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Latinx Mothers' Experiences With Linkage to Early Intervention

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This study explored the experiences and perspectives of Latinx mothers of children younger than 3 years who had participated in a developmental screening initiative provided by 2 Federally Qualified Health Centers in an urban setting, had positive developmental screenings, and were referred to early intervention (EI) services. A 2-phase mixed-methods explanatory design was implemented in English and Spanish. In Phase 1, a telephone survey was conducted with 62 parents. In Phase 2, qualitative semistructured interviews (regarding parental experiences with their child's developmental screening, the process of linking to services, the EI evaluation, and subsequent services received) were conducted with a subset of 13 Phase 1 mothers. Results from the phone survey showed that 91% of children were found eligible for EI and 92% were receiving EI services. More than 90% of mothers reported positive experiences with their children's developmental screening, learning about their child's development, and accessing services. However, results from the semistructured interviews revealed that mothers had mixed experiences with the developmental screening process and linkage to EI services. Findings from this study provide insights into the

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perceived value of EI services by Latinx families and the need for improved system supports to access and navigate EI services. **Key words:** *development delays, developmental screening, Latinx parents, linkage to early intervention services*

THE INDIVIDUALS with Disabilities Education Act (IDEA) Part C specifies that young children, aged birth to 3 years, with or at a high risk for developmental delays are entitled to early intervention (EI) services designed to improve developmental outcomes (U.S. Department of Education, Office of Special Education Programs, Data Analysis System, 2015). Prior research demonstrates that EI services have a positive impact on a child's language, cognitive, social–emotional, and behavioral development (Estes et al., 2015; Perry, Blacklock, & Geier, 2013; Pinto-Martin, Dunkle, Earls, Fliedner, & Landes, 2005; Vivanti et al., 2019). An estimated 15% of children in the United States younger than 3 years have developmental delays; however, only 3% of them receive EI services (Boyle et al., 2011; U.S. Department of Education, 2017).

The discrepancy between the need for EI and activation of EI services has fueled universal developmental screening initiatives, encouraging professionals across the service sector to engage parents, initiate developmental conversations, and link children to EI services when appropriate. A universal screening approach can also reduce the risk for racial/ethnic disparities in access to EI. Despite these efforts, however, data from the National Survey of Children's Health show that fewer than one out of three Latinx children receive developmental screenings (Rice et al., 2014). Other studies corroborate these findings, demonstrating that Latinx children are 78% less likely to be identified as having a developmental delay than White non-Latinx children (Magnusson et al., 2017).

Even when children are identified as having developmental needs, gaps in access to EI services exist because successful linkage to EI services is inconsistent. For example, a national study that examined implementation and outcomes of developmental screenings among 17 pediatric practices across 15 states found that only 61% of children whose screening indicated a possible delay were referred to EI services (King et al., 2010). There are multiple barriers that have been identified as negatively impacting families' linkage to EI services in the general population, for example, poor communication with health care providers, lack of adequate time to complete screening and linkage, lack of adequate reimbursement, physicians' fear of a positive screening and discomfort delivering negative news, physicians' limited knowledge about EI services, long wait times to access the EI assessment, and difficulties connecting with EI agencies (Denney, Itkonen, & Okamoto, 2007; Hendrickson, Baldwin, & Allred, 2000; Iland, Weiner, & Murawski, 2012; Jimenez et al., 2012; Jimenez et al., 2014; Marshall & Mendez, 2014; Pinto-Martin et al., 2005; Shannon, 2004; Zuckerman et al., 2014). Although these barriers apply to Latinx populations, the literature demonstrates that Latinx families experience additional unique barriers.

Latinx children and families, compared with non-Latinx children and families, appear to be at a greater disadvantage (Hirai, Kogan, Kandasamy, Reuland, & Bethell, 2018). One driver behind EI linkage barriers for Latinx families is the role of language. Only 51% of pediatricians speak Spanish, and most are located in New York and Texas (Zippia, 2020). A frequent obstacle faced by families with limited English proficiency is the lack of health care providers who can communicate with them about their child's health status, caregiving needs, and available services (Denney et al., 2007; Flores, Abreu, & Tomany-Korman, 2005). Latinx parents report feeling uncomfortable or unable to express themselves, limiting their capacity to share important development-oriented concerns or questions (Zuckerman et al., 2014). In addition to language, there are related cultural differences. In the United States, 34.5% of

children are Hispanic/Latinx, but only 9.7% of pediatricians identify as Hispanic/Latinx (Zippia, 2020; U.S. Census Bureau, 2019). These linguistic and ethnic differences accentuate unique barriers Latinx families face with successful linkage to EI services.

Cultural beliefs related to developmental delays and disabilities in the Latinx community impact access to timely screening and EI services, such as misconceptions and stigma about early childhood development (Zuckerman et al., 2014; Zuckerman et al., 2017). In a qualitative study of Latinx parents with children who were diagnosed with an autism spectrum disorder, researchers found that the parents perceived early childhood developmental delays, disabilities, and mental health needs as embarrassing or shameful (Zuckerman et al., 2014). For example, Latinx parents perceived that community members might label a child with autism spectrum disorder as a poorly behaved child that has not been properly disciplined by his or her parents. As a result, these perceptions brought shame to the parents and often prevented them from discussing developmental concerns with their social support networks—or health care providers. This perceived community-level stigma often caused delays in young children receiving appropriate developmental screenings and, by extension, receiving appropriate linkage to EI services.

Many of the challenges noted in the literature in identification of delays and linkage to EI for Latinx children occurred in the context of a health care system that does not typically employ universal screening, nor provide care coordination to assist families in accessing recommended services. The current study aims to expand the extant literature by exploring the experiences of Latinx parents of young children (aged birth to 3 years) who received a developmental screening *and* referral for EI services at a pediatric medical center designed to ensure access to state-of-the-art screening and linkage. The study aimed to understand how this process—from developmental screening at a pediatrician's office through linkage to EI services—was experienced by Latinx parents. Guiding this research was grounded theory, allowing for the collection of Latinx families' stories and construction of facilitators and barriers that make up parents' experiences with linkage to EI services. A mixed-methods approach was implemented, including a phone survey to evaluate outcomes (e.g., was the linkage successful), followed by an in-person semistructured qualitative interview to provide depth of understanding to the outcomes identified by the quantitative survey data.

METHODS

Study design and researcher characteristics

This study used a mixed-methods sequential explanatory design, consisting of a quantitative survey, followed by qualitative semistructured interviews (Creswell et al., 2003).

The quantitative data provided specific responses regarding the experiences of Latinx parents' following referral to EI services, designed to answer questions about the likelihood of a positive outcome and the types of barriers encountered. Results from the quantitative data informed the development of the qualitative interview questions and recruitment of a pool of interview participants representing both positive and negative experiences with the screening and linkage process. The qualitative interviews were designed to provide more in-depth and nuanced explanations that would capture the parents' attitudes and experiences when accessing EI services, including both positive and negative perspectives. (Creswell, 2003; Rossman & Wilsons, 1985; Tashakkori & Teddlie, 1998). The research team included Latinx professionals, several of whom were first-generation immigrants, with areas of origin including Mexico, Central America, South America, and the Caribbean. Their personal experiences as Latinx immigrants as well as their professional experience working with young

children with developmental delays informed their approach to research design, approach to talking with families in the study, and interpretation of results.

Setting and participants

Participants were recruited from two Federally Qualified Health Centers (FQHCs) located in an urban setting, which provided primary pediatric care to low-income, medically underserved families who were majority Latinx. The two FQHCs in this study participated in a larger parent project aimed at improving developmental screening and linkage to Part C EI services for young children from underserved communities. Both FQHCs received training on utilizing a developmental screening tool and ongoing technical assistance during the implementation process to ensure that staff met quality standards for developmental screening. In addition, training included information about family-centered and culturally appropriate approaches to discussing developmental screening results, education about bilingual language development, and information about the importance of supporting the home language of families.

Participants were parents whose children met the following inclusion criteria: (1) had been screened using the Ages and Stages Questionnaire, 3rd edition (ASQ-3) at one of the two participating FQHCs; (2) ASQ-3 results indicated developmental concerns in at least two domains; (3) the medical provider had referred the child for EI services; (4) the referral had occurred at least 6 months prior to the study survey (to ensure that sufficient time had elapsed for the EI agency to have conducted an evaluation); (5) the child was younger than 3 years; and (6) the parent identified the child as being Latinx.

Developmental screening procedures

Each FQHC developed its own universal screening protocol based on its agency needs and goals, as well as input from the training and technical assistance provider from the larger parent project. At both agencies, all families completed the ASQ-3 at ages 9, 18, and 24 months during their well-child visits. One agency also administered the Ages & Stages Questionnaires: Social-Emotional Development (ASQ:SE) screening tool, and the other also administered the Modified Checklist for Autism in Toddlers Revised (MCHAT-R) at 18 and 24 months. Medical providers discussed screening results with parents and made referrals based on screening results, their professional judgment, and a referral algorithm developed for the larger project. Office staff received training on the purpose of developmental screening, selecting the appropriate measure(s), explaining the screening to parents, and scoring the measures; both sites had Spanish-speaking, Latinx office staff in this role. Medical providers received additional training regarding how to interpret the screening results, identify referral resources, utilize a referral algorithm, and discuss screening results with parents. Results of screening and notes regarding referrals were entered into the patients' electronic medical record. Both sites had at least one Spanish-speaking, Latinx project coordinator or case manager who followed up with families and provided support if they encountered questions or barriers in accessing services. The ethnic background and language capability of the physicians were not measured as part of the study.

Participant recruitment and procedures

All procedures were approved by each FQHC and by the institutional review board at the affiliated institution. The researchers mailed a study introduction letter, informed consent form, and Health Insurance Portability and Accountability Act authorization to parents whose child met the inclusion criteria ($n = 113$); the letter was printed on the letterhead of the FQHC where the child received medical care. A phone survey and a follow-up semistructured interview developed by the research team were included in the study. Both instruments were translated into Spanish by a professional translator;

the final Spanish translation was reviewed by three of the current authors, who are bilingual and bicultural, to ensure accurate translation and cultural equivalence. Both the survey and the qualitative interview were pilot-tested with two Latinx parents of children with developmental delays or disabilities and their feedback was incorporated into the final versions of the measures.

Measures

Phone survey

A phone survey was developed for this study based on a review of the published literature (Zuckerman et al., 2014) and the authors' experiences with linking children to EI services (available upon request). The survey included yes/no and short answer questions regarding demographic information and participant experiences with (1) the developmental screening, (2) obtaining an evaluation for EI services, (3) the EI evaluation process, (4) receiving EI services, and (5) potential barriers experienced.

Two bilingual, bicultural research assistants were trained to administer the phone survey. Parents were called up to three times. They reminded parents of the consent form that had been sent by mail, read the consent form to the parent (in the parent's preferred language) if requested, and answered any questions about the study. Following this consent process, the survey was completed over the phone. The participants were sent a $15 gift card via mail. Each phone survey took approximately 30 min to complete.

Semistructured qualitative interview

A semistructured qualitative interview was developed on the basis of the phone survey analysis in an effort to further understand parents' experiences with the developmental screening, referral, and linkage process to EI services. The survey revealed that most parents had a positive experience with accessing EI services, yet almost half stated that they thought that Latinx families faced more barriers when accessing services than non-Latinx families. The interview was designed to elicit more in-depth responses through open-ended questions and to learn more about parents' attitudes, subjective experiences, and views about EI that might help guide providers in understanding families' perspectives. Sample questions included, "Tell me about what it was like for you when your child's doctor recommended you to have your child evaluated at the Regional Center." "Tell me about the process of calling or going to the Regional Center and describe that process." "Tell me about your experiences when you heard the results of your child's evaluation." "Pretend that you had a friend whose child seemed to have delays, but had not gotten an evaluation. What advice would you give to this friend?" "What advice do you have about how to improve the entire process so that families can have a good experience with early intervention?" The semistructured interview guide is available upon request.

Participants for the interview were selected from those who completed the phone survey, using purposive sampling, with a goal of including parents who reported both positive and negative experiences with linkage to EI. Parents were given the option of completing the semistructured qualitative interview at their home, their child's health clinic, or in the researcher's office. All families requested that the interviews be conducted in their home. The interviews lasted approximately 45 min and parents received a developmentally appropriate toy for their children as a thank you for their participation. All the interviews were audio-recorded and transcribed by research assistants. The bilingual research team coded all transcriptions in the language of the interview. Spanish quotes cited in this article were translated into English by the research team so as to communicate the findings to English-speaking readers.

Data analysis

Phone survey

Quantitative data were analyzed using descriptive statistics. Categorical variables were

summarized as frequencies and percentages. The differences in distribution of survey responses between language (English or Spanish) and agency were examined using χ^2 tests when an expected frequency cell was 5 and greater and Fisher's exact test when an expected frequency cell was less than 5. Statistical significance was set at 5% using a two-tailed test. Statistical computations were performed using Stata/IC 13.1 (StataCorp, College Station, TX).

Semistructured qualitative interview

Phenomenological methodology was used with the qualitative data, emphasizing the value of lived experiences when exploring Latinx parents' perceptions of the linkage process from their children's developmental screening to accessing EI services. To begin analysis, the research team engaged in *horizontalization,* a process that involves reading across the interviews repeatedly to identify significant statements in the data and grouping these into broad themes, with each statement given equal value (Moustakas, 1994). Based on this process, a preliminary codebook was developed. The researchers used related codes to examine the concepts, conditions, and paths between them (Corbin & Strauss, 1990). The team met regularly to discuss emerging themes of the interviews and to determine when saturation (i.e., sampling more data would not lead to more information related to the research question) was reached.

Through this iterative process, 28 codes were identified. All codes were developed by two members of the research team and reviewed by all research team members. Through these team meetings, five themes emerged from the 28 codes and the codebook was finalized. Each interview was subsequently coded independently by two research team members. Discrepancies were resolved through discussion or with a third team member when necessary. Interrater reliability was 0.70, demonstrating overall good agreement (Cicchetti & Sparrow, 1981). All qualitative analyses were performed using NVivo qualitative data software (QSR International, Doncaster, Victoria, Australia).

RESULTS

Phone survey

Of the 113 parents who were eligible to participate in the study, 62 participants (55%) completed the phone survey. More than half the interviews were conducted in Spanish ($n = 41$; 66%), with the remainder in English.

Spanish-speaking mothers were more likely to be reached by phone and were more likely to agree to participate than English-speaking mothers (44.6% of eligible Spanish-speaking parents participated vs. 23.1% of eligible English-speaking parents; χ^2 (2, $N = 113$) = 12.0792, $p = .002$). There were insignificant differences in participation rates between mothers from the two FQHCs. Eighty percent of the participants in the English group were born in the United States and 90% of the participants in the Spanish group were born outside of the United States, with the majority having immigrated from Mexico (see Table 1). Although we did not gather information about socioeconomic status or education level of the participants, all children whose parents participated had Medicaid insurance, due to meeting income eligibility. The age of the children at the time of the survey ranged

Table 1. Demographics of Participants ($N = 62$)

	Frequency (%)
Preferred language	
English	21 (34)
Spanish	41 (66)
Born outside of the United States	
Yes	40 (65)
No	20 (32)
Country of origin for those born outside the United States	
El Salvador	2 (5)
Guatemala	5 (13)
Mexico	26 (65)
Declined	7 (18)

from 11 to 36 months, with a mean age of 26.2 months ($SD = 6.13$). A total of seven regional centers that administer EI services were represented in the sample; this represents all geographic areas of Los Angeles County. Table 2 presents survey responses. No agency effect was found between the two medical provider agencies in the survey responses; therefore, the two agencies were combined for the remaining analyses. There were not enough participants from any one of the seven regional centers to be able to compare responses across different regional centers.

Regarding developmental screenings, mothers reported that physicians provided them with information about their child's development, as well as provided information about next steps after a delay was identified. The majority of mothers reported that after the developmental screening was completed, they gained understanding of their child's development and whether their child was developing typically or needed an EI evaluation.

Mothers reported high levels of satisfaction with the EI evaluation process. Few mothers reported barriers related to scheduling or

Table 2. Frequency of Survey Responses ($N = 62$)

Abbreviated Question	Total (%) "Yes"
Developmental screening and referral	
Screening helped understand child's development	60 (97)
Doctor provided written information to help understand child's development	36 (58)
After screening, doctor said that the child might have a delay in his or her development	51 (82)
Evaluation for early intervention	
Problem making or scheduling appointments for the evaluation	11 (18)
Problem with transportation	9 (14)
Problem scheduling the evaluation at a time that would work	9 (15)
Person who did the evaluation spoke my home language	50 (87)
Trouble understanding the evaluator's questions	10 (17)
Evaluator understood the child and got accurate information	54 (93)
Evaluator spent enough time to do a thorough evaluation	51 (88)
Evaluator got an accurate picture of the child, both strengths and your concerns	48 (81)
They talked about child's behavior and social and emotional development	46 (79)
Understood the results of the evaluation	53 (91)
Had an opportunity to get all questions answered about the child's development	52 (91)
Understood what to do next to get help after the evaluation	53 (93)
After the evaluation, the child was eligible for early intervention services	53 (91)
Met with a team to talk about services or results of the evaluation	29 (52)
Meeting was in home language	36 (90)
Early intervention services (asked of parents whose child was found eligible; $n = 53$)	
Started receiving early intervention services	49 (93)
Person providing early intervention services speaks home language	43 (88)
Early intervention services have been helping the child with his or her development	47 (96)
Perception of barriers for Latino families	
Latino families experience more barriers than non-Latino families when accessing early intervention services	29 (47)

attending an appointment, or communication challenges (e.g., language barriers) with the evaluator. Most mothers reported that the EI evaluations were accurate and captured their child's strengths and areas for improvement.

The time between referral and the first evaluation appointment ranged from less than 1 week to 24 weeks, with a median of 4 weeks. Of the 57 mothers who reported that their child had an EI evaluation, 80.7% reported that the evaluation was completed within 45 days (the timeline for completing the evaluation based on IDEA Part C regulations). Of the 11 mothers who reported more than 45 days, four mothers (36%) reported difficulties making an appointment or finding an appointment time that was convenient for them as the primary barrier. When comparing the English and Spanish groups, no differences were found in the median length of time to obtain an EI evaluation.

When asked whether they got all their questions answered in the EI evaluation, 100% in the Spanish group and 74% in the English group responded yes ($p = .003$, Fisher's exact test). In our sample (which included only those children who had at least two domains of concern on the ASQ-3), 91% of children were found eligible for EI services. Mothers reported that EI services were conducted in the family's home language and they felt included in those services. However, 46.8% of mothers reported that they believed that Latinx mothers experience more challenges than non-Latinx mothers in accessing EI services. Overall, 96% of mothers whose child had started EI services reported that the services were helping their child make developmental gains.

Semistructured qualitative interview

All of the participants who participated in phone survey were asked whether they would be interested in completing the semistructured interview. There were 39 mothers who agreed to complete the semistructured interview during the phone survey. From this pool of participants, purposive sampling was used to select a subgroup representing positive and negative views about the screening and EI process based on their phone survey responses. In addition, recruitment for interviews ended after saturation was reached and no new themes were emerging. There were 13 (33% of the original sample) mothers who completed the semistructured interview.

The interviews were conducted in the language requested by the mother, and 85% ($n = 11$) were completed in Spanish. To obtain a representative understanding of the families' experiences, the research team used purposive sampling and reached out to families who had expressed both a negative experience and a positive experience during the phone survey. Of the 13 families who agreed to participate in semistructured interviews, five families had reported barriers or challenges in their EI linkage process during the phone survey. During qualitative semistructured interviews, mothers endorsed five broad themes (briefly described later) regarding barriers experienced by families as well as recommendations for providers (see Table 3). Spanish quotations included in the article were translated by two researchers independently and reached consensus. In addition, the researchers used back translation to ensure accuracy of the quotes. An asterisk was added to the translated Spanish quotations.

Developmental screenings

Mothers reported mixed feelings and perceptions about the screening process. Although the majority of mothers reported feeling comfortable with the screening process and reported that it was an opportunity for them to ask the medical provider questions and learn about their child's development, some mothers reported feeling confused with the screening questions and expressed fear of repercussions. For instance, one mother stated, "I just answered everything cause I was like oh my God I don't want to go to jail if I don't answer the question right."

Table 3. Factors Contributing to Barriers Accessing Early Intervention (EI) Services Based on Study Findings and Recommendations for Providers

Themes	Barriers	Illustrative Quotes	Recommendations
Developmental screening	Limited understanding and knowledge about developmental screenings Confusion, concerns, and fear related to the screening process	"... whatever I didn't understand, I would ask him [the doctor] ... for a specific example, or if I would give him like a certain facial expression, like confused, the doctor rephrased the question in a different way where I understood it" "... So, as you were going through [the screening questions] ... and some of those questions were weird ... Like, does he still drink from a bottle and other stuff like that ... So it's like why does he [doctor] needs to know that ... So I'm thinking, OK, well you know I just need to answer everything because ... oh my God I don't want to go to jail if I don't answer the questions right."	Develop positive and collaborative relationship with parents/caregivers Explain the importance and purpose of developmental screenings Deliver screening results in a family-centered, strengths-based way
Early intervention (EI) evaluation experiences and perceptions	Challenges with EI assessment process Feedback from EI assessment	"The letter [with the EI assessment results] get there and then I get a visit from my [Regional Center] worker and she got through me just as like uh this is what your concerns, this is what we found out, this is where she's at, this is our goals, more not even specific, but she offered like if I want a specific from the results, they, she will have an appointment with the evaluator to go thru with me. She just going uh like general." "They sent me a letter ... saying that she [child] was fine that she didn't need the services."	Deliver results face-to-face to parents Explain EI services Explain eligibility process

(*continues*)

Table 3. Factors Contributing to Barriers Accessing Early Intervention (EI) Services Based on Study Findings and Recommendations for Providers (*Continued*)

Themes	Barriers	Illustrative Quotes	Recommendations
Early intervention services understanding and experiences	Feeling nervous, judged by EI providers Fear of social services	"the fear sometimes comes from the idea that I'm going to have a therapist . . . they're going to come to the house . . . and what about if I spank the child, and the child is going to say that I hit him very hard, that's how we see it. So we decide that it's better not get into trouble and let the child be*"	Explain the EI services, frequency, expectations, and rights and responsibilities of providers and parents Provide information about next steps without overloading parents with information or anticipating a negative experience Review options related to EI services (e.g., clinic-based vs. home-based)
Latinx-specific perceptions of developmental delays, developmental screening, and early intervention services	Limited or erroneous information and knowledge Beliefs/stigma related to delays and EI services	"I live in an area where it's mostly Latinos . . . , and you don't hear a lot of services going on and then if you have a kid [with delays], people think that you just take them to the doctor and then that's it"	Parents may benefit from thinking about their child's development and goals from a cultural perspective Explore parent's beliefs about EI services and provide information about benefits of EI services Use cultural brokers/system navigators with lived experience
Suggestions to improve access to early intervention	Lack of awareness Limited culturally and linguistically sensitive materials	" . . . I think it would be a lot easier if Regional Center's websites were a lot better . . . like their website is very confusing . . . "	Improve EI websites Increase modalities of materials available (pamphlets, videos, etc.) that explain DD and EI services

Note. An asterisk was added to the translated Spanish quotations.

One mother commented: "I thought [my child] was slow ... I thought like I did something wrong cause I didn't find out I was pregnant until like almost four months, so I thought 'oh my God' was it me?' ... family members told me that ... some kids are slower and because he's your first [child], he is spoiled ...."

EI evaluation experiences and perceptions

Some mothers reported feeling nervous or scared that their child was delayed, and others reported lack of understanding about their child's development and were surprised or shocked when the EI evaluation documented delays. The assessment process was described as a "phone call away" by some mothers, whereas others described it as a slow, confusing, and convoluted process.

EI services understanding and experiences

Mothers reported feeling that the EI services were helpful for their children. Mothers described themselves as an important collaborator, in that they had opportunities to provide input about their child's goals and treatment. One mother shared: "[the EI assessment] was pretty comfortable, I liked how they came over [my house] ... and I liked how they tried to work with him [child]."

However, some mothers reported feeling nervous and did not want to be judged by the therapists coming to their home. Some mothers expressed that they feared that they were going to be accused of mistreating or spanking their child and subsequently the Department of Child and Family Services was going to be contacted. Furthermore, these fears seemed to interfere with some of the mothers accepting the EI services.

A mother disclosed "I was really nervous [about receiving EI services] because there was going to be another person coming into my home and I was really nervous .... Yeah you know it's very easy for them [assessors, therapists] to come in and point things out and judge, ... so I was really nervous about it, because it's a new person involved in your child's life ...."

Latinx-specific perceptions of developmental delays, developmental screening, and EI services

Mothers reported that there are current factors that impact the access to services for the Latinx community, including lack of awareness and information about autism in the community, limited information about EI services, and lack of understanding about typical child development. Mothers reported that families may likely obtain information from family members that discourage them from seeking services or minimize concerns by saying that delays are *normal* in the family. Mothers also indicated that some Latinx families may feel that their children are *too young* to receive EI or therapy services. A few quotes from mothers:

Latinx mothers don't think [developmental delays] are a disease, and they believe that the child's delays are because of their age and child will outgrow the delay*.

Well sometimes my mom says, "Well maybe it is [child delays] because your child was born premature because many children are slower to do other things than other children ...*."

I think Hispanics are in denial when there's something wrong with my child ... I think education is showing that there's nothing wrong with [children with delays] and they are no different from you and me, and {they] are just a little behind.

Suggestions to improve access to EI

Mothers indicated that culturally and linguistically sensitive resources, pamphlets, posters, and information would need to be disseminated in the community, preschools, and medical offices to increase awareness of developmental delays and EI services. Dissemination or talking about their child's development through texting with a professional was another strategy suggested by mothers to increase engagement in screening and early identification. Finally, some mothers reported that a few of the regional centers'

websites were confusing and suggested that the websites be made easier to navigate with parent-friendly information.

> Maybe put a poster that says ask your doctor about [your child's development] or something like that. I would recommend [regional center] to a lot of people . . . but they [parents] are afraid . . . about what people are going to say if he's [child] getting therapy, and they're going to think there's something wrong with him [child] . . . you got to accept if there's something wrong here, if he can't talk, there is something wrong . . . and it can get better . . . .

DISCUSSION

This study focused on Spanish- and English-speaking Latinx parents' experiences with developmental screening and linkage to EI services for their young child. Prior research has recommended including Spanish-speaking families in research regarding linkage experience (Marshall & Mendez, 2014), and this study was successful in recruiting a particularly high percentage of Spanish-speaking parents, 90% of whom were immigrants to the United States. In fact, Spanish-speaking Latinx mothers were more likely to agree to participate in the study than English-speaking Latinx mothers. The overall response rate obtained for this study is considered acceptable when conducting this type of research (California Health Interview Survey, 2014). Several factors may have contributed to successful recruitment of Spanish-speaking families. First, recruitment materials were provided in both languages and used letterhead of the FQHC where the child was receiving medical care; this approach may have encouraged mothers to associate the study with a trusted medical provider. Second, the research personnel conducting phone surveys and semistructured interviews were bilingual and bicultural and spoke in the families' native language upon first contact. Finally, the survey was designed by bilingual, bicultural researchers and was pilot-tested on a bilingual, bicultural mother of a child with a disability.

This study focused on mothers of Latinx children who had participated in a universal developmental screening initiative embedded within one of two urban medical practices serving Medicaid-insured children. Families eligible for the study were those whose child was younger than 3 years and had scored in the concerning range in at least two domains of development and been referred to EI services. The majority of participants in the study reported a positive experience with the process of developmental screening and linkage to EI services. Most evaluations were completed within the IDEA Part C–mandated time line (i.e., 45 days); however, about 20% of mothers reported that the evaluation was conducted more than 45 days after the referral. Of those who had delays in completing an evaluation, 36% reported difficulty making an appointment (such as not getting calls back), whereas the remainder did not report any barriers. The majority of mothers surveyed reported no barriers in obtaining an evaluation for EI services or in scheduling an appointment at a convenient time. Ninety-one percent of the children were found eligible and 95.5% of those families reported that EI services were helping their child's development.

These proportions of successful linkage and satisfaction with services are higher than reported in previous studies (Jimenez et al., 2014; Marshall & Mendez, 2014; Marshall, Adelman, Kesten, Natale, & Elbaum, 2017) and higher than would be predicted on the basis of rates of enrollment in EI services in California where the study was conducted (U.S. Department of Education, Office of Special Education Programs, Data Analysis System, 2015). Several factors may account for the positive linkage experiences in the present study. First, the study included mothers of only those children with developmental screening concerns in two or more domains of development, increasing the probability that they would qualify for EI services. Developmental screening and linkage support was conducted in a systematic way by trained physicians and office staff involved in an

initiative designed to increase access to EI services. California's EI system is administered by Regional Centers, with staff specifically devoted to the Part C program. This system may have greater effectiveness in managing referrals, assessing young children, and providing appropriate EI services to those eligible, compared with systems in other states. Although California has not been found to provide EI to a higher proportion of children compared with other states (Rosenberg, Robinson, Shaw, & Ellison, 2013), the EI system may be effective at serving those children with significant delays, such as the ones included in this study.

Results of this study also found that, compared with English-speaking Latinx families, Spanish-speaking families were more likely to report that their questions had been answered during the EI evaluation process. One possible explanation for this finding is the Regional Centers' commitment to providing culturally sensitive and family-centered care, which includes conducting evaluations in the family's native language (California Department of Developmental Services, 2012). Early intervention providers and service coordinators may spend more time providing explanations to Spanish-speaking, immigrant families if they perceive that they require more assistance in navigating the system.

Previous studies have found that families' difficulties communicating with health care providers about their child's delays are a potential barrier to understanding the need for an EI referral and later receiving EI services (Denney et al., 2007; Hendrickson et al., 2000; Jimenez et al., 2012; Shannon, 2004; Zuckerman et al., 2014). In the current study, only 58% of participants reported receiving written information about their child's development following the developmental screening, yet more than 95% reported that the developmental screening helped them understand their child's development. Completing a parent questionnaire, such as the ASQ-3, may provide valuable information about a child's development. In addition, providers may be effective in verbally informing the mothers about their child's developmental functioning. Mothers may also obtain information about their child development from other sources. Similarly, only 57.8% of the mothers reported that they had a meeting with representatives of the EI program to review the results of their child's EI evaluation or learn about EI services. Nonetheless, the majority reported that they understood the results of the EI evaluation and what to do next for their child to receive services, indicating that informal discussions regarding the EI evaluation may be as effective as formal meetings. Moreover, families may process information in different ways (e.g., written vs. spoken) and families may have forgotten meetings that happened months prior to the survey.

Unlike the linguistic differences found in EI research creating a barrier for families during the EI process (Denney et al., 2007; Zuckerman et al., 2014), the majority of mothers in the current study reported that the evaluation and services were provided in their home language. Nonetheless, approximately 12% of participants reported that the evaluation and services were not conducted in their home language. It is hypothesized that although some of these families were monolingual Spanish speakers and may have needed a Spanish-speaking evaluator or service provider, some mothers may have been bilingual (English–Spanish) and been assigned to a monolingual English-speaking provider. It is important to continue to emphasize the need for more bilingual personnel to support families' participation in EI and to assist children in maintaining their home language.

Although participants reported minimal barriers in accessing EI services for their child, approximately half of the participants reported that they perceive Latinx families as facing more barriers than non-Latinx families. Previous studies found that Latinx families experience more barriers than non-Latinx families (Denney et al., 2007; Zuckerman et al., 2014) and a review of participants'

comments suggested that they have heard of other families in situations in which they have faced more barriers. The approach to conducting developmental screenings and linkage carried out by the FQHCs in the present study may have led to more positive experiences. On the other hand, it may be that negative experiences are more salient and discussed among community members compared with positive experiences, leading to a perception of more barriers than families are likely to encounter. The semistructured qualitative interviews conducted as part of the study helped elucidate some of the concerns and experiences that may be unique to Latinx families.

From the interviews, we learned that positive and collaborative relationships with medical providers, staff members, and case managers are important to Latinx mothers and increase the likelihood that they will be open to EI services for their child. Parents need help to understand the importance of and rationale for developmental screening; they may feel confused about the screening questions, and they may be concerned about being judged or giving "wrong" answers. These worries may be especially salient for Latinx parents who are undocumented, those who have limited English proficiency, and/or those who immigrated from a country with a different service system. Most parents benefit from engaging in conversations with their child's medical provider about typical/atypical development, parental expectations, and benefits of receiving EI services early instead of using a "wait-and-see" approach. When administering developmental screening measures, it is recommended to embed the process within a discussion about child development with the medical provider and encourage questions about the purpose of questions and the results of the screening.

Because most parents had a positive experience receiving the assessment through the Regional Center, we recommend providing information about next steps without overloading parents with information or anticipating a negative experience. Parents may be concerned about multiple people and/or new people coming into their home, whereas others may appreciate the option for home-based services. Therefore, it is important to invite questions about how EI services are delivered, address any concerns, and describe available options as well as parents' rights. The interviews conducted for the study revealed that many Latinx mothers hear opinions regarding their child's development and services from family and other community members, which is consistent with findings of a qualitative study of Latinx mothers of children with autism (Blanche, Diaz, Barretto, & Cermak, 2015). In this community context, Latinx mothers who have a child with developmental delays may fear being judged as a parent and may be encouraged by family members to take a "wait-and-see" approach rather than accessing services. Therefore, it is recommended that providers specifically invite discussion about the views of other family members, how the parent plans to talk about their child's needs with their family, and provide opportunities for other family members to be included in the process. In addition, cultural brokers or system navigators who have lived experience and come from the same culture as the population served may be helpful in increasing Latinx parents' comfort with accessing services. Conducting systematic developmental screening as part of well-child care, with the trusted medical provider linking families to EI agencies, was found to be a promising strategy to increase access to EI services for Latinx low-income families.

Limitations

The current study focused on Latinx parents of children who had participated in a model developmental screening initiative designed to reach underserved communities and provide comprehensive screening and linkage to EI services. However, this study did not have a control group of families who did not participate in a developmental screening, had concerns about their child's development, and sought EI services on their own.

Therefore, results should not be assumed to reflect the experiences of the majority of Latinx families who may not have access to high-quality developmental screening and linkage services. Moreover, the findings may not generalize to the EI experiences of families from other racial and ethnic backgrounds or those who are not low-income. The study also included only those parents whose child had clear developmental concerns and may not inform the experiences of families with children with less clear developmental delays. Research findings may not generalize to EI programs in other states, where EI systems are organized differently or have different eligibility criteria. In addition, the service system for older children (3 years and older) has different eligibility requirements and available services, so the findings are not expected to inform the potential experiences of families of older children seeking developmental information and support through such service systems.

An important limitation of this study concerned possible selection bias during the phone interviews; parents who had positive experiences may have been more likely to agree to participate than parents who had negative experiences. In addition, there may have been a bias to answer questions positively if parents did not want to criticize the system that they may have associated with their child's medical provider. The consent paperwork and phone survey conductors emphasized confidentiality; however, there may have still been effects of social desirability leading parents to answer positively to survey questions and to deny barriers or difficulties with the EI process. The survey questions and semistructured interviews were designed to be detailed and specific to minimize this possibility. An anonymous written survey may have reduced such bias but could have potentially been subject to other barriers such as education level and literacy impacting results.

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