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An abstract of
a thesis submitted to the Faculty of Emory College of Arts and Sciences
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This thesis explores the cultural perceptions and systemic challenges Hispanic families face in the diagnosis and treatment of autism spectrum disorder (ASD). Through semi-structured interviews with Hispanic individuals who have a family member with ASD, this study uses a qualitative approach to investigate lived experiences before and after diagnosis. Five core themes emerged: limited awareness and stigma, barriers within the healthcare system, struggles in the education system, gender roles in ASD caregiving, and fear for the future and long-term independence. Many participants reported not knowing what autism was prior to diagnosis and described how cultural beliefs, denial, and lack of community understanding impacted early recognition. Others described how language barriers and culturally incompetent healthcare providers led to delays in diagnosis or inappropriate care. Post-diagnosis, families often faced challenges navigating educational systems and voiced deep concerns about their child's long-term future. This research contributes to a growing body of literature calling for more inclusive, culturally competent healthcare and educational systems.

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Dedication

Para mi primo Jaimito, quien me inspiró a realizar este proyecto. Aunque no estoy contigo físicamente en el Ecuador, siempre estás en mi corazón. Jaimito, eres un niño increíble y tengo muchísimo orgullo de ser tu prima. Espero que proyectos como el mío inspiren a otros a dar voz a niños tan maravillosos como tú.

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Thanks to this incredible support system, I am proud of the work I present in this thesis.

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Introduction

Autism Spectrum Disorder (ASD) is a developmental disability characterized by deficits in social interaction and the presence of restricted interests in behaviors (Shaw, 2023). Using a system known as the Autism and Developmental Disabilities Monitoring (ADDM), which is an active surveillance program that provides estimates of the prevalence of ASD among children aged 8 years, the CDC found that 1in 36 children was diagnosed with autism in 2020. This is an increase from 1in 44 children in 2018. The CDC also reported on the prevalence of “profound autism” for the very first time that year, which showed that 6.7% with autism spectrum disorder have profound autism (Shaw, 2023). These findings demonstrate the growing prevalence of autism and highlight the spectrum’s complexity. The increased diagnosis rate may suggest not only a potential improvement in diagnostic practices but also a heightened awareness among parents, educators, and healthcare professionals. Additionally, the CDC’s new focus on profound autism brings attention to a group of those with ASD who experience more severe symptoms, such as limited communication skills, significant intellectual disabilities, and a need for intensive support.

The CDC also included race/ethnicity ASD prevalence data across 11 states, including Georgia. Across the 11 states, Hispanics had the highest prevalence among all races/ethnicities. They also found that compared to non-Hispanic White children, ASD prevalence was 1.8 times as high among Hispanics. This marks the first time that ASD prevalence has been reported as higher among Hispanic children than White children, representing a significant shift in observed trends. This increase in ASD diagnoses among Hispanic children may suggest screening and diagnostic efforts may be improving for historically underserved populations. Higher diagnosis rates in these groups may indicate better awareness, enhanced screening practices, and expanded access to services for Hispanic families. This is especially important because marginalized groups have often been underrepresented in ASD research, leaving significant gaps in understanding and resources. By highlighting ASD prevalence amongst different races/ethnicities, the study highlights the importance of equitable health practices. It lays the groundwork for future research and policy aimed at further reducing disparities in ASD diagnosis and care.

This new trend is vital to note as historically; there were often lower reported rates of ASD prevalence among Hispanics and other marginalized groups. The lower reported rates may have been due to various factors, such as limited access to healthcare, cultural stigma, language barriers, the lack of culturally responsive screening tools, and socioeconomic challenges. When researching Hispanic populations, researcher Katherine E. Zuckerman has noted that reasons for ethnic disparities in ASD diagnosis are poorly understood and under-researched. In 2014, Zuckerman conducted 5 focus groups and 4 qualitative interviews with parents of Latino children with Autism and found that Latino families in the study had not heard of ASD or had little information about it. Moreover, families assumed ASD signs were typical or due to family dysfunction. Having a child with a developmental delay was often associated with embarrassment and family burden, making it difficult for parents to raise developmental concerns with providers (Zuckerman, Sinche, Cobian, et al., 2014). This lack of awareness and the association of developmental delays with family dysfunction may reflect how cultural perceptions and limited information contribute to underdiagnosis.

Additionally, Zuckerman found there were several healthcare system barriers that Hispanic families faced when seeking a diagnosis. These challenges ranged widely, including difficulties in accessing primary care providers. Some parents felt their provider rushed them through the

ASD diagnostic process too quickly; others felt their concerns were ignored (Zuckerman, Sinche, Mejia, et al., 2014). In addition, many families felt the diagnostic process was too complicated. The complexity of the process was particularly challenging for less acculturated families. Many slight delays added up to more extensive delays for parents seeking diagnosis and treatment for their child (Zuckerman, Sinche, Mejia, et al., 2014). These findings are consistent with the delays in diagnosis from previous years. In a study published in the *Journal Academy of Child and Adolescent Psychiatry*, researchers found Latino children are diagnosed with ASD 2.5 years later than white non-Latino children and are more often missed in diagnosis despite meeting ASD diagnostic criteria (Mandell et al., 2009). Early ASD diagnosis is essential to ensure children have access to services they might need to support the development of these skills (Shaw, 2023). It may also lessen the familial and financial stress as they grow older, reducing the stigma that may arise from exhibiting such behaviors.

Although ASD prevalence rates have improved among Hispanic populations, this does not necessarily indicate a reduction in barriers or adequate access to treatment following an ASD diagnosis. Hispanic Americans continue to face several challenges when it comes to access to healthcare and medical treatments. Overall, Hispanic adults are less likely than other Americans to have health insurance and to receive preventative medical care (C. F. and M. H. Lopez, 2022). In a survey done by the Pew Research Center in 2022, they found that Hispanic Americans cite working in occupations with health risks as the top factor for why Hispanic people generally have worse health outcomes than other U.S. adults (C. F. and M. H. Lopez, 2022). Almost half (48%) say less access to quality medical care where they live is a significant reason for worse health outcomes among Hispanic people in the U.S. When it comes to navigating the healthcare system, 44% of Hispanics say that more communication problems from language or cultural differences are significant reasons why Hispanic people have generally worse health outcomes than other adults in the U.S. (C. F. and M. H. Lopez, 2022). The combination of language/cultural barriers, as well as factors such as higher levels of poverty, particularly among recent Hispanic immigrants, are among the social and economic dynamics that contribute to disparate health outcomes for Hispanic Americans.

Given the limited research on ASD prevalence and continued diagnostic disparities among Hispanic populations, this study aims to shed light on the unique challenges faced by this community. This study's goal is not only to increase awareness but also to provide valuable information that may help Hispanic families feel less isolated in navigating ASD diagnoses and support systems for their loved ones. Drawing inspiration from Zuckerman's research, this study employs similar methods to explore cultural perceptions, barriers, and needs within the Hispanic community. These methods will include qualitative interviews with Hispanic individuals who have a loved one with ASD. By expanding the body of knowledge on this subject, this research hopes to foster better collaboration between healthcare providers and families. Ultimately, it aims to contribute to more effective, culturally responsive strategies that ensure all families have access to timely diagnosis and support for children with ASD.

Positionality and Background

As a Hispanic American woman deeply passionate about healthcare within Hispanic communities, I am particularly concerned about the perceptions of autism spectrum disorder (ASD) in Hispanic culture. Mental disabilities and disorders, including ASD, are often misunderstood and stigmatized in these communities. This is because there are often no physical signs of these illnesses manifesting, so it is easy to assume the disorder isn't real. I chose to focus on ASD because I have witnessed firsthand how prevalent and misunderstood it is. Hispanic culture is incredibly diverse, and attitudes toward ASD can vary significantly depending on the family's country of origin. Cultural differences exist between Central America, the Caribbean, and South America, for instance. My heritage lies in Ecuador, a small country in South America. I am most familiar with Ecuadorian culture and that of neighboring nations like Colombia and Peru. Growing up, I lived in a culturally rich borough of New York, surrounded by Hispanic individuals from diverse backgrounds, including Mexicans and Dominicans. Like my parents, many of them were immigrants, and a significant number were undocumented, working jobs that did not require legal documentation. One consistent observation I have made is that Hispanic culture strongly emphasizes work ethic and prioritization of family. However, due to socioeconomic disadvantages and systemic barriers, many Hispanic immigrants have limited formal education, particularly regarding mental disabilities and disorders. This lack of awareness may contribute to the ongoing misunderstanding and stigma surrounding ASD in these communities.

I am the first in my family to receive a formal education in the United States. Both of my parents graduated from reputable universities in Ecuador, earning degrees in engineering. There is a strong cultural emphasis on STEM careers in Ecuador, with mathematics being especially revered in my family. My parents have always taken education seriously, and that was deeply instilled in me at a young age. While some of my extended relatives pursued careers in business or law, I was the first to develop a deep interest in medicine, ultimately leading me to pursue this thesis. Through my academic journey and involvement in research labs, I have gained experience in both qualitative and quantitative research. My lab experience was primarily biology-based, requiring adherence to detailed protocols and procedures. Some experiments spanned a single day, while others extended over a week. These experiments relied on careful documentation and knowledge of biology to understand the results. My fieldwork experience, on the other hand, stems from anthropology courses that taught me how to conduct thorough and effective interviews. These courses also taught me more effective reading skills and how to interpret qualitative data. This combination of skills has given me a solid foundation for conducting research and exploring interdisciplinary approaches to understanding complex issues.

My interest in studying ASD within my community began when I encountered it firsthand within my own family. As I delved deeper into research, I realized this was not an isolated issue but a community-wide challenge deeply rooted in Hispanic culture. As a college-educated woman, I am deeply grateful for the privilege of understanding and addressing the issues that affect my community. I recognize how fortunate I am to have the resources and support to bring attention to a topic that remains under-researched. I approach this research with an open mind, prepared to be surprised and enlightened by the stories and perspectives shared by families. My hope is that the findings will benefit the Hispanic community by providing education, fostering awareness, and reassuring families that they are not alone in facing these challenges.

Literature Review

This literature review is organized into specific subcategories to understand better the needs of the Hispanic population and their relationship with autism. It aims to provide an overview of the key themes relevant to this study, inform the methods, and offer context for the findings and issues likely to emerge during the research.

Autism in the Context of Anthropology

The understanding and definitions of autism have evolved significantly over time. Initially described as a rare psychogenic condition (Solomon & Bagatell, 2010), autism is now classified as a neurobiological disorder. This shift reflects fundamental transformations in theories of autism, driven by expanding research and efforts to understand the condition better. The prevalence of autism has also increased over the years, partly due to these advancements in research and diagnostic criteria. Today, autism is viewed in biomedical terms as a neurodevelopmental disorder that affects social cognition. Much of the research has focused on cognitive theories of autism, particularly its characterization as a disorder of “theory of mind.” This concept refers to the ability to infer another person's emotions, beliefs, thoughts, and intentions (Solomon & Bagatell, 2010). These evolving perspectives are critical to note, as they influence how autism spectrum disorder (ASD) is approached and treated.

Biomedical accounts of autism have primarily focused on the challenges affected individuals experienced in laboratory tasks. This has caused tension between biomedical perspectives on autism and the everyday experiences of individuals with autism and their families. Specifically, this tension emerges as the experiences, discourses, and ideologies of persons with autism and their families contrast with those doctors, therapists, teachers, and others who provide a range of services in institutional settings. The tension commonly arises at the interface of the personal and the institutional, between theories of competence and theories of disability, and among orientations toward measurable clinical change when contrasted with notions of a “good,” meaningful life (Solomon & Bagatell, 2010). Therefore, it is essential to have different perspectives on ASD, especially amongst the social sciences, to reduce these tensions. The context of anthropology encourages us to rethink autism by embracing its complexity, from the personal experience of those diagnosed with autism and their families to issues of healthcare and educational policy. Autism can be addressed in several subfields of anthropology, but it is most discussed in medical, linguistic, and cultural anthropology. The field of anthropology does not seek to sever ties with a biomedical construct but instead aims to add socio-cultural depth. These constructs do not have to exist independently to provide an understanding of autism.

When thinking about autism in anthropology, it is important to understand what exactly the field has done to address the complexities of autism. First, anthropology has made important contributions to understanding other human conditions and social processes such as agoraphobia, aphasia, anorexia, attention-deficit/hyperactivity disorder, illness and disability experience from family perspectives, mental disabilities, and more (Solomon, 2010). An anthropological perspective is rooted in encompassing otherness, which is the idea that there are life forms radically different from ours but still human. Hence, it is necessary to keep an open mind to all potential possibilities.

Anthropology makes contributions to the study of autism in three ways. First, the anthropological understanding of intersubjectivity and empathy is grounded in practice. It refrains from presuming the exceptional abilities of the ethnographer or fostering any illusion of a "preternatural capacity to think, feel, and perceive like a native." Instead, it emphasizes meticulous attention to and observation of how individuals "perceive 'with'—or 'by means of' symbolic forms" (Solomon, 2010). These symbolic forms—words, images, institutions, and behaviors—are analyzed to understand how people represent themselves and others in their specific cultural contexts. Second, the anthropological study of autism provides an ethnomethodological framework and a hermeneutic, interpretive approach to grasp the lived experiences of individuals with autism (Solomon, 2010). Finally, the ethnographic methods employed in anthropology enable an in-depth exploration of the everyday practices of individuals with autism and their families. These methods also shed light on how knowledge about autism is created, circulated, and reproduced within familial, community, and institutional contexts (Solomon, 2010).

An ethnographic perspective on autism utilizes person-centered, narrative, and life-history interviewing approaches. This methodology immerses researchers into individuals' lived experiences and personal stories, situating their perspectives within the broader context of the subject matter. This approach underscores the relevance of anthropological research, even in contexts often examined through a biomedical lens, such as neurological disorders. For this study, the ethnographic perspective is particularly significant, as it focuses on a population that is frequently overlooked in autism research, providing critical insights into their unique experiences and needs.

Barriers to Inclusion of Hispanic Families in ASD Literature

Despite the growing prevalence of ASD diagnoses, Hispanic families remain significantly underrepresented in autism-related research, limiting the development of culturally responsive interventions. As of 2022, the Hispanic population in the United States reached 63.6 million, accounting for 19% of the total population (C. F. and M. H. Lopez, 2022a). Despite this significant demographic presence, Hispanic populations remain underrepresented in research across various fields, including healthcare. Ethnic and racial minority groups, such as African Americans and Hispanics, have historically faced pervasive underrepresentation in research studies, a long-standing national scientific concern (Rojo et al., 2024). Efforts to address this issue, such as the NIH Revitalization Act of 1993, which mandates the inclusion of minority groups in NIH-funded research, have aimed to increase recruitment. However, despite these initiatives, participation rates among minority populations, including Hispanics, remain disproportionately low (Chen et al., 2014), underscoring the need for more targeted and practical strategies to bridge this gap.

This issue is prevalent throughout healthcare studies. Researchers have noted that the reporting and analyses of data based on minorities in clinical trials remain inadequate. They found that less than 2% of the National Cancer Institute's clinical trials focus on any racial/minority population as their primary emphasis (Rojo et al., 2024). This is an issue because the lack of diversity in research and/or clinical trials limits the generalizability of findings to minority populations. This consequently prevents researchers and policymakers from applying innovative treatment options, improving treatment safety and efficacy for minority groups, and developing policies and practices tailored to their needs (Rojo et al., 2024).

Rojo’s study is one of the first to use a validated instrument to assess barriers to research participation in the Hispanic population. This study aimed to explore Hispanics’ perceptions about participating in research, evaluate the level of research participation burden, and solicit recommendations for increasing their participation in research studies to develop recruitment and retention strategies. The top factors that researchers have linked to Hispanics’ lack of research participation are language barriers, fear and lack of awareness, mistrust of the government or institutions, acculturation, and immigration status (Hildebrand et al., 2018)(Rodríguez-Torres et al., 2021). These barriers not only hinder research participation but also mirror the systemic obstacles faced by Hispanics within the healthcare system, contributing to ongoing healthcare disparities. Zuckerman’s research on barriers specific to autism spectrum disorder (ASD) highlights similar challenges, particularly language barriers and a lack of knowledge, which have been linked to delays in diagnosis and treatment (Zuckerman, Sinche, Mejia, et al., 2014).

Rojo’s study focused on Hispanics’ perceptions and attitudes toward research studies, elicited solutions to increase their participation, and measured the perceived research burden of participation. This study took place in Arkansas, a Southern state that has experienced a significant surge in Hispanic population growth, so while it does not consider the entirety of the US, it is an appropriate sample size (Rojo et al., 2024). The study was qualitative; researchers used a 12-item demographic data sheet to collect participant demographics, the Perceived Research Burden Assessment (PeRBA), and face-to-face in-depth interviews. Hispanic participants reported a range of issues that served as barriers to participating in research studies and identified two strategies to increase the representation of Hispanics in research studies. The five major themes that emerged from the interviews were 1) lack of knowledge, 2) immigration status, 3) social isolation, 4) language and literacy, and 5) transportation. These themes are also consistent with past research studies, including Zuckerman's.

One theme that stood out in this study was social isolation. Participants described how their inability to integrate/assimilate and engage with the broader society restricted their access to potential research study opportunities. Because they lived in under-resourced neighborhoods that were geographically and socially isolated, residents often lacked access to diverse sources of information, such as community programs, educational resources, or career-related networks. This inability to engage with the broader societal context created limitations rather than opportunities to participate in research studies. This can be due to a variety of reasons, one of them being racial and ethnic residential segregation, which has been linked to high rates of poverty. Hispanic-concentrated poverty has been associated with several factors we considered, including Hispanic segregation from non-Hispanic Whites. This is also consistent with past studies examining Hispanic poverty rates. Poverty rates undoubtedly contribute to the isolation of Hispanics and other minority groups, further exacerbating their underrepresentation in research. This geographic and socioeconomic segregation reduces their visibility to researchers and reinforces systemic barriers such as inadequate healthcare infrastructure, language obstacles, and a lack of culturally relevant outreach.

Even when Hispanics are included in research studies, there is often a lack of diversity within the studied subgroups. Mexican Americans, who make up the majority of the Hispanic population in the United States (62%), are disproportionately represented in these studies (Espinoza-Gutarra et al., 2022). This is true in both Zuckerman's studies, conducted in Oregon with a primarily Mexican community, and Rojo's research, which took place in a Mexican-populated area in Arkansas. Rojo's study had so many Mexican participants that they earned their own category (Rojo et al., 2024). While it is essential to include Mexican Americans in research, given their significant representation within the Hispanic American population in the United States, the overemphasis on this subgroup often leaves other Hispanic groups overlooked. This lack of inclusivity is problematic, as it risks homogenizing the diverse Hispanic population by grouping individuals from distinct cultural backgrounds, such as those with heritage in South America or the Caribbean, under a singular Mexican identity. These generalizations fail to account for the unique experiences, traditions, and healthcare needs of these underrepresented subgroups, perpetuating inaccuracies and limiting the effectiveness of research findings for the broader Hispanic community.

Furthermore, the use and interpretation of the terms "Latino" and "Hispanic" present another layer of complexity and contention. The disparities in clinical research trials among Hispanic/Latinx and other minority populations in the United States often stem from the underreporting of race and ethnicity among trial participants. Most Hispanic/Latinx individuals identify their Hispanic/Latinx ethnicity or country of origin as their racial identity, so classifications by race can mask the participation of Hispanic/Latinx and other minority groups. Similarly, classifying Hispanic/Latinx as one ethnic category is also problematic and raises concerns. Although the terms Hispanic and Latino/a/x are often used interchangeably, each has a different meaning and history and refers to different ancestral origins (Espinoza-Gutarra et al., 2022) Hispanic refers to people with heritage from Spanish-speaking countries in Latin America and Spain. By contrast, Latino/a/x relates to individuals with ancestry from Latin American countries, including non-Spanish-speaking groups such as Haitians and Brazilians (Espinoza-Gutarra et al., 2022). Therefore, the use of Hispanic/Latinx underestimates the diversity and heterogeneity of the population and its impact on cancer risk, health behaviors, and outcomes. Several studies examining ASD within Hispanic communities have used the terms "Hispanic" and "Latino" interchangeably, which may have influenced the accuracy and scope of representation, potentially overlooking Hispanic subgroups in the research.

Studies such as Rojo's also suggested increasing Hispanic representations in research studies such as academic/community partnerships and engagement through social media and traditional venues (Rojo et al., 2024). Social media platforms, in particular, have several benefits, such as accessibility, low cost, and rapid transmission throughout a wide community (Anderson, 2021)(Sledzieski, 2023). According to the Pew Research Center, in the realm of social media platforms, Blacks and Hispanics emerged as prominent users, with 74% and 72%, respectively, using Facebook in 2021, in contrast to 67% of Whites (Anderson, 2021). Hispanics have stood out as predominant users on various other social media platforms, notably Instagram and WhatsApp (Newsletter, 2024). Therefore, providing solutions to this issue is possible, especially with modern technology. Using social media as leverage to encourage Hispanic populations to take part in research studies may benefit the community greatly.

The Role of Cultural Perceptions in Delayed ASD Diagnosis

To gain a deeper understanding of how Hispanics in America perceive ASD, it is crucial first to examine how autism is perceived and understood within the cultural and social contexts of Latin America. According to the Latin American Spectrum Network, approximately 6 million individuals with autism spectrum disorder live in Latin America (Landale et al., 2006). Much of the perceptions from Hispanic Americans have deep cultural roots. In a book chapter titled Hispanic Families in the United States: Family Structure and Process in an Era of Family Change, a common theme that is widespread in studies of Hispanic families is the idea that Hispanics are characterized by familism (“familismo”) or a strong commitment to family life that is qualitatively distinct from that of non-Hispanic Whites. Although the term has been used in somewhat varied ways since that time, there is general agreement that familism entails the subordination of individual interests to those of the family group (Landale et al., 2006).

In Hispanic culture, a family does not just refer to the nuclear family but to the extended family as well. “Familismo” is a cultural concept deeply ingrained in Latin and Spanish societies. It emphasizes the central role of the family in an individual’s life. Family members are expected to prioritize their immediate and extended families above all else, and this value fosters strong bonds that endure throughout generations (Nick, 2023). As a result, Hispanic Americans often maintain regular communication with family members who remain in their countries of origin. This is especially true for Hispanic immigrants, as they are still deeply connected to their home country’s culture. This can include any previous perceptions or notions of new concepts that may present themselves in a new nation.

Interventions are cultural products containing underlying elements of the culture in which they were developed (Falicov, 2009). Because most parent-mediated ASD intervention models and strategies were developed in the US or UK (Green et al., 2017), many of these interventions likely contain features or elements that align well with shared cultural values in the US and UK. However, some of these qualities may be distinct from the cultural values of many Latin American families. Latin American individuals come from a large group of countries and regions geographical area. They speak multiple languages, including many dialects of Spanish and Portuguese, as well as dozens of officially recognized indigenous languages. Moreover, the Latin American population contains a range of cultural groups. Despite this, multiple studies have identified similar cultural patterns many Latin American cultural groups share (Blanche et al., 2015). These patterns may lead to conflicts between Latin American cultures and the cultural values embedded in parent-mediated ASD interventions developed within the dominant culture of the US or UK.

The limited research on autism spectrum disorder (ASD) in Latin America likely exacerbates the challenges faced by Hispanic families in the United States. For many, their initial encounter with the term ASD may occur only after arriving in the U.S., hindering early understanding and intervention. This underscores the urgent need for accessible Spanish-language resources to support these families and enhance community awareness. Providing culturally and linguistically appropriate information can help bridge this gap, ensuring that Hispanic families possess the knowledge and support necessary to navigate an ASD diagnosis with confidence.

Medical Mistrust and Stigma in Hispanic Populations

Medical mistrust is a critical barrier in ASD diagnosis and care for Hispanic populations, often stemming from historical and systemic injustices. If trust is lacking, essential information that could facilitate an ASD diagnosis or proper treatment may be delayed or overlooked. This disparity disproportionately affects minority groups, including Hispanics. Historically, Hispanic/Latino people in the U.S. have faced racial, ethnic, and anti-immigrant prejudice, including discrimination in employment, housing, and education (Feagin & Cobas, 2015). For example, in the 1920s, state and federal government sought to change the diets of Mexican American families in the U.S. based on the mistaken belief that traditional Mexican foods were less nutritious than standard American diets. This resulted in adverse effects on Mexican American health. Today, children of Mexican origin in the U.S. are more likely to experience obesity than other children in the U.S. and children who live in Mexico (Hernández-Valero et al., 2012). Moreover, discrimination and distress related to immigration policies, such as the Illegal Immigration Reform and Immigrant Responsibility Act of 1996 (Perreira & Pedroza, 2019), have led many people who live in immigrant communities to avoid interacting with public officials. As a result, many Hispanic/Latino people who are legally eligible for public health insurance coverage or health services do not enroll. These issues are more structural and can be challenging to dismantle. But these issues may also explain why medical mistrust may be prevalent in Hispanic populations, as many believe the healthcare system does not have their best interests in mind.

Minimal knowledge exists on the correlates of such medical mistrust amongst Hispanic populations. Bazargan and colleagues analyzed cross-sectional study data from the Survey of California Adults on Serious Illness and End-of-Life 2019 (Bazargan et al., 2021). The analysis was based on 704 non-Hispanic Black adults, 711 Hispanic adults, and 913 non-Hispanic White adults. They ascertained race/ethnicity, health status, perceived discrimination, demographics, socioeconomic factors, and medical mistrust. Their multivariate analysis shows that compared with non-Hispanic White participants, non-Hispanic Black and Hispanic participants had 73% and 49% higher odds, respectively, of reporting mistrust with healthcare professionals. Additionally, more than 53% of non-Hispanic White participants trusted their clinicians "a lot," compared with only 36% and 37% of Hispanic and non-Hispanic Black counterparts, respectively (Bazargan et al., 2021) They also found a strong association between medical mistrust and perceived discrimination, attributed to two factors: perceived discrimination based on race/ethnicity and language, and perceived discrimination related to income and insurance type or lack thereof. This survey revealed that many non-Hispanic Black and Hispanic participants reported being treated differently or were unable to access the healthcare services they needed due to their insurance type. This could also be potentially because only about 7% of US practicing physicians identify as Hispanic/Latinx (A. T. and M. H. Lopez, 2023). This suggests that Hispanics aren't represented enough in the healthcare system.

Since Hispanic populations often struggle within systems meant to support them, it becomes easier to shift the blame onto them rather than holding accountable those who designed and maintained these structures. The discussion section of Bazargan's study draws on implicit bias to explain this. Implicit bias refers to prejudicial attitudes toward and stereotypical beliefs about a particular social group or its members. Implicit bias is not routinely addressed in medical and residency education, and training specific to underserved and vulnerable populations is infrequent. Hagiwara and colleagues suggest developing and implementing successful implicit bias training must focus on three stages (Bazargan et al., 2021). The initial stage is identifying strategies driven by relevant theories to reduce implicit bias in general populations. The second stage involves the development of implicit bias training based on the findings in the first stage and to test its effectiveness with health care professionals. Finally, the third stage must evaluate the effectiveness of implicit bias training after it is adapted into the existing curriculum and training. Implicit bias training targeted specifically for Hispanic populations with mental disabilities would largely benefit the community. Reducing stigma in both groups would lead to more effective and productive treatment. Participants who work in related fields may also suggest policies during interviews, drawing from their professional experience, if any.

Alongside these structural barriers that make it difficult for Hispanic populations to receive adequate healthcare, there's also the issue of ASD stigma within the Hispanic-American community. Stigma describes prejudicial attitudes, negative stereotypes, and discrimination targeting a subgroup (Goffman, 2014). The targeted group often experiences, to varying degrees, the process of labeling, stereotyping, separation, emotional reaction, status loss, and discrimination (Zuckerman et al., 2018). While stigma is often perceived to come from outside groups, it can also come within groups. This can become a cultural-wide issue within specific groups. Although all families uniquely interpret children's behaviors, strengths, and weaknesses, their cultural backgrounds strongly influence their understanding of psychological concerns. For instance, non-White parents are less likely than White parents to endorse physical causes of developmental disorders or to use medical language in discussing their children's difficulties. Non-White parents of children with ASD endorse similar barriers to services as do White parents; however, the extent of and reasons for these barriers differ (Rivera-Figueroa et al., 2022).

There is often some overlap between Latino and Black American caregivers to those with autism due to similarities in socioeconomic status and cultural factors (Rivera-Figueroa et al., 2022). One such commonality is stigma. White families already may experience significant stigma, but this exacerbates the healthcare disparities for Black and Latino populations. Latinx and Black American parents of children with ASD are at a greater risk of experiencing stigma due to being a member of a marginalized group *and* having a child with ASD, a phenomenon known as *double disadvantage* (Rivera-Figueroa et al., 2022). Marginalized communities already face microaggressions and negative stereotypes, and the added challenge of a neurological disorder further increases the barriers they encounter in a predominantly white society. Many families, including those from minority backgrounds, embrace raising a child with autism. However, the primary concerns and stigma often stem from external societal factors rather than from within the families themselves. Past research with Latinx families indicates that stigma is a meaningful concern. Parents report that their communities often perceive disabilities as shameful and experience pressure to conceal their children's atypical behaviors and diagnoses. Family and community members may also question the credibility of the diagnosis (Rivera-Figueroa et al., 2022). This can deeply affect how families choose to seek out help. Moreover, they may be more inclined to believe that their loved one has a different, less stigmatized condition, which could result in the ASD diagnosis going untreated into adulthood.

Additionally, a quantitative study (Zuckerman et al., 2018) of stigma in Latinx families found that non-U.S.-born parents and those with limited English experienced more significant stigma than White parents; stigma was also associated with poverty and greater symptom severity. Greater stigma was related to unmet treatment needs, controlling for the amount and type of treatment, suggesting that stigma has a significant impact on the quality of care. Latino families likely experience more stigma when providers are unprepared to interact with families of marginalized backgrounds and when language barriers are present (Zuckerman et al., 2018).

The interplay of cultural stigma and healthcare-related stigma creates significant barriers for families. These challenges prevent open discussions about ASD symptoms and delay access to appropriate care. Cultural stigma must be confronted within communities, and progress starts with increased education on the issue. Reducing the stigma surrounding mental disorders requires ongoing education and open discussions. Normalizing conversations about mental health can help lessen the perception of these topics as taboo, fostering wider understanding and acceptance.

Centering Culture in Autism Research to Address Systemic Gaps

In general, caregivers of children with ASD report higher levels of stress compared to parents without ASD. This can be due to various factors mentioned previously. The COVID-19 pandemic likely exacerbated these stressors. According to Colizzi, 78% of caregivers have reported difficulties in managing their children's free time and have observed increased intensity and frequency of their children's challenging behaviors since the beginning of COVID-19 (Colizzi et al., 2020). That's why it's essential to continue looking at this issue even after the pandemic, as there could be lasting consequences. Especially since Hispanic caregivers would likely face more stressors as well. Most evidence-based AS) interventions are tested with primarily White, middle -upper class, English-speaking populations, despite the increase in Latino children with ASD in early intervention programs throughout the United States.

Latine caregivers of recently diagnosed children on the autism spectrum have unique needs and face unique challenges in supporting their children. Latine families report feeling overwhelmed, confused, and concerned with information about the incidence of autism, the complexity of the diagnosis, and how to approach advocacy and support (Minot, 2023). Even once autism intervention is secured, there are still several barriers that may bar Hispanic families from receiving the proper treatment they deserve. These caregivers report limited direct coaching models within this system of care (Hampton et al., 2023), perpetuating the cycle of disparity. Given the limited cultural and contextual fit of interventions and the unique needs of the Latine population, significant adaptations are needed in terms of delivery, therapeutic process, inclusion of cultural knowledge, attitudes, and behaviors to make evidence-based practices more culturally appropriate. Although this work is promising, research in this area is limited to teaching direct strategies to caregivers and most cultural adaptations continue to rely on surface-structure adaptations, or changes to the materials, messages, and format of intervention delivery, as opposed to changes to the core components of the intervention that are thought to produce change outlined in the EVF framework (Minot, 2023).

There is evidence to suggest that cultural humility is important when addressing ASD. ASD is cross-cultural, and that is something ASD assessments should consider. Regilda Romero, a clinical Assistant Professor at the University of Florida’s Center for Autism and Related Disabilities, addresses cultural considerations as an important part of autism evaluations. Romero says, “Cultural sensitivity in assessments, in general, is important because context matters. When I say that context matters, I am thinking about a host of multicultural factors that may be affecting the presenting problems. While we still must look at the DSM-5-TR in terms of the ASD criteria, how we view some of these symptoms may be influenced by their context” (Stanborough, 2023. Romero recommends making autism evaluations more culturally adaptive by working within a cross-cultural framework. Additionally, she believes multicultural assessments are imperative in the diagnostic process as specific cultural factors should be considered. For example, for many Chinese children, avoiding eye contact with adults is considered a mark of social respect (Hus & Segal, 2021). Therefore, when evaluating eye contact, which is often considered in ASD diagnosis, cultural context may be crucial to avoid a misdiagnosis. Another example is Ethiopian children. In Ethiopia, social greetings are a matter of tradition. Greeting someone formally might be considered a positive social skill rather than a scripted or ritualized behavior or a communication deficit. When Ethiopian parents seek an autism diagnosis, social interactions are much less likely to spark their concern than other behaviors (Zeleke et al., 2018). A cross-cultural framework would benefit not only these families but also those in healthcare involved with the ASD diagnostic process as it would ease confusion.

While it is essential to have the support of the healthcare system, change cannot be made without community efforts as well. At the community level, increasing autism knowledge and resources via social media outlets and through on the ground methods such as handing out information at school and community events can reduce stigma and increase understanding of autism. Spanish and English information about autism should be made available at these events to enhance inclusivity. By increasing acceptance and understanding of autism, more Latino families may begin to seek diagnostic services and support (K. Lopez, n.d.). Therefore, it is. important that the Hispanic community works alongside healthcare professionals to make the ASD diagnosis process and treatment better.

The reviewed literature underscores significant disparities in autism research among Hispanic populations, highlighting recurring issues such as underrepresentation, cultural stigma, and medical mistrust. It also emphasizes the critical importance of incorporating cultural competence into healthcare practices. Despite increased awareness, there remains a substantial gap in understanding the nuanced cultural perceptions of autism within Hispanic communities and their impact on diagnosis and intervention efforts. This study aims to address these gaps by exploring the lived experiences of Hispanic families affected by ASD, with a particular focus on cultural perceptions and community-based approaches to care. It will also analyze how the healthcare system interacts with these communities and the potential mismatch between them. By bringing these cultural perspectives to light, this research seeks to inform culturally competent practices in ASD care and contribute to reducing healthcare disparities in underserved populations.

Methods

This research study was designed to address the significant gap in ASD research among Hispanic populations by employing an ethnographic approach. Inspired by studies such as Zuckerman's, it focuses on identifying the barriers Hispanic families face when seeking an ASD diagnosis and navigating the post-diagnosis process. Through qualitative methodologies, including in-depth interviews and participant observations, the study aims to capture the lived experiences of Hispanic families and explore the cultural, systemic, and socioeconomic factors influencing these experiences.

A total of seven participants were interviewed for this study. The participants included Hispanic parents, guardians, and relatives of individuals diagnosed with ASD. The age range of the participants spanned from 20 to 40 years, allowing for diverse perspectives based on varying roles within the family and generational differences. This range facilitated a more comprehensive understanding of how autism is perceived and managed within Hispanic families. Most participants were recruited from Georgia, where the study was conducted, while one participant resided in New York, which was done via Zoom. Given the geographic focus, recruiting participants locally in Georgia was logistically more feasible.

All participants self-identified as Hispanic and self-reported that they had a relative diagnosed with ASD. Ethnicity data was collected to provide more detailed demographic insights and ensure representation beyond the dominant Mexican population, which comprises the largest group of Hispanics in the United States. This deliberate inclusion of a diverse Hispanic population aimed to account for cultural nuances across different national backgrounds. The most common relationship observed among participants was that of a mother and her son diagnosed with ASD. This is consistent with trends showing higher diagnosis rates of ASD in boys compared to girls, and it reflects the relative ease of recruiting mothers, who are often primary caregivers. By including participants from varied familial roles and national backgrounds, the study sought to capture a richer and more nuanced picture of how autism is understood, managed, and experienced within Hispanic communities, which are, again, characterized by Familismo.

Participants for this study were recruited through the Marcus Autism Center, located in Atlanta near Emory University, and the focus was on Hispanic individuals who met the study criteria and expressed interest in participating. Following the guidelines approved by the IRB for this expedited study, no cold calls or unsolicited communications were made to potential participants. Instead, recruitment was facilitated by personnel who worked for the center. They provided initial contact with prospective participants and offered detailed explanations of the study. One speech pathologist at the Marcus Autism Center played a significant role in recruitment by connecting me with two individuals who had siblings diagnosed with autism. She also introduced the author to a mother who managed a Facebook group for mothers of children with ASD. A recruitment flyer was sent to this mother, who shared it with members of the group. The author did not directly access the Facebook group to maintain ethical boundaries.

The recruitment flyer explicitly stated that the study aimed to explore community perceptions of ASD, and the barriers faced before, during, and after the diagnostic process. It clearly outlined the eligibility criteria for participation, which included being between the ages of 20 and 60, self-identifying as Hispanic, and having a connection to or being a relative of a Hispanic individual diagnosed with ASD. All information provided by participants was self-reported, and since no medical records were collected, the study did not fall under HIPAA regulations. The flyer also informed participants that interviews could be conducted via Zoom or in person, depending on their preference, and that focus groups could be arranged if applicable. It emphasized that this was an Emory University research study and did not offer any form of compensation, underscoring the voluntary nature of participation. Interested individuals were encouraged to contact the primary researcher for further information via email at helen.andrade@emory.edu, with a phone number also provided for those who felt more comfortable reaching out by phone. A significant number of participants chose to contact the researcher by phone. Eligible participants were encouraged to refer others who met the study criteria to expand the participant pool. Proof of an autism diagnosis was not required, ensuring the process remained accessible and respecting participants' privacy.

The interviews were conducted in a semi-structured format, allowing for flexibility while ensuring key topics were addressed. Most participants opted to complete the interviews via Zoom due to convenience and time considerations. At the beginning of each session, the researcher briefly introduced her ethnicity, educational background, and personal motivations for conducting the study. Drawing on strategies used in prior research, she aimed to establish a warm and approachable environment for participants. This was especially important given the documented mistrust toward researchers within Hispanic communities, often rooted in fears of exploitation. To address these concerns, the researcher emphasized that the study's purpose was to support and uplift the community rather than solely serve academic goals. This reassurance was particularly relevant for Spanish-speaking participants who may have been less familiar with research processes. The researcher made a concerted effort to be patient and thorough when explaining the study's purpose and scope, ensuring participants felt informed and at ease. She clarified that the research was part of an undergraduate honors thesis and that all data would remain within Emory University's Department of Anthropology database. Participants were given an overview of the interview questions and an estimated time commitment to help them plan accordingly. Verbal assent was obtained by reading the IRB-approved consent form aloud in English or Spanish, depending on the participant's preference. After each interview, the researcher invited participants to ask questions about the study to promote transparency and trust.

Participants were asked questions about autism and their prior knowledge of the disability. The interview questions specifically explored how participants' cultural backgrounds shaped their understanding of autism and influenced their responses to a loved one's diagnosis. Participants were also asked to describe any barriers they encountered in their families, communities, or the healthcare system when pursuing an ASD diagnosis. The interviews followed a set of 12 main questions, though the semi-structured format allowed the researcher to adapt the flow of the conversation. Depending on the participants' responses, the researcher occasionally omitted questions or posed additional follow-ups to explore emerging themes. Despite these adjustments, all interviews remained grounded in the study's central objectives. To protect participant confidentiality, pseudonyms were assigned to each individual. Participants could either choose their pseudonyms or have one selected by the researcher. Audio recordings of the interviews were transcribed using Microsoft Word's transcription tool, after which the researcher carefully reviewed and refined the transcripts for accuracy and clarity. Once the transcription process was complete, all audio files were permanently deleted in accordance with ethical research guidelines to maintain participant confidentiality.

The researcher transcribed all interviews using Microsoft Word, maintaining the original language used by each participant. An inductive thematic analysis guided the data interpretation process. After becoming deeply familiar with the transcripts through multiple readings, the researcher identified recurring patterns across participants' experiences. These patterns were grouped into key themes that aligned with the study's objectives. Particular attention was given to meaningful responses and illustrative moments, and relevant quotes were selected to highlight each theme.

Despite the relatively small sample size of seven participants, the coding process was time-intensive due to the rich, nuanced dialogue in each interview. The researcher created a demographic table outlining participant characteristics to understand the sample's composition better. Among the participants, only two were of non-Mexican descent (see Table 1). All were female, and only two were not mothers. One participant from New York identified as mixed-race, making her the only participant with a multiracial background (see Table 1). These demographic details indicate that most perspectives shared in the study reflect a predominantly Mexican cultural lens. As a result, commonalities emerged regarding perceptions of autism in Mexico and the lack of available ASD-related resources. The researcher accurately identified each participant's ethnicity to ensure correct subgroup assignment and maintain cultural specificity in the analysis.

Pseudonym of Participant	**Ethnicity**	**Age**	**Gender**	**State of Residence**	**Relation to Autistic Individual**
Adela	Mexican American	22	Female	Georgia	Older sister of a girl with ASD
Orchid	Mexican American	23	Female	Georgia	Older sister of a girl with ASD
Melina	Mexican	Mid-40s	Female	Georgia	Mother of a son with autism
Ally	Puerto Rican/ German	Mid-40s	Female	New York	Mother of a son with autism
Suzie	Mexican	46	Female	Georgia	Mother of a son with autism
Kelly	Honduran	44	Female	Georgia	Mother of a son with autism
Lia	Mexican	41	Female	Georgia	Mother of a son with autism

Table 1. Participant Demographic Information

Results/Analysis

This section presents the key findings and recurring themes that emerged from the interviews. To ensure clarity and coherence, these findings were categorized into 5 major themes consistently observed across multiple participants. Each theme highlights the shared experiences, challenges, and perspectives of Hispanic families navigating autism diagnoses, healthcare systems, and cultural attitudes.

Theme	**Description**
1. Limited Awareness of ASD and Stigma Within the Community	Many participants reported little to no knowledge of autism prior to diagnosis. Misconceptions, stereotypes, and stigmatizing language (e.g., "loco") were common, often leading to shame, denial, or delayed recognition of symptoms.
2. Barriers to Healthcare	Language barriers, lack of cultural competence among providers, and long waitlists made accessing care difficult. Many families received little guidance post-diagnosis and struggled to find affordable, supportive services.
3. Struggles within the Education System	Schools were often unwilling or unequipped to support children with ASD, especially if symptoms weren't visibly severe. Participants described dismissive attitudes, lack of accommodations, and a need for more informed educators.
4. Gender Roles in ASD Care	Caregiving responsibilities primarily fell on mothers, with limited involvement from fathers. Cultural expectations around masculinity and caregiving shaped how families navigated diagnosis and treatment.
5. Fear for the Future and Long-Term Independence	Parents expressed deep anxiety about their child's future independence, safety, and quality of life. This fear was often heightened by limited ASD awareness and lack of visible representation within the Hispanic community.

Table 2. Summary of themes

Limited awareness of Autism and Stigma Within the Community

Most participants were unfamiliar with ASD before their loved one was diagnosed. One participant, who had prior experience working with children with developmental disorders, had some understanding of autism. This participant, referred to by the pseudonym Ally, stated, "I was familiar with it because I worked with disabled kids when I worked on a farm. I was the one who actually thought my child was autistic by the time he was one year old." However, Ally acknowledged that awareness of ASD is limited—not only within the Hispanic community but more broadly. She noted that, despite her familiarity with autism, she does not personally know anyone else with a child diagnosed with ASD. She states,

> I think that people's perception of autism is usually more of a severe nature. You know, they mean like when they picture autism. They picture kids who are nonverbal or who have a lot of stimming or whatever. I think that their perception of what autism is is very skewed. There's a reason why it's a spectrum, and that's something I have to explain a lot. There are other people that I don't. I don't really get like a lot of like advice like I personally don't have any friends who has a child on the spectrum So no one really. advice to you know what I mean.

Ally recognized that, in general, there is an issue with a lack of awareness of mental disorders in the Hispanic community. Ally stated that people within the Hispanic would rather ignore a problem than put a label on it. She states,

> What I have learned is that in the Hispanic community, they will ignore it rather than have their child have a label. I've heard this from other parents in therapy groups too—it's a big thing in the Spanish community and also in the Black community. The church community ignored it, too. My dad told them, 'He doesn't like to be touched, please don't hug him,' and they still hugged him. They just didn't care.

Ally believes in confronting the issue directly and assigning a label to it rather than avoiding it altogether. Additionally, she clearly values open discussions about ASD. Another participant, Lia, was familiar with ASD because a family member had already been diagnosed.

Lia states, “I was already familiar with autism because I have a 15-year-old nephew who was diagnosed in the U.S. He is my older sister’s son, so I learned a little about it through him.”[1]. Before Lia’s own son was diagnosed with ASD, her older sister had to navigate having a child with autism for the first time. Lia’s family had to undergo this process with two family members and seemed informed about her nephew’s treatment as well. Lia gave a brief insight into that by saying,

> At first, I thought my nephew was just fragile because he was born premature, and my sister was always very protective of him. When he threw tantrums, we assumed he was just spoiled. We used to say, ‘He just needs discipline,’ because that's what many Latino parents think when a child behaves differently.[2]

There was a range from how limited their knowledge on ASD was. A participant, Suzie, was very transparent about how limited her knowledge was of ASD, especially because, in her home country, it wasn’t talked about enough. Suzie states,

> Nothing, I was very ignorant. When I was younger in Mexico, I saw a commercial about autism. They showed a child staring at a fan and said that autistic children live in their own world. My idea of autism was that children would never speak or interact with anyone.[3]

Another participant, Melina, echoed similar experiences, as both women were originally from Mexico. Melina states,

> I had never heard the word autism in Mexico. There was a boy in my neighborhood who had a disability, but people just said he had 'mental retardation.' In elementary school,

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[1] Ya estaba familiarizada con el autismo porque tengo un sobrino de 15 años que fue diagnosticado en Estados Unidos. Es hijo de mi hermana mayor, así que aprendí un poco sobre ello a través de ella

[2] Al principio, pensé que mi sobrino era simplemente frágil porque nació prematuro, y mi hermana siempre fue muy protectora con él. Cuando hacía berrinches, asumíamos que solo estaba malcriado. Solíamos decir: "Solo necesita disciplina", porque eso es lo que muchos padres latinos piensan cuando un niño se comporta de manera diferente.

[3] Nada, era muy ignorante. Yo en México, cuando estaba más chica, vi un comercial sobre autismo. Mostraban a un niño mirando un ventilador y decían que los niños autistas están en su mundo. Mi idea del autismo era que los niños nunca iban a hablar o interactuar con nadie

> they told us that in Roman culture, babies with disabilities were thrown from the mountains. That left a mark on me[4]

Another participant, Kelly, had very little knowledge of ASD and did not fully understand its implications for her family. Kelly states, “I was somewhat familiar with it, but not 100%. When we received the diagnosis, it felt like a bucket of cold water. Psychologically, I was not prepared for this to happen in my family”[5]. From the limited information she did have about ASD, she initially perceived it as something negative.

Due to their limited knowledge of ASD or initial negative perceptions, many families experienced feelings of stress and parental failure upon their loved one's diagnosis. Some parents believed they could have done something to prevent their child from developing ASD, leading to guilt, self-blame, and emotional distress. The lack of accessible information and resources often intensified their feelings of helplessness, making it even more difficult to navigate their child’s needs and seek appropriate support. A participant referred to as Adela had a sister with ASD. While she initially did not know much about the condition, her perception of it was negative. She states, “Autism was something to be scared of… like a big, kind of, ‘that’s how I understood what autism was.’” Similar to how other mothers who participated in the study felt, Adela recalled that her own mother was devastated when her daughter was diagnosed with ASD. Adela’s family is Mexican, and she emphasized that her mother had little knowledge of ASD. She states,

> When my sister was diagnosed, my mom was crying so much… I thought she had cancer or something. My mom said, ‘I tried so hard to prevent this from happening. I feel like I failed as a mom.’

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[4] Nunca había oído la palabra autismo en México. Había un muchacho en mi barrio que tenía una discapacidad, pero la gente solo decía que tenía ‘retraso mental’. En la primaria, nos contaron que, en la cultura romana, los bebés con discapacidades eran arrojados desde las montañas. Eso me marcó.”[4]

[5] Estaba un poco familiarizada, pero no al 100%. Cuando nos dieron el diagnóstico, fue como un balde de agua fría. Psicológicamente no estaba preparada para que esto pasara en mi familia

Alongside their perceptions of ASD, families also faced stigma from their community. Another participant, Orchid, stated, “Some of my family members would say, ‘But she doesn’t look autistic.’ They would confuse autism with Down syndrome because they thought disabilities had to have visible physical traits.” Similarly, Suzie noted that most people she spoke to in the Hispanic community often mistook ASD for Down syndrome, as the latter presents with more noticeable physical characteristics. She states, “With children who have Down syndrome, people are more understanding because they can see it physically. But autism isn’t visible, and people judge.” These statements suggest that the Hispanic community may find it easier to empathize with conditions with more apparent physical traits.

Adela also recalled that when her sister was first diagnosed, people didn’t know how to act around her. When asked further, she stated,

> Yeah, it was definitely still, like, avoidant for sure. Like they would kind of just like step around it like they. They weren't really sure how to think, like, talk to her or like, treat her just because, like, the way. She is verbal in the way that she can, like, communicate and she can speak. But like she doesn't like if you're. ‘Hi, how's your day?’ She's not going to say good, you know, but she is able to still communicate.

It was either that reaction or that they pitied her sister deeply. She recalls,

> And I would tell like family members or even like my ex-boyfriend at the time, ex for a reason. He would be like I remember those responses that were like. Oh my God, no. I'm so sorry. Like a lot of, like pity and just like you guys will get through it, like, almost as if it was like a disease.

The most common phrase the Hispanic community used to describe individuals with ASD was “locos” or “crazy.” Melina highlighted this when expressing her frustrations about how others perceived children with ASD. To gain a deeper understanding of the community’s perspective, she conducted a survey, asking Hispanic community members what ASD meant to them and assessing their level of awareness. She states,

> Surveys, well, surveys, but I tell them to write it down on this little piece of paper. Who do you think it applies to? What is autism? Some people don't write anything, some have written that it is a disease, others have said that it is a delay, or that it is the sick children or the children who are crazy[6].

Kelly echoed a similar sentiment, stating that it hurts her when people dismiss those with ASD as "crazy." She states, "Tell me if it's because I have attended many events and heard many people, and it deeply hurts my heart because they say that autistic children are crazy[7]." Kelly also mentioned she had never heard the term "autism" in Honduras but looking back she recalls that she might have known children in Honduras who might have had ASD but it was never discussed. She states,

> I had never heard about it over there. It wasn't until recently that I found out my former boss has an autistic son and that a friend from university does as well. Then another girl I know also mentioned it, and that's how I started hearing more about it. But still, only a few people talk about it because most just say, 'Oh, those kids…' Even a former classmate once told me, 'I know one, and that one even talks to trees.' Basically, as they say in Honduras, they think they're crazy[8].

Lia said that this label of "loco" is likely what causes many parents to be apprehensive about bringing their child to see a specialist. She believes that there's not only a stigma with having a child with a mental disorder but also with getting help from a psychologist and therapist as well. She states,

> I believe that parents, when they have the right information, can be more aware that something is happening. What are some examples? We need to remove the taboo of closing ourselves off. 'My child has nothing, my child is fine.' For example, if someone

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[6] Encuestas, bueno, encuestas, sino que les digo escríbeme en este papelito aquí. ¿A quién tiendes? ¿Qué es el autismo? Hay unos que no me escribe nada, hay unos que me han escrito, es una enfermedad, hay otros que me han puesto que es este un retraso o son los niños enfermos o los niños que están locos

[7] Dígame que es porque andaba muchas veces muchos eventos y he escuchado muchas personas y me duele mi corazón profundamente porque dicen que son niños locos

[8] Nunca lo escuché. Allá. Hasta hace poco me enteré que mi ex jefe tiene un hijo autista y una amiga que era la universidad también. Luego otra muchacha que conozco y así ya me he ido. Rodeando ya y son las pocas personas que me hablan porque no dicen, Ay, es que esos niños, incluso un ex compañero en el Colegio, me dice, yo conozco uno y ese hasta los palos, resumen como dicen allá en Honduras y se están loco

> tells you, 'Does your child need psychological therapy?' The response is often, 'No, my child is not crazy, why would I take them to a psychiatrist? Why would I take them to a psychologist? My child is not crazy.' But no, again, it's not just crazy people who go to a psychologist. It's not just crazy people who go to a psychiatrist. These children need emotional support. Sometimes, if parents don't feel comfortable discussing these things, then why is there so much suicide?[9]

Lia suggests that when parents refuse to acknowledge a problem, it harms a child more than good. She emphasizes how important it is for a child to have emotional support. She believes there should be no shame in seeking help from a professional. While Lia was more open to educating others, Orchid expressed feelings of frustration with having to do that as she believes not everyone is open to understand ASD. She states,

> And I have this mindset of like if people don't want to listen or aren't empathetic, then there's no point in educating them or further seeking interactions or connections or relationship with them so. I guess the people that we do surround ourselves are very understanding of that.

Having a supportive community can make it easier for families of individuals with ASD, helping them feel less alone. However, some participants had greater access to this support than others. In Kelly's case, she was part of a religious community that lacked understanding of ASD and had no prior knowledge of what her son's diagnosis meant. She states,

> Basically, most of my husband's family are Evangelicals, and their religious beliefs are very strong. They think that what the child has are demons, but that's not the case. So, there is still a need to continue raising awareness. One can try to explain, but you know that religious beliefs are often stronger than anything we can say.[10].

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[9] Pues yo creo que los papás, pues teniendo la información podemos estar más alerta de que hay algo que está pasando. ¿Y a qué ejemplos? Quite ese tabú de de de de cerrarnos en. Mi hijo no tiene nada. Mi hijo es como por ejemplo. Si te dicen es. ¿Que tu hijo necesita terapia psicológica? ¿No, mi hijo no está loco, cómo lo voy a llevar a un psiquiatra? ¿Cómo lo voy a llevar a un psicólogo? Mi hijo está loco. No, nuevamente no solamente un loco va a ir a un sicólogo. No solamente un loco va a ir a un psiquiatra, o sea, necesitan estos niños necesitan apoyo emocional. ¿A veces con los papás no se van a sentir a gusto decirnos las cosas, pero por qué? ¿Hay tantos y suicidio?

[10] Básicamente, en la mayoría de la familia, mi esposo son evangélicos y sus creencias religiosas, son bien fuertes. Piensan que son demonios los que el niño tiene pero no es así. Entonces habría que seguir concientizando, pues uno habla, pero usted sabe que son más fuertes las creencias religiosas de ir que lo que uno logra explicar

Lia also felt uneasy and uncomfortable in religious settings. She states,

> For me, misinformation is what leads us to do things we shouldn't do. It's like they say in Church, *'An ignorant Catholic is a future Protestant,'* because sometimes we don't even know what we're doing or what we believe in. And the same applies to baptism—an ignorant parent won't be able to help their child, right?[11]

Lia points out the hypocrisy that religion may present and while religion is supposed to be a source of comfort for many people can be stressful when presented with an unfamiliar situation.

Barriers to Healthcare

Obtaining an initial diagnosis was challenging not only due to community perceptions but also because of systemic barriers within healthcare and unhelpful providers. Every participant faced obstacles when seeking a diagnosis or even basic information. Adela recalls that White practitioners, particularly those lacking cultural competence, often struggled to understand the situation fully. She states,

> Yeah, I think I saw it the most with therapies… or even kind of just like having like, I don't know, having white practitioners in the home is just, like, awkward. I think there's always kind of just like this, like an unspoken barrier, especially when they are, like, providing her care. Like, even if they were like the best people in the world, it was still just like, well, you don't know what she's saying.

The lack of Spanish-speaking healthcare providers presents a significant barrier to effective communication for patients and their families, often leaving them without crucial information and support. Adela's sister suggests that cultural differences may have contributed to delays in her diagnosis, leading to misinterpretations by practitioners. She states, "Like, the diagnostic process… I'm sure that she was talking a lot more… like showing more things that they just

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[11] Para mí sí. La desinformación es la que la que este, la que nos lleva a hacer cosas que no debemos hacer. Sí como como nos dicen a nosotros en la Iglesia este católico ignorante, futuro protestante, porque a veces no sabemos verdad lo que haces, lo que profesamos. Y así en el bautismo, o sea, papá ignorante. No va a poder ayudar. ¿A su hijo, podríamos decirlo en este caso, no?

didn’t account for, just because it was, you know, cultural stuff.” Similarly, Orchid expressed concerns about the post-diagnosis experience, noting that their family was provided with little to no information following the diagnosis, further exacerbating feelings of uncertainty and isolation. She states,

> Once we got the diagnosis, they didn’t really give my mom any resources. Just some suggestions on what type of therapy she may need, but we mostly needed the diagnosis to further develop her 504 plan for school. Honestly, they didn’t give my mom a pamphlet or anything on services. It was mostly me figuring out, ‘Okay, now she has this diagnosis—what can we do next?

In Orchid’s case, the healthcare incompetencies ended up leading to a delayed diagnostic process even though the family knew Orchid’s younger sister had ASD from a very early age. She states,

> She was officially diagnosed at the age of 10. She's 11 now, but we knew she had autism. She was first diagnosed with global developmental delay at the age of 2 and a half. But we knew that she had autism. It was autism.

Orchid also mentioned that even though they had a bilingual physician, the physician did not believe the family when they suspected her sister had ASD. This suggests that cultural differences may have also delayed the diagnostic process. She states,

> We did push a lot on the physician… He was the only bilingual physician in our area. And we kept insisting, 'Can you please send a referral for an autism diagnosis?' And he would be like, ‘She’ll grow out of it. Finally, he did send a referral, and she got diagnosed with autism.

Even after receiving the referral, Orchid’s family faced significant challenges in communicating with the psychologist due to the language barrier, as the provider did not speak Spanish. She acknowledges that access to translators has improved over time, noting that such resources were far less common in the past. She states,

> A bilingual physician did not diagnose her. It was an English-speaking psychologist. There were no translators back then. Now there are more. And I think, 'Wow, at least kids don’t have to translate for their parents anymore.' But back then, my mom didn’t really have any help.

Adela also observed that, in general, individuals with ASD face long waitlists and limited access to essential services. She states,

> I was in some webinar the other day with caregivers of autistic kids, and they were just like, 'The Emory Autism Center waitlist is another four years,' and it’s just like, well. Even just getting her formally diagnosed… I think it happened maybe in December that year, but even that in itself was still a really long time to wait.

The road to a diagnosis wasn’t easy for Adela, but the post-diagnosis journey was not easy either, as the family felt they didn’t have a lot of information on the proper services they needed. She recalls,

> When she was diagnosed, I remember the doctor just handed my mom a pamphlet and was like, 'OK, call this place to schedule a formal diagnosis.' But then depending on where they direct you, there’s this therapy or this other speech therapy clinic. He didn’t say it, but you could tell he was implying that there was a huge waitlist for everything.

Most recently, Orchid stated that they still have trouble struggles accessing therapy due to scheduling conflicts and that some therapists would change locations.

> My sister started receiving occupational therapy this past year, but they kept canceling her appointments because the occupational therapists would quit and go to work somewhere else. That happened like three or five times. It was always a different person, so it was hard for her to build any stability with therapy.

Kelly noted that some clinics were not meeting her son's needs. She recalls feeling that the evaluator lacked sensitivity toward her son's specific requirements. She states

> So we ended up in Atlanta, at the Autism Center, because I had taken him to a place in Duluth, and he didn’t connect with the person there. He just cried and cried because the

> man scared him. He pulled out a super thick book for him to answer all these questions, but my son didn't speak during the evaluation.[12]

From a mother's perspective, Melina believes that parents would benefit from mental health support when their child receives an ASD diagnosis. She states, "Before the diagnosis, parents should receive psychological support. It's hard to accept the diagnosis, and without help, many don't accept it.[13]" Melina also noted that the language barrier was the most significant obstacle in obtaining a diagnosis. However, she expressed gratitude for the interpreters who assisted her throughout the process. She states,

> Well, of course, the main barrier I feel was the language. I don't speak English to this day… but I was always given interpreters. Thank God I've always had interpreters, but it's not the same because there are things you want to say directly, and they don't always get conveyed the same way[14].

If there weren't issues with language barriers pediatricians be dismissive of parents' concerns. This was the case for Ally. She states,

> I thought my child was autistic by the time he was one year old. I asked the doctor about it… and they just ignored it. I switched pediatricians three times until I found one who believed me. Every time I brought up concerns, the doctors would say, 'Oh, he's a boy. Boys are different from girls. He'll grow out of it. They would say, 'Come back in a year.' And I would come back in a year, and I would say, 'He's got even more behaviors now,' and they'd still brush it off.

The constant denial of looking more closely into her son's symptoms delayed the diagnosis, despite Ally knowing her son had ASD. However, she felt fortunate to have access to

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[12] Entonces terminamos en Atlanta, Centro de Autismo, porque lo había llevado a dormir hermoso en Duluth y él no conectó con la persona. Que se lo hice. Solo lloraba y lloraba porque el señor lo asustó. Sacó un libro súper grueso ya que le contestara todo eso, mi hijo no habla en la evaluación.

[13] "Antes del diagnóstico, los padres deberían recibir apoyo psicológico. Es difícil aceptar el diagnóstico, y sin ayuda, muchos no lo aceptan.

[14] Bueno, claro, la barrera en sí que yo siento que sí fue el lenguaje. O sea, te digo, yo no hablo inglés hasta la fecha, no he podido hablar inglés… pero siempre me han puesto intérpretes. Gracias a Dios siempre he tenido intérpretes, pero no es lo mismo porque hay cosas que uno quiere decir directamente y no siempre se transmite igual

insurance, which alleviated the financial burden of treatment for her family. She notes, “Luckily, my ex-husband’s insurance had an autism unit at United Healthcare. They covered almost everything, and I only had to pay small copays. We also paid out-of-pocket for sensory therapy, which was crucial for him.” Ally acknowledged that many families are not as fortunate and may struggle to access the necessary resources for their children.

However, Suzie stated that while she didn’t have financial burdens because she had access to insurance, she knew of other Hispanic families who did. She stated, “I have known cases of children who are not from here, who were not born here, who do not have insurance, and even though the school tells them they have a diagnosis and everything, the parents cannot take them to therapy because it is too expensive[15]” So even if the participants weren’t directly affected, they were aware of other families who were struggling financially to cover treatment plans.

Financial factors are not the only reasons for access to therapy as it can be a variety of issues. Kelly states, “For example, right now, I am struggling with therapy because I can’t find a place. Either it’s too far, or it conflicts with the school schedule or other therapy appointments. Everything becomes complicated.”[16] In Lia’s case, the language barrier was a big issue as she felt that removing the language barrier would make scheduling easier. She states,

> Yes. Yes, it interferes a lot. I say this because, as someone from another country who doesn’t speak the language, you need intermediaries, like a translator, to help you make an appointment or understand things correctly. So yes, it makes things more difficult because it’s not as fast as just sending an email or writing something yourself. Sometimes, just to get someone to answer in Spanish… if you select the Spanish option to speak with someone, it takes much longer. So sometimes I just choose the English

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[15] Yo he conocido casos de niños que no son de aquí, que no nacieron aquí, que no tienen seguro y pues aunque en la escuela sí les dicen que tienen un diagnóstico y todo los papás no los pueden llevar al a las terapias porque es muy caro.

[16] Nosotros no, por ejemplo, ahorita yo estoy batallando con la terapia y bien y no encuentro dónde, porque luego que queda muy largo, luego que el horario en la escuela, el horario de las otras terapias, todo michoacán, entonces.

> option, even though it's harder for me to understand because if I wait for them to assist me in Spanish, it will take too long[17].

Lia feels compelled to communicate in English despite her limited fluency. Although she prefers not to, she is willing to do so if it expedites the process.

Struggles within the Education System

Alongside barriers to healthcare, participants also discussed significant struggles within the education system. Many parents expressed frustration, as schools often resisted providing the necessary resources for their children, adding another layer of stress to their experiences. Adela recalls noticing from a young age that schools failed to support children with ASD, a problem she observed adequately was even more pronounced for students of color. She remembers one specific boy who exhibited ASD-related behaviors, even though she was unfamiliar with ASD at the time. She states, "He could speak Spanish, and obviously I can speak Spanish, and he was Hispanic, and I was Hispanic, and it's just like, yes, I like to talk to him here and there. But when that like situation was happening, I wasn't by him at all like his aid was right next." The situation she refers to is when he would experience breakdowns. She states,

> The first time he had a crisis they had no idea how to react. But when the other like, not even like autistic, but just like when the other students with disabilities that were white, like when they would have like breakdowns and stuff like the reaction was more automatic right away, okay. Here's the issue"

Adela was also frustrated at the lack of transparency the teachers gave to their students regarding other students who had physical or mental disabilities. She states,

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[17] Sí. Sí, interfiere mucho. Le digo porque uno como persona de otro país, pues es que no habla el idioma uno necesita intermediarios, por ejemplo, el traductor que te ayuden para hacer la cita o para entender bien. O sea, sí interfiere más, porque no es tan rápido como cuando tú mandas un correo electrónico o escribes algo. Nada más a veces para que te conteste alguien en español… si tú pones la opción en español para hablar con alguien, tardan mucho más. Entonces a veces mejor pongo la opción en inglés, aunque me cueste más entender, porque si espero a que me atiendan en español, me va a tomar demasiado tiempo

> When something like that happened like the like, the school teacher would, she would never like talk about that this happened or whatever, but I remember multiple teachers wouldn't like would never sit down and be like, OK. This is what what Down syndrome is. And this is how it can affect him…etc

Orchid noted that her sister's school often resisted making necessary accommodations, making the process especially challenging. Because her sister was considered high-functioning, the school did not take her concerns seriously. She recalls,

> Yeah, we just had to fight a lot to pursue accommodations because they're like, oh, she can talk. She can do her homework and she is a great student. I remember, like the psychologist of the school, was like we can't give accommodations. We told him that if perhaps there's a fire drill practice or there's like a school assembly, she could have access to her headphones, like certain sounds like headphones and he's like, well, she can't t have that.

Orchid comments that the school was minimizing her sister's needs. She says,

> Because there's a conception of like, oh, just because you're able to talk, you're able to do be more independent. You don't need supports when that's not the case like we all need support and so there was a lot of that during the fight before meeting, OK. But like she still needs support.

Melina believed that the school system contributed to her son's delayed diagnosis. Instead of providing direct support, they continuously referred her to other centers, resulting in prolonged wait times and delayed responses. She states,

> When they start sending children to school, they told me, 'You need to go to Marcus Autism Center. It's a center for autism where they can give an official diagnosis.' [...] That's what they needed, and well, the only issue was that it took a while. It wasn't too bad, but it was almost 10 months, I think, something like that—it was a little long.[18]

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[18] Cuando los mandan ya escolarizarse, entonces ellos me dijeron, ¿Sabes Qué? Tienes que dirigirte a Marcus Marcos. Es un centro de autismo quien te puede ya hacer diagnóstico oficial. [...] Esa necesitan marco y pues fue lo único, así que sí fue un poquito tardado, fue bueno. Es que hasta esto no fue tanto, pero sí fueron unos casi como 10 meses, me parece que algo así como un poquito tardadito

Suzie expressed frequent concerns about her son's well-being at school, as his limited ability to communicate prevents him from expressing his needs or experiences to her. She states,

> I wonder, and if someone were to touch my child, how would my child be able to tell me? Or, for example, bullying in schools? If someone hits him or does something to him, how would he tell me? Mhm, that is difficult for me, that is what I say, it is different. Or when he gets sick and doesn't tell me what hurts. I have to watch him, meaning, I observe changes in his behavior, whether he stops eating or playing. I start noticing something is off, and that's when I take him to the doctor. But he never tells me, 'Mommy, my head hurts,' no?[19]

Kelly expressed similar feelings of frustration with the previous school her son was at when protecting him from bullies or other children who tended to be aggressive toward him. She states,

> He was previously in another school, but the county transferred him because there were no special services there, and unfortunately, he was bitten four times. [...] And the principal did not want to move the aggressive child, so I took the initiative to go to the county and report what was happening because they kept dragging out the issue. Even after multiple complaints, nothing changed[20].

Kelly voiced her frustrations to the school, advocating for improved conditions to support her son's educational experience better. She states,

> The principal told me, 'I cannot move the whole class just so your child can be happy.' So I told her, 'So my child's happiness means nothing to you?' [...] They were not prepared

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[19] ¿Yo me pregunto, y si alguien tocara a mi niño, cómo mi niño me lo podría decir? ¿O, por ejemplo, el bullying en las escuelas? Si alguien le llega a pegar o hacer algo, él como me lo dice. Mhm eso es difícil para mí, eso es lo que yo digo, es diferente o cuando se enferma y no me dice que le duele. Yo tengo que mirarlo, o sea, yo veo sus cambios en su comportamiento o si ya no come o si ya no juega. Yo lo empiezo a ver raro y ya yo lo llevo al doctor. ¿Pero él nunca me dice, Mami, me duele la cabeza, no

[20] Anteriormente estaba en otra escuela, pero el condado lo transfirió porque no había servicio especial donde estaba y pues desafortunadamente me lo mordieron cuatro veces. [...] Y pues la directora no quiso mover al niño agresor, entonces yo tomé la iniciativa de ir al condado y reportar lo que estaba pasando porque le dio mucha larga al asunto, incluso ella después ya ni quería atenderme

> for this, and when I brought in recommendations from his therapists about what could be done to help him, they ignored them[21].

After having enough, she decided it would be best to transfer him to another school since her current school was not listening to her or her son's needs. She states,

> He started having emotional breakdowns because of the routine disruptions, and he began acting out, hitting his classmates and teacher. I couldn't wait any longer—I wasn't going to let him hurt another child or his teacher or himself. So I transferred him to another school where, thank God, they treat him very well. He is happy with his teacher now[22].

Kelly was eventually able to find a school better suited to her son's needs, but she initially struggled to navigate the complexities of the school system. She believes this challenge could be alleviated if more teachers and early childhood educators were adequately informed about ASD. She states,

> Many teachers don't understand what autism is. They treated my son like he was just a troublemaker, not someone who needed support. The lack of trained professionals in schools makes it harder for our children to succeed[23].

Kelly believes that if teachers and other professionals were more informed about ASD, they would be more likely to respond sensitively to the needs of autistic students. Similarly, Lia faced challenges in finding an appropriate program for her son. She notes that the COVID-19 pandemic significantly delayed the entire (Individualized Education Program) IEP process for her family. She states,

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[21] La directora me dijo, 'Yo no puedo mover toda la clase para que tu hijo sea feliz.' Entonces yo le dije, '¿Entonces la felicidad de mi hijo a usted le importa un pepino?' [...] No estaban preparados para esto, y cuando llevé recomendaciones de sus terapeutas sobre qué se podía hacer para ayudarlo, las ignoraron

[22] Él explotó por la rutina, empezó a atacar a sus compañeros y a su maestro. Yo no voy a esperar, digo, que vaya a golpear a otro niño más fuerte o que golpee a la maestra y le pase algo más grave a él. Yo lo saco porque lo saco y lo transfiero para otra escuela. Pues ahí está en otra escuela y pues gracias a Dios, que pues lo tratan muy bien. Él es feliz con su maestra

[23] Muchos maestros no entienden qué es el autismo. Trataron a mi hijo como si fuera solo un niño problemático, en lugar de alguien que necesitaba apoyo. La falta de profesionales capacitados en las escuelas hace que sea más difícil para nuestros hijos salir adelante

> But I would ask the social worker, *"What's happening? What's happening?"* She said, *"I already submitted all the paperwork. I already did my part."* But because of the pandemic, there were so many cases already waiting, and so I kept insisting, insisting, insisting. By the end of the school year, that's when they finally evaluated him and completed the whole process[24].

Lia explains that her son was able to attend school under an IEP plan, a process she was familiar with due to her sister's child having previously gone through it. This prior experience gave her greater confidence in navigating the education system, despite the barriers she encountered. She states,

> And then he was finally able to go. In his second year of Pre-K, he was able to attend a public school with his individualized education plan (IEP). And from there, he completed his second year of Pre-K. Then he went to kindergarten at another school. And now he is at a different school completing his first year. So, since my sister had already gone through that process, she had already walked that path. I also joined a group of families with children with autism, where my sister was already a member. And there, among us, we learned from each other, right?[25]

Lia observed that her children without ASD had a much easier time enrolling in school. She believed that her son's special needs status introduced additional barriers, including complications with address requirements and limited access to specialized programs. She states,

> They supposedly don't have the staff to help him. Because automatically, when you already have an older sibling in the program, your other children are automatically admitted, right? That's what happened with my daughter. Since her older brother was already in the program, she was automatically accepted. But at first, they didn't accept my son because, based on my address, his home school was different. But because he was

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[24] Pero lo decía a la trabajadora social, qué pasa? Qué pasa? Dice yo ya sometí todo el papeleo. Dice yo ya hice todo mi parte dice, pero pues por la pandemia dice como que había muchos casos ya en espera publicados y y este, pero yo voy a seguir insistiendo, insistiendo, insistiendo ya para finalizar el año escolar ya fue cuando ellos me lo me lo evaluaron, hicieron todo el proceso

[25] Y ya entonces él ya pudo ir ya. El segundo año de pri k ya pudo ir a una escuela pública con su este con su plan individualizado de este y a mm-hmm. Y ya desde ahí el este, pues ya él ya terminó su segundo año de Brik. Y después se fue a kinder a otra escuela. Y ahorita ya está en otra escuela también curando su primer año. Entonces, pues ya, como ya mi hermana se puede decir que ya había caminado, ese es, ya había recorrido ese camino. Y ya este también me unía a un grupo de puras familias con niños con autismo donde ella también ya estaba mi hermana. Y ya pues ahí entre todas. Pues ya este, um, pues aprende uno, verdad

> a special needs child, they sent him to another school. And the after-school program, Agape, wasn't available at that school. So they couldn't accept him. They just wouldn't take him.[26]

The participant who was the most frustrated with the school system was Ally. She described in detail how difficult it was to make the school understand her son has ASD. She states,

> By the time my son was in fourth or fifth grade, the school begged me to medicate him—to get him to stop talking to himself. They literally begged me. I took him to the neurologist, and she said, 'That's going to have the opposite effect, but you know what? We'll do it, just to prove the school wrong.' So we put him on ADHD medication, and sure enough, within three weeks, it made everything ten times worse. The school called me and said, 'Can you please take him off that medication?

Ally was aware that ADHD medication would exacerbate her son's symptoms, yet the school remained unwilling to listen, insisting that medication would resolve the issue. Only after Ally provided tangible evidence demonstrating the medication's ineffectiveness did the school acknowledge her concerns. This ultimately served as proof that her son required the necessary support services. She states,

> I called the state for help when he was two, and they told me to wait until he was three and go through the school system. They said, 'He will absolutely fail the test, but that's good because then he'll qualify for services.' It's all designed to make parents prove that their kid is struggling. I was never so happy to be mortified by my son's behavior as when he had his evaluation for services. He scratched his face, hit himself, and had a full meltdown during testing. I thought, 'Good. Now they're seeing what I've been dealing with.

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[26] No tiene según supuestamente el personal para ayudarlo a él. Mm-hmm, él. O sea, porque automáticamente cuando tú ya tienes el hermano mayor, o sea, cuando ya tienes un hijo en ese programa, automáticamente sus otros hermanitos entran en el programa, verdad? Mm-hmm. Así pasó con mi hija. O sea, como ya estaba el mayor, su hermano entró ella automáticamente. Ah, pues primero no me lo habían agarrado porque él ah, de de parte de mi dirección donde yo tenía su tu home school era este bol en academy. Pero como él era un niño especial, pues me lo mandaron a una escuela que se llama en Jackson. Entonces agape así se llama after school agape no, no, no está en esa escuela, verdad? O sea, no podían agarrar. O sea, no lo podían recibir

Due to Ally’s efforts in ensuring her son received the necessary treatment, he was considered high functioning. As a result, the school attempted to remove the support services that had been instrumental in his progress, believing he no longer required them. She states,

> The administration goes out of their way to try to take away services from high-functioning kids. Every single year, I fight during the IEP meetings. They say, ‘Oh, he’s doing so well, so we’re going to take this service away.’ And I tell them, ‘He’s doing well BECAUSE he has that service! You’re not taking anything away.

She mentioned that the school attempted many times to get her to sign papers that would remove these services from him but she refused. She states,

> I learned from other parents: Do not sign anything. Do not sign anything until you have exactly what you want. They can’t take away a service unless I sign off on it, and I refuse to do that. Even if he doesn’t use a service right now, what if he needs it later?

Ally acknowledges that her son’s high-functioning abilities are the result of consistent access to services and therapies that supported his development. However, she notes that many people fail to recognize the time and effort required to achieve this progress. She emphasizes the need for school systems to be more aware of the challenges faced by children with ASD and other disabilities, ensuring that their needs are adequately met.

Gender Roles in ASD Care

Gender roles played a significant role throughout this study, particularly in the fact that all participants were female. Each participant highlighted a lack of support from fathers or spouses in managing the treatment and care of their loved ones with ASD. Additionally, those participants whose loved ones were girls mentioned that people were often shocked when they found out they had ASD. Adela states, “And I think like her, like being autistic didn't even cross anybody’s mind, especially as a girl.” The rarity of ASD diagnoses in girls contributed to a lack of recognition, making it more challenging for people to identify Adela’s sister as autistic. All participants observed that it was either their mother or themselves who took their child's ASD diagnosis seriously. Orchid emphasized this dynamic, noting that her mother was the primary advocate in ensuring her daughter received a formal diagnosis. She states,

> My mom was the one who noticed everything because she already had two children. She already had the experience of knowing what was normal for her other kids, so she noticed the delays right away. My dad… he was just there. We're three girls and my dad. He's just there.

Ally observed that other mothers with sons often dismissed her concerns, attributing her son's behaviors to typical male behavior. She also noted that her husband did not take their son's actions seriously and instead perceived them as amusing. She states,

> I definitely talk to like some of my friends that had boys and they all said the same. Oh, you know, boys line up their cars and their trains and like, whatever. And I'm like, yeah, but he seems super specific. If I take it out of order, he freaks. And I told my husband at the time And he just he would repeatedly laugh things off like, oh, like he just thought it was funny behavior, not anything that we needed to be worried about. Now he never once believed me that anything was different about Ethan or like he definitely thought that he was. Was like, oh, he's a funny kid and I'm like, no, I don't know if I call that.

Ally also noted that, even after their son's diagnosis, her ex-husband never fully understood his condition. He repeatedly asked whether their son would eventually "grow out of it," which frustrated Ally, as this misconception does not align with the nature of ASD. She states,

> We would go to the neurologist every year and every year he would say, oh, so do you think he's gonna grow out of this? Do you think he's gonna grow out of this thing? Finally, the neurologist would just look at me and her, and I'd like, yeah, I know I don't. I can't. I can't explain to him. And so then she literally was like. Going to grow out of it like autism is not something he's gonna grow out of. Will he eventually mature and lose certain stimming? Sure. But it's not gonna change the way his brain thinks. So to this day, he very rarely ever tells people his son has autism. Just acts like that he sees no reason to tell people that like, and I guess in some way I can understand that. But when your son is in a corner talking to himself or is being very antisocial and it comes across as rude, I think that's a good time to be like he's not being rude. He's got those headphones on because he's overstimulated. Like I think it's OK to say that, but his dad doesn't.

Ally stated that her ex-husband's lack of consideration extended to his family, who often disregarded their son's sensory sensitivities. She recalled specific events and settings where this occurred, even after she had explained his ASD diagnosis to them. She states,

> Anytime we went to a function that had to do with the church or whatever, they would tell them, 'He doesn't like to be touched. He doesn't like to be hugged.' And they just ignored that and would hug him and get in his face. I don't even know if it registered to them that that's not something you do with children like this, or if they just didn't care. But when my father passed away, we went to the funeral, and all of these people were there. My son was really upset and was crying, and everybody was coming up to him, getting in his face, saying, 'Don't worry, your grandfather is with God now, looking down on you.' And my son the whole time, was overwhelmed. They just didn't care. That diagnosis meant nothing to them.

Ally felt that her ex-husband's family neither understood her son's condition nor made an effort to do so. Similarly, Suzie described her husband as a "machista", a term referring to a rigid, traditionalist perspective on gender roles within the household. She states,

> And I told the doctors, and they returned us with the medicine and when we got home from the hospital, his father was like, "Good, I'm going to sleep now. Take care of the baby." Their ideology in the father of my child is very macho. Yes, the woman is takes care of her children and the man. Works. Mhm and that was the problem between him and me. Why did we separate, because I began to notice that he did not come to take care of the child, especially when the boy had convulsions and things like that, right? [27]

She explained that the primary reason for their separation was her realization that he was unwilling to support their son through his ASD diagnosis, leaving her to manage everything on her own. Even after their separation, Suzie noted that he made no effort to understand their son's condition, ultimately placing the full responsibility on her to navigate the challenges of his care. She states,

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[27] Y yo se los dije a los doctores, nos regresaron con la medicina y cuando llegamos del hospital su papá dijo bueno, ya me voy a dormir tú cuida al bebé. Su ideología en el papá de mi niño es muy machista de. Sí, la mujer es cuida Asus hijos y el hombre. Trabaja. Mhm y eso fue el problema entre él y yo. ¿Porque nos separamos, porque yo empecé a notar que él no venía al cuidado del niño, sobre todo cuando el niño tuvo convulsiones cosas así, no?

> And my child's father, well, when our son was diagnosed at the age of 2... At first, he didn't really acknowledge it. He was already living in his apartment, got remarried, and only came on weekends or every 15 days to see the child, but he acted as if nothing had happened. I would tell him, 'Look, he's going to speech therapy and things like that,' and sometimes he would think it would just go away. Well, yes, he has autism, and he was just like, 'Oh,' as if he didn't understand.[28]

Suzie's husband never fully understood their son's ASD, which affected his ability to be an engaged and supportive father. Similarly, Kelly noted that her husband also struggled to comprehend their son's diagnosis, attributing this lack of understanding to the influence of their religious community. She states,

> Basically, most of my husband's family are evangelicals, and their religious beliefs are very strong. They think that what the child has are demons, but that's not the case. Basically, because my husband's family is not like people from rural areas. Well, if you know, people from rural areas don't believe in this; they say it's just that the child is poorly raised. That with a good spanking, he would be fine, as they say. And that you just haven't known how to educate him. That's all—nothing about autism or anything like that.[29]

Kelly explained that due to her husband's religious background, he believed demonic influences caused their son's behaviors. She also noted that because he grew up in a small town, there was limited awareness and understanding of mental disorders, including ASD. In Lia's case, her husband has been supportive; however, she is unable to drive due to a past accident and relies on him for transportation. This has become increasingly challenging as he is currently battling cancer, further limiting their mobility and access to necessary resources. She states, "Because,

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[28] Y su papá de mi hijo puede, cuando a los 2 años tuvimos el diagnóstico de nuestro hijo ajá. Él no, él al principio, pues él ya vivió en su apartamento, se volvió a casar y él solo venía los fines de semana por el niño o cada 15 días, pero él actuaba como si nada paso. Yo le decía como ah, mira, está teniendo las terapias de habla y cosas así y él a veces lo tomaba como se le va a quitar. Pues sí, tiene autismo y él fue como de Ah, qué no entendía

[29] Básicamente, en la mayoría de la familia, mi esposo son evangélicos y ellos sus creencias religiosas, son bien fuertes. Piensan que son demonios los que el niño tiene ahí no es así. Básicamente porque la familia de mi esposo no son así como de pueblo. Pues si usted sabe que la gente de pueblo no creen en esto, dicen que que lo tiene muy mal criado. Uno que con chanclas se compone como dice. Y es que usted no lo ha sabido. Educar. Eso es todo, nada que el autismo ni nada.

well, no, no, it's not easy. Right now, my husband is out of work because he is sick with cancer. Uh-huh, but he is undergoing treatment, and I cling a lot to the Church”[30]. Gender expectations play a crucial role in how a child receives treatment for ASD. Nearly all participants expressed frustration over the lack of effort from fathers or husbands to understand ASD or provide emotional support throughout the process. As a result, the responsibility of caregiving often fell entirely on the mother.

Fear for the Future and Long-Term Independence

One of the most significant concerns among participants upon learning of their loved one's ASD diagnosis was uncertainty about their future. This worry was particularly pronounced among parents, who feared that their child might never achieve full independence and would remain reliant on them indefinitely. The combination of this fear and their limited knowledge of ASD contributed to significant anxiety surrounding the condition. Adela recalled that her mother questioned whether her daughter with ASD would ever be able to lead a life similar to her own. She states,

> I remember she made a comment about… the year my sister was diagnosed and like obviously, I was going to college. And she said something like, 'Oh, I really hope she can come here one day. I hope they allow her to.' But she said it in a tone that made it sound like she didn't really believe it would happen.

Adela’s mother was concerned that her youngest daughter’s ASD would prevent her from pursuing higher education. However, Adela reassured her that this was not necessarily the case. She states, “Over the years, I’ve been like, well, there's literally an autistic kid in my class. It’s possible. Like, I know autistic people who are in college, professors, authors, and scientists. But at the time, my mom didn’t see that as a reality.” Orchid expressed similar sentiments regarding

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[30] Porque pues no, es fácil, ahorita mi esposo está sin trabajar porque él está enfermo de cáncer. ¿Ajá, pero está en su tratamiento y pues yo me apego mucho a la Iglesia

her sister's diagnosis, aligning with her mother's concerns. While she did not want to fully speak on her mother's behalf, Orchid observed that her mother often worried about her sister's future. She states,

> I mean, I can't speak on her behalf, but I think she does worry her. Not that I—worry her in—it didn't stem from receiving a diagnosis, but in general, she worries about the future. So it may when we're calling on the functioning, no, suddenly that don't forget about your sister. Like if, God forbid, I'm not here. Your dad's not here like. You take care of your sister. I'm like, you know, of course we will.

Orchid also highlights a common misconception about ASD, which can contribute to increased anxiety surrounding the condition. She states,

> Yeah, there's like a misconception that, at least with autism, it also implies an intellectual disability. But that's not the case. Or learning something about. And I think my mom was afraid that that would be the case for my sister—that she had no shot the way that I would have been.

Melina initially experienced significant anxiety about her son's diagnosis, particularly concerning his ability to engage in social interactions. She states, "So then I thought, will he be able to talk? It's like, I've always had this thought, I never let it go. I said no. My son will be able to talk, Right?"[31] Melina recalls a story she once heard that profoundly shifted her perspective on her son's diagnosis. Inspired by this, she became determined to advocate for him. She states,

> I don't remember, but one of those two cultures, Greek or Roman, used to say that when people were born with deformities or intellectual disabilities, they would take them to the highest mountain and throw them into the void. So, I remember that it really stuck with me, and I felt sadness and anger, and I thought, how could they throw a baby? People with deformities have existed for centuries, and in Mexico, I used to see several like that. But I'm telling you, in Mexico, many people kept them locked in their homes. There

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[31] Entonces yo dije, a ver si va a poder hablar, o sea, como que siempre me ha así como cambiar foto, o sea, no me queda así de que no dije no. Mi hijo se iba a poder hablar y así, verdad?"[31]

> were people that I actually saw locked up in their houses. They wouldn't let them out at all. Were there screams? Yes. Or they would even chain them up so they wouldn't leave.[32]

Melina shared an extreme example to illustrate her fear of her child being shunned from society, emphasizing her belief that individuals with disabilities should not be hidden from the world. Similarly, Ally stressed her commitment to ensuring her son becomes self-sufficient despite his ASD diagnosis. She remains dedicated to providing him with the necessary tools and support to achieve independence. She states,

> But I want him to be as self-sufficient as possible and that's a big fear for a lot of people, especially Hispanic people, that. That their kids are not going to be self-sufficient. So they're just going to put hands off and try to force their kids to learn on their own how to be independent. But these are not kids that you can teach that you can force to be independent. You have to teach them how to be independent.

Ally acknowledges the concerns many Hispanic parents have regarding their children's ability to achieve independence. However, she firmly believes that independence can be taught, as she has been actively working to instill it in her son. Similarly, Suzie continues to grapple with the persistent fear of how her son will sustain himself in the future. She states,

> And what will happen when I'm not here, when I die and my son is left alone? Who will he have if he can't have a friend or someone else, or get married, or have a partner, or interact with the world if I'm no longer here? Because I thought to myself… Oh, and I just remember that his father told me, 'Well, we'll be his friends.' Oh, really? He can't have friends? And I told him, but it goes beyond that, because when you and I are no longer here, what will happen to our child? That is a fear I have never lost. Honestly, for me, it is a lot, a lot. A lot of fear, a lot, a lot of pain to think about whether someone will

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[32] No me acuerdo, pero una de esas dos culturas, griega y romana, este decían que cuando nacían personas con deformidades o así como retrasadas, se subían desde el monte más alto y lo los aventaban al vacío Entonces o sea, yo me quedo mucho, o sea, y me acuerdo que me dio tristeza y coraje y dije, cómo pueden aventar un bebé? Las personas con deformidades son desde años y porque en México yo llegaba a ver a varios así, pero te digo, o sea. Ya allá en México, pues mucha gente los encerrada en sus casas. Yo había gente que yo sí llegué a verlos encerrados en su casa. Si no los dejaban ni nada más. ¿Lo habías gritos? Sí. O que a la gente los encadenaban por lo mismo de que pues para que no se salieran

> be there in the world for him, someone who understands him the way I do, who loves him as much as I do.[33]

Suzie fears that no one will be there to support her son after she is gone, making this one of her most significant concerns regarding his ASD diagnosis. Similarly, while Lia initially shared deep worries about her son's future, she has since come to accept his diagnosis and believes he can lead a fulfilling life. She states,

> So I say, well, my son may have autism, but he has a life. I mean, apparently, he is, well, normal, because they are, rather, just like that. I think we should all be like them because they don't have prejudices, because they just are. Yes, well, yes, I mean, we humans have so many things, I don't even know how to describe it, but they are just pure love.[34]

This way of thinking was healthy for Lia, as it allowed her to accept her son's ASD diagnosis and trust that he would be okay regardless. By shifting her perspective, she was able to focus on his strengths rather than his limitations, reinforcing the idea that individuals with ASD can lead meaningful and independent lives. Ultimately, while concerns about the future remain, many participants emphasized the importance of providing continuous support, advocating for resources, and fostering self-sufficiency to ensure their loved ones can thrive.

Discussion

Each of these themes highlights why receiving an ASD diagnosis can be particularly intimidating for some families. The first theme (see Table 2) is a foundation for understanding

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[33] ¿Y qué va a pasar cuando yo no esté, cuando yo muera y mi hijo se quede solo? ¿Con quién no va a poder tener un amigo o alguien más, o casarse o tener una pareja o convivir con el mundo si yo ya no estoy porque yo pensé entre mí? Ah, y solo me acuerdo que su papá de mi hijo me dijo, pues nosotros vamos a hacer sus amigos. ¿Ah, sí? ¿Él no puede tener amigos y yo le dije, pero es que va más allá porque cuando no estemos tu y yo qué va a pasar con el niño? Es un miedo que yo no he perdido. Honestamente, ajá me eso es mucho, mucho. Mucho miedo, mucho, mucho dolor de pensar si alguien si alguien va a estar en el mundo para él, que lo entienda como yo lo entiendo, que lo que lo quiera mucho

[34] Entonces yo digo, pues mi hijo podrá tener autismo, pero pues tiene una vida. O sea, aparentemente, o sea, pues normal, porque ellos son más bien. Yo creo que todos deberíamos de ser como ellos porque no tienen prejuicios, porque ellos es. Sí, pues sí, pues o sea, nosotros los humanos este tenemos tantas, no sé cómo podríamos decir lo que pues ellos son puro amor

the broader challenges surrounding ASD within the Hispanic community. Nearly all participants expressed having limited knowledge of ASD or other mental disabilities before their child's diagnosis. Ally, who was born and raised in the United States and had prior experience working with students with disabilities, had some background knowledge of ASD. However, Ally acknowledged that the Hispanic community oftentimes is not aware of what ASD is. Similarly, Lia was familiar with the condition, but only because her older sister had a child with ASD, making it easier for her to recognize the signs. In contrast, the other participants—particularly the mothers—had never heard of ASD before. A common factor among these mothers was that they were immigrants from Hispanic countries, where awareness and discussions surrounding autism were minimal. Many noted that they had never encountered the term "autism" in their home countries. Upon learning about it, they recognized that if their family had remained in their country of origin, access to ASD resources and treatment would have been minimal. This is particularly significant, as immigration to the U.S. granted participants increased access to resources for their loved ones with ASD; however, they still encountered unexpected challenges within the U.S. healthcare and educational systems following the diagnosis.

This limited knowledge of ASD brought about several misconceptions that often led to feelings of anxiety and stress. Ally believed that the idea of labels was intimidating for the Hispanic community, especially if it involved something stigmatizing, like mental disorders. Not only that, but she explained how many Hispanic people tend to believe that ASD is always severe and don't realize there could be a spectrum. This is oftentimes because the little representation of ASD that there is in the media shows the more severe symptoms. Studies show that Media depictions may have negative stereotypes of autism, thereby leading to inaccurate views of autism and increasing stigma. Research indicates that media depictions can perpetuate negative stereotypes of autism, leading to inaccurate perceptions and increasing societal stigma. A study on the experiences of autistic higher education students found that stereotyping was one of the primary reasons students chose not to disclose their diagnosis to their peers (Jones et al., 2023). If parents' only exposure to ASD comes from media portrayals that emphasize extreme cases, they may struggle to understand that not every diagnosis presents in the same way. As a result, when a child exhibits behaviors associated with ASD, parents may attribute them to defiance or disobedience rather than recognizing them as potential signs of autism. A term among the participants who spoke English was “stimming.” Stimming is clinically known as ‘self-stimulatory behavior’(Kapp et al., 2019). This particularly applies to ‘motor stereotypies’ such as ‘hand or finger flapping’ or ‘complex whole-body movements. These behaviors have been considered as self-stimulatory acts that shut out external stimuli and interfere with the person’s (and others’) focus (Kapp et al., 2019). Stimming is most often associated with ASD. However, it can also be associated with other neurodevelopmental conditions.

Additionally, some parents may hold onto false hope that ignoring the signs will cause the issue to be resolved on its own or that their child will "grow out of it." However, this approach often does more harm than good. Several participants also noted that ASD is frequently confused with Down syndrome, a condition with more visible physical traits, making it easier to identify in a child. The absence of obvious physical markers in ASD contributes to misconceptions, leading some individuals to label those with ASD as "crazy" or “loco.” This term is profoundly dehumanizing, as it implies that individuals with ASD are not to be taken seriously. Furthermore, the blame for a child's behaviors often falls on the parents or the child themselves rather than being recognized as a neurodevelopmental condition that requires understanding and support.

Adela stated that she had no knowledge of ASD or mental disorders in general while growing up. She recalled that no teacher or adult ever provided information on these conditions. Although there were children with mental disorders in her class, they were separated during class time, a practice she did not understand at the time. Reflecting on this, Adela expressed a desire for conditions such as ASD to be introduced and taught at an earlier age, believing that this would help other children better understand the different behaviors exhibited by their peers with ASD. She emphasized that increasing discussions about ASD would not only reduce confusion but also help to destigmatize the condition, fostering more open and informed conversations around the topic.

Adela observed the stigma surrounding ASD within the Hispanic community. She noted that even after her sister's diagnosis, people around her struggled to communicate with her sister, likely due to a general lack of understanding about autism. For instance, Adela explained that her sister does not always respond to specific social cues, such as when someone asks, "How was your day?" Despite being informed, many people remained confused by her sister's behavior. Similarly, several participants recalled childhood experiences in which they encountered peers who exhibited ASD-like behaviors but were unaware at the time that these behaviors were indicative of ASD. Kelly, for example, mentioned that she knew children who displayed symptoms of ASD, but their behaviors were often dismissed as them being "crazy" or simply lacking discipline. Growing up in an environment where such misconceptions were prevalent likely contributed to the stigma surrounding ASD later in life. This also helps explain why many participants initially experienced feelings of anxiety and confusion when their children were diagnosed with ASD.

For some participants, receiving an ASD diagnosis was already overwhelming. However, Lia also highlighted the stigma surrounding seeking professional help for mental disabilities or disorders. Because conditions like ASD do not present with visible physical symptoms, they were often not taken seriously, and responsibility for the behaviors was frequently placed on the child or the parent. As a result, seeking professional help was sometimes perceived as an admission that something was "wrong," leading some individuals to prefer denial over confrontation. Lia, however, found this perspective problematic, emphasizing that ignoring the issue could lead to even greater consequences. This viewpoint was likely shared by other participants who recognized the importance of addressing ASD rather than avoiding it. Nevertheless, some participants felt that educating their community about ASD was easier said than done. Confronting deeply ingrained misconceptions can be exhausting, particularly when engaging with individuals who are unwilling to listen. Orchid expressed this frustration, stating that she did not always want to explain her sister’s condition to people who refused to be receptive to the information.

Furthermore, some communities are deeply rooted in their beliefs, making it challenging to introduce new perspectives on conditions such as ASD. This was the case for Lia, who belonged to a religious community with limited knowledge of mental disorders. In a faith-based environment, explaining a condition many have never encountered can be particularly challenging. For Lia, the best course of action was to leave that community and seek support elsewhere. She found solace among other mothers of children with ASD, who not only understood her son’s condition but also shared her cultural background. While she still experiences anxiety, she feels more at ease in a community that offers empathy and understanding.

However, not every Hispanic individual raising a loved one with ASD has the option to leave an unsupportive environment. Many must remain in communities where autism is misunderstood, perpetuating stigma on a broader cultural level. The findings of this study suggest that for meaningful change to occur in how the Hispanic community perceives ASD, there must be a collective effort to foster awareness and support. Nearly all participants echoed this sentiment, emphasizing the need for increased educational initiatives in Spanish. Because ASD is already highly stigmatized among minority communities, who often face additional structural barriers in society, an ASD diagnosis can be particularly overwhelming. Increasing access to information about autism could help dismantle stigma for families who may have never encountered the term before. Ultimately, fostering open conversations about ASD is crucial to reducing the fear and uncertainty that can accompany a diagnosis.

Each participant expressed frustration or confusion when navigating the healthcare system for their loved one with ASD. Adela believed that some early signs of ASD in her sister were overlooked, likely due to cultural differences. She noted that many of the practitioners they encountered were white and unfamiliar with these cultural nuances, which may have contributed to a delayed diagnosis. This issue is systemic, as Hispanic physicians remain underrepresented in the U.S. medical field. Even when families do have access to healthcare professionals, an ASD diagnosis can still be delayed if the physician lacks awareness of the condition’s symptoms. Orchid shared that her family recognized signs of ASD in her sister from an early age. Yet, despite their concerns, the diagnostic process was delayed, and she was not officially diagnosed until the age of 10. This delay was due to multiple factors, including long waitlists and a lack of available translators. The language barrier also presented challenges for Melina and Lia. While Orchid acknowledged that the availability of translators has improved in recent years, she emphasized that additional resources are still needed to ensure effective communication between healthcare providers and Hispanic families seeking ASD diagnoses.

The post-diagnosis period was often just as challenging, as both Orchid and Adela noted that their families received minimal guidance on the next steps. Even participants who were aware of available resources faced significant obstacles in accessing them, as many therapies and institutions had long waitlists or scheduling conflicts. In cases where scheduling was not an issue, the providers themselves could present a challenge. For example, Kelly recalled that the first psychologist she visited with her son did not establish a positive rapport with him and instead seemed to frighten him. Fortunately, she was able to find another psychologist better suited to her son's needs. However, finding the right provider can be a lengthy process, which is not always feasible for parents with limited time. This challenge is particularly pronounced among Hispanic families, as many work multiple jobs to support their households. The time and financial burden associated with accessing ASD-related resources can make it even more difficult for these families to secure the necessary support for their loved ones.

Some providers also fail to take parents’ concerns seriously. This was evident in Ally’s experience, as she had to switch pediatricians three times before a doctor finally acknowledged her concerns about her son's ASD. Ultimately, it was through the school system that her son received a formal diagnosis. However, even after his diagnosis, the school struggled to accommodate his needs. Ally noted that her son exhibited stimming behaviors at school and had difficulty maintaining attention. Instead of exploring alternative interventions, the school suggested medication as the primary solution. This approach reinforces the misconception that medication is a universal fix for all behavioral or neurological challenges. However, ASD is a spectrum, meaning that its effects vary widely among individuals, and certain medications may do more harm than good. To demonstrate that ADHD medication was not the right solution for her son, Ally worked with a neurologist to put him on the prescribed treatment. After several weeks, the school, witnessing the adverse effects firsthand, begged her to discontinue the medication. Only when they observed the negative consequences did they acknowledge her initial concerns. Due to Ally's advocacy and persistence, her son is now high-functioning. However, this has led to another challenge—the misconception that because he is high-functioning, he no longer requires additional services or therapies. This experience was a common theme among participants, as many encountered dismissive attitudes or a lack of understanding from the school system when advocating for their loved ones with ASD.

Orchid stated that her sister was also high-functioning, and as a result, the school refused to provide accommodations for her, even for simple requests such as allowing her to wear headphones during fire drills. This denial of accommodations was likely due to the school's lack of understanding of how to support a child with ASD who was more high-functioning. Adela recalled an experience from her school years when she knew a Hispanic boy with ASD. Whenever he experienced a breakdown, the school would often turn to Adela for assistance simply because she was the only other Hispanic student in the class. Since they were the only Spanish speakers, the school placed the responsibility on Adela to help manage his distress. Adela noted that this expectation was unfair and demonstrated negligence on the school's part, mainly because the school appeared to know how to support white students who had breakdowns but failed to extend the same level of care to the Hispanic boy. At the time, Adela was unaware that the boy had ASD because the school never addressed the condition with students despite the presence of multiple children with disabilities in the class. This lack of transparency can contribute to the perpetuation of stigma from an early age. Increasing awareness and openly discussing neurodevelopmental disorders within the school setting could foster a more inclusive and supportive environment. Reflecting on her experience, Adela expressed that she would have benefited from greater transparency and early education on ASD.

Participants, such as Suzie and Kelly, expressed concerns about bullying, which was likely exacerbated by the general lack of awareness about ASD among children. When children exhibit behaviors associated with ASD, their peers may misinterpret these actions as intentional or disruptive, increasing the likelihood of bullying. Suzie was particularly worried about her son, who is nonverbal, as she feared he would be unable to communicate with her if he experienced bullying at school. Kelly shared similar concerns and voiced them to the school administration. However, she found that the school was dismissive of her worries. As a result, she decided to transfer her son to a different school that provided a more supportive environment. Reflecting on her experience, Kelly emphasized the need for more teachers to be adequately trained on ASD and equipped with the knowledge to support and accommodate children with the condition.

Moreover, gender roles played a significant role in both parenting a child with ASD and shaping perceptions based on the gender of the child. Notably, all the participants in this study were female, which aligns with the tendency for mothers to be more actively involved in the lives of their children with ASD. They were more likely to try to understand their child’s needs and advocate for their care. For example, Orchid shared that her mother took the lead in securing a diagnosis for her sister and ensuring she received treatment post-diagnosis. While her father contributed financially to the family, he provided little to no emotional support. This dynamic reflects the influence of “machismo” in Hispanic culture, where men are traditionally expected to serve as financial providers. At the same time, the responsibility of childrearing and emotional caregiving is placed on women.

Nearly all participants reported that their spouses were uninvolved in their child’s ASD care. When fathers did contribute, it was typically in the form of financial support, which, while valuable, was often insufficient in addressing the child’s overall needs. Some participants, such as Suzie, ultimately separated from their husbands after realizing their partners would not provide the necessary support. She noted that even after their separation, her ex-husband still did not make an effort to understand their son’s condition. Similarly, Ally mentioned that her ex-husband refused to take their son’s diagnosis seriously, insisting that ASD was something their child could "grow out of," despite her repeated explanations that this was not the case.

Many participants expressed frustration that their spouses did not take their concerns seriously and expected them to handle all aspects of their child’s care. This placed an immense burden on mothers, reinforcing the gendered expectation that raising and supporting a child with ASD is solely the mother’s responsibility.

Gender biases also played a role in the diagnostic process for children with ASD. Among the seven participants, only two had female loved ones with ASD. Adela noted that obtaining a diagnosis was particularly challenging because she was a girl, and ASD remains significantly under-researched in females. Studies have shown that males are four times more likely to be diagnosed with autism than females. Despite ongoing efforts to improve the representation and understanding of autistic females, research studies continue to enroll disproportionately small samples of females or exclude them altogether (D’Mello et al., 2022). Orchid’s experience mirrored this pattern, highlighting the broader issue of gender disparities in ASD diagnoses.

However, even when boys exhibit ASD symptoms, they are often misinterpreted as typical "boy behavior," further delaying diagnosis. This was the case for Ally, who recalled that those around her dismissed her concerns, assuring her that her son’s behavior was developmentally normal for a boy. Another common misconception was that the child was misbehaving and would eventually "grow out" of these behaviors, failing to recognize that ASD is a lifelong neurodevelopmental condition.

These gender biases not only contribute to diagnostic delays but also create uncertainty for parents who may struggle to determine whether their child's behaviors warrant further evaluation. Addressing these biases in both research and clinical practice is crucial to ensuring that all children, regardless of gender, receive timely and appropriate support.

Lastly, one of the greatest concerns for parents—regardless of their prior knowledge of ASD—was the fear of the future and their child’s long-term independence. This overarching theme (see Table 2) resonates with many caregivers, as the uncertainty surrounding a child's ability to live independently is a common worry among families of individuals with ASD. Several participants were immigrants, which likely compounded their anxiety, as they believed that immigrating to the United States would provide their children with better opportunities. However, upon receiving an ASD diagnosis, some feared that their child's prospects for a successful future would be significantly limited. While finding supportive communities and gaining a deeper understanding of ASD helped to alleviate some of these concerns, the lingering worry for their child’s wellbeing remained. Participants who were not parents, on the other hand, had greater exposure to individuals with ASD who were leading fulfilling and successful lives, which contributed to lower levels of anxiety compared to parents who lacked that perspective. This highlights the need for increased autism representation—particularly within the Hispanic community—to reassure parents that individuals with ASD can achieve meaningful and independent lives.

All participants provided recommendations on improving the experiences of individuals with ASD, with most emphasizing the need for greater representation. While some offered practical suggestions—such as consulting a neurologist and researching state guidelines for obtaining a diagnosis—there was a collective call for systemic change within the healthcare system and the broader community. This was particularly relevant to Theme 1, which highlighted the role of limited knowledge and stigma in shaping perceptions of ASD. Systemic changes within the healthcare field must originate from within, beginning with improved medical education for future providers and physicians. Participants stressed the importance of increasing resources and support to help families navigate the complexities of an ASD diagnosis. Ensuring accessibility to medical and community-based services could alleviate the stress associated with seeking proper care.

At the community level, greater advocacy and awareness efforts are necessary to combat the stigma surrounding ASD and other mental health conditions. Increasing transparency and education within schools could serve as a foundational step toward reducing misconceptions and fostering a more supportive environment. By placing a greater societal emphasis on education and awareness surrounding ASD, families may find the diagnostic and adjustment process less overwhelming, ultimately leading to better long-term outcomes for individuals with ASD.

Limitations

This study faced several limitations, the most significant of which was time. Due to unforeseen delays in the Institutional Review Board (IRB) approval process, the interview phase began much later than anticipated. This constraint made it challenging to secure a large and diverse sample size, which was initially a goal of the study. Had the study commenced earlier, it is likely that more interviews could have been conducted, resulting in a broader and more representative participant pool.

Eligibility criteria allowed for any Hispanic individual with a relative diagnosed with ASD to participate. However, most respondents who volunteered were mothers, reflecting the prevalent reality that women are often the primary caregivers in ASD-related family dynamics. Efforts were made to recruit male participants, but the limited involvement of fathers in caregiving roles made it particularly difficult to include their perspectives in this study.

Additionally, while the preference was to conduct interviews in person, logistical challenges arose. Many participants were unfamiliar with Emory University's campus, making in-person meetings less feasible. While virtual interviews via Zoom did not appear to impact the depth or quality of responses, in-person discussions might have fostered a more natural and engaging dialogue. Scheduling conflicts also posed a challenge, as many participants had work obligations or had to cancel at the last minute due to childcare responsibilities or their child's medical needs.

Another significant limitation was participant recruitment. Given the current sociopolitical climate, it was difficult to find Hispanic individuals willing to participate in the study, despite extensive outreach efforts. Although the final sample provided valuable insights, its size limits the generalizability of the findings to all Hispanic families, as experiences with ASD may vary significantly across different cultural and socioeconomic backgrounds. This constraint also made it difficult to include diverse Hispanic subgroups, which has been noted as a persistent gap in previous literature. Furthermore, the absence of male participants restricted the exploration of gendered experiences within the ASD diagnostic process, particularly in themes related to caregiving responsibilities and societal expectations.

In the future, the nature of this study would require extensive planning beforehand to reach a larger and more diverse sample size. This would allow for greater representation of different Hispanic subgroups, ensuring a more comprehensive understanding of the cultural and structural factors influencing ASD diagnosis and care. Expanding the study across multiple geographic regions, including urban and rural communities, could further capture variations in access to healthcare and education.

On a larger scale, future research could incorporate both qualitative and quantitative methodologies to examine differences in the age of ASD diagnosis among various racial and ethnic groups. A comparative approach could help identify disparities in early detection, access to diagnostic services, and cultural perceptions of ASD across different communities. Additionally, investigating the role of socioeconomic status, healthcare policies, and parental education in shaping the diagnostic experience would provide further insight into systemic barriers that Hispanic families face. Another important area of future research would be to explore the role of fathers and male caregivers in the ASD diagnostic process. Since this study primarily included female participants, future work should actively seek to recruit fathers to understand their perspectives, involvement, and cultural expectations that may shape their engagement in their child’s ASD diagnosis and treatment.

Conclusion

This study has explored how cultural beliefs, language barriers, and systemic factors shape perceptions of autism spectrum disorder (ASD) within Hispanic communities. The findings align with past research, reaffirming themes such as a lack of ASD awareness, stigma within the community, and fears surrounding the future of individuals with ASD. Additionally, this study expanded upon systemic barriers in healthcare and education, offering new insights into how these structures influence the diagnostic process and access to resources. Another key contribution was the exploration of gender roles and their impact on the ASD diagnosis and post-diagnosis care, a topic that has not been widely addressed in previous literature. These findings highlight the persistence of challenges that have been previously identified while also shedding light on emerging issues that Hispanic families continue to face.

Due to the limitations of this study, further research is necessary to develop a deeper understanding of how to best support Hispanic families navigating an ASD diagnosis. By shedding light on these cultural perceptions, this study contributes to a growing body of research advocating for more inclusive and culturally responsive healthcare practices. Understanding these dynamics is crucial for bridging gaps in ASD diagnosis and intervention within Hispanic communities, ultimately promoting more equitable healthcare outcomes.

As the Hispanic population in the U.S. continues to grow, healthcare providers, educators, and policymakers must collaborate to develop more inclusive diagnostic and support systems. Addressing cultural barriers is not just about increasing awareness—it is about ensuring that every child and family has access to the resources they need to thrive. Future research should focus on expanding sample sizes to include more Hispanic subgroups, as well as exploring the role of fathers and male caregivers in the diagnostic process. Additionally, large-scale studies incorporating both qualitative and quantitative data could provide valuable insights into disparities in ASD diagnosis across different racial and ethnic groups. Investigating culturally tailored interventions and improving accessibility to bilingual healthcare providers and educators could further support Hispanic families navigating ASD.

By fostering greater awareness and advocacy within both the healthcare system and Hispanic communities, we can work toward a future where an ASD diagnosis is met with understanding, acceptance, and the necessary support for individuals and their families to flourish.

Appendix

A. Oral consent script for Hispanic Participants: English Version

Title: Cultural Perceptions of Autism among Hispanic Populations

IRB #: 00008227
Principal Investigator: Helen Andrade
Faculty Advisor: John Lindo

Introduction and Study Overview

Thank you for your interest in our autism research study in Hispanic populations. We would like to tell you what you need to think about before you choose whether to join the study. It is your choice. If you choose to join, you can change your mind later and leave the study.

The purpose of this study is to understand how people in Hispanic communities view autism. We want to look at how culture, society, and family affect their perspectives. The study also aims to point out where more research is needed about autism in Hispanic populations.

If you join, you will be asked to participate in a 1-hour interview that will be recorded. We aim to interview approximately 20-25 participants.

This study involves minimal risk so the only possible discomforts and risks would be feelings of:

- Stress
- Shame/Self-blame
- Anger/Resentment
- Sadness
- Guilt
- Possibly breach of privacy / loss of privacy

You might not see any direct benefits from joining this study. This study is designed to explore how perceptions of autism among Hispanic populations differ from those in other communities. The findings could be helpful for others in the future.

Storing and Sharing your Information

Pseudonyms will be given to the participants to protect their confidentiality. Audio recordings of the interviews will be transcribed and then deleted a week after transcription. All audio recordings, transcriptions, and participant contact information will only be accessible to the researcher.

We may also place data in public databases accessible to researchers who agree to maintain data confidentiality, if we remove the study code and make sure the data are anonymized to a level that we believe that it is highly unlikely that anyone could identify you. Despite these measures, we cannot guarantee anonymity of your personal data.

Contact Information

If you have questions about the interviews or other questions or concerns about the research or your part in it, contact Helen Andrade at 516-514-2868:

This study has been reviewed by an ethics committee to ensure the protection of research participants. If you have questions about your **rights as a research participant**, or if you have **complaints** about the research or an issue you would rather discuss with someone outside the research team, contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu.

To tell the IRB about your experience as a research participant, fill out the Research Participant Survey at **https://tinyurl.com/ycewgkke.**

If you are a patient receiving care at Children's Healthcare of Atlanta or Children's Healthcare of Atlanta at Hughes Spalding Hospital and have a question about your rights, please contact the Children's Institutional Review Board at 404-785-7477.

Consent

Do you have any questions about anything I just said? Were there any parts that seemed unclear?

Do you agree to take part in the study?

Participant agrees to participate: Yes No

If Yes:

Name of Participant:

____ _________________

Signature of Person Conducting Informed Consent Discussion Date Time

____

Name of Person Conducting Informed Consent Discussion

B. Oral Consent Script for Hispanic Participants: Spanish Version

Título: Percepciones culturales del autismo entre la población hispana

IRB #: 00008227
Investigadora Principal: Helen Andrade
Consejero de la Facultad: John Lindo

Introducción y Visión General del Estudio

Gracias por mostrar interés en mi estudio de investigación sobre el autismo en la población hispana. Antes de decidir si se une al estudio, me gustaría informarle sobre lo que debería considerar. Es su elección: si se une, puede optar luego por cambiar de opinión y abandonar el estudio.

El propósito de este estudio es entender cómo se percibe el autismo en comunidades de habla hispana. Queremos examinar cómo la cultura, la sociedad y la familia afectan a sus perspectivas. Mi estudio también pretende determinar si es necesario investigar más sobre el autismo entre la población hispana.

Si se une, tendrá que participar en una entrevista de 1 hora de duración, la cual se grabará en grabación de audio. Nuestra intención es entrevistar aproximadamente a unos 20-25 participantes.
Este estudio conlleva un riesgo mínimo, de modo que las únicas incomodidades o riesgos que podrían surgir son:

- Estrés
- Sentimientos de vergüenza y/o autoculpabilidad
- Ira y/o Resentimiento
- Tristeza
- Sentimientos de culpa
- Posible alteración o perdida de la intimidad

Es posible que no perciba ningún beneficio directo uniéndose a este estudio. Se diseñó para investigar cómo las distintas percepciones del autismo entre la población hispana pueden diferir respecto a las de otras comunidades. Los hallazgos podrían ser útiles para otras personas en el futuro.

Almacenamiento y Difusión de su Información

Se asignarán seudónimos a los participantes para proteger su confidencialidad. Las grabaciones en audio de las entrevistas se transcribirán para borrarse una semana después de la transcripción. Todas las grabaciones en audio, así como las transcripciones y la información de contacto de los participantes, estarán únicamente a disposición de la investigadora.

También podemos poner esta información a disposición de bases de datos publicas accesibles a investigadores que acepten mantener la confidencialidad de los datos, siempre y cuando eliminemos el código del estudio y nos aseguremos de que se mantiene la anonimidad de sus datos de tal forma que sea altamente improbable que alguien pueda identificarle. A pesar de estas medidas, no podemos garantizar el completo anonimato de sus datos personales.

Información de Contacto

Si tiene alguna pregunta relacionada con las entrevistas, o bien otras preguntas o preocupaciones respecto a la investigación de la que forma parte, póngase en contacto con Helen Andrade llamando al 516-514-2868:

Este estudio ha sido revisado por un comité de ética para asegurar la protección de quienes participan en la investigación.

Si tiene preguntas relacionadas con sus
derechos como participante en el estudio, o si tiene **quejas** respecto a la investigación o desea discutir algún problema con alguien que no sea miembro del equipo del estudio, póngase en contacto con la Junta de Revisión Institucional de llamando al 404-712-0720, al 877-503-9797 o escribiendo a irb@emory.edu.
Si desea hablarle al IRB sobre su experiencia como participante del estudio, complete la Encuesta al Participante del Estudio en **https://tinyurl.com/ycewgkke.**

Si usted paciente en Children's Healthcare of Atlanta o en Children's Healthcare of Atlanta en el Hospital Hughes Spalding y tiene preguntas relacionadas con sus derechos, póngase en contacto con la Junta de Revisión Institucional de Children's Healthcare llamando al 404-785-7477.

Autorización
¿Tiene alguna pregunta sobre lo que acaba de leer? ¿Hay alguna parte que no le haya quedado clara?
¿Está de acuerdo con formar parte del estudio?

El participante accede a participar: Sí No Si la respuesta es Sí:

Persona a cargo de la discusión sobre el consentimiento informado Persona a cargo de la discusión sobre el consentimiento informado

Nombre del Participante:

Fecha:

Hora:

C. Interview Guide for Hispanic Participants: English Version

1. How familiar were you with the term Autism before your loved one was diagnosed?

2. When you speak to your friends and family about your loved one's ASD diagnosis, how do they usually respond?
    a. Do they know any information on autism?
    b. Do you find it challenging to communicate this kind of information?
    c. Has the community treated he/she/them differently after they found out about their diagnosis?

3. Do you believe Hispanic people have a different viewpoint on Autism?
    a. Do you think it's due to a lack of information?

4. How was Autism perceived when you were younger? Was it called something else?

5. When you first detected signs of Autism in your loved one what did you think was going on?
    a. Did you talk to anyone in your community about these signs?

6. When did you decide to speak to a doctor? Or did the doctor notice first? If it wasn't a doctor and instead a teacher or another source, how did they tell you?
    a. How did you feel when they told you your loved one might have autism?

7. How long did it take you to eventually get an ASD diagnosis for your loved one from the doctor?
    a. Were there any concerns before you eventually brought it up?

8. When having this conversation with a doctor, did the doctor validate your concerns?
    a. Did the doctor think your loved one may have had another condition?

9. What other obstacles, if any, did you feel you had in obtaining a diagnosis (i.e.. Transportation issues, lack of doctor availability etc.)

10. Do you think being Latino, influenced the autism care your loved one received?
    a. For example, has any have doctors treated you differently because you were Hispanic or was there ever a lack of Spanish interpreters when you needed one?

11. If you had a friend whose loved one seemed to have autism but had not gotten an autism diagnosis, what advice would you give to this friend?

12. Some researchers have found that Latino children are diagnosed with autism less often than other children and at a much later age. Why do you think that is the case?

13. If you could give doctors (and the entire healthcare system as a whole) one suggestion to make things easier for Hispanic families to receive an autism diagnosis, what would you suggest?

D. Interview Guide for Hispanic Participants: Spanish Version

1. ¿Qué tan familiarizado/a estaba con el término autismo antes de que diagnosticaran a su ser querido?

2. Cuando habla con sus amigos y familiares sobre el diagnóstico de TEA de su ser querido, ¿cómo responden?
    a. ¿Tienen alguna información sobre el autismo?
    b. ¿Le resulta difícil comunicar este tipo de información?
    c. ¿La comunidad ha tratado de manera diferente a él/ella/elle desde que supieron sobre su diagnóstico?

14. ¿Cree que las personas hispanas tienen una perspectiva diferente sobre el autismo?
    a. ¿Cree que se debe a una falta de información?

15. ¿Cómo se percibía el autismo cuando era más joven? ¿Se llamaba de otra manera?

Preguntas relacionadas con las barreras para obtener un diagnóstico de autismo:

5. Cuando detectó por primera vez señales de autismo en su ser querido, ¿qué pensó que estaba pasando?
    a. ¿Habló con alguien de su comunidad sobre estas señales?

16. ¿Cuándo decidió hablar con un médico? ¿O fue el médico quien lo notó primero? Si no fue un médico, sino un maestro u otra fuente, ¿cómo se lo dijeron?
    a. ¿Cómo se sintió cuando le dijeron que su ser querido podría tener autismo?

17. ¿Cuánto tiempo le tomó obtener finalmente un diagnóstico de TEA para su ser querido por parte del médico?
    a. ¿Hubo preocupaciones antes de que finalmente lo mencionara?

18. Cuando tuvo esta conversación con el médico, ¿validó el médico sus preocupaciones?
    a. ¿El médico pensó que su ser querido podría tener otra condición?

19. ¿Qué otros obstáculos, si es que hubo alguno, sintió que tuvo para obtener un diagnóstico (por ejemplo, problemas de transporte, falta de disponibilidad de médicos, etc.)?

20. ¿Cree que ser latino/a influyó en la atención relacionada con el autismo que recibió su ser querido?

    a. Por ejemplo, ¿algún médico lo trató de manera diferente porque era hispano? ¿O alguna vez hubo falta de intérpretes en español cuando los necesitó?

11. Si tuviera un amigo cuyo ser querido pareciera tener autismo, pero aún no hubiera obtenido un diagnóstico, ¿qué consejo le daría a este amigo?

12. Algunos investigadores han encontrado que los niños hispanos son diagnosticados con autismo con menos frecuencia que otros niños y a una edad mucho más tardía. ¿Por qué cree que sucede esto?

13. Si pudiera dar una sugerencia a los médicos (y al sistema de salud en general) para facilitar que las familias hispanas reciban un diagnóstico de autismo, ¿qué sugeriría?

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