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Conversations with Panamanian Parents Regarding Their Children with Disabilities

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Abstract

Over 8 million children under the age of 14 live with a disability in Latin American and Caribbean (LAC) countries. These children are often denied educational opportunities and related services that have the potential to enhance their quality of life. In this qualitative study, we conducted a secondary analysis of interviews with eight parents of individuals with disabilities living in the Republic of Panama. The aim of this study was to examine the parental perceptions of disability, communication supports afforded to individuals with disabilities, and enablers and barriers families face when raising, educating, and finding services for their children. Four general themes emerged from the analysis of the transcript: child characteristics, child communication, sources of support, and barriers to inclusion. Implications and possible solutions are discussed.

Keywords: disability, parent perceptions, special education, Latin America, educational inequalities.

Developmental disabilities include a range of conditions due to physical, communicative, behavioral, emotional, social, or cognitive impairment (Zablotsky et al., 2019). Raising a child with disabilities remains a challenge for many families. This challenge can be amplified by the sociocultural context of society. The sociocultural context encompasses the diversity of settings, ecological, and historical conditions that can shape a person's development (Gauvain, 2013). It also includes all the experiences across settings in which members of a specific group share values, beliefs, and ideas about a specific topic and behave in response to it (Rogoff, 2003).

The sociocultural framework in which a person develops impacts different areas of life, such as cognition, emotional expression, forms of socialization, behaviors, decision-making, motivations, and ways of resolving conflicts or life challenges (Hofstede, 2001). Therefore, this is a fundamental process that can influence, hinder, or promote opportunities for the development of skills that allow individuals with disabilities to exercise autonomy and self-determination (Hofstede, 2001). In addition, the sociocultural context may affect how disability is perceived, supported, and experienced by different individuals (Bailey et al., 1999).

LATIN AMERICA AND THE CARIBBEAN (LAC) AND DISABILITY

Latin America and the Caribbean (LAC) is a category that describes the vast region that includes Mexico, Central

America, South America, and the Caribbean islands. Over 85 million people live with a disability in LAC (World Bank, 2021b), with poverty being one of the leading causes and consequences of disability (United Nations, 2013). As part of this group, we have more than eight million children under the age of 14 (United Nations Children's Fund Latin America and Caribbean Regional Office [UNICEF LACRO], 2019). Estimates indicate that only 3 out of 10 of these children attend school, and over 50,000 children and adolescents under the age of 18 still live in institutions (UNICEF LACRO, 2019). The lack of quality educational opportunities has a cascading effect that affects the entire family system.

Having a family member with a disability is a matter that impacts the whole familial ecosystem in LAC countries. The Latine/Latinx socio-cultural context is categorized as collectivist (Krys et al., 2022). In collectivist cultures, individuals have a long-term commitment and shared responsibility for the group's well-being (Gudykunst, 1998; Hofstede Insights, 2022) thus, immediate and extended family members in the LAC region often share the responsibility of having a relative with a disability.

As is the case in other developing countries, the socio-cultural context of disability has a negative connotation (Barnes & Mercer, 2005; Bornman, 2017). Although a great majority of the countries of the region ratified the Convention on the Rights of Persons with Disabilities, children with disabilities in LAC countries are often subject to abuse, violence, negative attitudes and stereotypes, social and educational exclusion, and stigma (Hincapie et al., 2019; UNICEF LACRO, 2019). These individuals and their families often struggle to attain rights that have been normalized in developed nations.

The primary reason for this struggle can be linked to governments in LAC countries largely ignoring issues related to disabilities (Lazcano-Ponce et al., 2008). Consequently, there is limited evidence on how disability is defined and how laws addressing inclusive education are designed and implemented in the countries in the region. However, in 2007 the United National Educational, Scientific and Cultural Organization (UNESCO) created and started implementing the Regional System of Educational Information for Students with Disabilities (SIRED) system. This system was created to identify the barriers faced by students with disabilities and the supports needed to access an equitable education. Eight LAC countries participated in this effort (Argentina, Brazil, Paraguay, Peru, Costa Rica, Guatemala, Mexico and the Dominican Republic). Findings from this project indicate that although all participating countries have identified many of the barriers to inclusion and have created the framework and/or laws required for the inclusion of children in general education classrooms, these educational initiatives are not being fully implemented in most countries (Paya, 2020; Pinilla-Roncancio, 2015; UNESCO, 2007).

This lack of government oversight translates to low educational opportunities and expectations for children with disabilities and, consequently, few employment opportunities for individuals with disabilities (Wolfensohn, 2004). Estimates indicate that this population's unemployment rates range between 80 to 90% (Wolfensohn, 2004). As a result, Latinos with disabilities experience poverty at much higher rates than their non-disabled peers. Calculations show that over 82% of people with disabilities in this region live in poverty, compounding the effects of disabilities (International Bank for Reconstruction and Development, 2021). For instance, households with a member with a disability have a higher possibility of being in the bottom two income quintiles (Inter-American Development Bank, 2020). The compounding effect of a lack of education, access to services, and employment opportunities, high poverty rates, and high unemployment for the general population, results in individuals with disabilities experiencing a lower quality of life than in developed nations (International Bank for Reconstruction and Development, 2021; Mercadante et al., 2009).

Previous research in LAC countries has also revealed that families who raise a child with a disability face barriers and difficulties in different areas. Caregivers have reported social difficulties due to a lack of knowledge about disability in their countries, as well as educational, employment, and health challenges because of the absence of access to adequate services (Giaconi Moris et al., 2017; International Bank for Reconstruction and Development, 2021). This can result in loneliness and frustration, unsatisfactory interpersonal relationships, family overload, difficulties for the primary caregiver to have a work life, sleep disorders, and mental and emotional disorders (Giaconi Moris et al., 2017; Pantano et al., 2012).

Furthermore, in a recent report, Hincapie and colleagues (2019) discussed how the lack of quantitative and qualitative data limits researchers' ability to assess the educational inclusion efforts in the LAC region. Nevertheless, available data from a small number of countries in the region is consistent with the barriers identified by the SIRED report, as researchers indicate that the goal of fully including students in all educational settings remains "an ambitious goal that is far from reality" (Hincapie et al., 2019, p. 17). Additionally, four main barriers to inclusion in LAC countries were identified: delayed age of diagnosis; a lack of qualified professionals; an absence of resources (e.g., assistive technology, adapted equipment, ramps, routes from school to home not being accessible); and the stigma associated with disabilities and inclusive learning (Hincapie et al., 2019). Given the lack of research in this area and the need for inclusive education and services, it is imperative that we increase efforts to investigate the educational needs of individuals with disabilities in LAC countries.

For this initial study, the Republic of Panama was chosen. The Republic of Panama is an upper-middle-income country with a population of around 4.5 million (World Bank, 2021a). Although the official language of Panama is Spanish, English is widely spoken and taught in both public and private schools. Like most other LAC countries, Panama is considered a collectivist society (Hofstede, 2001; Hofstede Insights, 2022). Panamanians typically work towards what is best for their 'group' (e.g., family, friends, relationships). Estimates indicate that around 8% of Panama's population has a disability, with rural areas having a higher incidence than urban communities (Inter-American Development Bank, 2020).

In Panama, the first records of students with disabilities receiving educational services date back to the 1940s (Instituto Panameño de Habilitacion Especial, 2014). However, it was not until 1999 that legislation to guarantee the rights of students with disabilities' rights to an inclusive education was enacted (Instituto Panameño de Habilitacion Especial, 2014). Currently, every government-funded school in Panama is required to have one inclusion classroom per grade (in some circumstances, there may be a multi-grade classroom instead of one per grade). The inclusion classroom could be compared to an American resource room as the teacher provides educational and life skills support for the students for parts of the day, and the student attends a same-grade general education classroom for the rest of the day. The length and courses the student participates in are based on decisions made by the child's educational team. It should be noted that government-funded schools in the country have morning and afternoon shifts. A different group of students attends each shift, so students are only in school for about five hours per day. The ministry of education has plans to eliminate the shift system and have students in school for eight hours a day; however, it has yet to be implemented in every school.

In addition to the inclusion classrooms, there are also 30 support centers (e.g., center schools, specialized programs for specific disability categories, specialized schools) in the most populated areas of the country that aim to serve students with more complex disabilities and transition-aged students. A separate governmental agency services all special education services afforded to students in government-funded schools under the Ministry of Education, the Instituto Panameño de Habilitacion Especial, commonly known as IPHE. The IPHE also provides early intervention services, educational resources for individuals with disabilities, and a variety of professional development activities for general and special education teachers (Instituto Panameño de Habilitacion Especial, 2014). Most of these programs are based in the city and have limited reach for those living in other provinces. It is worth mentioning that there are currently no guidelines or requirements for private schools to offer special education services to pupils with disabilities.

The reasoning for selecting Panama for this study was twofold. First, convenience. The first author is Panamanian and has connections to different disability rights advocacy groups in the country. Second, in the 1980s and 1990s Panama was regarded as a model for educating students with disabilities (Medina Rodriguez, 1995). However, general dissatisfaction within the special needs community (e.g., students, caregivers, educators) has suggested this needs to be revised.

This study and the interview questions were originally conceptualized to learn about the communication of individuals with severe disabilities, particularly those who required augmentative and alternative communication (AAC) supports. However, the interview results provided a much deeper insight into the daily lives of parents of children with disabilities and the barriers they faced. Given the rich information provided by the parents regarding the structural inequalities and barriers they and their children faced every day, the researchers conducted a secondary analysis of the data. This secondary analysis focused on examining the parental perception, enabling conditions, and barriers families face when raising, educating, and finding services for their children with disabilities. The analysis aimed to answer the following research questions: (a) How do parents of children with disabilities perceive and understand their child's disability? (b) What tools and strategies do parents use to support their child's communication and education? (c) What are the barriers to individuals with disabilities being fully included in Panamanian society?

METHOD

Participants

This project was submitted to be reviewed by the Institutional Review Board (IRB). After a review of the project's methods, the IRB categorized this study as exempt, given the low risk to participants. Following this designation by the IRB, parents of individuals with disabilities from Panama were recruited to participate in this study. Recruitment took place via social media flyers, word of mouth, and snowball sampling. To be eligible, parents were required to (a) be the biological or adoptive parent of an individual with a disability and communication difficulties and (b) reside in the Republic of Panama. Interested parents were asked to contact the first author for a screening. The first author was, at the time of the study, a doctoral candidate in Special Education. She identifies as a bicultural native Panamanian and fluent Spanish speaker. The first author conducted all interviews. A total of eight

Table 1
Participant Demographics

Participant	Age	Profession	Child's Name	Child's Age in years	Child's Diagnosis	Interview Method
Arturo	69	Handyman	Marcelo	10	Down Syndrome	Email
Diana	35	Mortgage Consultant	Olga	6	ASD	Email and WhatsApp
Deborah	62	Architect	Daniel	32	ASD	Email
Eva	41	Business Management Consultant	Mili	7	ASD	Email and WhatsApp
Laura	45	Former Banker- Full time caretaker	Ernesto	8	ASD	WhatsApp
Leticia	47	Administrative Assistant	Guillermo	n/a (school aged)	ASD	Email
Ursula	53	Nurse	Camila	31	Myelomeningocele and Hydrocephalus	WhatsApp
Pilar	50	Lawyer	Francisco	13	ASD	Email

parents (seven mothers and one father) participated in this study. Parents were between the ages of 35 to 69, and their children were aged 6 to 31. Disability categories for their offspring included autism spectrum disorders (ASD) ($n = 6$), Down syndrome ($n = 1$), and hydrocephaly ($n = 1$). Table 1 displays complete participant demographic information.

Design

The research team employed a qualitative thematic analysis approach to collect and analyze data (Saldaña, 2021). Once participants were screened and eligibility established, the first author asked parents for their preferred interview method. Choices included email, phone, video conference, or a popular online messaging system widely used in Panama (i.e., WhatsApp). The first author conducted asynchronous semi-structured online interviews (Merriam & Tisdell, 2016) with all parents via email, WhatsApp, or a combination of both. All interviews were transcribed, and all identifiable information was removed from the transcripts.

To answer the research questions, the researcher collected information regarding (a) child's interests and communication skills, (b) caregiver's disability knowledge, (c) informational resources and learning interests, and (d) attitudes regarding the educational and health system in Panama. A complete list of interview questions is presented in Table 2.

Development of Probe Questions and Interview Approach. Qualitative studies that investigated the experiences of families of children with disabilities from minority and/or Hispanic backgrounds were reviewed to develop the probe questions for this study (Huer et al., 2001; Huer & Saenz, 2003; Merriam & Tisdell, 2016; Parette et al., 2004). Although the probe questions served as a guide to encourage participation and build rapport with parents and caregivers, the author included additional follow-up questions as necessary.

Data Analysis. Transcribed interviews were read and analyzed by the first and second authors. The second author is a native of Mexico and, at the time of the study, was pursuing her doctoral degree in psychology at a university in Spain. Inductive and deductive analyses were used to code the transcripts (Saldaña, 2021). The first step

Table 2
Interview Questions

1. Tell me about your child
2. Tell about a typical day in your home?
3. What are some strengths/weaknesses of your child?
4. How do your students/child typically communicate?
5. How do you feel about your child's communication abilities?
6. What do you know about AAC?
7. How do you feel about AAC as a way to help children communicate?
8. When you want to learn something new to support your child, what sources do you consult?
9. What new topics would you be interested in learning about people with disabilities?
10. What do you think about the Panamanian educational system for children with disabilities?

involved open coding the interviews to pinpoint any potentially relevant information. Open codes were then grouped using analytical coding (Charmaz, 2014) to form categories that would answer the research questions. Each coder reviewed the transcripts and created categories independently. For a secondary analysis, both coders met and compared their categories. Redundant themes were consolidated, and the categories were named based on the overarching information they represented. Finally, the first and second authors pulled and translated quotes from Spanish to English that would best summarize each theme for the manuscript.

RESULTS

Using inductive and deductive approaches, four general themes emerged from the analysis of the 1,226 lines of transcript. The themes include (a) child characteristics, (b) child communication, (c) sources of support, and (d) barriers to inclusion. This section will be organized based on the aforementioned themes. Additionally, translated quotes from the participants will be used to illustrate the themes in a cross-participant way within each theme.

Theme One: Child Characteristics

Overall, parents used positive and poetic words to describe their children. Laura, the mother of an 8-year-old son with ASD, called her son 'prince charming' to describe how proud she was to have him in her life. Parents described in detail their child's abilities, temperament, personality, favorite activities, emotions, and interactions with others. Deborah, the mother of Daniel a 32-year-old man, described her son as a "calm young man, with a cheerful personality, willing to help, watches out for others, he likes to keep busy."

When discussing their child's weaknesses, most parents often expressed concerns about the impact of their child's disability. These included communication difficulties, adaptation to changes, socialization, sensory weaknesses, and struggles with fine and gross motor tasks. When asked to talk about what she considered to be her child's weaknesses, Laura, the mother of Ernesto, an 8-year-old boy with ASD, mentioned that "Sometimes he is insecure or frightful, but I think we all have a little of that…and the fact that he can't talk because it is difficult for him to communicate so we can understand him."

Several parents described a typical day in their house by making specific references to their child's ability to be independent around the house. References included the ability to cook, feed themselves, clean the house, and take care of their toileting needs. Leticia, Guillermo's mom used the following anecdote as a response to the question, "tell me about your child":

> What surprises me about [son] is his ability to be resourceful. One time, my husband left a piece of a sandwich in the fridge, and Guillermo got hungry, which is rare cause he usually doesn't have much of an appetite, and he gets the plate, sits on the table, and starts eating the cold sandwich. I could not believe it!

While describing their children's characteristics and a typical day at home, most parents included information regarding their child's school schedule, attachment to their routine and schedule, challenging behaviors, and favorite leisure activities. Pilar, the mother of Francisco, a 13-year-old boy with ASD, referenced his attachment to routines when describing a typical weekend for her family:

> If it's the weekend, we start the morning the same way, we work on his homework, even if we just work on part of it. I am the only one he does his homework with, with some breaks in between, he has lunch, and after this time he won't forgive us if we don't take him out the rest of the afternoon, so much so that this is one of the only times we hear him speak in whole phrases: 'want to go to mall to take a walk.'

Theme Two: Communication

Parents were asked questions about their child's communication abilities. Most parents reported high levels of frustration with their child's inability to communicate fluently and expressed a desire for their communication to improve. When asked what communication areas she would like her son, Daniel, to improve Deborah said, "I would like for him to communicate with his classmates; he usually does with adults (teachers and therapists) but not with his classmates." Similarly, Mili's mother, Eva, mentioned how she "would love her to improve (her communicative skills) so she can socialize more with her peers. Most of the times, peers tend to reject her because of her inability to communicate."

Parents also expressed concerns about their child's inability to communicate during difficult situations. Diana commented on her consent when she said:

> She doesn't know how to tell me what has happened. If someone hits her,she remains silent unless she mentions it at the exact moment of the event. For example, when her brother bothers her and hits her, she shouts at me for help or assistance. But if it happens while I am not around, she is not able to tell me, and I have to question her, sometimes with success and sometimes without. In the end, I end up discovering what happened because her brother tells me. I wish I could get her to express herself and not have to guess.

Parents identified that communicative challenges are not just due to their child's abilities but also due to a lack of supports that could help enhance communication between them and the child. In this regard, Pilar, the mother of 13 year old Francisco, expressed a desire to enhance their child's communication to avoid frustration "I would like for him to establish structured communication, I feel that he doesn't say or tell me everything because he doesn't know how to say it…and many times I feel he gets frustrated because some of us at home don't understand what he wants to say."

When asked about using alternative communication methods, such as augmentative and alternative communication (AAC) to help their children communicate, most parents reported being open to the idea. Diana mentioned her child's teacher had given her some pictures to use, but without any training so she had not yet started using them at home. She said:

> I had thought those pictograms were not necessary for her; however, I'm starting to change my mind. For if I learn to use them as a tool, maybe I will achieve an increase in her comprehension from an 80% to a 90% and like that little by little achieve 100%.

Later, when asked about her thoughts on AAC, she said, "I know that for many, it has provided the opportunity to substitute verbal language in a very successful way." Laura discussed downloading an AAC application out of curiosity to see if it would help her 8-year-old son, Ernesto, but since he did not seem interested in it, she did not follow through. Eva, one of the only participants with experience using picture exchange communication systems (PECS), mentioned being worried about overreliance on AAC and how it may impair the child's ability to communicate verbally a common AAC myth. She said, "…but based on my experience, these are tools to jumpstart the language, but you have to be careful with their use. We wouldn't want it to replace the child's verbal speech."

Eva also mentioned the importance of everyone involved in the child's life being educated as it relates to the child's communication. She said:

> It is not only the child who has to learn this system. Its parents, family, school, and society, everyone is involved … Its urgent that we ALL know how to communicate or support them (so they can) be a part of something.

Theme Three: Sources of Support

Several parents commented on how they relied on family members (e.g., grandparents, partner/spouse, aunts) and often paid personnel (i.e., tutor, nanny, maid, therapists) if they had the economic means to assist them with caretaking and educational duties. Interviewees also mentioned the big role their own parents played in raising their grandchildren. Leticia also commented on the assistance she received from her parents; she said:

> I feel I should tell you more about the primary caretaker because she is a big influence, Grandma. She spoils them a lot. She doesn't fight with them but it's not like she pays a lot of attention to them, either. She loves to clean the house and the patio, but playing with kids has never been a strength for her so basically, she does not supervise what they watch on tv or video…My mom helps me because it is not cheap to find help. I don't live downtown, so it is also difficult to find someone who can come to my house for a couple of hours to help him with his motor skills. It is difficult and frustrating.

Although they seemed to appreciate the support provided by the child's grandparents' there were mentions of disagreement over how to raise the child. Arturo, the father of 10-year-old Marcelo, said:

> I work and I am home very little so my boy is usually with his grandmother and that takes away my authority and ability to discipline. She wants to do it all for him, even feed him with her hand.

The interview also included questions about the resources the caregivers consulted to educate themselves about their child's disability. The most popular method was online resources (e.g., parenting blogs, social media). However, this was sometimes overwhelming, as Leticia stated, "I prefer to get recommendations from professionals. Searching on the internet without a compass only gets you what you are not actually looking for." Parents also mentioned they obtained information from print media (i.e., books, brochures) and learning from professionals (i.e., child's therapist, conferences). Pilar mentioned using a wide variety of resources to learn more about how to support her son:

> I follow a lot of links and autism websites, particularly from the USA and Spain, parent groups on WhatsApp, I go to symposiums, I watch 'lives' from professionals, I have a few books, I am always looking for local symposiums, but above all the team that cares for him, his tutor, his neurologist, psychiatrist, behavior therapist, speech therapist, etc.

When asked what topics they would like to learn more about, parents mentioned increasing communication, inclusion opportunities, independence, and assistive technology as evidence by the following quote from Eva, 7-year old Mili's mom, "I would love to learn more about how to make communication more functional, so that they don't depend on flashcards but that they are able to relate more efficiently with their peers or the people around them."

Finally, Diana expressed her desire to better understand the social-emotional aspects of Olga's behavior:

> I would like to know how to interpret her behaviors, for example, when she behaves a certain way because she is anxious, or when she wants to relax, when she's frightful. I need to learn how to observe it, not just look at it and make my own conclusions, but to understand more about which stimuli she needs to fulfill with that type of behavior.

Theme Four: Barriers to Inclusion

Throughout the interviews parents mentioned many barriers to their child being fully integrated into society.

Parents described access to the services as the biggest barrier. The most common complaint was access to the education system and related costs. Panamanian education includes public and private schools. Public institutions are funded by the government, while private institutions are fully funded by parents. Eva described her experience with both systems in the following excerpt:

> Decadent, even when on paper they have a good structure and a [good] number of people to help, there are two things that happen: the professional (call them teachers, therapists, or doctors) don't have the vocation, they don't serve to the kids the way they are supposed to. They only see the child between 1 to 3 times per year (with the exception of the teacher), they don't get parents involved and they don't have a set plan of development for the child where the parent can see and know how things are going.... In regards to private [schools] those that have structure are not open for everyone, the cost is too high, these are the ones that create a development plan for the child but most parents can't afford a school like that. Monthly tuition is above $1,500 to $2,000 [US dollars]. There are some middle-class schools that open the doors but they don't have the experience nor the knowledge in regards to accommodations for kids with special needs, where they don't have an educational plan for the child, or the parent ends up doing it or they force the child to integrate into the general education, and sometimes they even just give them high grades out of kindness.

Parents with children in public institutions complained about them being inconsistent at best. Grievances included a lack of trained personnel and the associated costs of trained personnel, which is often inaccessible for the average middle-class parent. In addition, parents criticized the system as their children could sometimes receive less than six hours of school per week. They also mentioned that a lack of available related services (e.g., speech and occupational therapy, behavior therapy) limited their child's progress.

Parents with children in the private system or with children who had switched from public to private (or vice versa) mentioned there was a large gap in the services provided by each system. Even within the private system, the quality of schools fluctuates greatly based on how much parents could afford. Eva mentioned some smaller, more affordable private schools didn't have the resources or knowledge to support students. Further, Diana discussed how even when teachers in public schools did receive training, these opportunities often happened during the school day:

> I believe that the educational system is not yet prepared to work with children with any type of disorder or condition, they don't have the experience, the organization of the educational system doesn't have set hours for symposiums or meetings [for teachers] that do not interfere with classes. It is not possible that so many school days are lost because of these types of activities [in public schools-subsidized by the government], in regards to private education [where parents pay for their child's education] they request for additional support for the child, which is good, but at the same time it's an additional expense for the family which added to the cost of therapies makes the resources of families with autism very reduced.

Parents of children in both public and private schools reported one of the biggest barriers for them was the need for a tutor or 'shadow.' Tutors and "shadows" were described as parent-paid paraprofessionals who assisted the child with their classes and hygiene. Eva stated that in her experience, these tutors charged between $600 to $700 a month to attend school from 7 am to 12 pm with the child. This, various parents mentioned, adds another layer of concerns and problems. Tutors who had received some training were often expensive and out of reach for the average parent. Some parents hired babysitters or untrained personnel to assist and serve in the role of the 'shadow' or tutor. Laura, whose son Ernesto was in a public school, reported serving as her child's tutor herself as she couldn't afford to pay for one "I have to go to school with him, I had to leave my job so that he can progress."

The reliance on tutors, also affected students as they were provided with very little opportunities of independence during the school day. Parents mentioned this lack of independence during their child's schooling years as a barrier to their being able to live independent lives after graduation. Several parents shared that sentiment, which can be best described by this quote from Deborah:

> Generally, schools ask for parents to send the child in with a tutor. There are kids that then get used to having a tutor with them at all times and once school is over, they don'tknow how to function on their own.

Additionally, parents expressed concern over the attitudes of professionals in the schools. Parents mentioned that negative attitudes coupled with a lack of training resulted in low expectations and a lack of inclusion opportunities for individuals with disabilities. Parents also expressed concerns over the cost of caring for someone with a disability, the availability of services, and schools and professionals not abiding by the current inclusion laws.

DISCUSSION

In this study, we aimed to investigate parental perceptions of their child's disability, tools and strategies used to support their child's communication and education, and the barriers to inclusion in the country. Our findings indicate that interviewees saw their children in a positive light and in relation to the independent living skills they had. Participants discussed using a variety of techniques to promote language, but a preference for verbal communication, feeling discouraged by the special education and related services available to them in Panama, and a belief that there should be more opportunities to raise awareness and inform society concerning the special needs of children with disabilities.

Perception of Children's Roles at Home and Community

Parents interviewed spoke highly of their children and their abilities. Further, parents often described their children by talking about their independent skills (e.g., their ability to groom themselves, complete chores, and feed themselves). This is consistent with previous research (Huer et al., 2001), where Mexican American parents of children with disabilities also mentioned their child's independent living skills when asked to describe their child. Given the negative connotations, stereotypes, and misconceptions stemming from having a child with a disability in several cultures around the world (Daruwalla & Darcy, 2005), it is encouraging to see that for the parents interviewed, this did not seem to be the case. Nevertheless, parents thoroughly discussed the physical and emotional challenges they faced daily raising a child with a disability. As suggested by Huer and colleagues (2001), practitioners working with this population will need to be open, caring, supportive, and nonjudgmental in order to gain the family's trust and thus provide services that align with the family's values.

Communication and Education

Individuals with limited communication skills are at a higher risk for social isolation, and limited opportunities for education and community participation (Howlin et al., 2000). Thus, communication plays an important role in the quality of life of individuals with a disability. Previous research has been mixed in the perceived refusal of historically minoritized parents to use AAC devices, given the stigma they may face in their communities and the misconceptions they may have regarding the effect AAC devices has on the child's development (Kulkarni & Parmar, 2017). Similar to the findings of Huer and colleagues (2001), parents in our study acknowledged the benefits of AAC systems for their children. This change could be due in part to the advances in technology seen in the last decade and the widespread use of mobile technology by parents and children. However, there may still be misconceptions regarding the role AAC systems have in the child's development.

Researchers and practitioners should continue community outreach efforts to debunk these myths. In LAC countries, community outreach should include professionals, caregivers, and extended family members so that everyone in the individual's ecosystem can be an active participant. At the university level, pre-service and in-service professionals in LAC countries should receive training on the benefits of family-centered services and cooperative partnerships with family members, as these partnerships have shown to be a critical factor in successfully supporting caregivers (Mandak & Light, 2018).

Family Systems of Support

As is often seen in many Latinx/Latine communications in the United States (DuBay et al., 2018; Parette et al., 2000), a strong relationship between members of an extended family is commonplace in Panamanian family dynamics. This is evidenced by parents in this study who reported different forms of support from family members, with grandparents being, in many cases, the primary caretakers of the individual with disabilities. This plays a key role in developing a family-centered service plan for these families. Consultation with family members that are involved in the everyday lives of the child and providing concise steps and reasons why and how they help the child may assist families when navigating different child-rearing styles. As Zayas and Solari (1994) recommended in their article on early childhood socialization in Hispanic families, to better support Latinx families, professionals should meet with caregivers to discuss their parenting values and incorporate them in intervention plans. In addition, given the respect that Latinx families have towards professionals (Huer et al., 2001), it would be beneficial for information to come directly from trusted professionals.

Barriers

Throughout the interviews, many barriers to successful inclusion and education of individuals with disabilities were mentioned. The main barriers identified by all parents was the lack of basic supports from the government (i.e., laws not being implemented) and the inadequate public-school system. Although several of the parents interviewed mentioned having the resources to provide their child with private school education, only the most prestigious and expensive schools (often over $10,000 US dollars a year) offered services comparable to those available by law in public US schools. Blanco and Duk (1995) discussed the need for comprehensive legislation to support and finance special education services in Latin America. Although we now have the required legislation (Paya, 2020), advocates still need to battle for their implementation.

Lack of Resources. As described in the report by Hincapie and colleagues (2019) lack of resources is one of the main barriers to inclusion. Parents in this study talked about professionals as lacking enthusiasm and vocation to work with their children, often seeing them as a burden in their classroom. In the past, teacher training in Latin American countries has focused on working with special education teachers, who work as specialists, with a focus on clinical training rather than inclusion of students

(Blanco & Duk,1995). Although these recommendations were made in 1995, there is still a lack of training for teachers and professionals regarding the inclusion of students with disabilities in general education, as various working groups in Latin America have identified teacher training in inclusive practices as a top priority (Paya, 2020). Based on our study findings, this lack of training is at the root of the problem. A lack of teacher training and human resources in the classroom may be the reason why we may see "shadows" or tutors being required for students to attend school. It will be key for governmental agencies to invest in the professional development of teachers and other practitioners in the areas of inclusion, communication, behavior management, and academic curriculum. A possible solution includes governmental organizations in LAC countries establishing funded opportunities for students to become professionals in special education and related services such as speech, occupational, and behavioral therapy. Finally, promoting caregiver-implemented interventions could be a more immediate first step to supporting families who are currently struggling as involving parents in therapies has been proven to greatly benefit the child as parents can continuously work with the child at home and in other familiar settings (Granlund et al., 2008). However, more research is needed to identify the effectiveness of parent-implemented interventions on a global scale (Gillespie-Lynch & Brezis, 2018).

Online resources were the most cited resource parents used to learn about their child's disability and needs. Parenting blogs, social media groups, and WhatsApp messaging groups were popular online choices for parents. WhatsApp groups allow parents to have a support system and share resources with one another. Interviewed parents also reported consulting their child's therapists when in need of guidance. Professionals looking to create resources for this population of parents should be mindful that given the lack of resources, parents rely greatly on social media, and other parents to educate themselves on how to help their children. In practice, creating free or low-cost instructional materials (e.g., webinars, modules, video-models) on evidence-based practices in Spanish, must be a priority to bridge this gap.

Limitations and Future Research

This study sheds light on some of the characteristics and barriers of special education services in one LAC country. However, more research is necessary to compare the available resources and barriers and determine the needs of other countries in the region. No study is without limitations. In this case, all parents were encouraged to participate and elaborate on their answers; however, some parents provided more in-depth and detailed information than others. Future research could include the perspective of teachers, "shadows", and other professionals involved in the educational system to investigate the Panamanian educational system through various lenses. Finally, this study is limited because of its small sample size. Future research could use survey methodologies to gather data from a wider number of participants. Additionally, it would be ideal to include recruit participants from other countries in the LAC region as it will allow us to compare experiences and thus make general recommendations that would be beneficial to the region.

To the best of our knowledge, this study is the first of its kind to explore the experiences of parents in Panama directly. We hope this study will serve as a foundation to create awareness of the needs of individuals with special needs in LAC countries and for policymakers and granting agencies to increase the funding opportunities for this area.

REFERENCES

Bailey, D. B., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M. E., Rodriguez, P., Vazquez-Montilla, E., & Skinner, M. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation, 104*(5), 437-450. https://doi.org/10.1352/0895-8017(1999)104<0437:NASRBL>2.0.CO;2

Barnes, C., & Mercer, G. (2005). Disability, work, and welfare: Challenging the social exclusion of disabled people. *Work, Employment and Society, 19*(3), 527-545. https://doi.org/10.1177/0950017005055669

Blanco, R., & Duk, C. (1995). The integration of students with special needs in Latin America and the Caribbean: Present situation and outlook. *Prospects, 25*(2), 219-228. https://doi.org/10.1007/BF02336460

Bornman, J. (2017) Preventing abuse and providing access to justice for individuals with complex communication needs: The role of augmentative and alternative communication. *Seminars in Speech and Language, 38*(4), 321-332. https://doi.org/10.1055/s-0037-1604279

Charmaz, K. (2014). *Constructing grounded theory*. SAGE Publications.

Daruwalla, P., & Darcy, S. (2005). Personal and societal attitudes to disability. *Annals of Tourism Research*, *32*(3), 549-570. https://doi.org/10.1016/j.annals.2004.10.008

DuBay, M., Watson, L. R., & Zhang, W. (2018). In search of culturally appropriate autism interventions: Perspectives of Latino caregivers. *Journal of Autism and Developmental Disorders*, *48*(5), 1623-1639. https://doi.org/10.1007/s10803-017-3394-8

Gauvain, M. (2013). Sociocultural contexts of development. In P. D. Zelazo (Ed.), *Oxford Handbook of Developmental Psychology* (Vol. 2, pp. 425-451). Oxford

University Press. https://doi.org/10.1093/oxfordhb/9780199958474.013.0017

Giaconi Moris, C., Pedrero Sanhueza, Z., & San Martín Peñailillo, P. (2017). La discapacidad: Percepciones de cuidadores de niños, niñas y jóvenes en situación de discapacidad [Disability: Caregivers' perceptions of disabled children and youth]. Psicoperspectivas, 16(1), 55-67. https://doi.org/10.5027/psicoperspectivas-vol16-issue1-fulltext-822_

Gillespie-Lynch, K., & Brezis, R. (2018). Parent-implemented interventions around the globe. In *Handbook of Parent-Implemented Interventions for Very Young Children with Autism* Springer.

Granlund, M., Björck- Åkesson, E., Wilder, J., & Ylvén, R. (2008). AAC interventions for children in a family environment: Implementing evidence in practice. *Augmentative and Alternative Communication, 24*(3), 207-219. https://doi.org/10.1080/08990220802387935

Gudykunst, W. B. (1998). *Bridging differences: Effective intergroup communication*. Sage.

Hincapié, D., Duryea, S., & Hincapié, I. (2019). *Education for All: Advancing Disability Inclusion in Latin America and the Caribbean. Policy Brief # IDB-PB-299. Inter-American Development Bank*. https://publications.iadb.org/en/education-all-advancing-disability-inclusion-latin-america-and-caribbean

Hofstede, G. (2001). *Culture's Consequences: Comparing Values, Behaviors, Institutions, and Organizations Across Nations* (2nd ed.). SAGE Publications.

Hofstede Insights. (2022). Country comparison. *Hofstede Insights*. https://www.hofstede-insights.com/country-comparison/

Howlin, P., Mawhood, L., & Rutter, M. (2000). Autism and developmental receptive language disorder—A follow-up comparison in early adult life. II: Social, behavioral, and psychiatric outcomes. *The Journal of Child Psychology and Psychiatry and Allied Disciplines, 41,* 561-578. https://doi.org/10.1111/1469-7610.00643

Huer, M. B., Parette Jr, H. P., & Saenz, T. I. (2001). Conversations with Mexican Americans regarding children with disabilities and augmentative and alternative communication. *Communication Disorders Quarterly,* 22(4), 197-206. https://doi.org/10.1177/152574010102200405

Huer, M. B., & Saenz, T. I. (2003). Challenges and strategies for conducting survey and focus group research with culturally diverse groups. *American Journal of Speech-Language Pathology, 12*(2), 209-220. https://doi.org/10.1044/1058-0360(2003/067)

Instituto Panameño de Habilitacion Especial (2014). *La Educacion Especial en Alineacion Curricular Transversal por Especificidad: "Politicas, lineamientos estratégicos y valoración de las dimensiones de la discapacidad"*. https://www.iphe.gob.pa/content/post/file/836/La-Educacion-Especial-En-Alineacion-Curricular-Transversal-Por-Especificidad-9b26fca9f7512b8402d5a5199e633d8d.pdf

Inter-American Development Bank (2020). *Panama to boost social inclusion and fiscal management with help from IDB* [Press release]. https://www.iadb.org/en/news/panama-boost-social-inclusion-and-fiscal-management-help-idb

International Bank for Reconstruction and Development. (2021). *Disability Inclusion in Latin America and the Caribbean: A Path to Sustainable Development* [Executive Summary]. The World Bank.

Krys, K., Vignoles, V. L., de Almeida, I., & Uchida, Y. (2022). Outside the "cultural binary": Understanding why Latin American collectivist societies foster independent selves. *Perspectives on Psychological Science, 17*(4), 1166-1187. https://doi.org/10.1177/17456916211029632

Kulkarni, S. S., & Parmar, J. (2017). Culturally and linguistically diverse student and family perspectives of AAC. *Augmentative and Alternative Communication*, *33*(3), 170-180. https://doi.org/10.1080/07434618.2017.1346706

Lazcano-Ponce E., Rangel-Eudave G., Katz G. (2008). Intellectual disability and its effects on society [introduction]. *Salud Publica Mex*. *50*(2), S119-S120.

Mandak, K., & Light, J. (2018). Family-centered services for children with ASD and limited speech: The experiences of parents and speech-language pathologists. *Journal of Autism and Developmental Disorders*, *48*(4), 1311-1324. https://doi.org/10.1007/s10803-017-3241-y

Medina Rodriguez, V. (1995) Special education in Panama: Experiences in the implementation of educational programs and teacher education. In Artiles A., Hallahan, D. (Eds.), *Special Education in Latin America: Experiences and Issues* (pp. 231-247). Praeger Publishers.

Mercadante, M. T., Evans-Lacko, S., & Paula, C. S. (2009). Perspectives of intellectual disability in Latin American countries: epidemiology, policy, and services for children and adults. *Current Opinion in Psychiatry*, *22*(5), 469-474. https://doi.org/10.1097/YCO.0b013e32832eb8c6

Merriam, S. B., & Tisdell, E. J. (2016). Designing your study and selecting a sample. *Qualitative research: A guide to design and implementation*. Jossey-Bass.

Pantano, L., Nuñez, B., & Arenaca, A. (2012). ¿Qué necesitan las familias de personas con discapacidad? Investigación, reflexiones y propuestas. [What do families of people with disabilities need? Research, reflections and proposals]. Lugar.

Parette Jr, H. P., Brotherson, M. J., & Huer, M. B. (2000). Giving families a voice in augmentative and alternative communication decision-making. *Education and Training in Mental Retardation and Developmental Disabilities, 35*(2), 177-190.

Parette, P., Chuang, S. J. L., & Blake Huer, M. (2004). First-generation Chinese American families' attitudes regarding disabilities and educational interventions. *Focus on Autism and Other Developmental Disabilities, 19*(2), 114-123. https://doi.org/10.1177/10883576040190020701

Paya, A. (2020). Inclusive and special education policies in South America. *Oxford Research Encyclopedia of Education*. https:/doi.org/10.1093/acrefore/9780190264093.013.1030

Pinilla-Roncancio, M. (2015). Disability and social protection in Latin American countries. *Disability & Society, 30*(7), 1005-1020. https://doi.org/10.1080/09687599.2015.1059316

Rogoff, B. (2003). *The cultural nature of human development*. Oxford University Press. doi: 10.5860/choice.41-1244

Saldaña, J. (2021). *The coding manual for qualitative researchers*. Sage.

United Nations Educational, Scientific and Cultural Organization (UNESCO). (2007). *The State of Education in Latin America and the Caribbean: Guaranteeing Quality Education for all*. http://uis.unesco.org/sites/default/files/documents/the-state-of-education-in-latin-america-and-the-caribbeanguaranteeing-quality-education-for-all-caribbean-regional-education-project-2008rev-en_0.pdf

United Nations Children's Fund Latin America and Caribbean Regional Office (UNICEF LACRO) (2019). *Children and Adolescents with Disabilities*. https://www.unicef.org/lac/en/children-and-adolescents-disabilities

United Nations. (2013). *Annual report of the Comisión Económica para América Latina, & el Caribe: Panorama social de América Latina*. https://www.cepal.org/es/publicaciones/1247-panorama-social-america-latina-2012

Wolfensohn, J. D. (2004). *Disability and Inclusive Development: Latin America and the Caribbean*. Washington: World Bank.

The World Bank (2021a). *Panama Data*. https://data.worldbank.org/country/PA

The World Bank (2021b). *Disability Inclusion in Latin America and the Caribbean: A Path to Sustainable Development*. Executive Summary. https://documents1.worldbank.org/curated/en/099245012012119963/pdf/P17538307e2d230450b71f0065aed6f1f75.pdf

Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., ... & Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009–2017. *Pediatrics, 144*(2), e20190811. https://doi.org/10.1542/peds.2019-0811

Zayas, L. H., & Solari, F. (1994). Early childhood socialization in Hispanic families: Context, culture, and practice implications. *Professional Psychology: Research and Practice, 25*(3), 200-206. https://doi.org/10.1037/0735-7028.25.3.200

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