

## Deaf Early Intervention in Puerto Rico: A Qualitative Study

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### Abstract

Deaf children can develop similarly to hearing children with appropriate intervention. However, when Deaf and hard of hearing children have deferred access to services, they can experience significant delays in language, socioemotional development, and cognition that can lead to problematic behaviors. Although early intervention services are free in the United States starting at birth, there is often a lag in Deaf and hard of hearing children receiving services, especially when residing in U.S. territories such as Puerto Rico. The current qualitative study was to explore the lived early intervention experiences of three parents and three professionals of Deaf and hard of hearing children under the age of six years old. Questions explored the lived experiences and perceptions of both professionals and parents regarding their access and delivery of early intervention services in Puerto Rico for Deaf and hard-of-hearing toddlers. Several salient themes emerged to include support for sign language, barriers to services, and family support.

**Keywords:** Culture, Deaf, Early Childhood Development, Early Hearing Detection and Intervention (EHDI), Puerto Rico

**Acronyms:** ASL = American Sign Language; EHDI = early hearing detection intervention; IEP = individualized education plan; IFSP = individualized family service plan; IPA = interpretative phenomenological analysis

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Infants are born primed and ready to learn. However, research suggests that when an infant is born Deaf<sup>1</sup> or with a hearing status outside of a typical hearing range, parents may have a difficult time adjusting to their child's communication needs (Ebrahimi et al., 2017; Hardonk et al., 2011), and this may ultimately impact the child's language development. Early access to language is critical for linguistic, cognitive, and socioemotional development in infants and young children. Language provides children with opportunities to develop critical thinking skills and

build socially reciprocal relationships. According to research on fetal and infant development, the auditory system develops by the 29th week of gestation (Graven & Browne, 2008), which means that most fetuses from this point forward have preliminary access to sounds including spoken language. However, infants who are born Deaf or with a hearing difference, experience various degrees of language deprivation because they have limited to no access to auditory language while in utero and for the early months to years of postnatal development.

<sup>1</sup>To be inclusive of the heterogeneity Deaf people (e.g., Deafblindness or auditory access levels), the authors use the capitalization of the word Deaf to represent all identities, cultures, and medical experiences of people across Deaf communities. The authors are also using Identity First language as it is the preference of the Deaf Community.

The development of Deaf and hard of hearing children is influenced by early communication between parent and child. It has been estimated that over 90% of Deaf infants are born to hearing parents (Mitchell & Karchmer,

2004). Many infants who are born Deaf or hard of hearing experience delays in language exposure when they are born into families who do not have fluency in a visual language such as American Sign Language (ASL; W. C. Hall et al., 2017). Deaf and hard of hearing infants and young children who do not have access to a full spoken language due to hearing differences have limited opportunities for incidental learning when compared to their hearing counterparts (Hauser et al., 2010), which can have a long-term developmental impact. Data on children born Deaf who gained access to language after the first year of life suggest that later language acquisition and challenges with fluency may lead to poorer developmental outcomes than Deaf children who had access to language at birth (e.g., children born to Deaf parents who were already fluent in a signed language; M. L. Hall et al., 2016; Netten et al., 2015). This delay in language exposure is referred to as language deprivation (W. C. Hall et al., 2017).

Screening and detection of a hearing difference is vital for understanding early intervention for Deaf children. In the United States, currently 43 states and the District of Columbia and Puerto Rico have mandates and guidelines for when hearing screening should occur. The Joint Committee on Infant Hearing (JCIH) recommends newborn screening at birth. If the inpatient screening detects a hearing difference, the newborn is then referred to an outpatient re-screening to be completed within a month (JCIH, 2019). If anomalies are found in the re-screening, the infant is then referred to complete an outpatient audiological evaluation by three months of age. Subsequently, JCIH (2019) suggests that early intervention services be implemented in a family-centered manner before the infant turns six months old. The Early Hearing Detection Intervention (EHDI) project reported 2019 data from 49 states and 7 U.S. territories to the Centers for Disease Control and Prevention (CDC, 2019). From the total births, 98.4% ( $n = 3,545,388$ ) of all newborns had documented hearing screenings. From these, 1.7% ( $n = 65,475$ ) of infants were referred to be further screened with 9.7% ( $n = 5,934$ ) being diagnosed with a hearing difference. Upon the infant being diagnosed with a hearing difference, 84.8% ( $n = 5,034$ ) of these families were referred to early intervention services; only 61.7% ( $n = 3,662$ ) enrolled in services.

Research has found that some parents of Deaf or hard of hearing infants exhibit emotional distress when they first learn of their child's diagnosis (Hardonk et al., 2011; Quittner et al., 2010; Zaidman-Zait et al., 2016). Because Deaf and hard of hearing children present with unique developmental needs and considerations in the areas of identification, diagnosis, and intervention, their parents have to learn to navigate services and programs that may have otherwise been foreign to them. Thus, parents of Deaf and hard of hearing children are thrust into learning about what it means to be Deaf from a variety of conflicting perspectives including cultural, medical, and federal (Flaherty, 2015; Luckner, 2011; Zaidman-Zait et al., 2016). In addition, since differences in hearing status are a low incidence diagnosis (Institute on Disability, 2019),

sometimes general practitioners and mainstream early childhood care providers are unaware of the needs of Deaf and hard of hearing children (Flaherty, 2015).

There is a significant gap in the early intervention literature examining the needs of Latinx<sup>2</sup> Deaf and hard of hearing infants and appropriate service delivery to their families. More specifically, there is a lack of narrative, representation, and perspectives including Puerto Rican families with Deaf and hard of hearing infants and early intervention providers. Therefore, it is likely that Deaf and hard of hearing children and their families receive services that are both culturally biased and exclusive of research containing Deaf intersectional communities.

Early intervention programs rely on evidence-based practices but more research needs to be conducted to consider the impact of services on children and families from diverse cultural backgrounds. For example, although Puerto Rico is a territory of the United States that adheres to federal laws, such as the Individuals with Disabilities Education Act (IDEA), the unique cultural needs of Puerto Rican children and their families, such as family structure, are not considered when implementing early intervention programs. The Health Department of Puerto Rico, Law #311 (P. del S. 2404) established in 2003, states that children who have a hearing difference must be screened, diagnosed, and provided with early intervention by six months of age (LexJuris, n.d.a). However, many Latinx families who have a Deaf or hard of hearing child, including Puerto Rican families, move to the U.S. with hopes of high-quality services for their child with a hearing difference because Puerto Rican early intervention services are not currently meeting the needs of children and families (Steinberg et al., 2003). This is significant because it is estimated that between 135,000 and 185,000 individuals in Puerto Rico are Deaf or hard of hearing with limited access to high-quality services (Quintero, 2013). Yet, limited research among Puerto Rican families with Deaf and hard of hearing children makes it difficult to ascertain the strengths, challenges, and needs of this population.

Although Puerto Ricans have a strong adherence and respect for their own culture, they are at times heavily influenced by U.S. customs and behaviors due to Puerto Rican territorial status, required bilingual education, and federal laws (Capielo Rosario et al., 2018). Therefore, considerations of Puerto Rican families who have Deaf and hard of hearing children should support a bicultural perspective. Latinx hearing families tend to embrace multilingualism, such as teaching Spanish and other native languages and passing down Latinx customs and traditions to their Deaf Latinx children (Lopez, 2014). These bicultural and multilingual values could be used when

<sup>2</sup>The authors used the gender expansive term, Latinx. It is understood that there is currently no consensus on the use of this term. Therefore, Latinx should be complementary to other ethnic identities like Latine, Latina, Latino, or Hispanic (Mora et al., 2022). The authors understand that the 'x' violates Spanish orthography; however, it is commonly used to represent all genders, and has been seen in Puerto Rican scholarly work as a gender expansive term (Logue, 2015).

working with Puerto Rican families with Deaf and hard of hearing children. For instance, this view of biculturalism may be demonstrated when the Deaf child exists in a family that has a balanced perspective of both Deaf and hearing cultures. Families that adopt a bicultural model for their Deaf or hard of hearing child, tend to both embrace ASL through formal language acquisition, while also supporting written English (Gravel & O’Gara, 2003). In this perspective, families encourage interaction within the Deaf and hearing communities for their children and may also choose to use assistive technology devices (e.g., hearing aids, cochlear implants, bone conduction hearing aids).

There have been few studies examining early intervention in Puerto Rico among families with Deaf and hard of hearing children. For example, Pérez Rodríguez (2014) found that (a) families supported assistive technology with the hope that their children might be able to speak, and (b) families with Deaf children tend to have high expectations for their children’s ongoing usage of cochlear implantation and speech. Families who seek services, whether for children ages birth to 3 years old (early intervention) or ages 3 years old and up, tend to establish a good relationship with professionals. However, many professionals do not provide families with a variety of communication alternatives, potentially leaving parents with limited knowledge about what it means to have a child with a hearing difference (Pérez Rodríguez, 2014). The same is true for the Puerto Rican Department of Education such that families view the Puerto Rican Department of Education as providing them with very limited services and information regarding what to do about their children’s diagnoses (Marrero Vélez, 2014). In contrast, Marrero Vélez explored the perspectives of health professionals in Puerto Rico and found that although they are often lacking information when it comes to comorbid diagnoses, like Deafblindness, families continue to feel supported by them regarding guidance for Deaf children. With this information in mind, the current study explored how professionals and parents of Deaf and hard of hearing children view, navigate, and experience early intervention systems in Puerto Rico.

### **Method**

A misconception in research is that philosophical stance does not matter when deciding how to conduct research. Contrary to this misconception, philosophical stance directly influences scientific methodology. The reported study was conducted in Puerto Rico and rooted in a transformative paradigm. A transformative stance allowed for the investigations of marginalized communities and for an increase in awareness of social justice and human rights topics with the research (Mertens, 2009). Moreover, proponents of transformative research explain that this stance allows for addressing societal problems; issues of power, discrimination, and oppression; and allows for changes in society (Mertens, 2009). The current study addressed the transformative paradigm by disseminating information about the perceptions of early intervention status in a marginalized population within the United States. This form of research warranted for

the investigators to refer to various assumptions: the ethical nature of the research (axiology), the perception of reality of the research (ontology), the understanding of the relationship between the researcher and participants and the understanding of the knowledge (epistemology), and the approach to how the research will be conducted (methodology).

As it pertains to the assumptions, the researchers followed principles of respect, beneficence, and justice to the community researched (Mertens, 2019). The authors unpacked and recognized their relationship with the Deaf community and Puerto Rican community. The investigators also maintained that there are many realities and perspectives to the research. For example, while paper-pencil questionnaires provide a quicker and more removed data collection experience for the researcher, face-to-face interviews with marginalized communities can often serve as a more human approach to data collection. The methodology selected was a qualitative approach based on the lack of literature in this community, the importance of having and maintaining an egalitarian relationship with the participants, and valuing the active involvement of participants in theme development. Finally, this approach prevented data manipulation by the authors, and it allowed for the data to be clearly understood during the analysis phase.

### **Research Questions and Procedures**

The research was reviewed and approved by the Institutional Review Board at the authors’ institution. The primary author also applied and received a small grant to fund travel costs and participant stipends. The purpose of the current study was to better understand early intervention services in Puerto Rico by answering the following two research questions:

1. What are the perspectives and experiences of Puerto Rican parents accessing early intervention services for their Deaf and hard of hearing child?
2. What are the perspectives and experiences of Puerto Rican providers regarding early intervention services in Puerto Rico?

### **Data Collection**

Data were anticipated to be collected via three sources: interviews of parents, interviews of professionals, and participant journals (see Appendices A and B for the Semi-structured Interview Guides). However, none of the participants completed their journals. As part of the transformative paradigm, the researchers followed up with the participants regarding their journals on two occasions across three months to no avail.

### **Recruitment and Participants**

Recruitment was completed via social media, provider referral, and word of mouth. Eligibility criteria included the following: all parent participants had to be residents of Puerto Rico, have a Deaf child between the ages of one to five years old, and receive early intervention services. Providers had to provide early intervention services to Deaf children ages one to five years old in any discipline.

Six participants joined the study; three parents and three providers. Three parents had Deaf children under the age of five who received early intervention services in the island within one to two years of the interviews. One parent lived in an urban area of Puerto Rico and two lived in rural parts of Puerto Rico. One of the parents had a master's degree and two of them held high school diplomas. One parent self-identified as trilingual (Spanish, English, and ASL), another parent self-identified as bilingual (Spanish and ASL), and the last parent self-identified as monolingual (Spanish). Regarding socioeconomic status, two of the families self-identified as being of low socioeconomic status and one of the families self-identified as middle class. All of the parents in the study were married and identified as cisgender women.

Three professionals (an audiologist, a teacher/educational therapist, and a special education teacher) who provided early intervention services in Puerto Rico participated in the study. Two worked in urban cities of Puerto Rico and one lived in a rural town of Puerto Rico. The two educators held master's degrees in education/pedagogy and the audiologist held a doctorate in audiology. All professionals self-identified as trilingual, cisgender women, and married. The researchers paid participants \$20 USD at the conclusion of the study for their participation. Phenomenological research suggests no minimum number of participants with research ranging from 1 to 325 participants (Creswell & Poth, 2018).

### **Phenomenological Analysis and Approach**

The researchers used interpretative phenomenological analysis (IPA) to analyze the data. This methodological analysis is experiential in nature, and it is used to learn what each participant is thinking about through various perspectives not limited to affective, cognitive, physical, and societal (Smith et al., 2009). As a tenet of IPA, the authors used thematic analysis to make sense of the participants' experiences and to find general commonalities.

Participants selected their preferred location for their face-to-face interviews. The primary researcher, who is a native Spanish speaker from Puerto Rico, conducted all interviews in Spanish. The researcher is also a certified trilingual (i.e., Spanish, ASL, English) interpreter, and has training and experience in language translation. The researchers conducted and recorded semi-structured interviews that lasted 45 minutes to 70 minutes. Post data collection included the interviewer listening to each recording once prior to analysis as the first step to experience the complete narrative with suspended judgment. The researchers used Dedoose version 8.0.35 to analyze the data (Dedoose, 2018), and they coded directly in the audio stream without transcribing separately to ensure fidelity to the Spanish language prior to translation. The native Spanish speaker author translated all of the selected quotes from Spanish into English.

The first step to coding included exploratory comments throughout the data. This notation allowed the researchers

to highlight anything of interest (Smith et al., 2009). These comments allowed for deductive and inductive commentary to identify rich points of the data (Mertens, 2019). During this phase, the researchers observed the participants' language use, their concerns about their experiences with early intervention, and the associated themes.

The researchers maintained data integrity through the process of epoché, which allowed for the researchers to analyze their preconceived notions. The epoché initially allowed the participants to gain an understanding of the preconceptions, reducing as much bias as possible. The primary author used journaling as a tool to monitor prejudice, favoritism, and bias. Upon completion of journal entries, the researcher discussed self-reflective assumptions identified in the journaling process with an expert early intervention researcher in Deaf and hard of hearing populations with more than 20 years of research experience. The process allowed for an additional layer of ethical rigor as a technique of credibility for research trustworthiness.

Moreover, after each interview, the researchers bracketed powerful recollections that occurred during the interview with the participant interviewed. Again, this process was ongoing and continued to take place until the data was fully analyzed. This part of the analysis also served as a criterion for quality, allowing researchers to monitor subjectivity as an ongoing process by using notes. Through member checks, which included sending typed transcripts of the interviews to participants one to three months post interview via electronic delivery, all participants accepted and approved their interview transcripts as transcribed by the Spanish-speaking researcher.

## **Results**

Three major and two minor themes emerged during the analysis of the data (see Figure 1). The analysis also identified several subthemes under the category of *Barriers to Services*. In the following section each theme is described and supported by selected direct quotes from the interviews.

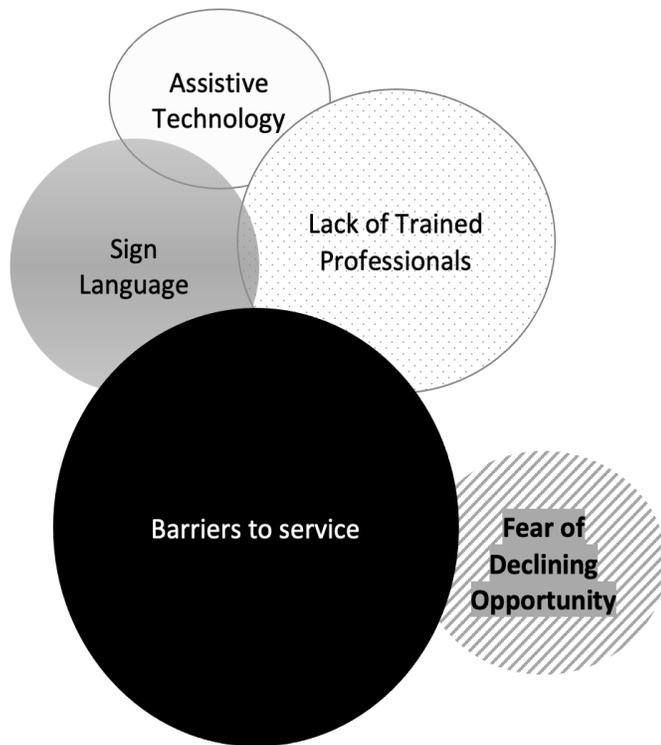
### **Major Theme 1: Barriers to Services**

The most prominent theme that emerged in the data suggested both parents and professionals experienced barriers in early intervention. Despite both groups experiencing difficulties, each group reported distinct barriers based on their specific role as either a caregiver or as an early intervention specialist.

#### **Accommodations**

A shared concern between groups was the overall lack of accommodations for toddlers and young children in early intervention. Both parents and professionals discussed frustrations with advocating for interpreters in educational programs and often not having an individualized family service plan (IFSP). In fact, none of the parents interviewed in this study reported having an IFSP for

**Figure 1**  
*Barriers to Service*



their child and the professionals shared that it was a rarity for Deaf and hard of hearing children to receive an IFSP. Parents and professionals reported that most Deaf and hard of hearing children who are eligible for early intervention services may attend an early head start program without appropriate communication access, such as an interpreter.

Parent 2: *It is really sad that my child was placed in Head Start. No one knows what to do with a Deaf child in Head Start here. People do not know what to do. There is no interpreter, no language, no access! At one point, I became my own child's assistant in school.*

Professional 2: *The established educational and legal system are hindering Deaf children's development in Puerto Rico. There are no interpreters or accommodations provided to families and children. When I became an itinerant teacher for children from ages 0-5, I told the parents what was going on. I explained the importance of IFSP and IEP [individualized education plan] to parents because the Department of Education here in my opinion takes advantage of families.*

### **Family Financial Burdens**

Another significant obstacle identified by parents of Deaf and hard of hearing children was financial hardships. Families had to make major financial decisions, such as having to sell some of their assets (e.g., houses, cars) to defray the expenses incurred in their children's

medical appointments and other needs. These out-of-pocket costs were often made in private healthcare and educational settings to avoid being placed on long waitlists in government-sponsored programs. Moreover, data revealed that Puerto Rican family values of caring for their children was of most importance, which resulted in two of the mothers having to quit their jobs to care for their young children.

Parent 2: *Many doctors in various specialties do not accept the government insurance I had, or they have longer wait lists for people like us with government-sponsored insurance. I ended up selling my house because we could not afford the doctors and I was concerned that something could worsen with my child.*

### **Advocacy**

Families reported challenges understanding how to appropriately navigate educational and healthcare systems and finding appropriate, high-quality services near their home. Parents reported frequently encountering inflexible government schedules that did not align with their child's or family needs. Furthermore, only parents with strong advocacy skills and those who were knowledgeable about their children's rights were able to access ongoing early intervention services and local educational programming.

Parent 1: *They wanted to only offer speech services. I called my local early Head Start and the school complained about my child [being Deaf]. They said they had no service. I was then told to call this lady in a private Deaf preschool program. I called immediately, and they said you need to call the Department of Education for permission. I went to the Department of Education and got her enrolled really fast.*

### **Government Funding**

Early intervention specialists discussed how the current sociopolitical climate in Puerto Rico was what primarily impacted early intervention services on the island. All professionals mentioned the lack of governmental funding for Deaf specific early intervention and educational programs. Additionally, professionals explained that all Deaf services in Puerto Rico are currently private or government-subsidized, which contribute to the difficulties in families obtaining timely services. Furthermore, these professionals also disclosed how well-established Deaf programs on the island have dwindled in number due to the general lack of support from administrators and their misunderstanding of the needs of Deaf infant and toddler programs. Professionals mentioned how training and workshops for professional development in Deaf early intervention are inaccessible in the workplace also due to limited government funding.

Professional 2: *The Department of Education is awful right now. We do not have any public Deaf schools in Puerto Rico. That is horrible and everyone is being mainstreamed. That hinders development on so many levels.*

Professional 3: *When I started teaching, we had a Deaf preschool here... As numbers and funding went down, the Deaf preschool and program were eliminated. The problem with this is that a regular mainstream teacher is the one providing work and accommodations to the Deaf kids in our school with no one specializing in Deaf education, not even me because there is no Deaf program... The point is Deaf kids on the island are all over the place and no one is supporting them.*

The group of professionals also unanimously discussed how integrated programs are grouping Deaf early intervention services with early intervention services for other populations that may have distinct needs such as children with neurodevelopmental disabilities (e.g., autism, intellectual disability) or sensory disabilities (e.g., blindness).

Professional 3: *My master's degree is in special education for children with autism, so they moved everyone into my autism specific classroom. So, kids are all over the place and no one is supporting them.*

## Major Theme 2: Sign Language

All participants discussed their perspective on sign language. The majority of participants reported being a proponent of sign language. No one was against the use of sign language, but some reservations were made by one of the parents.

Two of the three parents reported using sign language with their children through total communication at the time of the interview. They catered to their child's preferred method of communication which included using a combination of speech, sign language, or both speech and sign language (SIMCOM). These two parents also reported being well integrated with the Deaf community in Puerto Rico after the diagnosis of their children. The third parent reported considering sign language with her child. However, she indicated that the biggest concern is her lack of knowledge of sign languages and how they may further hinder speech development. She indicated that her child's audiologist has suggested the use of sign language and was looking for sign language classes for her and her child despite her fear.

Parent 3: *My speech-language pathologist wants me to learn sign language. I am unsure if I will teach him sign language because I think that would be good for him. However, if I teach him sign language, would he keep learning spoken language? The audiologist says sign language is the way to really go*

*with him, so that he could have both. I can do both. At home, we communicate well, he communicates with his own signs with our family. He hasn't learned sign language, but hopefully he will.*

All professionals reported supporting the use of sign language with Deaf children. Two of the early intervention providers discussed how making sign language an official language in Puerto Rico might help develop better programs for Deaf children in early intervention centers and in public schools. The professionals also discussed the importance of how sign language can be used as a foundational language and a building block for spoken and written languages, such as Spanish or English. Furthermore, they expressed how the lack of early language exposure can cause delays in language, cognition, and socioemotional development. Sign language was framed as an accessible language that supports typical development. Lastly, the professionals specified the need for more professions and families to serve as sign language models for Deaf infants and toddlers.

Professional 2: *When they go to first grade... Their role model in sign language is from the interpreter. That is also not appropriate language development for them... In public schools, we are seeing how a child just learns language from one person their whole life... This is a problem affecting Deaf culture because children no longer have access to their Deaf peers and teachers who know sign language. We are starting to close down schools for the Deaf or Deaf-specific programs without other avenues to facilitate Deaf culture.*

## Major Theme 3: Lack of Professionals Trained in Working with Deaf Communities

All participants discussed the struggles they faced finding well-trained professionals in Deaf and hard of hearing practices. Parents reported that they want to have accessible early intervention services in sign language for their children, healthcare providers who know how to work with culturally Deaf young children, and educational staff who are competent in the area of hearing difference and sign language.

Parent 1: *I keep fighting with the early intervention specialist because I request specialists that know about Deaf culture and ASL. The problem is that so many people do not know ASL. What if my daughter chooses to only sign? What if her hearing aids do not work? I have appealed and requested ASL fluent professionals. I have been waiting for a year!*

Professionals discussed that not having a wide pool of professionals whether early interventionists, educational staff, or health care providers impact the continuity of

services and sociocultural development of Deaf children. Further, the professionals discussed that having providers working with Deaf children who are not specialists in this area may lead to misdiagnosis, either over pathologizing or missing weaknesses. Most professionals raised the importance of at least speech-language pathologists, pediatricians, or teachers in being trained in cultural Deaf practices and being proficient in sign language to assist with adequate referral sources for services.

Professional 1: *Pediatricians are the medical home for Deaf children. They need to learn how to work with Deaf families. They cannot use the same skills they use with children with autism and intellectual disabilities. This is different [for Deaf children] because they are needing to focus on attachment, development including language, cognitive, and social aspects. Again, these medical doctors focus only on the physical part. Deafness does not make [someone] a disabled person unless healthcare and educational providers hinder development, [thus] making [someone] disabled.*

### Minor Theme 1: Use of Assistive Technology

Assistive technology presented as a less saturated theme despite it being generally endorsed by all parents and professionals. Although all parents considered cochlear implants for their children, ultimately, they elected for their children to have hearing aids. Parents' health literacy varied greatly on the topic of assistive technology. They preferred approaches including hearing aids, sign language, and speech/language therapy; in some cases, based on the belief that the time invested in cochlear implantation and habilitation could be better allotted toward allowing children access to the Deaf community.

Parent 2: *My daughter has been very successful using her hearing aids. She can speak clearly and can hear some. She loves music and watching tv with what she can hear. I do have a big concern with hearing aids and that is with the financial aspect. Here in Puerto Rico, audiologists charge a lot for hearing aid appointments. I was lucky that I befriended an audiologist [who] gave me a discount. I considered a cochlear implant for my daughter, but I don't think she will benefit from it at this point. However, professionals really would like for my daughter to get one.*

All professionals supported children using assistive technology whether hearing aids or cochlear implants. Early interventionists believed that using assistive technology with sign language allows for optimal social and linguistic development.

Professional 2: *I think that hearing aids and cochlear implants are crucial for Deaf children. Using technology with sign*

*language will only maximize the child's development. However, I want parents to know of all the options they have.*

### Minor Theme 2: Fear of Declining Opportunity

Worry for future discrimination emerged as the second minor theme for parents. Parents discussed their fears regarding having their children grow up and face discrimination by the larger society due to their hearing difference. Most of the fear stemmed from how others will perceive Deaf and hard of hearing children in Puerto Rico. However, one parent expressed concern of an inability to parent her Deaf child through later developmental stages.

Parent 1: *My worries for her in the future is that society doesn't open their minds. That she will be shunned and marginalized because she is Deaf. I would hate if she did a job interview and prejudice takes over the interviewer thinking that she has intellectual deficits. I do not want people to discriminate against her. I want her to be happy! I have been teaching her that everyone is different. I tell her you are Deaf, and I am fat. People will judge us but you can still do anything you set your mind to. It can be hard feeling like you are the only one like you.*

On the other hand, professionals worried about the future of their professions. Sociopolitical issues were highlighted at the government level (e.g., senators and legislators not supporting Deaf rights), professional level (e.g., lack of advocacy within the field of early intervention), and the individual level (e.g., families demanding rights).

Professional 3: *I am not sure what will happen to our profession. If it were for me, I would start the Deaf education and Deaf early intervention training again.*

### Discussion

The current study explored provision of early intervention services for Deaf and hard of hearing children in Puerto Rico from both parent and professional perspectives. The researcher maintained validity of this study by conducting a one-step member check process, involving a qualitative peer researcher, journaling, and by having a native Spanish speaker author from Puerto Rico, who is a nationally certified ASL interpreter, and a trained Spanish to English translator. These steps allowed the findings to be aligned with participants' intended expressions.

Participants in this study varied in terms of socioeconomic status, educational background, and understanding of what Deaf and hard of hearing infants, toddlers, and preschoolers need for early intervention. However, they shared many experiences and perceptions of what it means to have a child with a hearing difference in Puerto Rico or being an early intervention service provider of Deaf and hard of hearing children. Both parents and professionals identified prominent themes regarding accessing Deaf-specific early intervention, sign language,

and lack of trained professionals. Moreover, a couple minor themes emerged including lack of assistive technology and a fear of declining opportunities in the Deaf community and profession. All presented themes were related to developmental, family, and cultural needs in Puerto Rico.

Both parents and professionals discussed the multitude of barriers to receiving early intervention services for infants, toddlers, and young children in Puerto Rico and fear of declining opportunities for children and professionals. Public accommodations and appropriate placement for children were highlighted as a significant concern including the lack of access to language via an interpreter or a provider fluent in sign language. These findings are similar to the results from the Gerner de García and colleagues (2011) study that highlighted the lack of qualified early intervention professionals in Puerto Rico to work with young Deaf children. Many of these barriers would be nullified if agencies followed federal and local guidelines and mandates, including IFSPs and IEPs that require appropriate services and placements for these children. Moreover, local ordinances such as the Ley de Orientación sobre los Servicios Multidisciplinarios de Intervención Temprana en Puerto Rico ([P. de la C. 1469]; 2014, ley 200) stipulates Puerto Rico's Department of Health establish a strategic health plan for all children at-risk for any developmental concerns, which includes Deaf and hard of hearing children. Parents and professionals in early intervention in Puerto Rico are encouraged to advocate for these laws to be implemented according to their families' rights. Current advocacy strategies for children in the field are being driven by fears that Deaf and hard of hearing children will not have favorable long-term trajectories without the fervent intervention of adults.

Family advocacy will also need to include early intervention programming specificity. Study participants raised concerns about the lack of Deaf-specific early intervention programming. For example, instead of Deaf-specific programs and classrooms, Deaf and hard of hearing toddlers in Puerto Rico are being clustered with children who have neurodevelopmental needs, such as severe autism based on major classification of diagnoses (i.e., the International Classification of Diseases [ICD] and the Diagnostic Statistical Manual of Mental Disorders [DSM]). Some children with severe autism are unable to communicate using the full syntax, phonemes, morphemes, and context, which are needed in language development. Typically, signing communication systems that are used with children who have significant neurodevelopmental challenges are not fully formed languages. Therefore, this type of integration contributes to noteworthy language deprivation among Deaf and hard of hearing children because the needs of Deaf and hard of hearing children significantly differ from the needs of children with neurodevelopmental concerns, yet they are not being addressed in these programs.

Furthermore, the family's organizational structure continues to be an important factor for early intervention

service providers in Puerto Rico due to *familismo*, a cultural practice. Familismo is a central heteronormative cultural value in the Latinx community, which refers to the importance of family interdependence, loyalty, and placing the family's needs before any other areas of importance (Sabogal et al., 1987). Therefore, professionals should provide early intervention services using a family-centered approach (Störbeck & Young, 2016). A family-centered approach seeks to understand the family's strengths, priorities, and resources through thoughtful collaboration with the family to best meet the needs of the child. When a child has a different ability, the family prioritizes the child's needs. In familismo, the female figure, or the mother, becomes the primary caregiver and implementer of services. This change in the family often results in the mother having to redirect her efforts away from working outside of the home (Kelly, 2009, Magaña & Smith, 2006). Although the mother carries the brunt of the child-related services in these cases, the family as a unit continues to make healthcare and educational decisions for the child. A family-centered approach includes all individuals who are identified as *family* members (e.g., immediate versus extended family). The dynamic of familismo and the framework of family-centered approach was discussed throughout the findings of the current study especially in the area of barriers to service.

Limited funding, another barrier to service, appears to be a common reason for inadequate early intervention services in Puerto Rico. The impact of government funding to early intervention in Puerto Rico can be attributed to the fact that Puerto Rico is a colonized territory of the United States that has poor government administration of educational and health programs (Denis, 2015). Puerto Rico currently has a major education crisis with teachers inconsistently receiving pay increases and having poor professional development opportunities, as well as staff having limited resources (Onieva López, 2015). Since the passing of the Puerto Rico Oversight Management and Economic Stability Act (PROMESA) which required an American appointed oversight board to manage the island's budget, Puerto Rico has not managed their own finances (Villanueva, 2019). The PROMESA, established a year prior to the completion of the current study, has implications on early intervention difficulties that both providers and parents reported in this study. In fact, the government budget for special education services to provide therapy services in 2018, which includes early intervention services for Deaf and Hard of Hearing young children, was cut by \$78 million (Rivera Sánchez, 2018).

A significant finding in the sample was the limited use of sign language for Deaf children by both the parents and professionals. The findings of the current study align with previous research demonstrating that Deaf children who are exposed to a sign language develop in a typical manner (M. L. Hall et al., 2016). Research has found that many Puerto Ricans may not have access to accurate information regarding how a hearing difference may negatively impact typical social and language development when access to sign language is denied (Gerner de García et al., 2011).

However, no published research has been identified that demonstrates the amount of support for signed languages on the island of Puerto Rico. Related to language access, professionals and parents alike supported the use of assistive technology in Deaf young children as an opportunity for children to learn spoken and written English and Spanish. Unlike previous research, non-invasive technology (e.g., hearing aids) were the primary supported technology in the current study. Past investigations in Puerto Rico reflected how assistive technology, particularly invasive technology (e.g., cochlear implants), was important to Deaf children on the island (Pérez Rodríguez, 2014).

### Limitations

Phenomenological research allows for a rich and in-depth understanding of a specific phenomenon within a population. Although routinely the data collected in a study of this nature attempts to capture the experiences of a variety of people from the general population, the current study only provides experiences from a racially homogeneous perspective. However, the Puerto Rican community is a cultural group of people from many different racial backgrounds. The current study missed data from people who immigrated to the island or who identified as Black Puerto Rican or other racial backgrounds. This is problematic because Black Deaf individuals maintain a double marginalized status globally (Nelson Schmitt & Leigh, 2015; Foster & Kinuthia, 2003). Overall, racial identities and Deaf cultural identities tend to intersect and be multiplicative in nature for people from historically racialized groups. Therefore, representations of Deaf individuals are an important consideration for Deaf infants, toddlers, and children's development and in the services received. Furthermore, all participants, whether parent or professional, identified as cisgender women and had a marital status of married. Lastly, while there are few Deaf children in Puerto Rico who are enrolled in early intervention services, none of the children discussed in this study were receiving early intervention services at the times of the interviews.

### Recommendations and Future Studies

More research is needed in Deaf early intervention services in Puerto Rico, including the intersections of race that are reflective of the island. As with many of the studies, the current study had a sample population that was homogeneous, (i.e., White). A study that focuses on or includes the lived experiences of Black or Asian, for example, Puerto Rican families with Deaf or hard of hearing children would significantly contribute to the literature of these marginalized communities.

Future research could also focus on the language outcomes of Deaf and hard of hearing children in integrated classrooms in Puerto Rico compared to children in Deaf-specific programs. These findings may contribute to the understanding of how these classrooms affect the development of Deaf and hard of hearing children compared to programs tailored to Deaf children. In addition, retrospective accounts of Puerto Rican Deaf adults' views of their early childhood educational careers would contribute to a foundational understanding of

changes in Deaf-specific services and experiences for children in Puerto Rico.

This study opens the door for future studies examining the efficacy of early intervention services in Puerto Rico on the development of the young Deaf children being served, as well as replication studies with similar goals as the current research. Future research should consider using the qualitative model of participatory action research (PAR). In PAR research, parents, professionals, and Deaf community members would serve as the main stakeholders to develop best practice guidelines for Deaf early intervention services in Puerto Rico for young children. Furthermore, research needs to include advocacy efforts of families for culturally responsive and collaboration for high-quality early intervention services (e.g., interpreters, appropriate placements and programing, trained Deaf educators, and attention to familismo). To further explore access to early intervention services across the island, researchers should consider the feasibility and efficacy of virtual service delivery. Finally, research needs to be conducted on the continued effect of PROMESA and funding decisions on federally required services to examine the long-term impact on Deaf and hard of hearing children.

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## Appendix A

### Semi-structured Interview Guide—Providers

1. Tell me about your background and how you became involved in early intervention with children who are Deaf or hard of hearing.
2. What is your perception of Early Intervention services in Puerto Rico?
3. What are your experiences working in Early Intervention services in Puerto Rico?
4. What information do you provide families about their children's hearing status (e.g. hearing difference, Deaf, hard of hearing)? How about communication?
5. What type of services do you provide to Deaf and hard of hearing children and their families?
6. When are children usually referred to you?
7. What type of interdisciplinary work do you usually do when working with families?
8. What guidelines do you follow when working with Deaf children and their families?
9. What type of support do you receive to provide your services?
  - a. From the mentioned above (e.g. supervisor, etc.), what are their strengths and how does this improve your services?
  - b. From the mentioned above (e.g. supervisors, etc.), what do you wish they could support you better with?
10. How is the Deaf community involved in your program?

## Appendix B

### Semi-structured Interview Guide—Families

1. Tell me about your and your family's thoughts and feelings when you were first told that your child was Deaf (or hard of hearing)? How old was your child?
2. What type of supports have you had and from whom?
3. What type of communication do you use at home and how did you decide on the communication approach to use with your child?
4. What type of information have you received to understand your child's strengths and needs?
5. What type of early intervention have you and your child received?
6. What progress has your child made since starting early intervention services?
7. Have you and/or your child met Deaf adults? If yes, who did you meet and why did you meet them? If no, why have you and/or your child not met Deaf adults?
8. What services have you received that have helped your child and your family?
9. What services or resources do you wish you had for your Deaf child?
10. What advice do you have for the professionals who work with families like you who have a Deaf child?
11. In 10 years, what do you hope your child will be doing?