

Number One Advocate: A Qualitative Study on Latine Mothers of Children with Autism

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Abstract:

This qualitative study explored the lived experiences of Latine mothers raising children with autism. Interviews revealed key insights into their journey to diagnosis, cultural and systemic barriers, and the vital role of support networks, faith, and advocacy. Contrary to passive and deficit-based narratives, the mothers emerged as strong advocates, navigating services, coordinating care, and resisting systemic failures. Their stories reflect resilience, cultural strength, and a commitment to their children’s well-being. Future research should examine their evolving role across the life course and the support needed during transition stages.

Introduction:

- ASD is a neurodevelopmental disorder diagnosed in 1 in 36 children in the U.S., with Latine children experiencing even higher rates—1 in 32—yet they are often diagnosed later, around age 4, compared to White children who usually receive a diagnosis 1-2 years earlier (APA, 2022; Christensen et al., 2016; Maenner et al., 2023; Zuckerman et al., 2021).
- Delays in diagnosis limit access to early intervention services, which are critical for developmental progress (Elder et al., 2017; Kasari et al., 2015).
- Latine families** face intersecting **social, cultural, and systemic barriers**—including language differences, stigma, and bias from healthcare, educational, and service providers—that hinder access to timely and equitable support.(DuBay et al., 2018; Hull et al., 2020).
- This research aims to uplift the **lived experiences of Latine mothers**, identify systemic barriers, and offer insight into how service providers can develop more **culturally responsive** and equitable practices.

Methods:

This qualitative study, conducted through in-depth interviews, identified key barriers and sources of resilience to inform more culturally responsive and equitable practices for families navigating ASD-related systems.

- Approval was obtained from the Institutional Review Board (IRB) at California State University, Long Beach (CSULB).
- Fifteen Latine mothers were recruited using purposive and snowball sampling methods and interviewed in a semi-structured interview with 14 open questions.
- The interview questions were organized into several topics: experiences leading to the diagnosis, acquisition of services, mothers' emotional well-being, and plans for their children.
- All interviews were conducted in English or Spanish, based on the participants' language preferences, and were audio recorded and transcribed.
- Each participant was given a \$25 gift card to Target as an appreciative token for their time and participation.

Characteristics	%	f
Gender		
Male	0.0%	0
Female	100.0%	15
Age		
20-29 years old	13.3%	2
30-39 years old	60.0%	9
40-49 years old	6.7%	1
50-59 years old	20.0%	3
Marital Status		
Single	33.3%	5
Married	66.7%	10
Divorced	0.0%	0
Country of Origin		
United States		10
Mexico	33.3%	5
Employment Status		
Full-Time	46.7%	7
Part-Time	6.7%	1
Unemployed	46.7%	7
Highest Level of Education		
Elementary	13.3%	2
High School Diploma	13.3%	2
Some College	6.7%	1
Associate's	6.7%	1
Bachelor Degree	40.0%	6
Master's Degree	13.3%	2
Doctorate Degree	6.7%	1
Religion		
None	13.3%	2
Christian	6.7%	1
Spiritual	6.7%	1
Catholic	73.3%	11
Primary Language		
English	80.0%	12
Spanish	20.0%	3
Annual Income		
\$6-49k	26.7%	4
50k-99k	13.3%	2
100k-149k	20.0%	3
150k-199k	20.0%	3
200k- up	6.7%	1
N/A	13.3%	2
Supportive family in home		
Yes	33.3%	5
No	66.7%	10
Spouse living in home		
Yes	20.0%	3
No	80.0%	12

Table 1 shows the mothers' demographics, and Table 2 shows their children's demographics.

Characteristics	%	f
Gender		
Male	86.7%	13
Female	13.3%	2
Age		
3-4 years old	40.0%	6
7-10 years old	6.7%	1
11-14 years old	40.0%	6
15-18 years old	6.7%	1
18 and older	6.7%	1
Age at Diagnosis		
1-2	87.5%	6
3-4	12.5%	9
Other Siblings		
Yes	66.7%	10
No	33.3%	5

Results:

(1) The journey toward diagnosis and acceptance

Mothers (n=15) recognized early signs of developmental delays between ages 1 and 3. Their emotional responses included shock, grief, and eventual acceptance over time.

“Yes, as I told you, it was that I didn't know. So I had to learn to first accept it because at first I didn't accept it; [it was hard] for me to accept that one [has] a child like that, but once I accepted it, it was easier for me, and I learned to take care of her.” – Gorgina

(2) The struggle for diagnosis and acceptance

Most (n=11) faced dismissal or “wait and see” advice from providers, leading to delayed diagnoses and service access. Barriers included language, insurance, long wait times, and referrals to general developmental services without an ASD diagnosis.

“But soon after that, he stopped talking, he started grunting...I remember going to his pediatrician and I said, 'I also noticed that he's like walking on his tippy toes and he's arm flapping.' ... she said, 'Oh well, I think that's developmentally appropriate because he's little.' ... 'No, I sense something, not only as his mom, but also as I guess as a mental professional who knows a little something.' Years later, she apologized and said, 'I'm sorry I didn't take your concerns more seriously.' ... So that was touching....She did apologize because she said, 'I should have taken your concerns more seriously.' I think meaning...we could have started the assessment process sooner.” – Valeria

(3) Embracing the advocate role

Mothers (n=15) demonstrated commitment to advocating for their children. Despite the emotional strain, they emerged as empowered advocates who amplified their children’s voices within educational and medical treatment plans. This involved coordinating care, researching, collaborating with providers, and challenging the limitations of ableism.

I felt like I was the first one to notice it. So it's like it wasn't like news to me, but I remember, when I went to the regional center and then...when we got in the car, I was bawling my eyes out. And I don't know, it felt like such a weird feeling to know he's okay, but he's [pauses] he's not okay, but he is okay... Now that I know it's official, I really have to step up my game and be his number one because, at the end of the day, I'm his number one caretaker.- Karla

(4) Navigating roadblocks in supports and services

Post-diagnosis barriers included insurance-related delays (n=4), financial constraints (n=4), scheduling conflicts (n=3), waitlists for evaluations (n=3) and services (n=5), and provider turnover (n=3). Educational barriers included limited support (n=6), bullying concerns (n=4), and IEP decision pressure (n=1). Mothers (n=15) faced cultural stigma, misunderstandings, and criticism. Mothers with limited English proficiency faced language barriers. Many (n=13), providing psychoeducation to their community. Supportive doctors and regional centers were essential supports.

I will say at first, when he was diagnosed, my parents obviously were like, 'What is that? And how are you going to fix it?' And I had to kind of be like, 'We can't fix this. It's not something where we're going to fix him. That's not how this works.' ...Sadly, it's made me not be as close to my heritage or to my culture because [it's] a culture of...not accepting people [with] any kind of disability...It's like, 'You're just a bad kid. ' Like 'You don't discipline your child; the behavior is a result of your bad parenting. ' It's not understanding. ' – Griselda

(5) Finding strength through support

Mothers found strength through family (n=10), spouses (n=11), professional connections (n=7), community (n=9), and peer support (n=3). Maternal mothers and a mother-in-law (n=10) emerged as central supportive figures. Some mothers (n=9) self-isolated as a protective response to judgment. Faith also fostered resilience.

“There's a saying that my mom always says in Spanish, “Si Dios quiere/ God willing.” I think I stuck to that. I pray every night, and I pray for my daughter and to the Virgin Mary, as well. So I could say that I still have some of my culture, too, to pray, but to give me guidance, not to cure her.” - Natalia

(6) Planning for the future

Mothers (n=4) pursued healthier lifestyles, taught essential life skills (n=6), and financially planned (n=4) to ensure long-term care. They (n=4) feared future safety risks for their child’s adulthood, particularly with law enforcement. All mothers (n=15) discovered meaning and growth in their journeys. Faith (n=6) gave hope for the future, and the diagnosis was transformative for their self-identity.

“Really can happen to me like I cannot die [laughs]. I cannot die like I have to die when I'm really, really, nothing old...because I need to be there for him...Again, I see myself living a really long time in my ideal world.” - Valeria

“He needs to learn how to do something because when we're gone, what is he going to do?...Because our plan is to pay our house. We're like halfway there..., to try to pay off as soon as we can to have stability somewhere for them to stay...And then we have to do the trust for them, for the trust for the house. But my husband's like, 'I could leave him \$80,000, \$100,000. It's not enough to survive' - Yolanda

Implications:

Practice:

- Current findings highlight the **importance of culturally responsive care and the inclusion of Latine mothers as collaborators** in medical, educational, and social work settings.
- To build trust, **prioritize personalismo and confianza** in provider-patient relationships.
- Social workers** should advocate for families during IEP meetings and service planning, connect them to resources, offer workshops on autism, and encourage shared caregiving responsibilities to ease the strain on mothers.

Research:

- Ongoing research should focus on longitudinal studies to understand how Latine mothers’ roles evolve as their children grow.
- Continue examining **intersectionality through narratives of caregivers** and other family members. Research should further explore how undocumented status affects Latine families’ access to ASD services and supports.

Policy and Advocacy:

- The findings affirm the need for mandated **early developmental screenings, culturally responsive IEP protocols**, and healthcare providers to **respond to and assess parents' concerns**.
- Language-accessible systems and collaborative, family-centered care** must be prioritized, along with equitable funding and expanded lifespan support for autistic individuals.
- Practitioners and policymakers should receive ongoing training** on cultural responsiveness, implicit bias, language accessibility, and intersectionality.
- Policies should also prioritize hiring bilingual providers and offer family-centered ASD psychoeducation across healthcare, education, and social services.

Conclusions: The results show how systemic barriers continue to prevent early diagnosis and access to services for Latine children with autism. Latine mothers are portrayed as active and skillful advocates, contrasting with previous research that depicted them as passive. Culturally responsive care, education, and interventions can expand opportunities for children with autism and reduce the barriers faced by their caregivers. These interventions can address socio-cultural and structural barriers while improving lifelong support. Theoretical frameworks, such as ecological systems theory, critical race theory, and socio-cultural theory, offer helpful lenses for understanding the layers of Latine caregiving.

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