



## **Exploring Autism Disparities Among Young Latinas: A Collective Case Study**

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### **Abstract**

There is increasing evidence of ethnic and sex disparities in autism spectrum disorder (ASD) identification and receipt of services. Compared to White males, females and Latinos are both more likely to receive a delayed diagnosis and less likely to receive high-quality services. Little is known, however, about young Latinas (females) with ASD, including how their ‘pathway to a diagnosis’ compares to non-Latina White females. To address this gap, this collective case study draws upon interviews with four families from two larger qualitative studies investigating ASD disparities. The purpose of this study is to compare the ASD diagnosis experiences of three Latino families and one non-Latino White family of young females with ASD. Two researchers coded seven interviews using thematic and narrative analysis. The researchers identified three themes: 1) The Latino cases involved extended family members as both barriers and facilitators to the ASD experience, while the non-Latino case had little extended family involvement; 2) The Latino cases involved a tension between specialized ASD knowledge and culturally-influenced stigma around disability; 3) All cases suggest a female ASD phenotype that differs from the traditional ASD presentation. The study concludes with recommendations for improving support for Latino families with females with ASD.

*Keywords:* Latina, Autism Spectrum Disorder (ASD), Female, Health Disparities

### **Introduction**

Autism spectrum disorder (ASD) is a developmental disability characterized by deficits in social communication and engagement in restrictive, repetitive behavior (American Psychiatric Association, 2013). The estimated prevalence has increased over the past few decades and is currently one in 54 children age eight (Maenner et al., 2020). Experts agree that the true ASD prevalence is not dependent on characteristics such as race, ethnicity, sex, education, socio-economic status, or geography (Dyches et al., 2004). However, recent research suggests that certain populations of children are at risk of under-identification (Angell et al., 2018). This includes Latino children and females, who are less likely than non-Latino White males to be diagnosed, even when presenting similar ASD traits; and are more likely to receive a delayed diagnosis (Lai et al., 2015; Magaña et al., 2013). Little is known, however, about young Latinas

with ASD, including the processes by which they come to receive a diagnosis. This qualitative study aims to address this gap.

### **Latino Children with Autism**

Latinos are the largest ethnic minority in the United States, yet they are diagnosed with ASD at lower rates than other groups (Maenner et al., 2020; Ennis et al., 2011.) Compared to White non-Latino children, Latino children are less likely to be diagnosed even when presenting with ASD traits; more likely to be mis-diagnosed; require more healthcare visits before obtaining an accurate diagnosis; and are more likely to receive a delayed diagnosis (Benevides et al., 2016; Magaña et al., 2013; Zuckerman et al., 2017). Once diagnosed, Latino children have worse access to and utilization of high-quality healthcare (Parish et al., 2012).

These disparities are caused by complex factors, including culturally-influenced differences in parents' 'first concerns' (Issarraras et al., 2019); a lack of ASD knowledge in the Latino community (Zuckerman et al., 2014); implicit or explicit healthcare provider bias (Zuckerman et al., 2013); and a lack of Spanish-language services (Zuckerman et al., 2013) and culturally appropriate ASD interventions (DuBay et al., 2018). Little is known, however, about whether and how these factors relate to disparities for young Latinas with ASD specifically.

### **Females with Autism**

Like Latino children, females are also significantly under-identified with ASD. The ASD ratio of males to females is approximately 4:1, but experts increasingly agree that this is partially due to under-identification in females (Maenner et al., 2020; Lai et al., 2015). Females are less likely to be diagnosed, even when displaying ASD traits, and more likely to receive a delayed diagnosis (Giarelli et al., 2010; Loomes et al., 2017). It was previously believed that females with ASD were more likely to have intellectual disability than males with ASD, but it now appears that females without intellectual disability are simply less likely to be identified (Carpenter et al. 2019).

Emerging literature on a female ASD phenotype describes how females differ from males in their ASD presentation. Current literature is not definitive on its extant but provides evidence in favor of it. Studies have found that females with ASD demonstrate fewer social impairments and stronger motivations for social interactions (Allely, 2019; Hull et al., 2020). There is also support for females' ability to camouflage, or mask, their ASD characteristics in order to fit in with their social settings (Hull et al., 2020). The disparate ASD presentation in females could potentially

lead to under recognition of females with ASD as they differ from the traditional diagnostic criteria. Little is known however, about a potential female phenotype in Latinas.

### **Latinos and Mental Health**

Previous studies have found that Latinos have reduced access to mental health treatments, and that this may be influenced in part by mental health stigma. Latino children with mental health problems have been found to have greater unmet mental healthcare needs than non-Latino White children (Kataoka et al., 2002). Latino parents report fear of judgment from other Latinos and mistrust towards mental health professionals as cultural barriers in accessing mental healthcare treatment (Dixon De Silva et al., 2020). Few studies, however, focus on mental health stigma among Latinas specifically.

### **Intersectionality**

Intersectionality refers to how social identities i.e. race, sex, gender, ability, class, etc. interact to create complex personal experiences (Smooth, 2013). This study focuses on the intersection between being Latino, being a female and having a developmental disability. There is a dearth of research on this intersectional identity, but its complexity leads the researchers of this study to believe that young Latinas with ASD will face greater disparities than children without this intersectional social identity.

Although research increasingly points to the existence of ASD disparities among Latinos and among females, no studies to date have focused on Latina females with ASD. There is a critical need for further research to understand the ASD diagnostic experiences of Latino families with females with ASD. Understanding these narratives provide a first step in reducing disparities in this vulnerable population.

### **Aims and Hypotheses**

This qualitative research study aims to address this gap in the literature by investigating how Latino families of females with ASD experienced the ‘pathway to a diagnosis’ (Hurt et al., 2019). The purpose of this collective case study (Creswell et al., 2007) is to compare the experiences of Latino and non-Latino White families in obtaining an ASD diagnosis for their daughters. The specific aims are to: 1) Collect family narratives about how Latino and non-Latino White families came to obtain an ASD diagnosis; and 2) Compare the experiences of Latino and non-Latino White families of females with ASD.

As a qualitative study, it is not possible to conduct hypothesis testing nor make statistical inferences to a larger population. However, the researchers expected Latino families of females with ASD, who hold intersecting identities with documented health disparities, would face unique challenges in receiving an ASD diagnosis, compared to non-Latino White families.

## Method

### Study Design

Drawing upon two larger qualitative studies, the researchers used a collective case study approach to compare the experiences of Latino and non-Latino White families of females with ASD (Creswell et al., 2007). The researchers used semi-structured narrative interviews to understand the families' experiences of obtaining an ASD diagnosis. The cases were drawn from two studies: 1) A study of Latino families' experiences with ASD in Los Angeles County, California (Angell, 2016) (from here on, Study 1); and 2) A study of the experiences of families of females with ASD in Gainesville, Florida (Study 2).

### Participants and Recruitment

**Table 1.** Participant Pseudonyms

Study	Parent	Daughter
Study 1 (Latino)	Fabiana	Isabella
Study 1	Miriam	Olivia
Study 1	Sarah	Gabriela
Study 2 (Non-Latino White)	Elise	Katelyn

Participants included three Latino families of females with ASD from Study 1 and one non-Latino White family of a female with ASD from Study 2 (see Table 1). Study 1 was approved by the University of Southern California Institutional Review Board (#HS-13-00589), and families were recruited through a local Regional Center. The Regional Center sent study flyers to random families in their database that fit the following eligibility requirements: Age 18 or older; self-identification as Latino or Hispanic; bilingual (Spanish/English); and parent/caregiver to a child 8 years old or younger diagnosed with ASD by a licensed professional. Study 2 was approved by the University of Florida Institutional Review Board (IRB-02 IRB201902919), and families were recruited through the University of Florida Center for Autism and Related Disabilities (UF CARD). UF CARD distributed study flyers via their email listserv and Facebook page and displayed flyers at their office. Inclusion criteria were: Age 18 or older; able to speak English or Spanish; parent/caregiver of a female diagnosed with ASD by a licensed professional within the

past five years; and lives in or can travel to Gainesville. Parents in Study 1 received a \$75 stipend for two interviews. Parents in Study 2 received a \$20 gift card for one interview.

### **Data Collection and Analysis**

The data corpus for this study includes seven audio-recorded interviews, two for each Latino family and one for the non-Latino White family. Interviews took place in-person using open-ended questions to elicit family narratives about their ‘pathway to a diagnosis,’ i.e. their experiences obtaining an ASD diagnosis and services for their children. The interviews with the Latino families took place at a location of the family’s choice i.e. the family home or a coffee shop and the non-Latino White family’s in the researchers’ university office. The interviews lasted between 60 and 90 minutes. Each interview was transcribed verbatim, using pseudonyms to replace identifiable information. Two researchers independently coded the transcripts using thematic analysis (Braun & Clarke, 2006). They developed an initial codebook then utilized an iterative process of discussing and resolving any differences, identifying patterns across the Latino and non-Latino White cases. Throughout the analytic process, the first author reflected on her experiences as a Latina and the second author on her experiences as a mother (Frank, 1997).

### **Results**

The researchers identified three major themes: Family Support, ASD Knowledge, and Female ASD Phenotype. The themes and supporting quotes are described below.

#### **Theme 1: Family Involvement**

The Latino families’ extended family members were involved in their daily lives, both as challenges and support. Fabiana described how, as Isabella’s ASD related behaviors became more challenging, Fabiana’s in-laws were unwilling to help and even attempted to disrupt Isabella’s therapies. Fabiana said, “My in-laws weren’t on board [with the therapies], so they would distract [her].” Fabiana perceived this to be related to traditional views that Fabiana and her husband should have consulted with the in-laws about when when and how many children to have. She said, "I felt like they're singling me out, like why should I be asking for anyone to help me when I wanted these kids?" Her own parents were also initially unwilling to help, but they eventually became supportive and even provided respite care. Miriam described how her parents helped pay for vitamins and supplements that Miriam used to treat Olivia’s ASD. Sarah’s aunt provided her and her daughters with a place to live, which was critical after Sarah’s divorce.

However, she felt limited support in helping to manage Gabriela's behavior. She felt this was related to traditional views about divorce. She said:

So it's just me and the females, and it's hard, when you need someone to be there for you. And you need someone to say [to them] , "You know what, please stay with her five minutes. Let me go outside and get a break." And I don't have that. I don't have that and it makes it harder. And [my] family does not understand that you need a break from your kids. I think this is where tradition takes place, of, "You decided to get separated from your husband, so now you handle your kids."

By contrast, the non-Latino family had very little extended family involvement. When asked if others had expressed concerns about Katelyn's development, Elise said, "We don't have a huge family. So she doesn't have a lot of intervention and her other grandparents aren't interested in anything. So they wouldn't have noticed anyway."

### **Theme 2: ASD Knowledge and Attitude**

Often, the lack of support from Latino extended family members was rooted in a lack of ASD knowledge. Fabiana's in-laws did not believe Isabella's diagnosis and blamed Fabiana for Isabella's challenging behavior. They felt Fabiana should simply "work harder as a mom." She attributed this belief to them being "old school Mexicans." Similarly, Sarah was blamed for not being able to control Gabriela's behavior. She attributed this to Latinos generally being in "denial" about mental health and disabilities and said that Latino families commonly think, "There's nothing wrong with my child. He'll grow out of it," or "We need to be strict [with] him."

The Latino parents in the study, despite developing specialized ASD knowledge, still experienced a culturally influenced stigma around disability. Fabiana and her husband knew about ASD from prior work in behavior therapy and special education, yet for some time, she nevertheless was "in denial" about Isabella's diagnosis. Fabiana said, "I was in denial. [Then] I was like, 'Put your pride aside (...) 'Cause it's better to know [that your child has ASD] than to (...) go through life like, 'Oh, well nothing's wrong with my kid.'" Miriam obtained ASD knowledge from her job in recreation but experienced a tension between knowing that ASD is a lifelong condition and believing that with the right services, Olivia's ASD would 'go away.' Miriam said, "She's going to have it for now, but I don't think she's going to have it forever." Sarah learned about ASD from studying child development and working at a child development center, but she too had difficulty accepting Gabriela's diagnosis. She said, "It was hard, because

as a teacher, and taking the child development classes, I kind of knew that she might have symptoms of autism, but as a mother, I was in denial.”

Elise, like the Latino parents, actively sought ASD information but did not experience the same culturally influenced tension. However, she described her husband’s initial denial about Katelyn’s ASD, and the process of helping him to see ASD differently. Elise said:

Initially he [said], “There's nothing wrong with her.” I was like, “Nobody said there's anything wrong with her. They said she thinks differently.” And he had to get there emotionally. (...) I said to him, “Autism just means she thinks differently. She sees the world differently than the way we see the world, and we are going to have to change how we deal with her, trying to understand how she sees the world, and (...) try to make her understand how we see the world.”

### **Theme 3: Female ASD Phenotype**

All cases support emerging research on a distinct female ASD phenotype. The females in the study presented with early concerns, but their development and abilities raised challenges for accepting an ASD diagnosis. Fabiana and Miriam remembered their daughters reaching developmental milestones at appropriate ages, except for language. Fabiana said, “She did all the normal stuff. Like sat at an appropriate age. I remember she was right on point with everything.” Miriam said, “I mean everything else was fine, she ate fine, she was healthy, she wasn't sick (...) So we didn't think anything of it, you know, other than the speech.” Sarah had more typical ASD ‘first concerns’ for Gabriela, such as playing alone and difficulty with transitions, but as Gabriela developed more skills, Sarah’s denial grew. She said, “She's able to communicate with others, she's able to play around with other children, she's able to tell me her needs. So, to me, it's like, ‘No, she's not autistic.” Elise’s first concerns about Katelyn included sensory sensitivities and emotional regulation issues, but because of Katelyn’s social abilities and intelligence, healthcare providers were slow to diagnose her. Elise said:

[They] told me, ‘She's just so social and she makes eye contact. She's not autistic, you're trying to just make excuses for her. (...) So I just felt like all the way along everyone wanted to put a roadblock, because she's charming (...), and say ‘It can't possibly be autism because she likes people.’ Um, O.K., it presents differently in girls!

The researchers expected that the Latino families would face unique challenges in receiving an ASD diagnosis for their daughters. This study provides an initial understanding

of the challenges, but much more research is needed, for example to understand the possible female ASD phenotype and how it manifests in Latinas.

### **Discussion**

The findings of this study provide a deeper understanding of an under-researched, underserved community, young Latinas with ASD. This analysis revealed that family supports were important, culture influenced ASD knowledge, and the daughters may have aligned with a distinct female phenotype.

All three Latino families discussed their desire for familial support, suggesting support is intrinsically part of Latino culture. The Latino parents expected their family members to be more involved with their daughters' ASD care, just as previous research indicates that Latino families of children with disabilities rely heavily on family for support (Bailey et al., 1999). A particular challenge for the Latino families in this study was their extended family members' lack of knowledge about ASD. Two of the Latino families and the non-Latino white family experienced stigma related to ASD, and all experienced initial denial about the diagnosis. This is consistent with previous research that shows a lack of access to ASD knowledge in the Latino community and Latino parents' reports of embarrassment, shame, and rejection associated with mental health issues (Zuckerman et al., 2014). There is a continued need for ASD information, which can reduce stigma, in Latino communities.

Another challenge for parents in this study was that their daughters' ASD presentation did not meet what they, and/or providers, expected. Two of the Latina mothers discussed how their daughters reached developmental milestones, causing the families to disbelieve the ASD diagnosis. The absence of social difficulties, or lack of delay in certain developmental areas, could relate to growing research on a potential distinctly female presentation of ASD. Although studies on sex differences in ASD symptomology have yielded mixed findings, there is emerging evidence that females may have less social impairment, or may have more subtle developmental challenges, compared to males (Constantino & Charman, 2012; Little et al., 2017). Our findings show the need for future research to examine the female ASD phenotype in Latinas.

Several limitations of this study should be noted. The Latino cases may have differed from the non-Latino White case due to geography, state service systems, and timing of data collection (2014 to 2020). Due to time constraints, only one interview was conducted with the non-Latino White family. Qualitative research cannot be used to generalize to broader populations, as it does



not use hypothesis testing or inferential statistics. Rather, these findings can be used to develop further research questions and hypotheses and may be applicable to broader populations.

The findings of this study point to the need for interventions to increase knowledge about ASD in the Latino community, supportive services such as respite for Latino families of females with ASD, and education of providers on how ASD can present in Latina females.

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