Parental Understandings of the Meaning of Autism Spectrum Disorder (ASD)

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PARENTAL UNDERSTANDINGS OF THE MEANING OF AUTISM SPECTRUM DISORDER (ASD)

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To: Yolanda, Diana, Jose Miguel, Nena, Elisa, Joaquin & Antonio
PARENTAL UNDERSTANDINGS OF THE MEANING OF AUTISM SPECTRUM DISORDER (ASD)

by

KYLARA JEAN LEYVA, BA Psychology

THESIS

Presented to the Faculty of the Graduate School of
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MASTER OF ARTS

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ABSTRACT

This study examines how parents understand autism, their child’s behavior and development. Parents can understand their child’s behavior and development through a medical model perspective, which sees the child’s autism as a series of deficits and deviations. However, a growing number of parents understand their child’s behavior and development through a neurodiversity perspective, where a child is seen as having differences in behavior, instead of deficits. Parents’ understandings of autism can influence how they see their child’s behavior and development and be a driver for seeking diagnosis. In-depth interviews were conducted with parents of children with autism to probe for parents’ experiences before and up to the diagnosis of autism. Interviews were transcribed and analyzed for emergent themes. The central theme for this thesis was “meaning of autism” and additional subthemes emerged in relation to the meaning of autism for parents. Subthemes that emerged included how parents talked about autism, factors that influenced how parents understood autism, and how parents accepted the diagnosis of autism. Parents’ understanding of autism changed based on their knowledge of autism. As parents learned more and interacted more with other parents and children with autism, the meaning of autism changed for them. While some parents understanding of autism can lean more towards one model or the other, many parents used a combination of medical model and neurodiversity understandings finding each useful in different situations.
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INTRODUCTION

Among the general public, little is known about autism spectrum disorder, or ASD as it is referred to by researcher and clinicians, (Zuckerman, Sinche, Cobian, Cervantes, Mejia, Becker, and Nicolaidis 2014). The only point of reference that some parents have to autism, prior to their child’s diagnosis, is from television and films such as Rain Man. However, as one mother who was interviewed for this thesis stated, “If you’ve seen one kid with autism, you’ve seen one kid with autism”, meaning that no two children with autism, even in the same family, are alike or even similar. Children and adults with autism vary broadly in traits, severity, areas of difficulty, and thought processes (Verhoff 2012). Those diagnosed with autism can range from completely withdrawn and unable to communicate to those who excel professionally but struggle interpersonally (Verhoff 2012). There are many traits and behaviors that are commonly associated with autism, such as clapping, rocking, or other self-stimulatory behavior, avoidance of eye contact, inability or disinterest in interacting with peers or others, inappropriate emotional responses, flat affect or lack of affect, compulsive behaviors such as lining up or ordering toys or other objects, inability to imaginatively play, limited and focused interests, irritability, outbursts or aggressive behavior, inability or difficulty changing plans or routines, as well as others (CDC, 2016). Despite the many behaviors and traits that have been observed and recognized by mental health and medical communities, there no traits all people with autism share. This variation can make it difficult for people to recognize or understand autism. Parents’ understandings of their child’s behavior in general or autism specifically can be a driver for them seeking to obtain a diagnosis for their child, as well as understanding what a diagnosis means for their child, i.e. will their child be helped or harmed by a medical label, such as autism (Karp, Ibañez, Warren and Stone 2017; Sarrette 2015; Singh 2016; Stronarch and Wetherby 2017). This study examines the
experiences of parents living in a city with a predominantly Mexican-origin population with the process of their child’s diagnosis with autism. The aim of this study is to see how parents (of children with ASD) understand autism. Parents were asked questions about the time between when they first became concerned about their child’s behavior until they received a diagnosis.
MEDICALIZATION AND STIGMA

In the discussion of autism, it is important to first discuss the constructs of medicalization and stigma. Medicalization has been much studied in relation to health, mental health, and its effect on policy in sociology and disability studies as since the 1970s. Medicalization is the formalization of a health or mental health disorder, disability, or issue through the medical community. This is usually has the effect of empowering those experts within the medical field as the voices of health care professionals come to have more weight in diagnosis and treatment than those of the people who are affected (Valentine 2010). In mental health areas, this medicalization begins with the general recognition of a disorder by psychiatric and psychological communities, and is formalized with its placement within the Diagnostic and Statistical Manual of Mental Health Disorders (DSM). The DSM, organized and published by the American Psychiatric Association (APA), is the most widely used tool for the diagnosis of mental health disorders by mental health professionals in the U.S. (Surís, Holliday, and North 2016). The DSM categorizes disorders, as well as providing a list of not only symptoms but symptomatic criteria for providing a diagnosis (Surís et al. 2016), which can have great impact on the social construction of a disorder.

Among the impacts of medicalization on the social perception of mental health disorders is stigmatization. Stigma, as sociological concept, was popularized in 1963 by Goffman. While Goffman (1963:1) viewed stigma as the marker of moral deviance in people with physical and mental disabilities, in the years since, stigma has come to be seen as the negative social perceptions that can be internalized by stakeholders, or people affected by disability as well as those with disability (Gray 2002). Medicalization can affect stigma in positive and negative ways and both are tied together as medicalization and stigma are both related to societal norms.
Medicalization can be seen as the labeling of disorders as biologically, genetically, or psychologically “deviant.” While at its root, stigmatized perceptions of illness, disorder, or disability can be seen as a reaction to that “deviant” label.

Aside from the negative effects, medicalization can provide people with validation for their experiences, access to services, accommodations, and protections. Medicalization can validate people’s experiences, feelings, and behaviors (Kapp, Gillespie-Lynch, Sherman and Hutman 2012; Morgen and Mason 2015). For people with depression for example, they are not just “blue” or “down”, they have a clinical ailment that is not managed as easily as by just being positive. A medical label also qualifies people for a number of services, treatments and accommodations such as speech therapy, extended time for taking tests, or service animals (Thomas, Ellis, McLaren, Daniels, and Morissey 2007; Súriš et al. 2016). In some programs, such as with public school districts, the diagnosis of a medical label can be part of the process of requesting services or accommodations. Lastly, a medical label can provide people with protections against certain forms of workplace, residence, and educational discrimination under the Americans with Disabilities Act (ADA 1990).

THE MEDICALIZATION OF AUTISM

The earliest use of the term “autism” as a psychological disorder, was the paper “Autistic Disturbances of Affective Contact” by Leo Kanner in 1943 (Blacher and Christensen 2011). At around the same time, the Australian researcher Hans Asperger released his study of children with similar but milder symptoms (Blacher and Christensen 2011; Ozonoff, South and Miller 2000). Although similar symptoms to those observed by Kanner and Asperger were noted by other researchers, they were previously being identified as a form of childhood schizophrenia. Kanner viewed autism as separate from childhood schizophrenia, and as less of a psychotic
disorder than a behavioral disorder (Blacher and Christensen 2011). Clara Claiborne Park took this a step farther to attribute autism to the “cold” and “dispassionate” parenting by “refrigerator mothers” (Langan 2011). In this way, autism was labeled, much like the early days when obsessive compulsive disorder was thought to be the result of “traumatic potty training”, as a problem caused by unfit and poor parents, particularly mothers.

Much more recently, Asperger syndrome and autism were seen by mental healthcare professionals as similar but separate disorders. But, under the DSM-IV released in 1994, they were classified as related to pervasive developmental disorders, alongside the diagnosis of pervasive developmental disorder, not otherwise specified (PDD-NOS; Allred 2009; Blacher and Christensen 2011). The main difference between autism and Asperger syndrome diagnoses was that children with Asperger syndrome had less noticeable difficulties with speech, language, and social interaction. Additionally, children with Asperger syndrome had little cognitive disability and no intellectual disabilities (Allred 2009; Ozonoff et al. 2000). The early distinction of Asperger syndrome as not having intellectual difficulties was instrumental in creating a public perspective of children and adults with that diagnosis as being gifted but socially awkward as opposed to children with an autism diagnosis.

During the years between the release of the DSM-IV (1994) and the DSM-5 (2014) there was much debate among the medical and mental health communities as to whether Asperger syndrome was really a different diagnosis from high functioning autism. High functioning autism also presented with mild social and communication difficulties and little to no intellectual difficulties. Many MHCPs contended that high functioning autism was closer Asperger syndrome than it was to moderate autism or PDD, and the diagnostic difference was both arbitrary and subjective (Allred 2009; Ozonoff et al. 2000). It was in the late 1990s that autism
began to be viewed by MHCPs as a “spectrum”, as proponents argued that autism was could not be viewed as a single diagnosis of “high” or “low”, but that the interaction between communication, social interaction, behavioral, and cognitive abilities was much more complex (Blacher and Christensen 2011). It was in the middle of these debates about the conceptualization of autism and Asperger syndrome among the mental health community, that committees for the overseeing the new addition of the DSM were taking place. The changes in the DSM-5 (2014), the collapsing of autism, Asperger syndrome, and PDD into one diagnosis of ASD, in which the aforementioned dimensions are measured separately, met with considerable resistance from the autism community (Morgensen and Mason 2015).

The long process of the medicalization of autism was evident in the new diagnostic category of in the DSM-5: neurodevelopmental disorders. The shift from categorizing autism as a pervasive developmental disorder to a neurodevelopmental disorder firmly establishes autism as a biological and ultimately medical disability. Autism is now largely seen, by health care and mental health professionals as a disorder that interrupts the development of neuro-cognitive pathways within the brain. While the cause of this disruption is largely unknown, a number of environmental exposures, particularly heavy metals such as lead and mercury, are suspected as blocking neuro-cognitive development during gestation, infancy, or early childhood. The variation in when and how this disruption takes places could be one of the reasons for the variability in difficulties and presentation of ASD (Verhoff 2012). The double-edged sword of this medicalization is that while the medical model endorses the early detection of ASD through medical and mental health “experts” (Zuckerman et al. 2014), it is ultimately up to parents to navigate and initiate the diagnostic process.
THE NEURODIVERSITY MOVEMENT

The neurodiversity movement in the autistic community began in the 1990s in the face of the stigmatization and medicalization of autism (Block 2015; Grinker 2015; Kapp et al. 2012; Langan 2011). Despite its opposition to the medical model, neurodiversity’s perspective, as noted by Ortega (2009) and O’Dell, Rosqvist, Ortega, Brownlow and Orsini (2016), has its roots in neuroscience. Proponents of neurodiversity in the autistic community state that autistic persons have differences in cognition, social interactions, and behaviors that do not represent deficits. The autistic community argues that behaviors, such as avoiding eye contact, are medically labeled as “deficient” because they are undesirable to non-autistic people (Grinker 2015; O’Dell et al. 2016; Ortega 2009). It is important to note that the neurodiversity movement is more widely accepted by autistic adults or self-advocates than among parent advocates (Block 2015; Grinker 2015; Kirkham 2017). The acceptance and adoption of the neurodiversity perspective is more mixed among parents of children with autism, and is not promoted by many parent advocacy groups, such as Autism Speaks (Hart 2015; Kirkham 2017; Langan 2011).

The divide in ideology between self-advocates and parent advocates is one of many similarities between autistic and d/Deaf cultures. Maudlin (2016) coined the term “ambivalent medicalization” to describe the how parents of children in the cochlear implantation process simultaneously accepted and resisted the medical model perspective. Parents of deaf children are usually not part of the Deaf community prior to their child’s diagnosis, as such their first introduction to these communities is through medical professionals. Parents accept the medical model of understanding their child, according to Maudlin (2016), because this is the perspective that is their first introduction to deafness or autism. Parents of children with autism are also usually not part of the autistic community prior to their child’s diagnosis.
For parents of children who are deaf, acceptance of a medical model can mean accepting that their child needs to be tested for and implanted with a cochlear hearing device. For parents of children with autism, this acceptance means accepting that their child needs behavioral therapies such as applied behavior analysis (ABA), both of which are controversial treatments in Deaf and autistic communities (Kirkham 2017; Maudlin 2016). Ambivalent medicalization occurs as parents begin to reject aspects of the medical model, particularly those aspects of the medical model that implies that something is wrong with their child that needs to be fixed (Maudlin 2016; Sarrett 2015a; 2015b). Sarrett (2015a; 2015b) saw a similar ambivalence among parents of autistic children in India, who initially accepted the medical model, but endorsed it less wholehearted over time.
THE LANGUAGE OF AUTISM

The language that parents use when discussing autism reflects their understandings of autism and what autism means to them. Parents of children with autism can understand autism through the lens of the medical or the neurodiversity models of understanding (or something in between). The medical model refers to the ways health and mental health professionals understand disorders, disabilities and illness and is closely tied to medicalization. The medical model of understanding autism focuses on treating aberrant behaviors, and can view autism in relation to perceived deficiencies (Barker and Galardi 2015; Kapp, et al. 2012). The neurodiversity model of understanding autism is part of a growing movement within the autism community that shifts focus from perceived deviance from the norm to differences in cognition and interaction (Kapp et al. 2012; Sarrett 2015b). This could be seen in education programs that focus more on changing teaching strategies to facilitate learning more than on making children fit into a classroom. Aside from the division between the medical and neurodiversity models of autism, there are also terms that are used within the autism community not only as a label, but to describe traits and behaviors as well. For many parents, the language of autism begins with the medical community.

The medical definition of autism in the U.S., as well as a many other nations, is provided by the Diagnostic and Statistical Manual of Mental Health Disorders (DSM-5). Autism, according to the DSM-5 (2014), is a neurodevelopmental disorder that can affect how a child communicates, socializes, their behavior, emotional control, and sometimes their cognitive abilities. Aside from the label of autism spectrum disorder or ASD used by researchers and clinicians, parents use medical terms to discuss their child’s traits and behaviors. When children are diagnosed, parents are told about their child’s “functioning” and “deficits” as being “mild”,
“moderate”, or “severe.” The use of such language by parent could indicate that they have a medical understanding of autism (Barker and Galardi 2015; Kapp et al. 2012). While the current, diagnostic label is ASD, parents of children with autism often refer to their children as having “autism”, “Asperger’s”, being “on the spectrum”, “autistic”, an “aspy” or “neuro-atypical” (Cascio 2014). Some parents and their children continue to use labels related to Asperger syndrome, such as “Asperger’s” or “aspy,” even though it is no longer included in the DSM 5 (Morgensen and Mason 2015).

In the language of autism, there are many differences in between the medical model and neurodevelopmental perspectives, first and foremost is the distinction between person-first and identity language. Person-first language (e.g., a child with autism) is preferred among proponents of the medical model, not just for autism but for all people with medicalized illness, disability and disorder (Block 2015; Cascio 2014). For proponents of the medical model, person-first language is used to separate the individual from the illness, disorder, or disability. For example, within the medical community it is preferred to talk about the “people with cancer” instead of “cancer patients” to preserve the humanity of the person. Proponents of neurodiversity, as previously stated, view autism as a difference, or human variation. From this perspective, person-first language designates autism as an illness, which is in conflict with the view that autism is part of an autistic person’s identity (Block 2015; Cascio 2014). While parent advocacy groups support person-first language, self-advocate groups support identity language.
PARENTAL UNDERSTANDINGS OF AUTISM

INITIAL CONCERNS

Whether initial concerns about a child’s development originate from their parents or others, it is often the parents who must pursue a diagnosis. Often parents’ concerns about their child’s development precede the diagnosis by months or years (Abbott, Bernard, and Forge, 2012; Chamak, Bonniau, Oudaya, and Ehrenberg 2011; Karp et al. 2017; Neely-Barnes, Hall, Roberts and Graff 2011). Parents can be concerned that their child is not meeting developmental milestones such as sitting up, walking, talking and potty training or by their behaviors (Chamak et al. 2011; Karp et al. 2017; Neely-Barnes et al. 2011; Robinson, York, Rothenberg, and Bissell 2015; Singh 2016; Wong, Yu, Keyes, and McGrew 2016). Many parents see several healthcare professionals, both pediatricians and specialists, before their child is diagnosed with autism (Robinson et al. 2015:2315; Wong et al. 2016:201)

Community perceptions of their child’s behavior and responses to their child’s behavior can also influence parents understanding of their child’s behavior and desire for a diagnosis. Prior to diagnosis, parents commonly experience stigma because of their child’s behavior, particularly in public. Some autistic children can be irritable, aggressive, and prone to tantrums (Farrugia 2009; Gray 2002; Karp et al. 2017; Robinson et al. 2015). Other people often attribute an undiagnosed child’s behavior to poor parenting (Farrugia 2009; Gray 2002; Robinson et al. 2015; Singh 2016; Zuckerman et al 2014). Black and Hispanic families often report that family and friends believe that their child needs more discipline (Singh 2016; Zuckerman et al. 2014). Parents are often driven to find a diagnosis in order to explain their child’s behavior (Robinson et al. 2015).
AUTISM AND HISPANIC PARENTS

Hispanic individuals in the United States represent the largest growing minority group at 17% of the population, with Mexican Americans encompassing 64% of the Hispanic population according to census data (U.S. Census Bureau 2016). According to the Autism and Developmental Disorder Monitoring Network (ADDM), an organization reporting to the Centers for Disease Control and Prevention (CDC), 1 in 68 children in the U.S. have been diagnosed with autism (ADDM 2014). Of that, approximately 10 Hispanic children out of every 1,000 are diagnosed with autism compared to 15 out of every 1,000 non-Hispanic white and 12 out of every 1,000 black children in the U.S (ADDM 2014). In other words, Hispanic children are diagnosed with autism less often than white and black children (ADDM 2014). Many researchers attribute the difference in the prevalence and rates of autism diagnosis to intercultural differences in the social understandings of autism, or perceptional differences in the development trajectory of Hispanic children compared to other children by parents and health professionals. In reality, there most likely are not fewer Hispanic children with autism than white children with autism; Hispanic children are more likely than white children to be misdiagnosed with another disorder or not diagnosed at all (Blacher, Cohen, and Azad 2014; Hughes, Valle-Riestra, and Arguelles 2008; Palmer, Walker, Mandell, Bayles, and Miller, 2010; Zuckerman et al. 2014).

Research on the diagnosis of autism among Hispanic families shows that they often view a child’s behavior as being indicative of family harmony. When a child is behaving badly, it is not a problem for a doctor, but a sign for parents (Zuckerman et al. 2014). Some Hispanic families do not place value on a child meeting certain developmental milestones at expected ages. For example, Puerto Rican parents do not expect their children to have speech development beyond baby talk until 3 years old, which is later than the norm among other groups of parents.
Instead, Hispanic parents and families see children as developing differently (Blacher et al. 2014; Zuckerman et al. 2014). In a study on Hispanic families living in Oregon, Zuckerman and colleagues (2014) found that Hispanic parents will commonly note how other members of the family or community have had delays in differing areas of development, but “are just fine.” Unlike, Blacher’s (2014) study, Zuckerman (2014) did not discuss the country of cultural origin of participants in the study. These behaviors and attitudes among Hispanic parents could be related to mental health stigma within the community. Perception of stigma and feelings of embarrassment or shame can play a role in whether parents voice or act on concerns for their child’s development or not (Zuckerman et al. 2014; Hidalgo et al. 2015). Mexican American parents have noted that diagnosis of autism did not exist in Mexico, where autistic people were more often labeled as “idiots” (Zuckerman et al. 2014).

More research is needed with regards to the understandings of autism, especially among Hispanic parents of Mexican origin. While some studies have been conducted, researchers often discuss sociocultural groups in terms of dominant experiences, but even within an ethnic group such as Hispanics, experiences can be very different. Hispanic parents can possess a variety of different attributes related to socioeconomic status (SES), education, marital status, military affiliation, family construction, and sexual identity, which should be considered. Previous research on parent understandings of autism, used the DSM-IV diagnostic codes, often studying Asperger syndrome separately from “classic” or “general” autism (Barker and Galardi 2015). The goal of this study is to analyze how parents (of children with ASD) in a predominantly Mexican-origin Hispanic community understand autism.
METHODS

SETTING

The study was conducted in El Paso, Texas, a city on the U.S. and Mexican border. An urban metropolitan area, El Paso has a minority-majority population with 82% of the population identifying as Hispanic (U.S. Census 2016). The majority of the Hispanic population of El Paso are people who identify as Mexican or Mexican American. El Paso shares a reciprocal relationship with its sister-city to the south, Juarez, Mexico. Many El Pasoans have family living on both sides of the border, and citizens of both cities travel across the border for work, shopping, entertainment, and health and other reasons. Many El Pasoans are bilingual English/Spanish speakers, or monolingual Spanish speakers. El Paso culture is a rich blend of Mexican, American, and Texan.

El Paso is medically underserved, with one physician for every 2,170 persons in the population (Robert Wood Johnson Foundation 2017). While the city has access to medical care, the number of doctors, clinics, specialists and other medical services are not enough to meet the needs of the community. Many practices are full and not accepting new patients, or have adopted a “concierge” or “VIP” approach that requires additional retainer fees above and beyond insurance co-pays (Graff Cohen 2013). This environment results in some El Pasoans not having access to a regular doctor (El Paso Department of Public Health 2012). Instead, El Pasoans without insurance rely on clinics, urgent cares, or emergency rooms, where they see a rotation of doctors, medical assistants and nurse practitioners without regularity (El Paso Department of Public Health 2012).

DATA COLLECTION

Qualitative data was gathered through 12 semi-structured in-depth interviews with 14 parents of children with an autism diagnosis (in two cases, two parents were present for the
interview, in the other 10 cases, just one parent was present). All parents lived in El Paso, Texas. Eligible participants had at least one child diagnosed with ASD, although some participants had more than one child diagnosed, or in the process of being diagnosed, with ASD. Participants were recruited purposively using a snowball or volunteer sampling method (Cridland, Jones, Caputi, and Magee 2015; Seale 2014). Flyers were distributed to two local El Paso clinics that specialize in behavioral, occupational, and speech therapy for children with autism spectrum disorder and a pediatric treatment office of an El Paso branch of the Texas Tech Department of Psychiatry. In all three settings, flyers were displayed in the waiting area. In the Texas Tech Department of Psychiatry, parents who qualified were informed that flyers were available in the waiting area and, if interested, they could participate, but were not asked or directed to participate. Copies of flyers were also posted on the Autism Society of El Paso Facebook page, and reposted to other El Paso autism and parent support group pages, such as the Autism Network of El Paso. Interested participants contacted interviewers using the information on the flyers. 7 of the parents were recruited from the Autism Society, 4 parents were recruited through the Autism Network of El Paso, and 3 parents were referred by other participants.

Parent interviewees and their child’s demographics are provided in Table 1.1. Pseudonyms are used for all parents and children to protect their identities. In many cases, the younger sibling experienced earlier diagnosis of ASD compared to the older sibling. Each interview was recorded and transcribed (Seale 2014). Parents were given a $25 gift card as incentive after completing the demographic survey. 11 interviews were conducted in English and 1 interview was conducted in Spanish, and the interviews ranged from 36 minutes to more than 2 hours. The Spanish interview was conducted and then translated and transcribed in English by Melissa Montelongo, an assisting MA student in Sociology. The interview questions focused on parent experiences and perceptions.
during the diagnostic process. Some of the questions are about interactions with healthcare and educational professionals. These questions target the influence of social factors such as language, culture, and education, on these interactions. Other questions centered on parents’ beliefs or knowledge of ASD prior to, and after, diagnosis. These questions target influences on parents’ decision-making process, such as whether or not to pursue developmental testing. A smaller number of questions concern access to care. These questions target differences in private insurance, Medicaid, and not having insurance in influencing diagnosis. Participants completed a demographic survey after the interview. The demographic survey asked questions about the interviewee, the child, the child’s diagnosis, family living in the home, income, education, insurance, transportation, and sources of autism information. The interview guide and demographic survey were translated into Spanish by Ms. Montelongo as well. The interview guide and demographic questionnaire can be found in the Appendix.
Table 1.1 Parent Demographics

<table>
<thead>
<tr>
<th>Parent</th>
<th>Child(ren) with autism</th>
<th>Age at diagnosis</th>
<th>Parent ethnicity or race</th>
<th>Parent education</th>
<th>Household annual income</th>
<th>Child’s insurance status</th>
<th>Primary language(s) spoken in home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marianna</td>
<td>Phillip Derek</td>
<td>14</td>
<td>Hispanic</td>
<td>Associates Degree</td>
<td>$70,000+</td>
<td>Private</td>
<td>English</td>
</tr>
<tr>
<td>Denise</td>
<td>Sean</td>
<td>2</td>
<td>White, not Hispanic</td>
<td>Master’s Degree</td>
<td>$40,000-$69,999</td>
<td>Medicaid</td>
<td>English</td>
</tr>
<tr>
<td>Amanda</td>
<td>Keith</td>
<td>12</td>
<td>Hispanic</td>
<td>Master’s Degree</td>
<td>$40,000-$69,999</td>
<td>Private</td>
<td>English</td>
</tr>
<tr>
<td>Isabel</td>
<td>Jason Matt</td>
<td>2</td>
<td>Hispanic</td>
<td>Master’s Degree</td>
<td>$40,000-$69,999</td>
<td>Private</td>
<td>English/ Spanish</td>
</tr>
<tr>
<td>Nancy</td>
<td>Grace</td>
<td>3</td>
<td>African American</td>
<td>Associates Degree</td>
<td>&lt;$20,000</td>
<td>Military</td>
<td>English + 3 more</td>
</tr>
<tr>
<td>Name</td>
<td>Last Name</td>
<td>Age</td>
<td>Ethnicity</td>
<td>Education</td>
<td>Income Range</td>
<td>Insurance</td>
<td>Language(s)</td>
</tr>
<tr>
<td>------</td>
<td>-----------</td>
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<td>-----------</td>
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<td>--------------</td>
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<td>Cordelia</td>
<td>Lydia</td>
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<td>High school</td>
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<td>CHIP</td>
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<td>Bachelor’s Degree</td>
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<td>Master’s Degree</td>
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<td>Private</td>
<td>English/ Spanish</td>
</tr>
<tr>
<td>Carol</td>
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<td>Master’s Degree</td>
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DATA ANALYSIS

A preliminary coding framework was developed from recurring themes in initial interviews and the research questions (Cridland et al. 2012; Seale 2014). Transcribed interviews were coded in the preliminary framework using NVivo 11 software. After preliminary coding, additional coding developed in response to emergent themes (Seale 2014). All coding was done by me as the principle and only investigator. To answer the research question, how do parents understand autism, the initial code was “meaning of autism.” Areas where parents discussed their understanding of their child’s behavior and development or autism were coded as “meaning of autism.” The variation of themes between interviews was examined (Seale 2014). Then, I created sub nodes related to “parent concerns”, “parent reactions to dismissal of concerns”, “parent research of concerns”, “parent’s educational experiences”, “parent’s work experiences”, “family/community understanding”, and “parent language of ASD.”
RESULTS

LANGUAGE OF AUTISM

The parents interviewed used a mixture of clinical and less formalized terms in relation to their child’s autism. For example, none of the parents referred to their children as having “ASD.” Most of the parents discussed their children as having “autism” or being “autistic.” Two parents specified that their child formerly held a diagnosis of PDD-NOS, but that the child was now within the autism umbrella. One parent stated that their child had a diagnosis of Asperger syndrome, but only referred their child as having autism and not Asperger’s. One set of parents, referred to their child as having Asperger’s. It may be notable that this set of parents did not have any ties to the autism community, and was not referred to me for an interview through the Autism Society or the Autism Network.

Many parents learned the language of autism by researching their child’s behaviors and development. These were mostly parents of younger children with autism or parents of higher socioeconomic status. This can be seen particularly in the case of Marianna, the mother of two boys with autism, who was in two very different social locations when she began having concerns for her sons, Phillip (14) and Derek (3). Marianna was a single mother on state assistance at the time her older son, Phillip, began to have behavioral problems at school. The school and a psychiatrist evaluated Phillip as having attention deficit hyperactivity disorder (ADHD) when he was in 1st grade, but he continued to have problems socializing with other children and behaving in a classroom. When Marianna began to be concerned about her son Derek’s developmental delays, Marianna was married with a middle class income. While she did
not discuss researching Phillip’s behaviors, she did recall searching the internet for answers about Derek:

I started looking up twirling hands and feet on the internet. The first thing that came up was autism. Early, you know, early signs or flags or anything like that. I knew for sure, you know, that he had autism because I kept watching videos online of mothers who would record their children. There were too many coincidences. You know, he would stim. He would put a lot of stuff in his mouth. He would spin in circles with his eyes to one side without getting dizzy. He would pick up objects just for hours. If you gave him like a fry, he could pick up the French fry and, you know. He would hiss. He would flap his hands repeatedly. He would run and hit himself on the wall. Or bang his head if it was too loud.

From researching Derek’s behaviors on the internet, Marianna learned the language of autism. She was able to recognize his “stimming”, or self-stimulating behaviors, his sensory behaviors. Moreover, Marianna used her new resources and knowledge to recognize Phillip’s ongoing difficulty with social interactions and his anxious behaviors such as breaking pencils as a less severe form of autism from his younger brother. Phillip, at 14, was just beginning the evaluation process again when I interviewed Mariana.

Nearly all the parents interviewed noted that the diagnosis of autism in their child made them seek out information about autism from a variety of sources, including books, magazines, film, television, organizations, blogs, vlogs, and parenting or support groups. For many parents the meaning of autism changed through their research. Nearly all of the parents reported using the internet to research autism in their surveys, although only a few parents discussed the ways they researched online, such as Carol mentioned earlier. Denise, whose son Sean was diagnosed
at 2 ½, states “I didn’t know much about developmental disabilities but I started reading and researching online and ordered books off of Amazon.” Cordelia, whose daughter Lydia was diagnosed at 2 ½ as well, noted that “[The behavioral therapist] gave me the [literature] I think for the autism…and a lot of books and websites that you can go through. You know anything that you need with autism and ADD.” Parents like Isabel and Matt, whose work and educational paths exposed them to children and adults with autism, researched ways to manage behaviors and patterns in relation to autism to supplement behavioral and family therapy techniques. Isabel explained, “with the research we’ve been doing his sleep has gotten much better. I’ve been researching techniques with autism.” Other parents search for local resources, as Janice, whose son Fernando was diagnosed at 19 months, did:

When I found out that my son had autism, the first thing that I did was to research in Google. I was looking for talks. I don't know something about autism. It sent me to El Paso del Norte, I called and they received me right away. I went and I enrolled in a 3 month academy for parents. I used to go twice a week for four hours, it was like a school for parents, and that really helped me.

Parents also discussed not only having to learn about autism, techniques, and therapies, but also having to disseminate that knowledge to family, friends, and teachers.

Nearly all of the parents discussed their child’s autism positively. Parents were asked to tell interviewers one thing they liked about their child. In many cases, parents chose an area of their child’s personality related to their autism. One parent noted that her children with autism had “unique” perspectives, that she loved how they saw the world differently. Another parent stated that she loved her son’s detail-oriented and methodical nature. Other parents talked about their child’s curiosity, the way they wanted to see how things worked, or their ability to focus
intensely on a particular project or hobby. These parents used the term “love” even though the question asked for something they “liked” about their child, having embraced autism in their child.

**Meaning of Autism**

Parents were asked to recall their experiences before and at the time their child was diagnosed with autism. Before their child was diagnosed with autism, the meaning of autism was different for parents interviewed based on their prior level of experience with autism, which influenced their recognition of autism in their child. Some of the parents were exposed to autism as educators, advocates, or health professionals. For instance, Isabel worked as a disability lawyer, advocating for clients seeking services and benefits. Isabel discussed both personal and business exposure to disability and illness, as well as exposure the variations in childhood development, as influencing her recognition of developmental delays in her child:

> With our son, the reason that I saw it was because, as a disability attorney, I’m exposed to having clients with disabilities both physical and mental. I saw a lot of red flags. First thing, of course with autism, is speech delay. I saw the speech delay and that became a big concern of mine… It’s the lawyer in me. Law school totally brainwashes people. I told my husband that. I mean, there’s an issue, see it, identify it, what are the solutions? Go for it. That’s law. And that how I identify things now. That’s how my mentality is: Okay what’s going on with Jason? Get a diagnosis. Get medication… Address the issue. There’s solutions. That’s the kind of person I am.

For Isabel, the disability was not the issue, but she believed it needed to be identified in order to find the right solutions. For example, although autism and schizophrenia may have similar
symptoms, the solutions for one will not work for the other. This understanding of disability was a driver in Isabel’s tenacity in acquiring a referral for her son, even when her pediatrician repeatedly refused. Isabel noted that she followed the same advice she gave her clients, which was to demand referrals from their doctors and to find another doctor if the current one refused. After demanding a referral one last time, Isabel and her husband interviewed several pediatricians before finding one who listened and responded to their concerns. Matt, Isabel’s husband, has a graduate degree in education and is currently pursuing a law degree as well. Matt recalled his experiences interning in special education during college as it influenced his understanding of Jason’s development and behavior:

I do have some experience working with young people with autism. About 10 years ago. I was a care professional in Minneapolis working at a high school, with a class of 8 boys with all different things going on. You know, all different points on the spectrum. So that gave me an insight, just a little window into what it would be like. But they were all different than how my son is now. The development of the field in the last 10 years has made a lot of the conventional wisdom from then really isn’t or may not be applicable now. Again, I wasn’t that well versed then or am now. But I did have a feeling around, about two months before he was diagnosed. I thought it could be a possibility that he was on the spectrum.

Isabel and Matt’s familiarity with disability as advocates and educators helped them to identify autism in their child. In addition, their experiences with disability helped them to navigate the diagnostic process to obtain a diagnosis for their child at 2 ½ years, which is relatively early to be diagnosed.
Cordelia, a mother of two children with autism, studied education, particularly special education, in college. According to Cordelia, her husband was suspect of her concerns about their daughter Lydia’s development:

Because when I was at [university] I wanted to study autism and I wanted to be a special ed teacher. And I was just in love with autism and kids who had autism. And special needs in general, but I had a soft spot for autism kids. And he just thought that maybe I wanted to see autism in my kids.

As a student of special education, Cordelia had wanted to work with autistic children in particular. As an infant, Cordelia’s daughter Lydia exhibited sensory issues, an aversion to being held, a resistance to transitions, such as taking a sippy cup, along with developmental delays, which Cordelia recognized as possible early signs of autism. When Cordelia discussed this with her husband, he did not believe these issues to be signs of autism. Her husband’s interpretation of the situation led Cordelia to report her concerns to her pediatrician and later a specialist, without voicing her thoughts on the possibility of autism. The doctors, however, came to the same conclusion as Cordelia, which was that her daughter had autism. The experiences that Cordelia had with children with autism as a college student provided her with positive associations with autism. Her positive feelings about children with autism along with her familiarity with autism traits may have caused her to be more vigilant for these behavior patterns in her own child which seems to have contributed to her daughter Lydia’s early diagnosis at 3 years old.

Parents’ understandings of autism can sometimes be very narrow and in reference only to a particular presentation of autism. For instance, Carol worked as a case manager in the department of corrections. Her understanding of autism was shaped by her acting as a government-appointed advocate for clients with special needs. In this capacity, Carol explained
that she understands disability through legal definitions and as “fitting into boxes.”. When asked about what her initial concerns about her son, Carol stated:

I kind of started looking things up. Autism popped in my head but it didn’t really stay there because even looking at autism, he just didn’t fall anywhere, not like on the spectrum. Not Asperger or autism. I couldn’t fit him somewhere, because it wasn’t so specific. I’ve been doing mental health for so many years. I was looking too close to want to put him specifically somewhere, that I kept overlooking it.

Prior to diagnosis of her son Diego at age 5, Carol was unable to connect her understanding of autism as a case worker with her son’s presentation, in part, because of the broadness of the spectrum. When he was a toddler, her son Diego would become very focused on playing with his arms or other objects for long periods of time. He did not sleep at night, but was hyperactive during the daytime. However, Diego met all of his developmental milestones and despite a lisp, he was very verbal. Although her son’s actions did not fit with her understanding of autism, she did voice her concerns to her pediatrician, who felt that since Diego was doing so well in other ways, that these behaviors were not enough for a referral. In this way, the pediatrician supported Carol’s feeling that Diego did not quite meet the criteria for autism, and Carol decided that she did not need a referral for him. Diego was diagnosed a couple of years later under the DSM-IV code of Asperger syndrome, which is recoded in the DSM-5 as high functioning or mild autism.

Several parents interviewed did not have personal or professional exposure to autism, which influences how they understood autism prior to their child’s diagnosis. Some of the parents had heard the term “autism”, but did not have an understanding of it. For some parents, autism was a terrifying prospect. In her interview, Christine noted that because of her studies in biology, she had become afraid of birth and childhood disorders such as Down syndrome and
autism. She had not had any particular research or interaction with autistic people, but had an understanding of autism as a biological disorder. Christine’s son Nick was diagnosed at 3 years old. Prior to that, she described how she was fearful that something might be wrong with her child:

I don’t know, maybe because I’m a biology teacher and all this stuff interests me. Even when I was pregnant. Please let my baby be okay. Then, it became sudden infant death syndrome. For the first few months, let my baby be okay. Then after that, it was please don’t let him or her have autism.

For Christine, autism was included in her worries about her children’s health and wellbeing before Nick was diagnosed. Despite an abrupt and dramatic change in Nick’s behavior at 16 months, Christine notes that she accepted pediatrician and family assurances that Nick would grow out of it in part because she wanted it to be true. However, these fears about autism and other developmental disorders also prompted Christine to obtain early intervention services for Nick on her own, when her pediatrician would not supply a referral. The early intervention services provided by early childhood intervention (ECI) were transferred to the school district when Nick turned 3. The school district began the process and Nick was diagnosed, between 3 and 4 years old, and admitted into pre-school special education.

Several parents, both those with and without exposure to autism through work or school, discussed the 1988 film *Rain Man* as their point of reference for autism, despite the fact that Dustin Hoffman’s character in the film is never stated as having autism. He is instead presented as having savant syndrome, which is comorbid with autism in approximately half of all presentations and people with this condition are popularly referred to as being autistic savants (Treffert 2009). When recalling how her son, Roberto, used to line up toy cars, Veronica states,
“The only thing I think I knew about autism was Rain Man. So I would see him put all the cars in line and I would think, oh my god he’s so cute! He’s parking them!” When Roberto was diagnosed, Veronica recalled thinking that she did not want to her son to be institutionalized like Rain Man. Later, when Veronica began to learn more about autism, she began to understand that that image of an autistic savant was not how all people experience autism. Then she was able to enjoy her son’s methodical nature and even noted it as one of her favorite things about Roberto.

Isabel and Marianna, mother of two boys with autism, discuss the film not as their own reference, but as that of family and friends when autism is discussed. Isabel states: “When he’s acting a certain way, they just label him as a brat. Or he’s just misbehaving. And I tell people no, he’s autistic. And then they go ‘oh, Rain Man,’ because that’s what most people associate autism with. That’s their basic knowledge.” While more literature, research, and popular depictions have appeared in the years since, Rain Man persists as a generally recognized depiction of autism among the general population.

Despite being educators, Amanda and her husband had little knowledge of autism. As Amanda states, they “didn’t hear the word autism until in the 2000s, he was born in 1998 so autism wasn’t… It was there, but in the 2000s, you started to hear more about autism.” Amanda did not have an understanding of autism until after Keith’s diagnosis. They first became concerned when Keith was a toddler, he would scream “bloodcurdlingly.” Amanda and her husband thought that he was afraid of bugs, but they would later learn that this was a sensory issue because the sounds of bugs, particularly flying, hurt his ears. Although she and her husband took their concerns to the pediatrician when their son was a toddler, Keith was diagnosed with attention deficit disorder (ADD), his other symptoms were attributed to a “developmental phase” that his parents were assured he would outgrow. Later, when Keith had been diagnosed, his
parents recognized that he had very sensitive hearing, as well as irritability and aggression associated with autism. Amanda recalls:

They didn’t want to test him because he was making excellent grades. He was in the A and B honor roll. And so we just left that at that until he had the incident with that boy that he hit. And that’s when we learned that his anger was growing. He was always angry all the time. So and when that incident happened that’s when we went right away to the school counselor and let her know about it. And she’s the one that gave me the outside resources. You know she gave me a list of counselors to look into because of that aggression that he was building up because that would lead to other behaviors. So, that was the hardest thing. Yeah going back and seeing that he was an angry little boy.

After the diagnosis, Amanda looked back on her son’s behavior and understood it differently. She saw that he had had many characteristics of autism that they had not understood as being autistic in origin at the time. One of those characteristics was Keith’s anger leading him to struggle socially, if not academically, at school, and in the home.

Cisco, a child of the same era and diagnosed around the same age, was also diagnosed initially with attention deficit hyperactivity disorder (ADHD). Paula recalls the way the psychiatrist diagnosed her son by looking at his shoes. He pronounced that children with ADHD wore out their shoes faster than other children. Paula never stated if Cisco’s shoes were worn out, but that doctor did give Cisco a diagnosis of ADHD. Looking back, Paula recalls that because she did not understand the diagnostic process, she did not question the psychiatrist’s methods of diagnosis, although it made her uncomfortable. She also did not know enough about autism at that time to question the diagnosis itself. Paula recalls:
He was diagnosed with ADHD when he was about 5 or 6 years old. He was in kindergarten then. I always knew there was something else but I didn’t know what and I wasn’t educated about it. So it wasn’t until I started going to school and reading about diagnoses and the symptoms and that was when I was able to identify what it was.

Currently, Paula is a social worker. The meaning of autism began to change for her while she was pursuing her social work degree. By working with people and children with autism, Paula was able to recognize the symptoms in her son, she also began to understand how the similarities between autism and ADHD symptoms could make diagnosis harder. When she began to suspect Cisco might have autism as well as ADHD, in middle school, Paula requested and received a referral from her pediatrician.

**COMPARISON TO OTHER CHILDREN**

Regardless of prior exposure to autism, many of the parents interviewed understood their child’s behavior and development, prior to diagnosis, compared to other children. This could be in relation to their own or other people’s children. For many of the parents, this comparison needed to go no further than their own home. Veronica had 2 grown children at the time when her son Roberto (eventually diagnosed at age 3) began to concern her. As well as two older sisters, Roberto also has a younger sister, Jenny, who was diagnosed at the age of 6. Veronica stated that the development of her older children was “completely different from Roberto’s… And I saw this development that looked kind of normal, but at the same time, was not equivalent to my other two daughters.” Veronica recognized the differences in Roberto’s speech acquisition. At the age when his sisters had been speaking in sentences, Roberto was still mostly pointing and gesturing. Roberto’s sister, Jenny, was a year and a half younger than him, which further complicated her diagnosis because the evaluators at the school were hesitant to diagnose Jenny.
before she was 6 years old because they suspected Jenny of copying her brother’s mannerisms. While Roberto’s differences from Veronica’s older daughters were helpful in diagnosing him early, his younger sister Jenny’s diagnosis was additionally delayed because her presentation of autism was in many ways different from that of her older brother. For Veronica, Jenny’s comorbid ADHD also proved difficult because “I know about autism and I know about ADHD, but I didn’t know about autism with ADHD. So it’s a whole different experience now.”

Like Veronica, Laura and Erin have two children with autism and found themselves comparing and contrasting their children’s presentations as well as to their children without autism. In their eldest child, Tom who was diagnosed at 4, his mothers’ Laura and Erin recognized differences in how their son developed, learned, and interacted early on as compared to other children. However, Laura or Erin did not suspect autism until a relative working in the medical field suggested that Tom might have Asperger syndrome. Their daughter Kristen (age 7) was about to begin the diagnosis process shortly after the interview. Laura and Erin recognized Kristen’s similarities to Tom, as well as developmental differences from her sister Sylvie, who is the same age. Laura explained:

Kristen was different [than Tom], but once she started getting older, we noticed that they had a lot of similarities in their behavior. Like the outbursts, the tantrums, just like flipping out where they’re inconsolable. For something little, and that’s something that we’re still dealing with right now. Same thing at school as far as not making friends.

Kristen and her sister Sylvie were born within days of each other to their mothers Laura and Erin. The girls grew up together like twins. In school Kristen and Sylvie were placed in the same classes two years in a row. Unlike Tom who was an only child at the time that Laura and Erin
had their initial concerns, Laura and Erin were able to understand Kristen’s development compared to her sister Sylvie who does not have autism.
DISCUSSION

For parents of autistic children, their understandings of their child’s behavior and autism can encourage them to push for a diagnosis for their child. Parents can perceive their child’s behavior and development in relation to other children and in relation to their own knowledge or understanding of child development and autism. Many parents perceive differences in their child’s development during infancy or toddler years and discuss these concerns with pediatricians and other health care professionals. For many parents, these different social locations influenced their understandings of autism to conform into medical model or neurodiversity terms.

Despite research showing that Hispanic children with autism are diagnosed more than a year later than white children (Blacher, Cohen, and Azad 2014; Zuckerman et al. 2014), most of the Hispanic parents interviewed for this study reported having concerns about their child’s development as early as during infancy and discussing them with others. Consistent with research on parent experiences with the diagnosis process, many of the parents (most of who are Hispanic) reported that pediatricians initially dismissed their concerns. Many of the parents whose child was diagnosed before the age of 4 either demanded a referral or found a new pediatrician who listened and responded to their concerns. Wong and colleagues (2016) found that the parents they interviewed saw an average of 3.3 healthcare professionals before their child received an autism diagnosis. Wong (2016) identified professionals as general doctors, pediatricians, specialists, school evaluators, social workers, therapists, and nurse specialists. Despite the difficulties and barriers to diagnosis, parents sought out and accepted the diagnosis of autism within their child. As parents understood it, an autism diagnosis meant that their child
would have access to services, treatments, and accommodations, as well as providing an explanation for their child’s behavior.

Parents recognized the potential negative effects of medicalization, particularly of a mental illness label, on their child (Barker and Galardi 2015; Kapp et al. 2012; Morgenson and Mason 2015). A medical label can mark one’s child as different, aberrant or deviant. Moreover, medicalization implies that an autistic child can and needs to be fixed (Kapp et al. 2012). Many of the parents whose children were older at the time of diagnosis noted that because of their children’s academic successes, school administrators did not want to evaluate them. It was not until behavioral or social issues became problematized, interfering in their child’s education that the administration conceded to evaluation. For many parents, bullying was the catalyst for parents to push for an I.E.P and accommodations for their child, despite any fears they had about mental health labels.

Parents seek a medical label, or diagnosis, for their child because of the advantages and access to care that a diagnosis of autism can bring, as well as providing them with a way to understand their child (Barker and Galardi 2015; Morgenson and Mason 2015; Thomas et al. 2007; Surís et al. 2016). Many parents discussed the lack of autism services within the area as well as the cost of therapies and treatments paid out of pocket as a problem, especially before diagnosis. After their child was diagnosed with autism, some parents were able to apply for Medicaid or Children’s Health Insurance Plan (CHIP), where they could receive free or low cost services. Parents were also able to access services through the special education department in their school district after diagnosis that augment treatments for speech, emotional, and behavioral development based on the child’s need. One school district in the area even had an autism specific special education program that many of the children were able to access upon receiving
diagnosis. This aligns with another study which reported that parents may seek a medical label because otherwise services are too costly or limited (Thomas et al. 2007).

Despite the value of the medical label, many parents do not see this label as defining their child. Many parents reject the medical models of “normal/abnormal”, instead embracing their child’s differences (Kapp et al. 2012; Neely-Barnes et al. 2011). In this study, many parents found their child’s behavior bewildering prior to diagnosis, but after diagnosis they were able to accept their child’s autism as being a positive aspect of their child’s personality, consistent with Maudlin’s (2016) conception of parental transition to ambivalent medicalization. Similar to Sarrett’s (2015) study of parents in Kerala, India, parents were less fearful and more positive about their child’s diagnosis after learning more about autism through parenting intervention groups.

For parents of children with autism, their understanding of autism changes as they travel from pre-diagnosis to post-diagnosis (Blacher et al 2014; Farrugia 2009; Neely-Barnes et al. 2011; Wong et al. 2016). Prior to diagnosis parents can be overwhelmed by their child’s unexplained behavior. They can feel shame because others perceive their child’s behavior as being reflective of the home environment (Farrugia 2009; Wong et al. 2016). Laura and Erin discussed how their parents viewed Tom’s and Kristen’s behavior as symptoms of their non-traditional home, and that they were acting out because they have two moms. However, just as Laura and Erin’s understanding of autism changed over time, so has their families’ understanding of autism changed. When parents’ concerns about their child are dismissed by pediatricians and family members, parents can feel distressed (Farrugia 2009; Wong et al. 2016). Research on parent stigma shows that their understanding of their child’s behavior and development pre-diagnosis is that it is somehow their fault, or at least perceived by others as
being their fault (Farrugia 2009). None of the parents interviewed indicated that they felt responsible for their child’s autism.

Parents in this study seem to have both medical model and neurodiversity understanding of their children’s autism. Parents with work experience or education in areas of health, special education, or advocacy often discussed their child’s autism in medical model terms. Parents such as Isabel and Matt understood autism as a hybrid of the medical and neurodiversity models because of their personal and professional experiences with disability. They find instrumental value in the label of ASD since it leads to treatment and services for Jason, but they avoid using labels such as “normal” and “abnormal” to describe him, which is more aligned with the neurodiversity model. They have focused on changing their parenting and family functioning for Jason’s emotional and behavioral wellbeing, while seeking services for Jason that will help his physical wellbeing. The medical model of understanding their child’s autism is useful to parents in obtaining services for their child (Kapp et al. 2012). In this situation parents are not only encouraged but expected to be the wardens of their children’s symptoms – as it is seen in this framework – and needs (Singh 2016).

Simultaneous adoption of the neurodiversity model allows parents to focus instead on their child as a person and not as a label. The neurodiversity movement is a response to stigma and other negative perceptions of people with autism (Kapp et al. 2012). Adopting this view allowed parents in this study to accept and understand their child’s autism as positive aspect of their child’s identity because of which their child lives in and processes the world differently. They were able to hold these neurodiversity views, while still instrumentally deploying the medical model. The parents in this study had little or no contact with autistic adults or with the autistic community. Their exposure to autism was mostly confined to autism parent groups and
autistic children, as evidenced by their adoption of medical model language. However, their understanding of autism was still developing in ways consistent with neurodiversity perspectives. It is important to note that while parents moved away from seeing that their child needed “fixing” and picking and choosing which interventions were necessary for their child, they did not adopt a complete neurodiversity perspective, as they still felt some interventions were necessary. Nor did parents adopt neurodiversity language, particularly identity language such as calling their child autistic, although they did speak positively about their child’s autism.
LIMITATIONS

There are a number of limitations of with this study. Firstly, many of the parents were recruited through the Autism Society of El Paso, which is a parenting support group. This caused some homogeneity in the education levels and SES of the participants. All of the parents, aside from Matt, were mothers, limiting the perspective of fathers. Finally, although several of the parents reported having bilingual English/Spanish households, only one parent was more comfortable being interviewed in Spanish. This limits the information I could gather about Spanish-speaking parents and their understandings of autism, including anything related to language barriers in communicating with school officials or doctors.

Recruitment proved to be difficult. Although I sought a partnership with Texas Tech Department of Psychiatry, which would have greater diversity of client families, no participants were recruited from their clinic, or any other autism treatment center where materials were left. I believe that this may have been because while recruitment material was made available to them, there was no personal contact regarding the study. In future studies, I will make time to wait in clinics to make direct contact with parents. This may also help because many parents of autistic children have limited time and it is difficult to schedule a time and place for an interview. As many interviews lasted about the length of therapy appointments, interviews could be collected during the therapy appointment, since the parent is already required to be there, but not always actively involved in the treatment session.
IMPLICATIONS FOR FUTURE RESEARCH

Some of the Hispanic parents that I interviewed were already stigmatized by not conforming to Hispanic cultural norms, such as by being an older mother or being LGBTQ in a community with emphasis on traditional gender roles; they may be more resistant to applying medical labels to their children than the average Hispanic parent. The majority of parents that I interviewed were recruited through participant referrals and through the reposting of flyers from the Autism Society page to other autism and parenting groups. This resulted in my interviewing parents with some unique and interesting experiences that warrant more research. For instance, the experiences of non-traditional families within the autism community imply that multirole stigma, or the intersections of different stigmatized identities, may play a role in how parents understand autism. This was the case for Laura and Erin, but more research is needed on other LGBTQ families of children with autism.

Many of the mothers, including Isabel, implied that fathers have greater difficulty accepting the label of autism. The dismissal of parental concerns by fathers may also play a role in mothers’ understanding of their child’s behavior pre-diagnosis. Education or general knowledge about autism also played a role in how parents understood autism in this child. Parents with formal understandings of autism prior to diagnosis discussed their child’s autism in medical model terms. Most parents accepted and rejected different aspects of the medical model understanding of autism, consistent with ambivalent medicalization. Parents adopted coded-switching practices where they used medical model language more in educational and medical settings, while using language consistent with (but not derived from) neurodiversity perspectives in other settings. If there was increased communication and coordination between educational, medical, support and community settings, parents would be able to better navigate these systems
to find the best options for their child. Studies of autistic parents of autistic children may produce similarities to the differences in language and understanding that is found in Deaf parents of deaf children, where parents are already part of the community.

Many of the parents discussed continued resistance among the medical and educational communities to provide referrals and evaluations for children with ASD-like behaviors. Increasing autism awareness in communities (beyond Rain Man) would create better understanding of autism and lead to earlier and more accurate diagnosis. Within the U.S. educational system, the special education and diagnostic departments are overwhelmed with evaluation requests, which could possibly contribute to school officials’ hesitancy to evaluate children who are not suffering academically. From beginning to end, the evaluation process can take weeks to months depending on the backlog in the district. As some parents in this study noted, this can result in their child losing an entire academic year. In addition, evaluations can be financially and temporally expensive for schools as Action, Review, Dismissal (ARD) committee guidelines require testing, observation, parent and child interviews, as well as coordination between the educators, administration, special education, and diagnostic departments for an IEP evaluation. Many parents noted that their own ability to interact with educators, administrators, and evaluators at the school with medical model understandings of their child’s autism facilitated better outcomes at the continued ARD meetings to re-evaluate their child’s IEP over the years.

While there are structural barriers to diagnosis in the schools, the same impediments are not present in the primary care sector. It is relatively easy for pediatricians to make referrals. In the extreme, a referral can cost as much as the time it takes the clinic staff to contact a specialist and secure an appointment time. More often, it is simple matter of the doctor signing a form, and
the parents contacting the specialist directly. Future research should focus on barriers preventing pediatricians from providing these referrals. Others areas of future research may be in how multirole stigma can influence parental understandings of autism and the role of co-parenting strategies in relation to understanding child development.
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APPENDIX

Interview Guide

**Barriers to Autism Diagnosis – Individual Interview for Parents of Children with ASD’s**

SECTION 1: WARM UP

1.00 Please tell us your first name, the first name of your child (or children) on the autism spectrum, how old your child is, and one thing you like or admire about your child.

SECTION 2: INITIAL CONCERNS OF CHILD DEVELOPMENT

*We are going to talk about your first experiences with autism. We want you to think back to when you first noticed that something was different about your child. We are going to talk about the experiences you had during the diagnostic process from initial concerns about your child’s behavior and development to testing and diagnosis.*

**Tell me about the process through which your child received an ASD diagnosis. How did it happen?**

2.00 *When were you initially concerned about your child’s behavior and development?*

2.01 *What were your first concerns about your child’s behavior and development?*

2.02 **PROBE:** Were you first concerned about your child’s:

- Speech and language development?
- Hearing?
- Social development, such as poor eye contact?
- Play skill, such as inappropriate toy play?
- Behavioral concerns?
- Feeding?
- Sleeping?
- After they say which concern, ask: Why were you concerned about X?

**Did you have other concerns at a later date?**

2.03 *Did you talk to anyone about your concerns? What did they say?*

2.04 *What kind of services, such as speech therapy or physical therapy, did your child receive prior to diagnosis?*
2.05 PROBE: Did you talk to the treatment staff about your concerns? What did they say?

2.06 Who was the first person to be concerned about your child’s behavior and development? Was it you or someone else? Who? Where you initially concerned about your child or was someone else concerned about your child’s behavior or development?

2.07 PROBE: What did you think was going on at the time? Who was the person or people who were concerned about your child’s behavior or development?

2.08 Does your child have a regular doctor? If so, when did you first discuss your concerns with your child’s doctor?

2.09 PROBE: What did they say about your concerns?

2.10 PROBE: What did they do?

2.11 Did you ever discuss your concerns with the school? If so, when did you first discuss your concerns with your child’s teacher, school counselor, school nurse, or administrator?

2.12 PROBE: What did they say about your concerns?

2.13 PROBE: What did they do?

2.14 When did you receive a referral to a specialist for ASD testing? Who did you receive it from? How did you feel at this point?

2.15 Did you meet with the specialist? Why or why not? If yes, what happened there? Who did you meet with?

2.16 What was your child’s diagnosis? How did you feel when the child received this diagnosis?

2.17 PROBE: Were you the first one to notice something, or did someone say something to you?

2.18 PROBE: Did you talk with anyone about your concerns? What did they say?

SECTION 3: BARRIERS TO AUTISM DIAGNOSIS

3.00 What happened now think about the first time you talked with someone outside of the family about your child’s behavior? What happened when you talked to a specialist, such as a psychiatrist or psychologist? A teacher? A or school principal or VP?

3.01 PROBE: What did they say?

3.02 PROBE: What did what did they do?
3.03 PROBE: What was good about that experience?
3.04 PROBE: What was difficult about that experience?

3.05 Was autism your child’s first diagnosis? If not,

3.06 PROBE: What other diagnosis did your child receive?
3.07 PROBE: When did you become concerned that this diagnosis may not have been right?
3.08 PROBE: What did you do about your concerns about your child’s diagnosis?
3.09 PROBE: What was different about the process of this diagnosis compared to your child’s diagnosis of autism?

3.10 Now think about the first time someone told you that your child had an autism diagnosis. This may have been from a specialty doctor, like a psychologist or psychiatrist, a counselor, or a teacher.

Who was the first person to tell you that your child has autism?
3.11 PROBE: How did they tell you about your child’s autism?
3.12 PROBE: How did you feel when you found out?
3.13 PROBE: What was good about that experience?
3.14 PROBE: What was difficult about that experience?
3.15 PROBE: Was autism your child’s first diagnosis? If it was not, what was different about the process for the first diagnosis?

3.16 Now, we would like you to think about difficulties that you might have experienced in the process of finding out that your child had autism. Difficulties can be anything that was hard for you. For instance, knowing how to drive to the autism clinic might be difficulty. Doctors not believing that your child needed an autism evaluation might also be a difficulty.

3.17 Tell us about any kind of difficulty you experienced. (Return to this question until there are no more difficulties)

3.18 PROBE: Why was that thing difficult?
3.19 PROBE: What would have made it better?
3.20 PROBE: What about….

--Problems making or scheduling appointments
Problems getting to the specialist doctor, such as transportation, or having to travel a long way.
Problems understanding what you were supposed to do.
Getting insurance to cover doctors’ visits.
Language or interpreter services.
Trusting the doctors to make the right diagnosis.
Having to wait a long time for an appointment.
Not knowing where to go.
Family issues (e.g. spouse).
Documentation concerns.
Religious concerns.
Discrimination based on economic status, gender, race or ethnicity.

3.21 Of all of these problems, which ones do you think are the most serious?

3.22 PROBE: Why?

3.23 Do you think that your race or ethnicity has influenced the autism care that your child has received? What about that your child is a girl/boy? Or your economic status (Probe: the fact that you have Medicaid, as applicable)? The part of town that you live in?

3.22 PROBE: Was your child ever misdiagnosed with something else?

SECTION 4: PROCESS IMPROVEMENT

Pretend that you had a friend whose child seemed to have autism, but had not gotten an autism diagnosis.

4.00 What advice would you give to this friend?

Some researchers have found that minority children are diagnosed with autism less often than other children.

4.01 Why do you think that is the case?

SECTION 5: CONCLUSIONS

Doctors are trying to make it easier for minority families of children with autism to get diagnosed and treated.
5.01 If you could to give doctors one suggestion to make things easier for minority families, what would you suggest?

**Barreras para Diagnosticar Autismo- Entrevista Individual para Padres de Niños con TEA**  
**SECCION 1: PARA EMPEZAR**

1.00 Por favor diganos su nombre, el nombre de su hijo/a(s) con el espectro de autismo, la edad de su hijo a(s), y una cosa que le guste o admire de su hijo/a(s).

**SECCION 2:**

Vamos a hablar acerca de experiencias que usted haya tenido durante el proceso de diagnostico, desde preocupaciones iniciales acerca de el comportamiento de su hijo/a(s), hasta su desarrollo y su diagnosis.

Cuénteme acerca de el proceso mediante el cual su hijo/a(s) recibió el diagnostico de TEA. ¿Cómo fue que paso?

2.00 ¿Cuándo comenzó a preocuparse inicialmente sobre el comportamiento y desarrollo de su hijo/a(s)?

2.01 ¿Cuáles fueron las primeras inquietudes acerca de su comportamiento y desarrollo?

2.02 SONDEO: Estuvo preocupado inicialmente acerca de su hijo/a(s):

- Sentido del habla y desarrollo de lenguaje
- Audición
- Desarrollo social, por ejemplo poco contacto visual
- Habilidades para jugar, jugar inapropiadamente con juguetes
- Preocupaciones sobre su comportamiento
- Alimentación
- Sueño
- Después de que que digan cual preocupación, pregunte: ¿Por qué estaba preocupado por X?

¿Tuvo otras inquietudes más adelante?

2.03 ¿Habló con alguien acerca de sus inquietudes? ¿Qué le dijeron?

2.04 ¿Qué clase de servicios, como de terapia de lenguaje o terapia física, recibió su hijo/a(s) previamente a ser diagnosticado?

2.05 SONDEO: ¿Habló con el personal que proveía el tratamiento acerca de sus inquietudes? ¿Qué le dijeron?
2.06 ¿Quién fue la primera persona en preocuparse por el comportamiento y desarrollo de su hijo/a(s)? ¿Fue usted, o alguien más? ¿Quién?

2.07 SONDEO: ¿Quién o quienes fueron las personas que se preocuparon por el comportamiento y desarrollo de su hijo/a(s)?

2.08 ¿Tiene su hijo/a(s) un doctor de cabecera? Si es así, ¿cuándo discutió por primera vez sus inquietudes con el médico de su hijo/a(s)?

2.09 SONDEO: ¿Qué le dijeron acerca de sus inquietudes?

2.10 SONDEO: ¿Qué hicieron al respecto?

2.11 ¿Alguna vez habló de sus inquietudes en la escuela? Si lo hizo, ¿cuándo? ¿Con quién? ¿Maestro, consejero de la escuela, enfermero de la escuela, o con el director?

2.12 SONDEO: ¿Qué le dijeron acerca de sus inquietudes?

2.13 SONDEO: ¿Qué hicieron al respecto?

2.14 ¿Cuándo recibió una referencia para ver a un especialista y ser examinado de TEA? ¿De quién? ¿Cómo se sentía en este punto?

2.15 ¿Vio al especialista? ¿Por qué sí o por qué no? Si lo hizo, ¿Qué pasó? ¿Con quién se reunió?

2.16 ¿Cuál fué la diagnosis? ¿Cómo se sintió cuando el niño/a(s) recibió la diagnosis?

SECCION 3: BARRERAS PARA LA DIAGNOSIS DE AUTISMO

3.00 ¿Qué paso la primera vez que usted habló con un doctor acerca del comportamiento de su hijo/a(s)? ¿Un especialista como un psiquiatra o psicólogo, un maestro, o un directivo de la escuela?

3.01 SONDEO: ¿Qué le dijeron?

3.02 SONDEO: ¿Qué hicieron al respecto?

3.03 SONDEO: ¿Qué fue bueno acerca de esa experiencia?

3.04 SONDEO: ¿Qué fue difícil acerca de esa experiencia?

3.05 ¿Fue Autismo el primer diagnóstico que obtuvo su hijo/a(s)? Si no,

3.06 SONDEO: ¿Qué otro diagnóstico recibió su hijo/a(s)?

3.07 SONDEO: ¿Cuándo comenzó a preocupar por que ese diagnóstico no fuera correcto?

3.08 SONDEO: ¿Qué hizo acerca de sus inquietudes respecto al diagnóstico de su hijo/a(s)?
3.09 SONDEO: ¿Qué fue diferente en el proceso de esta diagnosis comparada con el proceso de diagnosis de autismo de su hijo/a(s)?

3.10 ¿Quién fue la primera persona en decirle que su hijo/a(s) tenía autismo?

3.11 SONDEO: ¿Cómo le dijeron acerca del autismo su hijo/a(s)?
3.12 SONDEO: ¿Cómo se sintió al enterarse?
3.13 SONDEO: ¿Qué fue bueno acerca de esa experiencia?
3.14 SONDEO: ¿Qué fue difícil acerca de esa experiencia?

3.15 Ahora, nos gustaría que pensara acerca de las dificultades que usted pudo haber experimentado en el proceso de descubrir el autismo de su hijo/a(s). Pueden ser consideradas como dificultades, cualquier situación que haya sido dura para usted. Por ejemplo, aprender a manejar hacia la clínica de autismo, pudo haber sido una de ellas. Doctores que no creyeran en que su hijo necesitara una evaluación de autismo, podrían ser considerada como otra dificultad.

3.15 Díganos acerca de alguna dificultad que usted haya experimentado. (Regrese a esta pregunta hasta que no hayan mas dificultades)

3.16 SONDEO: ¿Por qué fue eso difícil?
3.17 SONDEO: ¿Qué pudo haberlo hace mejor?
3.18 SONDEO: Que tal acerca de…

—Problemas para hacer citas
—Problemas para obtener acceso al especialista, como transportación, o tener que viajar una distancia larga
—Problemas para entender que era lo que tenía que hacer
—Obtener asegurancia que cubriera las visitas al médico
—Lenguaje o de servicio de interprete
—Confianza para los doctores en hacer la diagnosis correcta
—Tener que esperar por un largo periodo en una cita
—No saber a donde ir
—Problemas familiares (ej. cónyuge)
—Inquietudes acerca de documentación
—Inquietudes religiosas
—Discriminación basada en condición social, genero, raza o grupo étnico

3.19 ¿De todos estos problemas, cuál cree que es el mas serio?

3.20 SONDEO: ¿Por qué?

3.21 ¿Usted cree que su raza o grupo étnico han influenciado el cuidado del autismo que su hijo/a(s) ha recibido? ¿Qué tal el sexo de su hijo/a(s), o su estatus económicó (Prueba es el hecho de recibir Medicaid, si es aplicable)? ¿O la parte de la ciudad en la que usted vive?
3.22 SONDEO: ¿A sido su hijo/a(s) alguna vez mal diagnosticado con algo más?

SECCION 4: PROCESOS DE MEJORAMIENTO

Pretenda que usted tiene un amigo cuyo hijo parece ser autista, pero no ha obtenido una diagnosis de autismo aún.

4.00 ¿Qué le recomendaría a su amigo?

Algunos estudios an encontrado que niños provenientes de minorías son diagnosticados con autismo menos frecuentemente que otros niños.

4.01 ¿Cuál cree que sea la razón?

SECCION 5: CONCLUSIONES

Los doctores están tratando facilitar a las familias provenientes de minorías con hijos con autismo, a ser diagnosticados y tratados.

5.01 ¿Si usted pudiera darles a los doctores una sugerencia para hacer las cosas más fáciles para las familias provenientes de minorías, qué sugeriría?
Demographic survey

Survey for Parents of children with ASD

Short answer questions to be given to parents after the interview.

1. What is your relationship to the child or children in question? (circle one)
   
   (1) Mother
   (2) Father
   (3) Other?, Please specify: ______________

2. What other adult relatives of the child, aside from yourself, live in the home? (check all that apply)

   □ Mother
   □ Father
   □ Aunt(s)/Uncle(s), how many? ______
   □ Grandparent(s), how many? _____
   □ Cousin(s), how many? ____

3. How many children live in your home? ______

4. How many of the children living in your home have a diagnosis of ASD? _____

5. Do any of your children have a diagnosis of a psychological or medical disorder that is not ASD, such as ADHD or schizophrenia?

   □ No
   □ Yes, what? __________________________________________

6. Does your child or children with ASD have any other co-occurring psychological or medical diagnoses, such as ADHD or a chromosomal disorder?

   □ No
   □ Yes, what? __________________________________________

7. In what city and state do you currently live?
   ______________________________________________________

8. In what neighborhood or area of that city do you live?
   ______________________________________________________

9. What is your race and ethnicity? (check all that apply)
☐ White, not Hispanic
☐ Black, not Hispanic
☐ White, Hispanic
☐ Black, Hispanic
☐ Native American
☐ Asian

If Hispanic or Asian, what is your ancestry (e.g., Mexican, Chinese, etc)?
______________________________________________________________________

10. What is the race and ethnicity of your child, if different from yours? (check all that apply)

☐ White, not Hispanic
☐ Black, not Hispanic
☐ White, Hispanic
☐ Black, Hispanic
☐ Native American
☐ Asian

If Hispanic or Asian, what is his/her ancestry (e.g., Mexican, Chinese, etc)?
______________________________________________________________________

11. What is the primary language spoken in your home? (check one)

☐ English
☐ Spanish
☐ Bilingual, English/Spanish
☐ Other _________________________________

12. Which of the following best describes your total household income before taxes? Please include your income and income from anyone else in your household from jobs, investments, public assistance, unemployment insurance, social security, disability/pension funds, and all other sources. Your best estimate is fine. (check one)

☐ Less than $1,999 (Less than $166/month)
☐ $2,000 - $4,999 ($167 - $416/month)
☐ $5,000 - $9,999 ($417 – $833/month)
☐ $10,000 -- $14,999 ($834 – $1249/month)
☐ $15,000 – $19,999 ($1250 – $1666/month)
☐ $20,000 - $29,999 ($1667 – $2500/month)
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<td>$150,000 or more</td>
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13. What was the highest level of education that you completed? (check one)
   - Less than high school
   - High school
   - Certificate or technical program
   - Associate’s degree
   - Bachelor’s degree
   - Master’s degree
   - Ph.D. or doctoral degree

14. What was the highest level of education that your spouse completed? (check one)
   - Less than high school
   - High school
   - Certificate or technical program
   - Associate’s degree
   - Bachelor’s degree
   - Master’s degree
   - Ph.D. or doctoral degree

15. What kind of insurance coverage does your child with ASD have currently? (check all that apply)
   - Private insurance
   - Children’s Health Insurance Plans (CHIP)
   - Medicaid
   - Medicare
   - No insurance
   - Other ____________________________________________

16. What kind of insurance coverage did your child with ASD have prior to being diagnosed? (check all that apply)
17. What kind of insurance coverage did your child with ASD have after being diagnosed? (check all that apply)

- Private insurance
- Children’s Health Insurance Plans (CHIP)
- Medicaid
- Medicare
- No insurance
- Other ________________________________

18. What is your mode of transportation? (check all that apply)

- Personal vehicle
- Shared/family vehicle
- Public transportation
- Rides from friends or family
- Other, please specify: ________________________________

19. How do you gain information about autism? (check all that apply)

- Teachers/School
- Therapists
- Pediatrician/Physician
- Internet
- Books/Magazines
- Conferences
- Autism parent support groups (e.g., Autism Society of El Paso)
  - Do you attend regularly?
    - Yes _____
    - No _____
    - N/A
- Family members/friends
- Other parenting groups (e.g., Birth to 3)
20. Rate your level of satisfaction with the information sources listed above. (check one)

☐ Dissatisfied
☐ Somewhat Dissatisfied
☐ Neutral
☐ Satisfied
☐ Very Satisfied

21. Have you (or spouse/partner) changed work since your child was diagnosed with ASD (e.g., took a 2nd job, stopped working, etc.)?

☐ No
☐ Yes______________________________

22. Have you (or spouse/partner) made changes regarding family planning since your child was diagnosed with ASD (e.g., decided to have another child, decided to not have another child)?

☐ No
☐ Yes______________________________

23. Anything else you wish to share? _________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

Entrevista para padres de niños con TEA
Preguntas con respuestas cortas serán aplicadas a los padres después de la entrevista.

1.-¿Cuál es su relación con el niño/ña en cuestión? (circule una respuesta)

(1) Madre
(2) Padre
(3) ¿Otra? Por favor especifique:________________________

2.-¿Qué otros parientes del niño/ña, aparte de usted, viven en la casa? (seleccione todas las que apliquen)

• Madre
• Padre
• Tío/a(s)/Primo/a(s), ¿cuántos en total?_____
• Abuelo/a(s), ¿cuántos en total?_____
• Primo/a(s), ¿cuántos en total?_____

59
3.-¿Cuántos niños viven en su casa?_______

4.-¿Cuántos de los niños que viven en su casa han sido diagnosticados con TEA?_____

5.-¿Alguno de sus hijos ha sido diagnosticado con un desorden psicológico o medico que no sea TEA, como por ejemplo TDAH o esquizofrenia?
   • No
   • Si, ¿cuál?________________________________________________

6.-¿Alguno de sus hijo/a(s) con TEA tiene otro diagnostico psicológico o medico simultáneamente, como TDAH o mutación cromosómica?
   • No
   • Si, ¿cuál?________________________________________________

7.-¿En qué ciudad y estado vive usted actualmente?
   _____________________________________________________________

8.-¿En qué vecindario o area de la ciudad vive usted?
   _____________________________________________________________

9.-¿Cuál es su raza o etnicidad? (selecione todas las que apliquen)
   • Blanco, no Hispano
   • Negro, no Hispano
   • Blanco, Hispano
   • Negro, Hispano
   • Nativo Americano
   • Asiático
   ¿ Si es Hispano o Asiático, cuál es su descendencia (ej. Mexicana, China, etc)?
   ___________________________________________________________________

10.-¿Cuál es la raza o etnicidad de su hijo/a, si es diferente a la de usted? (selecione todas las que apliquen)
   • Blanco, no Hispano
   • Negro, no Hispano
   • Blanco, Hispano
   • Negro, Hispano
   • Nativo Americano
   • Asiático
   ¿ Si es Hispano o Asiático, cuál es su descendencia (ej.Mexicana, China, etc)?
11.-¿Cuál es el lenguaje principal que se habla en su casa? (seleccione una)

- Ingles
- Español
- Bilingüe, Ingles/Español
- Otro_______________

12.-¿Cuál de las siguientes describe mejor el total de su ingreso familiar antes de deducir impuestos? Puede incluir su ingreso y el ingreso de alguien mas en su casa proveniente de trabajos, inversiones, asistencia publica, asegurança de desempleo, seguro social, fondos de incapacidad/pensiones, y de cualquier otra fuente. Su mejor estimado esta bien. (seleccione una)

- Menos de $1,999 (Menos de $166/mensual)
- $2,000 - $4,999 ($167 - $416/mensual)
- $5,000 - $9,999 ($417 – $833/mensual)
- $10,000 - $14,999 ($834 – $1249/mensual)
- $15,000 – $19,999 ($1250 – $1666/mensual)
- $20,000 - $29,999 ($1667 – $2500/mensual)
- $30,000 - $39,999 ($2501 – $3333/mensual)
- $40,000 - $49,999 ($3334 – $4166/mensual)
- $50,000 - $59,999 ($4167 – $5000/mensual)
- $60,000 - $69,999 ($5001 – $5833/mensual)
- $70,000 - $79,999 ($5834 – $6667/mensual)
- $80,000 - $89,999 ($6668 – $7500/mensual)
- $90,000 - $99,999 ($7501 – $8333/mensual)
- $100,000 - $149,999 ($8334 – $12500/mensual)
- $150,000 or more ($12501 o más/mensual)

13.-¿Cuál fue su nivel máximo de educación? (seleccione una)

- Menos que preparatoria
- Preparatoria
- Certificado de preparación tecnica
- Licenciatura Maestria
- Doctorado

14.-¿Cuál fue el nivel máximo de educación que obtuvo su cónyuge? (seleccione una)

- Menos que preparatoria
- Preparatoria
- Certificado de preparación tecnica
- Licenciatura
- Maestria

15.-¿Qué clase de cobertura medica su hijo/a con TEA tiene actualmente? (seleccione todas las que apliquen)
16.-¿Qué clase de cobertura médica su hijo/a con TEA tenía antes de ser diagnosticado/a? (seleccione todas las que apliquen)

- Aseguranz privada
- Children’s Health Insurance Plans (CHIP)
- Medicaid
- Medicare
- No tiene asegurada
- Otra ____________________________________________________

17.-¿Qué clase de cobertura médica su hijo/a con TEA tenía después de ser diagnosticado/a (seleccione todas las que apliquen)

- Aseguranz privada
- Children’s Health Insurance Plans (CHIP)
- Medicaid
- Medicare
- No tiene asegurada
- Otra ____________________________________________________

18.-¿Cuál es su medio de transportación? (seleccione todas las que apliquen)

- Vehículo personal
- Compartido/Vehículo familiar
- Transporte público
- Aventones de amigos o familiares
- Otro, por favor especifique: ________________________________________

19.-¿Cómo obtiene información acerca del autismo? (seleccione todas las que apliquen)

- Maestros/Escuela
- Terapistas
- Pediatra/Doctor
- Internet
- Libros/Revistas
- Conferencias
- Grupos de soporte para padres con hijos con autismo (ej., Autism Society of El Paso)
  - Va regularmente?
    - Si _____
    - No _____
    - N/A
- Miembros de familia/Amigos
- Otros grupos para padres (ej., de nacimiento a 3 años)

20.- Califique su nivel de satisfaction con los medios de información mencionados anteriormente. (seleccione una)

- Insatisfecho
- Un poco insatisfecho
- Neutral
- Satisfecho
- Muy satisfecho

21.- ¿Han cambiado de trabajo usted (o su cónyuge/pareja) desde que el niño/ña fue diagnosticado/a con TEA (ej. consigo un segundo empleo, dejo de trabajar, etc.)?

- No
- Si_______________________________________________

22.- ¿Usted (o su cónyuge/pareja) han hecho cambios relacionados con la planificación familiar desde que su hijo/a fue diagnosticado/a con TEA (ej. decidieron tener otro hijo, decidieron no tener otro hijo)?

- No
- Si_______________________________________________

23.- ¿Algo mas que le gustaría agregar? ______________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

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VITA

Kylara J. Leyva is a Master of Arts of Sociology student at the University of Texas at El Paso, with a Bachelor of Arts degree in psychology from the same university. She was born in Dover, New Hampshire and grew up in the small town of Sanford, Maine, where she graduated from Sanford High School in 1998. Her father was a retired Airforce technician and her mother was a graphic designer. In 2003, Kylara married and became a mother to her first child. Kylara had two other children by the time she began her collegiate career in 2010 at El Paso Community College.

Kylara became interested in the study of autism spectrum disorder as an undergraduate, when her two younger children were diagnosed with autism. Her academic interest was encouraged by her study of social psychology where Kylara began to study the impact of society on mental health. She quickly realized that her interest in autism had greater relation to public policy for diagnosis and treatment than to administering treatment, prompting her to enroll in the sociology MA program.

In 2014, Kylara became the first member of her family to graduate from college, when she was awarded her Bachelor of Arts degree. The Psychology Department at UTEP recognized Kylara by presenting her with the award for Outstanding Academic Achievement. As a graduate student, Kylara co-authored “Motherhood as a Marker of Achieving Womanhood” with Dr. Angela Frederick. At the time this thesis was filed, this article was being reviewed for publication.

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This thesis/dissertation was typed by Kylara J. Leyva.