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“Knocking on Doors that Don’t Open”: Experiences of Caregivers of Children Living with Disabilities in Iquitos and Lima, Peru

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Abstract

Background—More than one billion people worldwide live with a disability. Despite advances in recognizing inequalities experienced by people with disabilities, barriers to services and stigmatization still exist. The aims of this study were to explore: 1) perceptions and experiences of services specifically available to people with disabilities and their caregivers, and 2) the perception of disability.

Methods—In-depth interviews were conducted with 20 caregivers of persons with a disability and 14 key informants in two cities in Peru; Lima and Iquitos. The social-ecological model was used as a framework to analyze and present data, stratifying the key barriers and opportunities at each level.

Results—At the individual level, interviewees reported a lack of support at the time of diagnosis, poor coping strategies, and communicated their desire for, and willingness to, participate in support groups if they were established. On the community level, education and awareness were reportedly lacking and acts of discrimination and stigmatization were common. Participants described opportunities for community level campaigns to increase exposure and awareness of disability rights and inclusion. A dissatisfaction with government programs was reported, as services were not available to everyone, in part due to geographical and socioeconomic barriers.

Conclusion—The main findings were the lack of emotional, informational, and tangible support available to caregivers of people with disabilities, often exacerbated by lower socio-economic

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Conflict of Interest

All authors declared having no conflict of interest.

status; a lack of transparency of care pathways available to people with disabilities; and a lack of visibility of people with disability in both Lima and Iquitos.

Keywords

Disability; Access; Healthcare; Discrimination; International Health; Peru

Introduction

There are more than one billion people worldwide living with a disability, and this number is growing due to aging populations and improved survival and access to health services[1][2]. There is also an increasing awareness and understanding of disability, which in turn is encouraging diagnosis [3]. Definitions and perceptions of disability have shifted within the past two decades, transitioning away from being seen as a biomedical impairment and increasingly as socially constructed and characterized by environmental discrimination [4] [5][6]. The World Health Organization International Classification of Function is recognition of the shift to understand disability and a person's level of functioning within unique environmental and personal contexts[7]. Despite these shifts people with disabilities and their families continue to be more likely to face barriers that negatively affect their quality of life, including limited access to healthcare services, education opportunities, and political participation, which is magnified in remote and rural areas [6][8]. Despite the vast number of people living with, or at risk of developing, a disability and the evidence highlighting the inequalities experienced by people with disabilities, programs addressing and research examining these inequalities are scarce [1][9][6].

The global rate of disability is approximately 15.6%, though rates as high as 18% in lower-middle income countries and closer to 11.8% in high income countries are commonplace [6]. Most developing countries tend to *report* prevalence rates *lower* than those in developed countries, possibly due to the wording of survey questions or the lack of representative populations in the groups studied [10][6][4]. This is exemplified in Peru, an upper-middle income country, which reports that as low as 5.2% of its population is currently living with a disability, or mental or physical limitation[11][12]. Other reports suggest Peru has among the highest reported rates of disability in Latin America (13.1%), higher than the global average [13]. This disparity is indicative of a bigger argument regarding how disability is defined [13].

Whilst Peru has been proactive in recognizing the rights of people with disabilities, being the first country in Latin America to sign the United Nation's Convention on the Rights of People with Disabilities Agreement in 2007 [14][15], the limited visibility of people with disabilities in Peru has been a deterrent for social action, policy, or government programs [16]. The lack of data and research on disability in Peru is one substantial obstacle for policy-makers, which has had practical repercussions for people with disabilities and their limited access to health and other necessary services [6]. There has been a move to improve the visibility of disability data by the National Institute for Statistics and Information (Instituto Nacional de Estadísticas e Informática) who, in 2014 and 2015, collected data through the National Household Survey (Encuestas a Hogares) and the National

Demographic and Family Health Survey (Encuesta Demográfica y de Salud Familiar) to estimate the number of people with disabilities, as well as characterize the living conditions of people with disabilities [11][17][18]. However, to encourage true progress for the rights of people with disabilities in Peru, it is crucial not only for the government, but also for the public, to be aware and understanding of the magnitude of disability in their communities, as well as the impact on the day to day lives of those living with and/or families of people with disabilities [4][16]. It is estimated that only 10% of people with disabilities in Peru have access to suitable rehabilitation services, with even lower numbers among people of lower education or socioeconomic status[19][20], and likely much lower in remote and rural areas.

The barriers encountered by people with disabilities and their caregivers often limit their ability to participate in everyday activities, and can increase the financial challenges experienced by the family of the person with disabilities. Some studies have shown that when caregivers of people with disabilities perceive support from others, they are also more likely to report lower levels of depression, stress and a comparatively lesser burden on the family [21][22][23]. Likewise, literature also shows some of the positive benefits social media and virtual support groups have on people with disabilities and their families [24]. This includes community-based and participatory research programs that engage people with disabilities in the design of support groups, policy and community education campaigns [10][24][25].

There are two specific aims of this study, the first aim was to explore the perceptions and experiences among community members regarding services specifically available to people with disabilities and their caregivers in two distinct areas of Peru; Iquitos and Lima. This includes health, education and other support services available to people with disabilities living in both high and low income settings, thus including both public and private services. We wanted to gain an understanding of how these systems work, including perceptions and experiences of using the systems, from the viewpoint of both caregivers and key informants. The second aim was to develop an understanding of how disability is perceived in both Lima and Iquitos. We were specifically interested in how caregivers and key informants feel disability is understood within their local communities and how this impacts on their caregiving experience. Caregivers of people with disabilities and key informants on disability matters give firsthand insight on the barriers people with disabilities encounter, as well as the opportunities for improvement they have identified through their experience [27].

Methods

Design

This was a qualitative, exploratory research project. Qualitative methods were selected due to our interest in collecting rich data, in the words of caregivers and key informants, that permits exploration of a broad range of experiences and themes [28][29].

Ethical Considerations

This study was approved by the Institutional Review Board of both a Peruvian non-governmental association, Asociación Benéfica PRISMA (CE1425.17), as well as at the

Tulane School of Public Health and Tropical Medicine (#1040307). All participants interviewed gave verbal informed consent to be interviewed and recorded, and were provided a copy of the informed consent script which included the principal investigator and institution contact details.

Recruitment

Purposive and snowball sampling were used to recruit caregivers and key informants in both Lima and Iquitos. The inclusion criteria for both key informants and caregivers were to be over 18 years of age, living within one of the two study sites, and able to consent and participate in the interview. For caregivers, we were looking for people who were primary caregivers to a person with a disability. Any caregiver of a person with a disability was invited to participate, but we did not collect formal data on the types of disability as many people living in low-income settings may lack formal diagnoses. We relied on the caregiver's identification of the person with a disability, through the attendance at a school for children with disabilities or groups for people with disabilities. Sampling began by approaching caregivers outside schools for children with disabilities by an experienced fieldworker in Iquitos. In Lima, participants were recruited through existing research networks where fieldworkers have been visiting homes for a number of years and have an established, trusted presence. Homes where fieldworkers knew there was a person living with a disability were approached first and invited to participate. In both Iquitos and Lima, these are small communities where our affiliated research networks have been working for several years and know and have a rapport with the community members. This recruitment technique, in this context, allowed for snowball sampling, as the first participants suggested other caregivers and key informants to include in our research.

The Key informants included anyone who worked in a role related to people with disabilities and/or their caregivers, including professionals and volunteers. In both Lima and Iquitos the key informants were also recruited through existing research and professional networks. In both Lima and Iquitos we worked closely with UNICEF Peru to start to recruit key informants and begin our snowball sample.

Setting

The interviews were conducted in two different regions of Peru to explore issues that arose in locations with distinct geographies and availability of resources. The two cities selected were the capital city of Lima, which has a rising population upwards of 9 million people and the majority of national resources are centralized here [30][31]. Three different districts were selected to obtain perspectives from caregivers of different socio-economic backgrounds to reflect the socio-demographic disparities in Lima. The second study site was Iquitos (pop. 471,730), the capital of the Amazonian department of Loreto (pop. 1,039,372) [32]. Iquitos is an isolated region, accessible only by boat or plane, and is comprised of 4 main districts[33][34].

These cities were selected in part to their contrasting aspects, and in part due to the existing trained research networks and infrastructure accessible to our research team. All interviews were collected in people's homes or in the key informants' institutions.

Research team

In Iquitos, local research assistants worked alongside our Peruvian, American, Uruguayan and British research team, to guide us through cultural barriers and assist in the participant recruitment and data collection process. The team members had completed relevant training, and had experience conducting qualitative research. A semi-structured interview guide was developed and followed in all interviews. The interviews were co-facilitated by two members of our research team, who were fluent in Spanish, and accompanied by a local research assistant. Additional note takers were present at all interviews. Following the interviews, the team would come together and write a detailed account of the interview to augment to the recording, using data collected via detailed notes (by the note takers). Audiotapes were all transcribed, and transcripts were checked for quality. Interviews were conducted until saturation was reached in all themes.

Data Collection

The semi-structured interview guide focused on three main topics: the perception of caregivers regarding access and availability of health services, the emotional effects of caring for a person with disabilities on the caregiver, and perceptions and treatment of people with disabilities within local communities. The interviewees were also prompted on what they thought would be the most important structural changes to be made in Peru to benefit people with disabilities and their caregivers.

Data Analysis

A codebook was developed by the research team prior to data collection based on a review of the literature and the interview guides. During data collection, the codebook evolved as the team reviewed the codes and made changes to reflect new themes that emerged. One evolution was that the findings reflected issues at a range of levels – from individual to community to societal – fitting well within the framework of the social ecological model. Thus, the codebook was adapted to reflect a modified social ecological model framework: individual/interpersonal, community, and societal. The social ecological model is grounded in the idea that a behavior or opinion is affected by multiple levels of influence, ranging from the individual to society as a whole[35]. The individual and interpersonal levels of the classic social ecological model were converged during analysis of the data due to the fact that we interviewed caregivers and key informants, not people who had a disability themselves.

Each interview transcription and set of post-interview notes were de-identified and given an identification code. The transcripts were then uploaded to Dedoose, a qualitative data analysis program [36][37], where the interviews were thematically coded using the codebook framed by the social ecological model. During the coding process, the codebook continued to evolve, with agreement from both researchers applying the codes. Every time the codebook changed, all interviews were re-coded to ensure each interview was coded using the same codebook. Two team members blind coded every fifth interview to check for bias and consistency in coding. This method is based on grounded theory, and allows the unbiased collection of data prior to forming conceptions on disability practice in Peru, as the conclusions were built through the iterative process of coding the interviews[38].

Results

Participants

A total of 34 interviews with key informants and caregivers of people with disabilities were completed. The interviews varied in length, ranging from 15 to 90 minutes, and were semi-structured to ensure standardization between interviews; thorough accounts were captured from each participant. Two of the 11 recordings were lost due to a technical error, so for these interviews, the detailed field notes were used in lieu of transcriptions for the analysis.

In Lima, 16 interviews were conducted, 9 of which were with caregivers of people with disabilities: 5 in San Juan de Miraflores, a peri-urban, low-income community on Lima's outskirts experiencing rapid urbanization [39][40], and 4 in the relatively affluent, middle-to-high income districts of Miraflores (n=3), and Santiago de Surco (n=1). (Note: San Juan de Miraflores and Miraflores are 2 distinct sites.) Key informants in Lima were identified using connections from PRISMA, a local non-governmental organization (NGO) with prior experience with studies on disability; a United Nations (UN) organization; a private educational institution, and other independent researchers connected with the Tulane University Health Office for Latin America. The interviews with key informants in Lima (n=7) took place over a three-week period.

A total of 18 interviews were conducted in Iquitos, with 19 participants over a two-week period. (Note: one interview was done with two representatives from the same organization). Of these, 11 were conducted with caregivers recruited through a combination of purposive and snowball sampling beginning with a sample of caregivers identified outside of a school for children with disabilities in the district of Iquitos and Punchana. Additional caregivers in San Juan were found through snowball sampling (introductions) after conducting initial interviews. Key informants from organizations in different sectors were recruited for interviews via existing research networks (many introductions being provided by UNICEF Peru) and snowball sampling. The key informants in Iquitos (n=7) span diverse fields of expertise: public schools, civil society organizations, a local disability support group, and government organizations. The number of key informants by type of institution is summarized in table 1. Caregivers (n=11) were recruited from three districts-- Punchana, Iquitos and San Juan Bautista--to acquire opinions from participants who differed in socio-economic and educational backgrounds.

It is important to note that whilst we did not define types of disability or recruit based on any diagnosis, the research team observed that the vast majority of caregivers were supporting a person who had an intellectual disability. There were also a few different family structures observed by the research team, including caregivers who had adopted the person with a disability, aunts or grandparents taking on primary caregiver roles, single parent families, and the involvement of step-parents. However we did not collect any formal socio-demographic data.

The results are presented based on the framework of the social ecological model. Both barriers and opportunities for improvement were identified in each of the three levels of the social ecological model, and are presented in table 2.

Individual and Interpersonal Level

Barriers—Personal experiences and relationships with family and friends played a central role in shaping the lives of people with disabilities and their caregivers. The interviews revealed the hardships experienced by parents upon finding out their child had a disability, and the lack of emotional, informational, and tangible support available to them, often due to a lack of understanding, including from family members. Interviewees reported the absence of a clear process and care pathway/attention route at the time of diagnosis, and dissatisfaction with how doctors informed them of their child’s disability, without emotional support or guidance for accessing services. One caregiver of a person with disabilities in Lima described: “*When I gave birth, nobody told me he had Down’s Syndrome. Nobody. Not the gynecologist, not the pediatrician, no one.*” Some parents, mostly in Iquitos, described a sense of isolation caused by facing this challenge on their own, and how this led some parents to commit or consider acts of neglect, or infanticide: “*Others would’ve committed suicide or abandoned their children. That’s what some mothers do*”. Other caregivers vocalized their worry for what would happen once they passed away, knowing they were the only ones who would take care of their children: “*My God, the day that I’m no longer in this world, what will they do to him? The day I die will they take care of him? No... so I told them, ‘If I get sick, buy some poison, bury him first, then me, so in the next life I can rest in peace’*” (Caregiver of person with disabilities, San Juan de Miraflores, Lima).

The themes that emerged in the interviews with caregivers were similar to the issues discussed by key informants. Key informants talked about the difficulty in accessing resources and services – describing that it is hard enough for people who are professionally trained in this field – and hence much harder for parents suddenly facing an unexpected situation. One representative from a civil society organization in Iquitos described:

“If here, even the technical team isn’t properly trained to approach this... imagine [how this is for] the parents: there’s no school to prepare them before [their child is born], and they may seek help... They look, but there is none. They’re knocking on doors that aren’t opening...”

Key informants in Iquitos mentioned the possibility of child neglect and even infanticide in some situations. One representative of a private organization in Iquitos revealed: “*There have been cases they have found kids dead, some because they weren’t cared for, weren’t fed. A lot of parents don’t have information and they leave them there, abandoned...*”

In Lima, similar stories were shared by key informants, for example a doctor shared a story about a patient with Down’s syndrome whose “*father could never accept having a daughter with Asian eyes, because he is not from Asia, and his wife is not Asian, so he said that all the people would talk about him because his wife had cheated. She decided to put her in the last room in the house, close the door, and let her die*”. Both key informants and caregivers in Iquitos and Lima alike shared stories which demonstrate how the lack of support which they felt could lead to some degree of neglect. However, when caregivers found some support- whether it be joining local associations, groups, or via social media outlets- they were much more likely to report a positive perception of their role as a caregiver. Though

socioeconomic information wasn't gathered, caregivers recruited from Santiago de Surco and Miraflores, who appeared to have a higher income than those in Iquitos and San Juan de Miraflores, were more likely to have access to international online support networks and expressed how this support allowed them to accept and embrace their child's disability with more security. Caregivers in Iquitos and San Juan de Miraflores were more likely to report having felt more and longer lasting isolation at the time of diagnosis due to the lack of support they could access.

Caregivers in both Lima and Iquitos also mentioned how they've grown since the moment of diagnosis. A caregiver from Santiago de Surco, Lima, noted: *"my son teaches me what I'm supposed to learn in life, if he hadn't come with the disability he has, I wouldn't be learning."* Many expressed the sense of purpose and empowerment they had from their child, though this was sometimes mediated by financial factors.

Opportunities—When prompted on what they would like to have available to reduce the feelings of isolation and fear that comes with having a child with disabilities, caregivers reported that they would like support groups comprised of other caregivers of people with disabilities who had similar experiences, who could offer empathy and local support and knowledge. Many caregivers who had previously noted how busy they were said that if this service were available, they would take time out of their day to attend support group meetings. Other caregivers who had received support were very content with the backing they received: *"Speaking with people who had more or less the same experienced as me helped a lot"* (Caregiver of person with disabilities, Santiago de Surco, Lima). This desire for support and guidance permeated in the interviews in both Iquitos and Lima, regardless of socioeconomic backgrounds. A caregiver of a person with disabilities in Santiago de Surco, Lima expressed the broadness of this sentiment:

"When associations like the Peruvian Association for Down's Syndrome, Special Olympics, whatever it may be, appear, parents go... They really show up, they look for an opportunity for their children, nobody guides them, even if they can pay... I didn't know the routes either."

Community Level

Barriers—One key theme revealed in the interviews with caregivers in both study sites was the systemic discrimination of people with disabilities by individuals as well as institutions in their communities. This discrimination ranged from people with disabilities being treated as invisible and being mocked by others, to being called antiquated, offensive terms like *"mongoloid"* and *"retarded"* by strangers and family members alike. Two caregivers, one from Iquitos and one from Lima, describe their experiences: *"We've had problems [with how he's treated]. That's why we don't let him go outside"* (Caregiver of a person with disabilities, Iquitos). And from Lima: *"Before [my son] was born, personally [people with disabilities] were like, they didn't exist. You just don't put yourself in others' shoes. When he was born, I realized that there are many things to do. It's because as citizens, we don't see [people with disabilities]. We are not seeing those needs."*

Both key informants and caregivers alike reported a lack of education and distribution of information regarding disability issues for the public as well as professionals who work directly with people with disabilities. As one doctor from Lima described: “*During those 7 years [becoming a doctor], you don’t receive any information regarding how to treat a person with disabilities*”. However, the health professional’s lack of exposure to people with disabilities was more commonly reported in Lima than in Iquitos, where caregivers were more likely to want short-term aid to move out of more desperate situations.

The acts of discrimination were reported to be on the decline, with older caregivers reporting that within the last decade they felt that the awareness, understanding, and the use of appropriate language around disability had improved, but remained an issue. An educator from a public facility in Iquitos described the discrimination that they had seen at the family level: “*Let’s say someone has 5 kids, 4 of which are ‘normal’, they wager on those 4, make them study, and the child with disabilities, they’re the last to get supplies, the last to be taken care of*”. This sentiment was more clearly evoked in Iquitos than Lima. In Lima, many of the interviewed caregivers had stopped working to dedicate their time fully to the person with a disability, which wasn’t found with any of the caregivers interviewed in Iquitos—likely due to socio-economic possibilities.

Opportunities—Key informants and caregivers alike voiced the sentiment that the best way to combat the discrimination faced by people with disabilities was through education; in both the family and community spheres. Many suggested that campaigns to promote modern, non-discriminatory language, as well as simply making disability more visible, would be a positive first step. A caregiver of a person with disabilities in Santiago de Surco, Lima, suggested that “*there’s information lacking, because [discrimination] is still being seen, but more than anything because parents aren’t teaching their children*”. The problem perceived by most participants was the lack of awareness people had about disability, which made them more likely to discriminate when faced with it. One suggestion for improving awareness mentioned by a few participants was to encourage inclusion of people with disabilities in community activities. One more specific example was to improve inclusion of people with disabilities in educational and medical training facilities or programs so when students become professionals they feel prepared and less likely to discriminate.

Additionally, key informants on the subject of disability acknowledged their responsibility, as experts on the matter, to educate others, tackle discrimination, and promote inclusion. A psychologist at a private educational facility in Lima expressed that “*the professionals who have this philosophy and these goals, [they are] the domino effect. [They] are the people who, respectfully, need to form people and educate by example*”. Two key informants, one from an NGO in Lima, and one from a civil society organization in Iquitos, stated the importance of introducing “*campaigns, like journeys of disabled people, exposing their cases, showing that it is possible to be part of the society...*” as well as to “*sensitize [society]- they [people with disabilities] too are important in society... understanding that they’re also humans that deserve to be involved in society, with whatever ‘defects’ they may have, but accepted*”.

Societal Level

Barriers—The most recurrent theme among all the interviews- whether it from Lima, Iquitos, a caregiver, or a key informant- was the lack of services available to people with disabilities. Interviewees in both settings described the disorganization they encountered when it came to finding an attention route, general and specialist healthcare, education, and other services for people with disabilities, in both the public and private spheres alike. Two caregivers of people with disabilities in Iquitos expressed their frustration: “*There’s no place here to help him. I’ve grown tired of looking and haven’t found anything*”, and “*I’ve never heard of anything [to help us]. I’ve heard of NGO’s, but I don’t know how that works, no one’s ever explained it to me*”. In terms of what the government provides for people with disabilities, caregivers felt confused by the lack of defined programs available. Many reported that this sentiment was echoed by other caregivers of people with disabilities they knew of. In some cases, people had heard of programs, but could not access them due to the time that had to be dedicated to getting an appointment in a public clinic or therapy center. A psychologist from a private educational facility in Lima states:

“Obviously, we’re a more vulnerable population, more at risk, but the reality with the government is that they can’t do enough even with the programs [that exist]. There are programs to help, but the reality is they aren’t [well] administered.”

In addition to the confusion, there was disillusionment and distrust expressed by caregivers, as shown by a caregiver of a person with disabilities in Iquitos, who stated: “*I’ve heard they could give me a pension, but they don’t tell me how to get it. Sometimes they don’t want to tell us. They’ll say, ‘It’s easy to get it’ but they don’t tell us how*”.

Legislation in Practice—Legislation exists in Peru making it mandatory to include people with disabilities in public schools, and to hire 3% or 5% of people with disabilities within the private or public workforce, respectively. However, the interviewees reported that these ideas are good in theory, but impossible to put into practice when teachers and businesses aren’t being properly trained to teach or employ people with disabilities. It was also reported that the programs that exist are not properly advertised to families of people with disabilities, and that the different organizations don’t work together due to internal politics and agendas. A representative from a private educational facility in Lima stated that families “*don’t have the information in their hands, so if there is any place to go, many people don’t know they have that opportunity. The information is not getting to the people who need it*”. Often, it was stated that organizations feel unprepared or underqualified to work with people with disabilities, so they send people away due to a fear of working with them. In Iquitos, a civil society organization representative expressed the lack of preparedness, saying professionals often “*re-direct the issue, the ball’s in another institution’s court, but sometimes they’re not trained either*”. A representative from a private educational facility in Lima described a lack of understanding of disability issues by legislators, causing a lack of appropriate available services: “*Those who work behind the scenes to legislate, or design programs or projects, they have no idea what it’s really like in the field*”. These problems are barriers to the inclusion and participation of people with disabilities in society, as expressed by this multidisciplinary organization consultant in Lima:

“What really limits them isn’t their disability, but the barriers society places to limit their participation as citizens.”

Government Services and Identification Processes—The ‘Consejo Nacional para la Integración de la Persona con Discapacidad’ (CONADIS), [National Council for the Integration of Persons with Disabilities], is responsible for issuing official disability identification cards. Approximately half of the caregivers we interviewed had gone through the process of acquiring a CONADIS card on behalf of their dependent, with no apparent differences of possessing one based on location, socioeconomic background, or age of the person with disabilities. The reported benefits from having an ID card mainly include free use of public transport, and free entry to parks and museums. Some mentioned possible access to a pension from the state if their income was low. However, many participants were not aware of any of the possible benefits, including some who had already acquired an ID card. The process of obtaining an ID card was described similarly by key informants and caregivers: long, tedious, and bureaucratic. Sometimes these accounts included rumors rather than experiences, which often discouraged families from beginning the process to acquire one. A doctor working closely with a civil society organization from Lima reported that *“working with CONADIS is [unbelievable], to get the certificate, it could take like 4 years”*. A selected group of public facility doctors must certify the person’s disability, but are described as difficult to get an appointment with due to their scarcity. A consultant from a multidisciplinary organization in Lima stated that *“it’s difficult [to obtain a CONADIS card] because very few doctors are accredited to give these ID cards, for example in Loreto, they were telling me, there are only 14 or 15 doctors that can certify [disability] for the whole population”*. This, in addition to the lack of benefits the card gives the person with disabilities, and the possible marginalization having a card would evoke, discouraged many from getting a disability ID. There were evident differences between caregiver’s reasons for not getting an ID card in Iquitos and Peru. In Iquitos, it was often due to financial and time constraints, along with a lack of understanding about the process and its potential benefits. In Lima, it appeared to be more of an ideological decision, either because it offered no tangible benefits, or because it would stigmatize their child and lead to future discrimination. One key informant who is also a caregiver of a person with disabilities commented on the discriminatory language used in the process which makes caregivers less likely to go through the process of acquiring an ID card, stating that *“you have to go to a public hospital, which entails showing up and hoping a doctor is there, hoping they treat you well. Even the terminology they use, they might say, ‘oh, your son is mentally disabled, right?’ or ‘your son is Down, right?’... They [doctors] are, excuse the expression, beasts”*.

Regionalism and Centralization of Resources—A common sentiment identified in the interviews conducted in Iquitos was that government programs were focused within the capital city of Lima and often the services don’t reach peripheral departments, like Loreto. Interviews in Lima also acknowledged that despite the limited resources available to them, they were fortunate because further from the capital, in more remote or rural parts of Peru, the services were even more scarce. A caregiver of a person with disabilities in Miraflores, Lima, admitted that *“there should be a couple [public schools for people with disabilities] close to here, in Lima, well... everything is in Lima”*. Several of the interviewed caregivers

in Iquitos had felt obligated to move to Lima or travel there for therapies, medical procedures, or school opportunities. Others couldn't access the services due to their location and financial constraints. Most caregivers in Iquitos mentioned these regional differences, including: *"In Lima, yes. In Lima, CONADIS supported me, they gave me medicine and diapers, but not here. They told me they don't have the resources"* and *"they're asking us to get a brain analysis that they don't have here in Iquitos, they have it in Lima"*. Some of the caregivers interviewed expressed gratitude for being able to go to Lima to get treatments and access to better resources, while others unfortunately couldn't. A representative from a private organization in Iquitos discusses how this issue affects the raising of a child with disabilities:

"For a lot of families, a lot of moms, it's difficult to go to the capital; it's very difficult to just say 'we're going to Lima to get this training'. So instead, they raise their children without a lot of information, a little bit... carelessly."

Private Resources—Aside from government programs, many private programs were identified during the interviews. Many programs for private therapies and education were mentioned that spanned from full, well-equipped, specialist institutions to tutors that can assist children attending inclusive public schools. Universally, these sorts of resources can only be accessed by a relatively small sector of the population due to the cost of the specialized attention. A representative from a private education facility in Lima acknowledged that *"the opportunities [they] offer are for a limited few right now, they're for a population that has significant economic ability."* Many of the caregivers interviewed mentioned their lack of financial capabilities to access private facilities, mainly in San Juan de Miraflores and Iquitos, and those who could access them acknowledged that those with less money could not. A caregiver of a person with disabilities in San Juan de Miraflores, Lima, voiced her financial concerns:

"There are some [NGO's], but they're expensive... 400, 500 [soles] monthly [~120–150 USD]. They're expensive. Between getting in, enrolling is 500, plus 500 monthly, that's 1000 soles [~300 USD]. Where am I going to get that from? Even this house I live in is rented."

Notably, some private facilities did offer scholarships to try to include a wider sector of the population. A caregiver of a person with disabilities from San Juan de Miraflores, Lima, articulated the benefits of a scholarship:

"[The school] is private, but I had to find the way to pay the hours, my son has a half scholarship, because yes, without it, I wouldn't be able to pay."

Opportunities—When asked what they would like to see improved, caregivers and key informant gave distinct responses. Caregivers wanted to see better services available to them in all sectors: health, education, and within the labor market. In Iquitos, caregivers were yearning for tangible changes that would help their children live a full life, as well as support. In Lima, it was more common for caregivers to seek long term changes in society so their children will have more future opportunities. A common suggestion was that a clearer route to services should be given to families to facilitate diagnosis and access to help

and support. Not only did the interviews suggest that the options available should be made clear, but also that government organizations should leave aside their own agenda and aim to help the population of people with disabilities. A representative from a private organization in Iquitos mentioned the importance of “*working together. But they don’t organize that way, everyone wants to work on their own. They don’t think about the greater good, they think about themselves. They should join forces.*”

Key informants in Lima emphasized the importance of increasing the visibility of disability and the magnitude of how disability affects the general population. A UN organization consultant in Lima expressed the importance of “*making children with a disability visible... they are perhaps the least visible in all of the programs*”. Likewise, a representative from a local support group in Iquitos mentioned that “*organizations and the higher ups in local governments don’t work the subject [of disability], they don’t visualize it*”.

One opportunity that was mentioned a few times was the desire to include disability in the national census in a competent and sensitive manner. A representative from a private education facility in Lima discussed the inclusion in the census as a route to improve the visibility of disability: “*If I want to make a census and really pull [estimate] the percentage of people with disabilities in the country, what I have to do is point out to every single person with a disability the importance of visualizing the problem... and having a good survey team and a well-designed survey.*” A caregiver of a person with disabilities in Santiago de Surco, Lima, also stated that “*it’s a problem that there is no real census [of people with disabilities], I ask ‘how many people [people with disabilities] are there in Peru?’ and no one’s got a clue*”. It was also mentioned that to ensure proper statistics, the census must use careful, precise, and inclusive language that encourages the families of people with disabilities to report disability, rather than contribute to the stigmatization of disability. Overall, it was evident that prevalence data is crucial for future legislation and program development, as noted by another representative from a private education facility in Lima:

“Of course, statistics are important. Really knowing, visualizing the problem, the government policies... or wanting to make legislation and having them say ‘but for what sector of the population’? Sure, for 1% you will mobilize, but when you know it’s for 10%, or 20% of the population - you’ll say ‘wow, that’s worth it’.”

Discussion

In relation to the aims of the project we found that the services specifically available to people with disabilities and their caregivers were mitigated by both geography and wealth. All participants commented on the bureaucracy and lack of clarity regarding available services, but those with higher incomes could circumvent this by investing in private services. With regards to the second aim, we found that disability is stigmatized in both Lima and Iquitos, and caregivers and key informants alike voiced their concern over a lack of education and awareness regarding disability within their communities. Again, those with higher incomes appeared to be more resilient to perceived negativity which may be because they were able to find support through groups, social media or other services.

The individuals interviewed emphasized the lack of support received at the time their child was diagnosed with a disability, leading to feelings of loneliness and hopelessness—in Iquitos and Lima. This hopelessness seemed to start the cycle that led to problems at every level, like a lack of investment in people with disabilities, which often ends, in a lack of inclusion in society and futility for the person with disabilities. However, there was an evident desire for more information and for support networks from all the interviewed caregivers. In other settings, support groups have been shown to improve the quality of life and well-being of people with disabilities and their caregivers [21]. Increasing access to support groups and information for people and families affected by disability could offer support to caregivers, especially those with limited resources.

At the community level, caregivers and key informants alike reported a lack of education about disability in the general population. Though the interviews revealed that the culture surrounding disability had seen improvements in the last few decades, it became evident that little is being actively done to promote awareness of disability within Peruvian society. Another study had similar findings of implicit discrimination towards people with disabilities in Peru but also reports the community's willingness to attend education sessions or advocacy campaigns if they existed [4].

Literature from other countries report similar barriers regarding community attitudes towards people with disabilities, and how policymakers have addressed this issue by implementing both large and small-scale education campaigns to sensitize and inform the general population [41][42]. Without prompting, many interviewees in both professional and caregiver capacities commented that education is a vital first step in moving towards a more inclusive, equal society. Globally, there have been some successful government and non-governmental campaigns to reduce the stigma and discrimination of people with disabilities [43][44]. These have been especially successful when led by, or with significant involvement from people with disabilities [45][8][25][26]. Similar campaigns could be adapted to be run in Lima, and all of Peru.

At the societal level the lack of appropriate, meaningful inclusion of disability within the census was brought up as one way of addressing the under-reporting of disability in Peru. Whilst a move to revise the language and methods for capturing disability within the national census would be a positive move, other countries have successfully opted for specialized surveys with specific questions to capture national data on disability, however measuring the national prevalence of disability is a topic that warrants further investigation and discussion[46].

At the individual level, the interviewees emphasized their dissatisfaction with the unclear and unsystematic nature of social programs and services, which could be mitigated by the creation of easily understood and transparent care pathways for anyone newly experiencing disability, or parents who are learning how to care for a new child with disabilities. Parents often appeared overwhelmed with fear, especially at the time of birth or diagnosis, and the lack of a clear path to aid and services for their children can lead to giving up. The most unexpected finding was the lack of consistency between government aid among caregivers of people with disabilities. We found few people receiving economic support, but those who

did followed no apparent pattern qualifying them to receive funds over other families. It was evident that socioeconomic status was a good indicator for level of education, health, and therapy services people with disabilities could obtain. This somewhat correlated with geography, with those within the capital receiving better services and more attention than those in Iquitos. These financial or geographic barriers can be addressed by promoting the support groups which are free of cost and only require connecting people with disabilities and their families to other with similar experiences.

While not one of our aims, several interesting differences and similarities were observed between Lima and Iquitos. One stark difference was the participant's reactions during the interviews. In Iquitos, participants were incredibly open, sharing private, compelling stories regarding their hardships, and every participant expressed their gratitude for the opportunity to talk and discuss their experiences. In Lima, participants appeared relatively nonplussed by our presence, sharing their stories through their windows, then returning to their lives. Another difference came from an interesting topic – social media. Every participant in Lima mentioned social media in their interview as a method for exposure to and education on people with disabilities matters. Sometimes it was also mentioned that social media created new opportunities for discrimination of people with disabilities. No participants in Iquitos mentioned this, which could pertain to socioeconomic differences. The third and last contrast gathered from these two regions were family structure. All but one of the persons with disabilities in Lima were raised by a mother and father in a traditional family configuration. In Iquitos, not a single participant lived in a traditional home setting. We saw many single parent families, as well as adoptive families and aunts, uncles, or grandparents raising a person with disabilities. Many times, we heard of parents of a child with disabilities having to leave their child in Iquitos to find work in Lima, leaving their child to be raised by a family member. This suggests an area for further research into how family structure influences people with disabilities, or how people with disabilities impact family structures based on need. Though there were some differences, there were also similarities: it was evident that many of the issues faced were the same for all participants, both in Iquitos and Lima, like discrimination and lack of inclusion services, as mentioned above.

It is important to point out the limitations of this study. Though subjects were recruited and interviewed from four different districts, we only interviewed participants from the capital cities in the districts of Lima and Loreto (Amazon basin). Peru is a large nation with an extremely heterogeneous geography and population [32], so more interviews could be conducted in culturally and geographically diverse areas of the country in the future, with different findings. That said, as is the case with health and educational facilities for anyone in the population, we would only expect difficulties to be exacerbated in rural, remote areas. There were also cultural and language barriers. Though the research team members conducting the interviews were native Spanish speakers, neither were Peruvian, so some jargon and cultural anecdotes needed explaining. The addition of a local field team was crucial in Iquitos, where local slang is commonly used and cultural practices differ more. Additionally, the recruitment of interviewees in Iquitos was done through snowball sampling as well as recruiting outside of schools for people with disabilities, which limits the population studied to a select few who attend schools for people with disabilities and not inclusive public schools or private schools. This population thus was generally from the

middle of the socioeconomic scale in Iquitos. No sociodemographic information was gathered from participants, which limited our ability to stratify access to resources by factors including socioeconomic status, family structure, type of disability or age, thus limiting our analysis of the results. The sample of people with disabilities whose caregivers were interviewed all had an intellectual disability, sometimes with motor and psychological effects, but never without an intellectual disability. This occurred at random, and can likely be attributed to the snowball sampling technique used. The services required and used may differ from those with other types of disabilities, and it would be interesting to explore this further and interview a more representative sample. Lastly, the interview guides were not developed using the social-ecological model used to digest the results. Due to this, it is possible that the team may have missed certain prompts that could have expanded on themes in each level.

These interviews have brought to light some of the barriers present for people with disabilities and their caregivers in Peru, and this work should be seen as a springboard for further research such as how inclusion may differ between people with different types of disability, what programs are being used to increase inclusion globally, and how demographic factors including socioeconomic status and geography may affect access to healthcare and support for caregivers and people with disabilities.

Conclusion

The main findings were the lack of emotional, informational, and tangible support available to caregivers of a person with disabilities. On a community level, it was found that public information and exposure relating to disability is lacking. Finally, the interviews revealed the lack of visibility of people with disabilities by the government and their policies. From our findings, the opportunities for improvement are as follows: 1) groups could offer support to caregivers of people with disabilities in Lima mitigating existing gaps in services for people with disabilities and their families, 2) education campaigns could be implemented on a community level to curb discrimination and stigmatization of people with disabilities, 3) a census with sensitive language and methodology specifically designed to capture the percentage of the population currently living with a disability would give a real indication of what services are needed in Peru, and 4) the provision of clear, publically available routes of attention to assist caregivers and families to access services for people with disabilities.

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Table 1:

Key Informant Demographics

City	Sector	Roles and Quantity
Lima	Multilateral Organization	(1) consultant
	Private Educational Organization	(4) 1 psychologist, 2 educators, 1 representative
	Non-Governmental Organization	(1) advocate
	Civil Society Organization	(1) representative (*also a public-sector doctor)
Iquitos	Public Educational Organization (Governmental)	(2) educators
	Civil Society Organizations	(2) representative
	Local Support Group	(2) representatives (who were interviewed together)
	Governmental Organizations	(2) representatives

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Table 2:

Key Themes by Social Ecological Model Level

Social Ecological Model Level	Themes	
	Barriers	Opportunities for Improvement
Individual/interpersonal	<ul style="list-style-type: none"> • Emotional and Informational Support 	<ul style="list-style-type: none"> • Support services and groups
Community	<ul style="list-style-type: none"> • Stigma and discrimination 	<ul style="list-style-type: none"> • Education and campaigns
Societal	<ul style="list-style-type: none"> • Difficulty accessing services • Poor design of policy • Regional and economic disparities 	<ul style="list-style-type: none"> • Design of a new census • Cooperation among service providers

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