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# Undocumented Mexican mothers of children with autism: navigating the health care and educational service systems

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In the field of education and health care, researchers and educators attempt to close the diagnosis/identification and service gaps that persist for low-resourced, underrepresented families with children with autism. One group of families particularly difficult to engage in research and interventions is undocumented immigrant families. We know little about whether these families are obtaining a timely diagnosis or services for their children with autism. This study addresses how undocumented Mexican immigrant mothers of children with autism navigate the special education and health care systems, challenges they face in doing so, and the helpers who assist in navigating the process. Six undocumented Mexican immigrant mothers of children with autism participated in one-on-one interviews. Participants were interviewed in a semi-structured format and transcription, coding, and final analysis were conducted in Spanish using analytic software. Three broad themes emerged during the content analysis process: (1) immigration driving force and experience, (2) autism-specific challenges, and (3) autism-specific helpers. Additionally, a case study of each participant is presented and discussed.

**Keywords:** Autism; immigrant families; undocumented; community-based; mothers; Latinx

## Introduction

Autism spectrum disorder is an equal opportunity developmental disability in that it exists across racial, ethnic, linguistic, and socioeconomic boundaries. However, access to diagnostic and intervention services are not equal, with the most vulnerable families and children having limited access (Stahmer *et al.* 2019). Among the most vulnerable are immigrant families from Mexico who reside in the U.S.A., with unauthorized immigration status (i.e. undocumented) (Yoshikawa *et al.* 2016). While there is an expanding body of research examining the lives of undocumented families and students in the U.S.A. (Enriquez 2015, Yoshikawa *et al.* 2016) we know little about undocumented immigrant families with children with disabilities. The number of undocumented immigrants residing in the U.S.A. is an estimation which varies by the methodology used. A recent report shows an estimated number of 11.96 million (Office of

Immigration Statistics, US Department of Homeland Security 2018). Importantly, in one study, the author estimated that 16.6 million people are living in mixed status (undocumented and documented) families in the U.S.A. alone (Enriquez 2015). Given that autism is one of the fastest growing disability categories in the U.S.A. (Center for Disease Control and Prevention 2018a), it becomes imperative to learn more about this population of families. More importantly, given the fact that much of the current xenophobic and racist rhetoric is often focused on immigrants from Mexico and Central America (Wray-Lake *et al.* 2018), it should be of great interest to researchers, educators, and policy makers alike to examine the challenges and facilitators that this community faces within the education and health care system.

## Review of the literature

As background information, autism is characterized by restricted interests, repetitive behaviors, and deficits in social communication that can impact an individual throughout life (American Psychiatric Association, 2013). The current autism prevalence rate in the U.S.A. is 1/59

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(Center for Disease Control and Prevention 2018b). In the U.S.A., children with autism are typically entitled to school-based services and instructional accommodations under the Individuals with Disabilities Education Act (IDEA). This federal public education law provides free services and supports for students with autism and other disabilities whose education is negatively impacted and who qualify for an Individualized Education Program (IEP). Additionally, children with autism and their families may qualify for other free services and treatments in individual states' health care and service systems (e.g. the Regional Centers for developmental delays in California). The Regional Centers in California are organizations that are tasked with helping families coordinate and access services available to individuals with developmental disabilities and their families. As the number of cases of children identified with autism increases, the need for early identification and early intervention becomes evident (Peacock and Lin 2012). In a recent report of a longitudinal study, Lord (2020) noted that accessing early treatment the first months after diagnosis was a significant predictor of long-term positive outcomes (i.e. into adulthood) for individuals with autism and their families. Delaying intervention services may limit children's abilities later in life. Because most research samples are White and higher Socio-Economic Status (SES), we know less about the identification and treatment with Culturally, Linguistically, and Economically Diverse (CLED) populations. We do know, however, that there have been documented gaps in the age of diagnosis/identification and service access for Latinx and African-American Children (Angell et al. 2018, Magaña et al. 2017, Mandell et al. 2009).

Due to a multitude of factors, parents of immigrant-origin students, and Latinx parents in particular, may be at a disadvantage when advocating for early identification and intervention services and educational placements for their children (e.g. special education vs. inclusion setting). For instance, earlier studies have found that Spanish-speaking Latinx families reported that schools often lack the supports necessary to bridge communication gaps and misunderstandings in the IEP process (Larios and Zetlin 2018). Other plausible explanations for the delay in identification and diagnosis for children of Mexican parents specifically include cultural differences in parent's perceptions of autism symptoms. Blacher et al. (2014) noted that Mexican heritage mothers did not expect their children to speak until after 3 years of age. Thus, when their children exhibited delays in language, they were not concerned.

The gaps in diagnosis and treatment have been the focus of recent autism research in the Latinx community, particularly with Spanish-speaking families (Magaña et al. 2017). This line of research addresses

some of the challenges faced by Latinx families. For example, some community-based interventions have focused on understanding barriers in the Spanish-speaking community (Zuckerman et al. 2014b). Other research has focused on increasing advocacy and child development skills for Latinx Spanish-speaking parents (Magaña et al. 2017).

Importantly, it should be noted that Latinx immigrants and Mexican immigrants are not a homogenous group, and their identity and challenges are shaped by a multitude of factors (Chavez-Dueñas et al. 2019). While immigrant parents face barriers in obtaining a timely diagnosis, identification and services in schools and beyond (Zuckerman et al., 2014a), obtaining a diagnosis may prove especially daunting for Mexican immigrant parents with undocumented status (i.e. unauthorized immigration status). Because of the sensitive nature of being undocumented, we have very little information on how or if parents seek an autism diagnosis/identification and/or access services in public service institutions (e.g. clinics, schools). This information is critical for health care services providers and educators serving immigrant and vulnerable communities. This might be an important step in addressing inequities in autism diagnosis and services for minority children.

This study aimed to address the need for further research with undocumented parents of children with disabilities by investigating the experiences of undocumented Mexican mothers of children with autism in obtaining an identification/diagnosis and services in school or other public institution (e.g. early intervention programs, regional centers). The research questions for this study were 1) How do mothers of children with autism describe their immigration experience to the U.S.A.? 2) How do mothers of children with autism describe their driving forces that lead to immigration? 3) How did Latinx families obtain an autism spectrum disorder (ASD) diagnosis and services for their children; and what challenges and facilitators did Latinx families find in obtaining a diagnosis and services for their children with ASD?

## Methods

A social-ecological framework was implemented in this study to examine different factors that might affect the educational and health care outcomes for children growing up in households with at least one family member with undocumented immigration status (Suarez-Orozco et al. 2011). Suarez-Orozco and colleagues developed this socio-ecological framework of the effects of mixed-status families. In this study, we employed this method and further developed this framework to include parents in mixed status families (i.e. at least one undocumented parent). More specifically, we considered the interplay between parents, community, and societal factors that impacted the participants in the

**Table 1. Participants' immigration and background information.**

Participant	Years living in the US	Annual income	Method of arrival	Place of origin in Mexico	Age of child's diagnosis
Maria	18 years	\$10,000–\$19,000	Overstayed tourist visa	Puebla	2.5 years
Ramona	14 years	\$10,000–\$19,000	Unauthorized Entry: Hiding in the trunk of a car	Guadalajara	6 years
Ana	22 years	\$10,000–\$19,000	Unauthorized Entry: Unknown method	Puebla	10 years
Victoria	13 years	\$10,000–\$19,000	Unauthorized Entry: Crossing a River	Michoacán	5 years
Laura	28 years	\$39,000–\$49,000	Overstayed tourist visa	Guadalajara	4 years
Fernanda	14 years	\$10,000–\$19,000	Overstayed tourist visa	Los Altos de Jalisco	9 years

study from recruitment to data analysis. Furthermore, in order to address the research questions, we recruited participants through a community-based organization focused on helping Spanish-speaking families navigate the special education and health care systems in California. Participants were recruited to participate in a one-on-one interview with the help of a trusted community leader from the same organization. The community-based setting allowed researchers to take a *familismo* approach. *Familismo* refers to a family-centered orientation that characterizes Latinx families and which is critical for building trusting relationships with this community (Magaña, 2020). More specifically, both the first author and second author are Latinx and immigrant-origin. The first author had a working relationship with the community-based organization and communicated constantly with parents in Spanish and English.

### Participants

A total of six undocumented Mexican immigrant mothers of children with autism participated in one-on-one interviews. Undocumented status was self-reported and confirmed by the community organization parent coordinator. Participant inclusion criteria for the study included a) Undocumented immigrant parent (i.e. self-reported unauthorized immigration status), b) Spanish-speaking and self-reported lack of English proficiency, and c) Had a child, regardless of age, with an autism diagnosis as documented by the community-based organization. Exclusion criteria included a) Immigrant parents who had obtained legal status in the U.S.A. and b) Had a child with a disability other than autism. Exclusionary criteria were determined based on the scope of this investigation on parents of children with autism. More specifically, we aimed to look at how undocumented status in families impact the existing inequities in autism diagnosis and services. Additionally, there was a specific emphasis on undocumented parents from Mexico who speak Spanish. Recruiting was done through a trusted community leader who was personally aware of the varying immigration status of families previously enrolled in their advocacy programs. The first author was able to build rapport and a trusting relationship with the community

leader through years of working together on various community-based initiatives (e.g. autism conference, training for parents). The recruiting strategy allowed the first author to build rapport with the community leader and with participants. Using purposive sampling through the community leader, a total of six participants completed the interview (Table 1). Hence, the community leader reached out to her social network of parents who she knew were undocumented from a database of parents who take part in the community-based organization. The autism diagnosis was verified by the community-based organization via Regional Center enrollment. The community-based organization enrolled participants in their programs using their Regional Center client number, but this information was not verified by the researchers. Participants were interviewed in a semi-structured format in settings ranging from a community center for immigrants, a public library, and a participant's home in a large city in Southern California.

### Measure

#### Interview protocol for undocumented parents of children with autism

The researcher adapted an interview protocol from an earlier study on barriers and facilitators to obtaining an autism diagnosis and services for minority families (Stahmer et al. 2019). The adapted measure included 15 open-response items divided in three domains (i.e. life and immigration experience, autism evaluation, and autism services) (see Appendix A). The life and immigration experience domain aimed to capture participants' experience in arriving in and establishing a life in the U.S.A. (e.g. Tell me about your immigration experience?). This was important in order to explore the motivation for immigration (e.g. Did they immigrate in order to obtain services?) and how this experience had helped or undermined their caregiver role (e.g. Did their method of arrival created possible family trauma that prevented them from seeking diagnosis and treatment?). The autism evaluation domain included items that prompted participants to describe how they first noticed signs of autism, who, and how they obtained a diagnosis (e.g. Who first noticed the signs of autism in your child and when did they notice them?). Finally, the third domain asked about autism-specific services, if

they have any and how they obtained them (e.g. What are some autism services that your child receives, if any?). The interviews, transcription, coding, and analysis were conducted in Spanish by native Spanish speakers.

### **Researcher identity**

The first author conducted all six interviews. The first author is a Latinx Mexican-origin male and a native Spanish speaker who had been working for two years in research studies with the community-based organization from which the mothers were recruited. Participants were aware that the researcher was examining ways to help Latinx Spanish-speaking families of children with autism and other disabilities. While the first author had a working relationship with members of the community-based organization, he did not know the participants before the interviews. Furthermore, the first author established *familismo* (family-oriented) by introducing himself and his background, and describing his past experience working to empower Spanish-speaking families within the community-based organization. Additionally, the author explained the oral consent process and the purpose of studying undocumented families (i.e. addressing inequities in autism). Lastly, the first author reminded participants that their information was going to be kept confidential and that they were free to not answer the questions or stop the interview at any time. The second author was involved in the data analysis process. She was a female research assistant who was also a native Spanish-speaker and from a Latinx immigrant-origin background.

### **Procedure**

The study was approved by the Institutional Review Board of a large university in Southern California. Numerous procedures were put in place to safeguard confidentiality for this vulnerable population of participants. Specifically, all participants were asked to provide a pseudonym at the beginning of the interview. None of their personal information was kept by the research team (i.e. names of family members, addresses, names of schools, or places of work). Likewise, participants were asked to give verbal, rather than written consent, so there would be no paper trail with their names. Interviews lasted between 25–55 min and were audio-recorded. All audiotapes and records of correspondence were destroyed after transcription.

After the recruitment phase, the first author contacted individual participants to provide information about the study and schedule the interviews. Participants were asked to select a place for the interview. Then, at the beginning of each interview, the first author read and explained the consent process, that they could withdraw at any time, and that their testimonial was going to be kept confidential. Specifically,

participants were informed that none of their personal information was going to be collected and that no written consent was required. Additionally, participants were asked to give a pseudonym at the beginning of the interview. Participants were informed that the audio records were going to be deleted after transcription. Participants received a \$20 gift card for their participation, and one participant declined the gift card.

### **Data analysis**

The research team employed established criteria for reporting qualitative research studies (Tong *et al.* 2007). In this method of data analysis, two raters, the first author and the second author used an inductive approach to content analysis designed to address the research questions. The content analysis was an iterative process that involved four steps at each phase after the data collection and transcription of the interviews. First, the first author and the second author read the transcripts individually and took notes to identify emerging themes addressing the study's research questions. Second, they met to discuss the emerging themes and codes. Third, after a discussion and consensus on the themes and codes, a preliminary codebook was developed. Fourth, a reliability test was created in the data analysis software using the preliminary codebook by selecting random excerpts from the transcripts. This process was repeated and revised at least three times, until the first author and the research assistant obtained an inter-rater reliability at or above the 0.70 level. Inter-rater reliability was established using Pooled Cohen's kappa at 0.78, and a final version of the codebook was completed. A total of eight codes were included in the final coding of the transcripts. The authors coded all the excerpts in the transcripts and disagreements were resolved through consensus until thematic saturation was reached. After thematic saturation was reached, a final consensus meeting was held to analyze the results and decide on the overarching themes. Figure 1 shows thematic saturation by themes and frequencies (i.e., the number of times the code was identified in the interview transcript). Additionally, in order to confirm and improve the readability of the findings, case studies of each of the participants were employed (Yin 2014). Hence, the first author created case studies that summarize each of the participant's personal story in order to illustrate the overarching themes in the study. Coding was conducted in Spanish. Results were translated to English.

### **Participant case studies**

In this phase of the data analysis, the first author conducted a case-by-case analysis of the transcripts in order to improve readability and confirmation of the findings (Yin 2014). The first author summarized each of the participant's experiences as they relate to the

Media	Codes								
	Access to Care Challenges	Access to Services Challenges	Cultural Barriers	Diagnosis Challenges	Fear of Deportation	Financial Challenges	Helpers	Immigration to the U.S.	Totals
Interview 6	4	5	1	3			8	1	22
Interview 5	1	4	1	1		5	10	2	24
Interview 4	1	6	3	6	4	4	9	6	39
Interview 3	2	5	7	12		3	8	3	40
Interview 2		4	11	3		1	12	2	33
Interview 1	1	2	11	4	3		6	2	29
Totals	9	26	34	29	7	13	53	16	

Figure 1. Number of times a code was applied in each interview transcript (media by code).

results of the thematic analysis. The purpose of these case studies is to illustrate and expand what is captured in the thematic analysis.

### María

María came to the U.S.A. 18 years ago (at the time of the study) from Puebla, Mexico. She overstayed her stay with her two daughters and eventually got married. Her husband was also undocumented, and she reported that they struggled to achieve some ‘American’ dreams, like buying a house.

El reto más duro creo yo, ha sido como salir adelante porque pues mi esposo tampoco es de este país, y yo entonces, debido a todo eso si tenemos desventaja en como tener una vida mejor. No poder comprar todavía nuestra casa pues porque no tenemos todavía un seguro social, a lo mejor todavía nuestros ingresos son bajos, y pues muchas cosas. Pero, pues de una u otra forma hemos salido adelante.

The hardest challenge, I believe, it's been how to move forward, because my husband is not from this country either, so because of that we are disadvantaged on having a better life. We cannot buy a house because we still do not have social security number and/or our income is low, and many other things. But, one way or another we move forward.

Their income is considered low (\$10,000–19,000 per year), and the lack of social security number has presented many barriers. For example, in terms of health insurance, María and her husband do not receive any benefits. When María has been very sick, they have gone to the emergency room. This is where she usually gets pain medication, but not any follow-up treatment (California law prohibits refusing medical attention in the emergency room to anyone, regardless of documentation). María has big dreams for her children. She has

two older daughters who were brought here as minors from Mexico and who are attending college, both can be considered ‘dreamers’ (i.e. Undocumented immigrants that brought here as minors and were able to remain legally in the U.S.A. during the Obama administration) and one young son with autism who was born in the U.S.A.

Tengo a mis dos señoritas y pues las dos están en el colegio. Yo quiero verlas graduadas, ese es mi mayor reto yo creo, en ellas... y aun en los niños chiquitos, yo veo, como a mi niño el más chico, yo veo que él se va a graduar, él va a estudiar.

I have my two young ladies in school. I want to see them graduate, that's my biggest challenge with them both. And even in young children, I see, how my youngest child, I see how he will graduate, he will go to school.

One of María's daughter was going to college to receive a B.A. in child development at the time of the diagnosis. It was this one daughter that raised red flags about the young son's early development, noticing delays in speaking and crawling. María took her son to the Regional Center as recommended by her daughter. She also eventually took her child to a pediatrician. While María and her husband do not have health care or any other social benefits, her child qualifies for health care and educational services under California law. Importantly, María and her husband contribute tax payments through payroll deductions from their employers, without ever getting any tax returns due to their inability to file yearly tax returns.

María's son was diagnosed by age 2.5, which is a typical age of diagnosis. Nonetheless, she struggled to understand what the diagnosis meant. At first, María was

surprised that autism had no cure. Then, she struggled to navigate the different service systems (health care and school services) which are plagued by paperwork, appointments, and legal issues. Not speaking English, language represented a significant barrier for Maria. Additionally, not having legal status in the U.S.A. represented a constant fear in approaching social-benefit institutions (e.g. Regional Center, School).

Maria received help from community-based organization helping Spanish-speaking parents in order to obtain services for her child. Maria did not qualify for family-centered services because of her lack of U.S. legal documents (i.e. social security). While Maria encountered multiple challenges getting a diagnosis and services, she stays positive.

Pero yo creo en que ese diagnóstico va a desaparecer con toda la ayuda que él va a ir recibiendo.

The diagnosis will disappear with all the help my son will be receiving.

### Victoria

Victoria came to California with her husband 13 years ago with the purpose of seeking a better life for her family. Victoria is from Michoacán, Mexico, a State with high levels of poverty in southern Mexico, and with currently high levels of drug-related violence. Victoria and her husband have very little formal education. They crossed the border into the U.S.A. on their third attempt through the New River in the Mexicali-Calexico border in California. They grabbed themselves to a floating tire as they crossed the U.S.-Mexico border.

Fue en el 2002 y fue difícil porque tuvimos que cruzar la frontera mi esposo y yo. Y pues para tener una vida mejor, la verdad, porque como mi esposo tampoco no tiene muchos estudios.... Por un río, cruzando un río y agarrados de una llanta.

It was in 2002 and it was hard because we had to cross the border my husband and I. And, well, it was to have a better life, that's the truth, because my husband nor I have much schooling.... It was through a river, grabbing ourselves to a < floating > tire.

Once in the U.S.A., Victoria and her husband faced many barriers, including institutional discrimination. Public institutions, she says, look at them as people that come to 'take and take' when in fact they cannot access any social services. Likewise, Victoria stated that her husband works hard and pays taxes but neither of them receive any benefits from the government nor any tax credit or social services.

A veces que va a alguna institución de servicios sociales, siempre miran a uno como que viene a quitar algo que no es de uno. Pero yo lo miro así: mi esposo trabaja y también paga impuestos, ¿verdad?

Sometimes, you go to a social service institution, and they look at you like you are there to take something that does

not belong to you. But, I see it this way my husband works and pays taxes, you see.

Victoria did not know much about autism until her young son's teacher raised some concerns about her son's development. She recommended that Victoria take her son to the Regional Center, nonetheless, Victoria delayed this visit. After a couple years, at 5 years of age, Victoria's son was diagnosed with autism at the regional center. Around the same time, her husband was stopped at an immigration checkpoint and deported back to Mexico. Victoria is a homemaker, and she struggled financially while her husband was in Mexico, before he crossed back to the U.S.A.

Han sacado mucha gente, mucha gente se movió y mucha gente sacaron. Y su único delito era no tener— no estar legalmente en el país. Era el único delito.

A lot of people have been kicked out, many people moved, and many people were kicked out. Their only crime was to be here illegally. That was the only crime.

Victoria struggled to understand autism or to know the services that her son needed. The fact that neither she nor her husband speak English well, added an additional barrier to navigating the different service systems for their child. The lack of authorized immigration status imposed a constant fear of deportation. Victoria, her husband, and her son eventually moved to Los Angeles, where she received help from a community-based organization on getting some services she needed for her child.

### Ramona

Ramona came to the U.S.A. 15 years ago in search of a better future for her daughter, who was brought here as a minor. Ramona and her daughter crossed the border hiding in the trunk of a small car. Since arriving in the U.S.A., some of her expectations were shattered from the beginning. For example, she expected people to be friendlier here and did not realize the significant language barrier she would encounter. At the same time, Ramona appreciates the education that both of her children are getting. In similar fashion, while in Mexico her family was poor, in the U.S.A. they are poor, too, she says, but appreciate always something to eat.

Y me vine para acá, para Estados Unidos, pues para un mejor futuro. Para mi hija, pues mi hija, yo estaba pensando en ella. Siempre en ella. Y pues, aquí ya me quedé. Aquí nació mi hijo después... En México somos pobres y somos bien pobres. Y vienes acá y dices, 'o soy pobre,' pero tienes un plato de comida en tu mesa. Lo bueno que me gusta de aquí.

And I came here, to the United States, well, for a better future. For my daughter, well it was my daughter, I was thinking about her. Always her. And then, well, I stayed. My son was born here after... In Mexico, we are poor, and we are very poor. You come here and then you say 'I'm poor' but you have a plate of food on your table. This is what I like about it here.

Even when Ramona noticed red flags in her child's development (e.g. language delays), fear of deportation

was a deterrent for Ramona to seek a diagnosis. Because of this fear, Ramona delayed seeking a diagnosis for years after noticing delays in development in her child.

Luego me le dije, 'pues no, porque a lo mejor me va a hacer como otro gancho. Para, nada más agarrar mi información y van a llegar a mi casa. Me van a agarrar y me van a dejar mi niño tirado por ahí. Y me van a aventar para Tijuana.' Era mi miedo. Sí, yo pensé que sí iba por ejemplo a un centro regional o con un doctor o a pelear en las escuelas yo pensé que me iban a aventar la migra. Yo dije y a lo mejor es nada más un gancho.

I said to myself, 'well, no, it will be another trap, just to get my information and then they arrive at my home. They will take me and leave my child somewhere. And they will throw me to Tijuana.' That was my fear. I thought that if, for example, I went to the regional center or to a doctor, or argue in a school, they will send immigration for me. I said, maybe it's just a trap.

Ramona, eventually looked for help, finding some parent support groups. It was within these support groups that she educated herself about her child's developmental delays, eventually obtaining a diagnosis and some school-based services for her child (e.g. special education, language and speech therapy).

### Ana

Driven by poverty in her native Puebla, Mexico, Ana came to the U.S.A. in 1994 without documents. At the time, it was possible for her to obtain a commercial driver's license in California, which she used to work as truck driver for 8 years. After that, changes in the law prevented her from renewing her driver's license. Her children stayed behind in Mexico for 15 years, while she sent economic support to them on regular basis. Thanks to this, she says, her children had 'made a lot of progress'. At the time of the study, Ana had not been able to visit her parents or siblings for 17 years, who are still in Puebla. She hopes to see them again someday, she says.

Tengo mis papas y cuatro hermanos allá. Estábamos hablando que son 17 años que no nos miramos físicamente. Pues sí, tengo la esperanza que algún día pudiera regresar.

I have my parents and four brothers there. I'm talking about 17 years that we do not see each other physically. I do have the hope to go back some day.

Like the other mothers in the study, Ana did not know much about autism. It was her son's fourth grade teacher who raised a red flag in language development for her child. The teacher encouraged Ana to seek help for her son but did not initiate a formal referral for special education. It was when she finally looked for speech and language therapy where another parent, informed her of school-based services through the IEP and even suggested that she look for legal help. Ana eventually got a diagnosis from the regional center, but services took another 4 years. At some point, her family paid about \$270 for three months of therapies through a university-based program. When asked about the

services that the regional center or school offered her son, Ana replied that they did not offer them at all initially. She expressed that professionals at school and the regional center would say 'everything is okay' and that she just needed to sign paperwork once a year. It was until she started learning about special education services and other related services that she started asking for them. As the saying goes, she says, 'Knowledge is power'.

Como dicen, el conocimiento da poder, y es cierto.

Like they say, knowledge is power, and it is true.

### Laura

Laura came from Guadalajara, Mexico, in 1988 to work. At that time, there was an amnesty policy in place that allowed her to stay legally for some time. However, she eventually did not qualify to stay and decided to stay and find another job without proper documents. Laura explains that an additional driver behind her immigration was a search for freedom. For example, she explains that at the time, while legal, it was not traditionally accepted for women to drive cars in Guadalajara, Mexico. Once in the U.S.A., the ability to buy and drive a car gave Laura a sense of freedom and autonomy that she did not enjoy in Mexico.

Pues aprende uno a manejar y tiene más libertad que en México, porque en México— Pues ya ahorita la gente maneja y muchas mujeres manejan, pero en aquel tiempo, no.

Well, you learn to drive and that means more freedom than in Mexico. Now a lot of people and many women drive < in Mexico > but not back in the day.

Laura encountered many challenges in accessing health care for herself and her family. At first, she would go to a doctor and pay in cash, which would cause her to be ashamed—she didn't see people pay doctors with cash and doctor offices would ask for insurance. She would work 12-hour shifts in the sewing industry of Los Angeles and get paid below minimum wage, in cash.

Yo no tenía servicios médicos ni nada. Y entonces cuando yo iba al doctor y pagaba cash, me daba pena... Trabajaba en costurería, tu sabes, no eran 8 horas al día, llegaba a las 6am y me iba a las 6pm, y Bueno ni siquiera el salario mínimo (llanto)

I did not have any medical services or anything. So, when I went to the doctor I would pay in cash, I was embarrassed... I used to work in sewing, you know, it was not 8 h a day, I would arrive at 6AM and leave at 6PM. And well, not even making minimum wage {sobbing}.

Her child was young when a preschool teacher approached her with language delay concerns about her son. At first, she delayed going to any public institutions to ask for a diagnosis or services. When she finally asked the public school for an evaluation, they took many months to respond, claiming that the school would



respond with ‘come back at another time’ for months. These factors delayed the identification of her son.

Bueno, la primer, primera persona fue una monjita cuando estuvo en el Head Start, pero ella no era la maestra, ella era la asistente. Y simplemente me dijo: ‘¿Su hijo ha recibido terapia del habla?’ Y le dije: ‘No, ¿por qué?’ [Llanto] Es que dice— [Llanto] Es que no le entendemos, no le entendemos ni en inglés ni en español. [Llanto].

Well, the first person was a nun when he was in Head Start, but she was not the teacher, she was the teacher assistant. She simply said: Has your son received any speech and language therapy? I said ‘No, why?’ She says, well, because we do not understand him, we do not understand him in English nor in Spanish (sobbing).

At 4 years of age, Laura’s son was officially identified with autism in the public school system. Her son received language and speech, and it was the language and speech therapist who helped Laura navigate the special education system thereafter. She even recommended to switch school districts in order to receive better help for her son.

### Fernanda

Fernanda immigrated with her husband to the U.S.A. 14 years ago. She is from a small town in Los Altos de Jalisco, near the city of Guadalajara, Mexico. Just one week after getting married, Fernanda and her husband left to the U.S.A. in search of a better life. She has not seen her immediate family since she left Mexico. Coming from a very small town in the mountains to a large city in Southern California was a shocking change for Fernanda. She did not know anyone. But her challenges went from significant, like not knowing how to get around the city, to the trivial, at one time confusing unrefined salt with sugar in her husband’s coffee.

Fernanda’s preschool teacher raised red flags about her son’s delays and recommended an evaluation for an IEP in school. Fernanda was afraid, and she delayed asking for help in school. When she initially did it, the school misidentified her son with Attention Deficit and Hyperactivity Disorder (ADHD). She was afraid of approaching other institutions (e.g. regional center), finding out what the problem with her son was, and acceptance on the father’s side. Eventually, her son received a delayed autism diagnosis in fourth grade with the help of a community-based organization.

Miedos. Porque cuando fui a la clínica que lo evaluarán, había muchas preguntas que a mi me daban miedo. Y yo muchas de las preguntas no las contesté. Hasta cuando después ya empecé a mirar que en realidad pues el niño tenía su problema. Y cuando mi esposo también aceptó el problema del niño entonces fue como pudimos ayudarlo más. Porque cambio su diagnóstico a autismo. De ADHD [trastorno de atención por déficit y hiperactividad] a autismo.

Fears. When I went to the clinic to get an evaluation there were so many questions that I did not answer because I was afraid. It was later when I started to realize that the child did have a problem. Also when my husband accepted the problem it was when we were able to help the child more.

The diagnosis was changed from ADHD [Attention Deficit and Hyperactivity Disorder] to autism.

### Results of thematic analysis

Three major themes emerged from the systematic thematic data analysis phase. First, the codes ‘Immigration,’ ‘financial challenges (due to undocumented status),’ and ‘Fear of Deportation’ resulted in the broader theme of Immigration Driving Force and Experience. Second, the codes ‘Diagnosis Challenges (autism specific)’ and ‘Cultural Barriers (Due to undocumented status),’ ‘Access to Care Challenges (Due to undocumented status),’ and ‘Access to Services Challenges’ resulted in the broader theme of Autism-Specific Challenges. Third, the codes ‘Helpers’ or facilitators resulted in the theme of Autism Specific Helpers.

### Results of the thematic analysis

Research Question 1) How do mothers of children with autism describe their immigration experience to the U.S.A.?

Research Question 2) How to mothers of children with autism describe their driving forces that lead to immigration?

#### *Theme 1: immigration driving force and experience*

This overarching theme captured participants’ experience in immigrating to the U.S.A. and revealed the motives behind their immigration journey. Within this overarching theme, the frequency of code applications for cultural barriers such as language is salient (See Figure 1). Participants experienced various means of arriving in the U.S.A. Three of the participants arrived here through very risky methods such as hiding in the trunk of a car and crossing the border through a mountain or the desert. The other three participants came here with a tourist visa and overstayed their allowed time in the U.S.A. The motives behind the immigration were invariable to look for a ‘better life’ for their family. Importantly in all instances, participant reasons behind immigration were completely unrelated to seeking autism-specific services. Cultural differences and barriers, including lacking the ability to speak English, proved invariable daunting to all participants.

Era el 2002, fue difícil por que tuvimos que cruzar la frontera yo y mi esposo. Fue para tener una mejor vida, eso es la verdad.

It was in 2002, it was hard, because we had to cross the border my husband and I. It was to have a better life, that’s the truth.

Vinimos sufriendo. Cruzamos en la cajuela de un carro con cuatro personas mas, un carro pequeño.

We came suffering. We came in the trunk of a car with four more people. A small car.

En Riverside hay 'checkpoints', como de policía, pero son de migración. Han echado a mucha gente, mucha gente se mudo, y mucha otra gente la echaron. Su único crimen fue estar aquí ilegalmente. Ese fue su único crimen.

In Riverside (California), there are checkpoints, like a police checkpoint, but they are immigration officers instead. They have kicked out a lot of people, a lot of people moved out and a lot of other people were kicked out. And their only crime was not being here legally. That was their only crime.

Research Question 3) How did Latinx families obtain an ASD diagnosis and services for their children; and what challenges and facilitators did Latinx families find in obtaining a diagnosis and services for their children with ASD?

### Theme 2: autism-specific challenges

Autism diagnosis challenges were consistent for all mothers in the study. Likewise, all participants expressed financial challenges on arrival and beyond. Many of the financial challenges arose from not having a social security number but other challenges had to do with the need to care for a child with special needs. For example, families in the study were unable to obtain family-centered autism services (e.g. respite). Likewise, mothers expressed precarious living and employment situations that were only exacerbated by having a child with autism. For example, participants described abuses by employers because of their inability to demand basic legal rights, like minimum wage. Likewise, participants articulated multiple challenges in accessing a diagnosis and services for their children with autism. Mothers expressed being unaware of the early behaviors (i.e. red flags) that might indicate autism. At the same time, all mothers noticed something was not typical in their child early on but expressed they did not have the specific knowledge to describe it. More importantly, in addition to not being able to specifically identify the red flags of autism, participants were afraid of approaching public institutions (e.g. schools, regional center).

Pensé que el centro regional era un gancho de deportación, que si iba por ejemplo al centro regional o a pelear en la escuela, me iban a echar a inmigración.

I thought the regional center was a deportation trap, that if I went, for example, to the regional center with a doctor or to argue in a school, I thought they would tell immigration.

Le decía al doctor que mi hijo no hablaba, que ya estaba grande. La doctora me decía que era normal, que son flojos los niños que no hablan. Era una doctora americana, así que no me escuchaba, ni si quiera lo checaba bien. A veces una tiene miedo de preguntar, o pedir que lo vuelvan a checar, por que tal si se enojan, uno no tiene la confianza, ¿me entiende?

I would tell the doctor that my child was not speaking- that he was old. The doctor said it was normal, they are lazy -kids- that do not speak. It was an American (White) doctor, so she wouldn't listen. She wouldn't even check him well. Sometimes you are afraid to ask, or ask them to check again, because what if she gets mad, one doesn't have the confidence, you understand?

### Theme 3: autism-specific helpers/facilitators

While all participants expressed distressing challenges in obtaining a diagnosis and services, all expressed

gratitude toward being here, such as the free educational system that their children enjoyed. Hence, 'Helpers' or 'Facilitators' in the study were defined as any person (e.g. family, professional) or institution (e.g. school, regional center, medical office) that helped the family obtain a diagnosis and access autism services. In five out of the six cases, the red flags for autism were identified by a 'helper' other than the mother (e.g. older sibling, teacher, community member, school staff). The frequency of the code application for 'Helpers' illustrates this overwhelming trend on the part of the mothers to feel grateful for the help they received in getting a diagnosis and services and in other aspects of their life as immigrants (Figure 1).

Lo que mas me gusta de los Estados Unidos es la ayuda que tienen para los niños.

What I like the most about the US is all the help/supports they have for children.

En México somos pobre y somos bien pobres. Aquí venimos y somos pobres También, pero por lo menos tenemos un plato de comida en la mesa.

In Mexico we are poor, very poor. Here you come and we are poor, -too- but at least we have a plate of food on our table.

## Discussion

All mothers in the study expressed the desire for a better life as a main driver of immigrating to the U.S.A. Also, all mothers in the study did not know what autism was at the time of their child diagnosis. In all instances, their children received an autism diagnosis in the U.S.A. Hence, it is fair to assume that the participants did not migrate for autism-specific public services. While all participants in the study were able to secure some public service for their individual child with autism, they were not able to obtain any family-centered services. It is important to note that all mothers reported paying payroll taxes as deducted by their employees, but never claimed any tax return. In fact, undocumented immigrants nationwide pay 8% of their income in state and local taxes, while the top 1% of taxpayers pay an average of 5.4% of their income (Gee *et al.* 2016). In California alone, undocumented immigrants are paying an estimated \$3.1 billion (Gee *et al.* 2016).

Participants in the study received a late diagnosis of autism and delayed critical early intervention services. This was because of a multitude of factors but the fear of approaching public institutions was a main driver. This finding is consistent with other research on Latinx parents of children with autism. For example, research suggests that undocumented parents delay access to autism services because of their undocumented legal status (Zuckerman *et al.* 2014). Importantly, five of the six children of the mothers in the study received an autism diagnosis at or after 4 years of age—this can be considered a late diagnosis (Mandell *et al.* 2009). One child

received a diagnosis at the age of 2 because the older sibling was studying child development in college and noticed atypical behaviors in the child. This prompted the mother to look for a diagnosis in a timely fashion. Research is clear that early intervention is critical, and delayed diagnosis and treatment can have negative long-lasting effects on the child (Kasari *et al.* 2015). Hence, the late diagnosis that the majority of mothers obtained shed light into how undocumented status of a parent can play a major role in a timely diagnosis and services for Latinx children with autism. Social network, community-based organizations were instrumental in getting a diagnosis and services (daughter, sister in law, teachers). The findings of this study are also consistent with previous research that suggests a lack of awareness about autism in the Latinx community (Zuckerman *et al.* 2014). However, it is important to note that families in the study faced an additional layer of challenges related to their undocumented status. Finally, it is important to note that even in the face of adversity, all mothers in the study expressed an overwhelming amount of gratitude. This overly positive thinking overlaps with research that shows that Latinx mothers are more likely to report positive outcomes for their child with autism (Blacher *et al.* 2014).

There are at least 4.5 million children in the U.S.A. who have at least one undocumented parent (Suarez-Orozco *et al.* 2011). With a current autism prevalence rate of 1/59 in the U.S.A., this could translate into a rough estimate of about 76,000 children with autism in the U.S.A. who may be living in mixed immigration status households. Besides the evident explanation of the fear factor in approaching social services that undocumented parents face, non-autism specific research with this population of parents points to additional educational and economic challenges. For instance, even after controlling for different socio-economic and educational factors, children of undocumented parents with or without a disability are less likely to have a high-school diploma than those who have parents who are documented (Yoshikawa *et al.* 2016), which was also evident by the majority of participants in the study. A number of factors may be producing these results. For example, low levels of education may contribute to the consistently low-wage and low-skilled occupations that undocumented parents receive. In addition to these challenges, undocumented workers in general have fewer sick days, less vacation, less overtime, or health benefits (Yoshikawa *et al.* 2016).

### Limitations

A potential limitation of this study was the small sample size. However, working with such a vulnerable population is a difficult task given the sociopolitical context of the times (i.e. increased anti-immigrant rhetoric, and particularly toward Latinx Immigrants). It is

possible that this sample of participants may be contributing a unique perspective in such perilous times. However, thematic saturation was reached with six participants for the purpose of our study. To recruit the mothers in this study, we needed to establish a trusting relationship with this community and such trust required time and a genuine commitment.

### Implications for research and practice

The study points to the additional barriers that Latinx minority parents face when they are undocumented in the U.S.A. This suggests that health care providers and educators need to approach diverse families with an open mind. For example, practitioners must not make assumption about families that simply do not show up to a Regional Center and/school appointment. Likewise, practitioners should assume a relationship with *confianza* (trust) when working with Latinx families (Magaña 2020). Instead of making an assumption of lack of family involvement, practitioners could work on building *confianza*/trusting relationships with parents who might be afraid of approaching public institutions (Magaña 2020, Zuckerman *et al.* 2014). Additionally, professionals could build working relationships with undocumented families by focusing some developing skills in critical Latinx constructs such a *familismo* (family-orientation) (Magaña 2020).

This study indicates that intervention and services for children with autism are hampered by income, fear of deportation, language limitations, and awareness of autism for undocumented Mexican parents. While the challenges of undocumented parents with children with autism are many, one salient point of this study is the resiliency of parents. Amid discrimination, language and cultural barriers, a myriad of diagnosis and services systemic barriers, all mothers expressed a positive outlook for the future of their children. This is confirmed by other research on undocumented Latinx parents, who sacrificed a lot in order to provide a better life for their children (Cuevas 2019). In their way, they are accomplishing their goal of a 'better life' by immigrating to the U.S.A. This 'better life' is not necessarily for themselves, but for their children. Future research should include a larger sample of undocumented parents of children with autism. It may also be useful to consider immigrants from other countries as a contrast to those from Mexico to determine similarities and differences in experiences and how this can drive policy toward immigrant families with children with disability. Future research also needs to address how different programs or strategies can families from mixed status/undocumented status on accessing timely autism diagnosis and services. Importantly, undocumented families with children with other disabilities should be included to expand on the strengths and needs of the families that

can inform practices for health care providers, educators, and researchers.

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