gray and Holden's (1992) may suggest changes in the economy over time causing mothers to have to work outside of the home.

This study showed that having a child with an ASD often helped define how these women saw themselves and their different roles within society. Cashin (2004) found that parenting a child with autism has a profound effect on a parent's sense of self and that their lives become structured around the child with autism. The majority of the participants in this study reported that their careers, among other things, had been

affected by their children's' diagnoses, which supports Cashin's findings. Having a child with an ASD did affect the participants' choices of careers as well as their decisions to stay home, if they were able to. However, Cashin stated that parents viewed the impact in a negative light, while this study found that the majority of the participants did not perceive the impact that ASD had on their careers as negative.

The findings in this study showed that being a mother to a child with an ASD can be stressful and demanding. Montes and Halterman (2007) found that mothers of children with ASDs displayed higher levels of stress than mothers of children without the diagnosis, but also found that they were able to cope as well as the mothers of children without an ASD. Although this study did not utilize quantitative measures for stress, the participants all reported having a child with an ASD as hard work. The participants all reported functioning at extremely high levels with regards to all the obstacles they were facing on a daily basis.

#### *Difficulty in Obtaining the Diagnosis*

The findings in this study demonstrated how difficult it was for participants to obtain an ASD diagnosis from medical professionals, even when they themselves knew that this was the probable diagnosis for their children. Midence and O'Neill (1999) discovered that parents had experienced the process of obtaining the diagnosis of autism for their children as difficult and extremely stressful. This study's findings supported this. The majority of the participants in this study spoke of a long difficult journey where they knew that there was something wrong with their children and professionals did not believe them. Grinker (2007) described how his wife had been accused of being neurotic

when she brought up her concerns regarding her child with the pediatrician and some of the participants in this study shared similar stories.

The findings in this study showed that a number of participants felt blamed or disrespected by medical professionals. Kanner (1949) attributed the development of autism to bad parenting. Although this theory was disproved a long time ago, one of the participants shared how a doctor had told her that her child's problems were due to a lack of discipline and rules. This occurred only six years prior to this study.

#### *The Effects on the Mother/Child Relationship*

The findings of this study suggest that participants felt that their children were generally affectionate and loving towards them. Rutgers et al. (2004) found that children with autism were less securely attached than neurotypical children. Hoppes and Harris (1990) also reported this, stating that children with autism displayed fewer attachment behaviors and mothers felt a lower sense of gratification with regards to attachment than in neurotypical children and their mothers. Slightly more than half of the participants in this study reported that their children with an ASD were spontaneously affectionate and loving. All the participants reported feeling loved by their children, which may contradict the findings of Rutgers et al. (2004) and Hoppes and Harris (1990). This may suggest that assessing attachment in the ASD population needs to be assessed differently than attachment in neurotypical children.

#### *Loss*

The theme of loss was seen throughout this study. The mothers in this study experienced loss in a number of areas including the loss of an idealized child, family, finances and friendships.



The findings in this study suggest that some of the participants felt that they had lost the opportunity of raising a neurotypical child. Brazelton and Cramer (1990) spoke of how a pregnant woman idealizes her unborn child and visualizes how the child will somehow be a projection of her ideal self. All mothers go through a process of discovering that their children are not perfect, but this is magnified if a child is born with a disability. The mother may go through a period of mourning. This supports the findings of this study as two of the participants compared the experience of having a child diagnosed with an ASD, to death. One of the participants described it as more difficult than someone dying, as the child with autism is a constant reminder of the loss incurred. A number of participants spoke of dreams that would never be realized for their children such as going to college or even being able to write their own name. This study showed that some of the participants compared their children diagnosed with an ASD to their neurotypically developing children, which in some cases seemed to intensify the perceived loss of their children with an ASD.

This study found that participants experienced strong emotions in reaction to having a child with an ASD. Oppenheim et al. (2007) described feelings of shock, anxiety and despair on hearing the diagnosis, comparing the experience to that of losing a loved one in death. The findings in this study supported this as all the participants described how difficult it was parenting a child diagnosed with an ASD. They described feelings of anxiety, despair, guilt and anger. Many of the participants experienced these feelings in response to the medical and educational professionals who they encountered throughout the process.

To some degree, the findings in this study suggest that participants went through different stages of mourning in relation to parenting a child with an ASD. Bowlby (1980) described stages of loss and mourning that a parent may go through in response to the discovery that their child is terminally ill. The first was detachment from the emotions. Although the participants did not describe being detached, when speaking about the process of acquiring the initial diagnosis, none spoke of emotions other than anger. Bowlby's (1980) second stage was that of anger generally directed at the medical profession. This was seen with the majority of the participants in this study, who spoke of anger and frustration due to multiple diagnoses given prior to an ASD, the time taken in obtaining this diagnosis, not being believed by physicians and being blamed for their children's' problems.

The next stage Bowlby (1980) described was that of intense caring, where the parent ignores everything in their lives apart from the child. This can be seen with the participants within this study, who have had to submerge themselves in the lives of their children diagnosed with an ASD. The majority of the participants had altered their careers to accommodate the needs of their children. In addition, so much of their time was spent finding therapists and doctors, advocating for their children at school and constantly trying to understand and provide for their children's' needs. Unlike parents of terminally ill children, the mothers of children diagnosed with an ASD in this study saw this as a stage that does not have a definite ending. During this stage Bowlby (1980) stated that parents often blamed themselves for their children's' illnesses. This was not seen in this study.

The next two phases described by Bowlby (1980) occurred following the death of the terminally ill child. These he referred to as disorganization and reorganization. During the disorganization stage, parents either grew closer to each other or their relationships ended. They experienced feelings of sadness and depression during this stage. This can be seen to some degree in this study. Some of the participants spoke of being treated for depression related to parenting a child with an ASD. Findings in this study showed that having a child diagnosed with an ASD had a definite impact on marriages and other intimate relationships.

During the reorganization phase, Bowlby (1980) wrote that healthy mourning involved withdrawing emotional investment from the deceased child and forming a new relationship with another. With regards to this study the reorganization phase may have been seen in the mothers who participated, accepting that their children had an ASD and forming a relationship with the actual child rather than the idealized child. The findings show that the majority of the participants had found meaning in their children's disorders and had reorganized their lives in order to accommodate their children's specific needs.

Oppenheim et al. (2007) described acceptance by a parent of a child with an ASD as having gone through changes after hearing the diagnosis. This supports the findings in this study as all the participants described a process that they had gone through. It did seem however, that the stages that Bowlby (1980) described might not have been mutually exclusive when used as a theoretical framework for this study. It would appear that the participants here were constantly moving back and forth between stages, and could have been experiencing multiple stages at any given time, depending on the day.

One participant described her experience as a “roller coaster ride”, which may have described the constant movement between the stages.

What this study does suggest is that having a child diagnosed with an ASD is both rewarding and devastating at the same time. The process that mothers may go through may be similar to the process of mourning, which supports Oppenheim et al.’s (2007) findings. Bowlby’s (1980) stage theory on mourning a terminally ill child may be a useful framework in which to work with parents with children diagnosed with an ASD.

#### *Limitations of this Study*

This study is limited by the small sample size utilized. Due to the sampling method used, it was difficult to obtain a racially diverse sample. The lack of racial and ethnic diversity was difficult to control due to the sampling method and the unavailability of participants. With additional time, the geographical area could have expanded to include more racially diverse areas. Many obstacles arose in acquiring this small sample due to participants’ shortage of time and resources. With additional financial resources it is possible that child care could be arranged for participants in order for a larger sample to be obtained.

#### *Contributions*

Few studies have been previously done where such rich, narrative data has been obtained from mothers of children with an ASD. This study provides insights into the lives and needs of these mothers who are constantly rewarded and challenged by the unique needs of these children. This study shows that families with a child diagnosed with an ASD need more support in a number of different areas. With autism and ASDs in general being diagnosed more often than ever, social workers may be required to gain

more knowledge within this field. In therapy with families with a child with an ASD, it would be useful to ask questions about the process of obtaining the diagnosis, how their lives have changed since the child was diagnosed and if they feel like they have adequate services and resources. It would also be important to be sensitive to the perceptions that the family may have of health care professionals and try and not be just another professional that blames or does not understand their unique struggles. These families may not be aware of the resources that become available to a child who has been diagnosed with an ASD and social workers should be educated on how to help families access these. This study has shown that it is not only the children with an ASD that need more services, but also the caretakers and families of these children.

Mothers of children diagnosed with ASDs have unique experiences and needs, as both previous research as well as this study shows. The field of social work needs to be more understanding of these unique needs and make services available to address these. This study demonstrates that mothers of children diagnosed with ASDs may be mourning losses on a number of different levels and this should be taken into account when planning interventions for this population.

### *Conclusion*

This study provides a mere glimpse into how mothers experience their relationships with their children diagnosed with an ASD. More research in this area is suggested to gain more of an understanding of the struggles and needs of this population. It may be useful to do a larger study regarding the needs of these families and what they feel needs to change with regards to the systems who are dealing with theirs and their

children's needs. This would be useful for both the families of children with ASDs as well as the professionals who may be working with them.

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## Appendix A

### Recruitment Letter

Dear \_\_\_\_\_,

I have received your contact information from \_\_\_\_\_, who thought that you might be interested in participating in a study exploring how mothers experience their relationships with their children who have been diagnosed with autism.

I am currently a masters' level graduate student at the Smith School for Social Work, and am conducting this study for my thesis. For this study I will be interviewing mothers, who have children who received a formal diagnosis of autism before they turned five. For the purpose of this study, the child must currently be under the age of 18. If you and your child meet these criteria, I would appreciate your consideration to participate in this study.

If you agree to participate, you will be interviewed at a time and place that is convenient for you. The interview will last between 60 and 90 minutes. The interview will be audiotape recorded for my use only. Any information that would identify you to others, will be kept confidential.

I believe that by participating in this study, you will:

- 1) Have the opportunity to share your experiences of being a mother of a child diagnosed with autism
- 2) Help other mothers who are looking for information and validation of their own experiences
- 3) Create awareness among mental health professionals as well as the community.

Please contact me if you would like to participate and we can set up a time, date and place for the interview. If you require further information, feel free to call or e-mail me.

Yours sincerely,

**Amanda Gane**

## Appendix B

### Informed Consent

Nov 19<sup>th</sup>, 2007

Dear Potential Research Participant,

My name is Amanda Gane, and I am a graduate student at Smith College School for Social Work. I am conducting a study on mothers' experiences of their relationships with their children diagnosed with autism. The information I obtain from this study will be included in my Master's thesis and possibly be used for publication and/ or presentation.

Your participation is requested because you are the mother of a child diagnosed with autism. I am requesting that all participants should have a biological child who was diagnosed with autism before the age of five and is currently under the age of 18. If you choose to participate, I will ask you a number of questions regarding your experience as a parent of a child with autism and your perceptions regarding your relationship with him/her. In addition, I will ask you to provide information about yourself including age, ethnicity, marital status. The interview will be conducted in person. This will be tape-recorded, and will last approximately 60 to 90 minutes.

The risk of participating in this study may be that some interview questions are of a personal nature, which could cause some discomfort. Enclosed in this mailing is a list of resources in Massachusetts and Vermont that you may refer to if you feel that you need support following your participation in the study.

The benefits of participating in this study are that you have the opportunity to share your experiences with other parents and professionals. Your opinions would be extremely valuable to social workers struggling to keep up with the needs of children with autism and their families. Unfortunately, I am not able to offer financial remuneration for your participation.

Your name and other identifying information will remain confidential. . No identifying information will be used when quoting you in the thesis. Audiotapes will be labeled with a code number, rather than your real name, for identification purposes. These will be kept in a locked drawer throughout the compilation of the thesis and for three years thereafter, in accordance with federal regulations. After such time, I will either maintain the material in its secure location or destroy it. Personal information will not appear with corresponding participants interview responses, but will be used in a comparison with other participants to establish the overall common characteristics of the participant sample.

If at any time you change your mind about participating in this study, you are free to withdraw before March 1<sup>st</sup> 2008 when I will begin compiling the results. Participation in this study is voluntary. If you feel uncomfortable answering any of the questions, you may decline to answer.

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.**

_____	_____
<b>Signature of Participant</b>	<b>Date</b>
_____	_____
<b>Signature of Researcher</b>	<b>Date</b>

If you have any further questions, please feel free to contact me. You may also contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974 if you have any questions or concerns about this study. Thank you for your time. Please keep a copy of this for your records.  
Sincerely,

Amanda Gane

## Appendix C

### Human Subjects Review Board Letter of Approval

January 9, 2008

Amanda Gane

Dear Amanda,

Your revised materials have been reviewed and all is now in order. We are happy to give final approval to your very interesting project.

*Please note the following requirements:*

**Consent Forms:** All subjects should be given a copy of the consent form.

**Maintaining Data:** You must retain signed consent documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Ann Hartman, D.S.W

Chair, Human Subjects Review Committee

CC: Mary Beth Averill, Research Advisor

## Appendix D

### Interview Guide

#### **Demographic Questions**

Age:

Ethnic Background:

Level of Education:

Current Age of your Child:

Age of Child when Diagnosed with an ASD:

What is the child's actual diagnosis?

Does your child receive special education services?

Does your child live at home with you?

Marital/ Relationship Status:

#### **General Interview Questions**

- 1) What is it like having a child diagnosed with autism?
- 2) What was your experience of discovering the diagnosis?
- 3) How would you describe your relationship with your child?
- 4) How does your child communicate emotions to you?
- 5) When do you feel loved by your child?
- 6) What is the most difficult part about your relationship with your child?
- 7) What is the most rewarding aspect of your relationship with your child?
- 8) If you had to describe your child using three words, what would they be?
- 9) Is there anything else you would like to tell me about or you think would be important for me to know?