

Changes in Mothers' Experiences of Receiving an Autism Diagnosis:

A Contextualized Case Study

by

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ABSTRACT

Autism has a unique history. The definition has broadened and changed over time, from an emotional disturbance with psychogenic origins to a neurodevelopmental disability with suspected environmental and genetic origins. Diagnosis occurs later than children born with obvious disabilities such as cerebral palsy or Down syndrome, but earlier than milder, high-incidence disabilities such as dyslexia or attention deficit disorder. Historically, parents have advocated for changes in the way children with autism receive services and how federal funding and educational services are provided. There is often tension between these parents and the medical establishment. There can also be tension between the community of parents and the community of adults who have high functioning autism and Asperger syndrome. Studies have examined individual aspects of autism, from the diagnosis, caring for a child with autism, educational interventions, and genetics to characteristics of the internet community of adults with autism spectrum disorders (ASDs). This study includes interviews with mothers whose children were diagnosed with autism between 1974 and 2004, observations of appointments with developmental pediatricians at which diagnoses were given in 2010, and an analysis of media representations of autism over the same time period. These different data were analyzed together to create a new understanding about the history and present state of autism diagnosis.

DEDICATION

To my parents, who when they were told to put my brother with autism in an institution replied, “We don’t throw away our children.”

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Chapter 1

Introduction and Rationale

“Just take him home and love him. That’s all you can do” (Psychologist to Emma).

With these words, a mother was told that her son was diagnosed with autism. Decades before this parent received the diagnosis, other parents were told that “refrigerator mothers” caused autism and their only option was to institutionalize their child. Today, children with autism spectrum disorder reside with their families instead of in institutions. There are evidence-based behavioral interventions that offer hope to parents that their child may learn to speak and function with varying degrees of success in the world. “Diagnosis is not the end of the road but the beginning.” These words were spoken in 2010 by one of the developmental pediatricians included in this study. He was referring to the opportunity to access services and watch the child grow and develop. The psychologist’s statement to Emma did not offer this kind of hope.

The process of obtaining a diagnosis of autism and the conversations that occur during the moment of diagnosis have changed over time. This study includes interviews with mothers whose children were diagnosed between 1974 and 2004, observations of appointments with developmental pediatricians at which diagnoses were given in 2010, and an analysis of media representations of autism over the same time period. These different data were analyzed together to create a new understanding about the history and present state of autism diagnosis.

Context for the Study

Autism as a disability and as a growing community of individuals and their families has a unique history and current context. The definition of autism has broadened and changed over time from an emotional disturbance with psychogenic origins to a neurodevelopmental disability with possible environmental and genetic origins. Diagnosis occurs later than children born with obvious congenital disabilities such as cerebral palsy or Down syndrome, but earlier than milder, high-incidence disabilities such as dyslexia or attention deficit disorder. Historically, parents have advocated for changes in the way children with autism receive services and the manner in which federal funding and educational services are provided. There is often tension between these parents and the medical establishment. There can also be tension between the community of parents whose children are diagnosed with autism spectrum disorder and the community of adults who have high functioning autism and Asperger syndrome. In the past, studies have examined individual aspects of the autism experience from the diagnosis, caring for a child with autism, educational interventions, and genetics to characteristics of the internet community of adults with autism spectrum disorders (ASDs).

This study seeks to analyze the history of autism diagnosis and how various aspects of society have influenced it. Those influences include parents, doctors, and researchers as well as popular media, such as books, films, and news magazines. The final product will analyze individual experiences of parents and

diagnosticians, as well as the historical significance of the interaction among the medical profession, activist organizations, and popular media.

Stress and Caring for a Child with Autism

A large number of studies have confirmed that parents of children with autism have higher levels of stress than parents of typically developing children or children with other disabilities (Abbeduto et al., 2004; Dale, Jahoda, & Knott, 2006; Gray, 2003; Kuhn & Carter, 2006; Weiss, 2002). Parental adjustment and functioning is an important issue, not only because it is of interest to improve parental quality of life, but also because it is associated with parental ability to care for and teach their children with autism (Romanczyk, Weiner, Lockshin, & Ekdahl, 1999).

There are notable differences between mothers and fathers in how this stress manifests. Mothers are more likely than fathers to feel guilt or shame about the diagnosis of autism (Gray, 2003). Mothers are more likely than fathers to have depression (Gray, 2003). Fathers are more likely to suppress feelings, while mothers are more likely to “vent” to friends or family (Gray, 2003). The severity of the child’s autism is correlated with the level of parental stress. The more severe the disabling affects of autism, the higher the stress levels in the mother (Tobing & Glenwick, 2002). Mothers stress levels were more affected by daily child care tasks that were impacted by the child’s characteristic ASD behavioral difficulties (e.g., eating, sleeping, and emotional regulation), while fathers associated stress with more externalizing behaviors (e.g., aggression) (Davis & Carter, 2008).

The stressors of caring for a child with autism are unique. Parents whose children have other disabilities can engage in reciprocal exchanges of affection. Parents will seek affection from their child with autism, but the child may seem aloof or unresponsive to these attempts (Abbeduto et al., 2004; Gray, 2003; Olley & Gutentag, 1999; Weiss, 2002). Often parents report a sense of isolation (Gray, 2003; Weiss, 2002). Mothers in particular report sacrificing their career to care for the child with autism, which includes taking the child to medical appointments and attending educational meetings for purposes such as writing an Individual Education Plan (IEP) (Gray, 2003; Weiss, 2002) as well as going to frequent therapy sessions. While children with mental retardation demonstrate delays across all domains, children with autism often have “splinter skills,” which are high levels of ability in one area along with severe deficits in other areas. This leads to the parents being confused about the child’s true intellectual ability (Gray, 2003; Weiss, 2002).

Another aspect of autism is the absence of a visible difference from a typical child. Since there are no physical differences in appearance associated with ASD, a child’s temper tantrum in the presence of others can easily be misconstrued as “bad parenting.” Farrugia (2009) explored Goffman’s concept of stigma by analyzing parent interviews. He found that the experience of stigma typically happened in situations in which the other adults (e.g., teachers) did not accept that the child’s challenging behavior was due to their autism. Therefore, in public situations, others labeled the parenting skills or the child as “bad” when they do not know the child has autism.

The process of seeking and attaining an autism diagnosis also has unique stressors associated with it. From the moment in which parents first suspect something is “wrong” with their child to the moment when they receive the autism diagnosis is often a longer period of time than for other disabilities (Brogan & Knussen, 2003; Dale et al., 2006; Mandell, Novak, & Zubritsky, 2005; Vostanis et al., 1998). When the diagnosis is given, parents often report it was unclear what the diagnosis was or what it meant (Brogan & Knussen, 2003; Dale et al., 2006; Mandell et al., 2005; Vostanis et al., 1998). The prognosis for the child was also unclear (Weiss, 2002). The cause of autism is a controversial topic that adds to the stress of receiving an autism diagnosis (Brogan & Knussen, 2003; Dale et al., 2006; Mandell et al., 2005; Vostanis et al., 1998).

Unlike genetic syndromes, there is no medical test to determine if a child has autism (Nissenbaum, Tollefson, & Reese, 2002). To receive a diagnosis, the child must demonstrate a number of behaviors and patterns of behavior consistent with the criteria listed in the Diagnostic and Statistical Manual (DSM) of the American Psychological Association. The average pediatrician may lack experience with children with autism and would be unable to recognize the signs of the disorder. This often leads pediatricians to advise parents to “wait and see” if the child “grows out of it” before referring the family to a specialist (Mandell et al., 2005). It appears that certain behaviors are more likely than others to cause a pediatrician to refer a family to a specialist in autism. These include severe language deficits, toe walking, hand flapping, and sustained odd play. “Physicians may be more familiar with these symptoms from portrayals of ASD in the popular

media, or they may be more disturbing to parents and physicians alike, prompting additional evaluation” (Mandell et al., 2005, p. 1484).

In a study conducted in the United Kingdom, first year and fourth year medical students were given a 10-item questionnaire on basic facts about autism (Shah, 2001). The mean number correct out of 10 items was 1.97 for the first year students and 4.15 for the fourth year students. A study conducted in the United States compared responses from primary care providers, such as pediatricians, with professionals who specialize in autism spectrum disorders (Heidgerken, Geffken, Moi, & Frakey, 2005). A significant number of misconceptions were revealed.

Primary providers believed that children with autism do not share social attachment to their parents and that autism occurs more frequently in upper socioeconomic categories. Those professionals were less likely to recommend parents pursue special education services, and they believed children with autism would grow into adults with schizophrenia. None of these statements are accurate according to current research. More alarmingly, primary providers were more likely to endorse Bettelheim’s (1959) “refrigerator mother” outdated and disproven theory of the cause of autism. Primary providers were also more likely to believe that children could grow out of the disorder despite the fact that research shows that children on the severe end of the spectrum will likely need constant care and supervised living placement into adulthood. Both of these studies speak to the lack of training that pediatricians have received in basic information about autism.

Parents of children with Down syndrome typically receive the diagnosis before or at the time of the birth of their child and the diagnosis is confirmed with genetic testing. This allows the parents to immediately begin processing the diagnosis, and the prognosis for the child's future is somewhat more predictable. For parents of children with autism, there is a lengthy delay in the diagnostic process. Since there is no definitive medical test for autism, the parents may have concerns that the diagnosis is not "correct" (Abbeduto et al., 2004; Nissenbaum et al., 2002).

Parents of children with Down syndrome report that their children have less difficult temperaments than what is reported by parents of children with autism (Abbeduto et al., 2004). Lower levels of stress and higher amounts of support from social networks are reported in parents of children with Down syndrome compared to parents of children with autism (Abbeduto et al., 2004). In addition, parents of children with Down syndrome report fewer family problems, less pessimism about their child's future, and are less likely to interpret their child's noncompliance negatively than parents of children with autism (Abbeduto et al., 2004).

When examining the individual characteristics of parents of children with autism, they are more likely to have social impairments, learning disabilities, psychiatric disturbances, and deficits in communication than other parents (Abbeduto et al., 2004). This suggests that, in addition to the challenges of raising a child with autism, which causes higher stress than raising a child with a different disability, the parents of children with autism may be less equipped to

handle the stress due to these characteristics than other parents (Abbeduto et al., 2004).

When parents initially approach their pediatrician or another medical professional with concerns about their child's development and their suspicions about a possible diagnosis of autism, many parents are acutely aware of the history of doctors blaming parents for causing the child's autism and dismissing parents' beliefs about their child if they conflict with current theories (Dale et al., 2006; Silverman & Brosco, 2007). While the theory that autism is caused by cold, unresponsive parents has been debunked, mothers still feel that they are viewed as responsible for their child's behavior. If the child's behavior is atypical, it threatens the perception of the mother's competence (Gray, 2003).

Parenting literature of the late 19th century crystallized the idea of "scientific motherhood," the idea that "traditional knowledge of mothering was deficient and that proper mothering must be guided by developments in scientific knowledge relevant to child care" (Ong-Dean, 2005). In the 1950s and 1960s, the focus was on following the advice of a recognized medical professional such as Dr. Spock. "Early advice books emphasized the primacy of professional authority and the danger that parents' (in particular mothers') judgments might be clouded by emotion" (Ong-Dean, 2005, p. 146). This move towards professionals knowing more about child development and parenting than mothers could contribute to parents concerns when they approach pediatricians with questions about their child's behavior or development.

Parents of children with disorders on the autism spectrum often suspect that they are regarded as “problem parents” because of their insistence on alternative disease models for autism. Many, like authors of autobiographies on parenting a child with autism, Clara Claiborne Park and Karyn Seroussi express the sense that their status as parents invalidates their observations about their children in the opinion of medical practitioners. Meanwhile, pediatricians are concerned about the willingness of parents to fully disclose the range of interventions that they are using with their children, and many have voiced concerns that unproven treatments might be used in favor of behavioral and educational interventions (Silverman & Brosco, 2007).

This tension between parents and pediatricians is present in every interaction and assumptions are made by everyone involved. The doctors might assume the parent is overly anxious about nothing or is lying to him or her about interventions provided at home. Mothers may be on the defensive when they enter into conversations with doctors before their authority or expertise as a parent has even been questioned.

Definitions

Autism – Autism spectrum disorders (ASD) are characterized by impairments in communication and social skills and the presence of stereotypic behavior including a rigid adherence to routines or rituals (American Psychiatric Association, 2000). Communication impairments can include lack of verbal communication, echolalia (repeating words immediately after they are spoken or after a delay, such as reciting lines from a television commercial hours later), or

strange uses of words. Social impairments include inability to read nonverbal cues or body language, lack of eye contact, or complete disinterest in other people. Stereotypic behavior includes physical movements such as rocking or flapping hands, vocally repeating a sound over and over, or rituals such as lining up or spinning toys repeatedly. Children with ASD can present symptoms from birth or appear to develop normally and then lose skills in the first years of life, which is referred to as “late onset.” There is a push in the field of ASD to diagnose children earlier in order to start intervention earlier and therefore decrease the impairments by teaching skills (see Table 1 in Chapter 2) (Mandell et al., 2005; Stahmer & Mandell, 2006).

Experience – A mother’s “experience” receiving the diagnosis of autism is considered to be the time period from the mother’s first suspicion something was “wrong” with the child to the moment when the autism diagnosis was given.

Diagnosis – A label given by the medical establishment to a child that the service providers use to assist in determining eligibility for, amount of and type of services. While this study examines the period leading up to and including the moment of diagnosis, it is important to consider that there is much to examine in the period after diagnosis as well. McLaughlin (2005) writes “a diagnosis is not the conclusion for parents, but the beginning of a journey that will continue throughout the child’s life...The journey involves ‘cognitive reconstruction,’ where parents swap the child dreamed of for their child and a new narrative for their future is written” (p. 285). Others argue that “diagnosis is a form of ‘active interpretative work’ that patients participate in” (McLaughlin, 2005, p. 285). It is

recommended that professionals have “awareness of the ‘meaning-making process’ that will enable families to work through diagnosis in a way that is manageable for them” (McLaughlin, 2005, p. 285).

Purpose and Research Questions

The purpose of the study was to analyze the history of autism diagnosis over three decades using multiple qualitative methods. The desired outcomes of the study were to create a more complete picture of autism diagnosis in terms of depth and breadth than previous studies have produced, as well as to form recommendations for diagnosticians giving the autism diagnosis in the future.

The primary research question guiding this study was: How have mothers’ experiences receiving an autism diagnosis for their child changed over the last three decades? The data used to answer this question included interviews with mothers who have children with autism diagnosed between 1974 and 2004, as well as data collected during 2010 while observing diagnosticians giving the autism diagnosis.

The secondary research question was: How do parents, medical professionals, and media portrayals negotiate between the medical model and social construction of disability? Each set of data (i.e., interviews with mothers, observations of appointments, and media portrayals mentioned by participants) were analyzed for statements that suggested underlying assumptions about the nature of autism that aligned with either the medical model, the social construction of disability, or a negotiation between the two.

Organization

The organization of the work is as follows. In Chapter 2, the disability theories used in this study are described using a critical lens. Previous research on autism diagnosis is described and the gaps in the literature that are filled by this study are discussed. Methodological literature is reviewed. The methods of the study and its different components are described in Chapter 3. Chapter 4 presents the findings of interviews with seven mothers of children with autism who were diagnosed between 1974 and 2004. Chapter 5 analyzes media portrayals of autism from the late 1970s through today. Chapter 6 presents the results from observations of appointments with two developmental pediatricians giving families the diagnosis of autism for their child. Finally, Chapter 7 presents meta-inferences about the data collected, implications for future studies, parameters of the current study, and a researcher reflection.

Chapter 2

Literature Review

In this chapter, the two theories of disability used to analyze the data are presented, followed by my personal theoretical framework. A history of autism is presented to give the greater context for the data presented. Previous studies on the topic of autism diagnosis are summarized to establish what has been done and how this current study fills the gaps in the literature. An introduction to the methods used in this study concludes the chapter as well as lead into the third chapter on methods.

Disability Theories

In the past, autism has been theorized as an emotional disturbance that is caused by parents but now is viewed as a neurodevelopmental disorder with possible genetic and environmental causes. Both of these theories fall within the medical model of disability, which is one of several ways in which disability is theorized. In the following section, the medical model will be contrasted with the social model of disability using a critical lens. Parents have negotiated these models in terms of ASDs, while adults with ASDs have negotiated these models in a different way.

Medical model. The medical model assumes a binary opposition between the categories of normal and disabled (Landsman, 2005). One way in which this belief manifests itself is when doctors give a diagnosis. For example:

If the teller assumes the news is ‘bad’ and needs to be ‘broken’ it denotes a negative conception which is likely to be imparted to the parent. . . . the

claim is that the medical approaches to diagnosis and disability generate an overly pathological approach to communication that confirms for parents that this indeed is a truly awful thing that is happening to them and their child. It is something which signifies no future or quality of life for their child or for their family. (McLaughlin, 2005, p. 285)

A child does not have a disability until the medical establishment places a label on the child (McLaughlin, 2005). Particularly in cases in which there are no physical abnormalities, such as autism, the disability does not really exist until a medical professional puts a name to it. A child with a physical disability that is visually obvious is “diagnosed” by the person looking at him or her, with or without a medical diagnosis. A person who appears “normal” but behaves in an unusual way merely confuses those who interact with him or her. A formal, medical diagnosis creates a disability that otherwise might have been a set of quirky behaviors associated with an individual’s personality.

Social model. In contrast, the “social model locates the impediments to a high quality of life not within the body of the disabled person (such that the person should be cured, put out of his/her misery, or prevented from being born in the first place) but rather within the society that discriminates against persons with disabilities” (Landsman, 2005, p. 131-132). A disability is not defined by what is different, injured, or not present in the individual, but instead by the discrimination that results from being compared to the majority of the population. “Therefore, intervention is not necessarily with the person who has the disability,

but with the society that creates and harbors the definition” (Mackelprang & Salsgiver, 1999).

Mothers’ negotiation. Mothers of children with autism appear to negotiate between these two models of disability. Once the diagnosis is given, mothers’ concerns are not internal to the child, but how society will respond to the child, if life will be difficult due to discrimination by others (Dale et al., 2006; Landsman, 2005). Mothers have more faith that a child can be changed than societies can (Landsman, 2005). This suggests recognition that while something may be “wrong” with their child, thus placing them in the “disabled” category, society discriminates against those outside of the “normal” category, exacerbating the situation of disability.

This leads mothers to set the goal of helping their child “pass” as normal. By assisting their children to pass as nondisabled, mothers hope to ensure full participation in community life for them (Landsman, 2005). This is often referred to as normalization; “Normalization prescribes acceptable behavior based on norms and relies on professionals to train their clients to follow the standards of nondisabled communities” (Bumiller, 2008, p. 976). Working towards normalization has consequences in terms of beliefs and actions. “The pressures for social integration that accompany these practices result in professionals devaluing deviant groups or accepting them only when they appear like members of the mainstream” (Bumiller, 2008, p. 976). The atypical behavior that is the hallmark of autism makes this idea especially pertinent. More specifically:

This tendency is particularly strong when applied to people with autism, whose disability is in fact medically defined by an inability to understand social conventions. The social development of children with autism is often measured in terms of their progress toward acquiring normal social skills...Simply 'acting normal' is a form of adaptation and is even hypothesized as conducive to brain development. (Bumiller, 2008, p. 976)

Parents who do not have past experience with individuals with disabilities must think in a new and different way when confronted with their child's autism. "Parents must come to locate, interpret, and often advocate for the personhood of one they would previously have known only as 'the other'" (Farrugia, 2009, p. 1013). Through this advocacy, they do not entirely accept that their child is only valuable if he or she normalizes. Farrugia explained:

Parents deploy discourses drawn from medicine and the life-world in order to understand their children and negotiate an identity for themselves and their children which, whilst not 'normal,' is valuable and not necessarily inferior . . . Parents creatively appropriate medical knowledge, as well as directly challenge conceptions of normality to resist the pessimistic teleology of the medical narrative . . . Parents assert the uniqueness and individuality of their child and may use the ambiguity of medical constructions in order to achieve this . . . The negotiation of different ways of knowing disability and the disabled subject are central to the process of parenting children diagnosed with ASD" (Farrugia, 2009, p. 1013).

Neurodiversity. It is not only parents that negotiate between the medical and social models of disability; adults with ASDs do this as well. While adults with ASDs have difficulty during in-person interactions, they have flourished in connecting with others over the internet. Many of them use the term “neurodiversity” to describe their community. These adults believe that the characteristics of autism are genetic variations that are present in the general population and are not symptomatic of underlying pathologies (Bumiller, 2008). Rather than putting themselves in the “disabled” category of the medical model, they ask society at large to accept a wider range of behaviors as “normal.” This argument is somewhere between the medical and social models of disability.

Adults in the neurodiversity movement are offended by parents who believe that mercury caused their child’s autism because they do not like the idea that they have been poisoned by mercury and are now damaged (Bumiller, 2008). They believe that their autism is genetic and should be considered within the spectrum of “normal” behavior. They also oppose interventions such as Applied Behavior Analysis that try to normalize them. “Antinormalization strategies potentially form the basis for a more far-reaching project whose aim is to shift the goal of the disability movement from simple demands for inclusion to a utopian vision of a society that values human diversity” (Bumiller, 2008, p. 979). There is also a strong identity component to the neurodiversity movement:

Neurodiversity spokespersons promote a positive understanding of autism, oppose those who advocate for a cure, resist the appropriation of their voices by sympathizers and nonautistics, and struggle for a collective

sense of identity...Activists have developed an extensive range of Web sites that amass information from popular media and academic sources and provide vehicles for online discussion. (see <http://www.neurodiversity.com>) (Bumiller, 2008, p. 968).

Members of this group argue that the behaviors and idiosyncrasies that caused them to be labeled as autistic often serve a purpose for the individual. Asking people with Asperger syndrome to modify that behavior to make other people comfortable is unreasonable and even oppressive (Bumiller, 2008). Many other disability groups have similar beliefs including the Deaf community and Blind community. Departments of Disability Studies in various universities use anthropological methods of research to try and describe the experience of living with a disability using the social model.

Feminist reaction to Baron-Cohen. A final theory that should be mentioned begins with a proposed theory of the nature of autism. Simon Baron-Cohen has developed cognitive theories of autism for many years. In the past, he has focused on a “theory of mind,” the idea that a person with autism is incapable of taking another person’s perspective and this causes the various characteristic behaviors of autism (Baron-Cohen, 1997). More recently, Baron-Cohen has proposed that autism is a form of “extreme maleness” (Baron-Cohen, 1999). This theory states that the lack of empathy, preference for pattern, routine, objects over people, and savant/genius skills are all characteristics of males rather than females but taken to the extreme. The feminist response finds this theory problematic on a number of levels:

The essentialist version of autism is a disturbing reconstruction of gender and disability stereotypes in the guise of new scientific knowledge. Baron-Cohen's explanation for autism has the twin effect of normalizing the condition (by suggesting it includes all of us) while essentializing gender differences (by rooting the condition in biological maleness). . . . For example, it furthers the idea of autistic genius as an expression of an exaggerated male attribute. On the other hand, it is also problematic to suggest that treating autistic children is akin to treating the usual problems associated with socializing boys, an analogy that potentially reassures those who believe that mainstream education can easily respond to these children's needs (Bumiller, 2008, p. 973).

In addition, there is evidence to support genetic theories in terms of families having multiple children with autism and the parents having mild characteristics of autism carrying a gene that might result in a child with more severe ASD. There is no evidence that supports the theory that autism is linked to the male chromosome (especially since one in five individuals with autism is female). In terms of evidence:

The biological basis of neurological disability is contested. There is considerable evidence that some of the unique information-processing skills that children with autism demonstrate (and are verifiable as brain activity) are related to atypical forms of brain development (which have nothing to do with genetic maleness) (Bumiller, 2008, p. 973).

This supports the neurodiversity argument that autism is genetic rather than the result of exposure to an environmental toxin and that manifests as neurological diversity rather than anything associated with gender.

This theory is also problematic for females with ASDs:

Gender identity matters in one's experience as autistic. Girls are much less likely to be diagnosed and to receive services, especially if they are not on the severe end of the spectrum. We also know that disabled girls and women are often worse off than men in terms of employment and receiving adequate medical care and as the targets of social discrimination (Bumiller, 2008, p. 974).

Baron-Cohen's theory of autism further supports the idea that autism is a unique disability category in terms of its unknown origin and history of controversial theories of cause. These theories, when reported in the popular media, have an effect on service providers, medical professionals and parents. I have considered all of the theories described here and have chosen to negotiate my own theoretical context for the purposes of this study.

Theoretical Framework

For this study, I do not reject the medical or the social models of disability, but instead use my own negotiation of the two models. This is similar to what is present in the parent community and the community of adults with ASDs. "For mothers hoping for the best lives possible for their disabled children, neither the medical model of mainstream American culture nor the social/minority

group model as currently articulated in disability rights politics appears sufficient in and of itself” (Landsman, 2005, p. 137).

Since this study will examine the process of diagnosing ASDs, the way in which parents and medical professionals come together and “create” a child with a disability is an important lens. “Diagnosis does not occur in a social vacuum; both medical professionals and parents bring with them existing discourses of disability that influence the way in which they discuss and frame a diagnosis” (McLaughlin, 2005, p. 285). It is the unique aspect of autism that includes lack of a medical test such as a blood test or genetic test that leads to parents and medical professionals together creating the existence of this disability.

The making of a diagnosis classifies individual differences into those that qualify as bona fide disability conditions and those that are due to other circumstances. Until this classifying practice tells us that we have a disabled child, it is not a question of whether the problems of the child will be viewed through the lens of the medical or the social model of disability, but whether the child will be seen as disabled at all...the medical model of disability is not only a way of understanding disability, it is also a way of making individuals with disabilities (Ong-Dean, 2005, p. 142).

An autism diagnosis requires a combination of parent report to establish patterns of behavior and professional observation of hallmark behaviors of autism. The information provided by the parents combined with the interpretation of the

professional observations determines whether the child has autism or not and thereby creates a child with a disability.

When mothers reject a diagnosis or disagree with medical professionals, they are not necessarily rejecting the medical model. If there were a blood test, they would be less likely to argue. It is due to the observational nature of the diagnosis that parents may reject the particular professional's expertise, not the ability of the medical profession to diagnose their child (Landsman, 2005). In fact, the history of autism parent advocacy often demonstrates parents challenging the institutional authority of the medical and education professions using the very terms, concepts, and categories of those professions (Ong-Dean, 2005).

Parents who reject medical opinions are viewed as in denial and medical professionals see their job as helping the parent to come out of denial and into acceptance. This speaks to the idea that there is an expectation of the way parents should behave when receiving the diagnosis (McLaughlin, 2005). If the parent deviates from this expectation, the medical model says there is something wrong with the parent. The parent is rejecting the scientific motherhood idea that medical professionals know more about the child than the parent does. The parent is redefining him or herself as the expert rather than the medical professional (Landsman, 2005). This expert identity is understandable considering that even using parent report instruments to assist in making the diagnosis, doctors do not have a complete picture of the child when they give the diagnosis based on behaviors rather than blood test. This limited knowledge of the child contributes to parents doubting the truth or correctness of the diagnosis.

To summarize, I accept that the medical model is used in that professionals observe and label a child as autistic, thereby putting him or her in the “disabled” category. I also acknowledge that society discriminates against individuals with atypical behaviors, such as the atypical social behaviors associated with autism. I am interested in exploring through this study how the medical and social models of disability are negotiated by parents and diagnosticians. See Figure 1.

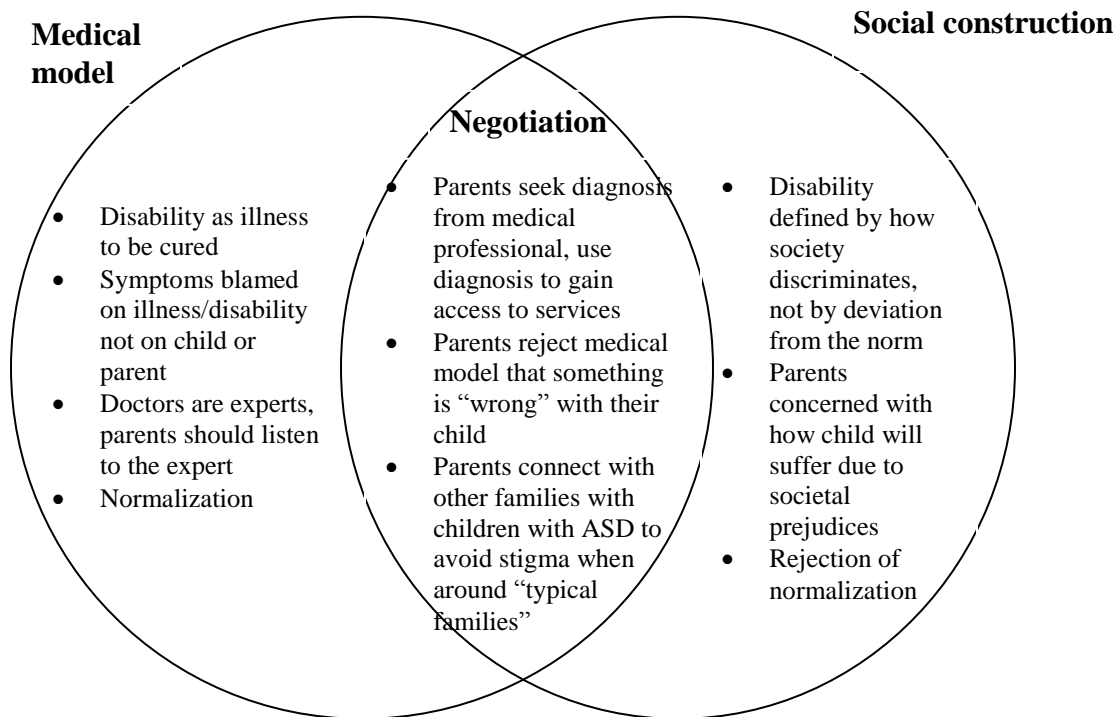


Figure 1. A Venn diagram displaying the characteristics of the medical and social models, and the overlap between them that has served as the theoretical framework for the current study.

History of Autism

Some people are intrigued by the possibility that autism was present in the past. They suggest that stories about “mythic wild children” are actually stories about children with autism. Others suggest that geniuses in the past had autism based on reports of quirky personality characteristics or habits. Without reliable documentation, we cannot know if any of these individuals in the past had autism. This section provides a very brief history of autism from the 1940s to present day and includes both scientific sources and most cited work as well as popular media portrayals.

Autism, as the fields of medicine, psychology, and special education define it today, began when Dr. Leo Kanner published an article in 1943 on a subset of psychiatric patients who demonstrated unique behaviors that included appearance of deafness, amazing rote repetition skills, and extreme aloneness (Kanner, 1943). Separated by only a year, an Austrian physician, Dr. Hans Asperger (1944/1991), published a paper about a set of psychiatric patients with similar characteristics. Both authors used the term “autism” based on the Greek root *aut*, meaning “self,” to describe the isolated, self-centered behaviors of the patients. “Prior to this research, children with these symptoms who were brought to the attention of the medical profession were seen either as severely deprived of social stimuli or chronically insane” (Bumiller, 2008, p. 969).

Most of the characteristics described in Kanner’s original study are still part of the diagnostic criteria today, including “isolated play, unusual language traits, insistence on ritual behavior, and resistance to change” (Olley & Gutentag,

1999, p. 4). Kanner also noted a lack of physical abnormalities or characteristics and stated that children with autism had “good cognitive potentialities” (Olley & Gutentag, 1999, p. 5). This suggested that beneath the cloud of autism there was a “latent genius,” a myth that has spurred countless fad treatments offering to cure the autism and reveal the normal if not genius individual within (Olley & Gutentag, 1999). In more recent decades, autism has been found to co-occur with identifiable medical disorders such as epilepsy, mental retardation, and genetic disorders such as fragile X syndrome, conflicting with Kanner’s original observations (Olley & Gutentag, 1999). Some studies have reported as high as 66% of individuals with autism also have mental retardation, contradicting the “latent genius” idea (Olley & Gutentag, 1999).

Refrigerator mothers. The next period in the history of autism is known for the theory that parents cause autism. Leo Kanner (1943) noted that the parents of his patients were highly educated and middle or upper class families. He was grateful for their obsessive tendencies, because it allowed him to create highly detailed case study descriptions based on the parents’ highly detailed reports. He even went so far as to criticize the parents’ social skills, saying that the parents had “defrosted” only long enough to have a child. Bruno Bettelheim, a Holocaust survivor and University of Chicago psychologist, took this description by Kanner and developed it into a theory in which maternal rejection of the child caused the child to withdraw and become autistic. He compared the mothers of children with autism to the guards in the concentration camps in which he was imprisoned during the war (Olley & Gutentag, 1999). He coined the term “refrigerator

mothers” and took pride in making his theories understandable to the public, rather than just publishing them in academic journals. He appeared on the Dick Cavett television show on May 17, 1974, published an article in *Reader’s Digest* magazine, and, in 1969, published the seminal work *The Empty Fortress*.

Response to Bettelheim. The mother of a child with autism wrote a book about her experience and disputed Bettelheim’s theory. *The Siege* was published in 1967, and Bettelheim dismissed the work within the pages of *The Empty Fortress*. The author, Clara Claiborne Park, argued that perhaps Kanner found the parents of the patients with autism to be cold because of the institutional setting, and therefore, “Refrigerator professionals create refrigerator parents” (Ong-Dean, 2005; Silverman & Brosco, 2007). *The Siege* was one of the only books written by a parent about autism for many years and, as such, was often given to parents at the time of diagnosis into the 1980s.

Bernard Rimland (1964) attempted to bring an end to the era of “refrigerator mothers” with the publication of his book, *Infantile Autism*. Rimland, a psychology researcher, had a son with autism and a son who was typically developing. He questioned how his wife could have caused one son to develop autism but not caused the other son to have autism when he observed no difference in the way that his wife parented the two children. He argued instead for a genetic theory, proposing that parents of children with autism have milder forms of the disorder, which would explain the refrigerator behaviors Kanner observed. Rimland wrote the book not only for the medical establishment, but also to empower parents of children with autism. The “scientist-as-parent” wrote

the book for “parent-as-scientist” (Ong-Dean, 2005). In addition to the book, Rimland organized a group of parents and together they founded the Autism Society of America, which is now a national organization with state and local chapters across the country (Olley & Gutentag, 1999).

It took multiple decades for Bettelheim’s theory to be replaced by Rimland’s. There are still some parts of the world and fields of study that use a modified version of Bettelheim’s psychiatric basis for the cause of autism. The Office of Special Education Programs (OSEP) categorized autism as an emotional disturbance in the 1970s, in line with Bettelheim’s theory. It was through the efforts of parent advocacy groups that autism was reclassified as a developmental disability in 1980. The American Psychiatric Association (DSM) (2000) listed autism under schizophrenia, childhood type in versions one and two. In the third version of the DSM-III, infantile autism was added as a category with six criteria. In DSM-III-R, the revision of the third edition, the category was renamed autistic disorder and the criteria were greatly expanded (see Table 1).

Table 1

Diagnostic and Statistical Manual Changes Over Time

DSM-I (1952)	000-x28 Schizophrenic reaction, childhood type Here will be classified those schizophrenic reactions occurring before puberty. The clinical picture may differ from schizophrenic reactions occurring in other age periods because of the immaturity and plasticity of the patient at the time of onset of the reaction. Psychotic reactions in children, manifesting primarily autism , will be classified here.
DSM-II (1968)	295.8 Schizophrenia, childhood type This category is for cases in which schizophrenic symptoms appear before puberty. The condition may be manifested by autistic , atypical and withdrawn behavior; failure to develop

	identity separate from the mother's; and general unevenness, gross immaturity and inadequacy of development. These developmental defects may result in mental retardation, which should also be diagnosed.
DSM-III (1980)	<p>Infantile Autism</p> <p>A. Onset before 30 months of age</p> <p>B. Pervasive lack of responsiveness to other people (autism)</p> <p>C. Gross deficits in language development</p> <p>D. If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, and pronominal reversal.</p> <p>E. Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects.</p> <p>F. Absence of delusions, hallucinations, loosening of associations, and incoherence as in Schizophrenia.</p>
DSM-III-R (1987)	<p>Autistic Disorder</p> <p>At least eight of the following sixteen items are present, these to include at least two items from A, one from B, and one from C.</p> <p>A. <i>Qualitative impairment in reciprocal social interaction (the examples within parentheses are arranged so that those first listed are more likely to apply to younger or more disabled, and the later ones, to older or less disabled) as manifested by the following:</i></p> <ol style="list-style-type: none"> 1. Marked lack of awareness of the existence or feelings of others (for example, treats a person as if that person were a piece of furniture; does not notice another person's distress; apparently has no concept of the need of others for privacy); 2. No or abnormal seeking of comfort at times of distress (for example, does not come for comfort even when ill, hurt, or tired; seeks comfort in a stereotyped way, for example, says "cheese, cheese, cheese" whenever hurt); 3. No or impaired imitation (for example, does not wave bye-bye; does not copy parent's domestic activities; mechanical imitation of others' actions out of context); 4. No or abnormal social play (for example, does not actively participate in simple games; refers solitary play activities; involves other children in play only as mechanical aids); and 5. Gross impairment in ability to make peer friendships (for

	<p>example, no interest in making peer friendships despite interest in making fiends, demonstrates lack of understanding of conventions of social interaction, for example, reads phone book to uninterested peer.</p> <p>B. <i>Qualitative impairment in verbal and nonverbal communication and in imaginative activity, (the numbered items are arranged so that those first listed are more likely to apply to younger or more disabled, and the later ones, to older or less disabled) as manifested by the following:</i></p> <ol style="list-style-type: none"> 1. No mode of communication, such as: communicative babbling, facial expression, gesture, mime, or spoken language; 2. Markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction (for example, does not anticipate being held, stiffens when held, does not look at the person or smile when making a social approach, does not greet parents or visitors, has a fixed stare in social situations); 3. Absence of imaginative activity, such as play-acting of adult roles, fantasy character or animals; lack of interest in stories about imaginary events; 4. Marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation (for example, monotonous tone, question-like melody, or high pitch); 5. Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (for example, immediate echolalia or mechanical repetition of a television commercial); use of "you" when "I" is meant (for example, using "You want cookie?" to mean "I want a cookie"); idiosyncratic use of words or phrases (for example, "Go on green riding" to mean "I want to go on the swing"); or frequent irrelevant remarks (for example, starts talking about train schedules during a conversation about ports); and 6. Marked impairment in the ability to initiate or sustain a conversation with others, despite adequate speech (for example, indulging in lengthy monologues on one subject regardless of interjections from others); <p>C. <i>Markedly restricted repertoire of activities and interests as manifested by the following:</i></p> <ol style="list-style-type: none"> 1. Stereotyped body movements (for example, hand flicking or twisting, spinning, head-banging, complex whole-body movements); 2. Persistent preoccupation with parts of objects (for example,
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	<p>sniffing or smelling objects, repetitive feeling of texture of materials, spinning wheels of toy cars) or attachment to unusual objects (for example, insists on carrying around a piece of string);</p> <p>3. Marked distress over changes in trivial aspects of environment (for example, when a vase is moved from usual position);</p> <p>4. Unreasonable insistence on following routines in precise detail (for example, insisting that exactly the same route always be followed when shopping);</p> <p>5. Markedly restricted range of interests and a preoccupation with one narrow interest, e.g., interested only in lining up objects, in amassing facts about meteorology, or in pretending to be a fantasy character.</p> <p>D. Onset during infancy or early childhood Specify if childhood onset (after 36 months of age)</p>
DSM-IV (1994)	<p>299.00 Autistic Disorder</p> <p>1. <i>A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):</i></p> <ol style="list-style-type: none"> 1. Qualitative impairment in social interaction, as manifested by at least two of the following: <ol style="list-style-type: none"> 1. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction. 2. failure to develop peer relationships appropriate to developmental level 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest) 4. lack of social or emotional reciprocity 2. Qualitative impairments in communication as manifested by at least one of the following: <ol style="list-style-type: none"> 1. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

	<ol style="list-style-type: none"> 2. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others 3. stereotyped and repetitive use of language or idiosyncratic language 4. lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level <ol style="list-style-type: none"> 3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least of one of the following: <ol style="list-style-type: none"> 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus 2. apparently inflexible adherence to specific, nonfunctional routines or rituals 3. stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole body movements) 4. persistent preoccupation with parts of objects <ol style="list-style-type: none"> 2. <i>Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.</i> 3. <i>The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.</i>
DSM-V (2013)	<p>PERVASIVE DEVELOPMENTAL DISORDERS (PDD)</p> <p>1) The Workgroup is considering a change in DSM-V that would replace the Pervasive Developmental Disorder (PDD) category with the title “Autism Spectrum Disorders” (ASD). The change would utilize a single diagnosis for the disorders currently entitled: Autism, PDD-NOS and Asperger disorder. Several factors support making this change:</p> <ul style="list-style-type: none"> • A single spectrum better reflects the pathology and symptoms. • Separation of ASD from typical development is reliable and valid, while separation of disorders within

the spectrum is variable and inconsistent.

- Individuals with autism, PDD-NOS or Asperger disorder often are diagnosed by severity, rather than unique, separate criteria defining the three diagnoses.

2) To better reflect the symptomatology and clinical presentation of ASD, changing the three current symptom domains (social deficits, communication deficits and fixated interests/repetitive behaviors) to two (social communication deficits and fixated interests and repetitive behaviors) is also being considered.

Streamlining the current PDD (ASD) criteria to better clarify diagnostic requirements is being examined. The criteria might be presented as relatively brief “bullets” with more extensive examples provided in the accompanying text to better describe symptom presentations at various ages, developmental stages and levels of cognitive functioning. Gender and cultural factors will also be considered to ensure that the ASD diagnosis is made appropriately in diverse patient populations.

3) Symptom severity for ASD could be defined along a continuum that includes normal traits, subclinical symptoms and three different severity levels for the disorder. One possible model:

	Social Communication	Fixated Interests and Repetitive Behaviors
Most severe ASD	Minimal or no social communication	Nearly constant, complete preoccupation, strongly resists interference with ritual
Moderately severe ASD	Some social communication but interactions noticeably disturbed	Frequent and interfering rituals, repetitive behaviors and fixated interests
Less severe ASD	Clear impairments in social	Occasional rituals, repetitive behaviors and

		communication. Meets all diagnostic criteria including symptom severity greater than threshold	fixated interests; some interference
	Subclinical AS	Has some symptoms from one or both domains but no significant interference or impairment	Odd mannerisms, some excessive preoccupations but distractible, may have ritualized behaviors but they don't interfere with daily activities
	Normal Variation	Socially isolated or "awkward"	Some ritualized behaviors and preoccupations but these are normal for developmental stage and cause no interference

Note. Adapted from *Unstrange minds: Remapping the World of Autism* by Roy Richard Grinker, 2007, New York: Basic Books, 2007, retrieved from <http://www.unstrange.com/dsm1.html>. Copyright 2007 by Roy Richard Grinker. Also adapted from *Report of the DSM-V neurodevelopmental disorders work group* by Susan Swedo, 2009. Copyright 2011 by the American Psychiatric Association.

Rimland (1964) was also pivotal in terms of organizing and expanding parent advocacy groups. He founded the Autism Society of America and the Autism Research Institute. Both organizations offered parents a support network and a clearinghouse for current research on autism including treatment options and educational interventions. Autism parent advocacy groups went beyond these goals to lobby the federal government for research funding and the diagnostic

professionals for adding or changing the diagnostic criteria for autism to reflect current research and theories (McLaughlin, 2005; Silverman & Brosco, 2007). These groups have been compared to AIDS activists who not only got the federal government to provide and increase funding for research, but also made demands on how the research should be conducted (Silverman & Brosco, 2007).

In 1979, a television movie was made based on the book *Son-Rise* by Barry Neil Kaufman. The book and movie detail the story of a boy with autism who is cured through a specific method of intervention developed by his parents (the author and his wife). The form of intervention is referred to now as the Option method, and the family continues to train parents in this method today. The TV movie was the first glimpse into autism for many through popular media.

Behavioral intervention. In 1987, a seminal research study published by O. Ivar Lovaas claimed that by using intensive Applied Behavior Analysis (ABA) therapy for an average of 40 hours per week with 16 children with autism, nine “recovered,” as defined by scores in the normal range on standardized tests and inclusion in the general education classroom. Many have criticized the methodology of the study and the results have never been replicated, however ABA therapy is considered the only evidence-based practice for children with autism. Many parents now have therapists employed in their homes to provide ABA therapy one-on-one with their children and some private and public schools and classrooms provide ABA instruction in a school setting.

In 1988, the movie *Rain Man* was released to critical acclaim and garnered a large audience (Johnson & Levinson, 1988). The film received Oscars for Best

Picture and Best Actor for Dustin Hoffman. For years, Dustin Hoffman's portrayal with his head cocked to the side talking in an odd voice about the TV show *Judge Wapner* was the public perception of autism. In addition, the public was led to believe that all individuals with autism have savant skills such as Raymond's ability to count instantaneously, memorize the phone book, and do complex math calculations in his head quickly.

While the Lovaas study was published in an academic journal in 1984, it was through a book written by the mother of two children with autism that introduced ABA to the general population. *Let Me Hear Your Voice* (Maurice, 1993) described a mother's journey through diagnosis and intensive intervention with her children to finally reach a point where her children no longer met the criteria for autism. She considered them "cured" by ABA therapy. While academics may have heard about ABA and autism earlier through journals, parents could now access this information in their local bookstore or library.

Facilitated communication. In addition to the ugly history of the Bettelheim period, blaming mothers for their child's developmental disorder, a second ugly period in the history of autism began in 1990. A professor at Syracuse University, Douglas Biklen, introduced the idea of using a technique called facilitated communication (FC) to "unlock the previously unrecognized expressive language skills of individuals with severe disabilities or autism" (Olley & Gutentag, 1999). He had brought the already existing technique from Australia, where a mother used it with her son who had cerebral palsy (Crossley, 1994). The way the technique worked was that an individual called a facilitator molds the

hand of the individual with autism into a point and then introduces a letter board that the individual with autism can use to type out messages. The facilitator holds the individual's hand the entire time to help control any motor issues.

Anecdotal reports described miraculous, instantaneous communication in the form of eloquent poetry from the individuals with autism (Olley & Gutentag, 1999). Soon after, some individuals were typing messages (via their facilitator) claiming sexual abuse by family members. This was then reported to authorities and parents and other caregivers were often arrested based on the facilitated communication (Palfreman, 1993). Researchers began to test the authorship of the facilitated messages.

These studies indicate that the facilitator, and not the individual with autism, is actually the source of the communication. Indeed, numerous controlled studies directly measuring the efficacy of FC have found facilitator-influenced results, consistent incorrect responses, and at best random responses, thus, failing to support the validity of this technique (see Jacobson, Mulick, & Schwartz, 1995). The American Psychological Association and other professional organizations have passed resolutions identifying FC as “controversial and unproved” and expressed caution about the unsupported efficacy of this approach. (Olley & Gutentag, 1999, p. 16)

Biklen and other advocates of FC claim that the research “cannot be valid because the nature of the testing situation elicits an atmosphere of doubt that prevents successful communication by the individual with autism” (Romanczyk et al.,

1999, p. 25). This stance makes FC something that cannot be tested by research methods to prove or disprove the authorship of the messages. While no longer a popular or widely used intervention for children with autism, it is still used and still highly controversial.

Another change occurred in regard to education of children with autism in 1990. The federal law requiring public schools to educate children with disabilities, the Individuals with Disabilities Education Act (IDEA) was reauthorized and added a category for autism. Up until this point, students qualifying for special education services who were diagnosed with autism had come under the categories of either emotional disorders or mental retardation. The initial law was passed in 1974.

Vaccine theory. The next period in the history of autism began in 1998. In that year, Andrew Wakefield published a study in the British medical journal, *The Lancet*, suggesting a link between autism, bowel symptoms, and mercury found in the measles-mumps-rubella (MMR) vaccine. Wakefield targeted thimerisol, a type of mercury used as a preservative in some vaccines. Parents who heard about Wakefield's research looked at previous studies on mercury poisoning that occurred in utero and the subsequent developmental delays and they saw similarities to autism. However, the form of mercury in those studies was from fish found in contaminated water and was a different chemical compound than thimerisol (Baker, 2008).

The wide availability of info on the Internet, combined with an increasing skepticism toward medical authority, has led to the formation of advocacy

groups with an unprecedented interest in taking part in research on particular disorders and to very specific ideas about both the disorder and the ways that research should be carried out. (Silverman & Brosco, 2007, p. 396)

In 1997, New Jersey Congressman Frank Pallone appended a rider on the Federal Drug Administration (FDA) Modernization Act to assess all products for mercury content (Baker, 2008). In 1998, Congressman Dan Burton (grandfather of a child with ASD) began a series of congressional hearings on autism and vaccine safety (Baker, 2008). Also in 1998, the FDA initiated formal risk assessment of thimerisol in vaccines (Baker, 2008). The American Academy of Pediatrics and the Centers for Disease Control and Prevention (CDC) released a joint statement in July 1999 recommending vaccines containing thimerisol should be removed as soon as possible (Baker, 2008). The removal of vaccines containing thimerisol was completed by 2001. However, when thimerisol was removed from vaccines, there was no decline in autism diagnoses. In 2001, after eight safety review panels the Institute of Medicine concluded that vaccines did not cause autism (Baker, 2008). Recently, the British medical journal *The Lancet* has not only retracted the original article but removed it from the archives to further distance itself from the study that has since been found to have been fraught with violations of ethical research conduct. In addition, the *British Medical Journal* published an article by a journalist stating that Dr. Wakefield was “extremely fraudulent” in his research (Deer, 2011).

Prevalence. While parent groups continue to argue that vaccines caused their child's autism despite the removal of thimerisol, and news outlets continue to publish stories on the controversy over the link between vaccines and autism despite the research community's dismissal of the theory, a new story has taken over the popular media in regard to autism: prevalence. In the late 1980s the prevalence rates of autism were between 0.7 per 10,000 to around 2 per 10,000 (Boyd, Odom, Humphreys, & Sam, 2010). In 1999, a report came out that the number of children receiving services for autism in California public schools increased 273% in the past ten years. IDEA only started using autism as a category for public school special education services in 1990. Before that, students were served under other categories. The study was the result of Rick Rollens (father of a child with ASD, associate of Gray Davis, then governor of California) persuading the California legislature to fund research at the University of California at Davis (Baker, 2008). Since that time, the CDC has released subsequent reports that the prevalence of autism, once reported as 5 in 10,000, increased to 1 in 110, with prevalence four times as likely in males as females (CDC, 2009). This led to headlines in newsmagazines and television programs alerting the public to an "autism epidemic."

Researchers have debated whether changes in the diagnostic criteria to include milder forms of autism as well as possible over-diagnosis can account for the increase (Shattuck & Durkin, 1997). While most family practice doctors and the public had never heard of autism in the 1970s or 80s, awareness of autism today is high and the delay in time between a parent's first concern and receiving

the autism diagnosis is shorter. In the past, these children were a mystery until someone who recognized the characteristics of autism diagnosed them. Today autism is on everyone's radar. Boyd et al. (2010) suggested that the ability to give reliable and accurate diagnoses to two year olds, broadening of the spectrum to include individuals with milder characteristics, the creation of specific autism categories in the 1990s for autism in service agencies (e.g., the U.S. Department of Education), and public awareness all led to the increase in prevalence.

Benefits of the media attention to the supposed increase in prevalence include increased federal funding to examine causes and consequences of ASD and the development of new assessments and interventions (Conroy, 2010). In addition, there continue to be a "plethora of interventions with limited or no scientific evidence and that some interventionists have suggested 'cures' for ASD" (Conroy, 2010, p. 100). Another interesting effect of public awareness of autism is closely related to prevalence.

There are 10 areas of California that are considered "autism clusters" (Schwartz & Sandall, 2010). The explanation for these clusters is "not related to toxins, natural sources of pollutions, or other factors related to environmental risks" but was associated with "areas of higher parental education and close proximity to major autism treatment centers" (Schwartz & Sandall, 2010, p. 106). To clarify, unlike Kanner's (1943) theory that there is something about highly educated parents that causes autism, it is proposed here that higher parental education and access to expertise simply leads to early and accurate diagnosis. Just as parent advocates were key to the passage of public laws ensuring access to

services such as special education, highly educated parents have heard the discussion in the media and online about autism, including vaccines and prevalence, and seek out expertise when concerns arise about their child's development. Related to this is the lower likelihood of children who are Black or Hispanic to be diagnosed with an ASD (Schwartz & Sandall, 2010). The prevalence conversation has not yet focused on the disparity between age of diagnosis and access to early intervention by different ethnic and minority groups, but hopefully researchers and parent groups will bring this area of concern to the forefront.

Insurance. The newest policy change in treatment for children with autism is a series of lawsuits in various states across the United States in which parents are suing health insurance companies for discriminating against children with autism. The result of these lawsuits (all of which have been ruled in favor of the parents) is that health insurance companies are now required to pay for ABA therapy for children with autism. Each law has specific requirements and loopholes but the theme throughout is that home-based ABA should be covered as a medically necessary treatment for autism. Most special education classrooms do not use ABA and are not required to under IDEA, but these new state laws are requiring it in the home through insurance. Coverage of ABA therapy for individuals with autism is also included in President Obama's national healthcare reform bill. Once again, parent advocacy has changed the field of autism intervention.

Summary of the history of autism. There are multiple academic journals dedicated to autism (e.g., *Autism, Focus on Autism and Developmental Disabilities*, and *Journal of Autism and Developmental Disorders*). The Autism Society of America, along with many other parent organizations, continues to provide support and information to families and service providers as well as advocate for research funding in the quest for answers. The days of blaming parents for causing their child's autism are generally behind us. The blame has shifted to vaccines, and genetic theories persist. The cause is still unknown and, while some interventions have proven helpful, a cure has not been found. With this unique history and continuing elements of controversy, the autism diagnosis is a unique experience that deserves further exploration in order to inform and support diagnosticians as they seek to improve the experience of informing parents of their child's diagnosis of autism.

Studies on Autism Diagnosis

A small number of studies have examined aspects of autism diagnosis. One study used a web-based survey to collect information from 494 families across the United States, Canada, the United Kingdom, Australia, and New Zealand found that children who were age 11 to 22 had been diagnosed at an older age and had seen many more professionals before getting the ASD diagnosis than children who were now younger than age 11 (Goin-Kochel, Mackintosh, & Myers, 2006). This suggests that in the 1980s and 1990s children were diagnosed at an older age than children diagnosed between 2000 and 2006. Children with Asperger syndrome or PDD-NOS were also diagnosed later, as were girls

compared to boys. The age of diagnosis for the child was negatively associated with parental satisfaction with the diagnostic process. Parents with higher levels of education and greater family income had children who were diagnosed younger and the parents had higher satisfaction ratings for the process of diagnosis. While racial groups were not found to be associated with age of diagnosis or satisfaction with the process, level of education and family income are usually associated with race.

In 2003, Brogan and Knussen used a mailed questionnaire with 126 Scottish families of children with autism to assess satisfaction with the disclosure of the diagnosis. More than half were satisfied with the disclosure. They were more likely to be satisfied if the child was not yet in an educational placement, was given a definite diagnosis, given written information at the time of diagnosis, or was diagnosed with Asperger syndrome rather than autism.

Nissenbaum, Tollefson, and Reese (2002) interviewed 11 nonmedical professionals (primarily school personnel) and 17 parents of children with autism about giving and receiving the diagnosis. Differences were found in the perception of autism, the outcomes of autism, whether the diagnosis was stated clearly, and reactions to the diagnosis between the two groups. Nine recommendations for practices when informing families of an autism diagnosis were given, including becoming knowledgeable about autism, using good communication skills, providing a list of resources and interventions, provide follow-up, and provide hope.

Dale, Jahoda, and Knott (2006) interviewed 16 mothers of children with autism as well as assessed the mothers using measures of depression, parenting stress, and expectations for their child's future to explore the mothers' attributions following the diagnosis. Their coding of interviews focused on (a) statements relating to an explanation about a cause for the disorder and perceived blame for cause; (b) statements relating attributions about the stability of ASD as a disorder and how the child would progress in the future; and (c) statements relating to controllability over the disorder through attributions about mothers' beliefs about responsibility for helping their children. Parental stress scores fell in the significant range while most participants only fell in the minimal range for the depression measure. Mothers spoke about a wide range of causes and the amount of guilt they had about contributing to their child's autism. Most mothers saw autism as a disorder that can change over time, but two mothers believed the child may "grow out of it" or a cure will be discovered in their lifetime.

Two studies conducted in Israel used Pianta and Marvin's (1992) concept of "resolution of the diagnosis" to examine child and parent characteristics by visiting the family's home and conducting a number of assessments (Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010; Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009). The concept of resolution includes putting "aside questions about the causes underlying the child's condition" (Milshetin et al., 2010, p. 89). To further explain:

Parents who are unresolved with respect to the diagnosis of their child often present cognitive biases regarding their child and her/his abilities

and difficulties. They are preoccupied with possible causes for the disability; they maintain an unbalanced view regarding the effects that their child's condition has on them; they seem to lack the energy to move on with their lives; some may be detached from the experience and the feelings surrounding the diagnosis; and some may still manifest a state of confusion. (Milshtein et al., 2010, p. 90)

The Milstein et al. (2010) study did not find that resolution was correlated with duration of time since receiving the diagnosis, parental age, socioeconomic status, severity of the child's ASD, or aspects of ASD found in the parent. The authors were unable to conclude whether resolution was a stable status or whether resolution is something that can be changed through intervention.

The second study examined whether resolution was linked to "insightfulness" in mothers and whether mothers who were both resolved and insightful had more securely attached children (Oppenheim et al., 2009). The authors found that mothers who scored as both resolved and insightful had a much higher likelihood of having a child who scored as securely attached. A third study (Wachtel & Carter, 2008) also suggested that intervention for parents target emotional resolution and cognitive engagement. All three of these studies are new, modern, medical model ways of suggesting that if we change the parents, we can change the children with autism, frighteningly similar to Bettelheim's prescription of psychotherapy for the mother to cure the child. There is a distinct difference between teaching parents behavior modification strategies to use with

their child and intervention to change the way the parent thinks or feels about their child's ASD.

A 1998 study compared parents of children with autism, Asperger syndrome, atypical autism, learning disabilities, and semantic-pragmatic disorder on their concerns about their child's development when he or she was between 12 and 18 months on a questionnaire given at two child mental health centers (Vostanis et al., 1998). The results of the questionnaire differed significantly between the autism and learning disability groups. Questionnaire items related to play and gestures best predicted autism while the group with semantic-pragmatic disorder had high rates of early difficulties in social skills.

One study interviewed mothers about their perceptions of developmental regression in their children with autism (Davidovitch, Glick, Holtzman, Tirosh, & Safir, 2000). Of the 39 participants, 19 reported that the children had regressed at an average age of 24 months. More mothers of children who regressed, than those of children who did not, expressed guilt feelings regarding the development of autism, and almost all of them had an "explanation" for the possible mechanisms that might have influenced their children's developmental course.

These studies typically interviewed parents one year after receiving the diagnosis or mailed a questionnaire and captured parents' perceptions at one moment in time. The questionnaires and assessments, even the semi-structured interviews, restricted the data as opposed to observation that can capture what happened in all its complexity. These studies examined only certain aspects of autism diagnosis without considering the larger context of the media, policy,

changes in diagnostic criteria, and public awareness of autism. The study proposed here will have participants who describe receiving the autism diagnosis between 1974 and 2004 and observe appointments in which parents receive the diagnosis today. By interviewing mothers to obtain their perspective, observing appointments in which the developmental pediatrician gives the diagnosis to obtain the diagnostician perspective, and analyzing media portrayals of autism over the years that increased public awareness of autism, this study provides a fuller picture of the historical and current experience of autism diagnosis than previous studies have reported.

Theories Related to Method

In my training in early childhood special education, I read Bronfenbrenner's (1977) work, in which he argues that it is impossible to isolate an individual from the various contexts in which he or she lives. Bronfenbrenner's theory is often visualized in terms of concentric circles, with the individual in the middle, the family in the microsystem, the community in the mesosystem, the culture, including laws and social structures in the exosystem, the world at large as the outer circle or macrosystem, and finally the history in the chronosystem. These systems affect everything we do and every interaction we have. Engeström (1998) used triangles to describe activity theory in terms of moving between these systems constantly. Both of these theories will be used as I analyze the data I collect in terms of how larger systems have affected individuals giving and receiving the autism diagnosis.

To incorporate the larger systems such as the exosystem, macrosystem, and chronosystem, I examined the history of the DSM criteria and how it has changed, the connection between policy and diagnosis, and the effect of autism in the media on public perception. I used all of this information to analyze data from parents and diagnosticians about the process of giving and receiving the diagnosis of autism. This provided a broader picture of autism diagnosis than if I focused only on what happened in the appointment when the diagnosis was delivered, and would ignore the emotional baggage that the parent and diagnostician carry into that appointment.

Methodological Literature

This study used a number of qualitative methods to create an overall picture of autism diagnosis. Interview and participant observation data was analyzed using grounded theory and the constant comparative method (Corbin & Strauss, 2008; Glaser & Strauss, 1967; Rubin & Rubin, 2005). A further description of methodological literature is included in Chapter 3 (see Data Analysis). Chapter 3 describes the rationale, assumptions of the researcher, participants, data collection, and analysis.

A few articles have analyzed transcripts of appointments in which a doctor is giving a diagnosis to a patient or the parent of a patient. Heritage and Maynard (2006) described the structure of an appointment as an opening, description of the presenting complaint, followed by the doctor's examination, statement of diagnosis, discussion of treatment, and closing. In this conversation, there are power dynamics at play. Peräkylä (2006) pointed out that both patient and doctor

have ideas about the ailment and this causes a dilemma that threatens the doctor's authority.

Mehan (1993) discussed the hierarchy of whose speech has authority in a medical appointment. The higher authority of the doctor is based on technical expertise, while the lower authority of the patient is based on firsthand observation. The doctor presents information while the patient has their information elicited from them (Mehan, 1993). Another difference between the doctor and the patient is the language used. When a doctor uses a technical term, he or she might not be asked to clarify by the patient, to request clarification is to challenge the authority of the expert and by remaining silent the patient appears to understand what was said. Patients use the vernacular or lay language and doctors often ask the patients to clarify these terms, even though the converse was not observed in Mehan's (1993) research. The reaction by the patient after the doctor states the diagnosis is also part of this implicit acknowledgment of power differential. Patients are often silent after the statement of diagnosis:

By withholding response to the medical assessment . . . patients relinquish or subordinate their knowledge and opinion concerning the illness . . . and render the co-participant's version as the objective, scientific, and factual assessment of the condition. (Peräkylä, 2006, p. 216)

Other interpretations of reactions to the diagnosis include silence as an indicator that the patient is waiting for further elaboration, minimal acknowledgment tokens such as "yeah," "yes," and nodding can also serve to elicit further elaboration or explanation, or when the patient provides an extended verbal

response, which prevents the conversation from moving on to treatment options (Peräkylä, 2006). Ultimately, the desired situation is one in which both patient and doctors have equal power.

The consultation could and should be an encounter between two differently but equally resourceful agents where they negotiate diagnosis and treatment. In an ideal case, the parties' views will merge. (Peräkylä, 2006, p. 214)

When analyzing the diagnostic statement itself, Peräkylä (2006) divided the statements into three categories: plain assertions, inexplicit references to evidence, and explicating evidence. Plain assertions are direct descriptions of reality said in an unproblematic, taken-for-granted manner. No verbal descriptions of the reasons or the grounds for the diagnosis are given. Plain assertions might come at the end of an examination, establishing an “inferential link” between the examination and the diagnosis. This is used when “relevant events in the examination are transparent to a lay participant” (Peräkylä, 2006, p. 228). Inexplicit references to the evidence point to the source of the diagnosis using “evidential” verbs (e.g., “to appear” “to seem” “to feel”) to allude to sensory evidence on which conclusions are based. In contrast to plain assertions, these statements are often marked as tentative. Finally, explicating the evidence is when:

Doctors present their descriptions as reasons for, or evidence of, their diagnostic conclusions . . . By explicating the evidence, the doctors make a part of their medical reasoning available to the patients, thus constructing

them as *understanding recipients* of that reasoning. (Peräkylä, 2006, p. 221)

Sometimes the strategy of explicating the evidence is used when the doctor is unsure of his or her diagnosis. The doctor must explain what he or she does know to maintain authority despite uncertainty in the diagnosis. This strategy was also used when the diagnosis disconfirms what the patient has said he or she thought it was (Peräkylä, 2006).

Looking deeper into the diagnostic statements, Maynard and Frankel (2006) categorized statements as “good news” or “bad news.” The authors noted that good news was presented in an exposed fashion with no disfluencies. Disfluencies break up the flow of speech, including pauses, saying “hm” or “um” in the middle of a sentence, stopping and starting. Body language included direct eye contact, facing the patient, and was “regarded as enhancing the social bond between physician and patient” (Maynard & Frankel, 2006, p. 270). Bad news, on the other hand, was shrouded; the statement was broken up by disfluencies. This showed restraint on the part of the doctor, a subtle cue to the patient to also show restraint. Bad news was delivered later in the conversation than good news. There was less eye contact and the doctor may be facing away from the patient. The authors theorized that the doctor may be afraid the patient would lose control of his or her emotions. Maynard and Frankel (2006) found that “each physician begins a preface to an upcoming announcement. In turn, each patient produces a go-ahead signal that occasions a delivery of diagnostic news” (p. 266). When giving bad news, the doctor started out with asking the patient to recall or agree

that they both saw something or that the doctor saw something or the patient said something that is evidence of the diagnosis then gives the diagnosis, “co-implicating” the patient (Maynard & Frankel, 2006, p. 263).

The literature summarized here informed the analysis of the observation of diagnostic results appointments in this study in terms of attending to the structure of the appointments, coding the statements made by the developmental pediatricians, and developing themes from the parents’ comments and questions during the appointments.

Chapter 3

Design and Research Methods

This chapter provides a more in depth overview of the design and methods used in the sub-studies comprising this dissertation. It begins with a review of the purpose and rationale and includes researcher assumptions. The participants, data collection, data analysis, and parameters of study are also discussed.

Purpose and Research Questions

The purpose of the study was to analyze the history and process of autism diagnosis over time using multiple qualitative methods. The study could be considered to be composed of three sub-studies. First, interviews with seven mothers whose children were diagnosed with ASD between 1974 and 2004 were conducted. Second, diagnostic results appointments with two developmental pediatricians were observed in which the diagnosis of autism was given. Third, media portrayals of autism mentioned by the participants of the first two sub-studies were analyzed. The desired outcomes of the study were to create a more complete picture of autism diagnosis in terms of breadth and depth than previous studies have produced, as well as offer recommendations for diagnosticians giving the autism diagnosis in the future. The study situated diagnostic interactions with parents (mothers) in a larger societal context, including social constructions of autism through popular media and common sense assumptions about autism over four decades.

My primary research question was: How have mothers' experiences of receiving an autism diagnosis for their child changed over the last three decades?

The data used to answer this question include interviews with mothers who have children with autism who were diagnosed with autism between 1974 and 2004 as well as data collected in 2010 while observing diagnosticians giving the autism diagnosis.

The secondary research question was: How do parents, medical professionals, and media portrayals negotiate between the medical model and social construction of disability? Each set of data (interviews with mothers, observations of appointments, media portrayals mentioned by participants) was analyzed for statements that suggested underlying assumptions about the nature of autism that aligned with either the medical model, the social construction of disability, or a negotiation between the two.

Rationale

The history of autism is unique and the current pressures of attaining an autism diagnosis and caring for a child with autism are also unique. Research has demonstrated repeatedly that parents of children with autism have higher stress levels than parents of children with other disabilities or parents of children without disabilities (Abbeduto et al., 2004; Dale et al., 2006; Gray, 2003; Kuhn & Carter, 2006; Weiss, 2002). The lack of a medical test such as a blood test or genetic testing to confirm diagnosis often leads parents to question whether the diagnosis is accurate, leading to tension between parents and the medical establishment. Studies have explored parents' reactions to receiving the autism diagnosis through interviews and questionnaires in the past but have not sought to examine how these experiences have changed over time. Recent studies have

involved interviewing or sending questionnaires to parents within one year of receiving the diagnosis. A parent's perspective on the autism diagnosis, their child, and the medical professionals with whom they met can change over time as interventions produce changes in the child's behavior and more information about autism is learned by the parent. By interviewing parents years after the diagnosis, as well as observing parents currently receiving the diagnosis, a more complete depiction can be compiled.

Assumptions as a Researcher

The researcher for this study grew up in the southwestern city in which all participants currently reside. She has an older adult brother with ASD. Two of the participants know the author through a sibling support group that their typical daughters attended and the author facilitated. One participant previously employed the author as a behavioral consultant. One of the participants is the author's mother. Two participants know the author through the non-profit agency run by the author's mother.

The researcher's personal experience having a brother with ASD and working as a special educator with children with ASD and their families provides an insider view and allows the researcher access to this population. If an individual with no experience with ASD tried to interview or observe these participants, there would be a great deal of terminology to learn and difficulty understanding a description of specific autistic behaviors if one has not seen them directly. An example of this is the word "stemming," which refers to self-stimulatory behaviors such as rocking, flapping, lining up toys, etc. and is

common to all children on the autism spectrum, but varies in how it manifests across individuals.

This study is unique, because it is about mothers' experiences with medical professionals but it is being conducted by a special educator. In a recent issue of the *Journal of Early Intervention* (2010), leaders in the field of autism and early intervention debated current issues in a series of articles. Maureen Conroy (2010) proposed,

As the medical profession makes progress on its quest to understand the etiology of ASD and diagnose children, early interventionists must partner with physicians to help them use assessments accurately and appropriately, as well as help them understand the limitations of these tools and the implications of diagnosing infants and toddlers with ASD. Additionally, early interventionists have a responsibility to educate physicians, other allied health professionals, and families about the variability in the characteristics and idiosyncratic features of children identified with ASD so that the disorder can be more accurately understood and ameliorated. (Conroy, 2010, p. 101-102)

This quote encourages members of the field of early childhood education to interact more with the medical field that gives diagnoses. The use of the word "amelioration" denotes a medical model to theorizing disability but the collaboration between the fields via research, intervention, or training can still lead to a broadening of perspectives on disability and the validity of family input.

Participants

Interviews with seven mothers of children with autism from one metropolitan area of the U.S. Southwest were completed in 2008. . Convenience sampling was used to recruit mothers who children were born approximately every five years over the three decades included in the sub-study. All came from middle to upper middle class families. The participants were known to the researcher and selected to represent children receiving the diagnosis at different points in time from the 1970s to the present. See Tables 2 and 3 in Chapter 4 for more information on the participants.

Participants were recruited for observation of diagnostic results appointments upon arrival at the clinic. After explaining the purpose of the study, participants were asked to sign consent forms. If consent was given, the researcher accompanied the participants into their appointment with the diagnostician to take field notes while the parents heard the results of the diagnostic assessment of their child. The clinics were located in large hospitals. Both diagnostic clinics charge for their services but accept both private insurance and State-based insurance for those in poverty, so the possible participants either had the financial means to pay for the assessment or had insurance that paid for this service. The diagnosticians who participated in this phase of the study were also consented and interviewed on their process of diagnosing a child. Questions included which assessments are used, approaches to disclosure, and their perspective on how the diagnosis process has changed over time.

Data Collection

In 2008 data collection was completed for the seven mothers interviewed about their experiences regarding obtaining an autism diagnosis for their child. Participants were recruited either by phone calls or e-mails. Participants who agreed to be interviewed during this initial contact were e-mailed a consent letter, which was faxed back to the researcher. Interviews were conducted by phone using a speakerphone so that the conversations could be audio taped for later analysis. Field notes were taken during the interview by the researcher and certain sections of the interviews were transcribed after initial analysis of themes. See Appendix A for the interview protocol.

Questions were individualized and follow-up probes were added during the interviews. One question was added after initial interviews. The subject of the mother's perception of autism prior to her child's diagnosis emerged through the first two interviews. After these first two interviews, each participant was asked if they had heard of autism before their child's diagnosis and what they knew about it at that time.

After the interviews were completed, the participants were asked if they would be willing to fax the researcher a copy of the initial report they received with the ASD diagnosis. Once field notes were completed, they were e-mailed to the participants for feedback (member check).

The completed interviews (the first sub-study) were approved under the Institutional Review Board (IRB) of Vanderbilt University and were collected in the spring of 2008. For the 2010-2011 sub-study, an application was approved by

the Arizona State University IRB as well as the Saint Joseph's Medical Center IRB and the Phoenix Children's Hospital IRB.

For the families recruited for participation in the observation of diagnostic results, the administrative staff at the clinics determined which appointments met the inclusion/exclusion criteria for the study and directed the researcher to consent those families upon arrival at the clinic. The researcher silently attended the appointment and took field notes on what both the diagnostician and the family members said or asked, as well as any body language that was noticed.

Participants who consented to be observed during the diagnostic results appointment had the option to consent to the researcher receiving a copy of the diagnostic report provided after the appointment. They were also given the option for a follow up interview, which will use the same interview protocol used for the seven mothers whose interviews were completed. Only one family completed a follow up interview.

The diagnosticians observed during the study were asked the following questions:

1. Tell me about the assessment process you use to diagnose autism. What happens when a parent brings their child to you for assessment and diagnosis?
2. What assessment tools do you use and why?
3. What is the purpose of diagnosis?
4. What do you think has changed about autism diagnosis over the years?

Depending on the diagnosticians' answers to the questions, follow-up questions were asked to clarify.

Methods

This study implemented interviews, participant observation, document analysis, and media analysis. By using multiple methods, analysis can look for how the data are both convergent and divergent to develop theory and determine future directions for research and triangulate findings. The design included some components that were predetermined, such as interview questions, and some components that emerged through initial data collection and analysis, such as the media analysis component and the codes for the participant observation data. The entire process was reflexive, using each phase or sub-study to go back to previous data and refine themes and categories as well as develop meta-inferences.

Data Analysis

Initial analysis of the seven interviews used the constant comparative method (Glaser & Strauss, 1967) to analyze field notes from the interviews for themes. The author met with a peer three times during data analysis to debrief and review the interview sub-study to discuss emergent themes. Field notes were typed up within 24 hours of the interview and theoretical notes, methodological notes, and personal notes were added at this time. None of the participants expressed concern with how their story was portrayed in the field notes when asked for feedback through a member check. Each participant's response to each question was compiled into new Microsoft Word documents to analyze for commonalities and variations. For example, all participant responses under

question 1a were copied and pasted into a new document so they could be compared. If certain words or phrases were used by multiple participants then all interviews were re-examined to look for those words or phrases. If one mother told a story that was quite different from the experiences described by the other mothers, this was noted as a negative case for further analysis. If multiple participants described a similar event, all interviews were re-examined for that type of event description. These commonalities and negative cases were then grouped into themes or categories.

Four interview participants and five observation participants provided written diagnostic reports. The reports were analyzed for confirmation of the description provided in the interviews. The reports were also examined to see how they compared to the participants' responses to the question 6a (see Appendix A) regarding what doctors should keep in mind when giving the diagnosis.

For the data collected during observation of diagnostic results appointments, field notes were typed up after the appointment. The constant-comparative method was used to find themes within and across observations as well as across the observations and interviews combined.

To analyze field notes from the observations of diagnostic results appointments with developmental pediatricians the literature on the structure or medical appointments (Heritage & Maynard, 2006), the types of statements made by diagnosticians (Peräkylä, 2006), the types of statements made and questions asked by patients (Peräkylä, 2006), and the possible power differentials occurring within a medical appointment (Mehan, 1993) was used to create a thick

description of what occurred in the appointments. Transcriptions of the field notes taken during observations of appointments were coded for themes including explicating the evidence, inexplicit evidence, and plain assertions.

Other themes also emerged, and the doctors observed in this study did not necessarily match what the doctors in the literature did. Similar to how the interview data were coded, the field notes from the observations of diagnostic results appointments were examined for similarities in the structure of the appointments, questions, words, or phrases that the developmental pediatrician said, questions, words, or phrases that the parents said, stories shared by the parents regarding accessing services, noticing behaviors in the child, interacting with other professionals, interacting with other children and families, etc. If a participant in an observation described a unique event or experience, this was coded as a negative case for further analysis. The language of both the developmental pediatricians and the parents were analyzed for words or phrases that suggest the medical model of disability, the social construction of disability, and/or the negotiation between the two.

By comparing the diagnostic appointments described in the interviews with the diagnostic appointments observed, the similarities in experiences of autism diagnosis over time were determined. Through negative case analysis, themes that were not consistent over time provided direction for further analysis. Analysis of the diagnostic reports from the observation participants looked for statements and phrases that were used in the conversation during the appointment, including results of standardized questionnaires, descriptions of behaviors that

were examples of the diagnostic criteria for autism, and recommendations. This analysis was used to confirm themes in the field notes from the corresponding appointment, as well as establish themes across reports over time, including comparing the reports from the observation of appointments to the reports provided by the interview participants.

In analyzing the handouts given to the parents by the diagnosticians, the relevant media (e.g., books, news articles, films, television movies), and policies (criteria to qualify for educational, state, and insurance services) the texts were coded for language that indicated the medical model of disability, the social construction of disability, or the negotiation between the two. Medical model language included clinical and diagnostic terms or direct comparisons to a norm. Social construction language was more about identity and personhood. An example of language that suggested a negotiation pointed out that the autism was not the entirety of who that person was. Other themes emerged from these texts through constant-comparison.

Both the interview sub-study participants and the observation sub-study participants (parents and the developmental pediatricians) mentioned specific media texts that have portrayed autism over the years. The effect of these media portrayals was seen as important, and so a third sub-study was conducted to analyze the media portrayals of autism that were mentioned by participants in the first two sub-studies. The media portrayals were examined for how they portrayed autism in terms of words, phrases, behaviors, body language, and imagery. Each media text was examined for either a scene in which the character is diagnosed

with autism or one character explains autism to another character. In addition, just as the other sub-studies were analyzed for examples of the medical model of disability, the social construction of disability, and the negotiation between the two, the media texts were examined for these examples as well.

Once each component or phase of the study was completed, inferences from that component were compared to inferences from each previous component to begin to develop meta-inferences. In the final stage of the dissertation findings were combined from the media analysis phase of the study with the interview, document analysis, and observation sub-studies to form meta-inferences. Meta-inferences were refined after incorporating each new phase of the study.

Limitations and Parameters of the Study

None of the individual components of the study have the prolonged engagement of most qualitative research. Interview participants were not necessarily representative of cultural and language groups or socioeconomic groups in the community in which the study was conducted. The participants observed at the two developmental pediatric clinics had more diversity in socioeconomic status and ethnicity than the interview participants (see Tables 4 and 5 in Chapter 6).

Limitations of the mothers' interviews include the use of only seven participants, the use of only one interview each, and the reliance on the mothers' memory. A strength of this component is the representative sample of mothers whose children were born approximately every five years between 1971 and 2001, achieving a snapshot of the progress in diagnoses in the three decades. The

use of member checks and a peer debriefer demonstrate the trustworthiness and credibility of the method of this small-scale study. Transferability is addressed by the thick description of the cases and themes.

The author's relationship to the interview participants can be seen as both strength and a limitation. The author's insider status in the autism community allowed her to easily sample mothers of children that represented the time span of 1971 to 2004. It is expected that an outsider would have a different perspective on this data and perhaps would have asked different questions and/or focused on different aspects of the diagnostic experience.

For all of the interview participants, including the author's mother, new information was revealed to the author that was not previously known to her. In two of the interviews, the author was included in the story. The author's mother mentioned receiving one of the early misdiagnoses immediately after receiving the news she was pregnant. Another participant told the story of the author at age nine saying that the participant's son was just like her brother, and it appeared that they both had autism. Two of the participants spoke of meeting the author's mother as a turning point. They both felt she was the first person to provide information, support, and a model that life (with a child who has autism) can go on.

The use of hand written field notes instead of transcripts from audio or video recordings of the appointments could be seen as a weakness of the observation sub-study. While hand written field notes can be seen as less intrusive to participants, transcripts provide exact wording and videos can capture non-

verbal aspects of communication including body language, gestures, and facial expressions. In addition, this study was limited to only participants who spoke English. Both clinics use interpreters over the phone for patients who speak other languages.

The use of both interviews and diagnostic reports demonstrates triangulation of the data describing the experience of obtaining an autism diagnosis. The examination of the evolution of the autism diagnoses across versions of the DSM and consideration of media exposure concerning autism add yet another dimension to the story. In contrast to these strengths, this component by no means has reached data saturation or redundancy. Using multiple interviews with each participant (parent and developmental pediatrician) in both the interview and observation sub-studies as well as a larger number of participants overall would have allowed the study to reach a point of data saturation and redundancy. Many aspects were similar across participants but others were quite different. It is not possible to determine if the patterns and negative cases found in these sub-studies are generalizable in any way due to the small sample and limited interaction the researcher had with each participant.

Chapter 4

Interview Results and Analysis

Seven mothers were interviewed over the phone in the spring of 2008 for this study. They were asked to recount their memory of obtaining the diagnosis of autism for their child using the interview protocol in Appendix A. Convenience sampling was used to recruit mothers whose children were diagnosed approximately every five years between the mid 1970s and mid 2000s. All of the mothers were known to the researcher through her work in the community. Each mother's story is summarized briefly, followed by a discussion of themes across the interviews.

Case Studies

The following are brief summaries of each participant's effort to obtain a diagnosis of their child's condition. Table 2 gives the year of birth and year of diagnosis for each child. Table 3 provides information on the number of professionals seen and the type of professional who gave the autism diagnosis. The following summaries are presented in chronological order from 1971 to 2004. All names are pseudonyms.

Table 2

Interview Demographics

Mother's name	Child's name	Child's birth date	Year diagnosed
Rosa	Alan	2001	2004
Kelley	Shawn	1995	1999
Molly	Kendra	1992	1995
Lisa	Tim	1984	1989
Emma	Joey	1981	1983

Betsy	Jason	1974	1977
Catherine	Danielle	1971	1974

Table 3

Interview Summary Information

Participant name	Duration seeking diagnosis	Number of professionals seen	Number of diagnoses received	Specialty of diagnostician
Rosa	2 years	4	2	Developmental pediatrician
Kelley	1 month	1	2	Developmental pediatrician
Molly	18 months	3	2	Clinical Psychologist
Lisa	3 years	4	3	Clinical psychologist
Emma	1 year	4	3	Child psychiatrist
Betsy	2 years	5	5	Pediatric neurologist
Catherine	2 years	3	2	Child psychiatrist

Catherine. After pleading with her pediatrician multiple times for assessment because her daughter Danielle was not speaking, Catherine was sent to the Child Evaluation Center. A multidisciplinary team told her that Danielle had an IQ of 45 and was mentally retarded. This did not make sense to Catherine and her husband. They knew Danielle was intelligent, because she expressed her wishes by taking Catherine's hand and pointing to words representing what she wanted. Catherine enrolled Danielle in a preschool for retarded children. The director of that preschool recognized that Danielle was different from the other children at the preschool and referred Catherine to a child psychologist who had

recently moved to town. This doctor diagnosed Danielle with autism and connected Catherine with the newly created Autism Society chapter. Catherine had never heard the word autism prior to the diagnosis. Danielle was diagnosed in 1974.

Betsy. Betsy's son Jason fell off a ladder in the garage onto a hard, concrete floor when he was 21 months old. Betsy took him to the pediatrician when, after the fall, she noticed he had stopped talking, stopped looking at them, and was frantically running around the house when he had not displayed hyperactivity before. Dismissed by the pediatrician, she sought a hearing test at the local university speech clinic. The clinic could not test him, because he ignored the clinician so they could not give him a diagnosis, but he began speech therapy. The clinic requested a child psychologist from a nearby university assess Jason. The diagnosis was severe, profound emotional disability, caused by Betsy, and directed that speech therapy be discontinued until Betsy sought counseling. The psychiatric social worker Betsy saw for counseling taught her behavior modification techniques and, after a lack of progress, recommended pediatric neurological testing for Jason. Jason was tested by pediatric neurologists in two cities out of state. One neurologist diagnosed Jason with acquired aphasia due to seizures. The other neurologist suggested Jason could have a "Jewish disease" and suggested they "put him in an institution and forget they ever had him." Frustrated by the lack of agreement by the two pediatric neurologists, the parents arranged for a third pediatric neurologist to be seen. This assessment was multidisciplinary and resulted in the diagnosis of acquired aphasia with autistic symptoms. Betsy

thought individuals with autism were severely retarded and played with their feces. The neurologist explained to Betsy that her son had high-functioning autism. Jason was diagnosed in 1977.

Emma. Emma knew something was wrong with Joey the moment he was born. He did not cry at the time of his birth. When he did start to cry as a newborn, he could not be comforted. Emma had been interested in autism as an undergraduate and suspected this could be what was wrong with Joey. She researched signs of autism early on and approached her pediatrician with numerous examples of how his development was not typical. The pediatrician told Emma Joey would “grow out of it.” She took Joey to a developmental clinic at a local hospital. The developmental pediatrician hypothesized that Joey had lost oxygen during his lengthy birth and his behavior was due to brain damage. Joey was then seen by a child psychiatrist who told Emma to learn sign language because Joey would never speak and suggested Emma put him in an institution. Finally, Emma took Joey to the psychiatric institute at the local university and a child psychiatrist there delivered the diagnosis of classic autism. Joey was diagnosed in 1983.

Lisa. Lisa noticed that her son Tim was not talking and asked her pediatrician for help. She saw a child psychologist who diagnosed Tim with mental retardation and very low cognitive skills and said he “would never do anything.” Next, Lisa saw a developmental pediatrician who diagnosed Tim with global developmental delays. After years with this diagnosis, Lisa took Tim to a university clinic in another state where he spent 30 days as an in-patient being

assessed. At the end of the 30 days, Lisa was given Tim's diagnosis of autism. Lisa had heard of autism in her undergraduate coursework. When she went back and looked it up in her textbooks, they referred to Bettelheim's theory of refrigerator mothers. Lisa remembers throwing the textbook across the room. Tim was diagnosed in 1989.

Molly. Molly's second child Kendra did not respond to her name but turned to look if her parents sang songs. Molly approached her pediatrician but her concerns were attributed to Kendra's series of ear infections. After a hearing test, Molly was referred to a developmental clinic. The diagnosis was Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) but no one explained to Molly and her husband how that diagnosis was related to autism. PDD-NOS is a mild form of autism. Molly thought autism meant head banging and isolation from others. She did not see this in her daughter. Finally, Kendra was seen by a clinical psychologist at a university in a nearby city and diagnosed with autism. Kendra was diagnosed in 1995.

Kelley. Shawn had trauma at birth due to meconium aspiration. As a result, he was part of a program to follow-up with a neonatologist. His physical development was slow due to this early trauma, but the unusual behavior seemed to be a separate issue. He became upset easily and was difficult to comfort. The first developmental pediatrician to see Shawn focused on the physical delays and the early trauma but did not see the signs of autism. Shawn was enrolled in developmental preschool, and the teacher recommended seeing a developmental pediatrician specifically for the behavior issues. One month later, the parents saw

a second developmental pediatrician specializing in autism and received the diagnosis. Kelley had heard about autism in college coursework and the best man at her wedding has a son with autism. Shawn was diagnosed in 1999.

Rosa. Rosa had an older child who was premature and born with cerebral palsy, visual impairment, and a seizure disorder. She worried that her second child would have autism because she had heard about autism from the media. She noticed Alan was not talking. When she approached professionals and friends, they dismissed her because they could not believe “God would do that to her twice.” Rosa made an appointment with a child psychologist. Alan was reading and writing and she thought he was gifted. The psychologist referred them to a developmental pediatrician and suggested it might be Asperger Syndrome. The developmental pediatrician diagnosed Alan with autism. Alan was diagnosed in 2004.

Themes

Five themes were constructed from the interview data, aligning with the six topics in the interview protocol: first signs of autism, interaction with a pediatrician, isolation, reactions to the diagnosis, and recommendations to doctors giving the diagnosis.

First signs of autism. This category had two strands: (a) signs that the mother noticed and (b) incidences in which friends of the mother commented on the child’s development. Almost all of the mothers interviewed mentioned either a mommy group or one friend who had children very close in age to the participant’s child. These play dates offered opportunities for comparison between

the children. This often led the mothers to notice their child differed from peers because he or she was not talking, not playing, or became easily upset by things compared to other children his or her age. Rosa remarked how “natural” it was for the other child to give things to his mother while her child never did that. A subset of the mothers focused on a lack of verbal communication as the first sign, while others focused more on the child being upset easily and crying all the time. In addition to these concerns, some mothers noticed odd behaviors including lining up toys, sensitivity to food textures, and compulsive behavior.

Two of the mothers mentioned a lack of knowledge of typical child development. Other mothers also stated the overwhelming nature of being a first-time mother, regardless of having a child with autism. Two mothers had an older child. Despite having experience with their first child, the stories for these mothers were still similar to the first-time mothers concerning their child with autism.

Five mothers had a story of a friend communicating concern for the child. Two of the mothers had friends who went behind their back to talk to a professional about their concerns. One of these mothers reacted with gratitude; the other was hurt and angry. Both acknowledge that the friend had good intentions. Betsy had already started the process of seeing specialists in search of a diagnosis, when her friend showed her a definition of autism. Betsy dismissed the idea immediately and was very defensive. Kelley also had a friend suggest that perhaps her child had autism. The friend had a son with autism so Kelley assumed that this friend saw autism in everyone’s child and dismissed the idea as well. It is

unclear from these women's stories whether friends should say something if they notice signs of autism or not.

Interaction with pediatrician. In all of the interviews conducted, the first professional approached by the mother with her concerns was a pediatrician. In each of the cases, the pediatrician dismissed the mother's concern. This dismissal of mothers' instincts often led to diminished self-esteem and self-confidence in the participants. Multiple mothers spoke to the cultural norm of viewing doctors as experts not to be questioned. Betsy described growing up to believe that "doctors were God." Catherine said that she and her husband "did everything [the professionals] told us to do."

Only Molly said that she felt the doctors "weren't the experts." Catherine said she felt the professionals on the team "didn't know Danielle." Catherine also pointed out that the pediatrician only saw Danielle for ten minutes on a typical visit, and he never asked Catherine any questions.

Often the mother persisted with additional visits requesting referral for testing or therapy. The mothers had to advocate strongly to get referrals from their pediatrician or bypass the physician to get services and assessment. One parent said that after multiple requests, she "pleaded" with her pediatrician for answers. Perhaps pediatricians are more dismissive of first-time mothers. Two of the parents interviewed, Rosa and Molly, had another child before having the child with autism.

Rosa's story is unique. Her first child was born prematurely and, due to malpractice by the doctors, had cerebral palsy, visual impairment, and a seizure

disorder. When she approached her pediatrician, friends, family, etc. with her concerns about Alan, she was dismissed because these individuals could not imagine the horrible reality of a family with one child with severe physical impairments and another child with a developmental disability. These professionals and friends had guilt over the situation with the eldest child, and couldn't handle the idea that this mother would have another tragedy befall her. The friends and family members chose denial due to emotions as opposed to dismissing a mother's concerns as trivial like the other participants in the study.

Molly was working as a pediatric nurse when she approached her pediatrician about her second daughter, Kendra's development. She felt that the pediatrician took her concerns seriously because of her work in the medical field. Nonetheless, the doctor dismissed Kendra's lack of response to speech as a result of numerous ear infections.

The American Academy of Pediatrics (Johnson & Myers, 2007) now recommends all children be screened for autism, suggesting that pediatricians might be more knowledgeable about ASD now and more likely to respond to pleas for help from mothers with an autism screening. Hopefully, mothers' concerns about their child's development will be taken seriously in the future. In addition, screening for all children will lead to earlier diagnosis than the children described in this study.

Isolation. Each mother agreed that she felt isolated during the process of seeking a diagnosis. The isolation consisted of feeling alone in seeing things in her child that others would not acknowledge. Rosa referred to the isolation of

seeking a professional opinion concerning her son's development and being dismissed due to her older son's disabilities. No one would listen to her, and no one would "tell her what was going on."

The other aspect of isolation many mothers described was the feeling that her experience raising this child was completely different than that of her friends raising children the same age without these developmental issues. Kelley described play dates as "too stressful" and mentioned getting a baby sitter in order to socialize with friends. She also mentioned that if they brought Shawn to a gathering, one parent had to be "on him" at all times, and they could not socialize freely. Lisa said she believed people were staring at Tim when she took him out in public because of his behavior. Betsy and Lisa had both moved to new cities while pursuing the diagnosis. They described the difficulty in making friends with other mothers during that time.

Reactions to the autism diagnosis. The emotional words used to describe the moment they first heard the word autism ranged from "devastating" and "stunned" to "relief." Mothers explained the term relief by saying that having an explanation for what they had been seeing was satisfying. Emma said her initial response to the diagnosis was, "Yep, I was right!" Other mothers explicitly stated that they had hoped the diagnostic process would confirm that nothing was wrong with their child and that their instincts had been wrong. The reality that something was actually wrong led to devastation, crying, and anger. Molly described the feeling as "my balloon deflated." Only one of the mothers was angry with the diagnostician due to his matter-of-fact bedside manner. Other mothers were

neutral about their diagnostician's matter-of-fact approach. Three of the participants saw the same developmental pediatrician at different stages in the diagnostic process.

Multiple mothers mentioned that they recognized that diagnosticians have to give numerous diagnoses every day and they understood why a professional would try to remove his or her emotions from the situation to protect oneself. This detachment from emotion could be part of the culture of medicine. Another mother qualified her anger. It was not directed at the team giving the diagnosis; she was mad at the diagnosis itself.

Recommendations to doctors giving the diagnosis. All the mothers mentioned the benefit of the diagnostician giving a list of resources to parents including web sites, books, local organizations, or other resources available. The doctor who diagnosed Danielle with autism gave Catherine a book by Lorna Wing (1985). The book expressed hope and was greatly appreciated by Catherine.

Many mothers spoke about discussing the role of the mother of a child with ASD. Too often, mothers feel pressure to be a therapist 24 hours a day, seven days a week. "Sometimes you just have to look at your child and see your child," Rosa said. Another recommendation given by multiple mothers was to tell the parents not to fight or blame the other parent. Lisa recommended that the doctor tell the parents that the family's life does not have to center on the child. Two of the mothers addressed the issue of time and not feeling rushed through an appointment. Multiple mothers spoke about giving the parents a sense of hope and not predicting the child's limited abilities in the future.

A few of the mothers mentioned one of their first thoughts upon hearing the diagnosis of autism was to wonder what it would mean for their child's adult life. Another mother described how the professionals spoke to her about legal issues (such as guardianship), which she could not even consider regarding her then three-year-old daughter. These mixed results suggest that offering additional ways for some parents to learn about adults with autism would be positive, but it should not be automatically presented to every parent.

Betsy affirmed the benefit of a multidisciplinary assessment. She felt that specialists she saw only gave her 30% of an answer, while the final, multidisciplinary assessment results explained 100% of her child to her.

Diagnostic reports. The written reports provided by Rosa, Lisa, Betsy, and Catherine provided assessment results, medical and developmental history, and a range of recommendations. Recommendations pertained to educational placements, supplemental therapies, medications, future medical and psychological follow-up assessments, and referrals to other professionals. None of the reports spoke to emotion. Within the reports, there were a few positive, hopeful statements about the child's skills or personality. The language was extremely technical, with only a few changes over the years to more politically correct terms. For example, low IQ was "mental defective" in Betsy's report (1977), "mental retardation" in Lisa's report (1989), and was not mentioned in Rosa's report (2004).

Differences across the years. The main difference found across the interviews with mothers whose children were born from 1971 to 2001 was their

knowledge of autism prior to their child's birth. Catherine described driving past a school that included adults with Down syndrome. She would catch a glimpse and notice how different they looked. This was her only experience with cognitive disabilities before her daughter Danielle was born. Betsy associated the word autism with severely mentally retarded individuals who were violent and played with their feces. She did not know about high-functioning autism until her son was diagnosed. Molly associated autism with head banging and isolation from others. Emma had studied autism as an undergraduate psychology student and thought it was fascinating. Lisa and Kelley had heard about autism in undergraduate coursework as well. Rosa, the participant whose child was born in 2001, had heard about autism through the media and was concerned about vaccinating her child.

While all the mothers approached their pediatricians with concerns that were dismissed, it can be gleaned from the interviews that the pediatricians from the 1970s and early 1980s did not know what autism looked like. Even other professionals, including psychologists and neurologists, did not recognize the signs of autism. Danielle was misdiagnosed as having mental retardation, Jason was misdiagnosed as psychotic, and Joey was misdiagnosed as brain damaged.

Chapter Summary and Discussion

The mothers interviewed for this study had similarities and differences in their experiences pursuing and receiving the diagnosis of autism for their children. Their interviews provide evidence that the pediatrician was the first professional approached and the first to dismiss the mother's concerns. Education and training

on the symptoms of autism along with how to speak to parents in an empathetic way should be provided to all pediatricians.

Each of the mothers mentioned the need for physicians to provide resources to parents when they receive the diagnosis. The main complaint Molly gave regarding receiving the diagnosis was that “nothing was offered.” Parents may not wish to explore these resources right away but having them available when the parent is ready provides comfort and security. These information sheets, pamphlets, packets, etc. should be tailored to local resources but also have national resources such as the web site for the Autism Society of America.

The findings of this sub-study suggest a theory of how the autism diagnosis has changed over time. Due to a combination of media exposure and an evolution of the definition of autism in the DSM, mothers and pediatricians’ knowledge of autism has increased over the years. Mothers’ awareness of autism has changed from none to severe retardation and violence to splinter skills like *Rain Man* (Johnson & Levinson, 1988) to a link to vaccines. Pediatricians are equally affected by media exposure but also receive more examples of the signs of autism now than in earlier versions of the DSM.

Trustworthiness, Strengths, and Limitations

Limitations of this sub-study include the use of only seven participants and the use of only one interview each. A strength of this study is the representative sample of mothers whose children were born approximately every five years between 1971 and 2001, achieving a snapshot of the progress in diagnoses in the three decades. The use of member checks and a peer debriefer

demonstrate the trustworthiness and credibility of the method of this small-scale sub-study. Transferability is addressed by the thick description of the cases and themes.

The author's relationship to the participants can be seen as both a strength and a limitation. The author's insider status in the autism community allowed her to easily sample mothers of children that represented the time span of 1971 to 2004. It is expected that an outsider would have a different perspective on this data and perhaps would have asked different questions and/or focused on different aspects of the diagnostic experience.

For all of the participants, including the author's mother, new information was revealed to the author that was not previously known to her. In two of the interviews the author was included in the story. The author's mother mentioned receiving one of the early misdiagnoses immediately after receiving the news she was pregnant. Another participant told the story of the author at age nine saying that the participant's son was just like her brother, they both had autism. Two of the participants spoke of meeting the author's mother as a turning point. They both felt she was the first person to provide information, support, and a model that life can go on.

The use of both interviews and diagnostic reports demonstrates triangulation of the data. The examination of the evolution of the autism diagnoses across versions of the DSM and consideration of media exposure concerning autism add yet another dimension to the story. In contrast to these strengths, this sub-study by no means has reached data saturation or redundancy.

Many aspects were similar across participants but others were quite different.

There is more to uncover in this story. The portrayal of diagnosis in the interview represents only one side, the mother's perspective. Interviews with diagnosticians and pediatricians add to the triangulation of the data and, therefore, the credibility of the study.

Chapter 5

Media Analysis

This chapter provides a critical analysis of media depictions of individuals with autism. One of the changes seen over time in the process of obtaining a diagnosis of autism is parent awareness of what autism is and looks like. Media portrayals and mentions of autism contributed to this increase in public awareness. This analysis became part of the study as study participants in both the interviews with mothers and the observations of appointments with developmental pediatricians mentioned a few media portrayals of autism.

The earliest media portrayal discussed was the 1979 made-for-TV movie of the autobiography *Son-Rise*. Other portrayals included the Oscar-winning 1988 film *Rain Man* (Johnson & Levinson), the fiction book *The Curious Incident of the Dog in the Night-time* by Mark Haddon published in 2003, actress Jenny McCarthy's 2007 appearance on the *Oprah Winfrey Show* to discuss her son's recovery from autism, and finally the 2010 made-for-TV movie *Temple Grandin* (Saines & Jackson). The films, television shows, and book that were mentioned by participants in this study were analyzed for themes in how they portrayed autism and its characteristics, as well as whether the disability was presented under the medical model or social construction of disability. Just as the interview and observational data were used to determine how the process of obtaining an autism diagnosis has changed over the years, the portrayal of autism in the media was examined for general themes, what behaviors were described or depicted to signify the person has autism, how autism is explained, diagnosed or described in

the media, and whether the authors, characters, or interviewees are presenting the medical model of disability, a social construction of disability, or a negotiation between the two.

Son Rise

In 1979, a made-for-TV movie was broadcast based on the autobiographical book *Son Rise* by Barry Neil Kauffman about the intervention he and his wife used to bring their son Raun “out of autism.” The film depicts the family from Raun’s birth through the first few years of his life. The Kauffman family had two daughters, and Raun was their third child. As an infant, he had ear infections that caused his eardrums to burst and doctors warned the Kauffmans that Raun might be deaf. As a toddler, they noticed Raun was often in his own world and would not respond to his name or any sounds, appearing deaf, but at other times would respond to sounds. This contradictory behavior led them to take Raun to have his hearing tested. During the test, while wearing headphones that were emitting tones, Raun was waving a pen in front of his face. The doctors told the Kauffmans that he did not demonstrate any response to the tones, not even the aspects of the test that did not require Raun to actively indicate whether he heard the tones. When they took the headphones off, Raun sang a short sequence of the tones he heard. This scene depicted autism as a child who appears deaf but is not, a child waving objects in front of his face as a stereotypical movement, and a child who echoes what he hears.

Since the parents were still concerned that Raun seemed to be in his own world and did not respond to others, they continued to seek help from medical

professionals. One doctor told them Raun would grow out of it. Professionals who would recommend intervention said that they had to wait since they only treat older children. During the 1970s, the time period depicted in the film, early intervention for children with disabilities was almost non-existent. In 1986, IDEA added Part C, requiring states to provide early intervention to infants and toddlers. Prior to Part C, children needed to be school age (i.e., 3 to 5 years old, depending on the school) to receive any intervention.

While the film did not include a scene in which the parents were told that autism is caused by a cold, unfeeling mother (the Bettelheim (1959) theory), the parents were asked if there was a history of mental illness or breakdowns in their family. They were also asked to describe their courtship. Both of these questions suggest that the medical professionals were working either under the theory that autism is an emotional disturbance that could have been passed down through the parents' genes, explaining why the medical professionals asked about family history of mental illness, or that it could have been caused by the parents' behavior, explaining why the medical professionals asked about their courtship. They told the Kauffmans that Raun had autism, that his IQ was below 30, and that they could not treat him at this young age (i.e., he was not yet two years old in this scene). The psychiatrist said that, "At best he will have minimal function, he will never talk, and to hope for more is destructive fantasizing. Accept the truth, and later we can talk about placing him in a facility." Leaving the office, Mrs. Kauffman says that she "hates doctors, they're cold and unfeeling. I need something different, something to warm my soul."

While the Kauffmans rejected the prognosis that Raun would never talk and only have “minimal function,” as well as rejecting the idea that they could not start intervention while Raun was a toddler, they seemed to accept the theory that autism is an emotional disturbance. They frequently referred to Raun as being in his own world as if he had a choice to come out of it. Mrs. Kauffman said, “He’s not in a prison, he’s at peace inside there. We just have to show him a way out.” Mr. Kauffman replied, “I know he’s in there somewhere.” Mrs. Kauffman responded, “I’m not looking for a miracle, just a beginning, just a place to start.” In a later scene, Mr. Kauffman said, “I wonder what’s in his world that’s so much more fascinating than ours.” Mrs. Kauffman replied, “Maybe someday he’ll tell us.” These quotes depict autism as the result of a child making a choice, rather than the neurological disorder that it is now considered to be. The Kauffman’s experience also demonstrates that, despite Dr. Rimland’s book *Infantile Autism* being published in 1964, medical professionals still believed that autism was an emotional disturbance rather than a neurological disorder in the 1970s. Catherine and Betsey’s stories confirm this.

The depiction of autism in the film included Raun staring into space, unresponsive to his name and delayed in responding to a cookie being dangled in front of his face. Raun spent hours spinning plates on their edge and flapping his hands. When someone took the plate away, Raun switched to rocking. As Mrs. Kauffman tried to engage Raun one day, she started rocking with him. “I’m not judging you, I accept you. I wanted him to know that whatever he does, wherever he is, it’s OK.” The couple decided to have Mrs. Kauffman spend all of Raun’s

waking hours with him in an empty bathroom, stripped of all distractions, to see if imitating his autistic behavior would show Raun that they accepted him as he is, so that he would feel safe to come out from his autism to engage with them.

After many weeks of spending all day in the bathroom, Raun walked over to the refrigerator, pointed and cried to request juice. Another scene depicted Raun standing in front of the refrigerator and approximating the word water, saying, “oo-wah, oo-wah.” A montage followed in which Raun began using words to label and request activities, foods, and objects. After this period of a series of successes, Raun woke up one morning and appeared to have regressed, reverting back to rocking and spinning plates. He stopped using words or attempting any communication. So the Kauffmans started over again with the empty bathroom and rocking alongside Raun. Mrs. Kauffman said, “Maybe if we allow him to be where he is, then he’ll see that we really accept him.” One day, Raun woke up speaking once again, picking up where he had left off. The film ends with Raun speaking in full sentences, the epilogue stated that he now attended a regular neighborhood school.

The Kauffmans rejected the prognosis of the medical establishment but still reflected the medical model in that they wanted Raun to choose to leave his autistic world to join them in their world, thus suggesting that there is something “wrong” with Raun that they wanted to fix. By approaching intervention through imitating Raun to send the message that they accept him where he is, the Kauffmans also incorporated the social construction of disability. It would be

interesting to ask the Kauffmans if they would have continued to accept Raun if he never came out of his autism.

Rain Man

In the film, the fictional character Raymond lives in a private institution, despite the fact that the deinstitutionalization movement had occurred prior to the film's development. The film does not include a scene in which Raymond is diagnosed with autism, but it does have a scene in which his brother Charlie learns about Raymond's diagnosis for the first time and what it meant. The following is an excerpt from this scene (Johnson & Levinson, 1988):

Charlie (C): What is he, crazy?

Head of the institution (H): No

C: Is he retarded?

H: Not exactly.

C: He's not crazy, he's not retarded, but he's here.

H: He's an autistic savant.

C: I don't know what that means.

H: Some people like him used to be called idiot savants. They have certain deficiencies, certain abilities.

C: He's retarded.

H: Autistic. Actually, high functioning.

C: What does that mean?

H: It means there's a disability that impairs the sensory input and how it's processed.

C: English here, you're talking over my head.

H: Raymond has a problem with communicating and learning. He can't even express himself or probably even understand his own emotions in a traditional way. There are dangers everywhere for Raymond. Routines, rituals, it's all he has to protect himself.

C: Rituals. That's a good one.

H: Well, it's the way he acts, sleeps, eats, uses the bathroom, walks, talks, everything. Any break from the routines and it's terrifying.

The explanation given by the head of the institution differentiates between mental retardation, mental illness, and autism. The use of the word "deficiencies" denotes the medical model of disability. The anxiety caused by a break in routine or overstimulation of the senses sets up many of the film's scenes in which Raymond screams and hits his head.

Raymond's autism was portrayed as a series of contradictions. He memorized everything he read or saw. When his brother Charlie was looking around his room for the first time, he took a book of Shakespeare's works from the bookshelf. The action of taking a book off the shelf upset Raymond, leading him to repeat phrases to calm his anxiety. Charlie asked Raymond if he likes Shakespeare, if he has read Macbeth, Hamlet, etc. and, each time, Raymond replied, "I don't know." Charlie was shocked that Raymond had read and memorized the book but couldn't answer whether he knows or likes Shakespeare, or even acknowledge that he had read the book. Raymond was probably unable to answer these questions primarily due to the anxiety of a new person touching his

things, especially considering he was able to accurately answer other questions at different points in the film. For example, when Raymond saw a waitress' name tag and immediately recited her phone number, he was able to answer Charlie's questions about how he did that. "You said to read the phone book." C: "You read the whole phone book?" R: "Only to G, (states name he read to)."

Raymond could accurately count toothpicks as they spilled out of box and multiply large numbers in his head, but he did not know the value of money. The following passage conveys a scene that exemplifies the contradictory portrayal of autism depicted throughout the film.

Doctor: Do you know how much the square root of 2130 is?

Raymond: 46.15192304.

Charlie: That's amazing; he should work for NASA or something.

Dr: If you had a dollar and you spent fifty cents, how much money would you have left?

R: About 70, 70 cents.

C: So much for NASA.

Dr: Ray do you know how much a candy bar costs?

R: 'Bout a hundred dollars.

Dr: 'Bout a hundred dollars huh?

R: Yeah.

Dr: You know how much one of those new compact cars costs?

R: 'Bout a hundred dollars.

If the character of Raymond had been spent supervised time in the community and taught how to use money to purchase things, he might have learned greater independence. However, the portrayal was one of an individual who is incapable of living in the community and must remain within the confines of an institution, which was an antiquated idea even in 1988.

Another feature of autism portrayed in the film *Rain Man* (Johnson & Levinson, 1988) is Raymond's rigid adherence to routines, including his choice of foods and television shows. Raymond had been allowed to develop and retain habits that made it difficult for him to live outside his institution, such as eating with toothpicks rather than using utensils, eating exactly twelve cheezballs every night, and going to bed at precisely eleven o'clock despite any other considerations. In real life, it is possible to teach individuals with ASD to be more flexible in these routines and rituals, but this is not part of the fictional portrayal in *Rain Man*.

In the film, two characters represent the medical model and social construction of disability, respectively. The head of the institution represents the medical model. He introduces autism by its "deficiencies" and insists that Raymond is "not capable of living in the community" in the final scene of the movie in which the decision is made to return Raymond to the institution. Raymond's brother Charlie, on the other hand, represents the social construction of disability. Charlie discovers Raymond's existence only after his father dies and left Raymond three million dollars. Charlie did not inherit any of his father's money. At first, he wonders if Raymond was not part of a large conspiracy to

prevent Charlie from inheriting his father's fortune. While driving across country, Raymond blurts out that he is not wearing underwear. Charlie said he gave him a pair of his own underwear that morning. Raymond is not wearing them because they were different from the brand of boxers to which he was accustomed. He insists on going to the Kmart in Cincinnati to purchase new underwear so they would be exactly like his other pairs. Charlie is frustrated that Raymond will not even accept going to a different Kmart. He pulls over, gets out of the car, walks away and yells, "You know what I think? I think this autism is a bunch of shit 'cause you can't tell me that you're not in there somewhere."

Throughout the film, Charlie expresses his belief that Raymond can hear and understand him, but is willfully refusing to respond or comply. This tendency suggests either that Charlie believes Raymond is faking his autism, or that autism is not an acceptable excuse for Raymond's behavior. While Charlie does not perceive Raymond's behavior as normal, he does believe that Raymond was capable of more than what the institution had allowed him to do or learn. At the end of the film, Charlie takes pride in how far Raymond has come over the course of their road trip in terms of adapting to the changing locations, learning to play Blackjack, learning how to slow dance, and appreciating Charlie's jokes.

It is important to note that the savant characteristics portrayed in *Rain Man* (Johnson & Levinson, 1988) are not present in the majority of individuals with ASD. The overall portrayal that individuals with ASD must live in institutions to be safe and cannot learn practical things like the value of money are also inaccurate. The film was released shortly after a major event in the history of the

field of autism intervention. The seminal research study conducted by O. Ivar Lovaas, in which nine children with autism were “cured” using Applied Behavior Analysis approximately forty hours per week, was published in 1987. When the film was in production, it was generally assumed that there was no effective treatment for autism. Today, the intervention methods in the Lovaas paper are the basis for the only research-based treatment for ASD.

Curious Incident of the Dog in the Night-time

The book by Mark Haddon, published in 2003, is a fictional portrayal of a teenager, Christopher, who shares many of the traits of Raymond in *Rain Man* (Johnson & Levinson, 1988). He lives an isolated life limited to home and school, in which he is allowed to cultivate rituals; including eating only certain colored foods and refusing to talk to anyone or complete school work if he deems it a “black day.” “Black days” occur when Christopher sees four yellow cars while riding the bus to school. Just as Raymond was not taught how to use money, Christopher does not know how to locate the train station clearly within sight distance of the school he attends or how to use it independently. When Christopher describes his plans to go to college, he states that his father will move with him rather than learning to live independently, similar to the idea that Raymond must stay in the institution.

The word “autism” is never mentioned in the book but the characteristics of autism are demonstrated through the first person narrative of Christopher. Like Raymond, Christopher memorizes things and excels at math. He prefers to keep to a schedule and becomes anxious if something that was scheduled to happen

cannot or does not occur. While Raymond would scream and hit his head when upset or overwhelmed by sensory stimuli, Christopher screams and hits others, followed by kneeling, pressing his forehead to the ground and groaning to calm himself. Neither Raymond nor Christopher likes being touched. The portrayals of autism in Raymond and Christopher offer an interesting comparison of the use of expressive language. Raymond demonstrated echolalia, either immediately repeating what was heard or repeating memorized phrases from TV, movies, etc. but Christopher does not use echolalia. Portraying echolalia in a video format may be easier than in written form, but the author might have described how reciting certain phrases or TV show excerpts can be calming to the person with autism.

Christopher does not regard himself as someone with a disability that he wishes could be fixed. His self-portrayal compared to other typical people follows more of the social construction of disability. Christopher sees himself as normal and wishes that the world was made up of only people like him. He describes a recurring dream toward the end of the book:

And in the dream nearly everyone on earth is dead, because they have caught a virus...And eventually there is no one left in the world except people who don't look at other people's faces...and these people are all special people like me. And they like being on their own and I hardly ever see them because they are like okapi in the jungle in the Congo, which are kind of like antelope and very shy and rare. And I can go anywhere in the world and I know that no one is going to talk to me or touch me or ask me a question. (Haddon, 2003, pp. 198-199)

This description is similar to the Aspies movement online, which suggests that the rest of the world should expand their concept of a continuum of what is considered normal to include high-functioning autism or Asperger Syndrome and not to expect those individuals to change their habits or behaviors. While the character of Christopher expresses the social construction model of disability that might not be the purpose of the inclusion of this dream in the book. The author might want the reader to sympathize with Christopher's plight in terms of difficulty interacting with others. The author could be using the dream as a way of communicating how people with ASD differ from the reader with Christopher's desire to kill off all the people meant to demonstrate how abnormal and disturbing Christopher's disability is.

It is surprising that the depiction of autism in the book, published in 2003, is so similar to the depiction in *Rain Man* in 1988 (Johnson & Levinson). However, the deinstitutionalization movement is reflected in Christopher's life living at home with his father, as opposed to Raymond who remains institutionalized. The use of ABA and even inclusive education are not as common in the United Kingdom, the book's setting, compared to the United States. However, it seems odd that the author did not include anything to reflect the effect of Lovaas' (1987) work in the field of autism in the previous fifteen years. In part, this may be because these two works are fictional and the choices the authors made serve a purpose for the plot and/or emotional tone of the work. Perhaps it serves the literary plot to have the disability be a fixed aspect of the character, while the bond between Raymond and Charlie or Christopher and his

father is a characteristic that is fluid and can change.

Temple Grandin

In 2010, HBO premiered a made-for-TV movie based on the actual life of Temple Grandin, a woman with high-functioning autism who has written several books about living with autism and speaks regularly at autism conferences (Saines & Jackson). The film won multiple Emmy and Golden Globe awards and Temple Grandin was seen in the audience throughout the award show telecasts.

Unlike the *Curious Incident...* (Haddon, 2003) or *Rain Man* (Johnson & Levinson, 1988), the *Temple Grandin* (Saines and Jackson, 2010) film has a scene depicting Temple's mother receiving the diagnosis of autism. The year is 1955 and the doctor establishes that four-year-old Temple does not yet speak and has frequent tantrums. He tells Temple's mother that she is autistic, also known as infantile schizophrenic. He recommends institutionalization, saying Temple will never speak and that there is no course of treatment. The mother says that Temple was not atypical as a baby but changed as she grew older, referring to the unique aspect of autism in which development is typical and then either halts or regression occurs. The mother asks the doctor what caused this change in the following dialogue:

Doctor: It is suggested that it may be a lack of bonding with the mother, that at a crucial phase the mother was cold, aloof when the child most needed physical affection,

Mother: But that is not what happened! We have another child and she is not like this and I did not do anything different. Temple rejects me, I want to hug her and she won't let me. (Saines & Jackson, 2010)

This reference to the Bettelheim (1959) theory of “refrigerator mothers” is softened by the doctor’s choice of words, using a generic “the mother” as opposed to saying this particular mother was aloof, cold, etc. This scene represents the medical model of disability, both in how the doctor gives the diagnosis and prognosis and how the mother asks what can be done to help her daughter learn to speak.

The characteristics of autism are demonstrated in a similar way in *Temple Grandin* (Saines & Jackson, 2010) as they are in *Rain Man* (Johnson & Levinson, 1988) and *Curious Incident...* (Haddon, 2003). Temple does not like being touched; she only eats yogurt and Jell-O; she needs a sign on her room to know that it is her bedroom; she becomes upset when the sign falls down. She complains to her mother and aunt about how confusing people are to her and that she does not understand what their facial expressions mean. In *Curious Incident...* (Haddon, 2003), Christopher’s teacher Siobhan drew faces to explain emotions to him. Temple’s aunt takes photographs of Temple in a variety of expressions and helps her label each one. The HBO film illustrates Temple’s savant skill, visual memory. She begins the film by saying, “I’m not like other people. I think in pictures and I connect them” (Saines & Jackson, 2010). In a classroom scene, she glances at a page in the textbook and announces that she has read it. The teacher comes over to Temple, takes the book away and asks her what the page says.

Without missing a beat, Temple “reads” aloud the words through a picture of the page in her mind. Temple also displays skill in designing and constructing things. For example, she invents a system to enable a visitor to her aunt’s ranch to drive up to the gate and pull a handle that automatically open the farm gate so the car can drive through without the driver stepping out of the car to open and close the gate. She also builds her own squeeze box to create a calming, deep pressure, intervention for her anxiety, based on a device used to restrain cattle for inoculation.

Throughout the film other people stared, taunted, and teased Temple for her strange behavior. Teachers and employers were quick to suggest that she was not suited to be in their setting. Temple and her advocates (her mother, aunt, and high school science teacher) fought for her inclusion in regular schools and the workplace. Unlike *Rain Man* (Johnson & Levinson, 1988), which ends with Raymond’s return to the institution as his proper place in society and *Curious Incident...* (Haddon, 2003) in which Christopher returns to his father’s house and his self-contained school for students with disabilities, Temple is never seen in a specialized, therapeutic environment for individuals with disabilities in the film. There is a scene in which Temple’s mother shows her flash cards, hinting at the hours of one-on-one intervention her mother provided when Temple was a child, but none of her schools were therapy-based. Part of this is due to the time in which Temple grew up. She attended high school and college in the 1960s and attended graduate school in the early 1970s, all before the passage of the Federal law IDEA mandating public schools to have special education programs.

Rather than allow Temple to develop rituals and routines that prevented her from being successfully included in the community, people intervened and insisted that she change. Temple had consequences for hitting students who teased her, and her boss gave her deodorant and asked a female co-worker to take her shopping to learn about hygiene and appropriate dress. While Raymond and Christopher could not be left unsupervised, Temple lives alone in an apartment during graduate school scenes. This is a more accurate depiction of a real individual with ASD whose family and teachers intervene to extinguish the defining characteristic of rigid adherence to routines and rituals.

The film *Temple Grandin* negotiates between the medical model of disability and the social construction of disability (Saines & Jackson, 2010). Temple frequently recognizes that she does not understand people's behavior while everyone else seems to have this ability. She realizes in high school that other people do not see the world in pictures the way that she does. A recurring phrase that both her mother and Temple use in the movie is "different not less." This suggests the social construction of disability. In addition to the diagnostic scene, the idea of teaching Temple to compensate for and overcome challenges presented by her autism represents the medical model. The purpose of the squeeze machine was to calm Temple's anxiety as well as make her feel more like her non-autistic peers. As Temple describes, "I've always wanted to understand the gentleness that other people feel when they're being hugged by their mothers. Now I've made a machine that lets me do that. It feels like a wire gets reconnected, like something gets repaired" (Saines & Jackson, 2010). This

suggests the medical model in terms of applying a treatment to fix something that is wrong with her.

At the end of the film, Temple speaks to a crowd of parents at an autism convention. She poignantly says:

Overstimulation hurts. People talking too much at once can cause us to panic. I'm not cured. I'll always be autistic. My mother refused to believe that I wouldn't speak. And when I learned to speak, she made me go to school. At school and at home, manners and rules were really important. They were pounded into me. I was lucky. All these things worked for me. Everyone worked hard to make sure I was engaged. They knew I was different but not less. I had a gift; I could see the world in a new way. I could see details that other people were blind to. My mother pushed me to become self-sufficient. I worked summers at my aunt's ranch I went to boarding school and college. (Saines & Jackson, 2010)

It is possible to interpret Temple's description of her autism as a "gift" as a social construction of disability. She did not see her autistic features as something wrong that she needs to fix, but as something to celebrate because they make her special. By embracing this identity of autism while still learning to compensate in certain ways to succeed in society, she negotiates between the two models of disability. This negotiation between the medical model ("Everyone worked hard to make sure I was engaged") and the social construction of disability ("I had a gift; I could see the world in a new way") reflects the perspective of a significant number of mothers and professionals in the field of autism today.

Newsmagazines

Unlike fictional films and television shows, news media often focus on young children with autism. One reason for this may be that fictional media use actors to portray characters with autism, and teens and adults can do this more convincingly than child actors. News media can document the lives of real children with ASD through photos and video to depict the defining characteristics of autism throughout a life span. These stories frequently present autism as a horrible disease that is hiding the real, typically developing child within. During the years in which the vaccine and thimerisol controversies were regularly in the news, articles frequently had titles labeling the “autism epidemic” and questioning the safety of vaccines. Other current news articles celebrate treatment benefits or specific children’s unique successes, such as the teenager with autism who assisted his school basketball team all year and, when finally allowed to play in a game, scored three shots from a great distance (Skytz33, 2006).

The depiction of autism has changed over time as the general awareness and the prevalence of children diagnosed with ASD have increased. During the interview with Dr. Kohn, he showed a slide from a power-point presentation on autism he gives that features two magazine covers (see Figure 2). In the first cover, from 2002, the child with autism is looking away and has a strange body and hand position, depicting the stereotypic behavior that is part of the diagnostic criteria. The second cover photo, from 2006, shows a typical looking child staring straight at the camera with his hands in his pockets. The change in the photos correspond to cover stories on autism that correlate to the increase in children

with very mild symptoms being diagnosed and the decreasing stigma previously associated with the diagnostic label. This portrayal of a child appearing typical does not accurately represent all individuals today who are diagnosed with ASD. Children with moderate to severe autism still avoid eye contact and position their hands in unusual, purposeless ways. Most news media articles assume a medical model by referring to autism as a disease and the search for cures, or by reporting medical research on possible causes or biomedical treatments. A social construction of autism would not avoid showing a photo of a child performing stereotypic behavior but would embrace it, thus refusing to force a child to meet the cultural norm of eye contact and smiling at the camera.



Time, May 6, 2002



Time, May 15, 2006

Figure 2. Newsmagazine covers from 2002 and 2006 that demonstrate the difference in how children with autism are portrayed in the media. Cover one is the *Time*, 2002, May 6 and cover two if from *Time*, 2006, May 15.

Jenny McCarthy on *The Oprah Winfrey Show*

Actress Jenny McCarthy wrote a book about her son's diagnosis and subsequent recovery from autism using biomedical interventions including the gluten-free, casein-free diet and yeast elimination from his body. She appeared on *The Oprah Winfrey Show* on September 18, 2007 to promote the book and discuss her experience.

Ms. McCarthy described receiving the diagnosis as “devastating” and said, “I just remember closing my eyes and dying inside” (Winfrey, 2007). Unlike most concerns about language or odd behavior that bring parents to medical professionals for a diagnosis, Ms. McCarthy's son experienced seizures, which initiated the diagnostic process. Her son was diagnosed by a neurologist rather than by a psychologist or developmental pediatrician, and Ms. McCarthy reported being given no information on what to do for a child with ASD. The neurologist said to Ms. McCarthy, “This is the same little boy you came in the room with”

(Winfrey, 2007), suggesting that she could negotiate the medical model of the diagnosis with the social construction of how she identified her child. Because it appears that her son was most likely diagnosed in 2005 (he was five years old at the time of the taping in 2007 and he was diagnosed at age two and a half), it is surprising that she was not given information on educational services and research-based therapies like ABA. She said, “You hear that the typical therapy is ABA, speech, OT, but that’s it. You don’t hear about recovery stories” (Winfrey, 2007). Perhaps she did receive information on research-based interventions but was expressing frustration that a medical professional did not give her information on alternative interventions that have no research to support them. Since typically the autism diagnosis is made by a psychologist, psychiatrist, or developmental pediatrician, it is also possible that the neurologist did not have a prepared packet of materials about autism to give a parent at the time of diagnosis.

When Ms. McCarthy was asked to look back on her child’s development, she described signs that she now recognizes as characteristics of autism including hand-flapping, spinning wheels on cars rather than pretending to drive the cars, playing with door hinges, tiptoe walking, and an obsession with moving objects such as escalators. She discussed how she thought at the time that he might become a mechanic and was not aware these behaviors were signs of ASD. She said that she knew what autism was. She tells the following story:

I knew what it was because the month before it was on *Time* magazine that says autism is on the rise, and I said, thank God my son doesn’t have

autism...My child smiles. My child looks at me. My child doesn't have autism. (Winfrey, 2007)

Similar to the experiences of the mothers interviewed for this study, Ms. McCarthy heard other people express concerns to her about her son's development. As she explains:

And people did come to me and say, you know, my mother-in-law said, he doesn't really show affection, and I threw her out of the house. I went to a play gym, the woman says, does your son have a brain problem? I got her fired...How dare you say something about my child? I love him. He's perfect...I just had no idea. (Winfrey, 2007)

This is similar to reports from the mothers interviewed in this study in terms of other mothers in play groups suggesting the child needs to be evaluated.

Once Ms. McCarthy obtained the diagnosis, she "made the decision in that moment that said I'm gonna get him out." Her first step was to enter the word "autism" into the Google search engine. She said, "The university of Google is where I got my degree from." This is one of many statements in the episode that suggests that Ms. McCarthy rejected the medical establishment in favor of "mommy instinct." Later in the televised interview, she said "Evan (her son) is my science" (Winfrey, 2007). She found sources on the internet that do not necessarily have research to support them and, along with her maternal instinct, used them to make her choice of intervention over what the medical establishment recommended. This suggests that Ms. McCarthy rejected "science" and the

medical establishment. However, Ms. McCarthy did not appear to reject the medical model of disability.

The gluten-free, casein-free diet is based on the theory that children with autism are allergic to gluten and casein. Rather than get a rash or go into anaphylactic shock, in the case of a child with autism, the allergic reaction results in brain damage and developmental delay. The scientific, medical model theory assumes that if you remove the allergen, the allergic reaction will go away. The intervention used to eliminate yeast in the body also follows a medical model by proposing that there is too much yeast in the body, which requires a medical intervention to eliminate it and thereby cure the child. There is no rigorous research to support the success of this form of intervention. The rejection of the scientific model is in direct contradiction to the assumptions behind the interventions Ms. McCarthy chose to use. In addition, Ms. McCarthy did use video modeling upon the recommendation of her child's speech therapist, and that is an intervention with a strong, emerging research base.

Ms. McCarthy displays a contradiction when rejecting the scientific establishment that says autism is a brain-based disorder that has no medical course of treatment to cure it in favor of employing methods based on pseudo-science that posits that significantly altering the child's diet can affect behavior and cognition. She chose to employ biomedical treatments, which use the medical model scientific theory that too much yeast is not normal and therefore eliminating it should cure the abnormality.

As Bumiller (2008) described, parents of children with autism often “negotiated” between the medical model and social construction model of disability. They believed that something was “wrong” with their child that needed intervention, but worried that society would discriminate against their child for being different. Ms. McCarthy’s perspective is different than negotiating between the medical model and the social construction of disability. Mothers engage in a negotiation when they say that their child has autism and they pursue interventions to help the child learn to speak, etc., but the mothers are worried about the rest of the world discriminating against their children because they do not fit the norm. It is logical to believe both sides. Professionals who believe that autism exists and is a disability while recognizing the artificiality of the DSM criteria and realize that the purpose of diagnosis is a pathway to services are negotiating between the two models in a way that is not contradictory.

If Ms. McCarthy rejected science, accepted that her son has autism and embraced that as his identity and his unique version of normalcy that would be consistent with the social construction of disability. It appears that Ms. McCarthy is primarily relating to a medical model which, assumes that autism is not a natural part of her son but something from which she must “get him out” through interventions. Temple Grandin’s mother also rejected the Bettelheim theory of refrigerator mothers, which was the scientific establishment theory of her time. She did not, however, reject Temple’s autism as something that must be fixed or cured. She described Temple as “different, not less,” and advocated for the world to accommodate Temple, while also teaching Temple how to behave

appropriately in the world. Ms. McCarthy seemed determined to only fully accept her son if he recovered from autism. This demonstrates the difference between Temple's mother's negotiation between the medical model and social construction of disability versus the medical model that somehow still rejects science as employed by Ms. McCarthy.

In the televised interview, Ms. McCarthy said: "I'm just a mom telling a story of other moms. We wanna share it and say, you know, our child did get better. And it's the same thing is like chemotherapy. It doesn't work for every cancer victim" (Winfrey, 2007). Using the medical model terminology, Ms. McCarthy did not use the word "cured" to describe her son, explaining:

A really great analogy is this. If you got hit by a bus, you don't become cured, but you recover from it. But you'll have a little boo-boo here and there. And that you've got to constantly kind of go through therapy to keep it maintained. (Winfrey, 2007)

To use the cancer analogy in a different way, part of the diagnostic process is to take a biopsy and view cancer cells in the microscope before treatment occurs. If treatment cures your cancer and eliminates the cancerous cells from your body, you would no longer see them under the microscope. However if you are an alcoholic, your brain cells may differ from those of a non-alcoholic. Even when you stop drinking alcohol, your brain is still different; you are in recovery but not cured. With these variations on "cure" versus "recovery," it would be interesting to ask Ms. McCarthy if she believes that her son's brain is still different despite eliminating the yeast, gluten and casein. Temple Grandin said in

the film that she is still autistic but learned how to speak, learn and succeed in the world due to behavioral interventions (Saines & Jackson 2010). There is a noticeable lack of endorsement from children or adults with autism among the biomedical intervention advocates. Support is expressed primarily by parents and doctors.

Conclusion

The media portrayals of ASD range from individuals perceived to be best served in institutions and special schools located away from mainstream society, or individuals whose parents persevere through sometimes intolerant community settings to parents rejecting science and only accepting their child if they are no longer sick. From an attitude of no hope for any remediation to the belief in the potential to recover and live as independently as possible, the media has provided the general public with an evolving vision of dignity and hope for children and adults who have autism. The fictional portrayals of autism depicted the characteristics of autism as unchanging, while the autobiographical portrayals all demonstrated the individual with autism growing, learning, adapting to the world around him or her. The medical model was present in all the pieces analyzed here, the social construction of disability was present in the films and book, but not in the news magazines and *Oprah* interview. These pieces were selected because when participants in this study first heard their child had been diagnosed with autism, these were the media portrayals they used as a reference point for what autism looked like, what autism meant. The depiction has changed over time in terms of institutionalization versus inclusive education and moving from an

emotional disturbance theory to a more biological/neurological one. It will be interesting to see what the next iconic depiction of autism in the media will be, what will be the next *Rain Man* (Johnson & Levinson, 1988), *Curious Incident...* (Haddon, 2003), or *Temple Grandin* (Saines & Jackson 2010). Perhaps it will be a news story or interview like Jenny McCarthy's TV appearances, rather than fictionalized. Each generation of parents have a media portrayal to connect to.

Chapter 6

Observation Results and Analysis

Overview

In this chapter the themes that emerged from field notes of observations in two clinics led by developmental pediatricians are presented. The researcher sat in on appointments and took field notes by hand. She was not part of the conversation and was not employed by either clinic. Clinic staff assisted in determining which appointments were appropriate to recruit from and the researcher conducted the consent conversations with each family. Both clinics had each family come twice; data were collected during the second appointment in which families received the results of the developmental assessment and the diagnosis of ASD for their child. Each clinic is described and examples are given for each theme. Relevant literature is cited, to situate findings within the context of previous research.

Observations of Appointments

Dr. Kohn. The first diagnostician observed for this study was a developmental pediatrician at a private hospital in a large, metropolitan city in the southwestern United States. The doctor evaluates and diagnoses children with autism spectrum disorders, attention deficit hyperactivity disorder, oppositional defiant disorder, and other developmental disorders. The clinic personnel consisted of one developmental pediatrician who is a European American man in his 50s and a number of registered nurse practitioners. The patients' parents initially saw the nurses to discuss their concerns and received questionnaires to be

completed by the parents and the child’s teacher. For purposes of this study, the second appointment was observed. It was often held many months after the first visit. By that time, the questionnaires had been completed, returned and scored. The appointments with the developmental pediatrician lasted approximately 90 minutes and all seemed to follow a similar structure (i.e., opening introduction, reviewing results of questionnaires, reviewing diagnostic criteria for autism, recommendations). Dr. Kohn’s patients that participated in this study are described in Table 4.

Table 4

Appointments From Dr. Kohn’s Office

Number	Who came to the appointment	Age of child	Ethnicity	Diagnosis
1	Mother & daughter	6	Asian American	High-functioning autism
2	Mother & son	4	Caucasian	High-functioning autism
3	Mother & son	4	Hispanic	Autistic disorder
4	Mother & son	3	Hispanic	Autistic disorder & hyperactivity
5	Mother, father, & daughter	2	Caucasian	Autistic disorder
6	Mother, father, & son	4	Caucasian	High-functioning autism
7	Mother & daughter	4	Caucasian	Autistic disorder
8	Mother & son	10	Caucasian	High-functioning autism & depression
9	Mother & son	12	Caucasian	Asperger Syndrome
10	Mother, father, & son	2	Caucasian	Autistic disorder
11	Mother, father, & son	8	Hispanic	Autistic disorder

Dr. Bayles. The second site in which participants were observed was also located in a large private hospital centrally located in the same metropolitan city

in the southwestern United States. The clinic reserves Mondays for appointments related to autism. The developmental pediatrician, Dr. Bayles, is a European American woman in her 40s who conducts this “autism clinic” assisted by pediatric residents. On one of the first two Mondays of the month, patients come for their first visit. The resident takes a complete history of the child and completes the Modified Checklist for Autism in Toddlers (M-CHAT™; Robins, Fein, & Barton, 1999) as an initial screening for ASD. Dr. Bayles then met the family, completes a physical exam of the child and scores the M-CHAT. The family is given the Gilliam Autism Rating Scale (GARS) and the Child Behavior Checklist (CBCL) to complete and ask the child’s teacher to complete before the next appointment. The family returns two weeks later (the second two Mondays of the month) for a second appointment, which was observed for this study. The GARS and CBCL are scored and Dr. Bayles reviewed the Childhood Autism Rating Scale (CARS) and the DSM-IV criteria with the parents before giving the scores and final diagnosis to the family. Often the child is sent for bloodwork to measure nutrient levels and do genetic testing before or after the second appointment. The schedule of appointments two weeks apart is a new system Dr. Bayles put in place a few months before data were collected. Participants from Dr. Bayles’ clinic are described in Table 5.

Table 5

Appointments From Dr. Bayles’ Office

Number	Who came to the appointment	Age of child	Ethnicity	Diagnosis
12	Mom & son	5	Hispanic	Autism

13	Father & son	4	African (immigrants)	Severe Autism
14	Mother, father, & son	2	Asian (immigrants)	Moderate Autism

Heritage and Maynard (2006) described the structure of an appointment as an opening, description of the presenting complaint, followed by the doctor's examination, statement of diagnosis, discussion of treatment, and closing. Dr. Kohn's appointments deviated slightly from the structure described by Heritage and Maynard (2006) since it was the second appointment the families had at the clinic. The doctor started with an opening, followed by reviewing the completed questionnaires with the parents. The doctor then introduced each article in a large stack of handouts given to the parents to take home and concluded with a summary of recommendations and next steps. Interspersed within these segments of the appointment were questions and answers posed by either Dr. Kohn or the parent. Dr. Kohn often redirected the conversation back to the questionnaires or handouts. Dr. Bayles' appointments followed a similar structure. She would review the scores on the GARS and CBCL briefly but would also ask a series of questions to complete the CARS and examine the DSM-IV criteria during the appointment. Dr. Bayles also had a packet of articles and resources she gave to families towards the end of the appointment. Parents posed questions throughout the appointment.

Setting. The doctor entered the room and greeted both the child and the parents. The room had a round table, a small chair labeled "Dr. Kohn's chair" and four other chairs, some child size and some adult size. There was a play kitchen with buckets of toys with which the children could play as well as a structure with

stairs for children to climb and a rocking chair. Crayons and paper were kept in a pocket by the door as an alternative activity for children. Dr. Bayles' appointments were conducted in an exam room that had a desk with a computer at which Dr. Bayles would enter information as the appointment progressed so the family would walk out with a final report, an examination table covered with paper, chairs for the adults, a mat on the floor for children to sit, a full length mirror on the wall, and a bucket of blocks.

Case Descriptions

Appointment #1 was an Asian-American mother and her daughter. When they arrived for their first appointment with Dr. Kohn, the mother reported that her daughter was having frequent tantrums in her kindergarten class. This year, the child seemed to have learned "how school works" and was having less frequent tantrums. When tantrums occurred, it was usually when an anticipated event or routine did not go as planned. Because her scores were borderline between autism and PDD-NOS, Dr. Kohn explained that she may be too high-functioning to qualify for some services. The main area of need for the child was social skills, because she was making progress in speech therapy and had no difficulty with academics in her private school setting.

During appointment #2, a Caucasian mother and son, arrived at the appointment with a Lego airplane. When Dr. Kohn entered, the boy told the doctor all about his airplane, its pilot and the airport he built at home. Dr. Kohn presented a container of Legos for the boy to play with. The boy spelled out "L-E-G-O" while pointing to the letters on the container and handed the container

silently to the doctor so he would open it. Speaking to name the letters but not using spoken communication to request opening the container is an example of how children with autism have unusual social-communication skills. The mother's main concern was communication. When frustrated, her son would "shut down" and revert to "turkey talk" (gibberish) and often violently attack his brother. The boy had been receiving speech and feeding therapy until a few months previous to this appointment when the family's insurance stopped covering it. The issue of educational placement was also a topic of interest for this mother. She felt her son was functioning above his classmates in special education and wondered if her son could attend the same private school that her other son attended, since it had a smaller teacher to student ratio. Once the diagnosis was given, the mother mentioned that her husband would disagree with the autism diagnosis.

Appointment #3 included a Hispanic mother and son who related the story of meeting with a Women, Infants, and Children (WIC) (a federal program for low-income families whose children are at nutritional risk) professional who assumed the boy was already diagnosed with autism and made a comment about his disability. When the professional realized based on the mother's response that her son had not been diagnosed with a disability, the WIC professional backtracked and was embarrassed. The mother wanted to know why her son didn't talk and why, even after months in preschool, he still cried every day at drop off and pick up. Dr. Kohn explained the characteristics of autism. The mother had little to no knowledge of the disorder. The doctor further explained

how various services could help her child with interventions and other assistance, such as paying for diapers.

Appointment #4 shared some similarities with Appointment #3. Both families were Hispanic. In Appointment #3 the father was absent from the family. However, both the father for Appointment #3 and the husband/father for Appointment #4 did not believe there was anything “wrong” with their son. When the mother in Appointment #4 and her child had their first appointment, his father accompanied him. At the second appointment, the mother came without the father and said that her husband thought it was a waste of time and the boy would “grow out of it.” The mother also had similar concerns to the mother in Appointment #3 regarding school. She described extreme difficulty getting her son in and out of his car seat during pick up and drop off from school. The mother needed a teacher to assist her in getting her son into his car seat and buckled. She worried for her son’s safety. The mother also expressed such intense frustration with his behavior that, at times, she was scared she might hurt him. Dr. Kohn reassured her that many other parents have the same concerns at one time or another. He discussed her son’s hyperactivity and the possibility of medication when she was ready to explore it.

Appointment #5 included a Caucasian mother, father and toddler daughter. The parents were well-versed in ASD and the terms and treatments associated with it. They had tried the gluten-free casein-free diet for a few months and did not see a difference; in fact, they described seeing an increase in “stimming” (stereotypical behavior such as hand-flapping) since starting the diet. This

suggests the parents had done a lot of online research about ASD. They were already registered to participate in a parent training program at a local autism center when the mother went on maternity leave for their second child. The main concern was communication. The daughter spoke in an almost constant stream of gibberish with occasional echolalia, but the parents and others could not understand her. The daughter also seemed impervious to pain, which led her mother to worry that the child might break a bone and not even cry. Dr. Kohn described the trend in the 1990s of giving Secretin to children with ASD and how that treatment was debunked as a warning concerning biomedical interventions. He did not go into such detail about the way in which research measures effectiveness of treatments with every family. When the topic of the vaccine theory came up, the father said he could tell from infancy something was different and they knew she was “born with it.”

Appointment #6 included a Caucasian boy who came with his mother and father. The parents told the story of fighting with their local school district to get preschool special education services and, even after qualifying, the district officials told the parent that the child “wouldn’t always have an IEP.” Dr. Kohn acknowledged that he had past experiences with families from the same school district having difficulty getting services. The parents talked about how they divided the advocacy efforts between them; the father dealt with insurance claims and the mother handled school and outside therapies. They asked other mothers of children with ASD for advice. The parents appeared very grateful for recommendations and advice from Dr. Kohn. Similar to his conversation with the

parents in Appointment #5, Dr. Kohn gave a longer explanation about why he did not support biomedical interventions. The mother replied that she was also in the medical field and she agreed with him.

Appointment #7 had a unique and disturbing story. The Caucasian mother was bringing her younger daughter for diagnosis. Her older daughter had already been diagnosed with autism and was lower-functioning. The younger daughter was much higher-functioning and the mother suspected an emotional or behavior disorder rather than autism. The school teachers had noticed some bruising on one or both of this woman's children and brought both girls into the nurse's office where they were strip-searched because the teacher suspected abuse. All of this was done without notification or consent from the parent. The mother not only complained to the district, but she had the local news cover the story. Her children were clumsy and often had bruises due to motor coordination issues, and not because they were being abused. After the incident, the school district tried to "graduate" the younger daughter from special education, saying she had met all of her goals. The mother sought answers to the reason for her younger daughter's behavior as well as further assistance in dealing with a school district that had labeled her a "problem parent." Dr. Kohn explained how autism can look very different from one child to another, as this mother could see when comparing her two children.

Appointment #8 was an example of when children fall through the cracks of "the system." This Caucasian mother and her ten year old son had seen professionals, including Dr. Kohn, on and off for years. The boy received

treatment through the state's mental health system for attention deficit hyperactivity disorder (ADHD), but had undiagnosed Asperger Syndrome and depression. Dr. Kohn focused on these two health concerns but also discussed the problems dealing with the State's mental health system, which does not cover or treat autism. However, many of the medications used for treating symptoms of ASD are the same medications, such as antidepressants, antipsychotics, and stimulants that are used for mental health issues. Since the boy received his medication through the State mental health system, only their mental health psychiatrist (who did not have expertise in ASD) could prescribe his medication. Dr. Kohn, who does have expertise in ASD, could prescribe appropriate medications to treat ASD for this child but the State mental health system would not fill the prescription unless it comes from the psychiatrist in their own mental health system. The mother had been persistent in working her way through the various agencies, but felt she was not heard because she has had drug problems in the past, receives low income assistance, and lives in transitional housing. Dr. Kohn apologized for his part in letting her son fall through the cracks at a previous appointment and tried to use his position to help get the child the services and medications he needed.

Appointment #9 included an older boy, 12 years old, and his mother, who were both Caucasian. Like Appointment #1, the boy was very high-functioning and had the greatest difficulty with social interaction, rather than in academics. His school services were currently based on a 504 plan (part of the Rehabilitation Act instead of IDEA) and he was repeatedly suspended for fighting with students

and/or refusing to comply with teacher requests. He had extreme fine motor coordination problems and his resistance to teachers was often because he could not write fast enough to complete the assignments. When the teachers modified the work, they made it too easy rather than simply changing the mode of response to reduce the writing demand. The child was not getting occupational therapy to work on handwriting skills through the 504 plan. Just as the boy in Appointment #8 was lost in government programs' bureaucracy, this family was in the military and described the lack of developmental pediatricians on bases for military personnel to provide accurate diagnoses to children with some conditions. Although they had sought assessments and evaluation before, it was not until the child was 12 years old that they would start to get the services he needed.

Appointment #10 included an older couple with their young son. The father was incredibly nervous watching the son play on the stairs; he repeatedly flinched suggesting that he was worried the boy would fall and injure himself. A pediatric resident sat in on the appointment and played with the boy. Dr. Kohn tried to reassure the father that the resident would supervise the boy and not let him fall. Nonetheless, the father continued to flinch. The mother said, "I'm definitely not in denial." They were very happy with the preschool services and therapies the child was receiving and were trying to navigate their way through the red tape of State services. About two thirds of the way through the appointment, the boy grabbed Dr. Kohn's hand and tried to drag him to the door. Everyone laughed because the boy recognized who was "in charge" of the appointment and had the power to let them out.

The family in appointment #11 lived in the same school district that was problematic for the family in Appointment #6. The mother, father, and son, all Hispanic, told their story of the school district vacillating between labeling the child ASD and mentally retarded. Dr. Kohn explained the difference between the two diagnostic labels and talked at length about advocating for their son to be moved from the regular kindergarten class into a special education class where he can receive more beneficial services. Similar to Appointment #3, the parents had been told by a nurse's assistant and the school district representatives that their son might have autism, so they were looking for confirmation or more information from Dr. Kohn.

Appointment #12, the first appointment observed in Dr. Bayles' clinic, was a Hispanic mother and her son. The mother refused to continue vaccinations for her children. She also resisted Dr. Bayles' recommendation to return to the neurologist for seizure medication despite the fact that her son has had multiple seizures. Dr. Bayles stated that the boy would receive more services with an autism diagnosis but was actually more concerned that the seizures could lead to cognitive impairment if untreated.

Appointment #13 included a father who had emigrated from an African country and his young son. The son was in his pajamas and reportedly only ate stew at home, did not eat any other foods and did not eat anything at school. The boy would not allow his parents to brush his teeth regularly. The mother, who did not attend the appointment, was reported to struggle with depression. The father reported the son had severe pica, putting non-food items in his mouth constantly,

and sometimes swallowing them. Items included dirt and paper, and “everything.” The father wanted to know what kind of autism his son had, when he would learn to speak, and whether “when he start talking, other problems go away.”

Appointment #14 included a couple who emigrated from Singapore and their young son. At first, the little boy appeared afraid of the new adults who entered the room but eventually was willing to leave his parents’ arms to play near the pediatric residents on the floor. The parents had high expectations for their child’s behavior and were clearly embarrassed by the child’s tantrums in public. The mother said this was “not acceptable.” Dr. Bayles discussed how to ignore attention-seeking behavior. The parents also asked if they should constantly work with their child when he is awake to ensure he does not fall into the repetitive patterns he likes such as continuously walking around the dining room table. Dr. Bayles described ABA therapy and special education preschool services that would help him become engaged and learn to be more social.

Typical Appointment

Opening. Dr. Kohn began each appointment by asking the parents, “How can I be most helpful?” The parents’ answers to this question varied. Some parents appeared surprised to be asked and were silent or said, “No idea to be honest” (Father, Appointment #11). Other parents referred to wanting more information about their child to explain certain behaviors. “What is up with him? Is it lifelong? What is it? How can I help him?” (Mother, Appointment #3) “Why her behaviors happen, to get her on a typical track” (Mother, Appointment #7). These parents did not appear to know that their child had autism yet, while other

parents were seeking confirmation based on another person mentioning it (professional, family member, or friend) or from the first appointment with the nurse, for example, “(long pause) Mother: last time said we’re looking at autism & sensory processing disorder. The spectrum is huge so are we saying mild...” (Mother, Appointment #5).

Other parents answered Dr. Kohn’s question not by referring to a diagnosis itself, but rather by asking about school placement which would be an outcome of the diagnosis. “Where will he go to kindergarten one year from now?” (Mother, Appointment #2) “At the IEP meeting, the district said he wouldn’t always have an IEP, pushed regular ed” (Father, Appointment #6). One parent bluntly stated, “We need a diagnosis of autism. I know he has it. He has all the features, rocking, hand things, gets frustrated, and can’t talk” (Mother, Appointment #10). These varied responses suggest that the parents came to this appointment with different perspectives and expectations. Some parents did not know that the doctor would be giving a diagnosis or what that would mean, while others went straight to how the diagnosis affects the child’s life in school or access to services. In general, it seemed that some parents knew that the discussion would include autism, while others did not.

The decision to start every appointment with this question suggests that the doctor did not see himself as an expert controlling the appointment who is there to tell the parents what to do but rather as more of an equal partner who is there to assist the family with their individual needs. With that said, no matter what parents’ answers were to this opening question, the format of the

appointment did not change. This suggests that the purpose of the question was to use something in the parent's response to guide the conversation where Dr. Kohn wanted it to go. Dr. Bayles did not start each appointment with the same question, but instead explained that she would be typing as they spoke so that they would leave with the final report to give to service providers, etc. Dr. Bayles' system focuses on getting the diagnosis, and the doctor's report quickly to assist in initiating services. Dr. Kohn's office sends the written report to the families approximately two weeks after the second appointment. When asked about the system, Dr. Kohn said he has run his clinic this way for a long time and he is happy with it.

Reviewing questionnaires. After this initial question Dr. Kohn reviewed the questionnaires that the parents and the child's teacher completed. He described the results of the questionnaires as having been compiled into lists and compared to a large number of boys or girls the child's age. The doctor pointed out where the child's score was elevated in terms of percentile rank. The doctor typically stated and then defined technical terms such as "somatic complaints" and mentioned when a category can be misleading, such as "depression" when the behaviors can be attributed to the social impairment of autism rather than childhood depression. Dr. Bayles did not review scores on subscales within questionnaires in the same manner that Dr. Kohn did, but discussed the overall score and explained what range those scores placed the child in. Again, Mehan's (1993) suggestion that doctors establish the power hierarchy by using technical terms without clarification was not supported by the data collected in either

clinical setting in this study. The doctors did not wait for parents to ask what terms meant but immediately defined terms. If parents asked about certain terms, both doctors responded by rewording it in lay language.

Themes of Diagnostic Statements

To provide a thick description of the conversation that occurred in the diagnostic results appointments, the field notes were analyzed using codes from previous literature as well as allowing new themes to emerge. Combined with the case descriptions, this descriptions helps describe what is happening today when parents obtain an autism diagnosis for their child, which can then be compared to parents' experiences in the past, addressing the first research question of this study.

Explicating the evidence. Explicating the evidence is when, “Doctors present their descriptions as reasons for, or evidence of, their diagnostic conclusions” (Peräkylä, 2006, p. 221). Each time the doctor pointed out a category in which the child’s score was elevated (meaning in the clinical range) was coded as “explicating the evidence” or “implicit evidence,” depending on the wording used, thus building up to a diagnostic statement.

Examples of “explicating the evidence” included specific behaviors that were outside the norm on the questionnaires and the overall ratings on autism specific questionnaires. Some examples included referring to subscales within questionnaires and used percentiles to differentiate between the child and typical children his or her age. All of the following examples were said by the doctors. “Withdrawn behaviors are more different than 90% of girls her age”

(Appointment #1). Another example used one of the three areas of impairment in the DSM criteria. “In the spectrum the core challenge is social relatedness. Seems to be one of her greatest challenges. We’re in the right ballpark when we describe [child]” (Appointment #1). Other times rather than using an item, subscale, or score from the questionnaires, the doctor used behaviors the child demonstrated in the appointment as evidence. “When I came into the room he wasn’t interested in me. Going around entertaining himself, not crying, not interested in the other people here” (Appointment #4).

There were multiple examples of both doctors using the summed scores from the autism diagnostic questionnaires as evidence.

- “Your description on the GARS scores as very likely for autism” (Appointment #3)
- “The questionnaire to document three areas of autism. Your description puts her in the very likely range, not a surprise” (Appointment #5).
- “Autism questionnaire. Yours said very likely category, teacher slightly less but behaviors she described matched autism; I can see no other explanation for those behaviors” (Appointment #8).
- “Asperger questionnaire put him in high likely category” (Appointment #9).
- “OK your answers on the questionnaire on autism. Your description put him in possibly autistic range. But when I look at the behavior marked “sometimes true” it is very hard to come up with another explanation that would explain those behaviors” (Appointment #11).

- “He has enough criteria to meet the diagnosis of autism, mild to moderate range” (Appointment #12).
- “Last time we scored the autism screening questionnaire and he was at risk for autism. We scored this (GARS) it was 109 and anything over 85 is a likely probability for autism” (Appointment #13).
- “Let’s go through the DSM criteria see how many of the 12 he meets. He only needs six...He meets all 12 criteria for autism. Severely autistic range. Which does not mean he can’t learn. He needs intense therapy” (Appointment #13).
- “If we look at the four areas he has them all. If I score the CARS he’s in the moderate autism range” (Appointment #14).

All of these examples of explicating the evidence use the criteria built into standardized, normed diagnostic questionnaires to determine the diagnosis, rather than the statement being phrased as an opinion of the doctor. By referring to scores on questionnaires, even a single item or a subscale score, rather than on an impression the doctor got from his or her brief time with the child, the diagnostic statements appear more scientific, supported by evidence, therefore more valid and harder to question. It is as if the scores are diagnosing the child, not the doctor.

Inexplicit evidence. Inexplicit references to the evidence point to the source of the diagnosis using “evidential” verbs for example, “to appear,” “to seem,” or “to feel” to allude to sensory evidence upon which conclusions are

based. Statements that were coded as “inexplicit evidence” had wording that sounded less definitive. Examples the doctor said include:

- “Summary scale possibly in spectrum, there are certainly behaviors in kids on spectrum, so we’re seeing as possible, the teacher’s response matches your experience” (Appointment #1).
- “The behaviors certainly raise concerns about autism” (Appointment #3).
- “More frequently girls look different, identified later, present differently. I’m thinking autism. Prepared as you may have been you didn’t want her to fall on autism spectrum

Mother: yeah

Dr: no one wants to say that. I’m hesitating; I want to have a discussion with other people” (Appointment #7).

These statements by Dr. Kohn are less definitive, using words like “possibly,” “raise concerns,” and “I’m thinking autism” in contrast to the definitive statements that put the onus on the scores from the questionnaires.. Dr. Bayles did not have any statements that were coded as inexplicit evidence in the three appointments observed. This suggests that explicating the evidence, inexplicit evidence, and plain assertions vary by personality type of the doctor as well.

Plain assertions. Plain assertions are direct descriptions of reality said in an unproblematic, taken-for-granted manner. No verbal descriptions of the reasons or the grounds for the diagnosis are given. Plain assertions might come at the end of an examination, establishing an “inferential link” between the examination and the diagnosis. This is used when “relevant events in the

examination are transparent to a lay participant” (Peräkylä, 2006, p. 218). During each appointment observed, the diagnostic statement of autism spectrum disorder was stated multiple times in a variety of ways. These plain assertions that the child “met the criteria for autistic disorder” almost always came after statements of evidence within the presentation of the questionnaire results. In the example introduced earlier, after the mother said, “he has all the features, rocking, hand things, gets frustrated, can’t talk,” the doctor replied, “He has all the features. You know autism is not [child’s name] and [child’s name] is not autism” (Appointment #10). In this case, the doctor used the evidence presented by the mother for this first diagnostic statement. These statements were often the first time that the doctor in effect stated, “your child has autism.”

Examples of “Plain assertions” stated by the doctors included a number of comments, including the following:

- “I do believe he meets the criteria for autism” (Appointment #2)
- After reviewing the scores on the questionnaires, “Doctor: let me show you this stuff (handouts). With understanding [child] is in the spectrum, parts of the federal government involved in autism including the Center for Disease Control.

Mother: back up are you leaning towards PDD?

Dr: autism, high-functioning.

Mother: what makes you think that?

Dr: (explains numbers difference) even autism is itself a spectrum. There may be more than one autism, overlapping conditions, genetics, can't find one gene, so many different characteristics

Mother: gotcha" (Appointment #2).

- "I think [child]'s challenges more consistent with Asperger Syndrome.

Look at it in a more systematic way, came out consistent with that diagnosis" (Appointment #9).

Plain assertions were very direct and definitive. They were often followed by references to services, linking diagnosis to qualifying for those services. Dr. Bayles did not make any plain assertions during the three appointments observed. All of her diagnostic statements were in the context of the child's scores or number of DSM criteria met. This again suggests a style or personality difference, Dr. Kohn used explicating the evidence statements, inexplicit evidence, and plain assertions while Dr. Bayles only used explicating the evidence statements.

Another idea to be explored in a future study is whether female doctors feel the need to support their diagnoses and recommendations with evidence because they are not perceived to have the same authority as male doctors. Just as the parents' answers to the initial question of "how can I be most helpful?" varied, Dr. Kohn's plain assertions were made in different ways. Sometimes they were given immediately after explicating evidence, while other times they were connected specifically to issues of school placement or qualifying for services.

During Appointment #4 with a Hispanic mother and son, Dr. Kohn used three different plain assertions. Before going through the questionnaires, after the

mother explained that her son's teacher suggested she get him evaluated Dr. Kohn said:

The behaviors you described in the questionnaires are very consistent with diagnosis of autism. I do think [child] has autistic disorder. No doctor wants to say that, no parent wants to hear, but better to hear sooner than later. Like the teacher says this might not be best classroom.”

(Appointment #4)

After reviewing the scores on the questionnaires before introducing the handouts Dr. Kohn stated, “When I looked at the behavior tells me most appropriate diagnosis is autism and hyperactivity. His school should recognize this and they should find a better class for him” (Appointment #4). And at the conclusion of the appointment Dr. Kohn reiterated, “He does have autism and some disruptive behavior interfering with learning. I will write a report for DDD, ALTCS, SSI, and school. May benefit from a change in preschool placement, consider meds, your decision” (Appointment #4). It is unclear why this appointment had three plain assertions when others only had one. Perhaps Dr. Kohn was concerned about whether the mother understood the diagnosis. She asked Dr. Kohn during the appointment about “polar” (bipolar), which she had heard about and thought described her son.

Arbitrary criteria. Dr. Kohn also referred to the DSM of the American Psychological Association as “a book of lists that psychologists make up to explain the world.” Dr. Kohn referred to the artificiality of these criteria more

than once, suggesting a negotiation between the medical model and social construction of disability. Examples included:

- “There’s a question if she met criteria on the bookkeeping approach to diagnosis” (Appointment #1).
- “Does meet criteria for autistic disorder but it’s a bookkeeping thing, no one wants to hear that or give that info” (Appointment #2).
- “Based on inefficient way to count the symptoms [child] also seems to have many characteristics” (Appointment #7).

These three statements suggest that the diagnosis is about meeting certain criteria, checking off boxes, or having the correct numbers, rather than being true or perhaps the best way to diagnose. The use of the word “inefficient” is interesting. This could suggest that a blood test would be better, or that there could be a different observational method that might be “efficient.”

Just as Dr. Kohn always started each appointment with the same question, he also repeatedly used the phrase “autism is not [child’s name] and [child’s name] is not autism” in each appointment. This speaks to the locus of the disability. The literature suggests that doctors follow the medical model of disability and locate the disability within the child. This doctor is suggesting that the label is just one way to describe a portion of the child and is not necessarily located within the child. Statements regarding this trend included:

- “Other important thing for me to say. These labels don’t describe all of [child]. Describe some of challenges and strengths, not all of him. Autism

isn't [child], [child] isn't autism. If a label describes parts of him we take that, discard other aspects. We are treating your child" (Appointment #11).

- "Purely clinical behavioral diagnosis, written for what we see behavior at three years of age. Some behaviors might not be true for him now (10 years old) but still could be autism. Based on questionnaires I think that is the best to describe him. [child] is not autism, just describe him. He probably meets criteria but might slip out of some" (Appointment #8).
- "Autism doesn't define him but he still has autism" (Appointment #3)
- "Every child is different [child] is [child], [child] is not autism. We learn about some of her challenges through lens of autism" (Appointment #5).

A pattern emerged in terms of referring to the criteria as "bookkeeping" and that the label of autism does not equate to the entirety of the child, just describes aspects. When I interviewed Dr. Kohn after completing data collection, I asked him about the phrase "autism is not child, child is not autism, child is child" and what messages he tries to convey during these appointments. He answered,

Diagnosis is not the end of the road but the beginning. In the Temple Grandin movie, the phrase 'different but not less' resonated with me...I give the parents an article about her called *The Greatness of Autism*. The message is aim high, don't aim low. No one can predict, not everyone gets the full benefit from therapy (Dr. Kohn, interview).

These two frequently spoken statements suggest that the doctor leans toward the social construction of disability in which society sees certain behaviors or clusters of behaviors as outside of the norm and discriminates against certain

people as a result. The doctor might still believe the medical model concept that something is “wrong” with the child and interventions should be used to “treat” or “fix” it, but there appears to be at least a negotiation of the social construction and the medical model occurring in his approach. This negotiation is teased out further in the discussion of the purpose of diagnosis.

Purpose of diagnosis. Another theme that emerged from the negotiation between medical model and social construction is the purpose of diagnosis. The connection between the purpose of the appointment and obtaining services in school or from the State was frequently made. Both Dr. Kohn and Dr. Bayles made links between obtaining a diagnosis and qualifying for services.

Examples of the doctor linking diagnosis to services (definitions of acryonyms follow):

- “Having said this, heard it before, no physician wants to say this; no parent wants to hear this. But if that description is the best description of [child] we go through the process to get services. Hard to hear. Best opportunity to get the most help for [child]” (Appointment #11).
- “So in this biological difference you described enough to say it describes some of his difficulty. See behaviors similar to children with autism. Use the description to get most appropriate kinds of help. Different from help for a child with just language problems, just cognitive impairment. To access services that’s the description I would use. If you don’t want that description to go anywhere else, not shared with school, evaluation just for you. I recommend you do” (Appointment #11).

- “Our next steps are to finish writing things up. We’ll get you the autism packet of info to help you understand autism to help him get services. I’ll finish typing the report; you can use it to get services” (Appointment #13).
- “I will write the report. He will qualify for services. First, DDD. I’m surprised no one at school told you about it. Second, SSDI, which is additional financial support, but they’ll need school questionnaires. The other thing you’re eligible for is diapers
 Mother: diapers?
 Dr: Yes. I’m sure you spend a lot of money on diapers. First go through DDD. As soon as we make the report send it to DDD. He should get one year’s worth of diapers. I will write a script” (Appointment #3).
- “SSI from social security gives additional financial help to parents of kids with disabilities. Two levels of eligibility. I don’t know enough about your family but diagnosis of autism is eligible. I’ll write all this down for you, share report with them” (Appointment #4).
- “Even though high functioning on the spectrum, as she gets older there are few differences between high functioning autism and Asperger Syndrome. In these State laws she is eligible for more services with a diagnosis of autism but that’s not the only reason. Because she’s so high functioning she’s not going to qualify through DDD but may qualify through insurance” (Appointment #1).
- When the mother mentioned a specific local autism center, Dr. Kohn asked, “Did you find anything helpful?”

Mother: gave me a paper helped us qualify for social security benefits but I don't know what to do with them! I want parenting classes.

Dr: I'm the only doctor in this group, we don't have the resources to meet with families more than every 3-6 months but many of this responsibility falls on parents. We hope this will help you find resources. I'm not going to tell you what you must do. Will give you options, every child is different, you know your child best.

Mother: ok" (Appointment #8).

- "Third area is school, whether school is providing level of help. Are they helping him by this eligibility category autism?"

Mother: that's where he was under until last year, wouldn't do an IEP so 504 for ADHD

Dr: we can decide what's most important yes he has ADHD and he has Asperger Syndrome. An IEP doesn't mean he needs to be in special class" (Appointment #9).

These examples refer to both the State services, including the Department of Economic Security Division of Developmental Disabilities (DDD) and Supplemental Security Income or Social Security Disability Income (SSI or SSDI), and educational services in the form of special education (as indicated by an individualized education plan or IEP) versus a 504 plan, which is viewed as accommodations under an anti-discrimination law instead of special education services based on a diagnosis of disability. Dr. Kohn and Dr. Bayles provided parents with multiple articles and web site print outs about these services during

the appointments. The third area referred to in these discussions and the handouts was the new law passed in the State that requires medical insurance companies to cover Applied Behavior Analysis therapy for children with autism (Stephen's law). This is a third way in which children can receive services. The criteria for all three (state services, school services, and insurance coverage) are different and as mentioned in these quotes, result in some higher functioning children falling through the cracks because they qualify for some but not all services.

Both doctors were very direct when explaining how to respond to questions from State agencies about the child's functioning level. The following examples are from Dr. Bayles and all occurred towards the end of the appointment:

- “He has enough criteria to meet the diagnosis of autism, mild to moderate range. With that said I have more concerns about intellectual disabilities. I am going to give him a diagnosis of autism because in the State of Arizona it gets you more services” (Appointment #12).
- “Father: what is a part of autism he has? Any specific name? Because autism is broad.
Doctor: Good question. In Arizona we don't use a specific name to get services, we use autism. He has full autism but with intense intervention he can move on the spectrum. With proper treatment I have two patients who are now in college” (Appointment #13).
- “Mother: I read about high functioning autism. What does that mean? You said moderate.

Doctor: When he's older we can assess IQ and when he's using language. We don't say high functioning autism to State people. They want to deny services and save the state money. So don't say great things about him to state people. Research shows individuals who get ABA intensive therapy can increase their IQ by 25 points, can be mainstreamed in school, and be more independent" (Appointment #14).

Dr. Kohn also said to parents when he showed them the handout with the questionnaire used by the State to determine eligibility that it was not time to celebrate successes. Both doctors stressed that parents should be honest, but it is not a "glass half full moment" but more a "glass half empty moment" in terms of how the child's functioning should be described.

Interestingly, none of the discussions about the purpose of diagnosis included the use of specific language around autism as identity. The Aspies community, which follows a pure social construction view of Asperger Syndrome, considers their symptoms of Asperger Syndrome to be an identity in much the same way that members of the Deaf community views Deafness as a cultural identity. The absence of this perspective demonstrates that the doctor is not completely socially constructing autism in his mind but is negotiating between the medical model and social construction.

When I asked Dr. Kohn in the interview what he thought the purpose of diagnosis is, he replied that the "labeling process for the condition is not the whole description of the child. It is opening a pathway to services." He added that he feels parents need to understand their child's behavior to free up brain power

for other things, such as accessing services. When Dr. Bayles was asked the same question she replied, “to get services.”

Other people’s opinions. Another theme that emerged from the participants in Dr. Kohn’s practice was denial on the part of the fathers. Three of the mothers who came alone to the appointment reported that their child’s father did not believe that anything was “wrong” with their child and/or that the process of evaluation by Dr. Kohn was “a waste of time.” One husband who accompanied his wife to the appointment admitted that he “was in denial” at first. Another couple reported that the father’s siblings, who lived out of town and had rarely seen the child in person, did not believe the parents’ reports that there was something “wrong” with the child and blamed the child’s behavior on bad parenting. The number of fathers in disagreement with the mother’s suspicion that something was “not right with the child” warrants future exploration in another study.

In the earlier interview data, many mothers shared similar stories in which another adult commented to her about her child’s development. In most cases, it was the mother of another child in a play group. Since the data for these appointments was constructed through observation and not interview, this question could not be asked of the participants during their appointment. However, a few of the participants shared that a professional (e.g., a nurse, social worker or teacher) mentioned that the child might have autism or made the assumption that the child had already been diagnosed with autism. In one case, when the professional realized she was the first person to say the word “autism”

to the parent, she backtracked. One participant relayed the story of seeing a neurologist for her child's seizures and the neurologist's assistant suggested the child had autism. As with the interviewed mothers, these parents were upset and confused by a non-diagnostician professional saying their child has autism before the child was diagnosed.

This scenario in which a professional whose credentials do not qualify him or her to give a diagnosis says something to a parent before the diagnostician does has been found in the literature on Down Syndrome (Skotko, 2005). There are stories of candy strippers and nurses reading the mother's chart in the hospital after delivery and making a comment to the mother about the baby's diagnosis of Down syndrome before the doctor has told the mother. While it is a positive change over time that non-physician professionals are more aware of the characteristics of ASD it is unprofessional for teachers, nurses, social workers, etc. to seem to "diagnose" a child.

Media. Another theme that was present in the interview data was referring to autism as represented in the media. The participants mentioned a number of different times when autism appeared in the media during the appointments. One reference was made to the film *Rain Man* (Johnson & Levinson, 1988).

“Dr: mild to moderate autism, clearly high-functioning, not like in a movie

Mother: not like Rain Man” (Appointment #8).

Dr. Kohn includes an article called *The Greatness of Autism* that includes information about Temple Grandin. Since the HBO movie (Saines & Jackson, 2010) about her life came out the same year these appointments occurred, several

of the parents saw the name and mentioned hearing about or seeing the movie. Dr. Kohn also frequently mentioned the actress Jenny McCarthy, who published a book on how she used biomedical treatments to “cure” her son who has autism and spoke about vaccines on the *Oprah Winfrey Show* (Winfrey, 2007). The reference to Ms. McCarthy usually follows Dr. Kohn’s introduction to the handout titled *The Great Autism Rip-off*, discussing treatments that have no scientific basis and are quite costly. A few of the parents acknowledged having heard of Jenny McCarthy in connection with autism treatment, but had not looked into it yet. Due to the frequent mentions of the Temple Grandin film and Ms. McCarthy, these two media portrayals of autism were included in the media analysis for this study (see Chapter 5). In the three appointments observed with Dr. Bayles, there were no mentions of media portrayals or reporting on autism.

Summary of Findings

The major finding of the observation of appointments in which the diagnosis of autism is given was that not only did parents negotiate between the medical and social construction models of disability but the diagnostician negotiated the models as well. The diagnosis was framed as necessary to access services and the criteria used to determine the diagnosis could be viewed as arbitrary. Statements used by the doctor during the appointment were categorized as explicating the evidence, inexplicit evidence, or plain assertions. Each of these kinds of statements could be used to give the diagnosis in a way that allowed for parents to question the diagnosis (e.g., inexplicit evidence) or present the diagnosis as fact (explicating the evidence, plain assertions). Doctors varied in

their use of these statements depending on personal style. Parents came to the appointment with a variety of expectations and perspectives. Some anticipated the autism diagnosis, others did not. Some parents arrived wanting advice and assistance in advocating for services or educational placement; others wanted answers to why the child behaved in a certain way.

In the final chapter, each data source will be analyzed using the two models of disability. The data will also be analyzed using Bronfenbrenner (1977) and Engeström's (1998) theories to conceptualize how these different aspects of the diagnostic process fit together. Future studies, parameters of the current study, and a researcher reflection are also included.

Chapter 7

Discussion and Implications

In this chapter data from interviews with mothers whose children were diagnosed between 1974 and 2004, the observations of appointments with two developmental pediatricians, and the popular media analysis are examined using Bronfenbrenner (1977) and Engeström's (1998) theories as well as creating meta-inferences about the data across the historical eras of autism and the models of disability used to analyze the data. Implications for future research, parameters of the study, and a researcher reflection are included.

Bronfenbrenner's Framework

This study examined the process of obtaining an autism diagnosis from multiple stakeholder perspectives, using multiple sources of data, and examining changes across time. Using Bronfenbrenner's (1977) framework to illustrate the nested quality to the experiences of families seeking an autism diagnosis, this study creates a more expansive picture than other studies on this topic have done in the past (see Figure 3).

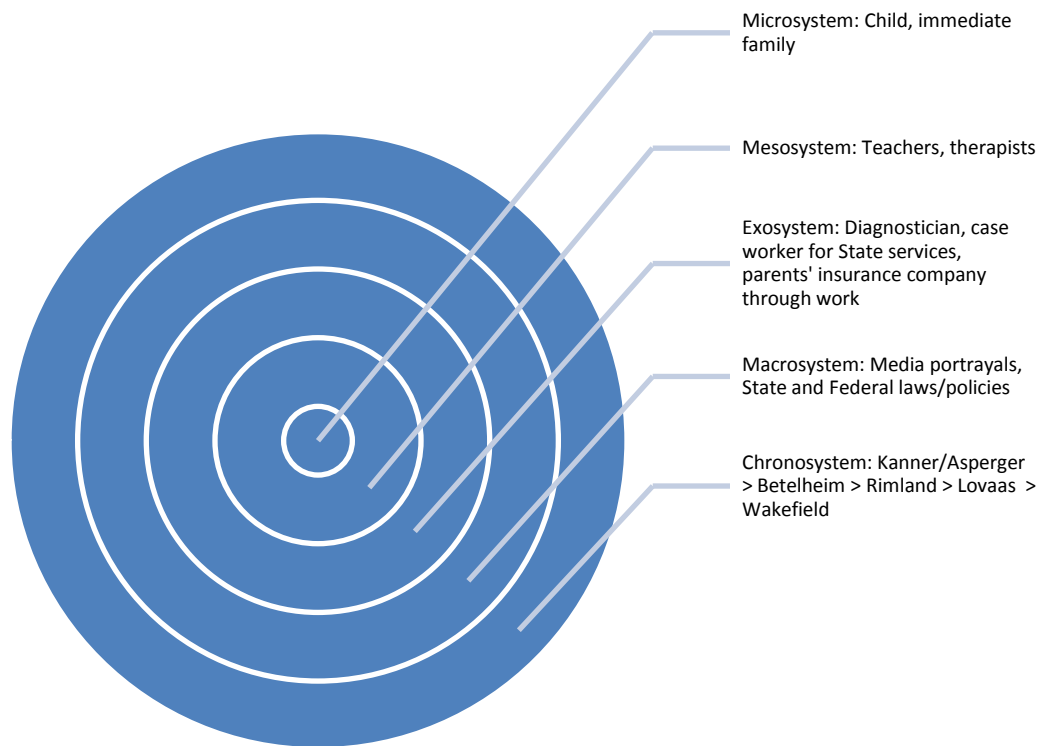


Figure 3. A diagram that depicts the main components of Bronfenbrenner's theoretical framework.

Microsystem and mesosystem. The microsystem consists of the child with an ASD and his or her parents who are seeking the diagnosis. The mesosystem consists of the child's current teachers and therapists during the time that the parents are seeking diagnosis. If the child is not currently receiving any services for developmental delays, the teachers could be from a daycare or private preschool. If the child has started services for developmental delays, the teacher could be early interventionists from the state, a school district preschool special education teacher, or a therapist provided by State services or medical insurance coverage. These are professionals that have weekly if not daily contact with the child and family.

Exosystem. The exosystem includes professionals that the family sees less often but are gateways to services. This includes the family pediatrician, the diagnostician (in this study, developmental pediatricians), the State services case manager, and the contact person at the parents' health insurance provider. These professionals do not provide direct intervention but are often required to refer or generate paperwork to initiate the process.

Engeström's framework. When the mothers interviewed described having an instinctive feeling that their child was not developing normally, this began a series of movements between institutions (educational, medical, state) and professionals that lend themselves to Engeström's (1998) visualization of triangles (see Figure 4). A mother might feel something is "wrong" but has no idea how to proceed. A friend or a professional working with the child may make a comment that further increases the mother's concern. She may start by asking her family pediatrician about these concerns. Whether the pediatrician provides a referral to educational, state, or medical diagnostic services or dismisses the mother's concerns, the data in this study shows that the parents then begin a process of bouncing between these agencies and professionals to seek their child's evaluation, diagnosis, qualification, enrollment, and initiation of services. Regardless of which agency or professional initiates the diagnostic process, the parents must still make contact with multiple services because they are all interdependent. The diagnostic report from the developmental pediatrician can qualify the child for state services and interventions covered by health insurance. The school district can evaluate and qualify a child for special education services

but the school still needs a medical diagnosis to place the child in the ASD category. Each of these services must be revisited periodically to determine if the child continues to qualify. Those efforts can ultimately result in the need to complete the circle with a return visit to the developmental pediatrician.

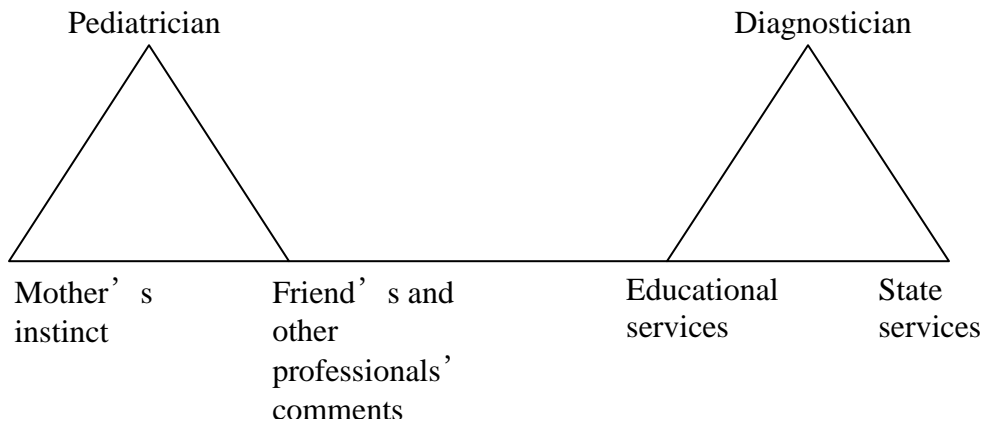


Figure 4. A diagram that depicts the main components of Engeström's framework.

Bronfenbrenner's (1977) visualization of concentric circles, described in 1985 as "nested systems" by Sally Lubeck, illustrates what is involved in the process of obtaining a diagnosis of autism for a child. Engeström's (1998) visualization represents the bureaucracy of the exosystem and the obstacles parents encounter in their desire for their child to receive services. According to the developmental pediatricians included in this study, that is the primary purpose of seeking an official medical diagnosis. Both are helpful to illustrate the complexity of the exosystem nested in the world in which families of children with ASD exist and the disjointed yet interdependent nature of the services provided to children with the diagnosis.

Macrosystem. The macrosystem represents policies and public knowledge. In the world of autism diagnosis and services, the relevant policies include special education resources provided by the IDEA at the federal level, State policies for monetary subsidies and therapeutic interventions, and State laws regarding health insurance coverage for behavioral interventions. Popular media in the form of newsmagazines, local television news, newspaper articles, television shows, films, and books contributes to public awareness and knowledge of autism, and that, in turn, can affect policy. If the mother has heard about autism through popular media, her initial concern about her child's development may be based upon her media-shaped concept of the condition, leading her to seek an expert opinion from a medical professional.

Chronosystem. Finally, the chronosystem represents the history of autism. The works of Kanner (1943), Asperger (1944/1991), Bettelheim (1959), Rimland (1964), Lovaas (1987), Biklen, Wakefield, McCarthy, and Grandin have made an impact on families receiving the diagnosis in the past and continue to influence families receiving the diagnosis today. Although some of the past theories and forms of intervention are no longer used, professionals in the autism field retain that history and elements of the past can linger in the diagnoses of the present. Dr. Kohn specifically described autism as biologically based in his appointments. Reading between the lines, he contradicted the previous theory of autism as an emotional disturbance. So even in appointments that took place in 2010, Bettelheim's effect on the field is still felt. Further examples were found across the data collected for this study.

The chronosystem is represented in the interview, observation, and media data in this study through references to the eras of autism history. The interviews with Betsy, whose son was diagnosed in 1977, mentioned being told by a child psychiatrist about the Bettelheim (1959) theory of autism being caused by the “refrigerator mother,” thirteen years after Rimland’s (1964) book was published refuting the theory with the implication that she might be the cause of her son’s condition. The mothers whose children were diagnosed before (Emma in 1983) and after (Lisa in 1989) Lovaas’s seminal study was published in 1987 were not blamed for their child’s autism, demonstrating the effect of Rimland’s theory (published in 1964) that autism has a neurological basis, but those mothers were not given any hope for a treatment or cure, a notion that was introduced when the results of Lovaas’ work became known to the general public. Rosa remembered seeing headlines about the link between autism and vaccines when her son was diagnosed in 2004. Dr. Kohn referred to Ms. McCarthy and Ms. Grandin in each of his appointments. These mothers’ stories that are contained within the larger context of the history of autism demonstrate the delay between the medical/research professionals changing their thinking about autism and the families feeling the impact of those changes.

Summary. This study included interviews with mothers whose children were diagnosed in the past and offers both the microsystem perspective and the chronosystem perspective by describing how the process worked in the past. The inclusion of observations of developmental pediatricians giving the diagnosis in 2010 incorporates the exosystem and reveals themes regarding the use of

diagnosis in order to access the services provided by the policies in the macrosystem. The media analysis of specific significant works mentioned by participants also represents the macrosystem. By representing these different aspects, which are nested, and acknowledging the influence the different systems have on each other, this study creates a more expansive picture of autism diagnosis than studies that look at one perspective at one moment in time and using one data source.

Specific Changes Across Time

One of the greatest differences between the appointments described by mothers in the interviews and the appointments that were observed in 2010 was the nature of autism information and resource handouts. Some of the mothers interviewed about diagnoses made between 1974 and 2004 said the diagnostician did not give them handouts or packets of information or told them how they could use the diagnostic report to help their child qualify for services. The diagnostic reports provided by a subset of the mothers interviewed did mention services for which their child could qualify. When mothers were asked what they would recommend diagnosticians do in future appointments, the most common response was to give parents more information.

In contrast, the two developmental pediatricians observed in 2010 both gave parents thick packets of information covering a large array of topics in the field of autism. Articles included theories on the cause of autism as well as evidence for and against different treatments and interventions; a variety of appropriate local services and how to qualify; local organizations that can provide

support, advocacy, and other resources; stories of successful adults with ASD; and material about the legal rights of parents in the public education system. Both doctors also included suggestions on how to pursue additional information and resources including the organization Autism Speaks, which provides a packet titled “The First 100 Days.” This packet guides families through the first 100 days after receiving the diagnosis. There was also information about the hospital resource library, which includes books, videos and other resources parents can borrow and then return to their local library.

While the Engeström (1998) triangles illustrate how parents still must pursue multiple professionals to initiate and maintain services for their child, the number of professionals parents must find to obtain an accurate autism diagnosis has decreased over time (see Table 3 in Chapter 4). It would benefit the parents and the child to develop a system in which professionals who first see the child quickly refer them to a diagnostician with expertise in ASD. This way, the parents and child can be evaluated by the appropriate professional, receive an accurate diagnosis, and begin the process of obtaining services. Some families may choose to seek second or even third opinions, but today’s medical professionals know enough about ASD to make it less likely that they will misdiagnose these children as deaf, electively mute, schizophrenic, mentally retarded, or having attention deficit disorder.

Models of Disability

Both the medical model of disability and the social construction of disability were represented in the data analyzed for this study. The negotiation

between the two models of disability was also evident in parents, professionals, and fictional characters in media portrayals.

Interviews. Catherine said that her family did not believe her when she expressed her initial concerns about her daughter because she “looked so normal.” One of the families observed in Dr. Kohn’s office also mentioned that family members who reside out-of-state did not believe them when they described their child’s developmental differences. Betsy described feeling insecure about her concerns about her son’s development because this was her first child and she didn’t have knowledge of what typical development looked like. Emma remembers the mother and baby with whom she shared a room when she gave birth to her son; she immediately noticed the differences between the babies. Her son cried constantly while the other baby lay serenely quiet on his mother’s chest.

This suggests that the mothers’ perception was based on the medical model in that a normal ideal exists and can be used for comparison. These reports also highlight the fact that children with autism do not display physical differences to indicate a disability as happens in Down Syndrome or cerebral palsy. Since Kelly’s son had complications during birth, medical professionals told Kelly, “Don’t compare” him to other children’s development when he was delayed in learning to walk. This acknowledgement of different developmental trajectories could be interpreted as a social construction of developmental delay.

Once Catherine joined the Autism Society of America and met other parents of children with ASD, she felt “reassured.” It was unclear whether this reassurance was the beginning of a negotiation of a social construction of autism

into Catherine's personal model of disability. For other mothers, they saw their children in a different light. "Sometimes you just have to look at your child and see your child," Rosa said. After receiving the diagnosis, Kelly said, "Whatever they are, they are." These two quotes speak more to the social construction of disability because the mothers knew that the label is not the child. A few of the mothers mentioned one of their first thoughts upon hearing the diagnosis of autism was to wonder how autism would impact their child's adult life. If part of this concern was whether their child's life would be more difficult because society discriminates against people with disabilities for being different, this is an example of social construction.

Observations. The doctors observed in this study used the DSM criteria and various standardized questionnaires to make note of ways in which the child differed from the majority of children his or her age and gender in specific areas of development that are markers for autism. These diagnostic tools, the assumptions of the standardized questionnaires, and the interpretation of their scores, follow the medical model.

Dr. Kohn frequently referred to the DSM criteria as "bookkeeping," suggesting that he used the medical model tools to provide a diagnosis in order to get the child services. The idea that the child needs services or intervention at all suggests reference to the medical model in which something is wrong that must be fixed. Dr. Kohn's idea that these criteria are arbitrary, along with statements that suggest that autism only describes "part of [child's name]," suggest that in some ways the doctors also subscribed to the social construction model of

disability. They used their power in the medical institution to “create” a disability by labeling a child for the sole purpose of getting access to intervention services.

The amount and type of intervention that will be accessed appeared to be up to the family. The doctors did not force the family to do anything with the diagnosis. Dr. Kohn explicitly said to one couple, “This does not have to go anywhere,” but he strongly suggested the family show his report to the child’s teachers and other service providers. This statement, along with Dr. Kohn asking families how he can be most helpful, suggests that he did not fully subscribe to the idea that the doctor is the expert and the families must recognize his authority. The lack of pressure for parents to follow the medical model demonstrates how the doctors negotiated aspects of the social construction into their practice and allowed the parents to create their own individual negotiation of the two models of disability.

Another view of the negotiation between the medical model and social construction of disability by doctors is not that it is a “negotiation,” which suggests finding a happy medium, but instead that it is a tension between the two models in which the doctors found themselves trying to deliver two different messages to the parents. The doctors saw the benefits of interventions for children on the autism spectrum and wanted to use their ability to diagnose to help get the child access to these interventions. At the same time, they also wanted to reassure parents that they still have the same child they brought to the appointment. The tone of the relationship between the two models, negotiation or tension, is unclear and would require more in-depth study of a larger number of diagnosticians.

Handouts. Dr. Kohn's packet of handouts for parents who are receiving the diagnosis of ASD for their child includes an article called *The Greatness of Autism*, which includes interviews with many adults with autism who are able to speak about their experience. This article is the only one in the sizable packet that represents the social construction of disability in which this diagnosis should not be interpreted as a failure or that dooms the child to a life of special services and "otherness." Dr. Bayles' packet of handouts did not include any articles that provide the social construction perspective. It is important for parents to have medical model articles that explain what autism is, how it is diagnosed, current theories on causes, how to qualify for services, parental rights under IDEA, and how to evaluate the plethora of interventions available. The recommendations of the mothers interviewed for this study included providing information on autism and relevant services, but they also expressed concerns about what would happen to their child in the future. The article on the "greatness" of autism could reassure parents and provide some hope as they work their way through an overwhelming amount of scientific and legal information.

Criteria for services. The criteria for services are based purely on the medical model. The various laws and state policies rely on the DSM criteria to define and diagnose ASD. Educational services require that the evaluation demonstrate a delay in academic areas. Some individuals with high-functioning autism, Asperger Syndrome or PDD-NOS do not qualify under IDEA because they have sufficient academic skills but have extreme difficulty with demonstrating appropriate social skills, which are not addressed in school

curricula. State services also require that the student be “at risk for institutionalization” even though individuals with disabilities are rarely committed to institutions anymore. Services are more readily available to individuals with more severe ASDs than those on the milder end of the spectrum. IDEA supports placement in the least restrictive environment, which speaks to a child’s civil right to be educated with typical peers, but in general, the laws are focused on labeling and providing special services, which in turn support the “othering” of individuals with disabilities.

Media portrayals. Each of the media portrayals analyzed in this study included elements of both the medical model and social construction of disability. In some instances, one character represented the medical model and another character represented the social construction. At other times, characters negotiated between the two models, as was also noted in the parents and professionals in this study. As each individual with autism is unique and manifests the characteristic behaviors of autism in different ways, each parent’s negotiation between the two models was specific to that person.

There was a difference between fictional portrayals of autism in *Rain Man* (Johnson & Levinson, 1988), and *Curious Incident of the Dog in the Night-time* (Haddon, 2003) and portrayals based on biographies and autobiographies in *Son Rise* (1979), Ms. McCarthy on *Oprah* (Winfrey, 2007), and *Temple Grandin* (Saines & Jackson, 2010). The difference concerned the potential for a person with autism to grow and change over time versus the inability to change, learn new things, or adapt to new situations.

Just as the parent interviews and observations revealed a delay of many years in the impact of major findings or theories on families seeking the diagnosis and what they were told for, the depiction of the life of a person with ASD in fictional portrayals demonstrated a time lag. As part of the diagnostic process, a child psychiatrist told Betsy about the Bettelheim (1959) theory of autism thirteen years after Rimland (1964) refuted it. *Rain Man* (Johnson & Levinson, 1988) depicted individuals with disabilities living in large institutions a decade after the deinstitutionalization movement in the United States. By depicting individuals with disabilities as living in separate residences (*Rain Man*) or attending separate schools (*Curious Incident...*[Haddon, 2003]) away from “normal” children and adults, media portrayals signify the character as “other” in the manner of the medical model of disability. On the other hand, the biographical portrayals depicted the individuals with autism learning to communicate, striving to reach goals, and participating in the larger society which represents the social construction of disability as described in the film *Temple Grandin* (Saines & Jackson, 2010). Grandin identifies herself as “different, not less.”

Historical eras. The historical eras of autism described in Chapter 2 overwhelmingly represent the medical model in their assumptions about disability. Starting with Kanner (1943) and Asperger (1944/1991) discovering and naming the condition they observed, the medical model is applied. Bettelheim (1959) continued this application by specifying a cause and prescribing a treatment, although both were ultimately found to be incorrect and ineffective. Rimland’s (1964) approach also falls into the medical model by suggesting that

autism is a genetic condition. His conclusion could be interpreted as a negotiation with some aspects of social construction because he introduced the idea of a behavioral phenotype in which the parents had elements of autism in their own personalities and passed on the condition through their genes. If the parents with the behavioral phenotype are still considered “normal” despite some deviations from typical behavior this suggests the social construction model of disability. Rimland’s studies and efforts after the publication of his book fit more of the medical model through his promotion of the use of high doses of certain vitamins and other biomedical interventions to treat autism.

Lovaas (1987) must also be considered a proponent of the medical model because he claimed that ABA “cured” nine of his study’s participants. In contrast, Biklen and the proponents of FC could be interpreted as using a social construction of disability. Advocates of FC assume that there is a “normal” person trapped inside a shell of autism and unable to speak. When given the opportunity to communicate using the FC method, the person with autism should be able to join the world and live as a normal person. It might appear that this is the medical model, but advocates of FC do not propose to stop the person from performing stereotypic behaviors or other manifestations of autism. They believe that this person is “normal” in all other ways but requires the use of FC to communicate. FC advocates believe that we should modify our world to include this different way of being and communicating, and that suggests the social construction model.

Biomedical interventions follow a medical model but reject the conventional medical establishment’s research, conclusions and treatment. The

Wakefield (1998) theory that preservatives used in vaccines lead to mercury poisoning which causes autism has led to the use of chelation to remove heavy metals from the child's blood. Another biomedical theory proposes that allergic responses to the proteins in wheat and dairy cause autistic behaviors. The recommended treatment is a gluten-free and casein-free diet. Practitioners of conventional medicine and advocates of biomedical interventions each refute the claims of the other, and no compromises appear on the horizon.

The increase in the prevalence of autism as portrayed in the media is based on the medical model. Articles and news reports appears to be worded to incite fear in the public that autism has grown to "epidemic proportions." The message leads parents to be frightened of the possibility that their child could have an ASD and that it would be a devastating diagnosis. Coupled with the seemingly never-ending debate about the safety of childhood vaccines, the portrayal of autism in the media has contributed to suspicion of the medical establishment and encouraged parents to question treatments that their doctors recommend for children.

Recently, some states have passed laws that require health insurance coverage for behavioral interventions. This new policy falls under the medical model because it equates behavioral interventions with medicines and other treatment for diseases covered by health insurance. The new laws also require the people that implement those interventions to have specific certifications or licenses or to be supervised by someone who is certified or licensed. This adds to the perception of autism as a disease. The state policies are supported by the

research on the effectiveness of the intervention and are therefore similar to the criteria for coverage of medications and other health care treatments.

The online community of individuals with Asperger syndrome represents the most visible example of the social construction view of autism in the history of autism. Unlike earlier periods in autism history, this movement consists of individuals with ASDs speaking for themselves. There are examples of the social construction model in other disability groups. Members of the Deaf community argue that Deafness is a culture, and individuals with physical disabilities advocate for acceptance and accessible facilities. The Aspies demand that the general public accept the wide spectrum of ways to interact socially or the choice not to interact at all. They object to the goals of ABA because it seeks to extinguish the manifestations of autistic behaviors. Similarly, Aspies object to chelation and vaccine theories because they do not see themselves as poisoned, delayed, or deficient in any way. They believe that they are whole and complete individuals who do not need behavior-changing interventions.

Implications for Future Research

When the interviews with parents were conducted, the theoretical framework about the negotiation between the medical model and social construction of disability was not in place. A future study might include interviews with parents who received the diagnosis at different times in history and questions that seek to uncover the negotiation between these two models of disability.

Using the negotiation of the two models of disability, future studies could examine the different treatments and interventions for ASD and what assumptions they make about the nature of the disability. This was discussed briefly here but could be examined in more depth. Part of that future study would be to evaluate the impact when the voice of individuals with ASD is considered and when it is unrepresented.

At present, there is a small literature base on fathers' experiences with a child with a disability. A theme emerged in this current data suggesting that fathers may demonstrate more denial of the early signs of autism than mothers. Future studies could interview fathers during and after the diagnostic process to explore these feelings and how they were or were not resolved.

The media portrayal of the vaccine theory of the cause of autism and the battle between parents who supported Dr. Wakefield (1998) and the government organizations and journal editorial boards that refuted his theories is a phenomenon that needs deeper examination. Even after international news media reported that the Wakefield studies were fraudulent and without merit, medical TV shows, including *Dr. Oz*, aired episodes that continued to discuss the vaccine theory. The fact that this story will not "die" in the media is worth further exploration. Learning why journalists are drawn to sustained reporting of this theory and why readers continue to show a demand for this type of story would be helpful in shaping future dissemination of information on autism.

Finally, the negotiation between the two models of disability found in the medical professionals provides multiple opportunities for further study. A larger

sample of diagnosticians could be observed and/or interviewed about their ideas and opinions about diagnosis and disability. Residency programs could be studied to see how these two models of disability are taught to future pediatricians and diagnosticians.

Parameters of the Study

The seven mothers of children diagnosed between 1974 and 2004 were only interviewed once. As the theoretical framework and other themes emerged, there was no opportunity to go back and ask the mothers new questions. The parents who participated in the observations of diagnostic appointments did not agree to follow-up interviews, thereby limiting direct comparison between the earlier interviews and the observation families' stories. The two groups of parents also differed in terms of ethnicity and socio-economic status, which could be a limitation in terms of comparing across the two sub-studies. Parents cited the need to drive a long distance to come back to the hospital for the follow-up interview as their reason for saying no. Other participants agreed to the follow-up interview and then failed to show up the following week at the scheduled time. Future studies could do follow-up interviews to seek answers to the same questions from families across decades.

The interviews were audio recorded but the observations were not. In order to increase the likelihood that parents would agree to participate in the study, I chose not to videotape or audiotape the observations of appointments. Video or audiotapes with full transcription might have provided more objective, accurate, and specific information for different types of analysis (e.g.,

conversation analysis, discourse analysis, etc.) than hand written field notes. In addition, video could have been analyzed for body language.

The small number of participants in the second clinic prevented a full comparison between the two clinics; that would be another area for future research. The protocol and system for the appointments in the two clinics differed significantly, and examining the pros and cons of these different approaches would be interesting for the medical community. While the diversity of the earlier interview participants was not varied in ethnicity, the participants in the two clinics represented a wide array of ethnicities and socio-economic backgrounds. The fact that the two diagnosticians were of different genders also increased the diversity in the study. The study created a broader picture of the history and current status of autism diagnosis than previous studies, but it also raised new questions.

Conclusion

The results of this study give new insight into the process of diagnosis for a child with ASD from 1974 to the present. The perspective of parents and diagnosticians as well as the portrayals in media were described and analyzed. The themes generated by this study can be used by future service providers of individuals with ASD and their families as well as medical professionals involved in diagnosis. The study paints a complete picture and also raises questions to be explored in future research.

Researcher Reflection

I came to this study hoping to find great improvements in the process of obtaining a diagnosis of autism for a child since my parents went through the process in the mid to late 1970s. My parents went through numerous misdiagnoses and the pain of the process is part of our family history. I learned that the process has undergone many changes over time, and the guilt-inducing Bettelheim theory is invoked far less frequently when doctors speak to parents. The symptoms of autism are better known and recognized by medical professionals, teachers and the general public because of more attention in the media. When I asked Dr. Kohn about the changes in families he has seen over time concerning autism diagnosis he said, “Parents are more hopeful, they have gotten the message that there is help available, progress is possible. Sometimes this turns to acceptance, this is who he or she is and I love them no matter what.”

Nonetheless, there are still many obstacles that create frustration and confusion for parents as they are sent from one professional to another and from one medical office, government agency, insurance provider or school to yet another place to unravel the red tape that winds through the service delivery system. The absence of a more efficient, streamlined system to obtain an accurate diagnosis and appropriate intervention services continues to exacerbate an already emotionally draining experience for parents and their child.

As a researcher, I learned that hospital IRBs are quite different from university IRBs. A researcher must allow for much more lead time to gain access to patients in hospitals if you are not currently employed there. I also learned that

transcription of video or audiotapes would have been much more useful and easier than writing field notes by hand. I expected many parents to turn me down during the consent process but only one parent said “no.” Their positive responses encourage me to do more studies in this setting in the future.

I was introduced to the theoretical framework of negotiating between the medical model and social construction of disability during the literature review for this study. I believe I will continue to negotiate between the two models for myself as sibling of an individual with autism and as a special educator for the rest of my life. My negotiation will change with my experiences, as it has changed through the course of writing this dissertation. Bumiller (2008) found this negotiation in interview data with mothers of children with autism and I found it particularly fitting to my study. The way this framework fit my data was fascinating and I hope to pursue a line of research that explores how this approach applies to other scenarios within the world of autism as well as other disability communities. The media portrayals are also a new interest I discovered in this study and hope to examine in the future.

While I would like to expand sections of this dissertation into discrete manuscripts for publication, I also would like to add more chapters and create a textbook for instructors to use in university classes focused on ASD. I believe the results of this study would add a personal component to the clinical aspects of ASD that is presently absent from textbooks.

I began this study hoping to find that parents today were not experiencing the same things my parents experienced in the late 1970s when they were seeking

a diagnosis for my brother. I do believe that parents are getting an accurate diagnosis sooner and seeing fewer professionals, but a lot of it appears to be luck. It depends on who you are referred to, where you live, what services you already receive. While I feel that I began to scratch the surface of the answer to my question, I stumbled upon a new world view. I now see things in terms of the medical model and the social construction, and how the negotiation between the two is constantly in flux.

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APPENDIX A
INTERVIEW PROTOCOL

The interviews were semi-structured and included the following topics:

- 1) First signs of atypical development
 - a. What did you observe in your child that led you to seek a professional opinion?
 - b. When your child exhibited a behavior that didn't look like other children's behavior, how did that make you feel?
 - c. Did others comment on your child's behavior before you noticed it?
 - d. How did you feel about others bringing your child's unusual behavior to your attention?
- 2) Seeking a diagnosis
 - a. Did you research your child's symptoms on-line or elsewhere? How did you feel when you found information that seemed to match some of your child's behaviors?
 - b. Who did you approach first with concerns about your child?
 - c. Did you see any other professionals about your concerns?
 - d. Did your emotions change as you went through the process of seeking a diagnosis?
 - e. Do you feel these professionals acknowledged and addressed your emotions?

- 3) Anticipating the diagnosis (wanting confirmation something was wrong vs. reassurance that the child was normal)
 - a. What were your feelings as you pursued a diagnosis? What were you looking for?
 - b. As a mother, how was getting a diagnosis going to satisfy your emotional needs? Did you feel alone or isolated in seeing things in your child that no one else seemed to recognize?
- 4) Retelling of the day of receiving the diagnosis
 - a. Tell me about the day you received the diagnosis. What time of day was your appointment? Did you go alone or did someone accompany you? I would like to hear the details as you remember them. Please take me through that day.
 - b. How did you find the person who gave you the diagnosis?
- 5) First reactions
 - a. What were your first reactions to hearing the word “autism?” (After all the time that has passed, can you still feel that emotional reaction?)
 - b. How did you feel about the professional who delivered that diagnosis at that moment?
 - c. In retrospect, do you think or feel differently today about the person who delivered the diagnosis?

- 6) Recommendations to make receiving the diagnosis easier.
 - a. What would you recommend that a doctor do differently when informing a parent that her child has autism spectrum disorder?

APPENDIX B
INSTITUTIONAL REVIEW BOARD APPROVAL

To: Elizabeth Swadener
EDUCATION

for **From:** Mark Roosa, Chair *sm*
Soc Beh IRB

Date: 03/26/2010

Committee Action: Expedited Approval

Approval Date: 03/26/2010

Review Type: Expedited F7

IRB Protocol #: 1003004916

Study Title: Changes in Parents' experiences receiving and autism diagnosis for their child: A contextualized case study

Expiration Date: 03/25/2011

The above-referenced protocol was approved following expedited review by the Institutional Review Board.

It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date. You may not continue any research activity beyond the expiration date without approval by the Institutional Review Board.

Adverse Reactions: If any untoward incidents or severe reactions should develop as a result of this study, you are required to notify the Soc Beh IRB immediately. If necessary a member of the IRB will be assigned to look into the matter. If the problem is serious, approval may be withdrawn pending IRB review.

Amendments: If you wish to change any aspect of this study, such as the procedures, the consent forms, or the investigators, please communicate your requested changes to the Soc Beh IRB. The new procedure is not to be initiated until the IRB approval has been given.

Please retain a copy of this letter with your approved protocol.

