COMPARATIVE AND CRITICAL ANALYSIS OF PARENTAL ACCOUNTS REGARDING DELAYED DIAGNOSIS OF AUTISM SPECTRUM DISORDER

by

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ABSTRACT

Autism spectrum disorder (ASD) is a common childhood neurodevelopmental disorder. Epidemiological studies have found a disparity in diagnosis for children from Hispanic and low-income families, as compared to Anglo (White, non-Hispanic) children, who are more likely to be diagnosed earlier. This study considered whether parents' discursive ability and resources could be a factor in delayed ASD diagnosis.

The purposive sample for this critical linguistic and discursive study included 10 Hispanic parents with a sociolinguistic heritage from Mexico, and 10 Anglo parents with a sociolinguistic heritage from the U.S. The Hispanic sample was less privileged than the Anglo sample, which had higher average levels of income, education, and English speaking skills. The sources of data included digitally transcribed texts from interviews of the 20 participant parents and the texts scraped from nine national ASD websites.

Phase 1 of the analysis coded, compared, and critically analyzed accounts of Hispanic and Anglo parents regarding their experience of assessing and obtaining a professional diagnosis of their child's behavior. Phase 2 employed critical linguistic/discourse analysis of the scraped texts from ASD websites and subsequent content analysis of those texts regarding the diagnosis and treatment of a child with ASD.

The findings from the first phase suggest that Anglo parents focused on constructing themselves as "good parents" who met ideological expectations for monitoring and caring for their children. In contrast, most Hispanic parents used their discourse and resources to construct themselves as concerned about their children’s linear progress in school, ability to communicate, and social adaptability. Findings from the second phase of analysis suggest that the same discourse used by privileged parents in this study, on a microlevel, were consistent with the dominant U.S. macrolevel discourse and ideology of the “good parent” as emerged from the ASD website data.

This study suggests that, the more closely parents, either Hispanic or Anglo, were aligned with the privileged discourse model or ideology of the U.S. Anglo “good parent,” the fewer barriers they reported to diagnosis. This study also suggests the need for further research, particularly about the Hispanic/Mexican discursive model of parenting.

This manuscript is dedicated to my husband, Keith

and to my parents,

James and Ann Tenney,

and to my children,

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all of whom have inspired and supported me

in this adventure of learning.

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CHAPTER 1

INTRODUCTION

Viewed from a standpoint of social construction, a diagnosis of Autism spectrum disorder (ASD) is the accomplishment of many overlapping discourses, including discourses from medicine, epidemiology, child development, and psychology. ASD is the subject of blogs, Internet sites, and countless articles and news stories in the popular press that also intersect with and contribute to our constructed notions about ASD. Information or conversations about ASD may be constructed within a given point of view or culture, but that is not to say that they are not real or that they do not have real effects or consequences. For example, a diagnosis of ASD is mainly constructed through best medical understanding of ASD at this time period; however, even though the diagnosis of ASD is partially constructed, it has real effects on the way a child is treated, classified in school, and helped.

This study defines discourse as the everyday language (and accompanying patterns of language, thought, and interpretation) that we use as we interact with others. Included in the everyday use of language is the use of the more formal language used by professionals, such as doctors, psychiatrists, and child developmental specialists, as they interact with each other, patients, and families. I used critical discourse analysis (CDA) to investigate the role of language and discourse in parental assessment and professional diagnosis of ASD. I examined the microlevel individual discourse and language used by parents from both Anglo and Hispanic families with differing relative levels of economic privilege and differing sociolinguistic heritage who had a child diagnosed with ASD

Current research about ASD suggests that early behavioral and developmental intervention produces generally consistent improvement in IQ (intelligence quotient) and adaptive behavior. Children who receive early intervention are more likely to have improvements in diagnosis, such as moving from a diagnosis of autism to pervasive developmental disorder (Dawson et al., 2009).

However, research shows more delays in diagnosis for racial and ethnic minorities and poor families, as compared to their wealthier Anglo counterparts, in current public and private systems for diagnosis of ASD (Liptak et al., 2008; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Novak, & Zubritsky, 2005). Because of the way medical, psychological, and developmental discourse constructs and analyzes the disorder from a dominant cultural frame that may not be shared by less privileged parents, a lack of awareness and delayed diagnosis may lead to delays in developmentally appropriate early intervention.

Specific Problem

Medical and psychological specialists describe ASD as a neurodevelopmental disorder that can cause deficits in communication, social interaction, and repetitive or restrictive patterns of behavior (CDC, 2012). Epidemiological studies estimated that ASD is one of the most prevalent developmental disabilities in the United States; about 1 of every 88 8-year-old children in the U.S. has an ASD (CDC, 2012). Public health and academic researchers, using the scientific paradigm and associated frames, have identified delayed diagnosis of ASD among preschool children as an important problem for children from low-income and diverse sociocultural linguistic heritage households (Liptak et al., 2008; Mandell, Listrud, Levy, & Pinto-Martin, 2002; Mandell et al., 2009).

Unfortunately, late diagnosis (after the preschool years) delays initiation of early intervention therapies specifically designed for young children with ASD, therapies considered as most effective developmentally at this age by medical, psychiatric, and child development specialists (Dawson, 2012; Frea & McNerney, 2008; Howlin, 2003; MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014). Early intervention, as measured by Dawson in a randomized trial using realist methods, has indicated promise with promoting improvements in IQ (intelligence quotient), communication, and social development (Dawson et al., 2009). However, current health systems that lead to or provide ASD diagnostic services often face additional language and cultural barriers to effective screening of racial and ethnic minorities and poor families, as compared to more privileged parents, and these barriers may lead to delays in diagnosis (Liptak et al., 2008; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Novak, & Zubritsky, 2005).

This study sampled from one minority group, Hispanics or Latinos (in this study, they are referred to as Hispanics, not as Latinos), who live in Utah. The U.S. Census Bureau Newsroom (2015) reports that the Hispanic population of the United States as of July 1, 2014 was 55 million, “making people of Hispanic origin the nation’s largest ethnic or racial minority” (p. 1). This study’s Hispanic sample was comprised of 9 (out of the 10) Hispanic participants from Mexico. (One Hispanic participant was not available to answer this question.) The other participants consisted of 10 Anglos (White, non-

Hispanic) parents, raised in the U.S. or Canada. I also attempted to recruit Hispanic and Anglo parents from different income levels; however, the end result was 7 Anglo parents below or near the 150% poverty, 3 considerably above 150% of federal poverty levels, and 9 Hispanic parents that were at or near the poverty level, with 1 Hispanic parent above 150% of poverty. (See the discussion of privilege in Chapter 1.)

The CDC's Mortality and Morbidity Weekly Report (MMWR) (CDC, 2012) indicates that in 2008, there was a 23% increase in the estimated prevalence of ASD since its 2006 report. The rate of ASD has greatly increased since the mid-1980s, when autism was considered to be a rare disorder (Kaiser, Giarelli, & Pinto-Martin, 2012). Even so, the estimated prevalence for Hispanic children (7.9 per 1,000, or 1 in 127) in 2008 was low compared to non-Hispanic Blacks (10.2 per 1,000 or 1 in 98), and even lower compared to non-Hispanic Whites, with an estimated prevalence of 12 per 1,000 or 1 in 83. 8 (CDC, 2012). While Hispanic children (along with Black and other minorities and marginalized groups) have the same *expected* rate of ASD as Anglo children, they appear to be diagnosed at a much lower rate than Anglo children (Division of Birth Defects, 2015).

Developmental and medical experts claim that diagnosis of ASD can be consistently made by the age of 2 years (Lord & McGee, 2001). Addressing the issue of delayed diagnosis is a significant problem for the following reasons: (1) Delays in diagnosis may mean missing critical developmentally appropriate early intervention and therapy (Altemeier & Altemeier, 2009; Frea & McMerney, 2008; Odom, Rogers, McDougle, Hume, & McGee, 2007; Ospina et al., 2008; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Rogers & Vismara, 2008); (2) With early diagnosis, parents would have the opportunity to more clearly understand their child's behavior and how they can assist their child's development at an earlier age; and (3) Early and continued intervention is much more cost effective than the custodial care for adults throughout their lives that can be a result without early intervention (Jacobson, Mulick, & Green, 1998).

Rationale for Use of CDA

While many studies have identified and quantified diagnostic delay for ASD, few have approached the issue using critical linguistic and discourse analysis (CDA). This study took the next step and used CDA to identify parental language and discourse and to compare differences in parental discourse according to sociocultural linguistic heritage. Analysis of parental linguistic patterns and use of discourse is important because discursive differences between the groups of parents by sociocultural linguistic heritage may explain why some groups are diagnosed more expeditiously than others. Diagnosis of ASD is often dependent upon parents' communicating their observations and interpretations of their child's behavior to their health care provider (HCP). If there were problems that might be alleviated in this communication process, it would also be important to understand them.

Parental interpretations and representations are important in the process of assessment, evaluation, and construction of ASD diagnosis by HCPs, because HCPs make decisions based on their own interpretations of the fit and reliability of parental reports compared to the HCPs' own interpretations. Some parents may not easily make the transition between their sociocultural linguistic and discursive heritage, and the resources and frames of medical or psychiatric discourse. In other words, such parents may have different discursive resources that may lead to discursive mismatch between HCP and parent. HCPs may also find it difficult to step out of their medicalized and scientific language practices to successfully use lay terms with the parent.

Lack of access to computers, to the Internet, to explanations of commonly used medical terminology, or concepts related to child development are other factors limiting access to discursive resources of the dominant culture. Discursive mismatch occurs as a result of these and other factors that stem from social and cultural experience and relative levels of privilege.

Health care professionals may contribute to discursive mismatch through their proficiency and competency in, and reliance on, medical discourse, including specialized language about the body and procedures, that is consistent with the medical model (Turner, 1995). The medical model promotes and sustains professional power and privilege through various legal and social aspects of their profession, but especially through the power to define (Conrad, 2000, p. 106). As an example of this power, before any state-funded ASD-specific services are provided, the majority of states require a diagnosis by a health professional that meets that state’s criteria for provision of specialized services. In this way, this power and privilege held by health care providers as “information providers, gatekeepers, institutional agents, and technicians” usually results in asymmetry of power as parents interact with them (Conrad, 2000, p. 111).

Of course this asymmetry in power is not fully one-sided and is made possible through interaction with parents (Maynard, 1991). It is also not necessarily intentional, but it is an issue of access to power through linguistic and discursive practices, resources, and level of privilege. This power shapes and regulates behavior and processes associated with obtaining a diagnosis. In this way, the HCP maintains control over the clinical setting and the interaction between the HCP and patient throughout the course of the clinic visit (Maynard, 1991).

This critical discourse analysis is the first to look at possible discursive mismatch between dominant culture and less privileged sectors as a factor in delayed ASD diagnosis. This analysis provides useful insights into the social determinants of delayed ASD diagnosis due to a mismatch in discourses and discursive practices between lay parents and HCPs. Understanding and identifying this potential discursive mismatch may be a factor in overcoming barriers to obtaining a timely ASD diagnosis (Janzen, 1987).

Methodology

The conceptual base of this study was the epistemology of social constructionism, along with the theoretical stance of interpretivism and critical theory of discourse analysis, with its focus on language and discourse. This framework, along with content analysis, is consistent with the goals of this research to explore and evaluate the influence of language and discourse on the process of ASD diagnosis.

This study explored how ASD was socially constructed—at least in part—by parents, and by the larger sociocultural and medically accepted discourse about ASD in the U.S. (Phillips & Hardy, 2002). Through use of CDA, I analyzed the study texts for discursive mismatch that may lead to delayed diagnosis of ASD for low-SES and linguistically and culturally diverse families (Hamilton, 2005). I analyzed readily accessible texts from nine national ASD websites using CDA and content analysis to assess dominant discourses about ASD. I compared these findings to findings from the parental texts to assess for mismatch or congruence between the discourses.

During the process of ASD diagnosis, both parents and HCPs communicate about ASD or its symptoms, but parents and HCPs may construct, define, and interpret ASD very differently because they each draw from different discursive resources or discursive frames (Fairclough, 2003). This may be especially true for parents who are new to, or whose lives are more removed from, the medical practices and resources that assign diagnoses. Because of this, the comparison of the mainstream or socially and culturally accepted dominant discourse about ASD—usually consistent with medical and psychiatric language or jargon—with lay or parental discourse about ASD helps to identify how parental interpretation of their child's behavior matches up or resists the dominant discourse. This comparison is a way to assess the levels of parental discursive competence and capital within the dominant medical/psychiatric discourse regarding ASD (Taylor, 2001).

Medical professionals are trained and become expert at drawing on discourses about the body, its biology, development, and psychiatric aspects (Turner, 1995). These medical discourses represent ASD in a particular manner through language use. For example, ASD was once considered to be purely a psychiatric condition, and this perspective excluded other possible causes, such as problems with pregnancy and delivery.

I explored the premise that ASD diagnostic disparities may be due in part to what happens at this intersection, where parents who are less discursively competent in the dominant ways of thinking and talking about ASD interact with HCPs who use the dominant discourse as their main frame of reference. At this intersection, HCPs and parents may be at high risk of discursive mismatch—a mismatch in ideas, language, and culture—resulting in a lack of understanding between the two groups (Rogers, 2002). This discursive perspective leads to a shift in analysis of the causes of delayed ASD diagnosis from a realist and epidemiological paradigm to a constructionist and CDA perspective, with its emphasis on the ASD diagnostic process as a discursive activity.

Aims

The purpose of this study was to compare and analyze parental accounts about the assessment and diagnosis of their child with ASD, including recognition, assessment, diagnosis, and initial interactions with HCP, and to assess for discursive mismatch between parental discourse and the dominant discourse. The hypothesis of this study was that discursive mismatch does exist between the two groups of parents from different sociocultural and linguistic heritages and may influence a parent's ability to obtain a timely diagnosis. This is based on the theory that discourse and language can provide important sociocultural information about how parents view the world and themselves, including values and taken-for-granted norms that are understood as truth.

The process for ASD diagnosis is initially observational because there is no definitive diagnostic test; beginning the diagnostic process is dependent upon the sharing of information through language and discourse. I used CDA because of its inherent attention to language use and the critical perspective needed to assess for disparity. This study had the following specific aims:

Aim 1: Explore and describe similarities and differences in language use and discourse in parent descriptions of their child's behavior and the process leading to professional diagnosis of their child with ASD

Aim 2: Assess for the dominant (macrolevel) discourse, including sociocultural and medical influences, about assessment and diagnosis of ASD, using the texts of readily accessible online ASD focused Web sites produced by national ASD support groups or organizations.

Aim 3: Analyze and describe how the language and discourse used by parents from two different sociocultural linguistic heritages and levels of privilege (microlevel), as described in Chapter 4, compare with or resist the dominant discourse (macrolevel), as described in Chapter 5.

Significance

The parent interviews and analysis of linguistic heritage provided information about the ways parents from two different linguistic heritages (a) learn about and understand their child's behavior before an ASD diagnosis is made, (b) how parents construct themselves and others through this process of assessment and diagnosis, (c) what information the dominant more privileged discourse about ASD tells us, and (d) how the microlevel parent discourses match up or differ from the dominant privileged U.S. discourse about ASD and its diagnosis

This information helps explain, first, how discursive mismatch occurs, and second, its role in producing the disparity of delayed diagnosis of ASD, if any. Marginalized populations may have access to different discursive resources about parenting and children. Their communications may not match up with the dominant U.S. discourse that is usually needed and expected to obtain a diagnosis of ASD in the U.S. These sociocultural and linguistic differences may lead to misunderstanding, confusion, and even fear of the unknown—along with delayed ASD diagnosis.

Findings about discursive mismatch and other discursive practices by parents may provide insight into cultural assumptions held by HCPs. Thus, this study will be useful to institutions, HCPs, public health and private practice clinics, and parent organizations that work with parents of children with ASD. The findings can facilitate the development of specific screening and intervention strategies that promote understanding of ASD and the need for a timely diagnosis. HCPs can understand more clearly the responsibility they have to bridge the gap between themselves and those who are less competent discursively. Additionally, these findings can lead to development of screening and diagnostic interventions that are more discursively accessible to marginalized populations.

This study will also prove useful in assessing how issues of ethnicity, privilege, and other marginalizing factors are layered, interact, and produce disparity in health and health care. Disadvantages may not be intentional, but disadvantages are a combined product of discursive practices, government policy, institutional procedures, and unequal distribution of social resources that continue to marginalize certain groups. More information about subtle and often unintentional practices that marginalize less privileged and linguistically/culturally diverse groups will help inform public policy decisions. It may also lead to a more informed distribution of limited public resources through improved outreach strategies to underserved parents.

Overall, these findings can facilitate the development of specific screening and intervention strategies that promote understanding of ASD. It may also provide improved understanding of the disparity in delayed diagnosis and possibly a new approach to design of studies for ethnic and racial health disparities.

Definitions of Terms

The following are definitions of key terms used in this document, presented in alphabetical order:

Anglo

The word Anglo is used instead of White, non-Hispanic in this study. The Merriam-Webster online dictionary defines Anglo as "a white inhabitant of the United States of non-Hispanic descent" (Merriam-Webster, 2015). This dictionary also states that the term came from the Spanish term "Anglo-Americano," and Anglo was first used in 1800 (Merriam-Webster, 2015). By using Anglo instead of White non-Hispanic, I am trying to avoid some of the negative historic associations related with phrasing such as White vs. Non-White.

Autism Spectrum Disorder (ASD)

ASD is a condition currently described by the American Psychiatric Association in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition,* part 299.00 (DSM-V) (American Psychiatric Association, 2013) as exhibiting the following symptoms:

- Persistent deficits in social communication and social interaction across multiple contexts;
- Restricted, repetitive patterns of behavior, interests, or activities;
- Symptoms must be present in the early developmental period; and,
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

ASD is a subset of Pervasive Developmental Disorders as described by the American Psychiatric Association (2000). As discussed in below, the interviews and analysis for this study were conducted based upon an earlier definition of ASD found in the APA

Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR (American Psychiatric Association, 2000), and thus the analysis in this study references the earlier definition.

Critical Discourse Analysis (CDA)

CDA seeks improved understanding of a social problem through discursive and linguistic analysis of text (talk, visual images, body language, transcripts of interviews, and anyway of signifying) through discourse and linguistic analysis, with the goal of providing options for change directed at overcoming or alleviating the identified problem (Fairclough, 2001).

Discourse

Discourse is the use of language to accomplish social goals or tasks within a given context and historical time period, such as making a speech or obtaining a dental appointment (Hardin, 2001). The use of discourse is the way we get things accomplished by employing specific patterns of language and word usage within a given context. Language and text includes images, sounds, and language—written or spoken (Hall, 1997).

Discursive Competence

Discursive competence includes the discursive skills, abilities, resources, and capital. This is a parallel concept to Bourdieu’s concept of cultural competence and resources. Bourdieu’s concept helps us understand how discursive competence helps overcome barriers to health and health care (McKeever & Miller, 2004).

Early Intervention (EI) Programs

EI programs help infants and toddlers with developmental delays or disabilities. EI focuses on helping children learn the basic skills that typically develop during the first 3 years of life but are delayed in children with ASD. EI may refer to either a public program that is free to all eligible children under the Individuals with Disabilities Act (IDEA) (Impulse, 2015), or to private pay early intervention programs. Private pay programs are often Intensive EI programs that often require 5 days a week with more hours total per week of therapeutic involvement in a school-like setting. Public systems usually provide most of the same services. These services are often provided less frequently in the home or in a group. The goal is often to support the family in a way that encourages families to be more independent and that encourages families to provide a therapeutic experience in the home. However, programs and funding opportunities vary from state to state, including how they define ASD and when the state will provide services (Howard, Stanislaw, Green, Sparkman, & Cohen, 2014).

Early Intervention (EI) Therapy

After an assessment of a child by professional specialists, behavioral EI therapy is usually provided along with other hearing, speech, psychological, and physical therapies as prescribed. Parents are usually involved in the process by re-enforcing good behavior and discouraging unwanted behavior, or they become involved in actually providing interventions at home (Division of Birth Defects, 2015).

Frame or Framing

Framing provides a short-hand way of communicating or understanding complex information that is consistent with a particular focus of study or belief system (such as medicine), or a particular culture or social group (such as middle and upper income Anglo parents). Framing also provides a schema, or way of organizing and labeling information used by a given group. This short-hand language is understood by the group or culture using it, but may require additional education or enculturation for those outside the group, culture, or organization (Kramsch, 1998).

Health Care Provider (HCP)

HCPs are professionals licensed by state authorities to diagnose, treat, and care for people with medical and psychological conditions, including ASD.

Health Literacy

Health literacy is defined in the Institute of Medicine report, Health Literacy: A Prescription to End Confusion (Nielsen-Bohlman, Panzer, & Kindig, 2004) as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (p. 4). According to that publication, more recent definitions focus on “specific skills needed to navigate the health care system and the importance of clear communication between health care providers and their patients. Both health care providers and patients play important roles in health literacy” (Nielsen-Bohlman, Panzer, & Kindig, 2004, p. xi). These definitions are similar to definitions of cultural and discursive competence and associated resources. It is important not only to understand the language, but also to have the sociocultural competence to accomplish tasks within a given sociocultural context with associated norms and expectations. However, health literacy is specifically focused on health-related processes and interactions.

Hispanic

Hispanics are individuals with ancestry from the Spanish-speaking countries of Central and South America, as well as Mexico and Spain (Passel & Taylor, 2009). The Hispanic participants in this study are mostly from Mexico (at least 9 of 10).

Ideology

Ideology consists of the assumptions and often-unconscious nature of shared belief systems or culture. Van Dijk (1998) states, "If a group is in a dominant relationship with respect to other groups, for instance on account of its privileged access to social resources, ideologies have the double function of maintaining or confirming the status quo…" (pp. 163-164). In this way, the system of power relations is also preserved in a subtle manner. Fairclough (1989) defines ideology as "[c]ommon sense assumptions, which are implicit in the conventions (or the norms of a society)" (p. 2), and these conventions are used to interact socially and linguistically. These assumptions influence a groups' understanding, through usually unchallenged notions, of what is considered right or wrong and good or bad within a given group or culture. Fairclough (1989) claims that ideology, power, and language are closely linked. Ideology is constructed in a way that is consistent with the dominant culture and is a way for the dominant culture to apply power through language, and not through direct force or coercion (Fairclough, 1989). Through ideology, some discourses (ideas, values, and beliefs expressed through language) are privileged over others, in ways that obscure or devalue other points of view, language, and discourse. According to Lamont and Fournier (1992), ideology sets up boundaries of difference within a culture, which promote and sustain inequality.

Interpreter

For purposes of this study, an interpreter is someone who interprets the meaning expressed in one language into another language in oral discourse.

Intersectionality

Kinberle' Crenshaw (1991) first developed the concept of intersectionality when defending a case for Black women that included race and gender discrimination. According to Patricia Hill Collins (2012), intersectionality theory posits that inequalities do not simply accumulate, like 2 + 2 in an additive process, but they constitute a "simultaneous production of race, class, and gender inequality" (p. 231). In this way, Collins (2012) developed a theory of how to analyze these three common inequalities—race/ethnicity, gender, and class—as they intersect and form unique inequalities within a given context. Then, Collins (2012) had an insight that applies to this study about the disparity in diagnosis of ASD when she stated, "When it comes to contemporary power relations in a decolonizing world, intersectional frameworks suggest that there are no pure oppressors or oppressed and that, instead, most social phenomena reflect a tangled set of relationships of privilege and penalty" (p. 233). Collins found in her new knowledge of intersectional theory and analysis that this theory can be applied to a broader range of issues such as health disparities, ageism, and more. Schulz and Mullings (2006) apply the theory and methods of intersectionality to health disparities, and

Beldolla (2007) cites this approach as the theoretical basis for design that helps us better understand the "the cross-cutting political effects of both marginalization and privilege within and among groups in the U.S." (p. 232). Note that, with such a small sample and uneven representation of men and women, the examination of gender as a barrier was not analyzed in this study.

Linguistic Repertoire

A person's linguistic repertoires include the resources of a language that they have available to use, for example, the size and range of their vocabulary, all the different structures they can use, and the different kinds of text they can understand or construct (Edley, 2001).

Macrolevel Discourse

Discourse at the macrolevel consists of the broader sociocultural discourse that individuals draw from depending on their sociocultural and linguistic heritage. Teun van Dijk (1997) states, "Thus, in social discourse analysis we also find that social reality may be constituted and analyzed anywhere between a more micro and a more macrolevel of description," e.g., social interaction of individuals as compared to larger groups or cultures, "and how both thus contribute to the production and reproduction (or challenge) of social structure" (p. 6). Macrolevel discourse includes ideologies that dictate or heavily influence notions of right and wrong and culturally appropriate behavior. For example, individuals that are well versed in scientific ways of thinking, believing, and talking, would expect scientific studies to support their ideas and ways of intervening for their child's treatment in preparation for school, or treatment of an illness or a developmental disorder (Hardin, 2001).

Microlevel Discourse

Discourse at the microlevel consists of the accounts, stories, and narratives as employed or constructed by individuals. The discourses used by individuals also include pieces of the larger sociocultural discourses found at the macrolevel. Microlevel resources depend on the income, education, training, linguistic heritage, sex, and discursive resources available to a particular individual (Hardin, 2001).

Parent

Parent is defined as a single, married, or partnered person who provided the care, shelter, and support for their child. Legal proof of this was not requested, but parent report was used along with their ability to identify their child's needs and interventions. It was clear, however, upon meeting the parents, that they were deeply concerned and invested in their child's care, well-being, and happiness.

Privilege

My focus was on comparing discourses by privilege, which is defined as: (1) relative level of income as compared to others in this study: above or below 150% of federal poverty guidelines; (2) sociocultural linguistic heritage: English language consistent with dominant medical/scientific discourse and language of the U.S., as compared to Hispanic, Spanish-speaking linguistic heritage; (3) level of education: post-high-school education or the level of a high school graduate or less. These measures were used to measure privilege, a different definition of class or SES to include linguistic and discursive competence within the dominant U.S. culture regarding ASD. See Chapter 2 for further discussion.

Relationship of Culture and Discourse

Through language and discourse, we understand the social and cultural aspects of life, along with creating meaning consistent within a given culture and context. Taylor (2001) states that discourse analysis assumes that “language use reflects the knowledge or skills shared by members of the same culture” (p. 25). In other words, language is understood within a cultural group and conveys a shared meaning accomplished through linguistic practice (Taylor, 2001).

Sociocultural Linguistic Heritage (Linguistic Heritage)

In line with semiotic theories, linguistic heritage is the idea that there is more to language than the straightforward transference or exchange of a message. Sociocultural linguistic heritage takes into consideration the use of language, discourse, and the social and cultural heritage of a person, including the primary language used in the home, cultural aspects of language use, and the history behind that usage. Sociocultural linguistic practices and repertoires (see definition below) are developed in a way that is consistent with sociocultural beliefs and ideology of a group or culture. Sociocultural appropriate linguistic practices include specific ways of constructing interaction and language use to accomplish social goals.

Translator

A translator is someone who translates from the written word in one language into the written word of another language.

Assumptions

This study assumes that ASD is the constructed product of many overlapping discourses. One interpretation of ASD is described by the APA in the DSM-IV-TR (American Psychiatric Association, 2000) and was used, prior to the DSM V, by U.S. health care practitioners, policy makers, and others as the framework for diagnosing ASD. Parents and family of a child with ASD may have their own interpretations, language, and discourse that they use to understand and construct for themselves the meaning of ASD. All of these historic, cultural, linguistic, and discursive influences contribute to the diagnostic process for ASD in the U.S.

This study presumes that the diagnosis of ASD usually occurs within a social setting and is dependent upon the linguistic or discursive ability of both the HCP and the parent. The process of discussing concerns about a child's behavior, description of behaviors, asserting the significance of symptoms, and facilitating the diagnostic process are all functions of sociocultural and linguistic ways of being, talking, and understanding (Gee, 2005). This process includes, for example, obtaining appointments, discussing financial issues, asking and answering questions about behavior, completing forms and questionnaires, assessing behaviors for significance, providing a diagnosis or plan for observation, understanding of recommendations and options for treatment/no treatment, and more. This is a linguistically and discursively intensive process that may influence the process (and possibly the success or failure) of parental assessment and professional diagnosis. Therefore, CDA is important to help assess the influence of culture through language and discourse as it applies to behavioral assessment and ASD diagnosis.

This study also assumes that, when parents become literate in medical discourses, it is as if they become discursively competent in the medical way of talking, thinking, and understanding the “state of knowledge” concerning ASD generally (Hall, 2001, p. 73). As a parent becomes more discursively competent about medicalized discourse, it is easier to interact with the HCP and have questions addressed in a way that is satisfactory to the parent and the HCP. It is also a premise that the discursively competent (and medically/scientifically literate) parent’s questions are generally not discounted in a way that ignores or downplays parental concerns. Conversely, those parents who are not as discursively competent are more likely to experience a discursive mismatch between themselves and those more skillful in the dominant medical discourse concerning ASD, often resulting in marginalization of parental perspectives in diagnostic process. When a person is less skillful in the dominant discourse, there is also the increased opportunity for discursive mismatch that promotes confusion and misunderstanding by the parent and the HCP.

Limitations

This study is subject to several limitations. First, this study was limited by my lack of Spanish speaking skills when I, as the investigator, performed qualitative interpretations of previously translated texts. However, this may represent some of the same challenges faced by most HCPs in Utah, and can help highlight some of these challenges.

Second, the inclusion criteria were changed during the study because recruiting Hispanic parents was difficult and many who were willing to participate in this study had children who had been diagnosed with ASD more than 1 year before their interview.

Third, Hispanics were the only minority represented in this study. Although they compromise the largest minority group in Utah (U.S. Census Bureau, 2010), other minorities were not represented; therefore, any generalizations to other minority groups should be limited (U.S. Census Bureau, 2010).

Finally, I took a critical approach to frame my interpretation of the data that is consistent with critical and disparities research, as compared to a more descriptive or noncritical perspectives. As an upper middle-class White woman, I may not be aware of or notice issues of specific concern to low-income and ethnic minority groups.

CHAPTER 2

BACKGROUND AND SIGNIFICANCE

Introduction

The diagnosis of ASD, especially the initial assessment in the clinic, is a challenging process due to the great variation in presentation, absence of a definitive diagnostic test, and a necessary over-reliance on observing and interpreting deviations from developmental norms. Our current professional and cultural knowledge about ASD is shaped by a number of intersecting discourses that reflect multiple points of view. The dominant discourse about ASD centers on scientific and medical-related models. These models contribute to our conceptions and understanding of ASD. But sociocultural linguistic heritage, medical and nonmedical models, disability models, and parental frames of reference also shape our sociocultural understanding of ASD. These all play a role in how a parent understands behavior that may be different from the expected norms of a group, and how we linguistically and discursively explain and understand those differences.

This literature review focuses on conventional definitions used in the dominant medical/psychological discourse about ASD in the U.S. as it is represented in the research literature on ASD diagnosis. First, I address the concept that ASD is socially constructed, including the constructed nature of medical and lay knowledge as it applies to ASD. Second, I discuss the historical construction of ASD. Third, I address ASD diagnostic discourse and controversies. Fourth, I discuss the epidemiological prevalence of ASD. Fifth, I address the problem of delayed ASD diagnosis as it is framed in the medical literature, along with a discussion of the research about causes of delayed ASD diagnosis. This literature review is organized within the context of social constructionism and critical discourse analysis, and I analyzed and considered all studies within that framework.

Constructed Nature of ASD

This study was based on the premise that a medical diagnosis of ASD is constructed, in part, within historical, social, and cultural parameters and is the result of a process that is interpreted and negotiated (Jorgensen & Phillips, 2002). Professional and scientific organizations have played a large role in the construction of ASD through their specific way of using language to categorize and define ASD. For example, in the DSM-IV-TR (2000), ASD is referred to as “Pervasive Developmental Disorders,” and described in part as “a clinically significant behavioral or psychological syndrome or pattern,” while the DSM-V (2013) refers to ASD as a “disorder.” However, in other cultures, ASD might be considered a normal or exceptional variant, such as “perpetual children” in the Navajo Nation or marvelous children of the Senegal (Grinker, 2007, pp. 52-53). The definition of ASD as a disorder, along with other specific descriptors and measures couched within a scientific and medical framework, provide the generally accepted view of ASD in the U.S. Professionals in science and medicine also have a dominant role in generating discourse about ASD because of their accepted role as diagnosticians and experts in these areas, including child development, neurology, behavioral science, and ailments of the body in general (Turner, 1995). This in turn influences how we think and what we believe about ASD and health and illness in general (Hacking, 2007).

The American Psychiatric Association (APA) provides the conventional or most used definition of ASD that is accepted by most health care, intervention programs, and school organizations in the U.S. in the 2000 DSM IV-TR (The Diagnostic and Statistical Manuel 4th Edition with Text Revision). The DSM-IV-TR defined ASD as Autistic disorders that included five subcategories: autistic disorder, Asperger's Disorder, Rhett's Disorder, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified (American Psychiatric Association, 2000). Because interviews for this study took place during the time that the DSM-IV-TR (American Psychiatric Association, 2000) was current, it will be used as a reference in this study instead of the more recent DSM-V definition of ASD (American Psychiatric Association, 2013).

The American Psychiatric Association's DSM is used as a reference in texts and articles for professional and lay groups (Feinstein, 2010; Pinto-Martin et al., 2008; Volkmar, 2005b). Many other organizations, such as local, state, and federal health organizations, rely on the American Psychiatric Association publications and the current DSM edition for the psychological/medical definitions of ASD. These organizations then develop their own definitions and criteria that determine access to care for the services each organization provides. Each of these professions or organizations has its defined area of practice and philosophy, and its own particular oversight that influences the way ASD is defined in various contexts

Most researchers have drawn on this widely accepted American Psychiatric

Association definition to examine the rate of ASD overall (CDC, 2007; Newschaffer et al., 2007; Shattuck, 2006), age at diagnosis (Bouder, Spielman, & Mandell, 2009; Liptak et al., 2008; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Novak, & Zubritsky, 2005), and use of services (Newacheck, Stoddard, Hughes, & Pearl, 1998; Zimmerman, 2005). Epidemiological research is the predominant way to explore the rate of ASD and ASD-related disparities; however, it may be useful to consider other options for understanding the ASD disparity in diagnosis, including language-use-based approaches that use discourse and content analysis. These options are discussed more extensively later in this chapter.

Medical and Psychological Interventionist Interpretations

During the time period of these interviews for this study (2012), the DSM-IV-TR (American Psychiatric Association, 2000) provided the most generally accepted interpretation of symptoms and behaviors exhibited by persons with ASD, and now the DSM-V (American Psychiatric Association, 2013) provides the generally accepted interpretation. However, the concept of ASD has historical roots reaching back to the mid-20th Century. Psychiatrists Kanner and Asperger both independently described ASD in the 1940s and tied it to some level of psychopathology due to poor parental interaction, e.g., the refrigerator mother (Giarelli, 2012). In 1978 Rutter, a child psychiatrist, proposed four criteria for the diagnosis of ASD, which are essentially the same criteria used today: signs and symptoms of autism by age 2½ years, impaired social interaction, impaired communication, and unusual repetitive, patterned behavior. Through this shift from ASD as psychogenic disorder to a biologic brain disorder, ASD became a disorder that was influenced by both psychological and medical discourses.

According to medical scientific discourse, the root cause of ASD is still poorly understood, but current medical and genetic research suggests that ASD is a neurodevelopmental disorder influenced by genetic and environmental factors (Altemeier & Altemeier, 2009; Lord & McGee, 2001; Smedley & Syme, 2000). Barbaresi, Katusic, and Voight (2006, p. 1167) theorized, before the new 2013 APA diagnostic criteria were developed, that the term ASD describes a set of conditions that are “related and may be difficult to differentiate,” with the current state of the science. However, ASD is often represented as a distinct disorder that is clearly defined and not contested.

Historical Construction of ASD

Children with socially odd behaviors, problems communicating, and difficulty fitting in have probably always existed; however, their behavior and status as a child was previously culturally situated and constructed by utilizing available discourses about what constituted “normal” child behavior in a given time period. Grinker (2007), for example, cited Uta Firths’ example:

> There are many records in Russia, from the sixteenth through the nineteenth centuries, of so-called ‘blessed fools,’ children and adults who were preoccupied with repetitive behaviors, needed to be confined so they didn’t wander away, and had seizures. They were often mute, and if not mute were echolalic (repeating back verbatim whatever they heard, but not initiating independent speech) or spoke gibberish. (Grinker, 2007, pp. 52-53)

No one in Russia during the 16th century diagnosed those “blessed fools” as autistic, because the concept of autism had not yet been conceived or constructed. No one in the 16th century talked about child development, the signs and symptoms of ASD, or had ever met a child diagnosed with autism, so they could not possibly know what it meant to be a child with autism. ASD, as we understand it now, is the product of historically and culturally specific frameworks and constructions that are mediated through language.

During the first half of the 20th century new ideas and professional practices “based on historical-cultural interpretive frameworks,” such as psychoanalysis and the biogenic medical model, opened up discursive space for the construction of new ways of thinking and talking about child behavior (Geiger, 2003). The early 20th century was a time that supported knowledge and practices that promoted increased observation and monitoring of children through expanded compulsory education, the field of psychiatry, professional teaching, and more free time for parenting. These practices increased the amount of childhood monitoring and analysis of childhood behavior (Nadeson, 2005). Medical discourse was influenced by texts from other discourses and related disciplines (Phillips & Hardy, 2002). For example, developmental discourses and notions of normality influenced and contributed to medical discourses about children and ASD (Grinker, 2007; Nadesan, 2005). Other discourses that overlapped with and influenced medical discourse concerning ASD included “good” parenting, morality, disability, and possibly others (Fairclough, 2001). Medical discourse has incorporated other discourses over time. This has broadened HCPs’ scope of influence and the breadth of the things they monitor.

In the early 20th century, Kanner used the term “autism” to describe the “idiosyncratic, self-centered thinking” of the children he studied, meaning that they lived in their own worlds (Avdi, Griffin, & Brough, 2000). This use of the term was interpreted by others to literally mean schizophrenia, because that was consistent with the usage of the 1920s to 1930s (Volkmar & Lord, 2007). Kanner also stressed the apparent lack of parental warmth, congruent with beliefs of the time that parents were to blame or made significant contributions to psychological problems (Volkmar & Lord, 2007). These interpretations, along with little or no attention to Kanner's observations about these children's developmental issues, led researchers to investigate autism as a serious psychological disorder (Wolf, 2004). Through these examples, we can better relate to the importance of historical context and the way we socially construct our world, and more specifically the way ASD has been constructed in the past.

In the 1960s and 1970s, Rutter corroborated the idea of autism as a syndrome and the features of autism (Wolf, 2004). Rutter described behavioral approaches as the best teaching method. In 1987, both Rutter and Howlin in the United Kingdom and Lovass in the U.S. investigated behavioral treatments for young children with autism (Wolf, 2004). These developmental and educationally couched studies showed meaningful gains in IQ and communication skills and decreases in repetitive and restrictive behaviors. Through these examples, we can better relate to the importance of historical context and discourse and how they affect the way we understand, talk about, and act with regard to ASD.

More recently, there has been debate over the diagnostic criteria for the World Health Organization's (WHO) *ICD-10* (endorsed by the WHO in 1990) and the American Psychiatric Association *DSM-IV* (American Psychiatric Association, 2000; Volkmar & Klin, 2005). The two groups, the WHO and the American Psychiatric Association, have had differing ideas and research about categories and conditions relating to autism (Harris, 2007; Wolf, 2004).

This former disagreement between *ICD-10* and *DSM-IV* over defining ASD reflects the constructed and historically situated nature of ASD. Volkmar (2005a) described the process between the two organizations that resulted in a consensus regarding the diagnostic system for ASD, which is now used in both the *ICD-10* and the *DSM-V*. Without understanding this background, someone looking at the current definitions of ASD might conclude that there is just one objective way to view and describe ASD, which may obscure other equally valid ways of conceptualizing and understanding ASD (Volkmar, 2005a; Volkmar & Klin, 2005). The most recent definition of ASD (American Psychiatric Association, 2013) now includes previously separate diagnostic entities: autism, Asperger's, PDD-NOS, and disintegrative disorder. This new conceptualization, according to the American Psychiatric Association (American Psychiatric Association, 2013), is intended to help improve the study and treatment of ASD; however, it also reconstructs autism in a new and somewhat controversial way.

More significantly, these constructions and related discourses prescribe the way we currently understand, act regarding, and treat ASD. Hacking (2007) pointed out that, before the 1950s, autism "was not a way to be a person" (p. 303). We knew how to be a person with polio or a broken leg, but not what it meant or how to be a person with autism (or ASD). It was not possible because we had no concept or circulating discourse about what that meant (Ainsworth-Fleishman, 2001). Medical categories or diagnoses are powerful, because they fix meaning in a certain way and produce effects such as how we think and act concerning a given condition (Hacking, 2007).

In sum, the diagnosis of ASD is generally conceptualized through the medical model—the idea that all illness and disability is a function of biochemical, genetic, and physical changes and/or differences from an established norm. It is important to note that the discourse of medicine incorporates and overlaps with other discourses, including select parts of our knowledge and discourses about parenting, development, moral standards, and values. These discourses, however, may not be as readily available to low-income parents or those whose linguistic and discursive heritage differs from that which “fixes” acceptable meanings of ASD. In addition, understanding ASD requires more than the examination of biological phenomenon and use of medical knowledge; it requires situating health and illness in a broader discursive framework that also includes economic issues, social and cultural interpretations, and economic and political power (Jorgensen & Phillips, 2002).

ASD Diagnostic Discourse and Controversies

Diagnosis of ASD is complicated by the lack of a definitive diagnostic test (Mandell, Listerud, et al., 2002; Shattuck et al., 2009) and comorbidity with other conditions such as intellectual disability, attention deficit hyperactivity disorder, seizures, anxiety, and depression (Geschwind, 2009). Rare conditions such as fragile X syndrome, phenylketonuria, and others are also associated with ASD (Deprey & Ozonoff, 2009; Lance & Shapiro, 2012). Studies indicate a strong genetic influence, although no specific gene has been found that fully explains autism other than the gene linked to Rhett syndrome and Fragile X (Insel, 2013, p. 1).

As discussed above, a dominant influence on the diagnosis of ASD is the APA’s Diagnostic and Statistical Manual of Mental Disorders (DSM). On the DSM-IV-TR (American Psychiatric Association, 2000) website the DSM is described as “the standard classification of mental disorders used by mental health professionals in the United States and contains a listing of diagnostic criteria for every psychiatric disorder recognized by the U.S. healthcare system." ASD was originally, and wrongly, classified as childhood schizophrenia within the DSM-1 and the DSM-2 (Volkmar & Lord, 2007).

Changes in the DSM-V, and thereby new medical/psychological interpretations of ASD (American Psychiatric Association, 2013), came with controversy and criticism. First, parent groups and some researchers were concerned that the new diagnostic criteria would result in loss of services because some children would not qualify as having ASD under the new criteria (Dawson, 2012). Second, the National Institute of Mental Health explained that it would begin developing its own taxonomy, with an increased emphasis on biology by "incorporating genetics, imaging, [and] cognitive science" (Insel, 2013, p. 1). Third, some families were concerned that the diagnosis of autism is more stigmatizing than Asperger's and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). Because of the influence of TV shows, one father stated, "Now, it's almost cool to have Asperger's … The Big Bang Theory and Parenthood feature characters who have it" (Lutz, 2013, p. 1). These and other discourses compete for dominance and privileged status in relation to each other, affecting how we understand and think about ASD.

Because of the ways medical and psychological discourse have defined what "counts" as ASD, these groups/organizations have played a large role in shaping our understanding of ASD, and it is reasonable to consider whether language-based differences might contribute to delay in or prevent the process of diagnosis. The potential mismatch in ASD discourses between HCPs, parents, and the larger North American context are often subtle and result from many aspects of discursive interaction, such as how we speak, from what position, and with what authority. The use of CDA has potential as a methodology to improve our understanding of the possible role of linguistic and discursive disparity in the ASD diagnostic process, and how this may contribute to linguistically and culturally diverse children being diagnosed later than children of dominant-culture parents.

Epidemiological Research

Prevalence is one of the chief ways to talk about and understand ASD within epidemiologic discourse (Giarelli, 2012). Prevalence rate for ASD is a calculation based on the number of reported cases divided by the total number of 8-year-old children within a given group (population); for example, 10 8-year-old children out of the total of 100 in a given city equals a prevalence rate of 10% (Polit & Beck, 2008).

It has been estimated that the prevalence of ASD in selected areas in the U.S. increased by 57% between the 2002 and 2006 surveillance years, as measured by the Autism and Developmental Disabilities Monitoring Network. Whether increases have been due to diagnostic substitution, expansion of the definition of autism, increased awareness by families and health care providers, deinstitutionalization of intellectually disabled children and adults, increased monitoring and surveillance of childhood behavior and development, and/or an actual increase in the incidence, the prevalence of ASD diagnosis is still being debated. Nonetheless, the recorded prevalence by the CDC has been increasing since 1987 (CDC, 2009b, p. 1167). Boys are more likely to have ASD, with a rate of 1 in 70, as compared with a rate of 1 in 315 for girls (Eyal, Hart, Onculer, Oren, & Rossi, 2010; Newschaffer, Falb, & Gurney, 2005).

All of the developmental disorders increased by 17% from 1997 through 2008, with most of the change associated with increases in the prevalence of autism and attention deficit hyperactivity disorder (ADHD). In the 1960s and 1970s, the prevalence of ASD in the U.S. was estimated at 5–10 per 10,000 (1 per 1,000–2,000); ASD was then considered a rare condition. In 2007, the Autism and Developmental Disabilities Monitoring Network (ADDM) reported that about 1 in 150 8-year-old children from multiple areas in the U.S. have ASD (CDC, 2009a). Socially and culturally, there is an increase in concern about ASD and its treatment, regardless of the cause for this increase.

Importance of Early Diagnosis and Intervention for the Child with ASD

Diagnostic Delays

The problem of late ASD diagnosis, as framed by academic researchers, is that it mostly affects poor children, who have the lowest rate of preschool diagnosis of ASD and racial and ethnic minorities (Newacheck et al., 1998; Zimmerman, 2005). Even though ASD symptoms, by definition, have an onset prior to age 3 (Durkin et al., 2010; Liptak et al., 2008; Mandell et al., 2007), children from families of low SES are more likely to have delayed diagnosis (American Psychiatric Association, 2000). Black, Hispanic, and other linguistically/culturally diverse children are less likely to have a documented diagnosis of ASD than White children (Begeer, El Bouk, Boussaid, Tergwogt, & Koot, 2008; Liptak et al., 2008). In sum, the challenges regarding ASD diagnosis are problems that disproportionately affect low-SES and linguistically/culturally diverse families.

Diagnosis Promotes Early Intervention

Delayed diagnosis generally postpones ASD-specific treatment and access to services, thereby missing the optimal treatment period or developmental window (the preschool years, ages 2 to 5) (Mandell et al., 2009). Many researchers have concluded that early and intensive behavioral intervention is the most effective treatment option available for ASD at this time (Altemeier & Altemeier, 2009; Corsello, 2005; S. Rogers & Vismara, 2008), that early intervention tends be more effective with younger children (Corsello, 2005; National Research Council, 2001), and that early intervention optimizes the long-term prognosis for children with ASD (Coonrod & Stone, 2005). Early intervention also prepares children for school because it occurs during the preschool years and helps children develop the communication and interaction skills needed for interpersonal accomplishment without competing with other key educational objectives such as learning to read and write. Early diagnosis does not guarantee early intervention, but it does remove a major barrier to that intervention.

Early Intervention

The purpose of an early intervention program is to facilitate improvements in skills that support social and academic learning. The goals of intervention include improving language and communication skills, social interaction skills, and decreasing maladaptive behavior where appropriate. Important components of early intervention also include parental involvement and training, individualized planning for the child, supportive teaching strategies (often based on applied behavior analysis), strategies to reduce interfering behaviors, gradual transition from a highly supportive environment to more complex and naturalistic environments, a very low teacher-to-child ratio, and identifying and beginning treatment as soon as possible (Dawson & Zanolli, 2003; Harris, 2007; National Research Council, 2001). Early intervention programs usually include intensive intervention using developmental and behavioral approaches. These are comprehensive and include a range of opportunities to improve joint attention, eye contact, language, and overall social interaction with a minimum of 25 hours per week for about 2 or more years (Coonrod & Stone, 2005; National Research Council, 2001).

Cautious optimism is growing about the increasing social and cognitive potential for children who receive early intervention (American Academy of Pediatrics, 2001). Plasticity of the brain requires “activity-dependent regulation” because it is structured to use learning to help direct the growth and development of the brain at certain ages. Plasticity means the ability of the brain to be molded by experience, including the capacity to learn and remember, and “activity-dependent refinement of neuronal connections and synaptic plasticity as a substrate for learning and memory” (Altemeier & Altemeier, 2009, pp. 168-169). Findings by Dawson focus on the idea that both biology (including genetic makeup) and experience contribute to the development of skills and abilities that influence communication and social interaction (Altemeier & Altemeier, 2009). Training and experience can help overcome the challenges of ASD while plasticity is optimal, at ages 1 through 5 (Dawson, 2008). Dawson hypothesized that if pathways for certain developmental deficits are identified and interventions focused on strengthening or developing those pathways, problems in areas such as social attention can be improved (Altemeier & Altemeier, 2009).

Interventional research and associated discourses concerning early intensive intervention claim that it significantly improves developmental outcomes and life course trajectory for children with ASD (National Research Council, 2001). Developmental studies have shown that children diagnosed early can make significant improvement in both expressive and receptive language, social skills, IQ, and academic placement (Dawson, Ashman, & Carver, 2000).

Many studies of early intervention have followed after Lovaas's success of mainstreaming 49% of the children in his study when he used behavioral treatment for children with ASD (Lovaas, 1987); it has been difficult to assess how the children selected would compare with ASD definitions today. However, according to Dawson et al. (2009), the subsequent studies attempting to duplicate the Lovaas's process and results lacked the form of "methodological rigor" that is expected in more realist/scientific-based research paradigms. A more recent study, Smith, Groen, and Wynn's (2000) randomized study using early intervention for PDD NOS, does support early intensive and behavioral approach to early intervention. Testing early intervention practices for children with Autism and PDD NOS, Dawson et al. (2010) conducted a randomized controlled study using intensive developmental and behavioral interventions with 48 children between the ages of 18 and 30 months. The children who qualified for the study were randomly assigned to one of two groups: (1) the Early Start Denver Model (ESDM), which used APA methods for toddlers as young as 12 months and included 20 hours per week of early intensive behavioral intervention from trained clinicians, parental training, along with initial assessment and then each year for 2 years; and (2) The AM (community-based intervention or control group) received the same rigorous evaluations, intervention recommendations and community referrals. The ESDM group had an average of 15.2 hours per week of clinician directed intervention, while the AM groups had 9.1 hours of individual therapy.

The results were based on comparisons at 1 and 2 years using the baseline measurements as the comparison. Two years after the interventions began, the ESDM group had significantly increased cognitive ability, adaptive behavior, and diagnosis. The

ESDM group was also able to maintain its rate of adaptive behavior improvement while the AM group was not. Dawson et al. (2010) state that the AM group began to show greater “delays in overall adaptive behavior” (p. e21). Overall, the ESDM group made the most significant progress with IQ, adaptive behavior and diagnostic status (diagnosis improved from baseline Autism to PDD-NOS at year 2 for 7 (29.2%) of the children in the ESDM group as compared to 1 child (4.8%) in the AM group). It is important to note, however, that some children still regressed from PDD NOS at baseline to Autism disorder at 2 years: 8.3% of the children in the ESDM group, and 23.8% in the AM group (Dawson et al., 2010).

Early intervention researchers have indicated that progress continues to be made in treatment modalities for children with ASD, and the success of early intervention has been demonstrated through many studies and documented in systematic reviews by various researchers (Wiggins, Baio, & Rice, 2006). When early intervention is employed, the results are generally consistent and mitigate autistic symptoms (National Research Council, 2001; Ospina et al., 2008; Rogers, 1996). Early intervention has been facilitated by improvements in the diagnostic process and increased awareness of ASD. This has led to a reliable diagnosis in children aged 2 years and younger when experienced practitioners make the diagnosis (Dawson & Zanolli, 2003; Howlin, 2003; National Research Council, 2001; Rogers, 1996; Rogers & Vismara, 2008).

As a result of current research, the American Academy of Pediatrics (2001) has recognized the importance of early intervention for ASD and recommends starting treatment as soon as diagnosis of ASD is suspected to avoid unnecessary delays in beginning needed interventions. This move by the AAP emphasizes the importance of early intervention for young children with ASD.

Cost Savings and Early Intervention

Studies about the cost-related effects of early intervention indicate that it results in major savings in lifelong care (American Academy of Pediatrics, 2001). Jacobson et al. derived cost-benefit estimates for early intensive behavioral intervention for children with two of the ASDs—autism and PDD-NOS—while accounting for the varying rates of effectiveness that occur with autism (Ganz, 2007; Jacobson et al., 1998). They estimated the cost of early intervention at $33,000 to $50,000 per year. This cost is modest compared to the cost savings, estimated at $187,000 to $203,000 per child for ages 3–22 years, and $656,000 to $1,082,000 per child for ages 3–55 years. These estimates reflect the cost of both treatment and support of the individual with ASD. The cost savings are a result of decreased dependency on specialized services for autism that are needed over a lifetime and improved skills, independence, and quality of life resulting from the early intervention. The family is trained and involved in ways that decrease costs by promoting understanding and adaptation to ASD. Early intervention can result in the child’s developing skills that promote higher levels of independent living later in life, which can reduce the cost of lifelong care by up to 66% (Jacobson et al., 1998).

Early Diagnosis and Discourses of Family Adjustment/Adaptation

Early diagnosis can assist parents in adapting to their child’s behaviors and needs, and results in improved overall understanding of ASD (Jarbrink & Knapp, 2001). Early diagnosis of ASD means that parents can begin to seek appropriate treatment and access to resources. This is important, because parents need to notify the school system early so their child qualifies for “free and appropriate education” under Section 504 of Rehabilitation Act of 1973 and its implementing regulations found at 34 C.F.R. Part 104. Parents can seek public and private services in the community if their child has been diagnosed. Some generic services for promotion of development are available without a diagnosis, but those do not include the intensive and ASD-specific treatments a child could otherwise receive.

Delay in obtaining a diagnosis is thought to delay a family’s ability to adapt more fully to ASD. The family is an integral part of any individual, and especially for a child with disabilities. Families provide economic support, daily care, recreation, education, self-identity, affection, and spiritual roots (CDC, 2009a; Mandell, Listerud, et al., 2002). If families have not received a diagnosis, it is difficult for them to fully acknowledge the problem and its impact on the child and family. Receiving an ASD diagnosis enables parents and families to appraise their situation and continue the process of adaptation in ways specific to their child’s condition and behavior (Seligman 2007).

Adaptation includes modifying roles, behaviors, and priorities in a family, in addition to seeking professional help and services specifically developed for ASD. Adaptation is essential to beginning the process of balance and stability (Hamilton, McCubbin & McCubbin, 1988; Twoy, Connolly, & Novak, 2007), which includes a state of normalization or regularity within the family (Lavee, McCubbin, & Patterson, 1985; McCubbin, Thompson, Thompson, McCubbin, & Kaston, 1993; Patterson & McCubbin, 1983). Normalization occurs when “life resumes a taken for granted quality” (Insel, 2013, p. 1) or a new type of normal for the family. Early intervention assists the family in the process of adaptation that supports the development of the whole family and the child with ASD. The diagnostic process, then, not only constructs a child as a child with ASD, but it also constructs parents and families as components in the diagnosis, intervention, and maintenance of a child with ASD throughout all aspects of the child's and family's life.

In sum, ASD research literature points out many benefits of early diagnosis. These include the potential of early intense intervention to improve outcomes for children with ASD, money savings nationally, and family adaptation through training and education. Conversely, these findings also suggest that delayed diagnosis limits opportunities to ameliorate the developmental challenges of ASD and increases the lifetime costs of care per child.

Health Disparities and Delays in ASD Diagnosis

As epidemiological studies have revealed disparities in both rates and timeliness of ASD diagnosis, researchers have increasingly turned toward social, economic, and cultural factors to explain these disparities, unlike earlier researchers, who focused predominantly on biogenic or psychogenic theories, or diagnostic criteria that focused only on symptoms. Health disparities research using discourse analysis promotes understanding of the inequality in discursive resources and the potential for linguistic and discursive disparity that increase the likelihood of delayed diagnosis for families of children with ASD.

SES and Delayed ASD Diagnosis

Socioeconomic status (SES) is a measure of class and economic well-being. Graham defined health inequalities as "health differences between groups occupying unequal positions in society" (Graham, 2007, p. 4). SES is usually measured by using one or a combination of measures, including income, insurance coverage, occupational status, level of education, and other measures of wealth and status. SES has proved to be a strong and consistent predictor of a person's health and life expectancy (Graham, 2007, pp. 30-32). I suggest that class and status can also be analyzed indirectly as a function of the level of linguistic and discursive resources and capital.

Durkin et al. (2010) found a strong positive correlation between SES (income) and increased prevalence of those diagnosed with ASD. The prevalence of diagnosed children varied by SES and not by race/ethnicity except for the low-SES category, which was comprised of more Hispanics and non-Hispanic Blacks (Durkin, 2010). Parallel to this finding is the work of Adler et al., Cockerham, and Fountain et al. concerning the influence of communities (neighborhoods based on zip code designation) on the rate of ASD diagnosis (Adler, Boyce, Chesney, Folkman, & Syme, 1993; Cockerham, 2004; Fountain, King, & Bearman, 2011). The researchers examined the differences in neighborhoods based on the median property value, percent of residents with a college degree, and percent of residents living below the federal poverty level. The higher-SES neighborhoods were likely to have more children diagnosed with ASD. The researchers further found that "there is a persistent gap in the age of diagnosis between high and low socioeconomic status (SES) children" that has become smaller but still significant (Fountain et al., 2011, p. 503). At the individual level, the amount of parental education remains an important factor because higher levels of education increase the chances of an early diagnosis (Fountain et al., 2011). This study also reinforced the finding that non-White and Hispanic individuals are generally diagnosed later than their White counterparts.

These studies by Fountain et al. (2011) and Durkin et al. (2010) highlight the importance of examining both race/ethnicity and SES to gain a more nuanced understanding about disparities in health and health care. The findings also support my approach in this study of examining the multiple social and economic influences exerted through discourse, which can marginalize groups or individuals and possibly delay diagnosis.

Liptak found that poor, near-poor, and nonpoor families have similar overall rates of autism (49 per 10,000, 44 per 10,000, and 47 per 10,000, respectively). Poor families, however, have the lowest rate of parent-reported autism for children age 6 years and under, with a rate of 16 per 10,000 (Liptak et al., 2008). This indicates that the poor with less education and resources (a) may be at an increased risk of discursive disparity, (b) may have fewer discursive resources to understand their child’s behavior, and (c) may lack the ability to be convincing discursively when speaking with a HCP. In Liptak’s study, poor families were measured as living at less than 100% of the poverty level, near-poor families from 100% to less than 200% of the poverty level, and nonpoor families as living at or above 200% of the Department of Health and Human Services poverty guidelines.

The levels of parental education and income, both measures of SES or privilege (as defined for this study), have been found to be inversely associated with the age at diagnosis of ASD. Children diagnosed at a younger age typically have parents with higher levels of education and higher income levels (Liptak et al., 2008). This supports Liptak’s findings of increased risk of delayed diagnosis for low-SES families with fewer overall resources, including fewer discursive resources (Liptak et al., 2008). In this study, I examined the interaction of ethnicity, SES, and the associated use of language, along with discursive resources and practices, which will help to further the study of this disparity of delayed diagnosis.

In this study, I assumed that low-SES and poor families have access to different discursive resources that diverge from mainstream dominant ASD discourse in the U.S. I also assumed they may have had less discursive competence with dominant discourse than their more privileged counterparts, who generally have different ways of being discursively competent and have different discursive resources. Delayed diagnosis based on linguistic heritage and level of privilege is not just about prevalence, biology, and development; it is also about how we socially and culturally construct our world—in other words, how we interact with those in authority or power, what discourses we draw upon about childhood, and what expectations we have for growth and development. These and many other issues are socially and culturally constructed within a historical context and have real consequences.

Race, Ethnicity, and Delayed Diagnosis

Epidemiology-based research has yielded conflicting results about the influence of race/ethnicity on the age of ASD diagnosis (Mandell et al., 2007; Mandell, Listerud, et al., 2002; Mandell & Novak, 2005; Mandell & Palmer, 2005; Mandell et al., 2009). Mandell et al. (2002) found significant differences by racial/ethnic status, based on data from Medicaid claims showing that Black children were averaging a diagnosis of ASD 1.6 years later than White children; however, a study conducted several years later (Mandell, Listerud, et al., 2002), based on a survey of caregivers, did not find significant differences at age of diagnosis. Mandell, Thompson, Weintraub et al. (2005) used a different design, which relied on voluntary participation. This might indicate that the most vulnerable did not participate, which could skew the sample enough to render non-significant results. This critique is significant because results from another study, by Mandell et al. (2005), again reflect differences based on race/ethnicity. Black and Hispanic children were less likely than White children to have a documented diagnosis. The researchers examined records from multiple sources and found that 58% of children who met the criteria for ASD had a documented diagnosis (Mandell et al., 2009); therefore, 42% of the children that fit the criteria for ASD had not been diagnosed, and linguistically and culturally diverse children were significantly less likely than White children to have had a diagnosis.

The work of Mandell et al. (2009) in his article about the racial and ethnic disparities in diagnosis of ASD found that Hispanic families were significantly less likely to report a diagnosis of ASD than either White or Black families. In another study about disparities in diagnosis, Mandell, Ittenbach, Levy and Pinto-Martin (2007) found misdiagnosis to be common in Black children with ASD. These researchers found that misdiagnosis prior to obtaining a correct diagnosis of ASD was more likely for Black children than White with Black children 2.6 times less likely to receive a diagnosis of ASD on the first visit than White children (Mandell et al., 2007). The authors concluded that parents may describe symptoms differently or the HCP may have different expectations or interpretations of parental explanations; these linguistic and discursive issues are central to this study. These two groups, Black parents and HCPs, are presenting and interpreting differently, which may be due to differences in socioculturally-based expectations and interpretations of presentation of the child with ASD. This is also a problem because the delays, due to misdiagnosis, are a barrier to early intervention.

These findings reflect the complex nature of disparities and the difficulty of separating the influence of disadvantages. It is difficult to separate the influence of these disadvantages because they are constitutive of each other. The problem of delayed diagnosis is more common for parents from a non-English speaking linguistic heritage because, in the absence of a definitive diagnostic test for ASD, U.S. English speaking discursive and linguistic competence is so important in the diagnosis of ASD in the U.S. Each health disparity may also vary based on the context of the disparity, the specific health problem, specific groups or culture at risk, and the history of the condition. For example, factors affecting disparity can include lack of HCP's, difficulty of diagnosis, cultural barriers to treatment, and fears about diagnosis. These disparities are socially and culturally constructed through language by the dominant culture. Understanding more about which groups are marginalized, how and why disparities are socially and culturally constructed, and the aspects of language and discourse involved, will help us better understand the disparity of delayed ASD diagnosis.

Cultural Influences and Health Disparities

Cultural meanings and structures interact with sociocultural linguistic heritage and with the context within which they occur either to promote or restrict health. Mandell and Novak (2005) stated that cultural influences "are intertwined with thoughts and behaviors, and thereby influence how parents interpret and act on differences in their child's development from accepted medical or social norms" (p. 110). Supporting this notion, Coonrod and Stone (2005) found that East Indian families were more likely to report social difficulties, while American families were less likely to comment on social issues unless asked. Levy and Hyman (2003) studied a small sample of Hispanic families and found that Hispanic parents of a child with ASD were six times more likely to use a nontraditional method of treatment than non-Hispanic families. Because of the small sample size, Levy and Hyman's study must be interpreted cautiously; however, it supports the concept that there are social and cultural differences in interpretation regarding the perceived need for medical intervention.

Differences between various ethnic discourses and cultures and dominant medical discourses and culture may create barriers to communication and understanding. At the same time, culture appears to influence parental constructions of the severity and urgency of their child's symptoms. For example, in a study of parent attitudes about their child's behavior, Lau, Garland, Yea, et al. (2004) found that Asian/Pacific Islanders and African American parents were less likely to agree with teachers that claimed that a health problem might be the cause of behavioral issues. In the same study, Lau et al. (2004) found that White parents were more likely to accept personality, relational issues, familial issues, or trauma as the source of a child's problem than African American, Asian/Pacific Islander, and Hispanic parents. These differences suggest that other culturally mediated differences in the discourse used to define ASD may influence assessment of a child's behavior and subsequent efforts by the family to obtain a medical/psychological assessment. These differences are difficult to assess without a critical examination of cultural, social, and contextual information.

Cultural interpretations and resulting constructions may also affect the professionals involved in making decisions about diagnosis and treatment of ASD. For example, the Institute of Medicine's (IOM) Unequal Treatment (2003) lists two areas of concern as focuses for research: (a) discrimination at the organizational and policy levels; and (b) discrimination at the individual, patient–provider level. The IOM committee (2003) defined discrimination as "differences in care that result from biases, prejudices, stereotyping, and uncertainty in clinical communication and decision-making" (p. 4). Many studies support the idea that, at the level of clinician interaction (as compared to interactions at an organizational level), clinicians contribute to disparities. This includes discrimination based on factors of race, age, SES, and normative expectations that "guide the therapeutic relationship" (Institute of Medicine, 2003, p. 4).

In their review of empirical studies that addressed these issues, Cooper and Roter (2003) identified areas of concern. First, social and cultural norms as defined or constructed by the health care provider may vary significantly when compared to the patient's. These differences may exacerbate communication problems such as missed nonverbal cues or unrecognized requests for information.

Second, Cooper and Roter cited studies supporting the idea that health care provider bias or negative stereotypes lead to assumptions about racial and ethnic groups' levels of intelligence, negative personality attributes, and likelihood of engaging in high-risk behaviors (Cooper & Roter, 2003).

Third, Cooper and Roter (2003) suggested that health care providers may be responding to socially patterned expectations for care that influence attitudes and beliefs about patient roles and treatment. Cooper and Roter noted that other researchers, including Geiger, had reached similar conclusions, analyzing racial and ethnic disparities in health care treatment and finding overwhelming evidence that provider and institutional bias contribute significantly to health disparities.

Disparities based on race, ethnicity, and language are issues that are difficult to capture through more traditional medical and epidemiologic research methods. These disparities are rooted in larger issues of culture, cultural expectations, and language, including social mores and norms. Moreover, the influences of medical and psychological culture are not noted as such; in these studies, cultural influences are most often attributed to patients and “others” and not to HCPs themselves. As a result, it is important to use methods that allow the critical examination of the role of culturally available and dominant discourses about ASD, and how these may give rise to diagnostic disparity. This process will help us understand how discourses used by parents and professionals are contributing to the production and reproduction of inequality in the diagnostic process.

Health Literacy

Health literacy is an important part of having sufficient discursive and linguistic resources to obtain health care, such as getting an appointment with a specialist or being persuasive when discussing parental concerns about a child’s behavior. Those most at risk for delayed diagnosis are also most at risk for fewer skills that support health literacy. Many health-related professionals are aware that Health and Human Services (HHS), through the Office of Disease Prevention and Health Promotion Department (2010), describes health literacy as an important public health issue as the U.S. becomes more diversified and health care more complex. However, we are often less aware of estimates of health literacy provided by the HHS Office of Disease Prevention and Health Promotion (2010) that suggest approximately “54 million adults with any kind of disability, difficulty or illness are especially vulnerable and are more likely to perform at the lowest literacy levels" (p. 9). Those 54 million adults are the ones HCPs care for in hospitals, clinics, and long-term care every day, yet it is often take for granted that they understand their care and treatment, when chances are, they do not. Health literacy issues are also recognized by professionals in colleges of nursing, hospitals, and clinics, as described by Cavillo, Clark, Ballantyne, Pacquiao, Purnell, and Villarruel (2009), when they suggest "including levels of health literacy into care plans and health education initiatives" (p. 141), and continued learning about health literacy by nurses and others.

Qualitative Studies Regarding ASD Diagnosis

In this section, I present a review of current qualitative research that provides background and facilitates examination of a possible discursive disparity between parents of differing SES and linguistic heritage and HCPs when evaluating a child's behavior.

A classic article on therapy management by Janzen (1987) described the process of obtaining a diagnosis, the selection and evaluation of treatment, as well as care for the sick person. The article examined some of the culturally distinct ways this process takes place using examples from Africa and Canada. In the area of Africa used in this article, it was the matriarch of the family who made decisions about the seriousness of the illness or affliction, where to get help, who is responsible to help family members if hospitalization is required, and so forth. The African family was compared to a Canadian family and the cultural differences in decision making about illness and other bodily problems. The aspects of therapy management examined in this inquiry were the process of parental assessment and then professional assessment and diagnosis, especially as it applied to parents' interpretation of the meaning of their child's behavior through discourse as compared with medical interpretations. The study found that parental assessment of the causation and gravity of the illness was pivotal in deciding whether or not to seek further help. Thus, the study suggested that it is important to understand how parents construct their understanding of their child’s behavior, because it drives their own therapy-seeking behavior, including diagnosis and treatment (Janzen, 1987).

Disparity research, CDA, and disability studies include a growing body of research directed at the social construction of disabilities, illness, and in general, the social determinants of health and health care (Daley, 2004; Young & Garro, 1982). Research supports the idea that by studying how illness or disability is socially constructed—emphasizing the centrality of language, culture, and interaction—one can better comprehend the forces that shape our understanding of health and illness (Biklen & Kliewer, 2006; Shakespeare, 2010; Shaw, Dorling, & Smith, 1999). Brown (1995) stated that, through this understanding of the socially constructed nature of our world, it is also possible to

> examine how social forces shape our understanding of and actions toward health, illness, and healing. We explore the effects of class, race, gender, language, technology, culture, the political economy, and institutional and professional structures and norms in shaping the knowledge base, which produces our assumptions about the prevalence, incidence, treatment and meaning of disease (and disability). (p. 34)

The medical model, for most in U.S. society, is the dominant framework through which health and disability is examined and explained. Brown (1995) differentiated between the social construction of medical knowledge and the social construction of illness. The medical model is based on biomedical science or framework of measurement, treatment, and control or cure of a condition, as compared to the lay construction of illness that is mostly concerned with the understanding of illness (Brown, 1995). Health care providers are trained for years in specific ways of thinking, assessing, and making sense of the body, which is often very different culturally, and thereby different conceptually, from the understanding or discursive repertoire from which parents draw to make sense of autism or some other condition. Goggin and Newell (2003) cited Fulcher's comments on the medical model, stating, "Through its language of body, patient, help, need, cure, rehabilitation and its politics that the doctor knows best, [medical discourse] excludes a consumer discourse or language of rights, wants and integration in mainstream social practices" (pp. 23-24).

Through this very specific way of seeing the world, health care providers assess, categorize, and make decisions about treatment for patients. Parents bring their own perspective couched in their cultural heritage and the class in which they live. Parents of low SES, or who are linguistically and culturally diverse, are especially vulnerable to differences in linguistic skills, education, and other discursive resources as compared to highly trained and generally higher-SES health care providers (Fulcher, 1989, p. 20). This may also be true for the professional who has trouble transitioning from the medicalized nature of the evaluation to assure understanding by lay parents. The distinction between lay and professional discourse about illness is also evident in discourse about disability, and sets the stage for a discursive mismatch between health care providers and parents.

This examination of the medical model is important to understanding the potential discursive mismatch between parents and health care providers in two ways. First, parents do not always interpret the differences in their child's behavior as problematic or as deviating from a normative standard of behavior. Differences in behavior may be attributed to many different sources, including a normal delay in development or unique qualities of a particular child. Second, health care providers and parents may seek to share information, but due to differences in power, language, SES, and culture, they may not be effective in sharing information and collaborating for the well-being of the child (P. Hall & Lamont, 2009; Marmot, 2005; Yates, 2001).

This discussion of the medical model should not be construed as a criticism of the field of medicine, which Smith (1999) described as "a discourse that seeks to understand physical pathology, diagnose that pathology, and provide a set of procedures to ameliorate its harmful effect" (p. 124). Rather, in this study I examined the effect of the medical model, related discourses, and accompanying metaphors to illustrate and describe the more abstract and social aspects of our experiences with medical science and health in general.

A problematic assumption of the medical model, according to Smith, is the idea that illness is considered to be a deficit or deviance from normal, and can be fully accounted for in this way without consideration of social determinants (Smith, 1999). Biklen and Kliewer summarized concerns about the medical model by identifying a deficit ideology within the model, which promotes a negative conceptualization about the challenges faced by people with a disability and their families (Engel, 1997). Ideology was defined by Schwandt (2001b) as a "set of social, political and moral values and attitudes that shape a social group's interpretation of its behavior and its world" (p. 11). Medical ideology defines how we act and think about illness and disability within our culture unless we challenge our taken-for-granted notions of what it means to be disabled, disordered, or sick. Prior to a diagnosis and exposure to the medical model, parents may not have access to the same discourses as their health care provider. Parents may have different cultural conceptions regarding disability and development that are not consistent with a deficit approach to the meaning of their child’s behavior. It is important to explore the meanings parents attach to their child’s behavior before a diagnosis is made. Doing so provides a better understanding of the way parents themselves construct behavioral differences.

Developmental issues are often a source of concern for parents; however, if there is asymmetry in the interactions between parents and HCPs, the HCPs may miss life world concerns of the parents (Schwandt, 2001a, p. 11). This process may occur through suppression of patient or client experience in favor of a clinical or medical model perspective that supports the HCP as the identified expert (Maynard, 1991).

Ahern (2000) used phenomenology to examine the experiences of parents of children with general physical developmental delays. The study was not specific to children with ASD or diverse low-SES families; however, the children and their parents did experience a process and setting similar to that used for children who are evaluated for ASD. One of the challenges identified by parents in Ahern’s (2000) study was frustration with health care providers during the diagnostic process because the parents felt that their parental observations and concerns were not validated or not acknowledged.

Some of the metaphors relating to ASD include the normal/non-normal binary conception of behavior and ways of thinking, autism as disabled, autism as fortress, and autism as a different world, their own world. Descriptions of ASD might include assumptions such as seeing a person with ASD as mentally retarded, ASD as a disease, or people with ASD as diseased. These metaphors and descriptions, and others more culturally specific, may produce a discursive mismatch when parents and health care providers interact and discuss behaviors of a child, or provide added meaning to the ways in which ASD is constructed in a given context. The influence and power of metaphors and different understandings of ASD need to be examined to better understand the effects of the assumptions embedded in them and how they contribute to the construction of ASD.

HCPs may not be aware of culturally patterned ways of expressing concerns, and therefore they may downplay issues they perceive as not being applicable. Critical discourse analysis is useful in teasing out these issues because language and how it is employed and exchanged is central to the study of discourse.

Broderick and Ne’eman (2008), along with Danforth and Naraian (2007), examined metaphors frequently associated with ASD. Metaphors can add additional meaning and insights to a concept that literal language cannot (Danforth & Naraian, 2007). ASD is often described as coming from or going to a foreign space. This is interpreted as being so very different—neurologically or otherwise—that the person with ASD must be alien, as if from another world (Danforth & Naraian, 2007).

Avdi, Griffin, and Brough (2000) performed an analysis of discourses used by parents as they described differences or “problems” in their child’s behavior. Parents had multiple and often conflicting messages in their talk. The authors found that in general, the perspectives and subjectivities of the parents were ignored, whereas professional accounts were championed. This finding supports the need for a critical discourse analysis to examine if parental discourses are different and marginalized, with special attention given to possible ways in which there might be a discursive mismatch between parents and health care providers that can be exacerbated by low-income or linguistically/culturally diverse status. It is also important to examine the way discursive and linguistic resources are employed or lacking when parents seek services for their child.

In conclusion, my analysis of the literature related to ASD and its diagnosis suggests that there may be meaningful benefits from conducting critical a critical study about parental constructions of ASD and how their discourses match up—or not—with the dominant U.S. discourse about ASD. Such research may prove to be very helpful in designing interventions to help parents from diverse linguistic heritages and HCPs make connections when talking about ASD.

CHAPTER 3

THEORETICAL FRAMEWORK AND METHODS

Introduction

This study focuses on the parental use of language and discourse and its relation to the ability of parents from diverse linguistic heritages and levels of privilege to obtain a timely diagnosis for their child with ASD. In this chapter, I first address the theoretical framework and study design used in this study. I then discuss phases of the study from obtaining a sample of parents and ASD-related websites, collecting data through parent interviews and websites, and then analysis of the data. Finally, I discuss procedures for human subject protections of persons involved in this study.

Theoretical Framework

I based this study on the epistemology of constructionism that supports critical discourse analysis. This basis provides the theoretical framework to guide the design and assumptions of this study. A growing number of researchers frame ASD as a social construction; however, only a few have introduced the ideas of the discursive construction of ASD. None have linked discursive disparity with diagnostic disparity. The potential difference in discourse and discursive resources relating to the diagnosis of ASD is an issue that has not been directly addressed in the literature. Thus, in this study, I used critical discourse analysis (CDA) as a theoretical framework, and CDA and content analysis as methods to explore how differences in language, discourse, and discursive resources may influence the timeliness of ASD diagnosis. Specifically, I investigated the accounts of parents of a child with ASD to critically explore whether and how parental accounts reflect elements of the larger U.S. sociocultural discourse of ASD.

A social constructionist framework provides the needed context for a linguistic and discursive study that facilitates better understanding of the disparity of delayed diagnosis. Social constructionism supports the idea that knowledge is discursively produced through interaction, and that it is contingent upon its historical and social context (Jorgensen & Phillips, 2002). This is not to claim that everything is discursive, but that what we know is made accessible to us through sociocultural discourse (Jorgensen & Phillips, 2002). This perspective values all knowledge (i.e., subjective and objective, parental accounts, scientific paradigms, medical studies), and considers all of them socially constructed (Crotty 2003).

Gavey (1989) summed this idea of meaning making when she stated,

> [A]ll meaning and significant knowledge is discursively constituted through language and other signifying practices. Any interpretation or understanding of an object or event is made available through a particular discourse concerning or relating to that object or event. (p. 463)

Social Constructionism, Critical Theory, and Intersectionality

Critical theory had its beginnings in Marxism, but more recent forms of this theory reject all-encompassing or grand theories about the social world (Cheek, 2002, p.5). As a result, there is no “universal knowledge, because there is no context free, neutral base” for knowledge production or claims of unadulterated or pure truth (Jorgensen & Phillips, 2002, p. 175). In line with postmodern theory, the focus is on the signifier—not the signified—and the production of meaning and discourse (Crotty 2003). We learn about the social world with the construction of meaning through social interaction, language, and discourse use within a given sociocultural context and time period.

According to Phillips and Jorgensen (2002), one of the main concerns of critical theory is with making oppression visible through the critical analysis of “dominant and naturalized understandings” (pp. 191-192), or unchallenged assumptions. One way this is accomplished is through critical discourse analysis of text and talk to explore assumptions, especially those made in relation to marginalized groups or marginalizing practices.

Intersectional theory, developed and refined by Crenshaw (1991) and Collins (2012), respectively, is an important concept in this study. Intersectional theory highlights the interconnecting and co-constitutive nature of multiple disadvantages. An example may be a low-income Hispanic woman without insurance, with a chronically ill child. These disadvantages not only intersect, but also constitute each other in different ways. This mother may have an a good education (associate degree in business), but she cannot hold down a full-time job due to the fragile condition of her 4-year-old child’s health which include ASD and gastrointestinal problems, and the inflexible human resources policy at her part-time job. This mother is recently divorced and currently without insurance. She and her child spend extra time in the emergency room and at times, they cannot afford the prescribed medication. However, she has a car and a social worker to help her navigate local resources and the ongoing need to apply and re-apply for insurance. Her experience is different based on her unique situation (single, recently divorced mother, with a chronically ill child). The intersection of class, race/ethnicity, and gender lead to the “simultaneous production of race, class, and gender inequality” (Schulz & Mullings, 2006, p. 5). In this example of a struggling mother, it is clear that she has some advantages also. In this study, I examine the way that linguistic heritage, income, and education interact and constitute the disparity of delayed diagnosis for certain groups. Gender, as a disadvantage/advantage, is not a part of the study design because of the small number of male parent participants recruited for this study.

The frameworks of CDA and intersectionality research provide a critical perspective that supports improved understanding of parental interpretation and construction of experiences regarding their child and ASD. Taylor (2001) claims that a basic assumption of discourse analysis is that “the language available to people enables and constrains not only their expression of certain ideas but also what they do” (p. 9), such as the ability to make a doctor’s appointment or the way a person allocates resources.

This analysis is significant because minority, poor, and marginalized parents are more at risk for having a delayed diagnosis of ASD. This study hypothesizes that parents with less privileged or marginalized linguistic heritages are less likely to obtain a timely ASD diagnosis for their children than their more privileged Anglo counterparts who have expertise in the dominant medicalized discourse. Level of privilege and sociocultural heritage, which influence the availability of sociocultural and linguistic/discursive resources, are co-occurring, and each influences the other.

In the U.S., it is an advantage to have a U.S. sociocultural heritage because parents are trained through culture, language, and discourse about appropriate ways to interact, gain access to resources, and apply language and discourse in ways that benefit them politically, socially, and economically. Privilege and heritage are linked, and it is especially apparent in this study where the Anglos were relatively more privileged, much of which stemmed from their ability to be fluent in English, in a country that mostly speaks English, and generally they had a higher level of education and income.

Discourse Theory

Discourse Is Context-Dependent

Discourse is naturally tied to and interacts with its context of culture and with specific social activities and settings of participants (Gavey, 1989, p. 463). For example, ASD may have multiple biologic and neurologic etiologies. However, the process of diagnosis occurs within a social context, with assessment and findings based on discursive frames that reflect culturally and socially accepted medical practices and perspectives at a given point in time (Gee, 2005; Taylor, 2001). Those most successful in attaining their objectives when meeting with a health care provider are discursively competent within the context of medical, social, and linguistic ways of interpreting the world, because discursive competence is an effect of sufficient power and knowledge (Waitzkin, 1989).

Wetherell (2001b) stated, “We only know what kind of thing an event is—even the most private and idiosyncratic events—through cultural and conventional codes” (p. 25). Cultural and conventional codes are expressed through discourse, which includes nonverbal or body language, written texts, spoken language, images, and sounds. A premise of this study was that parents need the cultural codes or mores of social settings to be effective in communicating with their HCPs. Middle- and upper-class Americans with access to medical care grow up learning how to act and understand the processes that take place in an office visit with an HCP, but those with less access or different experiences and resources are less successful with this socially mediated process.

Discourse Is Active and Constitutive

Discourse does work; we use language and discourse to know how to conduct meetings, make appointments, and to understand our world and the interactions within it. This is demonstrated with the medical/psychological definition of ASD. The medical definition constructs a child with ASD and how we can expect that he or she will act and respond to a variety of experiences. Wetherell (2001) stated, “As accounts and discourses become available and widely shared, they become social realities to be reckoned with; they become efficacious in future events” (pp. 16-17).

A child with ASD-related behavior is no longer defined as simply being “crazy”; rather, such a child is constituted as one with ASD (Hacking, 1999). Teachers in school can now be trained how to teach children with ASD and how to collaborate with their parents. Mothers of children with ASD are no longer considered to be a refrigerator mother or to have trouble expressing emotion and love to their child, but can now constitute or construct themselves as the mother of a child with a neurodevelopmental disorder called ASD (Hacking, 1999). The definition of ASD enables a pediatrician to be a “good doctor” for children with autism by taking seriously delays in development, making referrals to specialists, and helping parents sift through new treatments. The definition of ASD by the American Psychiatric Association has created or constructed a form of social reality (Hacking, 1999).

Discourse Is Never Fully Fixed

Discourses about the diagnosis of ASD comprise a formal set of understandings, and ways of talking about ASD that constitute a somewhat fixed, specific set of practices (M. Wetherell, 2001). The definition of ASD, however, continues to change as it is re-examined and interpreted by different groups. Discourse has shifted as medical and societal perceptions of ASD have changed.

Because medicalized discourse seems fixed and natural, it is difficult for those parents without the accepted medical words, categories, and definitions to be heard outside of the dominant discourse of ASD (Fairclough, 2001). Parental definitions may provide a different way of seeing or understanding ASD that is not as fixed or widely recognized, but when parents become literate in medical discourse, it is as if they become discursively competent in the medical way of talking, thinking, and understanding concerning the concept of ASD (Hall, 1997).

Discourse Is Cultural

The definition of culture is necessarily vague and contested. Culture includes social knowledge and skills, discursive and linguistic practices, and ideologies of a group (Taylor, 2001, p. 25; Van Dijk, 1997). Resources within culture include history, social movements, education, values, and institutions. Such resources play a role in how we think about and understand ASD.

Regarding the growth of a child, different societies and cultures and have different expectations for normal development, along with different views of the social acceptability of difference and disability (Fitch, 2001, p. 62). Grinker (2007) and Feinstein (2010) described areas in the world that do not share the U.S./Western

European conception of what it means to be autistic. Grinker (2007) stated,

> There are still cultures in the world today that do not have a name for autism, or that do not even see as pathological the symptoms we call autistic; there are the so-called "marvelous children" of Senegal, called "nit-ku-bon," or the Navajo Indian children with Autism in the American Southwest who are seen simply as perpetual children. (pp. 51-52)

France has had a different view of ASD and its treatment compared to other western European countries and the U.S. Historically, France made a major turn to psychoanalysis in 1968 through a series of events—especially the philosophical and social movement—that supported the idea that "human beings are shaped, distorted, and corrupted by culture, not by nature" (Feinstein, 2010, p. 103). This negative perception of the influence of culture supports a psychological view of ASD, which is in contrast to a broader view that includes physical/biological and environmental sources for the causes of ASD.

One of France's leading researchers skilled in American and European research methods concerning Autism stated:

> For some people—thankfully not all—even suggesting that there could be organic causes of Autism was a sacrilege. They considered autism to be a psychological and sociological disorder, and should not be tackled with medical language. They couldn't accept any attempt to examine the autistic child physically. (Grinker, 2007, p. 94)

These systems of meaning, developed through history and culture, unite them and support their identity as French.

A discursive approach to culture and meaning exposes the powerful ways in which people construct meaning, identity, and power imbalance through discourse. How we talk about ASD is a result of the cultural and linguistic practices we use and the discursive resources we draw upon.

Discourse is Part of a Discursive Frame or Model

A discursive frame or model is a metaphor to help establish that many smaller or distinctive discourses may fall within a larger discursive model. According to Cheek (2004), there “are a number of discursive frames for thinking, writing, and speaking” (p. 1143) about any given aspect of our lives. Some of these discursive frames are more socially and culturally prominent, accepted, and therefore more powerful than other discourses (e.g., ASD is a medical condition). Dominant discourses about ASD are rooted in medical, scientific, and psychological professional frameworks in that a doctor or psychologist/psychiatrist must diagnose a child before that child can receive federally funded services. Some discourses are not aligned with the dominant discursive frame regarding ASD. Nondominant discourses may include untested treatments and different assumptions about ASD in general (e.g., ASD is caused by a mineral imbalance in the child’s body).

Linguistic and Discursive Competence Affect Privilege

The concepts of discursive and linguistic competence and capital (hereafter referred to as discursive competence), along with the parallel notion of cultural capital, stem from the work of Pierre Bourdieu. Discursive competence provides us with know-how, skills, and information about the world that aligns with the dominant discourse of a group or culture (Feinstein, 2010, p. 103). Gledhill (1997, p. 375) describes discursive competency as “our capacity to use codes” (sociocultural meaning through discursive and linguistic practices) in order to communicate and accomplish social goals. Discursive competence is embedded in the specific interpretative frameworks and social practices of the dominant culture. However, discursive competence is also contextual, and may vary depending on what a person is trying to accomplish or the setting/context in which the discourse is being used. Discursive competence is always measured against the dominant discourse, because it is more powerful or dominant and more likely to convey the truth within a given culture or group. Therefore, a person who is highly competent in the use of discourse is also highly competent with the practices and know-how of the dominant discourse. I began this study with the premise that some people may have access to dominant forms of discourse and have higher levels of discursive competence and resources through privilege (social position or class), including education, economic influence, internships, employment, and other experiences and opportunities in life that build privileged individuals (Lamont & Lareau, 1988, p. 155). In this way, some individuals are situated within cultural and discursive boundaries that privilege them over others in their interactions (Alasuutari, 1995).

Individuals use cultural capital to accomplish social goals, such as obtaining information and resources, for example, admission to an Ivy League school. Discursive competence and capital provide not only skills with language and communication, but can also be a source of status, the social know-how to get things done, and the experience to provide context and understanding to a given situation. Bourdieu’s (Allan, 2007) work provides a framework for the idea that people have a variety of cultural standings, privilege, and discursive competence, and therefore different opportunities within a given context.

Parents of different social status, education levels, and linguistic heritages may represent themselves in a specific way in relation to the process of obtaining an ASD diagnosis (for example, assertive, helpless, fearful, or competent). This affects their engagement in the process—such as in their completing forms, talking with HCPs, and negotiating health care systems. All parents actively construct a representation of their child and themselves in relation to the dominant U.S. discourse about ASD as they explain their situation. These parental explanations help improve our understanding of the larger sociocultural issues that may contribute to delays in diagnosis, such as concerns over stigma or linear progress in development and school.

The concept of privilege, as defined for this study, is the combination of education (more than high school graduation), income (above 150% of federal poverty guidelines based on family size), and linguistic heritage (English language consistent with U.S. and the dominant culture). I included linguistic heritage as a measure of privilege because I assumed that being facile in the dominant language and discursive practices of a culture would be a positive facilitator in the process of assessment and diagnosis of ASD.

Design and Methods

The design for this study is based on social constructionist methodology and methods that are specific to each aim in this study and take place in a linear fashion to support the best outcome. This study is a two-group (Hispanic and Anglo) cross-sectional, comparative critical discourse analysis based on primary data collected through parental interviews of Anglo and Hispanic parents, and secondary data collected from ASD related websites to represent the dominant discourse. This study consisted of two phases.

In the first phase, after primary data collection of parent interviews and transcription of data, I applied qualitative coding and CDA to examine and analyze interview texts from parents of a child diagnosed with ASD based on linguistic heritage, Anglo parents with a U.S. sociocultural heritage and Hispanics with a sociolinguistic heritage from Mexico. I examined texts using critical linguistic analysis and CDA, assessing for evidence of discursive practices, common concerns, and issues such as stigma, power imbalance, and use of discourse that may have impeded interaction with their HCPs, and ultimately the diagnosis of ASD. The texts were also analyzed for ways parents constructed themselves, others, and ASD. In the second phase of the study, I analyzed a sample of easily accessed ASD websites with a national presence. Texts from selected sections of these websites were analyzed and compared to describe and explore the discursive elements used to construct ASD as represented in dominant discourse. In the next sections, I describe procedures used in both phases of research.

Phase 2 consisted of Aims 2 and 3 because of their interrelated goals of (a) assessing for the dominant discourse, (b) comparing the dominant discourse with the more privileged and less privileged participants, and (c) assessing for discursive mismatch. Specifically, Aim 2 assessed for the dominant (macrolevel) discourse around ASD by sampling and analyzing scrapings from easily accessible ASD websites. The dominant discourse was identified. I then addressed Aim 3 by describing and analyzing how the language and discourse used by parents from two different sociocultural linguistic heritages (microlevel) and two different relative levels of privilege as described in Chapter 4, compared with or resisted the dominant discourse (macrolevel), as described in Chapter 5.

Phase 1: Parent Interviews and Text Analysis

Parent Sample

This study included a total of 20 parents from two different groups, Hispanic and Anglo. The Anglo parents came from a more privileged perspective overall, with U.S. English-speaking sociocultural linguistic heritage from the U.S and Canada. Hispanic parents came from an overall less privileged perspective with a sociocultural linguistic heritage from Mexico while living in the U.S. (See Tables 3.1, 3.2, 3.3, 3.4, 3.5, and 3.6 at the end of the chapter.) Privilege is defined in this study as the combination of three conditions: relative income, education level, and sociocultural linguistic heritage. Income is measured as a positive indicator of privilege if it was at or above 150% of the federal poverty level, adjusting for family size. The contribution to privilege by education level is considered positive if the level of education is greater than a high school degree, i.e., starting or having completed a college degree. The contribution of language is considered positive if parents have the skills to be linguistically and discursively competent using the dominant English language. This was a subjective measure made by the investigator.

Demographics

In 2010, Anglos made up 86% (or 2,379,560), while Utah's Hispanic population, regardless of race, made up 13% (358,340) of Utah's population (Utah Hispanic Chamber of Commerce, 2015, pp. 1-2). The Hispanic population in Utah has increased 78% in the last decade and continues to be the largest and fastest growing ethnic group in Utah (Utah Hispanic Chamber of Commerce, 2015, pp. 1-2). As ASD prevalence estimates continue to rise, in 2008, the "overall estimated prevalence of ASDs among the 14 ADDM sites is 11.3 per 1,000 (one in 88) children aged 8 years living in those communities during

2008" (Centers for Disease Control (U.S.), 2008, p. 1). This report also states that there was "an estimated increase of 78%" increase between the years 2002 and 2008, when the estimated prevalence for 2002 was 6.4 per 1,000 (1 in 156) (Centers for Disease Control (U.S.), 2008, p. 1).

Theoretical Support of Sampling Plan

Purposive sampling supports the examination of the disparity of diagnosis by including a varied group of participants, and according to Flick (2007b, pp. 27-28), to increase the diversity of perspectives. The goal is to include high- and low-income parents for each group along with diversity in linguistic heritage. This diverse sampling was needed to explore whether differences in class and linguistic heritage might also contribute to differences in discourse, and in discursive competence. Such differences may contribute to delays in diagnosis because HCPs are expert in the use of medical discourse and frames, so they may be unaware that less discursively competent parents may not understand the subtle differences, expectations, and meanings that HCPs take for granted (Creswell, 2007; Flick, 2006). However, due to a lack of income diversity within each of the participant groups, comparison by relative levels of income within and between groups was not possible.

However, the attempt to obtain a more income diverse sample acknowledged the complexity of disparities and the intersection of culture, ethnicity/race, and income, and the associated challenges relating to the diagnosis of ASD and in the production of disparities (Turner, 1995). When ethnicity is mentioned in this paper, the main concern is with the participants' linguistic heritage. Hispanic linguistic heritage includes access to certain discursive frames, competencies, capital, and linguistic practices from a different perspective than the mainstream and dominant U.S. discourses about ASD. The findings from analysis of parental discourse were compared with the analysis of the broader, dominant ASD discourse.

Purposive criterion sampling along with a snowball approach meant that one of the criteria for this sample was that the parent must be a parent of a child recently diagnosed with ASD and was of Hispanic linguistic heritage or Anglo linguistic heritage. The original sampling plan called for 5 higher income and 5 lower income participants from in each linguistic/ethnic heritage. However, I was able to recruit a relatively more privileged Anglo sample with an English/U.S. linguistic heritage of 10 participants and a relatively less privileged Hispanic sample with a Spanish/Mexico linguistic heritage of 10 participants. The snowballing piece of the plan meant that participants told other similar people about study, and they contacted me about potential involvement. Some professionals gave their clients the study fliers, and I participated in activities (information carnivals) that focused on the needs of families with a child with ASD.

Inclusion Criteria

My goal was to recruit 10 Anglo and 10 Hispanic parents ages 18 and older with an age range of 18 to 60+ years. Parents were also recruited based on the age and diagnosis of their child. The goal for the age of the child was less than or equal to 16 years of age. The goal was also to try to recruit parents with a child professionally diagnosed with ASD within a year of their diagnosis to promote clear parental accounts based on a relatively recent experience, also to avoid naturalization of the dominant discourse of ASD. The recruitment was designed to focus on parent identification of the child’s status and when and how their child was diagnosed.

Originally, the goal was to recruit parents who had a recently diagnosed child—as close to 1 year as possible—and the child would be without other significant health problems. Because of self-identification, some of the sampled parents had children who were not diagnosed within the previous criteria of 1.5 to 2 years. In addition, I interviewed 1 parent who was referred to me and who had a child with an additional diagnosis of a chromosome defect; I was unaware of this until it was mentioned in the interview. All participants reported that diagnosis of ASD was determined by a qualified health care professional.

It was more challenging than anticipated to recruit parents with a Hispanic linguistic heritage. As a result, 4 non-English-speaking Hispanic parents were included in this study. Each of these parents understood some English, but 4 parents requested a Spanish-English interpreter when given a choice. Interpreters facilitated both my understanding as a researcher and the understanding of the 4 participants as we discussed questions about their child’s behavior and diagnosis. There are more challenges associated with interpreting both the language and the situated meanings of participants when the researcher does not speak the same language as the participants. However, the Hispanic parents in this study who did not speak English fluently provided more diversity of experience and more fully reflected the experience of marginalized parents than did a purely English speaking group of Hispanic parents.

Because recruiting Hispanic parents was so difficult, the number of years since diagnosis was increased; about half of them had children who had been diagnosed more than 1 or 2 years previously. One Hispanic participant had an 18-year-old son with ASD.

Exclusion Criteria

Parents were required to be at least 18 years old, to assure that parents were old enough to make informed decisions. Any parents that were neither Hispanic nor Anglo would have been excluded from this study. Any parents of children who did not meet the diagnostic criteria for ASD would also have been excluded. All participants in this study met these criteria.

Process of Recruitment of Participants

I used rolling enrollment until achieving the goal sample size of Anglo and Hispanic participants. I kept a list of those who called later (all Anglo) in case some participants decided to opt out later. The sample included 10 Spanish-speaking Hispanic parents, at least 9 of them with a Mexican linguistic heritage, and 10 Anglo parents with an English-speaking U.S. linguistic heritage. At least 9 of the Hispanic participants were originally from Mexico, with the possible exception of 1 parent. (I was unable to contact her again after the initial interview to confirm her country of origin.)

All participants were recruited in Utah from the Salt Lake, Weber, Provo, Carbon, and Cache counties, with 1 participant from Wyoming. Most participants, 17 of 20, were recruited from the cities along the Wasatch Front. Of the 3 outside the Wasatch Front, 2 were from Carbon County and 1 from Uinta County, Wyoming.

The settings for recruitment were diverse. Recruitment took place with the help of the Utah Parent Center (Parent Center), the Utah State Health Department (which includes the Salt Lake City and Ogden offices of the Department of Children with Special Needs), and the Valley Mental Health Department (which includes the Carmen B. Pingree Center for Children with Autism). These organizations were supportive and instrumental in recruiting sufficient participants for the study.

The Parent Center is the federally funded Parent Training and Information Center for the State of Utah. The Parent Center offers free training, information, referral, and assistance to parents and professionals through the provision of one-on-one consultation, workshops, and presentations. It also coordinates activities with the Utah State Department of Education in service planning, outreach activities, and training for people with disabilities and their families. In addition, the Parent Center is a resource center for ASD, because the Autism Society of Utah closed in 2003 and consolidated its resources with the Parent Center. Through this organization, families with a child with ASD can obtain the services listed above, and have access to peer support and printed resources. The Parent Center provided 318 autism-related consultations in 2009 (Director of the Utah Parent Center, 2012).

The Carmen B. Pingree Center for Children with Autism is a part of the Valley Mental Health organization, which receives funding from the Utah State Division of Mental Health. The preschool at the Center is publicly funded and provides for evaluation and assessment, as well as day treatment for the child with ASD and his or her family. The elementary program is privately funded. The fees for a given family are assessed based on parental resources; a few scholarships are available.

The Utah Department of Health, Division of Community and Family Health Services, provides infant and child developmental assessment and coordination of care services. It also houses the Utah Registry of Autism and Developmental Disabilities (URADD).

I was present at various functions and conferences for parents sponsored by the

Parent Center, the Carmen B. Pingree Center for Children with Autism, and the state and local health departments to recruit a diverse sample of low-income participants. The Parent Center also agreed to announce the study through its Internet-based newsletter. At the time of the study, the Parent Center maintained a current autism email list of 1,102 families and professionals concerned with ASD and ASD-related services.

I also attended two carnivals under the auspices of URADD. Various groups sponsored these carnivals to support families with a child with ASD. At the carnivals were activities for families and information for the parents. I conducted a free raffle for an iPod shuffle. If a member of the family listened to information about the study and provided his or her contact information, the family member was provided with one ticket to put in the jar. At the end of the carnival, a name was drawn and the prize was awarded to the holder of the winning ticket. This was a very good way to meet people and talk to them about the study and their experiences with ASD. I also met professionals who agreed to share information about my study with their patients.

Flyers with information about the study were prepared in both Spanish and English to use in conjunction with these methods. (See Appendices C and D.) Some parents called me after seeing the flyer that described this study, and some parents called after they talked to another participant in this study. However, I called most of the parents using the information obtained through recruitment at Autism information fairs, other researchers (who contacted their participants first), and through HCPs (who also obtained permission from their clients before contacting me).

Parent Participant Screening

I screened participants by phone to confirm they met the definition of “parent” and to gain information about the age and diagnosis of the child, and age of the parent. I made an appointment for the interview at that time. I made no further attempt to contact parents until the interview. At the parent interviews, I obtained more information about the parents through the demographic forms designed for this study.

Informed Consent

An important part of the process of informed consent was discussing with the participant the type of study and the kinds of information that would be sought. At the interview when the participant consented to the study, I took ample time to discuss the purpose and design of the study and the participant’s role in it. The consent form consisted of a single page that explained the purpose and importance of the study. It also outlined the possible benefits and risks. The consent also described the possibility of compensation, along with who to call if they had questions or concerns. I provided each participant with an informed consent document that the participant signed before being interviewed. I also allotted time at the end of each interview for questions and an overview of this study.

Compensation

Parents were compensated for their inconvenience with a $25 gift certificate to either Wal-Mart or Target, depending on their preference. All participants were sent a gift certificate by certified mail after their interview was complete. One parent refused the certificate during the interview, 1 parent moved within a few days, and three other certificates were returned to me by mail. I tried to contact those participants by phone, but was unable to contact them. I did not receive any phone calls or other forms of contact from any of the participants who missed their card delivery.

Demographic Questionnaire

Attached to the informed consent was a brief questionnaire that focused on demographic information about the parents, the child diagnosed with ASD, and some information about the type and time frame of intervention use. This self-reported information included questions about the race and ethnicity of the parent, the child's age at diagnosis, and the child's current age. Other demographic information was obtained to assess for privilege or class and included types of career, primary language spoken at home, spoken English literacy, education level, and income categories. I later asked additional questions about family size and country of origin by phone after the interviews were completed. I called the participants who did not mention the size of their family or country of origin during the interview process. I asked these questions to better assess the level of privilege and linguistic heritage of each family.

(The original design included the use of a measure of SES, and was very specific about how to set up income categories. However, one of the failings of the measurement tool was the failure to include a value for mothers who stayed at home. This led to my use of aggregate measures of privilege in this study based on income, education, and English proficiency, as defined in Chapter 1.)

Characteristics of Parent Participants

As a result of my recruitment criteria and efforts, I obtained participants with characteristics and levels of privilege as stated in Tables 3.1, 3.2, 3.3, 3.4, 3.5, and 3.6 at the end of the chapter.

Interview Procedures and Data Collection

Interview Questions

I contacted Hispanic educators and community members to provide input on the refinement of questions for the Hispanic participants and to promote the accuracy and appropriateness of the questions

The interview consisted of about 17 questions that were augmented with follow-up questions during the interview. Some of the predetermined questions included: What were the conditions surrounding your pregnancy and delivery with (name of child)? What were the first indications that your child might have different behaviors that you didn't understand? What did you think about or call your child's behavior before it was diagnosed? (See Appendix A.)

Interview Procedures

Data collection usually took place in the home of the participant when possible, and most parents preferred their own home as the setting for the interview. The 3 parents who were not interviewed at home selected a library close to their appointment with an HCP or other appointments in the Salt Lake area. Two of these parents had come over 2 hours for appointments in Salt Lake City.

Only 1 parent from each family was interviewed. Two participants had a spouse present who was consulted once or twice about the specifics of timing for diagnosis and other issues regarding the medical history of their child. These answers to questions did not provide information that addressed the sociocultural context or social interactions.

Participant interviews lasted for approximately 60 to 90 minutes and were designed to be semistructured to allow for unanticipated topics to be brought up by participants. The questions were open ended to allow participants to use their own words and add additional content that they deemed to be important or useful. Open-ended questions were important in facilitating parents' expression of discourse with as little interference or contamination from the interviewer as possible. This form of interviewing allowed the parents to express and explain the processes they used as they tried to understand and make sense of their child's behavior.

Preparation included briefing each participant for the interview, including a short overview of what to expect and their rights as a participant. This was accomplished through use of the consent form and my explanation of the process at the beginning of the interview. (See Appendix A.) Kavale (2007) stated that through this process, the interviewer would begin to establish rapport and respect for the sharing of information. I also discussed the possibility of a follow-up interview with participants.

This interview design, that included a semistructured format, promoted some comparability between participants from various backgrounds with different concerns. The last 5-10 minutes of the interview were reserved for the wrap-up of any questions or concerns that the participant might have, allowing for participant feedback and questions. I also took notes at each interview to document the context within which the interviews took place.

Recording and Transcription of Data

All interviews were digitally recorded with participant permission and signed consent. I used two digital recorders at most interviews to avoid loss of data due to technical or low-battery problems. I save digital recordings from the interviews to my password-protected laptop computer.

Transcription Conventions

All digital audio recordings were professionally transcribed to promote accuracy and quality of the resulting transcripts. The transcription company was also HIPAA compliant for protecting privacy and confidentiality. In addition, my goal was to de-identifying the data before transcription and follow-up to assure that some of the missed identifiers were eliminated. Also, my committee chair and I were the only people to see the interview transcriptions.

Care was taken with the transcription of interviews, because as Lapadat (2000) points out through the quote by Miles and Huberman, qualitative analysis "employs language as data" (p. 204). The data that are available to us through interviews are changed and presented within a certain perspective by the transcription conventions employed in the process. The conventions employed for this transcription included verbatim transcription that differentiated between the two speakers. The Spanish language that was used by 4 participants was not translated into English by the transcriptionist. The record in the text reflects the interpretations of Spanish into English by the interpreter. Other conventions included a dash for a slight pause. If there was a significant pause, a long underscore followed by the time of the pause was listed in the text, for example, [00.10.00] for a 10 second pause. Nonlinguistic sounds were also noted, for example, a chuckle, “Hmm,” or [whispers], or [inaudible].

Interpreters

The two interpreters used in this study were recruited from the Carmen B. Pingree Autism Center of Learning and from the Utah Parent Center, two groups at the forefront for education about and interventions for children with ASD in Utah. These interpreters were fluent in the Spanish language and were highly recommended by each institution. One interpreter from the Carmen B. Pingree Autism Center of Learning donated his time, and the other interpreter from the Utah Parent Center was allowed to help during her work schedule. Each interpreter had experience working with families of children diagnosed with ASD and interpreted my questions and the response from participants into Spanish on the spot. This enabled me to ask questions and follow-up questions in a timely manner. Each interpreter acted with integrity and respect for the participant, and would ask for clarification when needed. I would ask the question in English for the participant and the interpreter would state my question in Spanish. The participant would respond in Spanish and the interpreter would tell me the answer in English. The process was recorded digitally and these data were then used to make transcriptions of the data. However, the volunteer interpreters told me their summary of the Spanish spoken by the Hispanic participants in the third person, instead of a verbatim interpretation. Only the English language was transcribed into text. All transcribed data were used in this analysis.

Analysis of Data

I imported all transcribed interview texts into NVivo 10® QSR International computer software to facilitate organization, coding, and writing memos about these data. This software was very useful when organizing data and referring back and forth between codes and text samples. The coding tools were especially helpful and allowed for location specific memos and simple to complex queries.

Analysis of Participant Texts

Following transcription, I listened to the recordings while checking the written transcriptions and made corrections as needed to assure accuracy. This process also allowed for further memo writing regarding the context and impressions.

Coding

In this study, I used three stages of analysis: (a) descriptive coding of interview data, (b) comparative analysis of interviews by linguistic heritage, and (c) critical discourse analysis of interview data by linguistic heritage.

I also performed analysis also at the lexical level (word or phrase) and at the sentence or sentence pattern level. Analysis at the lexical and syntactical levels was used to assess for meanings and context.

Fairclough (2001) developed an approach to CDA that I used, in part, to guide coding and analysis, beginning with the analytic problem. The problem was the potential discursive mismatch between the less-privileged discourses of parents and the larger sociocultural discourses about ASD, along with other potential discursive and linguistic differences between parents and health care providers. These differences may restrict social and discursive interaction between HCPs and parents.

As indicated in the interview guide (Appendix A), I interviewed parents of children diagnosed with ASD about the following issues, among others: (a) their recollection of the first time they thought there might be something different about their child's behavior and how they constructed that difference; (b) with whom they discussed the difference(s); (c) what words they used to talk about the difference and their understanding of it; and (d) whether they had found other parents who had similar concerns. It was important to explore the repertoire of discourses and social practices available to parents, and how those influenced their choice of discourses. Discourse provides an explanatory model that influences parental interpretations of their child's behavior. Social practices are ways of interacting and accomplishing things, such as work, play, information gathering, and negotiations (Chouliarki & Fairclough, 1999). Understanding social practices by linguistic heritage provides important information about the differences in approach to diagnosis

Open Coding

The first step in coding was open or initial coding. I read each interview carefully multiple times; then I began initial coding and process coding (Charmaz, 2006; Saldana, 2009). To accomplish this, I broke down the data into smaller segments or phrases that describe some aspect of the process parents were describing, which included looking for words and sentences that described a situation/interaction that the parent experienced. Saldana (2009) describes this process as a search for "ongoing action/interaction/emotion" (p. 77) that are a result of participant circumstances and experiences. In this case, I was interested in what happened and the way parents interpreted their experience as they sought to understand their children’s behavior. For example, many parents included their experience of talking with the HCP and what that meant to them.

This first cycle was a very exploratory process to get a sense of the data. Initial coding consisted of over a hundred initial codes that focused on behaviors, impressions of the HCPs and family, expressions of judgment by family and others about the personality of the child, and other assorted concerns.

Gee (2001) recommends that this first phase of coding in discourse analysis should also be used to examine the data at the lexical (individual word patterns) and syntactical level (sentence patterns). After the first two rounds of coding, I began to focus more on the words and patterns of words the participants were using.

At the end of the first run of open coding, there were more than 100 initial codes, which were later organized into six different categories, namely pregnancy and delivery, early ideas about behavior, obtaining a diagnosis, treatment and early intervention, advice and suggestions, and miscellaneous issues.

Regrouping and Focusing

This stage marked the change to reassemble the data that were separated into smaller parts in the first stage, and to look for connections and patterns. To do this, Gee recommended assessing for nuanced and culturally tied meanings used in a specific setting with identified people and their respective roles (e.g., physician-patient interaction in an office setting for a physical exam) (Gee, 2001). Saldana explained this phase as process coding—looking for goals and activities as described by Gee, and how they are accomplished (Saldana, 2009). Charmaz added that this step is a time to start becoming more focused (Charmaz, 2006). All of these experts agree that this is the stage to begin looking for connections and categories in the data. At this stage, the word groups and sentences were categorized by activity, or what the participant was trying to accomplish or what he or she was experiencing. This process helped focus on the issues parents were concerned about and how they constructed their experiences.

After discussing the findings with my committee chair, the second coding focused on these issues: parenting, stigma, concern with progression with learning behaviorally and scholastically, concern with timing, and timeliness. Constant comparative analysis of these initial categories was crucial. At this point, I had anecdotal lists by topic for the second coding, generated through NVivo and included memos. For example, some of the topics included in the list for Anglos were stigma and resistance, courtesy stigma, stigma and biogenic paradigm, stigma and cognitive concerns. Second coding for Hispanic parents included stigma and resistance, felt stigma, courtesy stigma, linear progression, and concern with services, and access to information.

The second coding also included a process that helped clarify general areas of coding and to assess for these issues for each participant, and some of them included whether they intervened and acted like the “good parent” model, concern with timing, concerns with medical establishment, felt stigma, normalizing of child, level of jargon used, internet use, delays due to HCP, and whether or not they knew about ASD before their child was diagnosed.

By examining the language used at the lexical (at the level of an individual word or phrase) and syntactical (at the sentence or sentence pattern level) levels, the data were broken down in ways that help identify and better understand the social language of participants (Gee, critical literacy). Social language is defined by Gee (2001) as "a way of using language so as to enact a particular socially situated identity or kind of person" (p. 5) or activity or process. In this case, I sought an understanding of the social language used by parents around the diagnosis of ASD. The organizing themes that are discussed in Chapter 4 consist of interpretations about the parents' role in assessing their child's behavior and the process of diagnosis.

Cultural Models and Axial Coding

Cultural models identify group norms and the characteristics of key discourses that help define reality for a given group. Cultural models constitute common sense know how or "everyday theories about the world" (Gee, 2001, p. 12). Coding was now at the level of axial coding, with the tentative identification of categories and subcategories and the relationships between them. In this stage, it was important to identify how discourses were selected and applied to shore up reality and reinforce the way a group made sense of the world. Categories being formed should reflect the discourses and the social conventions of the group. For example, parental discourses about ASD after diagnosis may be focused on what the neighbors think. After the identification of discourses that were used to help parents make sense of the world, those examples were compared by ethnicity and relative level of income.

The third coding focused more on characteristics of being the "Good Parent." This coding focused on issues such as concern with timing, stigma, attempts to normalize their child, expertise of the parent, delays due to the HCP, programs used for intervention, level of understanding about ASD, and continued learning about ASD.

A comparison of participants based on income was not possible based on the homogeneity of income in the Hispanic sample, because most (9 of the 10) were low-income. However, discussion of trends between the Anglo and the Hispanic groups were ongoing.

Memo Writing

Memo writing was a technique that strengthened my analysis and promoted transparency. I used memos as I was in the process of coding, which kept me involved in the process of analysis, while facilitating abstraction about the data. Memo writing also helped thinking about the data at a more abstract level because I could refer back to these memos at a later time because these memos reflected my thoughts and questions as I initially coded the data (Charmaz, 2006). My memos were consistent with Saldana's (2009, p. 32) definition of analytic memos as a place to "dump your brain" about the context, participants, language, emerging ideas, connections, and "ah-hah" moments. I began making memos when interviewing participants to reflect the setting and make other notes about the physical and emotional context of the interview. Memos were also made throughout the analysis of the text.

Memos were recorded in NVivo 10® using the annotation feature, which tied my notes and emerging understandings to a specific section of the text. Through this method, I could return to specific areas of text that were important to emerging issues, such as stigma or the adequacy of services. The process of writing memos contributed to the analysis of the data through improved description, connection of ideas and concepts, and support of the overall analysis (Creswell, 2007).

Integration of Findings and Discourse Analysis

After coding, the next phase was focused on integration of findings and finalizing the proposed cultural model. Dominant discourses were identified, and the negative cases were explained. At this stage, I went beyond the findings to the level of abstraction. The analysis was focused on parental linguistic constructions within lay discourse and how these matched up with or resisted the larger sociocultural discourses.

The “good parent” model for the Anglo sample was becoming more complete with coding that reflected many consistent aspects of being the “good parent” in a privileged English speaking U.S. linguistic heritage, such as knowing about and monitoring for ASD already, concerns with development and progress, access to many resources (e.g., computers, higher education), and concerns with the level and quality of intervention.

Hispanic parents shared many of these qualities, including concern about linear progress behaviorally and at school, learning about ASD and how they could help, stigma-related issues, and futurity. They did not possess many of the resources that Anglos had, such as linguistic skills with language and discourses of ASD and its medicalized interpretations. However, they were persistent as they came to know more about ASD and wanted better resources as they came to know more about ASD, despite being overall less privileged than their Anglo counterparts.

Phase 2: Procedures for Analysis of ASD Websites

The second phase of this ASD study analyzed what is the dominant (macrolevel) discourse about assessment and diagnosis of ASD, using the texts of readily accessible ASD-focused websites produced by national ASD organizations or support groups. To accomplish this, I sampled and analyzed text, using content analysis, from readily accessible online ASD-focused Web sites, and then continued the analysis using CDA to assess for categorical themes and overall content.

Content analysis assisted in identifying patterns in the dominant medical discourse concerning ASD that are at work in the larger U.S. culture. I decided in advance to perform this website content analysis after conducting parent interviews, and to incorporate findings into further comparison and analysis in revision and summarization. I did this to ensure that my analysis of the parent interview texts and analysis were not skewed in favor of the medicalized discourse of the ASD website texts.

The sample of ASD-related websites was important because it facilitated examination of the larger sociocultural and medical discourses about ASD that parents encountered as they sought information (before and after diagnosis) from medical or educational staff, HCPs, and others who were experienced with and used medical discourse. Medical discourse is socially constructed and subject to interpretation about what does and does not constitute ASD. It is also the dominant discourse in describing and defining ASD in the U.S. (Lin & Harris, 2008; Schulz & Mullings, 2006). Fulcher stated,

> Medically related texts are the main institutionalized sites for its discursive practices and the professions that “deal” with disability. Social workers, therapists, physiotherapists, nurses, teachers, borrow the logic and politics of medical discourse on disability and deploy its authority and influence to legitimize their own professional practices. (Fulcher, 1989)

As a result, ideas or concepts and associated language that differs from the dominant discourses of medicine may be marginalized (Fulcher, 1989) For example, standards used in medical and psychological texts may seem fixed and unchanging, but these criteria are continually shifting and changing based on the interpretation of information that is culturally and historically situated (Cheek, 2000; Fairclough, 2003, pp. 206-207). However, parents and HCPs may not fully realize the constructed nature of medical discourses about ASD, and may marginalize alternate conceptualizations and information.

Sampling

I obtained this sample of sites by accessing easily available ASD websites through the Internet as described by Reichow et al. (2011). These sites were easily accessible through searches using the keywords “autism” and “autism spectrum disorder.” I looked for ASD websites that were lay focused, not highly theoretical or highly specialized for a given professional audience (i.e., scientists). The websites all contained information about ASD, including diagnosis, signs and symptoms, developmental criteria, *DSM-IV-tr* information that was used at the time this study was conducted, interventions, behavioral and physical challenges, and other general information about ASD. The current DSM is the fifth edition. I used Google as the main search engine because of its dominance in the U.S. market. When I exhausted that option, I also used Reichow’s list of the top 100 ASD websites accessed on the World Wide Web (Reichow et al., 2011). I also included Wikipedia and WebMD, because their sites popped up so frequently on Google searches. I selected websites for their coverage of the topics relating to diagnosis, developmental assessment, signs and symptoms of ASD, interventions and advice aimed at parents. In addition, their U.S. affiliation was also important since this analysis is focused on U.S. culture, discourse, and language use.

I also searched for websites aimed specifically at Spanish-speaking consumers, but I could not find any. The websites that had information in Spanish were either directly translated from the English language website that provided the translation, or the website was composed of information that simply repeated information found on mainstream sites with no attempt to provide culturally specific information. One website used Wikipedia's translation program. A volunteer skilled in the Spanish language provided transcription services and helped assure that the text was directly translated from English to Spanish.

Sampled websites consisted of two types: those produced by ASD support groups, and those produced by government or private organizations. Parent-produced sites often had an online forum for parent discussions with each other. Professional sites that were exclusive to their members were not included in this sample.

Two of the sampled websites were produced by national organizations that focus on parents of a child with ASD or parents who are wondering if their child has ASD: the Autism Society of America and Autism Speaks (the latter is more research focused). Another site was that of the Centers for Disease Control and Prevention (CDC), through its National Institute of Child Health and Human Development, which oversees research about the prevalence of ASD and has a large online presence to help non-medical professionals, parents, and others educate parents and others about ASD. I also sampled websites developed by smaller groups with a focus on scientific interventions, and two developed by websites that already had a large presence on the Internet.

In sum, my sample consisted of nine easily accessed English language websites, with no material explicitly related to culturally specific Hispanic information. Table 3.7 (at the end of the chapter) lists the nine sampled websites.

These sites provided a sample of discursive resources that may influence parents and HCPs and help shape their discursive repertoires.

I sampled all of these websites and informational resources within a time frame of approximately a 1-week period due to the changing nature and content of sites on the Internet to avoid pre and post significant cultural events that might change or affect the content (Margaret Wetherell, 2001, pp. 392-393).

Methods

I used an interpretive approach, informed by critical discourse theory (Fairclough, 2001; Gee, 2001), to study and compare a sample of texts from ASD web sites aimed at parents seeking information either prior to or after a child is diagnosed with ASD. This study used both discourse and content analysis. I used content analysis to assess the texts at a syntactical and microlevel to examine word frequencies, word and sentence patterns (collocations), key words in context, and how specific content was phrased and arranged. I used discourse analysis to link content and put it in context by identifying and interpreting how specific content findings were linked with larger concepts and ideological patterns, or dominant discourse themes and models (Gee, 2001).

Procedures

Websites were scraped (electronically searched and text saved) for information about the diagnosis and treatment of ASD. I selected for scraping information that related to the signs and symptoms of ASD, diagnosis, prevalence, cause, duration, treatments or interventions, and general information to support parents, such as how to present your parental concerns at the clinic or to the HCP. I selected these content areas to examine how ASD is constructed and assess whether or not these constructions match up when compared to parent constructions of ASD, as described in Chapter 4 of this study. I saved the samples from these websites as Plain Text Files (txt.) and downloaded them into NVivo 10® for Windows. I saved these nine text samples as individual internal sources on NVivo for content analysis, coding, and annotation, which started as 4,096 KG of data in NVivo.

Coding

I read the sample texts from the nine websites multiple times. As a result, I developed a primary descriptive content coding scheme to aid coding of these texts: (1) medical and psychological (neurological, physical health, Autism Spectrum or range of effects, and signs and symptoms of ASD); (2) diagnosis (screening and checklists, diagnostic process, school evaluation, medical evaluation, and child development); (3) social and psychological issues (coping with behaviors, social interaction); (4) genetics and environment (cause of ASD, and the questions relating to "what did I do?" and "what can I do?"); (5) prevalence (how often is ASD occurring?); (6) childhood development (social development and communication development); (7) parenting (families, resources, networking, attachment, advocating for their children, education and knowledge for parents); (8) exceptionality (ideas about children exceling in some areas, and some children who may have special abilities or disabilities); (9) intervention (types of interventions used or talked about, including early intervention, different kinds of interventions, behavioral therapy, increasing awareness); and (10) research. Text samples from each of the websites were coded according to these 10 content topics. The text coded at each of these 10 descriptive content categories across all websites was then aggregated and inductively coded line by line.

I made frequent analytic annotations to capture findings that crossed more than one text or described emergent interpretation of the discursive elements and themes, or provided insights into the coding process. Saturation occurred with redundancy when there were no new pieces of data that were unique or provided information that had not been previously coded several times. Saturation was also an issue of no new information that tied into the diagnosis of ASD or parenting as a part of the diagnosis of ASD, and all of the codes were interconnected and supportive of other coding. These codes and annotations were then integrated into an interpretation of the discursive themes and models found on these websites to be most dominant in shaping ASD, diagnosis, and the role of parents.

Content Analysis

The coding and analysis performed in this phase was informed by the previous analysis of the interview data, including linguistic and critical discourse analysis. This content analysis was performed using Linguistic Inquiry and Word Count software (LIWC) that provided an empirical examination of word usage on all of the data scraped from the nine sampled websites. I did this analysis for the purpose of exploring whether or not language related to the term “parent” had a significant and meaningful presence in the sample of scraped texts from the nine websites studied. Word frequencies were calculated for the appearance of words stemming from the root “parent” in each of the nine website texts. Using these frequencies as numerator and the total number of words in the text as denominator, Z scores were computed to see whether there were significant differences among these texts in the frequency of mention of terms related to parents or parenting.

I ran word frequency searches for the term “parent” and variations of “parent” on all texts using NVivo 10®. Based on previous analyses, this term is frequently associated with or implied in talk and text about the diagnosis of ASD. I then recorded frequencies of this term, parenting and its variants, for each text, and calculated those frequencies in relation to the percentage of overall text (i.e., the number of appearances of a version of the term “parent” as numerator, and the total number or words in the text as denominator). The texts were compared for significant differences in proportional use of this term by calculating and comparing Z scores for significant differences between groups of text (Cloyes, Berry, Reblin, Clayton, & Ellington, 2012).

Methods Used to Promote Quality

The terminology and methods used for assessing the quality of an interpretive inquiry is a contested area (McMillan, 2009). For the purposes of this study, I focused on transparency and peer debriefing as strategies to help ensure the quality of the processes and outcomes of the investigation. These strategies were selected based on available time, resources, and the specific design of the study.

Transparency

Transparency was used as a method to enable others assessing the study to understand how and why important decisions were made about the design and the process of data production and analysis (Creswell, 2007). Transparency required reflexivity and documentation about all aspects of the project. Through this process, the study can be evaluated for appropriate application of theoretical background and overall design in light of the stated problem or question. I carefully recorded decisions about the study (Flick, 2007a). Much of this information was tracked in NVivo 10®.

Transparency also promotes examination and justification of the aims of the study, adequacy of questions and answers, appropriate use of methods, steps used to reach conclusions, and ethical treatment of human subjects. This process of reflexive writing and ongoing justification of the processes used was important in ensuring that analysis was data-driven throughout the study. Transparency also provides the means for others to assess the quality of the study and the associated findings.

Debriefing with Committee Chair

I implemented mentor debriefing as my second strategy to promote quality. This process included the sharing of processes, interpretations, and findings with my committee chair as the study progressed. This method provided the opportunity for me to obtain an external check of the sufficiency of detail and of the analysis as the study progressed (Holloway & Wheeler, 2002). This course of action supported reflexivity and ongoing evaluation of my interpretations from someone outside of the study through questioning and challenging of my assumptions. This process of debriefing promoted quality (a) by preventing an overly narrow approach, and (b) by providing a sounding board to assist in evaluating the progress and course of the study overall. Ultimately, my committee and other experts in the field will decide the quality of the study. Evaluation will be based on the depth of analysis, assessment of arguments made, and the ability to explicate the process of analysis (Creswell, 2007).

Human Subjects Research: Institutional Review Board

I obtained institutional review board (IRB) approvals for this 24-month study through the Utah State Department of Human Services and the University of Utah. (See Appendix E.) The Utah Department of Health has an institutional review board that reviewed the proposal for the Salt Lake County Health Department (SLCHD) and coordinated with the University of Utah. In addition, the study's procedures were reviewed by the Utah Parent Center.

Vulnerable Populations

Because the purpose of this study was to better understand the disparity of delayed diagnosis of ASD for low-SES and linguistically and culturally diverse families, parents from those types of families were included as participants.

Potential Risks

Potential risks were minimal. There was some stress and emotional response associated with the interview process, questions regarding the behavior and life experiences of the children with ASD, and the prospects for the future of the families involved. Concerns about loss of privacy and confidentiality in the course of the study were answered and assuaged by the informed consent process. I was open to any questions and addressed all known participant concerns.

Recruitment

As discussed above, I recruited the participants with the assistance of local organizations that serve parents of children with ASD.

Protections Against Risk: Privacy

I maintained privacy by interviewing participants in their own homes, when possible. When needed, an assistant provided by me cared for children over the age of 2 years. When the participant's home was not available, a private room was scheduled at two different public libraries. All questions were answered prior to and after the signing of the consent form. (See Appendix B.) All parent participants signed a consent form, and all were assured that they could discontinue the interview at any time. Individuals were not identified by name in discussions of the study with faculty.

Protections Against Risk: Confidentiality

All audio recordings were professionally transcribed, and all recordings and transcriptions were stored in password-protected laptops and on encrypted flash drives in a locked safe at my home. No identifying information was attached to these files.

Memos and analysis did not include personally identifying information about participants. These data sources were made anonymous, and data were not discussed using real names. Storage of this information was on a password-protected computer.

Access to study data was limited to only the few members of the study team. My faculty advisor and I carefully scrutinized any use of a subject's quotation to ensure that no identifiers would be revealed in any subsequent reports.

I obtained demographic survey consent at the time the survey was administered. I also obtained informed consent before any of the interview process or audio recording began. (See Appendix B.) Furthermore, I made information about the overall study available prior to taking the demographic survey and before any interview process began.

Protection Against Risk: Coercion

Risks of coercion were minimal because I was never associated directly or indirectly with the provision of or payment for the health care provided to the children of the participants. I discussed and made clear that participation was voluntary and would have no effect on the provision of current or future services of any kind. I also advised the participants that they could stop their participation in the study at any time and for any reason or no reason. Participants were given a $25 gift certificate from a local food and clothing store to compensate for inconvenience as a result of participation.

Potential Benefits

The overall goal for this study was to ultimately minimize the disparity of late diagnosis for children with ASD through improved understanding of (a) the social construction of ASD by low-SES and linguistically and culturally diverse parents as they seek to understand their child’s behavior, and (b) the possible discursive mismatch between HCPs and parents. This information will be useful to private practitioners and public health organizations to improve strategies that promote a timely diagnosis of ASD and to improve outreach.

Limitations

One limitation of this study was the recruitment of 4 parents who were not fluent enough in English. This complicated discourse analysis because I, as the researcher, was trying to interpret an already interpreted interview. The two translators I used were both very qualified; however, translation was still an additional step between my question and the original answer from the participant. In addition, each translator chose how to ask the question and then how to translate the reply back to me; the translator may have left out parts altogether.

Second, discourse analysis focuses on the meaning of the text through analysis of the language and language patterns used. Trying to understand the situated meaning of a text was doubly difficult when working with translated copy because I am not familiar with the metaphors, linguistic traditions, and customs of the Spanish language from the countries represented by the Hispanic participants. However, the use of discourse and how it matched up with or resisted the larger discourse about ASD was reasonably clear and useful, and in some ways highlighted important differences.

Table 3.1

Demographic Description of Participants in Study

Demographic Indicators	*Anglo*	*Hispanic*
Parent Gender		
Male	1	3
Female	9	7
Gender of Child with ASD		
Male	9	10
Female	1	0
Average Parent Participant Age	35 years	39 years
Reported Problems in Pregnancy/Delivery		
Pregnancy	5	3
Delivery	4	4

Table 3.2

Number of Participants by Income Level and Linguistic Heritage

Income	*Anglo*	*Hispanic*
$0 to 19,999	3	5
$20,000 to 39,999	3	4
$40,000 to 59,999	2	1
$60,000 to 79,999	1	0
$80,000 to 99,999	1	0

Table 3.3

Number of Participants Above and Below 150% of Federal Poverty Level by Linguistic Heritage

Income	*Anglo*	*Hispanic*
Below 150% of poverty	4	7
Borderline*	3	2
Above 150%	3	1

*Poverty level is determined based upon exact income and number of family members. Because I only obtained categorical income information (instead of an exact amount) for each participant, some families are classified as borderline, meaning that they are close to, but may be above or below 150% of poverty level. Exact classification would have required specific income amounts, which were not sought from participants.

Table 3.4

Level of Participant Education by Linguistic Heritage

Level of Education	*Anglo*	*Hispanic*
Above HS Graduate	8	4
At or below HS Graduate	2	5
Not reporting*	0	1

*One Hispanic participant did not report her level of education. She gave no indication, however, that she had any post-high-school education.

Table 3.5

Researcher's Subjective Assessment of Participant's Fluency in Spoken English by Linguistic Heritage

Level of Spoken English Fluency	*Anglo*	*Hispanic*
Fluent	10	2
Less than fluent	0	4
Required a translator	0	4

Table 3.6

Summary of Assessed Privilege Level by Linguistic Heritage, Based Upon Income, Education, and Subjective Assessment of Spoken English Fluency

Level of Privilege	*Anglo*	*Hispanic*
3 of 3	3	1
2 of 3	5	0
1 of 3	2	4
0 of 3	0	5

Table 3.7

Nine Sampled Websites Used in This Study

Name of Website	*Internet Address*
Association for Science in Autism Treatment	www.asatonline.org
Autism Now	www.autismnow.org
Autism Science Foundation	www.autismsciencefoundation.org
Autism Society of America	www.autism-society.org
Autism Speaks	www.AutismSpeaks.org
Autism Web	www.autismweb.com
National Institute of Child Health and Human Development	www.nichd.nih.gov
WebMD	www.webmd.com/brain/autism
Wikipedia	www.en.wikipedia.org/wiki/Autism

CHAPTER 4

COMPARATIVE AND CRITICAL DISCOURSE ANALYSIS OF THE ACCOUNTS OF PARENTS OF CHILDREN DIAGNOSED WITH ASD

Introduction: Problem

The purpose of Phase I of this study was to address its first aim, namely:

Aim 1: Explore and describe similarities and differences in language use and discourse in parent descriptions of their child's behavior and the process leading to professional diagnosis of their child with ASD, comparing two groups of parents with different sociocultural linguistic heritages and different levels of privilege: 10 Anglo parents with an English language/U.S. sociocultural linguistic heritage and relatively greater level of privilege, and 10 Hispanic parents with a Spanish language/Mexican sociocultural linguistic heritage with a relatively lower level of privilege.

As described in the discussion of the parent sample, however, participant recruitment constraints affected the sample. Thus, the comparison was between the Anglo parent sample with a more privileged U.S. English language linguistic heritage, on the one hand; and the Hispanic parent sample with a less privileged perspective and Spanish language heritage of Mexico, on the other hand. Aims 1 and 2 were combined for this portion of the study.

In this phase of the study, I first described and compared linguistic and discursive differences through qualitative coding and discourse analysis of the interview texts of Anglo and Hispanic parents regarding their experiences of getting an assessment and ASD diagnosis for their children. Second, I used CDA to examine the language used in this same sample of texts of Hispanic and Anglo parents. Advi (2000) conducted two different studies using the same sample and examined the responses from one fairly homogenous group. In contrast, in this study, I compared texts from interviews of Anglo parents from a relatively privileged English language/U.S. sociolinguistic heritage with comparatively less privileged Hispanic parents with a sociolinguistic heritage from Mexico. This analysis provided a way to critically assess for systematic differences in the way these parents experienced the process of assessment and diagnosis through their language and discourse.

Findings Based on Analysis of Parental Discourses: Seven Organizing Themes

Descriptive and comparative analysis of the parent interviews showed both similarities and differences in how they talked about and represented ASD, the diagnostic process, and their roles as parents. While there were notable similarities in the accounts of all parents, there were also important differences in how parents talked about and constructed their experience of the assessment and diagnostic process with their child.

Most parents intervened because they wanted their child to have the best possible life. The way parents intervened, however, was different based on income and the discourse about parenthood and child behavior that parents drew from for understanding and direction in the care they provided for their child. A key issue was whether their discourse matched macrolevel socially constituted discourse, including models or frames that reflected the ideology of the dominant U.S. culture.

My analysis led to seven broad organizing themes that emerged from the data: (1) Validate Me: Parents Proving Themselves; (2) Ages and Stages: What a Parent Should Know; (3) The New Normal: What Parents Say About Their Child and Life Now; (4) The Good, the Bad, and the Ugly of Stigma: What Parents Are Feeling; (5) Timing is Almost Everything: Parental Critique of Themselves and Others; (6) From Here to There: Promoting Linear Progress; and (7) Back Me Up: Parents Searching for Resources and Support. I discussed each of these organizing concepts and compared Anglo and Hispanic parents in each of these themes. Then, building on the comparison analysis, I used critical discourse analysis to examine the social construction of Anglo and Hispanic parenting in relation to the diagnosis of ASD.

In the following quotes, parents are identified by an alphanumeric code. (The "a" was added to each number to distinguish participants from other numbers that might be referred to in this study.) Each parent has his or her own code so that the reader may know if the same person's text is being quoted again, or to compare it to other texts. Texts labeled 1a-2a, 4a-10a, and 22a comprise the Anglo sample. Texts labeled 11a-13a and 15a-21a comprise the Hispanic sample. (The person preliminarily numbered 3a ultimately did not participate in the study, but others had been previously transcribed using their assigned number, so it was too late to change the numbers assigned to the participants. 14a was not used due to technical problems.)

(1) Validate Me: Parents Proving Themselves

Does the perception that a "good parent" monitors using medically-based parameters reflect a U.S. middle class perspective? Does this perspective include the orientation to medically supervised checkups with a focus on developmental milestones? Do more privileged or middle class parents assume that they should be developmentally aware, in this time of increasing ASD rates and prevalence? McKeever and Miller (2004, p. 1182) assert that a mother's responsibility lies in promoting the "futurity" (level of success and productivity of a child) and health and wellness of their child. As a result, mothers are seen as partly to blame if the child is handicapped or developmentally delayed (McKeever & Miller, 2004). This theme of parental responsibility, especially a mother's responsibility, for supporting the health of their child may focus on parental help and presence, or in the case of autism, the watchfulness for developmental problems by the parent before and after diagnosis. In this study, parents' accounts often focused on positioning or constructing themselves as good parents by validating or proving themselves as a person who was organized and knowledgeable enough to act in a timely manner towards ASD diagnosis. The Anglo parents interviewed consisted of 9 mothers and 1 father. The Anglo father exhibited all of these traits and was emphatic about his role as a good parent. Seven of the 9 Anglo mothers validated themselves as good parents and exhibited higher levels of discursive resources. The Hispanic parents interviewed consisted of 7 mothers and 3 fathers. One of the 3 fathers was very well informed about ASD, assessment, and interventions, and he accomplished the role of the good parent through his language and access to discourse about ASD, education, and futurity. The other 2 fathers did not seem to have the same level of understanding about ASD, the probable prognosis, and the potential resources available and the school system in general. One of the Hispanic mothers had experience with Head Start and showed a high level of discursive resources concerning ASD. The remaining six Hispanic mothers did not have the same level of privilege.

Anglo Parents

The socially constructed idea of good parenting or intensive parenting is typified by a statement from an Anglo father (10a), who stated: “[K]ids come first and, if there’s an issue [found while monitoring], let’s get it figured out and then deal with it.” This father was not only stating that children come first, but was also rendering a socially accepted judgment and expectation for parents in general.

The following examples highlight how Anglo parents emphasized their monitoring and good parent role by using the using the pronoun “I” in conjunction with an example of their ability as a parent. One parent (1a) explained, “I had already wondered when he was going to start babbling or talking,” and “I would ask the doctors, you know, he’s still not speaking.” Another Anglo parent (2a) expressed, “But every time I mentioned it to the doctor . . . [he reassured her].” Another (7a) said, “[I] found there were like 3 months was when I was first concerned.” Similarly, other Anglo parents expressed their concerns: “I was worried, um, that it could be signs of a developmental disorder” (8a); “At his 18-month checkup, I brought it up with his doctor and, um, I even at that time, asked if he thought it could be autism or anything like that” (8a); “Um, and I kept asking the doctors, I think something is wrong with him,” and “I just knew there was something [that wasn’t right]” (9a).

These parents used the pronoun “I,” with a description of the action they took to help their child, to highlight their active role in monitoring and facilitating a diagnosis for their child—whether or not this was intentional. Other Anglo parents, who (1) did not notice that their child had a developmental delay or ASD, or (2) their child was diagnosed later (at least after 5 years of age) used the pronoun “I” much less frequently and in a different way. These parents were more defensive and emotional when they used the pronoun “I.” They made statements like “I didn’t know,” as compared with the parents who helped identify behaviors that supported a medical diagnosis. One mother (6a) stated her response, “I went home and cried,” and another (4a) responded to her sister’s recognition of her son’s ASD symptoms with “Don’t tell me that.” These 2 mothers focused on their frustrations and fears, in conjunction with their perceived lack of needed personal and financial resources, about a diagnosis of ASD as compared to the other Anglo parents who focused on what they knew and what they accomplished for their children.

Hispanic Parents

Most of the Hispanic parents in this study did not state, with or without using the pronoun “I,” what they had actively contributed to the diagnosis of their child—with two exceptions. The first exception was a Hispanic mother (17a) who had worked for Head Start and knew developmental expectations from a U.S. perspective and also knew the technical jargon associated with developmental theory. Her son was diagnosed at 18 months. This mother (17a) stated, “I think he should have gotten help sooner if they would’ve listened to what I was saying to them.” The second parent (11a) was a father of an 18-year-old son who had been diagnosed 13 years ago and had since been acculturated to a medicalized perspective of his son’s behavior, and blamed the delayed diagnosis on a lack of understanding in Mexico about developmental issues. He had not, however, heard of ASD or developmental disorders before the diagnosis of his son. The Hispanic mother with Head Start experience and the Anglo parents sound very similar. However, most of the Hispanic parents (9 of the 10) did not have exposure to the concept of Autism and developmental theory until after their child was diagnosed with ASD.

(2) Ages and Stages: What Parents Should Know

Many of these parents demonstrated through their discourse their knowledge of developmental stages and expectations for their children. Anglo and Hispanic parents showed different discursive skills and understanding concerning developmental theory as applied to assessing their children.

Anglo Parents

Eight of the 10 Anglo parents knew about ASD before their child was diagnosed. Five of the parents stated clearly their understanding of ASD, development, and/or monitoring in the context of a medical/developmental discursive frame or perspective as they talked about their own child.

Examples of developmental knowledge included these participant phrases: "[H]e was hitting all of his gross motor skills, just perfectly" (1a); a comorbidity of Dentatorubral-Pallidoluysian Atrophy (DRPLA – a progressive neurological disorder) in children "is Autism" (mother's husband had been diagnosed with this rare neurological disease) (2a); "Like he didn't speak for a long time . . . and he was delayed on that" (7a); "About 18 months is when it [Autism] was really showing, repetitive motion . . ." (10a); and "he didn't walk, he didn't talk. He didn't sit up" (9a). These parents were very aware of developmental milestones, and associated language and conditions.

For some of these Anglo parents, however, others in the community interpreted the signs and symptoms of ASD or developmental delay for them. For example, 2 parents had a nurse make them aware of the implications of their child’s behavior (4a, 5a), and a 3rd (6a) was through a teacher at school. One mother (22a), whose first child with ASD had been diagnosed approximately 12 years earlier, was only aware that her child was different and not doing the same things as other children his age, “I began to be concerned when he was about 3 because playmates were speaking . . . had a vocabulary far above his.”

Hispanic Parents

Hispanic parents usually did not apply a developmental perspective when assessing their child’s behavior because, it appears, they had not been acculturated to the medicalized/developmental perspective and discursive frame to the same extent as the Anglo group. When asked about the diagnosis of their child, most (9 out of 10) had not heard of Autism previous to their child’s diagnosis. Only 1 mother, who had experience working in the Head Start Program, recognized Autistic symptoms in her child (17a). The rest of the Hispanic parents based their concerns on other criteria, including a possible health condition, a child’s unique personality traits, and the expertise of others. For example, 1 father used a metaphor when he (12a) stated, that at “At [a]t 4 months . . . he was like a manikin,” rather than wondering if he had autism or was delayed or had problems developmentally.

Examples of a possible health concern, hearing, was expressed by this mother (19a) when she stated through a translator, “So at first she [the Mother] thought it was hearing,” and 2 other Hispanic parents (11a and18a) had the same concern. Three Hispanic parents (11a, 18a, and 20a) attributed their child’s behavior to differences in personality traits. For instance, a father (20a) stated, “I thought he was lazy, you know doing with his stuff"; and a mother (18a) commented, "His personality was a little off, so people started telling me he was a little snob." A father (11a) reported that, while living in Mexico (12 years earlier), "Another doctor told us that he was just—how do you say it when they don't want to obey? . . . Rebellious?"

Increased awareness in the community facilitated diagnosis of 4 Hispanic children through professional awareness and media resources. One parent (12a) was helped by social workers in obtaining early intervention services that later helped in the diagnosis of ASD. Three other parents received a diagnosis of ASD through routine doctors' visits (13a, 15a, 16a). A TV show helped 1 parent (21a) because an observant grandmother watched a Spanish language public service TV program about Autism. The grandmother recognized the symptoms of ASD in her grandson and encouraged her daughter-in-law to get him checked. (Since the grandmother was not interviewed, I was unable to obtain specifics about the show or how it led her to suggest her grandchild might have ASD.)

Most Hispanic parents recognized that their child's behavior was different or not what they would expect. The wider professional community knowledge (medical and school-related professionals) contributed to the diagnosis of most of the sampled parents' children, with only 1 Hispanic parent who knew about Autism and had enough exposure to a developmental perspective to interpret her child's behavior as Autism.

(3) The New Normal: What Parents Are Saying

Both Hispanic and Anglo parents wanted to discuss the changes in their life after their child's ASD diagnosis. Parents naturally tried to normalize their child as much as possible to avoid stigma and "resist the child's devalued body" (McKeeber & Miller, 2004, p. 2). The attribution of negative traits to their children with ASD was contrary to what parents wanted for their child. They wanted their child to succeed and to be accepted. Most parents looked for ways to avoid stigma and to normalize their child as much as possible. The following are examples of Anglo and Hispanic parents and their use of normalizing strategies to help themselves and others understand this new status, a new normal for their autistic child.

Anglo Parents

Parents reflected about how their life was at the time of diagnosis. They talked about how their child responded to everyday situations and how they, as parents, coped with these changes. They talked about their new normal, the reality of their life with a child diagnosed with ASD. At the same time, they discussed how they were constructing and supporting their child in a way that would avoid stigma and resist devaluing their child. One mother (6a) pragmatically explained her new normal when she stated, "And I'm like, it is not about normal or abnormal. It's whatever . . . trying to be patient with them . . . . But, yes it's hard, but it's not the end of the world."

Most parents were trying to help normalize their child for themselves and especially for others as they grappled with the reality of their new normal. One mother (2a) promoted her 3-year-old daughter's intellect instead of her social skills when she stated, "To sit down in nursery and play with other kids it's not so much . . . but, she knows her ABC's. I can draw them on a little doodle pad and she tells me every letter of the alphabet." Some Anglo mothers identified and extolled the less obvious talents of their children with ASD to illustrate their child's intrinsic worth. One mother expressed her child's worth this way, "There are incredible gifts that come with this as well. I mean I know both of these kids come with hearts of gold. They have emotions deeper than anyone realizes. And they are intuitive in ways people don’t realize” (6a). Another parent explained: “I just look at it as it’s what makes him and he’s a wonderful kid so it just gives him some extra quirks, and I don’t think he’d be the same kid without it” (7a). A 3rd parent added, “Like he’s very aware . . . I think he’s very anxious and afraid of what – kids think of him . . . . So, he’s just very aware” (5a).

Still other parents helped normalize their child through focusing on the progress their children were making through intervention and parental help. In this way, they could assert that their children could improve and that ASD is not totally a fixed condition. One parent expressed it this way: “I would help him do it all. I mean, now if I start to help him or I ask him to do something and he doesn’t understand and I start to help him, then he kind of clues in and will start to help me” (1a). Another mused, “He is making progress. He goes two steps ahead and one step back” (4a). A 3rd parent recounted, “Because instead of me trying to force words into him, we’ve been focusing on just how to help him communicate in the ways that he can” (8a). A proud parent stated, “So, he’s a sharp little kid, so. He’s figured out all the childproof locks already, opens all the doors. He’ll run in, and jump on the computer and start typing . . . they’re [HCPs] leaning more towards the Asperger end” (10a). Finally, a mother with 4 of 5 children on the spectrum explained, “Well, they all are doing so much better” (22a).

Hispanic Parents

Hispanic parents also normalized their children in a way that preserved positive ideas/beliefs about their child. They also focused on positive attributes of their children in hopes of increasing their worth in the eyes of others. One Hispanic parent explained, “We know that his disability . . . he’s disabled, but we treat him like a normal kid . . . let him know that he can be normal" (12a). Another added, "He's . . . he's, um, smart kid. He . . . he knows a little read and math, and he likes the puzzles" (15a). A 3rd explained, "I am happy because I can see that he can defend [fend or survive] for himself. I know that he doesn't speak very clear, but he understands and he—it's very good responding" (16a). When asked how her son was doing in school, a mother explained, "Wonderful . . . he's A-plus student . . . he had [just] 2 bad behavior days, and one of them was because we were staying vacation . . ." (18a). Another claimed, "Yeah, he's smart. He's, He's [number] one in the classroom to go to better [than] the other kids every time" (20a). Other parents were less direct in their praise, but still trying to be positive. One parent explained, "Yes, he is improving a lot" with the help of speech therapy (19a). Another added that her son can make his needs or what he wants known in several ways without using spoken language (17a). Finally, a Hispanic parent defensively explained, "It wasn't ever his intention to hit someone. He wouldn't do it on purpose" (19a).

(4) "The Good, the Bad, or the Ugly" of Stigma: What Parents Are Feeling

Parental discourse in both groups focused on coping with and adjusting to stigma, which is a spoiled identity that is the result of the association, as a parent or sibling, of a person with a disability (Francis, 2012). In particular, parents experienced the two subsets of stigma, felt and enacted stigma. Farrungia (2009) outlines these two types of stigma. Felt stigma consists of the "feelings of worthlessness and inferiority" experienced as a result of just the association with a child or person with a disability. In contrast, enacted stigma is the "overt act of social exclusion" towards a family member, such as the parent of a child with a disability. A person might experience enacted stigma through such acts as rude remarks, avoidance, and ill-mannered treatment of the parent or sibling (Farrungia, 2009, p. 1014).

Anglo Parents

Anglo parents defended and explained themselves within a U.S. paradigm of what they thought a parent should understand and be in their role as caregiver or parent. Through their accounts, many Anglo parents reflected concerns about defending themselves from the stigma of being considered “bad parents.” These Anglo parents emphasized this concern—more than concerns about courtesy stigma associated with the behaviors of their children (Francis, 2012). The Anglo parents emphasized their parental role and what they, as parents, accomplished for their children. Examples of defenses used against the stigma of being considered a “bad parent” (because they missed the signs of ASD in their child) included various comments about why an earlier diagnosis was missed. One parent explained, “[H]e was my first child and I didn’t have anyone or previous experiences to compare with his behavior” (1a). Another added, “They never suggested early intervention. I was kind of the one that figured out that that was the route I wanted to take” (1a). Similarly, other Anglo parents explained their perspective as to why the diagnosis was confusing or why they did not identify ASD earlier. They offered comments such as “I, um, knew that she acted a little different, but no one ever said autism to us before she was 18 months” (2a); “He was our first boy” (9a, 6a); “And his eyes would go everywhere but on my face, and that was when I was first concerned, but then I kept thinking, maybe he just can’t see very well or maybe there’s nothing else going on there” (7a); and “I really didn’t know. Well, maybe boys are different. I grew up with all girls, maybe boys are this different” (9a).

One of the parents commented on his positive parental approaches to helping his son when he explained, “We have the diagnosis now, but we treat him like any other kid. And hey, let’s do our alphabet and turn everything into a game” (10a).

Other Anglo parents defended themselves when they expressed their feelings of being wronged, overwhelmed, or frustrated about their situation and the delays in recognition of ASD. One mother explained her interpretation of a meeting she had with her child’s HCP: “[W]e actually ended up going to a different pediatrician. We could not—I could not stand it because he kept saying it was me, it was me. And I was like, I have five kids, this is not me, this is not normal” (4a). Another concerned mother (5a) seemed to equate ASD with mental illness, another stigmatized condition. She (5a) explained, “You know, so, she [Sunday School Teacher] just made that [me] aware . . . And the pediatrician was like well, he didn’t think it was . . . [ASD], you know, anything. Because like—because he’s [referring to her son], you know, [not] anything like mentally . . . He’s [the HCP] like well maybe he’s ADHD” (5a). Another Anglo mother explained her reasoning for missing the signs of ASD, “I didn’t feel qualified you know to think of those things [i.e., tentative diagnosis or theory about her son]. I thought well, um, maybe dyslexia is more of an issue than I realized, but I don’t know how to get help for that.” All of these comments were in defense of the parent’s assessment of their child or failure to act. These are very clear discursive moves to defend their status as a “good parent.”

Concerned about negative feedback, an Anglo mother (8a) explained, “[My] mother in law would comment, ‘You just need to read to him and work with him the way that you did with [his brother]’. And I would tell her, ‘he’s not interested . . . if I try to read a book, [he] runs away’” (8a). Another parent explained his approach to parenting, "Oh you have Asperger's, so it's okay if you do that. No you don't tell him it's okay just because he has this label. You know, I don't like affixing labels to him. Tell him yeah, you can do that, and we'll watch him succeed. You'll label a kid and they use it as a crutch . . ." (10a). Through his explanation, this parent was letting us know that he is a "good parent" and that he refused to label or allow others to label his child as disabled. As demonstrated in the previous examples, Anglo parents were very concerned to prove or defend their worthiness and status as a "good parent." Anglo parents were more concerned about avoiding the potential stigma of being considered a "bad parent," than they were about courtesy sigma that may come by association with their child's ASD-related behaviors.

Hispanic Parents

Most Hispanic parents in this study stated that they had not heard about ASD until their child was diagnosed. These parents seemed to be explaining their situation with little or no emphasis on defending themselves. The Hispanic parents had more experience with enacted stigma, but Hispanic parents were not as concerned with the felt stigma of being considered a "bad parent," as were the Anglo parents.

Some Hispanic parents, who previously lived in Mexico, cited shortcomings in the care they received there. One (11a) shared his view when he explained: "So they [HCPs in Mexico] focused not on behavior, [they focused on] any abnormalities in the brain . . . they couldn't find anything, and I guess they didn't have a lot of experience in behavior . . . in autistic behavior." A second parent related her account of her experience in Mexico when she (12a) had surgeries during her pregnancy and claimed she was given a lot of medications because of a mistake with her pregnancy test. And concerning a 3rd parent’s account (19a), it was that the child received a variety of medications for asthma “in Mexico . . . Yeah, a lot of shots. So the doctors didn’t know what he had.” Several parents believed that the extra medications contributed to or caused their child’s ASD. The accounts of the first 2 parents cited here (11a and 12a) were closer to the U.S. middle-class version of the “good parent.” Both of these Hispanic parents had a great deal of interaction with U.S. notions of development and health care. One of these parents (11a) had a social worker assigned to their family since the child’s birth in response to a traumatic birth and concerns about prenatal care. The other parent (12a) had been in the U.S. since their 18-year-old son was 4 or 5. As a result, both (11a and 12a) were acculturated enough to U.S. medicalized discourses about parenting to defend their actions about diagnosis and treatment of their children.

Communication or lack of discursive resources was a problem for both Hispanic and Anglo parents, but for Hispanic parents, the problem was especially acute. One Hispanic mother (13a) felt trapped between the conflicting concerns of her son’s teacher and the HCP. In the parent’s account, the school teacher wanted her son to have higher levels of the medication, while the HCP did not want to increase her son’s dosage. This mother felt stuck between the teacher and the HCP. This single mother lacked a high school education and did not speak English. She (13a) lacked the understanding, discursive resources, and skills to find a solution to this situation.

In another Hispanic mother’s account (18a), her concerns were ignored or downplayed by the HCP. She (18a) related that her doctor dismissed her concerns, suggesting that her son’s behavioral issues were a result of her spoiling her child.

Both of these parents seemed to be concerned with their lack of influence and power. The first (13a) did not speak English, and the second (18a) was moderately fluent in English. But both appeared to lack the discursive skills and abilities to be convincing as a U.S. version of the "good parent." Their situation may have been even more difficult due to prejudice or stigma associated with being of Hispanic ethnic/linguistic heritage.

One Hispanic father, not living at the child's home, was a source of enacted stigma to the child's mother (17a). This mother recounted the father's comment, "At least he doesn't *look* like he has it [Autism]" (emphasis added). This same mother (17a) described a second experience that occurred at a restaurant, "He sits on top, and one time this lady told him, and he goes, she goes, oh, it's one of those little kids that are hard headed. They don't listen. I go, no. It's not that, it's just that he's autistic, and she goes, 'oh.'" This mother (17a) used the diagnosis of ASD as a discursive move to ameliorate the enacted stigma directed at her, as a mother. She (17a) was successful in preserving her status as a good mother. But then, her son was not just a mischievous boy; he was constructed as a boy with ASD.

Another Hispanic father (20a) was concerned; he did not want to tell his family about his son's diagnosis, "Yeah, I have family in but we wouldn't told what happened when he, you know." This father was experiencing felt stigma or the fear of experiencing a more direct form of stigma—enacted stigma. Hispanic parents were more concerned with felt and enacted forms of stigma as compared to the majority of Anglo parents who were more concerned with the felt stigma of being a "bad parent." Most of the Hispanic parents in this study did not consider the possibility of being considered a "bad parent" in this context. They expressed more concern about the stigma associated with disability.

(5) Timing is Almost Everything: Parental Critique of Themselves and Others

Most of the Anglo parents (8 of 10) and 1 of the Hispanic parents were concerned with the timing of assessment, diagnosis, and interventions. These parents were responding to the dominant discursive model of parenting that focuses on monitoring development and quickly responding to any problems. This concern with timing proved to be a major difference between the Hispanic and Anglo groups. Most Hispanic parents were not concerned with timing, while the most Anglo parents were concerned.

Anglo Parents

Parental concerns with timely assessment, intervention, and timely growth and development were also signs of a "good" middle class U.S. parent. The following example typified the timeliness and watchfulness expected in a middle class Anglo culture: "I mean I do feel fortunate [my child] was diagnosed—or was—we figured it out around 2 years old. But, I mean, I still feel like I could have, you know—I could have had 8 more months" (1a).

Many of the Anglo parents shared their assessment of themselves regarding their parenting skills, and considered themselves to be timely and watchful of their child and his or her development. Anglo mothers made the following statements: "I mean, he was in Bridges 2 weeks later. So, I mean, we found what we could, as soon as we could, and got him into it, you know, to start" (1a); and another mother (2a) stated, "So I was a little concerned that she wasn't doing things as fast [developmentally] as [my other child]. But every time I mentioned to the doctor . . . [he said,] 'Oh she's fine, don't worry about [it].'" One disgruntled mother (4a) explained that she "had to switch doctors" because her prior doctor blamed her and ignored her concerns. This mother (4a) was trying to get an assessment, but the HCP was perceived as trying to shift blame to the mother in a way that labeled her as a bad mother. Another mother (8a) emphasized her frustrations because she raised concerns that were ignored at 18 months and she had to reemphasize her concerns when her child reached 2 and still was not talking. A mother (9a) who lived in a rural setting shared her perceptions that her son “went undiagnosed for quite a few years” because her HCP repeatedly ignored and discredited her observations.

In contrast, 1 father (10a) had obtained a timely diagnosis and felt good about that accomplishment when he stated,

> I do feel though catching it when I did and getting services started right away, like they tell you and told me in Minnesota anyhow, the sooner we catch it and get working with him the less likely they’re going to have to be medicated, and the better off they’ll be when they grow up as far as being in society and functioning and all that, so.

This father (10a) added, “Let’s get it going right now, so. We got the diagnosis on a Tuesday and he started on Wednesday going to school.”

Hispanic Parents

In contrast to the majority of Anglo parents, 8 of the Hispanic parents did not mention the issue of timing of diagnosis. The 2 Hispanic parents who raised timing concerns felt that their child needed to be assessed, but they stated that they were both put off or ignored several times. One of them (17a) described her experience, “I think he’s autistic and they [HCP stated]—no, boys are more delayed . . . but nobody would listen to me . . . . I had three referrals done” (17a). The second Hispanic parent (18a) stated,

> I just keep asking but he [HCP] wouldn’t tell me there was nothing wrong . . . so there’s a chance that you might be spoiling him, and that’s why he’s not doing what he’s supposed to do. That he might be confused because of the language spoken at home is different from the language used at school, and a lot of reasons why he might be racing around. (18a)

These 2 women did not feel that their concerns were taken seriously. These parents were frustrated because they did not have the discursive and linguistic resources to make a convincing argument after one or two meetings with the HCP. It seemed that as a result, their concerns about their child's behavior were not taken seriously by the HCP. Parents without adequate linguistic and discursive resources regarding ASD faced more barriers to diagnosis. One of the 2 children had their diagnosis delayed until the child was 4 years old due to this situation.

(6) From Here to There: "Good Parents" Promote Linear Progress

Both Anglo and Hispanic parents expressed concern about linear progress—their children's progress in school. Fisher and Goodley (2007) describe the linear heroic narrative as a dominant theme or discursive frame within Western culture. Both Hispanic and Anglo groups demonstrated this discursive frame concerning linear progress. It was difficult for most Anglo parents to find a balance of acceptance of the child and the situation while working to improve the child's skills and abilities.

Anglo Parents

Anglo mothers were often concerned with any the loss or potential loss of opportunity for their children to progress developmentally or at school. However, most parents discussed their concern for progress by looking for examples of progress, while they expressed the hope for more progress. This single mother (2a) of a child with ASD stated, "So I'm told that she will develop talking because she can sing. And [I] don't always understand her but I know her tune." Another parent (5a) explained, "[H]is teacher was like he's bright . . . . She didn't see him have a learning disability." Other comments included, “Um, just have him achieve the highest that he can do” (6a); “I would love to see his social skills improve, his speech is still not where I would like it to be” (7a); “Yes, Um in the past year he’s made a lot of progress . . . . [H]is communication has gone up drastically in the past year” (8a); and “He’s starting to talk more and more and more, you know, just repetitive. He’ll say his alphabet with you” (10a). Another mother expressed her concerns with an upcoming move and the effects of a new less specialized environment, “But it is going to be hard back home because he is going to be in a public school. He is going to be in a 23, 24-kid classroom, one teacher” (4a). This mother was concerned that it would be much harder for her son to make progress in school with such a large classroom and the lack of any specialized support.

The challenge with the linear model of parenting is that it is harder to live in the present and enjoy the individual strengths of a child with a disability. One parent described her recent experience of accepting their situation as a family and her ability to provide a “therapeutic home” for her children. After already having a child diagnosed with ASD, she stated that her next son “was evaluated soon after that and by that time I was like, ‘That’s okay.’ It’s okay if another one has autism. It’s not going to change the way I’m parenting” (22a). She was expressing her acceptance of her sons—several of them with various levels of severity with their ASD diagnosis—and her ability to parent them successfully. She also seemed to imply that life is fine or life is okay.

Hispanic Parents

Some Hispanic parents showed cautious optimism for their children’s ability to progress, because most were very concerned that their child progressed in some way. Some of the parents were unabashedly proud of their child’s achievements. The following statements are examples of their optimism for the progress of their children. One father (11a), who has struggled for many years to help his son develop math skills, stated, “So we [taught] him for years and years and years, and he—and he just still doesn’t get it [math] . . . for other things [getting something he wants] he is really smart.” Another Hispanic parent stated, “I don’t know what . . . he knows because he doesn’t express it” (15a). Then that same parent added, “He’s a smart kid.” Expressing a similar view, a parent (19a) explained, “So right now he’s in school and he is learning. [He] is progressing in school . . . He is not at the level that he should be, but he’s at an acceptable level” (19a). A Hispanic parent living in a rural area expressed concern about living in “a small town,” where services and help were limited (15a). Another Hispanic parent explained, “[F]irst she said that . . . um . . . they learned to talk – which is the speech therapy. Um . . . also occupational therapy has helped so that he doesn’t . . . yell. And they also tell him to take off his shoes . . .” (21a). Another Hispanic father with resources within his family, proudly stated, “My son is talking because my mom talks to him and makes him talk . . . plus he received therapy, early intervention and . . . they handle electronics like a professional” (12a). Other Hispanic parents gave their positive views. One parent, discussing her son’s academic success, explained: “[A]ll he needs is . . . to increase his social skills. . . . Yeah, he is near the academic accommodation [level]” (18a). Another, after explaining how well his son had done in school, explained, “I just want to see other kids, how they are doing, because I want to compare my kid to the other[s]” (20a). Thus, Hispanic and Anglo parents shared concerns about linear progress for their child, whether it was a behavioral or scholastic.

(7) Back Me Up: Parents Looking for Resources and Support

Many parents found the support they needed in their families and through use of the computer. But some parents were persistent enough to find sources of help that made a significant difference for themselves as parents and for their children. In this area, it was more challenging for Hispanic parents.

Anglo Parents

The Anglo parents as a group evidenced significant discursive skills in obtaining assistance with their children with ASD. For example, a single Anglo mother (2a) was especially skilled at finding resources and making alliances with professionals and others that helped her obtain needed services for her child. This mother was also able to recruit people to provide her with information, advice, and encouragement. These people included therapists, secretaries, a service facilitator, a family nurse practitioner, at least one manager, and others. She and others found that HCPs were some of the least helpful in guiding the future selection of services and interventions. Another Anglo mother (6a) remembered, “Because the weight just came off my shoulders when she [facilitator] came out of the first IEP and was like, they’re trying to put everything on you. And I’m like well yeah but my husband agrees with them.” The facilitator from Utah Parent Center was able to support this mother in the IEP process, allowing her son access to the services he needed and qualified for under the Americans with Disabilities Act.

Hispanic Parents

Many Hispanic parents developed new skills or found the resources they needed. But most were very frustrated with the lack of ASD information in Spanish except for very basic information. Many Hispanic parents stated that they wanted to learn more about ASD, but there was so little information translated into Spanish (15a, 19a, 20a, 21a). One Hispanic mother experienced enacted stigma when she asked for printed materials in English; she stated,

> I remember this real well, that when my child got the diagnosis, I saw that flyer for the ABC's [of Autism] and I asked for a copy of the flyer . . . and they responded, 'you may not understand it.' So, I asked the lady at the front desk . . . can I have a flyer? And [she] said, 'well, you may not understand, so no.' And of course, I probably wouldn't understand the whole thing, but you understand more than what you can speak of the language, right? So if I were have a piece of information about ASD, that would save me a lot of trouble (18a).

Some of the Hispanic mothers, in various ways, received help and information they needed through support groups or Autism parent organizations. The Utah Parent Center had helped several mothers in this study with translators and support for IEPs (13a, 16a). One mother (18a) started Autismo Utah as a way to obtain more help and support for Hispanic families because she was so frustrated with the difficulty in obtaining information and help from her HCP and others. Another Hispanic mother had access to and was very happy with the help she received from a Spanish-speaking caseworker who assisted her at home and school (15a).

Critical Discourse Analysis of Accounts of Parents of Children with ASD

Building on the seven organizing themes discussed above, I performed a critical discourse analysis (CDA) of the accounts of parents whose children were diagnosed with ASD. I discuss how Anglo and Hispanic parents constructed themselves in relation to their child's ASD diagnosis and some of the sociocultural influences.

Through the use of memo writing and many readings of the texts from parent interviews, I sought to capture the social models, language, and discourses employed by parents to construct themselves in a particular way. It was essential to try to understand how parental discourse differed by ethnic linguistic heritage and the broader discourses they drew upon as they constructed themselves and others.

I also integrated information discussed above regarding the comparison of concerns and perceptions of parents by ethnic/linguistic heritage and aspects of the social language they used. These categories describe the connections between social language and the way parents used the discourse of the "good parent" to construct themselves in the context of obtaining a diagnosis and intervention for ASD. At this stage, my findings reached a level of abstraction that promoted limited generalization to other situations or groups. I discuss these findings at the end of this chapter.

The Social Construction of Anglo Parenting in Relation to the Diagnosis of Autism

Anglo parents had their own way of viewing parenthood that had become taken for granted and a naturalized way of perceiving parents as "good" or "bad." These notions about good parenting influenced the way parents acted, talked about, and assessed their child's behavior and, through this, the ways in which they constructed themselves.

According to Gee (2005), discourse models, including cultural models, guide how parents develop their own ideas and theories about parenting. For U.S. families, the notion of "good parenting" through anxious monitoring, medicalized frames of reference, and awareness of developmental milestones has been evolving since the later part of the 19th century (Julian, McKenry, & McKelvey, 1994). Parents rely, consciously or unconsciously, on discursive models that are socially and culturally supported to assess and guide their actions as parents.

According to Nadesan (2005), some of these aspects of Anglo parenting began in the 19th century and continued through the 20th century and into the present. These changes happened within a sociocultural, governmental, and medicalized discourse system. North American industrialized governments began to require certain levels of education and increased monitoring of the health of their children, including those who were considered abnormal (Nadesan, 2005). At the same time, near the beginning of the 20th century, medicine and psychiatry were changing to include increased attention to child mental health, including increased assessment and monitoring of children (Grinker, 2007). It was also a time when differences in children, including developmental delays, were a shameful problem for the family, so children were often hidden away in institutions (Grinker, 2007). This history of assessment of normality and monitoring and later the development of child psychiatry and concern with child development and cognitive profiles in the 1930s provided a sociocultural pattern of child monitoring in North America.

The following examples illustrate how U.S. middle class Anglo parents constructed themselves through their notion of the “good parent” in relation to the process of acquiring an ASD diagnosis for their child. The Anglo parents used social language that demonstrated their discursive skills and resources as a “good parent” and as one versed in medical and scientific theory. None of the Anglo parents questioned the usefulness of a diagnosis or the importance of early intervention. These parents were anxious to prove and construct themselves through discourse as good parents.

Anglo Parents Constructed Themselves as Being a "Good Parent"

Anglo parents emphasized their monitoring and good parent role by using the pronoun "I" to heighten the focus on themselves as good parents. For example, one parent (8a) specified on three different occasions her concerns, including direct questions to her HCP about whether her son had a "developmental disorder," and she reported that she asked the question to her HCP on her son's 18th month checkup, "I brought it up with his doctor and um I even at that time, asked if he thought it could be autism or anything like that" (8a). This mother was not alone. Six of the 10 Anglo parents (1a, 2a, 7a, 8a, 9a, 10a) used the pronoun "I," along with a description of the action they took to help their child and to highlight their active role in monitoring and facilitating a diagnosis for their child. Three other parents (4a, 6a, and 22a) were also concerned with their child's behavior, but seemed as if they did not suspect ASD in their own child. Two of these 3 parents wanted to defend themselves against negative judgments or guilt, because they believed that they did not meet the expectations of the discursive model of the "good parent" due to delays in diagnosis. By expressing their lack of knowledge, "I didn't know," along with their dismay and worry about the diagnosis of ASD, they attempted to ameliorate negative judgments or stigma that they felt.

One parent (5a) had serious doubts about her son having ASD, so she presented a slightly different representation of herself. This mother (5a), who had experience with a family member with severe ASD, made clear in our interview that she had listened and acted upon all concerns from teachers about her son who was later diagnosed with borderline ASD. She (5a) stated that she had talked to her pediatrician, who had dismissed her observations and concerns. This family subsequently moved to Utah and their child started kindergarten. The mother stated, “And his teacher thought maybe he had Asperger’s. I said, ok. I’ll get a second opinion then.” The diagnostic process was repeated, and the mother (5a) related the following, “[T]hey didn’t really diagnose him. Because there’s just, they don’t know . . . He said, it just, it’s a gray area. They don’t . . . They’re not sure.” This mother did not push for a diagnosis; she was okay with the ambiguity because she could claim that he did not have ASD, “[He has a] learning disorder or [he’s] just quirky.” However, this mother did not want to be considered a bad mother, and she related how she made sure he had every opportunity to be diagnosed and had the appropriate interventions, such as occupational therapy. This mother organized her responses to let me know that she followed up in a timely manner with all recommendations and requests for assessment. She constructed herself as a “good mother” within a U.S. middle class discourse model with the competencies needed to take care of him at home (i.e., she sought out professional assessments and followed their recommendations, provided reading time, helped her son overcome behavioral problems, and continued to monitor him at school while assessing the need for further follow-up). This mother followed the pattern of anxious monitoring, seeking a timely assessment and diagnosis, and she defended her actions as a parent.

All of these Anglo parents constructed themselves as “good parents” through the evidence that they provided. These parents used the pronoun “I” to emphasize their role in helping their child with the assessment and diagnostic process; these parents also represented themselves as well-informed consumers of information about child development and ASD, and as dedicated champions of their individual children.

Anglo Parents Constructed Themselves as Vigilant or as an Anxious Monitor of Development

Along with constructing themselves as “good parents,” Anglo parents in this study constructed themselves as vigilant monitors of their children’s development. Eight of the 10 Anglo parents knew about ASD before their child was diagnosed, and this facilitated their ability to monitor for signs and symptoms of ASD. Some parents only had a vague understanding about ASD (1a, 2a, 9a), like the mother (1a) who said, “I knew there was something. And I wasn’t that familiar with Autism – I mean, actually hardly at all . . . I had heard that it was becoming . . . more common” (1a). Others were more familiar with ASD (4a, 5a, 6a, 7a, 8a, 10a), as the mother (8a) who stated, “I was hyper-focused about Autism.”

However, there were 3 Anglo mothers (22a, 4a and 6a) with children previously diagnosed with ASD. All of them were surprised to find that they had another child with ASD. They stated that they were unable to recognize the signs of ASD in a 2nd child with ASD. One mother (4a) told her experience of coming to understand that a 2nd of her children has ASD. She stated, “My sister, actually, was a nurse. When she came to visit she was like—she just said . . . ‘He’s autistic.’ And I was like, ‘Don’t say that.’ . . . Oh my gosh, it was like, I mean, it was instantly [that she recognized the signs and symptoms of ASD in her son].” Another mother (22a) remembered her sister-in-law’s question when she said,

> ‘Well, you’re not going to have [your son] evaluated?’ And I said, ‘Well why would I have [him] evaluated for Autism?’ And she said, ‘Because he does hand flapping,’ and I’m like, ‘He does?’ . . . I just thought kids do that. But they were tiptoe walking, they were hand flapping, they were repeating phrases, they had sensory issues, and I was so unaware.

All three of these mothers had an “a-ha” moment when someone else had recognized and then pointed out the symptoms of Autism in a second of their children. These mothers' experiences were the reverse of what would be expected. We would expect these experienced mothers to be among the first to recognize the symptoms of ASD in another of their children, but they did not because they felt that the 2nd child presented much differently than the 1st child diagnosed with ASD. Their understanding of the signs and symptoms was limited by their first experience or interpretation of ASD and, possibly, denial.

Five of the Anglo parents (2a, 7a, 8a, 9a and 10a) stated clearly their understanding of ASD, development, and/or monitoring in the context of a medical/developmental discursive frame as they talked about their own child. Examples of developmental knowledge included participants' statements that their child was meeting developmental expectations for gross motor skills (1a); and that Autism was a comorbidity of another neurological disease (2a). Others talked about developmental delays. For example, 1 parent said, "Like he didn't speak for a long time . . . and he was delayed on that" (7a). Another added, "I was worried that it could be signs of a developmental disorder" (8a). A 3rd parent explained, "About 18 months is when it [ASD] was really showing, repetitive motion . . ." (10a). These parents were actively monitoring their children and were keenly aware of developmental milestones, associated language and conditions that are in line with the U.S. discourse models, which were consistent with and supported medical models and the level and form of monitoring expected.

Anglo Parents Constructed Themselves as Aware of Their Child's Temporal Development

Parental concerns with timely growth and development, assessment, and intervention are also signs of a "good" middle class U.S. parent of a child with ASD. One parent typified the timeliness expected of a middle class U.S. parent, explaining that it was fortunate to have a diagnosis by age 2, but lamenting that the diagnosis could not have been 8 months earlier (1a). This mother used language centered in medical/developmental discursive frames to describe her concern about having "lost 8 months." She built significance about this issue of lost time by stating that she "still feels" the same; time and reflection did not change her mind. Then she expressed a sense of loss: "I could have had 8 more months" (1a). These words also conveyed a sense that they were cheated out of time; those 8 months are lost and she could not have them back because her son did not get a diagnosis and early intervention when he should have. She did not fully describe why the 8 months were so important. She apparently assumed that I, the interviewer, would consider important an early diagnosis and early intensive intervention. This mother used linguistic practices to build significance in order to express how she valued that loss of 8 months. This ability to build significance about a concern is much easier for those that are native English speakers who know the nuances of language use in specific contexts, such as explaining her concern with the timeliness of the diagnosis of her child. She also continued to construct herself as having the skills, knowledge, and the associated concerns of a "good mother" of a child with ASD.

Another mother (8a) stated her frustrations because she had been concerned for some time, "But then at his 2-year appointment . . . I called in and said I'm still worried, because he still isn't talking." She was able to obtain a referral because she was aware of developmental norms for a young child with delays in speech, but she also included her anxiety or worry about her child, which is a part of the anxious parenting discursive model. She implied that she was afraid to miss anything. She was also using recognized and accepted ways of voicing concerns within a medical/developmental context. This mother had the language and discursive resources and skills to make an effective request for a referral. She too constructed herself as an anxiously concerned, good, and competent mother of a child with ASD.

In the past, a person did not know how to be a parent of a child with ASD because there was not enough socially available knowledge about ASD for it to become a part of our social knowledge or awareness (Hacking, 2007). For example, in the 1950s, little was known about how to care for a child with ASD. Unlike being a parent of a child with a long-recognized type of medical problem, such as a broken leg, becoming a mother of a child with ASD is a fairly new phenomenon. Younger middle-class mothers in this study (1a, 8a, 5a) were more aware of ASD and how to be a parent of a child with ASD. Information about ASD and its prevalence has become more accessible, especially for middle-class parents, who have the education, time, and resources to do research and better understand how to care for a child with ASD (Hacking, 2007). However, this is not the case for all groups, including low-income and linguistically and culturally diverse parents.

Other Anglo parents (7a, 8a, 9a) also initiated the investigation into ASD. For example, a mother (8a) stated she had brought up her concerns about Autism at his 18-month checkup, which did not lead to a diagnosis, “But then at his 2-year appointment . . . he still wasn’t talking . . . And that’s where we started getting the ball rolling and getting him into therapies." In a similar example, the mother (9a) stated, "Um, and I just kept asking the doctors, I think something is wrong with him. I think something. There is just something. And you know they're like, oh you've read too many Jenny [McCarthy] books or you've watched too many doctor films." In this case (9a), the diagnosis was not until her son was 8, but she continued to seek out information and referrals as her son's symptoms continued. These parents initiated the process for assessment and diagnosis in response to symptoms of developmental delay that they recognized in their child. At the same time, they were also demonstrating that they were good parents.

Anglo Parents Constructed Themselves as Advocates and Initiators

Parents from the Anglo sample were usually more entrenched in the middle class U.S. model for parental behavior and talk about parenting through their concern for timeliness of assessment and interventions, the monitoring of their child for problems, and for timeliness of development for their child. Anglo parents more frequently initiated the process for an assessment, with 9 out of 10 Anglo parents, and with only 4 out of 10 Hispanic parents. Seven of the 10 Anglo parents suspected ASD, while 1 Hispanic parent suspected ASD at the time of assessment. One Anglo father (10a) typified these feelings of anxious parenting when he stated, "Yeah, I do feel though catching it when I did and getting services started right away . . . and the better off they'll be when they grow up as far as being in society and functioning and all that." Another parent (1a) also provided evidence that she initiated the process of assessment and diagnosis, when she stated, "But I actually kind of brought it up to her. I kind of started asking about early intervention to her and she was the one that said to me—she goes, 'You know, if you're noticing things like this,' she said, 'you might as well get him into early intervention.'" This mother (1a) and her husband also had the resources to get more information, and her husband looked up their son's symptoms on the Internet,

> And so he [the father] just typed in [the child's] symptoms on Google . . . . So it was at that moment that we realized that, 'Oh, our son has autism.' . . . So, I mean, we found what we could as soon as we could and got him into it, you know, to start. And we didn't have a diagnosis until December but we knew—we knew what it was at that point.

Anglo Parents Constructed Themselves as Discriminating Health Care Customers

Most Anglo parents were critical of their HCPs and claimed that they received very little support and direction from them (1a, 2a, 4a, 6a, 7a, 8a, 9a, 10a). For example, this mother (6a) was frustrated because of the misdirection she received, "Even the pediatrician, you know, was like, he'll talk eventually. Don't push him. Don't worry about it." Parents were frustrated because they received mixed messages from HCPs and expected more up-to-date ASD information, active guidance, and direction from HCPs, just as they were expected to know about developmental issues and find and consume as much information as they could about ASD. Discussing her experience with her HCP, 1 mother (7a) stated, "Well I don't feel like I've really gotten a lot of help from them, honestly, you know." She (7a) concluded by stating that "most of the direction I've got is from a social group, Tooele for Autistic Mom's so, and research online you know." They voiced their frustration by commenting that there was not a lot of support, as they sought out a diagnosis and treatment, in the same way that they expected there to be guidance and direction after receiving a diagnosis for some other condition. Many parents voiced their concerns about the HCPs who helped them. Parents wanted their HCPs to live up to the standards that they also expected of themselves, as parents of a child with ASD. These parents wanted HCPs to help with a timely diagnosis and provide direction and support in finding effective interventions. They also wanted HCPs who would listen and not criticize them.

Anglo Parents Constructed Themselves as Competent Decision Makers for their Child

Some parents in the sample felt just as competent (expert) as their HCPs, including therapists. One young mother (1a) expressed it this way, “Um, right now we are at the point where we know enough about ASD and we know enough about the treatments that are out there that we are kind of doing all of it ourselves.” A young father (10a) expressed his frustration not only with his HCP, but also with specific therapists when they recommended that he, the father, spend 20 minutes eight times a day doing therapy. This father stated, “It’s – no, I’m going to spend all day playing with him when I can and make it a game and watch what happens.” He added, “No, I think he’s gotten more out of me and my parents [versus the therapist]. And dad teaches high school, auto mechanics and my son loves cars, so . . . .” One of the more experienced mothers (22a) has developed her own book about ASD because of her own frustrations and the frustrations of others. She stated, “So this is why—now you can see why it was like, I’m writing this book to help people know about it; that they don’t have to be afraid of the diagnosis and that having a diagnosis only helps your child.”

Some Anglo Parents Constructed Themselves as Stigmatized

The middle-class U.S. “good parent” discursive model is largely composed of taken-for-granted norms that guide our perceptions of what a parent should be. Some mothers suffered the effects of stigma because they may not have fit within the sociocultural norms for some reason. One mother (4a) switched pediatricians because he blamed her and ignored her concerns. Another mother (6a) stated, "They [school teachers and HCPs] said he was having, it was my fault that he was having separation anxiety because I wasn't, you know, making him ride the bus." She (6a) also stated,

> I have had people say, 'Oh she just needs a firmer hand. You're not strict enough with her. You know, oh you're probably just tired because it's your eighth child,' on and on. No. You know what? Having nine kids, I can tell when there is a small problem and a gigantic one. This is gigantic and people don't see it. And it's very hard not to feel judged in general.

Mothers of children with "invisible" disabilities, such as is often the case with developmental delay and ASD, for the most part are judged by HCPs and people who know very little of their lived experience and can make judgments based on inaccurate or partial information about their child and about them as parents.

These mothers also expressed feelings of guilt and shame when interacting with their HCPs and teacher/therapists; they constructed themselves as vulnerable. One parent discussed being treated as responsible in some way for child's problems. When asked about her (4a) son's experience with HCPs, this mother stated that they (HCPs) "sucked." She then recounted her experience, "We had to switch doctors, switch pediatricians because he kept looking at him like it was just me; it was just me. And I was like this is not just me. I have five kids. This is not just me." This parent felt judged by her HCP that she was not a good parent and that her son's problems were attributed to her poor parenting skills.

A different parent (6a) had concerns about her son in school and had been repeatedly told that her son was okay or that he did not need special education classes. This parent's frustrations led her to obtain a professional nonschool diagnosis and the subsequent help of a social worker to act as a support person. Her son was diagnosed with ASD. She felt that the professionals at that school ignored the mother's concerns and also attributed her son's poor performance to the mother because they blamed her—the "bad mother"—for not "pulling him through this" (6a).

This same mother (6a), when asked what she thought was causing her son's challenges at school, stated, "I didn't feel qualified you know to think of those things. I thought well, um, maybe dyslexia is more of an issue than I realized, but I don't know how to get help for that." She emphasized her weakness as a way to counter the blame she had experienced for her son's lack of progress. She also described feedback from teachers and therapists at her son's school. In her view, they put the onus on the mother to assure her son's success or failure without presenting a more realistic or balanced perspective of her child's situation. Both of these parents (4a and 6a) seemed overwhelmed with the challenges in their life and frustrated with the blame that they had experienced.

HCPs are part of this co-construction of parents as either "good" or "bad." There is evidence, in the reports of parents in this study, that HCPs and others use U.S. middle-class discourse about parenting as a way to convey social norms, opinions, and judgments about whether they consider a given parent to be "good" or "bad" in terms of their parenting skills. If these mothers do not fit a HCP's notion of what constitutes a "good mother," the HCP may not even consider the mother's observations and concerns as legitimate. As a result, that opportunity for a diagnosis may be delayed. When the parent's or the HCP's expectations for ASD knowledge or good parenting (respectively) are not met, there is frustration and lack of trust between the HCP and the parent.

Summary of the Anglo Conception of the "Good Parent"

The discourse of the middle-class U.S. model of parenting as used by the Anglo parental group included (1) Anglo parents constructed themselves as being a good parent; (2) parents had a temporal sense of urgency to evaluate and treat their child; (3) parents demonstrated knowledge and concern with appropriate development—a general understanding of the importance of ages and stages; (4) parents often initiated the process of diagnosis and treatment; and (5) parents were critical of HCPs who were not up-to-date on ASD as it related diagnostic and treatment options. Through their discourse, these Anglo parents constructed themselves as competent and "good parents." This model of the "good parent" with its underlying assumptions are actively produced and reproduced within the historical and sociocultural U.S. context of medicalized middle-class expectations for the "good parent" (Hays, 1996; Ladd-Taylor & Umansky, 1998).

The Social Construction of Hispanic Parenting in Relation to the Diagnosis of Autism in Anglo Cultural and Social Settings

The discourse of most Hispanic parents in this study did not reflect the same linguistic and discursive resources as the dominant culture, namely the U.S. middle-class discursive model for parents. Such discursive resources might have helped these parents express their concerns about their child in a way consistent with U.S. expectations and the ASD-related medical theories. Nine out of 10 of the Hispanic mothers and fathers in this study did not know about ASD and knew very little about child developmental theory at the time of their child's diagnosis. Only 1 of the 10 Hispanic parents interviewed referred to developmental concerns as a reason to seek an assessment from an HCP, and this parent had significant exposure to developmental concepts through a past position at

Head Start.

Thus, with the exception of the parent with Head Start experience, Hispanic parents did not discuss concepts relating to ASD and developmental progress. Rather, they relied more on their ability to compare their child's behavior with that of children in a similar age category in their own extended family or group of friends.

Further, the Hispanic participants in this study did not demonstrate intensive monitoring, did not initiate the diagnosis, did not use nearly as much developmental language as their Anglo counterparts, or have a concern with timeliness of assessment and diagnosis as was found with Anglo parents. These activities were not a part of their discursive model about parenting a child with symptoms of ASD. The following organizing categories provided some indicators of the Hispanic culture, with the dominant cultural influences coming from Mexico and other South American countries.

Hispanic Parents Used Comparison to Assess Their Children

Hispanic parents gauged their children's progress regarding certain behaviors or accomplishments by comparing their child with siblings or other children—especially cousins and other relatives. If their child had not accomplished those same skills or tasks as the child's peers, then the Hispanic parents became concerned, increased their vigilance, and sought out more information. Most Hispanic parents voiced concerns about behavior, but did not tie those concerns to developmental theory or the concept of ASD as much as their U.S. counterparts. One Hispanic mother (16a) stated, "He was very different in between the girl and him." This mother had 2 children, and the daughter was older. Through comparison, she realized that her son was not accomplishing the same skills that her daughter had been able to do at his age. She took her son to a doctor that referred him to a specialist and, subsequently, he was diagnosed around age 2. This was a clear example of using comparison to gauge a child's growth and progress by a Hispanic mother who knew nothing about ASD and very little about developmental milestones, but had her own way of assessing their child. Many of the Hispanic mothers expressed that they understand that something was wrong or not right with their child by comparison with other children.

Anglo parents also referred to comparing their children with other children, but this was usually shored up with evidence of a more formal discourse of childhood development. This discourse was not present for most Hispanic parents, except for those parents who had access to more language and discourse about ASD since the time their child was diagnosed and 1 parent who worked at Head Start (11a, 12a, 17a).

Hispanic Parents and the Personality Etiology

In this study, Hispanic parents were more likely to attribute differences in their child's behavior to personality, hereditary, or similarities to a favorite uncle or parent, rather than have no reason at all for differences in their child's behavior. Falicov (1982) and Falicov and Karrer (1980), as cited by Seligman and Darling (2009), claim that Mexican mothers are more relaxed about developmental expectations, and tend to be more accepting of individual differences or behaviors. Consistent with these studies, Hispanic parents reflected this approach in discussing their child's behavior. For example, a Hispanic parent (18a) stated,

> Every time [friends and family] run out of topics [to talk about] people would say, 'Oh no, [your concerns] makes no sense, you know your husband's uncle start talking around five or so. There's really nothing, don't believe that. Or, you know every child has their own personality, or about the melt downs, some people say, well it's just that he hasn't character.' . . . Then even friends who [were] in

> college, they were saying, ‘Well, I don’t think he meets criteria for anything else, so you shouldn’t be concerned about anything at all.’

In another example, a father (11a) related his experience in Mexico, at first thinking that his son was deaf, and then having a doctor suggest his son was just “rebellious.” In a third example, a Hispanic father (20a) stated, “He wasn’t want to talk because when we found him, because it was time to start saying some words you know, be he don’t want to.” Again, behavior was attributed to personality instead of a cultural discourse model that included developmental delays as a possible cause.

Hispanic Parents and Catastrophic Changes

If a Hispanic parent saw a larger or more catastrophic decline in abilities, he or she sought help. However, without the Anglo attitudes of anxious parenting and the help of medicalized and developmental language, which is accepted as a norm in the U.S., it may be more difficult for Hispanic parents to obtain a diagnosis. The first example of this came from a father (11a) who remembered when his 18-year-old son was young when he stated,

> Yeah, one and a half or two. He started to talk. He welcomed me at home. He say, ‘Ola’ in Spanish. He run to open the door for me and say, ‘Ola Papa.’ You could talk with him. Like, how old are you? And he’d say, ‘Uno.’ Simple things, and then he suddenly stopped.

This led the family to try many evaluations and tests in Mexico, and then they moved to the U.S. for further help. Their son was diagnosed at about 3 years. This father later stated that the doctors, at that time in Mexico, focused more on physiologic problems, and less on developmental or behavioral problems.

Another example came from a Hispanic mother (18a) who received help from the HCP for her child after several previous attempts. This mother had become desperate and called the HCP again. She stated,

> When he was 4 . . . he was to the point where he was banging his head all day long and [not] responding, doing nothing, so I . . . I [called] the pediatrician and I said okay, there’s really something going on and I know that you might think its exaggerating, but there’s really something going on because there’s . . . [he needs] restraining . . . we don’t know what’s going on with him. And he [the HCP] said, ‘Well, that seems to be a behavioral problem and then he referred us to the Children’s Center.’

Previous attempts at describing her son’s tantrums and wild behavior resulted in platitudes from the HCP. However, according to the Mother, with desperation and persistence in describing her son’s behavior, her son was diagnosed with Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), now classified as an ASD. This mother expressed concerns at 18 months, and her son was diagnosed at 4 years.

Hispanic Parents Sought Understanding of and Resources for ASD

The Hispanic parents in this study were not idle, but they faced many barriers to assessment, diagnosis, and intervention. Consistently, these parents wanted more information about ASD, early intensive interventions, and ideas for therapeutic activities that they could do at home as parents. Many times parents were just unaware of the options they had for services and payment for early intensive intervention. This process of seeking more understanding was seriously hindered by the lack of information translated into Spanish about ASD and related services. Information was also difficult to obtain because they may not have access to computers and or the necessary computer skills. Many did not use or were not familiar or comfortable with local libraries and their resources. Many were not aware of the resources available within their local school districts.

Hispanic parents were especially handicapped by the lack of language and discourse models that helped them understand how to be a Hispanic or immigrant parent of a child with ASD (Hacking, 2007). Parents might know parts of the options and resources and what to do as a parent, but they lacked awareness of many choices and opportunities unless they had the help of someone (i.e., a professional social worker or therapist) who knew the ASD health care, school, and community resources. For example, 1 mother (15a) lived in a rural town in Utah and had a social worker, she stated, "I have a caseworker in Four Corners . . . And she goes to the school and she asks about [my son]. It's working, the medicine, and she talks . . . she calls me and we have appointments. And she speaks Spanish."

Another mother (19a) in an urban setting stated through a translator, who described the mother's comments in third-person:

> So . . . the therapist, she was the one that told them [the parents] about the 504 Option. She [the mother] said at the school they never told her and didn't give her any guidance as far as what help she could get there. So the therapist recommended the 504 option to them and they were able to access additional services.

For Hispanic and Anglo parents alike, finding out about resources in the community could be difficult, but it is even more difficult for someone not familiar with the culture and social practices, laws, language, discourse models, and resources available within the community.

ASD is a complex disorder and often requires multiple therapies, such as occupational, play, and speech therapy, along with an HCP, psychiatrist/psychologist, medications, IEPs (Individual Education Plans), special education, and/or help with mainstreaming. All of these interventions include choices, follow-up, interaction, discursive models about parenting, and learning the medicalized language required to communicate the specific needs of children with ASD. These sociocultural and linguistic practices are very difficult for a Hispanic parent with little or no English skills to accomplish. Navigating these issues involves more than learning English; it also involves having the discursive resources to communicate concerns, to obtain assessments, and to evaluate and access available treatments and resources.

Discussion

This study critically examined how both sets of parents used language and discourse to construct themselves, their children, and their experience with the diagnostic process for ASD. The diagnosis of ASD is a largely a linguistic and sociocultural process that includes medical, developmental, and psychological theories and their associated discourse. These language practices were part of a larger discourse about U.S. middle-class expectations for parents and parenting. This discourse model guides language use and everyday practices (such as how to accomplish a doctor’s appointment—the etiquette, follow-up, and language patterns or practices) that we often do not think about, and these practices are taken for granted. These discourse models also guide social expectations for parents, and those expectations are naturalized and assumed to be normal practices that can be expected of anyone. In other words, the norms of practice for U.S. middle-class parents are considered to be the standard for a successful parent—such as how to be watchful for problems in child health and development, and how to use language in context-specific ways to make a point that matches up with medicalized expectations for parents. The parents who were the most successful at obtaining early assessment, diagnosis, and intervention were those who were most adept at speaking, performing, and using the discourse of a middle-class “good parent.” Less successful in obtaining early ASD diagnosis and treatment were low-income and Hispanic families who had less exposure to this discourse model that expresses these socially accepted parental standards.

According to Gee (2001), it is difficult for us to be fully aware of the amount of shared cultural knowledge used in a conversation, because it is taken for granted. It is considered a “given,” and rarely re-examined among people from the same culture or discursive frame. This idea of shared cultural knowledge can also be viewed as discourse models (Gee, 2001). These discourse models supply discursive resources (conceptual, linguistic, and practice related resources) that parents draw from as they meet with HCPs and others who might be influential in the assessment of their child.

Discursive resources and discursive competence within a given culture facilitate or support the parent seeking assessment, diagnosis, and the attainment of other resources for their child. A newcomer to a culture may understand most of the language, but remain unaware for many years of the discursive resources or linguistic know-how that are needed to be persuasive in a particular context, such as language and practices for a doctor’s appointment or for a parent-teacher conference.

Cultural Influences on Anglo Parenting Discourse

The parents who used the “I” pronoun and gave an explanation of their attempts to obtain a diagnosis were responding to taken-for-granted social norms of parenting/mothering ideals and were trying to avoid the stigma of being considered a “bad parent” or, more specifically for most of the participants, a “bad mother” (Francis, 2012; Litt, 2004; Malacrida, 2009). There is the link between social practice of the individuals (through their texts) from Anglo parents to the larger middle-class U.S. discourse model regarding what it means to be a “good parent”—a “good parent” of a child with ASD. Through the responses of individual parents and the way they constructed themselves through discourse, it is possible to see the link or congruence with larger discourses about parenting in action, which are further explored through content analysis in this chapter. The assessment of the actions of the parents seemed amplified because these parents were caring for a vulnerable group, young children with a disability or developmental delay. Their most critical judges were most often themselves. They conveyed this through their careful reports of all they did to help and support their child. For middle-class Anglo parents, it was a taken-for-granted assumption that it is a parent’s responsibility to monitor their child, assess for problems, and then get the problems treated in a timely manner, as noted by McKeever and Miller (2004, p. 1182).

These parents were responding to taken-for-granted social norms of U.S. middle-class parenting/mothering and were trying to avoid the stigma of being considered a bad parent, or more specifically for most of the participants, a bad mother (Francis, 2012; Litt, 2004). Middle-class educated Anglo mothers are usually aware of their child’s developmental status, and they use their jargon to prove it (Reich, 2005). The Anglo parents have grown up in a society that values and expects parents to monitor their child’s developmental status and then to mediate, as necessary, to obtain assessment and treatment (McKeever & Miller, 2004).

The Anglo parents wanted to avoid stigma (felt or enacted) associated with the behavior of their child. At the same time, they wanted to avoid the stigma of being a “bad parent.” Being considered a “bad parent” is a part of a socially constructed dichotomy classifying parents as either “good” or “bad” based on how well they meet certain societal norms specific to middle-class North America. This burden of potential stigma is especially felt by mothers who are socially expected to be the main caregiver—an ideal mother—as noted by Malacrida (2009), “where mothers are positioned as ever available, ever nurturing providers of active, involved and expert mothering” (p. 99).

Middle-class Anglo parents therefore had expectations and practices that aligned well with the U.S. medical assessment and diagnostic processes needed for children with ASD to obtain appropriate services and, if possible, access to insurance and services. These middle-class Anglo parents were generally motivated and already equipped with anxious parenting and knowledge about development. Because of their privilege and education, they could more easily confront the challenges of obtaining a diagnosis. These parents, I am theorizing, had the potential to be a good parent of a child with an ASD because of their discursive skills and resources. Parents who understood developmental delays and the importance of early diagnosis and early intervention for ASD were also clear about temporal issues that would either serve to optimize or diminish potential outcomes for a child with ASD, according to some of the latest research. These temporal concerns were specific to Anglo parents in this study and were a possible indication of the U.S. medicalized discourse models of parenting that have become taken for granted as truth. This places a heavy burden on middle-class U.S. parents who feel responsible for their child’s health and well-being in accordance with the larger sociocultural expectations and discursive model of the “good parent.” Mothers are held more responsible for a child’s well-being, and in this case, the well-being of a child with ASD.

In North America, there has been a dominance of research and subsequent theory

development based on parental practices and discourses of the White middle and upper classes that have dominated the medical, educational, and legal systems. Because of this, most of what we know about parenting in the U.S. and Canada is based on the parenting styles of Anglo middle-class or privileged families. Julian et al. (1994) claim that these middle-class parental practices and norms for child development become the “benchmark against which other groups are compared” (p. 31). These Anglo parental practices become normalized. Thus, other cultural expectations and parental practices (discursive competence, capital, and resources) from different linguistic heritages become problematized as not normal (e.g., Asian, Hmong, or Hispanic linguistic heritage and associated practices). As a result, it is more challenging to analyze and describe discursive frames for parenting for Hispanic or other parents of a minority heritage.
A weakness of this study is that I did not focus more on the discursive frames for Hispanic parenting.

To paraphrase Hacking, being a parent of a child with ASD in North America is now a culturally understood way to be a specific kind of parent; conscious or unconscious understanding of this role depends on a parent’s discursive skills and resources within a U.S. context (Hacking, 1999). As one younger middle-class Anglo mother (8a) stated, her “hyper” focus about ASD resulted from “being a mom of a boy in today’s society, it was something that was kind of always in the back of my mind, um, to be watchful of.”

Cultural Influences on Hispanic Parenting Discourse

The Hispanic participants reflected their own dominant values, which presented differences from the values exhibited by the Anglo participants. The Hispanic culture is often characterized by a focus on family or *familismo.* This is a strongly held belief in being loving, true, and loyal to family members, especially the elderly. Parental values, as specified by Fisher et al. (2009), usually include, “deference to parental authority, obedience, family loyalty and personal honor” (pp. 296-297). *Familismo* was evident through practices that indicated their love and concern for their child. However, the level of monitoring and culturally supported scientific findings about child development were not a part of their sociocultural linguistic heritage, at least at this less privileged level.

Respecto is a second key value that indicates that Hispanic cultures accept a more hierarchical structure and that power will be unequally distributed based on income, position, or some other measure of status (Carteret, 2011). “*Respecto* means that each person is expected to defer to those who are in a position of authority because of age, gender, social position, title, economic status, etc.” (Carteret, 2011, p. 2). Hispanic parents generally appreciate the value of *respecto*, which is also referred to as “proper demeanor.” This idea of proper demeanor is valued behavior, not just for family, but for social encounters in general (Fischer et al., 2009, p. 305). This may lead to a tendency to be intimidated in situations relating to health (e.g., an appointment with a HCP) and education (e.g., an IEP meeting for your child) when the Hispanic parent does not speak English, leading to avoidance of assessments by HCPs and parent teacher conferences (Seligman & Darling, 2007).

Julian et al. (1994) claim that parents base their parenting style on “their cultural and reference group socialization” (p. 30). Parents from Mexico or other areas in South America and the Caribbean experienced different medical and cultural preferences or concerns through discourse that promoted the development of a different form of parental ideology (discursive model) and discursive abilities as compared to U.S. middle-class parents. Harkness, Super, and Keefer (1992) claim that becoming a parent involves the “integration of previous experience, general cultural models available in the parent’s environment, and the day-to-day events of life with a particular child” (p. 164). All of these circumstances contribute to the development of parental discursive resources and potential discursive capital within the context of a particular culture, social status, and historical period.

In an environment where Anglo parental practices and discourses become normalized, however, efforts by Hispanic parents to understand their child’s behavior may be presented in such a way that HCPs do not recognize ASD in their child because Hispanic parents are not acting within the U.S. paradigm and expectations of the “good parent.”

Through this analysis, though far from comprehensive, we do have some clues about the discursive model for parents from Mexico. I theorize from the responses of some of our parents that the “wait and see” perspective may be used to handle concerns for unexpected behavior. Some behaviors were also attributed to family or individual traits (e.g., because Uncle Harry was that way). Hispanic parents may not be as anxious as U.S. parents to acquire a quick diagnosis, but would rather take a wait and see approach. Hispanic parents in the U.S. may not have the same access to medicalized theories of development or to medical resources that they can trust or can afford that would allow them to express their concerns in a way that initiates a behavioral assessment. HCPs may not be culturally, linguistically, or discursively aware of how Hispanic parents think about their children, their child’s development, and how they express their concerns.

Hispanic parents who were not born in the U.S. were also less likely to obtain an early ASD diagnosis (Schieve et al., 2012). The majority of Hispanic parents who participated in this study had not been acculturated to the notion of medicalized monitoring, developmental milestones, and other taken-for-granted U.S. medical practices and expectations, such as timeliness of developmental interventions. This was evident from the lack of language, discourse, and associated practices from Hispanic parents regarding the need for parental validation, lack of knowledge about the developmental and medical expectations, and having fewer concerns for the timeliness of interventions.

These cultural influences from their country of origin are more profound and forceful in first-generation immigrants to the U.S. (Schieve et al., 2012). It also takes time to become culturally, linguistically, and discursively competent in U.S. culture. This occurs because newer immigrants (or those that stay immersed in the Hispanic community and culture) do not have the advantage of growing up with the U.S. language and culture in a way that helps them incorporate the nuances of language use in specific contexts. All of these cultural traditions and patterns of interaction, language use, and the influence of larger discursive models from their country of origin influence their world-view and what is real or possible. Parents then construct themselves, their children, and their interactions based on their socially constructed discursive models that guide their interpretations of their experiences, how they prioritize, act, and generally interpret the world. Coming to the U.S., these families are surrounded by and begin to interact with a new culture, a new language, and new discursive models about parenting, and about their children. They soon acquire bits and pieces of this culture and not others, but still making it difficult to obtain needed information and services.

Parents may feel intimidated or empowered based on the linguistic and discursive resources that help or hinder their ability to navigate the health care system in the U.S. and Canada, understand what the HCP is saying, or obtain services. Hispanic parents are also more frequently in poverty than other minorities (Therrien & Ramirez, 2000) and experience all the barriers to health care that other minorities face, including barriers to service use, such as access to child care, transportation, and insurance (Clark, 2002).

In contrast to the Anglo parents, the Hispanic parents largely did not reflect the U.S. ideology of parenthood. First, Hispanic parents were less concerned with emphasizing their role in the diagnosis of their child. Second, they did not use or had little understanding of medical theories of child development; they used a comparative method to assure proper growth and development. Third, the temporal issue about the timeliness of diagnosis was not emphasized as it was with the Anglo parents. For some Hispanic parents, after their child's diagnosis, they had become more aware of the emphasis on a particular type of parenting that included helping with the diagnosis, timing of the diagnosis, and especially, being more knowledgeable in the language of child development. However, Hispanic parents had their own ideologies of *familismo* and *respecto* (among others) within their own discursive models about parenting and families. Hispanic parents had their own sociocultural form of monitoring their child's growth through comparison with other children. Hispanic parents were concerned about being a "good parent" or "competent parent" in order to support and strengthen the family or the notion of *familismo* and help assure the success of their child.

Limitations

First, this study had weaknesses that are consistent with a qualitative postmodern small sample study. This study had 20 parent participants with varying levels of privilege. This sample is considered reasonable for a qualitative study, but not enough to generalize to other groups or populations.

Second, there was a lack of income diversity for the Hispanic sample: Most of the ten Hispanic participants were low income. (Their income ranged from $0 to 19,999 for four parents and $20,000 to 39,000 for another four parents. One parent had an income of $40,000 to 59,999, and 1 parent’s income was not known.) It was very difficult to recruit Hispanic participants, and I lacked sufficient budget to employ other forms of advertisement or incentives for participation in this study or to extend the date of this study. However, this sample reflects the group of people most at risk of delays because of their low level of privilege due to multiple factors: weak English linguistic skills, low incomes, low levels of education, lack of other resources (such as access to computers), very little access to HCPs that speak their language, minimal understanding of the U.S. health care and insurance systems, and few sources of ASD information in Spanish that go beyond the bare minimum of explanation. Hispanic parents have parental resources and understandings based of the sociocultural linguistic heritage from Mexico and experiences within their own current community and associations based on family and friends that share a similar sociocultural linguistic heritage of Mexico.

Third, I do not speak Spanish. Some of the participants needed a translator or did not fit the recruitment goals of (a) having been diagnosed within about a year and (b) being able to speak English well. It is very possible that subtle or culturally specific language was misinterpreted, because I am not familiar with the Spanish language. It is also more difficult to fine-tune follow-up questions through a translator. Since the emphasis was on language and discourse, having more direct access to Hispanic language and discourse around parenting and diagnosis could have yielded more information to contextualize study findings. Ideally, a follow-up study would interview Spanish-speakers in Spanish, and have Hispanic input into interpretation and analysis.

Conclusion

Hispanic and Anglo parents had some striking differences in discourse models that contributed to misunderstanding through discursive mismatch. Even with moderate English fluency, Hispanic parents confronted with many new medical concepts and vocabulary, along with developmental concepts and issues concerning interventions and community, medical, and psycho-social resources. They also faced the many nuances and culturally specific situations that provided barriers to care and different expectations about what it meant to be a parent. These could contribute to discursive mismatch between poor or Hispanic ethnic linguistic heritage parents and their middle class HCPs and schoolteachers.

Parents experienced the two subsets of courtesy stigma, felt and enacted stigma. In general, Hispanic parents recounted more experiences with enacted stigma, and Anglos recounted more feelings of felt stigma. This is an area that could use more exploration and study and the influence of stigma on the social and public experiences with a child with ASD.

More Anglo parents were knowledgeable in medical and developmental perspectives, including the concept of ASD. Since most Hispanic parents within this sample were not aware of the concept of ASD and knew very little about U.S. medicalized theories of child development, it was reasonable that they looked to other potential causes for their child's behavior. Some Hispanic parents felt that their child just had a unique personality and other parents were concerned that their child might have a hearing problem. These alternative explanations helped Hispanic parents explain their child's behavior for others and themselves.

Community and professional knowledge or awareness helped both groups (Hispanic and Anglo). However, the Anglo parents were able to deploy U.S. developmental and medical discourses to help bridge their gaps in knowledge. This extra background provided Anglo parents with enough concern, and sometimes a certain knowledge, that it was important to have their child's behavior assessed. Anglo parents had the advantage in obtaining an assessment from various professionals even though they as parents knew little about ASD. As theorized, the Anglo parents had a better fit or were better aligned with the discursive models and ideology and skills related to the diagnosis of ASD that is also consistent with the more privileged U.S. ideology of the "good parent." More Anglo privileged parents were able to assess their child in the toddler years because they were already skilled as a parent of a child with ASD; they were already ready to assess and care for a child with ASD

Hispanic parents had more difficulty recognizing the differences in development or behavior as significant, because only 1 Hispanic parent had the requisite linguistic and discursive resources, and sociocultural knowledge and know-how through her experience working for Head Start. Furthermore, only this particular parent knew about ASD (and probably developmental stages) before their child was diagnosed. The concept of ASD was not a part of the sociocultural linguistic heritage of the Hispanic parents. They did not say, “Oh, that’s such and such” in Spanish. ASD did not exist for them. Their tendency was to be more relaxed about children as they grew up. As mentioned before, there were three cases where Hispanic parents attributed behaviors to a relative or to an individual personality quirk. Hispanic parents had also had more difficulty convincing doctors of their concerns, and 2 parents had to be persistent over time. One parent with the Head Start experience and the other parent with concerns about major behavioral issues were repeatedly rebuffed.

The more privileged U.S. sociocultural environment also supported behaviors that have come to be known as anxious parenting and the ideology the “good mother” and “good parent.” These culturally generated conceptions support the idea that parents—especially mothers—should do everything possible to assure a child’s well-being through constant and vigilant monitoring through developmental stages and regular well child assessments. Also, the ideology of U.S. parenting is a part of a culture that has been socially accepted and modified over time and has interacted with changes in medical and developmental paradigms during the 20th and 21st centuries through books, education, and the media. These developmental and medical approaches are now generally accepted ways to understand ASD and child development within a privileged U.S. sociocultural and linguistic heritage, as opposed to the 1950s when it was a generally accepted and medically recommended to institutionalize children with mental and developmental disabilities.

These findings also support the idea that, to be effective in helping their children who have serious health care needs, parents need to have specific discursive skills and resources consistent within the ideology and discourses of a privileged U.S. parent. Some of those include having the discursive skills and resources to understand and navigate the health care system. In addition, an Anglo privileged status and education prepare parents to be able to converse and convince HCPs on a discursive and sociocultural level, in a way that their concerns and arguments are considered valid and taken seriously, and as a result, are more likely to be investigated. Privileged parents also have the economic resources that allow flexible scheduling, private HCP consultation, and possibly private schooling with intensive interventions, along with access to more specific and in-depth information about ASD through the Internet and other sociocultural resources.

Difficulty understanding, incorporating, and recognizing cultural and interpretive differences by those newer to U.S. culture supports the idea that health disparities are complex and that there are multiple potential contributions to disparities, such as social status, income, and discursive skills and resources. Recognizing these privileged and sociocultural discursive differences can facilitate culturally focused outreach and sensitivity by HCPs to reduce the disparities in ASD diagnosis for Hispanic children.

CHAPTER 5

CONTENT ANALYSIS OF WEBSITES DIRECTED AT PARENTS OF CHILDREN WITH ASD

Introduction

In this phase of the study, I compared microlevel parental discourse to the macrolevel U.S. discourse models that reflect societal norms and ideologies. The focus here was on interpreting the macrolevel or dominant discourse about ASD and its diagnosis through the use of content analysis findings from sampled easily accessible ASD websites (referred to as ASD websites). The findings from the content analysis included aspects of the dominant discourse regarding ASD and its diagnosis. I do not claim to have found "the dominant discourse" about ASD, but my situated and interpreted version of the dominant discourse about ASD and its diagnosis. This version of the macro/dominant U.S. discourse about ASD and its diagnosis was set in contrast to my interpreted version of the parental or microlevel discourse about ASD and its diagnosis. This comparison helps us better understand if there is a mismatch between microlevel parental discourse, either by Hispanic or Anglo linguistic heritage, and the U.S. medicalized dominant discourse model that reflected societal norms and expectations associated with the diagnosis of ASD.

Discursive Construction of ASD Diagnosis and Parents by ASD Websites

The ASD websites constructed parents as an audience of consumers, advocates, and caregivers in ways that were consistent with more privileged Anglo parent view of being a "good parent." Good parents are constructed as anxious parents actively involved in their child's development (Francis, 2012). These websites were constitutive and actively constructed and framed parents as the type of parents who would fit with the discourse model of "good parents"—parents as consumers who preferred medicalized and scientifically based information, parents who wanted to be skilled advocates for their child, and parents who were monitoring and reporting. Then these characteristics were cast as signs of understanding (enlightenment) and love.

The ASD websites also accomplished this by combining medicalized information along with positive messages about parents as medically and scientifically informed consumers. For instance, a website provided a summary of a scientific intervention and went on to explain how this work with the intervention was funded by "our family of parents" (Website: Autism Speaks). Through this process, parents who contributed were constructed as supportive of scientifically based intervention and as a part of that organization's extended family and therefore, as a part of a group—"our family of parents." This discursive move also provided a clear pathway for newer parents to become a part of this community or "family of parents" through donations to be used for scientific production of interventions to help their children with ASD. Broad themes emerged from this analysis: ASD websites constructed parents as audience and consumer, as needing hope, and as being advocates and monitors. Thus the ASD websites promoted the dominant U.S. Anglo sociocultural discourses about ASD and parenting.

ASD Websites Constructed Parents as Audience and Consumer

Throughout the sampled websites, there was an assumption that the parent is the both the audience (that listens, reads, and watches) and consumer (who uses and applies information). Therefore, unless cited as the exception, most information in the sites was arranged, organized, and directed towards the parent. For example, this excerpt was straightforward and addressed parents directly: “We encourage parents to trust their instincts and find a doctor who will listen and refer their child to appropriate specialists for diagnosis” (Website: Autism Speaks). One reason this website trusted the “instincts” of the parent, presumably, was because those instincts are grounded in middle-class discourses about parenting that rely on science and its research. The website also suggested that the parent find an HCP who will listen to the scientific and developmental concerns of the parent. This passage also implied that the parents may not find such an HCP on the first try; they may need to keep trying until they find a HCP that will refer their child to a specialist. This process provided a way of coaching parents to be persistent about finding an HCP that has a practice consistent with the values of the ASD website.

In the next sample of text, the positioning of parents was a little less direct, but still maintained a clear focus on parents:

> For more information and resources, please see our Video Glossary and FAQs and special sections on Symptoms; Learn the Signs, Treatment, Your Child’s Rights, Asperger Syndrome and PDD-NOS. We also offer a number of resource-packed tool kits for free download (here and here). They include our 100 Day Kit for families who have a child recently diagnosed with autism. (Website: Autism Speaks)

Not only did this draw in parents by the offer of more information and resources, but also the website asked parents to “please see our video.” Using the pronoun “our” was a discursive move that drew in parents almost as if it stated, “welcome to our home.” The pronoun “our” is ambiguous, and could be construed as inclusive of the parent. Therefore, “please see our”—yours also—“Video Glossary.” This process of constructing parents as included in this community of parents provided a feeling of belonging.

ASD Websites Constructed Parents as Needing Hope

The idea of hope was reinforced through examples of positive outcomes, new treatments, and scientifically-based information about ASD. All of these options are consistent and fit within our North American and U.S notions about the potential for cure, for safety, and hope within a medical/scientific paradigm. The “good parent” has hope and stays involved, donates, and volunteers for ASD scientifically-based research and projects and objectives. Maintaining hope is helpful for parents who live with the challenges of ASD everyday (Kearney & Griffin, 2001). The websites gave parents hope for improved understanding of their child, hope for better interventions and outcomes, and hope for their child’s well-being now and in the future. For example, the Autism Science Foundation website explained, “Studies show that about half of children with autism who are in an evidence-based early intervention program from age 3-5 can gain enough skills to be mainstreamed for kindergarten” (Website: Autism Science Foundation). These scientific findings provide another virtue to the good parent by adding hope or the quality of hopefulness to parents of a child with ASD.

The National Institute for Child Health and Development (NICHD) website claimed that age does not matter, which is a contrast to most ASD websites that encourage vigilance and early detection. However, this strategy is consistent with providing hope to parents who might think that it is too late for their son or daughter to benefit from therapy.

> [I]t is not too late to benefit from treatment, no matter how old they are when they are diagnosed. People of all ages, at all levels of ability, can often improve after well-designed interventions. . . . In some cases, treatment can help people with autism to function at near-normal levels. (Website: NICHD)

This implied that there is hope for everyone with ASD if they have a “well-designed intervention,” which was another way of saying scientifically and medically approved interventions. All the websites supported a positive, yet scientific approach to interventions. It also requires a more privileged parent who had the time, resources, and linguistic skills and abilities to find and pay for high-quality adult interventions that make a difference instead of providing very limited interventions or possibly adult daycare.

Another site explained, “But there are many ways to help minimize the symptoms and maximize abilities. People who have ASD have the best chance of using all of their abilities and skills if they receive appropriate therapies and interventions” (Website: NICHD). The site offered hope with “appropriate” or scientific therapies. I substituted “scientific” because scientific interventions and the dominant U.S. discourse about science as the way to progress and overcoming are supported by all of these websites, and as a result, they suggested that an appropriate therapy is scientifically-based. A different website also inspired hope through a statement that a child might have some special gift or talent that would help ameliorate the challenges that the family is facing: “About 10% of people with autism have some form of savant skills and special limited gifts such as memorizing lists, calculating calendar dates, drawing, or musical ability” (Website: Web MD).

The websites interpreted hope differently within different contexts. One website offered hope with a statement regarding the Administration on Intellectual and Developmental Disabilities (AIDD), the federal government organization that oversees the implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000. The following statement might sound basic for most children, maybe even trite, but to parents of a child with ASD, it offered hope: “AIDD’s work focuses on shaping attitudes, raising expectations, amending outdated or broken systems and empowering people with disabilities to make their own choices to pursue the lives they imagine for themselves” (Website: Autism Now).

The words “empowering,” “make their own choices,” and “pursue the lives they imagine” must be reassuring to parents who are usually given less than positive information about the hope for future independence of their child. Most of these hopeful comments were supported with general ideas of independence, such as “empowering” or “the lives they imagine.” But keeping parents hopeful might keep them more engaged in helping their child and more willing to expend resources such as volunteering, donating, or advocating for children with ASD.

One of the websites was especially skilled at helping parents feel hopeful—Autism Speaks. This website was adept at drawing parents in and further molding them to be a specific kind of parent, a “good parent” of a child with ASD. This website was able to build hope, hopeful good parents, through addressing some of the key worries of a parent with a child with ASD. The Autism Speaks website offered comments on the following encouraging subjects:

(1) Persons with ASD are deserving of help. Many parents of a child with a disability struggle to convince others as a way of overcoming stigma and

devaluing of their child by showing that their child is of worth, can change and grow, and achieve at school or work.

(2) Persons with ASD can have the opportunity to work. Parents are concerned that their children will be able to care for themselves and gain independence and have a useful and productive life through work.

(3) Persons with ASD can develop meaningful and fulfilling relationships. This is a major challenge to many children with ASD. It would also be an enticing incentive to stay tuned to that ASD website to find out more.

(4) Persons with ASD can enjoy life. Parents may ask, how do I help my child enjoy life when they do not want to change their schedule or play with other children. This also lures parents in to try to discover more ways to help their child. It also feeds in the scientific/medical discourse that we have found cures for many things, and there is every chance that we could cure this also, given the money and time and resources needed.

(5) These assertions made by the Autism Speaks ASD website are fulfilled through the claims that with better interventions and supports available—now:

> We also know that many people with autism go on to live independent and fulfilling lives, and that all deserve the opportunity to work productively, develop meaningful and fulfilling relationships and enjoy life. *With better interventions and supports available, those affected by autism are having better outcomes in all spheres of life* [italics added]. (Website: Autism Speaks)

"Better outcomes" was vague, yet offered hope by using medicalized words such as "outcomes" and "all spheres"; and that sounds very promising. Parents might be happy with any one improvement, much less "in all spheres of life."

A further subtle way to build inclusiveness, community, and ownership was again to use an ambiguous “our” to get parents thinking about and being a specific kind of parent, such as, “These resources are made possible through the generous support of our families, volunteers and other donors” (Website: Autism Speaks). Thus, it was “our” families, volunteers and other donors. This site included almost everyone that read its pages, and they made readers feel a part of their group. The website uses the words: “family” and “our.” This subtle use of language helped parents feel a part of this hope for a cure and a part of this website and its goals.

These ASD websites were also used to reassure parents, “Research is now delivering the answers” (Website: Autism Speaks). This and other sites reassured delivery of answers not only now, but also in the future, as explained in this text, “We are dedicated to funding global biomedical research into the causes, prevention, treatments and a possible cure for autism” (Website: Autism Speaks). Because science and medicine were socially and culturally accepted ways to approach and study ASD, the websites referred to science in their texts as a discursive move to provide hope, shore up claims, and provide an acceptable source for research methods and personnel to study and treat ASD. Medicine and science use discourse and language practices that match up and are consistent with the larger North American model of parenting.

In sum, these sites promoted themselves and encouraged parents by offering hope. These examples also help illustrate how these websites were educating and influencing parents to be a specific type of parent—a parent that fits within the discursive model of a good North American parent of a child with ASD.

ASD Websites Constructed Parents as Advocates and Monitors

ASD websites made use of their resources to construct parents as advocates to crusade, support, advise, prescribe, and fight (in a good sense) for their child in order to obtain the needed resources to diagnose and obtain interventions for their child. The websites constructed parents as needing coaching or refinement to become good and better advocates and the right kind of good parent through linguistic construction that is consistent with the dominant discourse in privileged U.S. parents.

One website explained that, even in preparation for pregnancy, parents needed to be the right kind of parent:

> A growing body of research suggests that a woman can reduce her risk of having a child with autism by taking prenatal vitamins containing folic acid and/or eating a diet rich in folic acid (at least 600 mcg a day) during the months before and after conception. (Website: Autism Speaks)

Here, the site suggested that mothers have the responsibility, as a good parent to act or advocate for their child, by starting with prenatal vitamins to prevent certain child development problems by taking vitamins.

These websites were skilled at building a sense of urgency and responsibility as demonstrated in the next quote, which emphasized that good advocates and monitor feel the urgent need to get their child diagnosed when concerned about behavior.

> The following ‘red flags’ may indicate your child is at risk for an autism spectrum disorder. If your child exhibits any of the following, please don’t delay in asking your pediatrician or family doctor for an evaluation. (Website: NICHD)

This statement may increase parental concern and the need for monitoring with the use of the metaphor “red flags,” which in medicine is typically used as a sign that something serious, maybe deadly, is about to occur and should be assessed immediately. This statement also reinforced the notion that scientific and medical care is recommended and you should not wait to seek out your pediatrician or other HCPs to obtain an evaluation because so much is at risk. In some cultures, the typical initial step might be first to consult a parent or friend, but the website made clear that a pediatrician or family doctor would be the best choice.

Another passage reinforced the urgent need to be watchful or monitor by stating, "Most children with autism are not diagnosed until after age three, even though health care providers can often see developmental problems before that age" (Website: NICHD). This quote put the responsibility for early diagnosis through monitoring squarely at the feet of parents to advocate their child by monitoring closely, just as a parent might to assure that his or her child be seen for a concussion or some other serious injury. Parents advocate for their children on many levels, such as by assuring that they get good teachers at school or have immunizations even if the child does not want them. Therefore, it is a useful tool to help parents feel the need and the urgency to monitor and then advocate by obtaining an evaluation.

The sites also encouraged a feeling of urgency when monitoring by presenting the opportunity to get the best outcomes for their child through early intervention. Parents would want to get the best results for their child. Thus, as was shown in texts of parent interviews, most parents who believed they had missed the diagnosis of ASD felt guilty. This guilt flowed from the assumptions or dominant ideology for privileged U.S. parents in assuring the well-being of their child through monitoring, i.e. regular well child visits, understanding of developmental stages, and awareness that ASD is increasingly being diagnosed and detected in our communities.

This concept of urgency was promoted in the following quote from the NICHD website: “Research shows that early detection and early intervention greatly improve outcomes, so it's important to look for these symptoms when a child is as young as possible” (Website: NICHD). The words used in this short excerpt are powerful because they connect us to the dominant discourse about parenting and being a good parent with words such as:

(1) research - adds credibility to the statement by building on the dominant discourse in the U.S. that science can help us fix health as it did with vaccines and clean water;

(2) early detection – suggests that monitoring is necessary for early detection and is a consistent admonition of ASD websites, and is used to warn and admonish parents to recognize their duty;

(3) early intervention – early intervention is based on a parents ability to carefully monitor their child;

(4) improved outcomes – it is your responsibility as a good parent to do all that you can to promote wellness and the futurity of your child, so it follows that is your responsibility to promote the improved outcomes for your child through early intervention;

(5) it is important to look for these symptoms – it important for you as a parent with responsibility for your child’s welfare to look or monitor for these symptoms;

(6) when a child is as young as possible (close to 2 years of age)—does that mean that you start at birth?

This linguistic strategy puts incredible pressure on Anglo parents to monitor and to know the signs of ASD—but most privileged Anglo parents already know this piece because their privilege gives them access to these ideas and discourses and because these ideas about ASD are already so much a part of the sociocultural environment. ASD is talked about in the news, in families that have experienced ASD, in school, on websites, on TV, and on the radio.

These ASD websites employed linguistic strategies to mold and instruct parents about how to monitor and advocate for their child through obtaining early intervention. Summing up this strategy, a site presented a comment that could keep good parents awake at night: "Know the signs: Early identification can change lives" (Website: Autism Society).

At the same time, ASD websites constructed parents as scientifically informed advocates for their child and for ASD in general, such as the importance of using science to determine what is a good intervention or treatment. For example, this excerpt explained that the use of the hormone secretin is unscientific:

> However, a series of clinical trials funded by the NICHD and conducted through the *Network on the Neurobiology and Genetics of Autism: Collaborative Programs of Excellence in Autism* found no difference in improvement between those taking secretin and those taking placebo. In fact, of the five case-controlled clinical trials published on secretin, not one showed secretin as any better than placebo, no matter what the dosage or frequency. (Website: NICHD)

This quote used scientific findings to state in several different ways that secretin in not a useful method for the treatment of ASD. Using science was consistent with more privileged Anglo parents.

ASD websites coached parents in a way that promoted advocacy in a timely and scientific way through the specific ways they used words and discourses to construct a good parent consistent with the dominant medical/scientific and cultural understandings of ASD.

How could any good parent resist *research* or *scientifically proven* options if it meant helping and supporting their child? This type of discourse was a fit for the U.S. privileged English-speaking parents. These statements illustrate how the websites were trying to linguistically and discursively construct a specific type of parent that advocated for their child by understanding the signs of ASD, by monitoring, and by being persistent with the type of assessment and interventions that are consistent with the dominant medical/psychological and developmental discourse about ASD. These websites constructed a very specific type of parent with specific skills; they were constructing a good parent of a child with ASD, namely a good parent who has the linguistic and discursive skills and resources that matched up with the larger discursive U.S discursive model of the “good parent.”

Websites and the Construction of ASD

In addition to constructing the “good parent” of a child with ASD, these websites constructed ASD by discussing scientific, medical, and psychological definitions and content; child development concerns; genetic and environmental issues; and interventions for ASD.

Scientific, Medical, and Psychological Content and the Construction of ASD

The current construction of ASD is based in part on the *DSM-V* (American Psychiatric Association, 2013), which is a product of the psychiatric community of professionals, and supported by other medically-related professionals. One of the main linguistic patterns found within this portion of the websites is the consistent and positive support of science/medicine, and especially the results of medical and scientific research, diagnosis, and interventions. The websites advocate for science when developing information for parents of children with ASD. Research/science was viewed as helping in the present with ASD, as along with having the potential of helping in the future, to benefit parents and their child with ASD. The scientific way of knowing was the socially and culturally accepted way of understanding and talking about ASD and its associated interventions. This short quote from an ASD website provided an example of this, “Not long ago, the answer to this question would have been we have no idea. Research is now delivering the answers. First and foremost, we now know that there is no one cause of autism . . .” (Website: Autism Speaks). The websites implied that research is “now delivering the answers” sought by parents, and those answers might include the cure or best intervention because now we know more about the cause of ASD. This website not only reaffirmed its support of medicine and science, it also led readers to feel as if science is bringing parents out of the darkness of not knowing about ASD and how to treat it. The discursive use of this phrase “the answer to this questions would have been we have no idea” about the cause of ASD to “delivering the answers” through research led the reader to believe that he or she could thereby be enlightened about ASD. This strong yet understated support of science and its research was typical of the sampled websites.

Autism Society of American provided a similar view of the progress concerning ASD and the role of science when it stated:

> Just decades ago, many people with autism were placed in institutions. Professionals were less educated about autism than they are today, and specific services and supports were largely non-existent. The picture is much clearer now. With appropriate services and supports, training and information, children on the

> autism spectrum will grow, learn and flourish, even if at a different developmental rate than others. (Website: Autism Society of America)

The National Institute of Child Health and Human Development website stated, “Research shows that early detection and early intervention greatly improve outcomes, so it's important to look for these symptoms when a child is as young as possible” (Website: NICHD). Not only were websites delivering the answers about the cause of ASD, they were also asserting the way to obtain the best outcomes. The other websites also supported this claim and emphasized the need for early diagnosis and intervention for ASD. Those that stated their support for early diagnosis and intervention included the Association of Science for Autism Treatment, Web MD, Autism Web, Wikipedia, Autism Now, and the Autism Society. The Autism Science Foundation stated, “Early diagnosis and early intervention are paramount to achieving the best outcomes” (Website: Autism Science Foundation).

If parents were concerned about ascertaining if their child had ASD, websites admonished parents to seek a scientific evaluation: “From birth to at least 36 months of age, every child should be screened for developmental milestones during routine well visits” (Website: NICHD). This quote assumed that parents would use a medically and scientifically competent physician to conduct the “well visits.” Parents were being tutored and developed to be good parents in terms of providing good medical/scientific care of their child.

The website Autism Speaks explained its view of what constituted a good evaluation:

> A typical diagnostic evaluation involves a multi-disciplinary team of doctors including a pediatrician, psychologist, speech and language pathologist and occupational therapist. Genetic testing may likewise be recommended, as well as

> screening for related medical issues such as sleep difficulties. This type of comprehensive [evaluation] helps parents understand as much as possible about their child's strengths and needs.

This was a medicalized and scientific view of what constituted a good diagnostic evaluation. It was also a middle-class notion of a good evaluation, because the expense to carry out this premium level evaluation is out of reach for most low-income parents. There was no streamlined or less expensive alternative provided. The website assumed that parents could arrange and pay for all of these tests and evaluations. This process of diagnostic evaluation, as outlined above, took the linguistic skills and resources of a middle class family within a North American medicalized culture to navigate and understand.

This next sample text (Website: Autism Speaks) summed it all up when it states, “We are dedicated to funding global biomedical research into the causes, prevention, treatments and a possible cure for autism.” This website used the term “research” to support the information provided and build trust overall for recommendations about ASD, interventions, and research overall. For example, this website also stated, “Research is now delivering the answers,” implying that research would not only help us understand the cause, but answers to other problems as well, such as how to help children with ASD improve. A search of these texts found that 77 passages used the word research within this category alone. Research was a term that invoked the idea of a medical and scientific approach to helping children with ASD, as with its use of this statement, “Research shows that early detection and early intervention greatly improve outcomes, so it's important to look for these symptoms when a child is as young as possible” (Website: NICHD). These statements were plainly directed towards a lay parent consumer because these texts lacked any specifics of the research mentioned (i.e., no reference to the citation, author, or sample size) and lacked the technical and more esoteric language used by professionals. These examples were designed for parents and others new to ASD and medicine, seeking information, reassurance, and hope about the interventions and the future of their child.

The websites constructed and examined ASD through a scientific perspective and framework, focusing on cause, signs, symptoms, and treatments. However, these websites modified and adapted the discussion of their scientific perspective to meet the needs of parents of a child with ASD. As mentioned, the terminology was basic for a college-level parent. Highly technical information was omitted so that the information was appropriate to the needs of educated lay parents. ASD was portrayed and interpreted through the socially and culturally accepted perspective of science, including the developmental, genetic, neurological, medical, and psychological branches. Despite these details, ASD was constructed in these website texts in a parent friendly and accessible manner.

Child Development Content and the Construction of ASD

The child development related texts compiled from the scraping of nine ASD websites constructed ASD in several ways. First, the websites constructed ASD as a scientifically defined condition with behavioral parameters, based in part on developmental theory and the age-related stages of development. The NICHD website stated, “ASD is a complex developmental disorder that affects how a person behaves, interacts with others, communicates, learns.” The NICHD website focused on developmental stages and provided more specific parameters based on child development theories. Child development theory, as found in the sampled websites, also provided these “red flags” of delayed development as noted here by the Autism Web website:

> There are a number of things that parents, teacher, and others who care for children can look for to determine if a child needs to be evaluated for autism. The following ‘red flags’ could be signs that a doctor should evaluate a child for autism or a related communication disorder:
>
> The child does not respond to his/her name.
> The child cannot explain what he/she wants.
> Language skills or speech are delayed. The child doesn’t follow directions.
> At times, the child seems to be deaf.

The list continued on with 20 more examples of red flags (Website: Autism Web). Similarly, the NICHD facts page also provided a list of warning signs. Consistent with this approach, eight out of the nine sampled websites provided some kind of check list or summary to help parents and others form initial impressions about whether this child’s behavior and development are appropriate for his or her age.

The child development content of these websites also constructed ASD as an atypical form of development. All of the websites constructed delayed development as atypical or not normal in many ways. Just by using the term Autism or ASD, they acknowledged that development is not normal, but is delayed. Red flags and warnings were used to point out developmental levels that were not meeting the guidelines, were not neurotypical, or were considered a “developmental disorder” (Website: WebMD), and or even suspicious of a developmental delay (Website: Association of Science for Autism Diagnosis). The websites portrayed parents as expecting “neurotypical” development and interactions with their child, but instead, parents encounter different types of behavior or delayed developmental stages consistent with ASD. Autism Speaks was very explicit on this point and stated, “Research suggests that children with autism are attached to their parents. However the way they express this attachment can be unusual*”* (Website: Autism Speaks). Children with ASD were constructed as expressing themselves in an unusual or atypical manner, as compared to the developmentally typical manner that their parents expected. For example, a child with ASD was constructed as bewildered:

> To a person who misses these social cues, a statement like ‘Come here!’ may mean the same thing, regardless of whether the speaker is smiling and extending her arms for a hug or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world can seem bewildering. (Website: Autism Speaks)

The use of the word “bewildering” for the child with ASD may also have resonated with parents who found their child’s behavior as confusing, puzzling, baffling, perplexing, and disorienting, all synonyms for bewildering. Thus, the website constructed a child with ASD as bewildered about many social aspects of the world. The website also constructed ASD, in many ways, as the same bewildering condition for parents, in part, because ASD was constructed as unusual and atypical in general. ASD was confusing, perplexing, disorienting to the parents also, because they were not familiar with their child’s “atypical behavior.” This atypical behavior was manifest, for example, when the child ignored or seemed not to hear a parent, was concerned with organizing his or her toys, and appeared not to care about the parent. Parents were also constructed as expecting certain behaviors that are consistent with developmental expectations, such as making eye contact or talking by a certain age. ASD was constructed as atypical and confusing to the parent and the child with ASD. The website constructed ASD through the experiences of the parent and child.

ASD was also constructed as detectable at an early stage and best detected through monitoring based on scientific knowledge of what and how to monitor. This website especially recommended monitoring for those that might be at risk of having

ASD, as described in the following quote, “But children who have a sibling with autism should continue to be closely monitored, because they are at increased risk for autism and other developmental problems” (Website: Web MD). So the recommendation was to always monitor everyone to a greater or lesser extent to find those with the symptoms of ASD.

The websites also constructed ASD as treatable. For example, the Association of Science for Autism Treatment discussed “evidence to support the fact that early intervention has the potential to make a significant difference for a child with Autism Spectrum Diagnosis.” Another site emphasized similar constructions with the following statement, “Early diagnosis and treatment helps young children with autism develop to their full potential. The primary goal of treatment is to improve the overall ability of the child to function . . .” (Website: WebMD). The website implied here and through previous statements that the therapy was based in science, or more precisely, scientific research.

The websites admonished parents of a child with ASD to rely on science, because ASD is treatable through research and scientifically prepared interventions as administered by scientific professionals, HCPs, and specialists. This construction was manifest through overt and implied support of scientific methods, perspectives, practices, and practitioners. This quote summed up many of the hoped for contributions from science and institutions, when it stated, “The National Institute for Child Health and Development (NICHD) supports and conducts research on what causes autism, how best to detect signs of autism, how best to treat autism and its symptoms . . .” (Website: NICHD).

Genetics, Environmental Content, and the Construction of ASD

The combined genetic and environmental content from the websites theorized that genetic influence is a part of the cause of ASD, with other potential contributing factors such as environment or problems with brain growth. The sites presented information about these theories at a basic level that most middle class parents could understand. For example, Wikipedia used this simplified explanation, “Autism has a strong genetic basis, although the genetics of autism are complex and it is unclear whether ASD is explained more by rare mutations with major effects, or by rare multi-gene interactions of common genetic variants.” Most of the websites did not use complicated genetic based jargon; generally, information was directed to the lay parents of children with ASD for their understanding as middle-class parents. ASD was constructed as a condition with a genetic component but without a clear cause (Website: Web MD).

Interventions Content and the Construction of ASD

The combined interventions content from nine ASD websites constructed ASD as a condition requiring intervention and as being responsive to interventions to a greater or lesser extent. For example, one website noted,

> While autism is usually a life-long condition, all children and adults benefit from interventions, or therapies, that can reduce symptoms and increase skills and abilities. Although it is best to begin intervention as soon as possible, the benefits of therapy can continue throughout life. (Website: Autism Speaks)

Less optimistic is the more cautious statement from Wikipedia,

> Intensive, sustained special education programs and behavior therapy early in life can help children acquire self-care, social, and job skills, and often improve functioning and decrease symptom severity and maladaptive behaviors; claims that intervention by around age three years is crucial are not substantiated. (Website:Wikipedia)

The following statement from the Autism Society website provided some middle ground as it also supported the need for early intervention:

> Intervention can help to lessen disruptive behaviors, and education can teach self-help skills for greater independence. But just as there is no one symptom or behavior that identifies people with autism, there is no single treatment that will be effective for everyone on the spectrum . . . but treatment must begin as early as possible and focus on the individual's unique strengths, weaknesses and needs. (Website: Autism Society)

Most of the sampled websites provided a promise and a warning to parents to start early to get the most from the intervention process. Thus, the websites constructed ASD as amenable to scientifically-based interventions that are specific to the child's needs and strengths.

In sum, the nine websites sampled for this study included the following types of texts that constructed ASD: (1) medical and scientific related texts, (2) child development related texts, (3) genetic and environmental related texts, and (4) ASD intervention related texts. The websites constructed ASD as a disorder partly defined by scientific parameters as outlined in the *DSM-IV*. They constructed ASD as a developmental disorder and provided other developmentally focused information. They also considered ASD to be a source of atypical behavior compared to typical behavior of a child for a given age range. These websites (and the organizations that designed, maintained, and funded them) constructed ASD as detectable at an early age—through intensive monitoring, and modifiable with the use of scientifically sanctioned interventions—usually referring to expensive and intensive interventions. They also referred to ASD as a condition that is genetically influenced, but without a clear cause, except in rare conditions—all scientifically-based and thereby consistent and supportive of the U.S. ideology about parenting a child with ASD. Lastly, the sites described ASD as needing interventions that improve overall functioning, increase the amount of neurotypical behaviors, and decrease the amount of behaviors that are constructed as debilitating or isolating for the child with ASD. Some parents and people with higher functioning levels of ASD reject this assertion that ASD is debilitating or not normal or are in need of help, but the goals and assertions of the websites are consistent with the dominant U.S and medical culture to fix or cure deviations from what is socially and culturally considered "normal."

Content Analysis of ASD Websites

My empirical LWIC analysis of the ASD websites showed a focus on parents. I found no significant differences in the rates at which "parent" and variations of "parent" appeared across the texts with one exception: The National Institute for Child Health and Development (NICHD) website used terms related to parents significantly less than the others (Z score = 2.01, p <0.05). I also used NVivo 10® to generate dendrograms showing 30 word concordances centered around each appearance of the term "parent" or "parenting" in the texts, and these were examined for insights into how the terms were being used.

Together, these results suggested that, with one exception, parent-related terms had an equal prevalence among the studied websites. This is surprising given the apparently varied nature and intent of the sites (i.e., parent-targeting information, parent support network, and science advocacy sites). The difference noted in the NIH site may result from the unique position of the NIH, because it does not rely on parents or the community for networking and donations, and a large part of its mission is to perform or fund research to improve child development. The finding that the mention of "parent" or parenting-related terms was similar across eight of the nine websites also supports the hypothesis that parenting is a central element in discourses about ASD and the diagnosis of ASD. The findings in Chapter 4 also support this finding. Findings from Chapter 4's comparative analysis indicated that the Anglo parents talked more about parenting than did their Hispanic counterparts. As discussed in Chapter 4, Anglo parents were more concerned about being validated as good parents within a larger discursive framework; they more often used the language of child development, and were more concerned about the timing of assessment, diagnosis, and intervention.

The three dendrograms that were generated as part of the content analysis showed that the word "parents" was associated with many themes that emerged through analysis, including intervention and educational issues for children with ASD, issues relating to diagnosis, advice for parents on how to be a parent with a child with ASD, and various concerns about social interaction and behaviors of children with ASD. Thus, the dendrograms visually and accurately depicted how interrelated the role or construction of parenting was to every aspect of issues relating to ASD and those affected by it.

Discussion of Findings

The nine sampled websites were parent friendly for privileged Anglo parents that were not only facile in the dominant English language but were reasonably skilled using computers and the website format. These websites lacked material culturally specific to Hispanic parents and their needs. I made attempts to find Spanish language websites, but found none except those that provided a direct translation of the information available on the U.S. English language websites.

As a result of analysis of these content areas, I found that the websites largely constructed ASD as a medical/psychological entity described within behavioral and communication parameters as described in the *DSM-IV*. All of the websites incorporated the *DSM-IV* language, categories, and medical and scientific views. This meant that ASD could be studied, measured, catalogued, and tested. Science about ASD could be applied in ways that were consistent with a U.S. middle-class parental discourse perspective.

The child development content of the websites constructed ASD as a complex developmental disorder with children often having atypical behaviors for their age; sometimes belligerent or acting out physically. The sites suggested that parents should monitor their children and be very aware of normal versus atypical development—thus constructing "good" parents as those who engage in such monitoring. In conjunction with developmental constructions of ASD, the intervention content area described ASD as being responsive to research approved interventions, especially early interventions.

All of the websites constructed parents as active or proactive consumers of their information, with almost all information placed, modified, and designed for the consumption of parents. The sites constructed parents as needing to know how to be a parent of a child with ASD.

These websites connect parenting and ASD in a way that makes them seem as if they are a constructed unit: In order to be a competent parent of a child with ASD, you must already have the proficiency and skills in ASD discourse to actually be and act and talk as a parent of a child with ASD. This is evident in the way the sites constructed parents, and developed content for parents to assure proficiency and skill level appropriate to the U.S medically informed dominant sociocultural discursive expectations. There seems to be as much information and emphasis on how to be a good parent as there is on the diagnosis and interventions. The sites instructed parents about the behavior of a child with ASD, about the need for scientifically verified interventions, and the use of scientifically prepared professionals. The sites also constructed parents as favoring a scientific approach and in need of a sense of urgency as they monitored (vigilantly) the developmental progress of their child along with the possible signs and symptoms of ASD. However, most importantly, the sites were grooming parents to be "good parents" consistent with the privileged U.S. discourse model of what a parent should be, and more specifically, of how to transform oneself into the good parent of a child with ASD within a privileged U.S. context. These areas of science, genetics and environment, child development, and interventions were co-constructing the diagnosis of ASD, and just as important, co-constructing the privileged good parent of a child with ASD. There was little if any discussion of less privileged parents with less access and resources to achieve the aforementioned levels of "good parenting."

As reflected in the ASD websites, the U.S. discursive model of parenting is constructed through the norms and history of the dominant North American middle-class medical/scientific expectations of what it means to be a "good parent" (Ladd-Taylor & Umansky, 1998). The U.S. privileged Anglo model of the "good parent" reflects cultural expectations placed on parents in general, but possibly more on a parent of a child with ASD. The whole notion of a parent as "good" or "bad" probably began with mothers in the late 18th century (Ladd-Taylor & Umansky, 1998). Ladd-Taylor and Umansky (1998) describe these changes in thought about mothering and children as associated with new ideas that came along with "industrialization, the American Revolution and Protestant evangelicalism" (p. 6). This theory about changes in attitudes about parenting is further explained:

> These historical sea changes continue to inform mothering today: in the beliefs that children are innocent, that good mothering and good government are intertwined, and that nurturing represents woman's essential nature. Vestiges of the Victorian ideal of motherhood persist: the 'good' mother remains self-abnegating, domestic, preternaturally attuned to her children's needs: the 'bad' mother has failed on one or more of these scores. (Ladd-Taylor & Umansky, 1998, p. 6)

The "good parents" of a child with ASD, including both genders, are subject to the same middle-class sources of judgment. Lower income and poor parents do not have the luxury of this model, because they do not have the language and discursive skills and resources to adhere to this model. Hays (1996) states,

> [T]he model of the white, native-born middle class [parent] has long been, and continues to be, the most powerful, visible, and self-consciously articulated, while the child-rearing ideas of new immigrant groups, slaves, American Indians, and the poor and working classes have received relatively little positive press. (p. 21)

In addition, more recent research suggests that parents, especially parents of a child with a disability such as ASD, are also expected to act in an intensive way (such as consistent monitoring their child for growth and development) consistent with a medicalized middle-class view of parenting (Francis, 2012). Parents are subject to criticism and stigma if they are unable to adhere to the social ideology of the good parent through their actions, language, and discourse (Francis, 2012).

This medicalized discursive model of parenting influences and interacts with criteria and processes for diagnosis of ASD that favors some parents over others. In the U.S., access to the resources and practices of the discursive model of good parenting privileges parents with an Anglo linguistic heritage in subtle and pervasive ways because parents with discursive skills and resources, such as college-level vocabulary, computer access, and medical/scientific literacy, have the advantage over those who lack such skills. As a result, parents with a Hispanic linguistic heritage who have fewer U.S. middle class skills and resources may experience a discursive disparity that impedes the process of obtaining a timely diagnosis. Discursive resources may include having even a basic concept of what constitutes a developmental disorder, how to obtain insurance, or how to discuss concerns in an effective manner. It is difficult to watch for something, such as a developmental disorder, that you know very little or nothing about.

This study found that website texts were used to construct parents as needing to learn how to be—and even master—being a parent of a child with ASD, before they actually became a parent of a child with ASD. This included the suggestions that, in order to obtain a timely diagnosis of ASD for their child and before they were officially parents of a child diagnosed with ASD, parents must be skilled or have mastery of the linguistic and discursive skills and resources consistent with the discursive model of the “good” middle-class North American parent. I use the term “good” because the websites promoted values associated with this ideology of being a “good parent,” such as timeliness of diagnosis and intervention, sensitivity and understanding of their child’s behavior, and putting the child’s needs above their own, to name a few. Thus, before a parent can be a “good” parent of a child with ASD, there is a subtle or unexamined sociocultural expectation that a parent be fluent in the actions, linguistic practices, and discourse models consistent with that of a parent of a child previously diagnosed with ASD.

Parents with a Spanish linguistic heritage may not possess the sociocultural linguistic and discursive tools and resources necessary to meet the expectations associated with the privileged U.S. model of parenting—as described on the ASD-related websites. They have a sociocultural linguistic heritage that does not include the medico-scientific concept of ASD and therefore do not necessarily have the associated discursive skills and practices that are consistent with the expectations and practices of medicalized and privileged U.S discourses concerning ASD or the “good parent.” The concept of parent and ASD are so closely constructed that it may be difficult for U.S. privileged health care providers to connect with the concerns of Hispanic parents. However, there is more research that needs to be done. These privileged and highly trained HCPs are comfortable and adept at the language and discourses of medicine and science that privileged Anglo parents can understand and reciprocate. Thus, HCPs commonly communicate and interact with all parents in a way that is consistent with the ideology, skills, and abilities of privileged Anglo parents. Such parents have the education, the medical system know-how, practical knowledge, and skills consistent with the often-unexamined sociocultural expectations (the “good parent”) that are needed to be effective with HCPs and within U.S. medical systems. When parents of Hispanic linguistic heritage lack these discursive and linguistic skills, the shortcoming can lead to a discursive mismatch with HCPs. HCPs are generally closer in privilege, sociocultural experience, and linguistic heritage with their more privileged patients than their experience with less privileged and marginalized parents. This mismatch impairs the ability of less privileged parents and HCPs to interact and communicate effectively.

Diagnostic disparity may occur when a parent’s talk, discursive ability, or presentation does not match the dominant privileged form of discourse (Hamilton, 2005; R. Rogers, 2002). This disparity in discourse may more easily occur with parents who have recently moved to this country, or are first-generation immigrants (Schieve et al., 2012).

These websites articulated the dominant discursive elements that are used to construct and describe parents, ASD, and the diagnostic process. These websites used medicalized discourse reflecting the dominant U.S Anglo privileged concepts of parenting. Thus, this website analysis suggests that parents lacking dominant U.S. discursive resources are at a disadvantage in assisting their children in obtaining a behavioral assessment and early ASD diagnosis. The website analysis highlights how those with fewer discursive skills consistent with the dominant and privileged discourses about parenting and ASD may delay an ASD diagnosis and thereby promote diagnostic disparities.

Conclusions

One of the main conclusions from this study is the finding that the larger sociocultural discourses in North America about ASD and parenting, as represented in the websites of national ASD related organizations, were consistent with the discourses of the middle-class Anglo parents recruited for this study. Parents, who accept the U.S. dominant discourses about ASD, whether consciously or unconsciously, used that discourse to guide decisions about their child (or the care of their child) and judgments about other parents. The analysis of these websites supports the idea that there is a dominant and privileged discourse about parenting. Parents that use this discourse usually have higher levels of education to understand ASD and defend their own parental observations using accepted medicalized language and discourse. Adequate income is needed to have the resources to find a different doctor or specialist if needed to obtain a timely diagnosis; they do not have to wait in line for a free consultation. They also might have easier access to professionals and other resources to find if there is support for their concerns. Lastly, they would have the linguistic and discursive know-how to be competent in presenting their concerns in a way that is consistent with the values and concerns of the HCP. These parents generally internalized practices of monitoring, timeliness of interventions, and sacrificing for their children. They supported scientifically and medically informed practices, and were developmentally aware of their children.

The macro U.S. sociocultural discourses about ASD and parenting—as reflected in the ASD websites—were partially not consistent with the Hispanic discourses about parenting that were reflected in this study. Hispanic parents in this study did not know about ASD before their child was diagnosed, except for 1 parent with Head Start training. Hispanic parents had their own discourses about what constitutes the behavior of good parents, but the study design was not focused enough on Hispanic notions about what it takes to be a good parent or possibly their constructions of ASD because at a sociocultural level they have little or no exposure to the concept of ASD. However, this study, as mentioned previously, provided a few clues, that (1) Hispanic parents were less concerned about the timeliness of diagnosis and were generally unaware of ASD; and (2) Hispanic parents did not monitor their children based on developmental milestones or stages. They used a comparative method that might have been born out of necessity due to the level of care available to them, by cost and by location. They developed their own screening methods because most citizens of Mexico were not covered by insurance previous to 2012, when full universal coverage was reached (Knaul et al., 2012). Thus, they did not monitor or seek medical services for their children in the same way as privileged Anglo parents. To be sure, Hispanic parents in this study reflected concerns for their children, including concerns for their child's linear progress in school and in other associated areas, such as the ability to interact socially and make friends, and to have the necessary communication skills for everyday interaction. However, their discourse did not include ASD-specific concerns for monitoring, medical assessment, or knowledge about ASD.

My analysis suggests that the closer a parent is to the dominant U.S. discourse and ideology of a "good middle-class parent," the easier it may be to obtain timely or early assessment and diagnosis of ASD in the U.S. I theorize that the reason for this is that the HCPs and others involved in the assessment and diagnostic process are also middle-class Anglo parents and share many of the same discourses and discursive skills, abilities, and resources as the Anglo middle-class parents that they serve. As a result, their discourses about parenting and ASD are very similar, making it easier to share ideas and convey the importance of obtaining an assessment. Those who are newer to this country with fewer of the same U.S. middle-class or privileged parental discourses are likely to face more barriers to diagnosis. These parents are more likely to experience a mismatch in discourse.

Situating This Analysis

This analysis of ASD websites is situated within a critical discourse analysis framework that has the goal of examining hidden assumptions and the subtle use of language to construct a situated perspective or ideology that privileges and values some groups or parents over others. Using CDA aids our ability to understand the sociocultural constructions and ideologies that may hinder the diagnosis of ASD for less privileged and minority parents as compared to more privileged Anglo parents who are more facile in the use of language and discourse to accomplish sociocultural goals, such as assessing and obtaining a diagnosis of their child's behavior.

This analysis does not suggest that these websites are of no value, or that they should not be used. Rather, this analysis hypothesizes that some of the linguistic and discursive practices used in the sampled ASD websites are privileging Anglo parents who are skilled at using the dominant medical/scientific discourse about ASD. This privileging process is accomplished by constructing the "good parent" through use of the dominant language (English) and discourse (medical/scientific/developmental discourse) that most privileged Anglo parents are skilled and adept in. Their privilege results from extensive schooling, sociocultural interaction with similar privileged people who write the texts and teach the classes, and set up organizations and professional careers based on the U.S. ideology of what it means to be a "good parent" in this historical time frame. I am a person facile in these discourses by education and profession, and I designed and conducted this study. Therefore, I know that I likely missed some key assumptions about parenting in the Hispanic culture because I am not familiar with it. But also because I am so entrenched in my own ideologies and ways of interpreting the world, despite my best efforts, I may have missed some of the ways I privileged the U.S. dominant sociocultural linguistic discursive practices over Hispanic discourses because they are different from my own.

Strengths and Limitations

One strength of this content analysis was the sample size of nine ASD websites, which is a reasonable size for a qualitative study. In addition, these sites include the most accessed U.S. national websites, Autism Society and Autism Speaks. The information from this part of the study may be used to help design and promote future research in this specific area. A second strength was that a significant difference was found between groups of websites. This indicated that there was enough diversity in the sample of websites to warrant a content analysis because the web sites were different enough to indicate whether the discourse of ASD was similar despite websites with a different focus or approach.

The limitations of this study concern the generalizability of this portion of the study. First, I was unable to find comparable Spanish language websites. With the help of an experienced Spanish speaker, we found that the Hispanic websites were literal translations of the Anglo websites, without any culturally specific information. Second, this content analysis would have been strengthened by a view from outside of the U.S. Comparison always strengthens content analysis, and using a site from outside of the U.S. would have provided some different perspectives as compared to U.S. notions about ASD.

CHAPTER 6

CONCLUSION

Introduction

The purpose of this study was to describe and critically analyze texts from parent interviews about the assessment and diagnosis of their child diagnosed with ASD. In this study, I interviewed 10 English speaking Anglo parents with a U.S. sociocultural heritage and 10 Hispanic parents with a sociocultural heritage of Mexico (now residing in the U.S.) with a range of English speaking skills. I did this with the goal of using linguistic and critical discourse analysis to complete the following three aims:

Aim 1: Explore and describe similarities and differences in language use and discourse in parent descriptions of their assessment of their child's behavior and the process leading to professional diagnosis of their child with ASD.

This study suggested that there are differences in language use and discourse between the two groups of parents. Parents, based on their level of privilege, expressed different concerns and values about themselves as parents and in their approach to assessment and diagnosis. Privileged Anglo parents (8 participants) and privileged Hispanic parents (2 participants) also constructed themselves as "good parents" according to the more privileged (middle- and upper-class education, income, and English language proficiency) discourse and ideology of parenting in the U.S.

Aim 2: Assess for the dominant (macrolevel) discourse, including sociocultural and medical influences, about assessment and diagnosis of ASD, using the texts of readily accessible online ASD focused websites produced by national ASD support groups or organizations.

The findings from this aim suggest that the dominant discourse from the ASD focused websites was consistent with the language and discourse of the privileged parents in this study. This dominant U.S. discourse around ASD creates and reinforces the privileged ideology of the "good parent," with associated responsibilities and characteristics such as (1) careful monitoring and awareness of child development, (2) knowledge and understanding of the signs of ASD, and (3) providing the help and care needed when at home, school, or therapy that supports their child's development and behavior as a way to overcome (as much as possible) the challenges associated with ASD. The Web sites constructed as "good parents" those who sought out and used early scientifically based diagnosis and interventions, and who committed significant time and resources to their child's improvement and well-being.

Aim 3: Analyze and describe how the language and discourse used by parents from two different sociocultural linguistic heritages (microlevel) and two different relative levels of privilege as described in Chapter 4, compare with or resist the dominant discourse (macrolevel), as described in Chapter 5.

The results suggest that parents with more privilege—and therefore more discursive and linguistic resources—used language and discourse consistent with U.S. ideology and practices of "the good parent," especially regarding parenting of children with ASD. The discursively skilled parents were those with enough privilege and discursive resources to reflexively provide the medicalized information that supported and defended their claim to the status of a “good parent,” and they reported fewer barriers in obtaining an ASD diagnosis.

Implications of Findings

These findings suggest that HCPs are more likely to discount the concerns of those who are less fluent and practiced in the privileged language, discourse, and presentation of a “good parent.” HCPs who view the parent in a negative light (as a less skilled parent through that HCP’s own taken-for-granted socioculturally-related assumptions) are less likely to trust parental accounts of the child’s behavior and are also less likely to take parent concerns seriously. Both of these possibilities lead to some level of delay in diagnosis or treatment. Conversely, parents who do not trust or understand the reasoning or concepts behind a HCP’s concerns and recommendations will not be as motivated to apply recommended interventions, unless recommendations are understood within the patient’s own sociocultural world views or discourse model in a way that makes sense to them. This can also lead to delayed ASD diagnosis or intervention.

This study highlights the influence of the ideology of the “good parent” and its associated discourse. Discourse is more than having the vocabulary, correct grammar, and pronunciation. Use of appropriate discourse is the ability to interact within a culture in a way that is consistent with the society’s values, ideology, and particular world view. For example, this study suggests that, in the U.S., parents are more effective in obtaining an assessment of their child’s behavior when they know how to use language and discourse in a way that matches up with the prevailing ideology about parenting.

Hispanic parents with a sociocultural linguistic heritage from Mexico may be fluent in the discourse and language of Mexico and successfully interact with and navigate Mexico’s health care system. However, this study was more successful analyzing the ideology of Anglo parents and only provided a partial view of the ideology and values of Hispanic parents in this study. More research is needed on this topic to assist in the development of culturally sensitive and appropriate interventions to improve ASD diagnosis for the Hispanic community. Currently, “Utah is the worst in the nation for enrolling Latino children for health insurance” (Davidson, 2016, p. 1). This may partly explain Utah’s disparity in diagnosis. However, having insurance does not guarantee that a parent will able to overcome barriers to diagnosis of their child’s behaviors if they do not have sufficient linguistic/discursive skills and resources.

This study suggests that, in order to be a parent with fewer barriers to an early-diagnosis for a child with ASD, that parent should already be as skilled as a parent of a child already diagnosed with ASD. In other words, to have a better chance of obtaining an early diagnosis, parents need to already have all the linguistic/discursive skills and resources of an experienced and privileged parent of a child with ASD. Without sufficient linguistic/discursive resources within the context of U.S. medicalized health care, a parent might not be able to explain his or her concerns in a convincing manner to the HCP, and this creates a risk for delayed ASD diagnosis. Some less privileged parents, both Anglo and Hispanic, felt that HCPs challenged their competence or worthiness by discounting their parental accounts of their child’s behavior by blaming the parents.

This study suggests that the dominant ASD discourse is just as much about being a skilled or “good parent” as it is about other technical aspects of ASD and its diagnosis. This reinforces the idea that the ideology of the “good parent” is powerful, and having the linguistic/discursive skills and resources to be a “good parent” is important to avoiding barriers to diagnosis. The ideology of the “good parent” emerged from the privileged parent data and from the content analysis of national ASD websites. Ideology had a “Foucauldian productive force,” as manifest in the privileged parent texts that produced an account of their “good parent” actions and concerns that were consistent with the ideology of the “good parent” (Phillips & Jorgensen, 2002, p. 63). National ASD websites reified the notion of the “good parent” by providing guidance about what the “good parent” should do and accomplish. Along with producing a socially supported model for the “good parent,” this ideology also marginalizes those not experienced in the discourse and ideology of the “good parent.” Marginalization of less privileged parents’ observations, concerns, and options produces barriers and subsequent delays in diagnosis of ASD. Ideology sets up power struggles by reinforcing the power of the medicalized culture and practices in the U.S., while marginalizing those who have different ways of knowing about ASD. Ideological practices also have a regulating or sifting capability. Through value related expectations and judgments, HCPs may place more barriers to diagnosis by expecting parents to come prepared with all the skills and resources of a more privileged U.S. parent. These value judgments discount and marginalize the accounts and concerns of less privileged parents.

There may be an additional explanation for some defensiveness of parents of a child with ASD when they provided specific information about their competencies as a “good parent.” Because the social and medicalized version of the “good parent” seems to be so entrenched in our culture, parents may feel that they have to defend themselves against ideologically supported judgments that may make them feel lower class or incompetent as a parent. Parents of a child with ASD may take steps to avoid stigma by supplying evidence that supports their standing as a “good parent.”

Implications for Practice

Nursing Practice Issues

This study suggests that nurses working with parents of a child with ASD (or with patients in general) will benefit from a better understanding of the importance of (1) language/discursive competency and resources, (2) the influence of ideology or world view, and (3) the impact of a parent’s level of privilege. Nurses and other HCPs should be aware of their taken-for-granted assumptions about parents and the difference between those they consider to be a “good parent” and those they consider to be less competent.

Nurses should understand their own U.S. privileged sociocultural expectations and ideology. They are privileged by their education and sociocultural and linguistic know-how, especially within the medicalized culture of a hospital, clinic, and other health-care-related situations in the U.S. However, nurses may not be aware of their sociocultural and linguistic/discursive expectations or ideology to the point that it provides barriers to effective communication and care for those less facile in those areas. Through education, nurses can become more socioculturally and linguistically/discursively aware of themselves and others. Nurses can and should better tailor their care to individuals from diverse sociocultural linguistic heritages.

The profession of nursing has long been interested in a holistic understanding of the sociocultural aspects of the patient, including cultural competency, cultural humility, and Leininger’s transcultural care developing theory and practice to improve patient care (Bentancourt, Green, & Carrillo, 2002; Jeffreys, 2008; Leininger & McFarland, 2006).

Because nurses provide care for and interact with patients from many diverse sociocultural backgrounds and languages, a critical component of nursing education is a focus on these cultural issues and assumptions.

Screening in Clinical Practice

Despite recommendations from the American Pediatric Association (2001), screening for ASD is optional in many clinics that serve children. Consequently, the initial contact with the HCP is crucial in the diagnostic process for ASD, because the HCP is assessing not just the child, but also the parent. This study suggests that the HCP—whether consciously or not—is also assessing the parent’s skills and abilities, through linguistics and discourse, against the ideological standards of the “good parent,” along with the child’s behaviors in the clinic.

This study suggests that less privileged parents may just have a general idea that something is wrong and they are not always able to use the more specific discourse and language around the diagnosis of ASD. As a result, HCPs might downplay parental concerns or not recognize the meaning of the parent’s report. Less privileged parents may have a discursive/linguistic disparity that prevents them from having the expected words, phrasing, and self-presentation to back up their claims and concerns.

Limited appointment times may also contribute to communication problems between a less privileged parents and the HCP. During a short appointment, a child may not exhibit the classic signs of ASD, and the parent may lack the discursive resources to point out “red flags” that would suggest an ASD diagnosis. When a parent lacks discursive resources, the HCP may need to spend extra time seeking to sort out the sociocultural differences in the parental account of a child’s behavior. More time is needed when scheduling appointments with less privileged parents and those newer to the U.S. These parents are more at risk of a discursive mismatch with their HCP.

Clinics should also develop screening protocols for less privileged parents to be implemented by staff prior to the time the child is seen by the HCP. Such protocols could include a focus on parental concerns that could help identify children who may be candidates for an ASD diagnosis or at risk for other health problems. At the same time, clinics and HCPs should use health literacy principles to improve the assessment and provision of health care with all patients. Options to improve patient understanding may include the need of an interpreter, pictures and videos, along with translated materials, and information presented in plain language with as little jargon as possible to facilitate understanding of information about their condition and associated care.

Providing ASD Information in Spanish

This study suggests the need to make ASD-related information available in Spanish (and other foreign languages) for dissemination by HCPs and ASD-related organizations who serve the needs of parents. The Utah Parent Center already is a clearinghouse in Utah for information for parents of children with ASD. In addition, the Utah Department of Health seeks to disseminate information to parents with special-needs children. Pediatric care providers and organizations also seek to inform parents about children’s health care needs. Hispanic and other minority community organizations seek to benefit their constituencies. All of these organizations and providers could benefit from having culturally focused information about ASD and its diagnosis available in Spanish. Hispanic parents, when interviewed for this study, almost universally asked for more translated information about ASD and more information about how they can help their child. Many less privileged parents did not have access to computers and some were not comfortable going to the library to ask for help. Hispanic parents also had different levels of literacy in English and Spanish, which meant that they liked information in both languages.

This study suggests that Hispanic and minority communities would benefit from establishment of a clearing house or sharing library for Spanish translation of information about ASD. Such a sharing library could provide PDFs and hard copies of information for Hispanic parents and the clinics that they visit. This information could be emailed or mailed to any location as needed. This organization could develop ties or co-operative agreement with national organizations that may have more resources and funding to develop or share Spanish translated information about ASD. Information could also be adapted to meet local needs for providing information about local ASD and disability resources. A broad variety of information is needed, such as defining ASD in more depth, describing and listing intervention options, explaining the benefits and risks of medication usage, and providing a glossary of terms with both Spanish and English translations. Such a sharing library may need extra funding, such as help from the Utah legislature or a government or private grant. This type of service would be a great help to less privileged families that may not have the resources or the skills to search for this information by themselves.

Recommendations for Future Research

Use CDA to Further Analyze Hispanic Ideology of Parenthood

This study illustrates the importance of ideology of parenthood as a potential influence affecting early ASD diagnosis. However, this study raises additional questions about the Hispanic ideology of parenting and suggests that understanding ideologies of parenting held by other minority groups would be useful in understanding disparate health care outcomes. Having concluded this CDA study, I suggest that the Hispanic parent ideology of the “good parent” has not been fully explored. I recommend doing an additional study that focuses on Hispanic parents and their values about parenting, the importance of family, respect, and patriarchal family structure, and other qualities that might shed light on the ideology of parenting from a Hispanic perspective, with an emphasis on parents from Mexico.

I would recruit Hispanic researchers fluent in Spanish and English to be co-researchers in the study. Together, we would seek to develop a coalition with the Spanish community in Salt Lake County area to facilitate recruitment of a diverse sample of Hispanic parents who have children diagnosed with ASD. I would also use the same CDA design, but recruit 10 Hispanic parents with a higher level of privilege, including more English fluency and time spent in the U.S.; and 10 less privileged Hispanic parents of children with ASD with less English fluency and less time in the U.S. This diverse sample will facilitate the assessment for the discourse of the “good parent” from a diverse Hispanic perspective. Semistructured open-ended questions would focus on the transition to the culture in the U.S. and the influence on their family and traditions.

The design of such a new study would be essentially the same as used in this study, using social constructionism and CDA theory and methods to analyze parental texts of Hispanic parents from different levels of privilege. The differences in design include involving at least one other researcher with bilingual skills in Spanish and English. Another difference would include the transcription of interviews by an experienced bilingual transcriptionist to enable both researchers to work together on analysis of the data. Questions would be developed to address family related issues, such as their transition to U.S. culture, changes in family functioning, any changes in children’s behavior or attitudes after the move, how they adjusted the U.S., and more. These questions would be developed and evaluated by the research team, along with feedback from members of the Hispanic community. These interview texts would be analyzed using CDA and critical language methods as discussed by Gee (2005). Researchers should examine texts for social language and study text at the lexical level (word or phrase) and the syntactical level (sentences) for data about the social language and ideology of Hispanic parenting. Researchers could then perform a content analysis of Hispanic (both in English and Spanish) ASD-related articles designed for Hispanic parents.

As done in this study, researchers could then use content analysis and findings from the CDA analysis of parental texts to assess for the dominant discourse or ideology about Hispanic parenting. In this way, they could seek to discern the dominant Hispanic discourse about parenting and possibly ASD, and compare these finding with the privileged and less privileged findings from the CDA. These findings about which groups of parental texts match up or resist the dominant discourse could inform future intervention studies or action research that involve the Hispanic community. Such research would help involve the Hispanic community to find better culturally compatible interventions to promote early ASD diagnosis. Such research could also help in addressing other issues around the problem of delayed diagnosis in the Hispanic community, such as improved understanding of ASD, its diagnosis, and treatment, and how to be involved in the care and interventions designed specifically for their child. On a community level, such research could suggest ways to facilitate use of community resources, to lobby for needed resources in school systems, and to develop programs such as intensive behavioral intervention.

Study to Assess Effectiveness of Experience-Based Teaching of Cultural Competence and Health Literacy

As discussed above, nurses and nursing students could benefit from learning how the level of linguistic and discursive competencies are tied to culture and measures of privilege. They could also benefit from a better understanding of how the differences in culture, ideology, education, language/discourse, and level of privilege influence a patient’s understanding of health-related issues and interventions. Additionally, they should better understand how disadvantages can intersect and combine in a way that compounds disadvantage in more than just an additive effect.

In order to accomplish these goals, I suggest developing an educational program using the results of this study and other current research about cultural competency and health literacy. The goal is to improve awareness and understanding of the challenges encountered by less privileged patients and those newer to the U.S., and the challenges associated with navigating our health care system. Such educational experiences should challenge their cultural assumptions about health care and adapting to a new culture.

Such an educational program could involve use of case studies involving cultural literacy problems, including involvement of faculty and students from different countries to help with mock scenarios. A study could develop scenarios in which Anglo students experience for themselves the challenges of learning a new culture by playing the role of a patient or parent seeking health care in the context of a different culture. Role playing could also involve addressing encounters with HCPs involving highly esoteric medical issues with which the students are not familiar. These experiences will illustrate challenges faced by persons who are less discursively privileged or who are unfamiliar with the U.S. health care system. Students will have to address these problems and work together in small groups to solve their scenario related to less privilege and a new cultural way of doing things in their role as a recent immigrant. Students would report back on their experiences with different scenarios to the larger class and write up their conclusions as a group.

This study would involve developing teaching scenarios and then testing their effect on nursing students. It would be a longitudinal study with two points of measurement: before and after. Students would also evaluate the quality of the experience, and their view of its effectiveness.

Final Reflections

I believe that this study reinforced four ideas that are useful in disparities research. These four ideas or concepts are presented below and, I believe, were supported through the findings of this study.

First, the ideology of the good parent is powerful—whether or not we agree with its focus on parenting as an intensive practice, as it is defined by the dominant Anglo and medical cultures in the U.S. Understanding its influence in the everyday world is an important idea that highlights how, as a society, we privilege the privileged in the diagnosis of ASD. As stated above, this study suggests that the less privileged parents experience more barriers to care at all levels, from the receptionist's desk to those that are licensed to provide a diagnosis. As Fairclough (1989) states, "ideology is overwhelming in favor of existing power holders" (p. 51). Those holding power around the discourse of parenting, currently and historically in the 20th century, include the dominant Anglo and medical cultures in the U.S. These two groups seem intertwined in the construction and reconstruction of the ideology of parenting. These dominant groups are able to make the ideology of parenting seem natural and as a taken-for-granted truth. This study also suggests that having the linguistic and discursive skills consistent with the ideology of the "good parent" is a key component to avoiding barriers to obtaining an early ASD diagnosis.

Second, the initial findings of this study reinforce the importance of understanding of the sociocultural influence, including discrimination, on disparities in health care. The Institute of Medicine (2006, p. 4) defined discrimination as, "differences in care that result from biases, prejudices, stereotyping." I believe that completing this critical linguistic and discursive study has yielded an improved understanding of the sociocultural influence on the diagnosis of ASD, a potentially important finding. As discussed above, the ideology of the "good parent" privileges the privileged Anglo parents and marginalizes less privileged parents, especially those from diverse sociocultural linguistic heritages. It then becomes an ethical issue for HCPs and others to find ways that lessen this disparity and the influence of the ideology of the "good parent" in ASD diagnosis. As a health care community, we should find and provide ways for less privileged parents or families to access health care without having to meet the high standard of the "good parent." Support of cultural competence for HCPs and health literacy for parents/patients are options available to assist in accomplish this goal.

Third, the role of critical linguistic and discourse analysis is useful in the study of disparities. Without the tools of critical and discursive analysis, these preliminary findings about the ideology of parenting as it applies to ASD diagnosis would not be available. Critical analysis of research interviews provides evidence of how parents want to represent or signify themselves and how some less privileged parents feel they were unfairly represented when seeking diagnosis of their child's behavior. Cloyes (2006) suggests that the use of critical strategic analysis as "one way to complicate prevailing discourses that (may) cast them [participants] as hapless victims" (p. 95), or, in this case, as less competent parents. The diagnosis of ASD is not simply an objective process or check list. HCPs interpret a child's behavior in the process of initial diagnosis, but they also appear to interpret and assess parents' accounts of their children's behavior. In doing so, HCPs are likely to be influenced by their assumptions about those parents based in part on their linguistic and discursive competence or a parent's ability to present himself or herself as a "good parent."

Fourth, critical linguistic and discourse analysis has an important place in disparities research and in supporting social justice. Certainly epidemiological methods are important for understanding health care outcomes and measuring disparities, but CDA of patient interviews provides key insights about the sociocultural influences, including commonly held assumptions or ideology, and thereby suggest potential causes of disparities for further examination. This study suggests that understanding how sociocultural interactions are mediated through language and discourse is an important step towards improvement in understanding health care disparities.

APPENDIX A

INTERVIEW GUIDE FOR ASD STUDY

1. **Tell me about your child as a newborn?**

Did you have a normal delivery?

Were you worried in any way about your child as a newborn?

2. **Describe how you decided that your child was doing well as a newborn**?

Did you have regular baby checkups?

Did the HCP check for height, weight, and head size of your child?

Did the HCP check for other things like hearing?

Did the HCP check for developmental milestones?

Did you feel that the HCP was easy to understand and provided the information you needed?

3. **Tell me about other people who might have helped you decide if your child was growing well and if he or she was healthy?**

Did you have family members near?

Were there other people in the community or in your church that gave you advice or support?

4. **Tell me about your experience when you first noticed something was different about your child?**

How old was your child when you began to suspect that something was wrong?

Were you worried at first? Did you think that your child might just grow out of it?

What were your observations?

Who did you talk to about your worries and concerns?

Did others observe your child and have questions about how your child was doing before you did?

Did you seek advice from family or friends before taking your child to a HCP?

5. Tell me your experience about getting your child evaluated?

How old was your child when first evaluated by a HCP?

Who evaluate your child first?

Did you have insurance that covered the evaluation?

6. Tell me your experience about obtaining an appointment?

How long did you wait to get an appointment?

Do you have a regular HCP? Did they know you at the clinic or office?

7. Tell me about explaining your concerns to the HCP?

-Was it easy to communicate your questions and concerns to the HCP?

Did the HCP talk about your worries or concerns? Did you feel that your concerns were taken seriously?

What did the HCP do to evaluate your child?

Did you feel satisfied that your concerns and questions had been answered?

Did you feel that your questions were answered in a way that was clear and easy to understand?

8. How many visits were needed to obtain a diagnosis

What was the first diagnosis you received?

Were you ever referred to a specialist?

How old was your child when he/she received a diagnosis?

9. What did you know about Autism Spectrum Disorder at that time?

10. Describe what you were feeling or thinking as you received the diagnosis or suspected that your child had an autism disorder?

11. Describe what others were telling you about autism?

12. Describe any situations or conditions that influenced this process of getting a diagnosis.

Was there a feeling of let’s wait and see?

Was there concern or stress in the family about getting a diagnosis?

13. Was there anything else you would like to add about your experience with the

assessment and diagnosis of your child – or just anything else you would like to comment about?

Tested at a 6th grade reading level.

APPENDIX B

CONSENT DOCUMENT: PARTICIPANT INTERVIEWS

You are being asked to take part in a research study about how parents experience the process of getting a diagnosis of Autism Spectrum Disorders (ASDs) for their child. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to volunteer to take part in this study.

BACKGROUND

This is a study about how ASD is understood and talked about by parents as compared to health care professionals. The study will examine whether there are differences significant enough that parents and medical authorities may be talking about and understanding ASD and a child's behavior in ways that do not connect, or cause misunderstandings. These issues are important because delays in diagnosis delay early intervention which is the best option available to minimize the symptoms of ASD in children. Some children are diagnosed after entering grade school and miss the most productive developmental time for intervention. The study may help us better understand why some children are diagnosed with ASD later than others.

STUDY PROCEDURE

First, you will be asked to read and sign this consent form if you choose to participate in this study**.**

Second, if you agree to participate in this study please fill out the attached questionnaire. There are questions about you (i.e., age, occupation, education, and marital status) and about your child (*i.e.* age, diagnosis, and age at diagnosis). Filling out the questionnaire should take about 10 to 15 minutes. These questions will help the research team select people with different experiences to participate in the interview portion of the study.

Third, as mentioned, you may be asked to participate in an interview with the researcher, which will take approximately 1 to 1 1/2 hours. This interview will be one-on-one between you and the researcher. All interviews will be audio recorded and later put into writing. If you do not want to be recorded, you will not be able to participate in the interview portion of this study. This interview will take place in your home or another place that is comfortable for you. The interview will be private, with only you and the researcher present. In this interview, you will be asked questions about your child with ASD, his/her behavior and your experiences with your child. The researcher will ask your permission to take notes during the interview. The researcher will give you a chance to ask any question(s) you may have before you sign this form by calling the contact person listed in this document.

Examples of the type of questions asked include:

- What was your child like as an infant?
- Did your child do anything as a toddler that surprised you?
- How did you first recognize that your child may have ASD?
- What resources did you use to understand symptoms of ASD?

RISKS

The risks of this study are minimal. Some of the things that we talk about may feel personal or be uncomfortable. You may feel upset thinking about or talking about personal information related to your child and family, or about ASD. These risks are similar to those you experience when discussing personal information with others. If you feel upset from this experience, you can tell the researcher, and he/she will tell you about resources available to help.

You may worry that being in this study could change the way other people treat you. Our interview will be private. All the information that you share with me will be kept private. I will not tell other health care providers, teachers, therapists or anyone else about the specific things you say. Your interview will not be used to identify anyone. Your name and other people’s names will be changed or deleted from the written record. No one should be able to trace the information back to you.

BENEFITS

There are no direct benefits for taking part in this study. However, we anticipate that the findings from this study will help improve our understanding of how ASD is understood and talked about by parents as compared to health care professionals. Additionally, we hope that these conclusions will help prevent delays in diagnosis for children with ASD.

CONFIDENTIALITY

Your data will be kept confidential. The researcher will keep all data in files and audio recordings on a password protected laptop and encrypted flash drives. Identifying information, such as name and age, will be removed from transcriptions and will not be used in any publications. Only the researcher and members of his/her study team will have access to this information.

What you talk about with the researcher will be kept confidential with 2 exceptions: If you disclose actual or suspected abuse, neglect, or exploitation of a child, or disabled person, or elderly adult, the researcher or any member of the study staff must and will report this to Child Protective Services (CPS), Adult Protective Services (APS) or the nearest law enforcement agency. Also, if you tell the researcher that you are thinking of hurting yourself or someone else or if you are in danger, the researcher must stop the interview and report this immediately.

PERSON TO CONTACT

If you have questions, complaints or concerns about this study, you can contact Kathy Kelly at 801-259-8476. If you feel you have been harmed as a result of participation, please call Kathy

Kelly at 801-259-8476. Please call Monday through Friday from 9 am – 5pm.

Institutional Review Board: Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

Research Participant Advocate: You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at participant.advocate@hsc.utah.edu.

VOLUNTARY PARTICIPATION

It is up to you to decide whether to take part in this study. If you decide to take part you will be asked to sign this consent form. If you choose to be in this study you can stop the interview without giving a reason. If you agree to be audio recorded, you can stop the recording at any time. You can choose to stop being in the study at any time, and any data you may have shared up to that point will not be included in the study. Choosing to stop being in the study will not have any negative consequences. This will not affect your relationship with the investigator.

COSTS AND COMPENSATION TO PARTICIPANTS

There is no cost to you to participate in this study. If you are asked to participate in the interview portion of this study with the researcher, you will receive a $25 gift certificate in the mail to a local grocery/clothing store as compensation for your time and inconvenience

CONSENT

By signing this consent form, I confirm I have read the information in this consent form and have had the opportunity to ask questions. I will be given a signed copy of this consent form. I voluntarily agree to take part in this study.

____
Printed Name of Participant

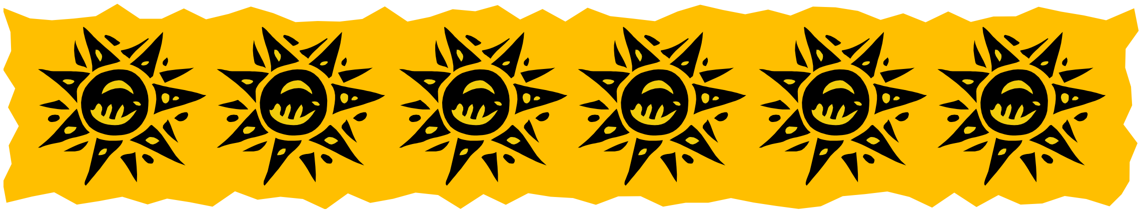
____________________________________ _______________________
Signature of Participant Date

____
Printed Name of Person Obtaining Consent

____________________________________ _______________________
Signature of Person Obtaining Consent Date

APPENDIX C

ENGLISH LANGUAGE FLYER

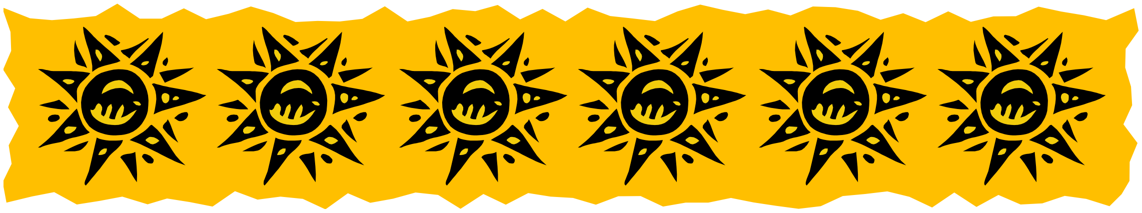


UNDERSTANDING HOW
PARENTAL & MEDICAL TALK
INFLUENCE THE DIAGNOSIS OF AUTISM

Parents…would you be willing to be in a research study about the diagnosis of Autism Spectrum Disorders (ASDs)?

- **Purpose of this study**: Understand the way that parental and medical talk is used in the diagnosis of ASD.
- **Who can be in the study?** A parent or guardian of a child recently diagnosed with ASD.
- **What will the study require**? (1) Take a short survey, and (2) if selected, take part in an interview with the researcher.
- **Compensation provided:** Participants who are interviewed will receive a $25 gift certificate.

Contact Kathy Kelly @ 801-259-8476



APPENDIX D

SPANISH LANGUAGE FLYER

Padres…¿Estaría usted dispuesto a estar en un estudio de investigación sobre el diagnóstico de trastornos del espectro autista (ASDs)?

<u>Indemnización prevista</u>: Los participantes que son entrevistados recibirán una tarjeta de regalo de $25.

-**<u>¿Qué el studio require?</u>** (1) Completar una breve encuesta, y (2) Identificacion del seleccionado, participar en una entrevista con el investigador.

-**<u>¿Quién puede participar en el studio?</u>** Un padre o tutor de un niño recientemente diagnosticado con ASD.

-**<u>Objetivo del estudio</u>**: Comprender la forma en que hablan los padres y médicos se utilizan en el diagnostic de ASD.

-Contacto Kathy Kelly, Enfermera 801-259-8476

* *

Parents…would you be willing to be in a research study about the diagnosis of Autism Spectrum Disorders (ASDs)?

-**<u>Commpensation provided</u>**: Participants who are interviewed will receive a $25 gift certificate.

-**<u>What will the study require?</u>** (1) Take a short survey, and (2) if selected, take part in an interview with the researcher.

-**<u>Who can be in the study?</u>** A parent or guardian of a child recently diagnosed with ASD.

-**<u>Purpose of this study</u>**: Understand the way that parental and medical talk is used in the diagnosis of ASD.

-Contact Kathy Kelly, Registered Nurse @ 801-259-8476

APPENDIX E

UDOH IRB FORM

PI Name __Kathy T. Kelly_____________ Date 8/15/2011________
Phone Contact _801-484-8476___________ Number
___________ Email Address [redacted]__ (assigned by UDOH IRB)

DEPARTMENT OF HEALTH
ETHICS/INSTITUTIONAL REVIEW BOARD

Request for Review by the Institutional Review Board
www.health.utah.gov/irb

Instructions: Please complete this form for any project you will be conducting involving the conduct of biomedical or behavior research involving human subjects. Please give completed form to Bobbie Lou Anderson, blanderson@utah.gov , at (801) 273-6601 or the Committee Chairperson, Iona Thraen, ithraen@utah.gov , at (801) 273-6601, P. O. Box 142002, Salt Lake City, UT 84114-2002 **two weeks prior** to the scheduled meeting (the 15th of each month). IRB meetings are held the first Monday of each month. Your request for review will be discussed at the next Ethics/IRB Advisory Committee meeting.

Any UDOH related project must have an internal UDOH staff contact and participant. An administrative review will be conducted to determine if your proposal is exempt. If you are using UDOH data and you assert that it is a de-identified data set, a UDOH data steward must review the data set using our PHI Attestation Check list and sign the attestation statement according to HIPAA standards. If a review is found necessary, your project will be discussed at the subsequent meeting of the committee. If your proposal is being reviewed by another IRB please submit your protocol summary and their determination with this application or as soon as you receive it.

1. Title of project: Analysis of Parental and Medical Discourse Regarding the Diagnosis of Autism Spectrum Disorder

2. Source of funding:
A. Who is funding your project? Self-funded, I am a PhD student at the College of Nursing, University of Utah

3. Has your proposal been presented to any other IRB? If so, which one? Include a copy of the protocol that you have submitted. I am also submitting to the University of Utah IRB.

4. Summary of project

A. Purpose: The purpose of this study is to examine the discourses of parents as compared with discourses of medicalized texts to better understand the influences of culture and socio-economic status on delayed diagnosis of ASD for poor and minority children. I propose that certain families and parents, such as those who are white, of higher SES and education levels are more likely to have both greater access to web-based resources and greater access to mainstream medical care, and thus are more likely to talk about and understand ASD and their child's behavior in terms of dominant medical or psychiatric discourse. This ability to draw on these discursive resources may mean that more affluent and resourced parents may be able to talk about ASD in ways that more closely align with dominant discourses, and which therefore lead to greater likelihood of their child receiving a medical diagnosis and related services earlier than those parents who cannot or do not talk about ASD in similar terms. This premise is explored through three aims:
<u>Aim 1</u>: Using critical discourse analysis, this study will compare and analyze: (1) the discourses of parents obtained from interviews, and (2) the discourses used in medicalized texts from ASD related websites to assess discursive practices, including discursive mismatch. Ongoing and multiple comparisons between texts will include the following comparisons:

(a) All parent groups compared to medicalized texts;
(b) Low-SES parents compared to High SES parents;
(c) Hispanic parents compared to White Non-Hispanic parents;
(d) Low-SES Hispanic parents compared to medicalized texts;
(e) Low-SES White Non-Hispanic parents compared to medicalized texts;
(f) High-SES Hispanic parents compared to medicalized texts; and
(g) High-SES White Non-Hispanic parents compared to medicalized texts.

<u>Aim 2</u>: This study will utilize findings of this critical discourse analysis to evaluate the implications of discursive practices and discursive mismatch on the disparity of delayed diagnosis of ASD for poor and minority children.

<u>Aim 3</u>: The long-term aim for this study is to apply findings to inform and develop culturally appropriate interventions for use by heath care providers, public health and private organizations to decrease delays in the diagnosis of ASD for poor and minority children.

B. Methods:

1. Sample size and number of samples:

The initial sample of parents taking the questionnaire will be open to as many as 100-150 in order to obtain a purposive sample of 20 parents according to the criteria listed below.

The sampling process is twofold and will include sampling of (1) parents of children with ASD (of diverse social and ethnic background), and (2) ASD related web sites that contain medicalized text about the diagnosis of ASD.

Parent Sample: First, parents of a child recently diagnosed with ASD will be recruited generally and go through the consent process. Participants will fill out a questionnaire to assess if they meet more specific requirements for the one-on-one interview with the Principal Investigator (PI). Second, based on the results of the questionnaire the PI will recruit a purposive sample of 20 English speaking parents 18 years of age and older. This sample will consist of 10 Hispanic and 10 White non-Hispanic parents. Parents must have a child with ASD 16 years of age or younger recently diagnosed (less than 12 months) by a qualified professional. Each of the two parent groups (Hispanic and White non-Hispanic) will contain 5 low-SES participants and 5 high-SES participants (See Appendix A Recruitment Goals). Additionally, the children of these participants must have ASD as their main diagnosis to simplify analysis of parents' experience. Exclusion criteria include families where the child with ASD also has severe mental retardation and other problems that would be the primary diagnosis and significantly obscure the diagnosis of ASD. Attention Deficit Disorder, learning problems, and seizures frequently occur in children with ASD and will not constitute exclusion criteria. This sampling design supports the examination of delayed diagnosis by including a "social distribution" of perspectives (Creswell, 2007; Flick, 2006).

Website sample: Two types of websites will be sampled: (1) websites designed by parent groups which seek to support parents of children with ASD or have questions about ASD, and (2) websites designed by government or private organizations that were not founded by parent groups and that may be more highly medicalized. Texts selected for analysis from each website will include descriptions of ASD, diagnostic criteria, and advice offered to parents on the website. Exclusion criteria for website samples include websites that are predominately used for advertisement of pharmaceuticals, equipment, treatment or services that are ASD related.

2. Research Design Research Design: Critical discourse analysis focuses on identifying patterns of language used in specific situations and communities of practice, and how social practices that stem from this language construct and reproduce broader constructs and understandings that shape discourse. Discursive practices are seen as central to the construction of knowledge, including medical and psychiatric knowledge, and as equally central to how people engage in daily practices (i.e., making an appointment or seeking a medical diagnosis) in relation to this knowledge.

This study will analyze discursive practices related to parents understanding their child's behavior prior to diagnosis of ASD, the process of seeking diagnosis, and the potential for discursive mismatch. Discursive practices or interpretive repertoires can be seen as "building blocks speakers use for constructing versions of actions, cognitive process, and other phenomena…using a restricted range of terms used in a specific stylistic and grammatical fashion" (Potter & Wetherell, 1987). Discursive mismatch will also be assessed and is defined as the interaction of two discursive fields of practice, each discursive field with its own values and priorities that promote a conflict within the individual caught between the two discursive fields of practice (Hamilton, 2005). For example, parents feel conflicted when caught between their own discursive field that includes cultural beliefs and values about their child's behavior versus a medical discursive field and its paradigms about a child's behavior and ASD. The shift from one discursive field to another may be more difficult for some than others based on social status, education, and familiarity with medicalized discourse and other possible variables. Investigating how discourses are constructed, contrast, and interact concerning a child's behavior and the possibility of ASD will improve our understanding and ability to ameliorate the problem of delayed diagnosis of ASD for poor and minority children.

3. Statistical treatment of results: The analysis of the questionnaire will be for the purpose of grouping the 20 participants by socio-economic status (using the BSMSS) and by ethnicity (using the demographic information). The BSMSS does not produce an absolute measure of SES, but it does provide a means of distinguishing between groups for the purposes of comparison and the possibility of some basic statistical analysis of information from the survey.

The overall framework for this study is based on critical discourse analysis and the work of Chouliaraki & Fairclough (Chouliaraki & Fairclough, 1999), Gee (Chouliaraki & Fairclough, 1999), and others (Cheek, 2000; K. G. Cloyes, 2006; Fairclough, 2003; Jorgensen & Phillips, 2002). First, texts from parent interviews will be transcribed and analyzed and then compared with each other to understand how parents are constructing their ideas and the meanings they attribute to their child's behavior before receiving a diagnosis of ASD. Second, transcripts from ASD websites containing medicalized discourses about ASD will be analyzed for ways in which ASD is constructed and the social organizing aspects of the discourses. All texts will be analyzed in part with the assistance of ATLAS.ti software to evaluate use of specific words to assess for frequency, co-occurrence (the way words are used in texts by different groups), and other patterns in the texts. The next step is to compare the discourses and findings from parent interview texts with the discourses and finding from the medical texts. Multiple comparisons, as outlined in the aims section, will contrast the parent groups with each other and with the medicalized texts.

Multiple close reading or immersion in the text is important to the analysis of parent interviews (Margaret Wetherell, 2001). Initially, the principal investigator will be assessing for ways in which discourse ascribes meaning to behaviors of a child being evaluated for ASD. In addition, analysis will include a description of meanings and values associated with other issues, such as the source of information about ASD, i.e., teacher, family member, Internet, and health care provider. Examples of struggle or contention between different representations of ASD will be examined (Jorgensen & Phillips, 2002). It will also be important to understand what parents construe as normal behavior. Throughout the analysis, examples of mismatch, discursive practices, and other related discourse issues will be noted and evaluated.

Memo writing parallels the process of coding, keeps the researcher involved in the process of analysis, and facilitates abstraction about the data. Memo writing will occur throughout the study and will also facilitate establishing the context of the interviews and support the overall analysis of this inquiry.

Coding will begin broadly, with overlapping categories, and will be based on careful and repeated reading and use of analytic tools listed above. Once salient issues are identified, the analysis will become more focused and evolve based on findings in the data. Coding will also be structured by group to reflect the influence of income and ethnicity. These processes carefully applied along with the ongoing evaluation and feedback from my faculty advisor will yield valid interpretations of the data.

C. Methods to be used in obtaining consent if applicable: Flyers explaining the study will be posted at participating clinics (Child Development Clinic, Neonatal Follow-up Clinic and Satellite Clinics through the Children with Special Health Care Needs Bureau, and the Baby Watch Program through the Bureau of Child Development) and online through the Utah Parent Center and the Autism Council of Utah. Parents then choose if they want to participate in the study by completing the consent form. The PI’s phone number is also listed and those with questions are encouraged to call. The consent form also emphasizes that the provision of services is in no way influenced by refusing to participate**.**

Parents of a child recently diagnosed with ASD desiring to participate will be able to obtain a consent document and the questionnaire at participating clinics and by contacting the PI who will either mail the packet to them or complete the consent and questionnaire over the phone. Packets will contain the consent form, the questionnaire, and a self-addressed stamped envelope that will go to the University of Utah College of Nursing for pick-up by the PI. Parents who meet the more specific criteria regarding SES, ethnicity, and date of diagnosis will be contacted directly by the PI. During this meeting, in person or over the phone, a short synopsis of the research study goals and the consent process will be reviewed and participant questions answered. If the participant is willing, an appointment will be made for the interview.

The Flesch-Kincaid score of the consent form is 10.5 grade level.

D. Methods to be used to manage & retain records after data are obtained:

1. Who will manage records? The Primary Investigator – Kathy Kelly

2. How long will records be retained? Any list of identifying information will be destroyed when the study is complete, within 24 months.

5. Potential benefits to patient: -No direct benefits anticipated for participants. Participants recruited for the interview process will be given a $25 gift certificate to local store, i.e. Wal-Mart or Target
-For Society :(1) Improve our understanding of how parents understand their child's

behavior before a diagnosis of ASD is made. (2) Better understand the implications of discursive practices by parents (both high and low SES, Hispanic and White non-Hispanic parents) as compared to the medicalized interpretations concerning ASD related behaviors and how that might delay diagnosis. (3) Utilize findings to inform and develop interventions for use by health care providers - public and private, schools, and others to decrease delays in the diagnosis of ASD for poor and minority children.

6. Potential risks to patient: The risks of participation in this study are minimal. Parents may experience frustration and or sadness as they are asked to recount their experiences relating to the diagnosis of their child with ASD.

INVESTIGAT0R NAME & TITLE Kathy T. Kelly, RN, FNP-BC, MHA	INVESTIGATOR SIGNATURE
TELEPHONE / FAX 801-259-8476	ADDRESS [redacted]

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