Original Research Article

Stakeholders' perspectives on a pilot project focusing on improving access to primary healthcare for adults with disability in Santiago Atitlán, Guatemala

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ABSTRACT

Background: Primary health care (PHC) has been identified as a key strategy in not only achieving Universal Health Coverage but also in Goal 3, Health, of the United Nation's Sustainable Development Goals. However, an estimated 4.5 billion people, more than half of the global population, lack access to essential health services, including PHC. Research shows that despite having often an increased need for healthcare, people with disabilities experience greater barriers to access health care due to discrimination, stigma, and social disadvantages. People with disabilities make up 16% of the world's population. Community-Based Rehabilitation (CBR) is a strategy developed to meet the needs of people with disabilities in low- and middle-income countries. It is a multisectoral approach based on implementing services through collaboration among governmental and non-governmental sectors, people with disabilities and their families, and the broader community.

Aim: This paper aims to explore the perspectives of the various stakeholders on a pilot project developed to improve access to primary healthcare for people with disabilities as part of a local CBR program in Santiago Atitlán, Guatemala.

Method: A qualitative approach was used to explore the perspectives of the program's stakeholders. A total of 27 participants were interviewed.

Results: Four themes were identified: program challenges, facilitators, impact and sustainability. The results indicate that despite challenges faced by the program, there was a positive impact on the community and improved access to PHC for people with disabilities.

Conclusion: CBR programming has the potential to increase the inclusion of people with disabilities in mainstream health services.

Implications: There remains a need for ongoing research on the impact of CBR-supported programming in improving access to and use of mainstream health care services by people with disabilities.

Keywords: Low- and Middle-income countries, Central America, Disability, Community-Based Inclusive Development, Community-Based Rehabilitation

INTRODUCTION

Primary health care, recognized as a comprehensive community approach to health, has been identified as a key strategy in not only achieving Universal Health Coverage (UHC) but also Goal 3, Health, of the United Nation's (UN) Sustainable Development Goal (SDG): 'ensuring healthy lives and promotion of wellbeing for all, at all ages' (WHO, 2018). It is estimated that 80-90% of people's healthcare needs across their lifetime can be met at the PHC level (Lancet, 2018; WHO, 2018). In 2021, however, an estimated 4.5 billion people - more than half of the global population - lacked access to essential health services, including primary healthcare (WHO, 2023a). Marginalized populations defined by age, gender, income, ethnicity, sexual orientation, and disability often experience significant barriers to healthcare services. Research shows that despite their increased need for healthcare, people with disabilities experience greater barriers to access due to discrimination, stigma, and social disadvantages, including physical and environmental barriers and other factors (Froehlich-Grobe et al., 2016; Reichard et al., 2017; Rotarou & Sakellariou, 2017). People with disabilities make up the largest minority group in the world, with an estimated 16% of the world population living with some form of disability (WHO, 2023b). This makes it impossible to meet a number of the SDGs, including Goal 3, Health, without considering the inclusion of people with disabilities (Kuper & Heydt, 2019; WHO, 2023b).

Community-Based Rehabilitation (CBR), also known as Community-Based Inclusive Development (CBID), was originally developed in the 1970s as a strategy to meet the needs of people with disabilities in low- and middle-income countries (LMICs) (Khasnabis et al., 2010). It is a multisectoral approach that delivers services through collaboration among governmental and non-governmental sectors, people with disabilities and their families, and the broader community (Khasnabis et al., 2010). Health is one of the five key sectoral components of CBR, consisting of promotion, prevention, medical care, rehabilitation and provision of assistive devices. In many locations where health is the focus, CBR programs work closely with the 'mainstream' health sector, providing services to the whole population to promote an "inclusive health" approach and ensure that the needs of people with disabilities and their family members are addressed alongside those of others (WHO, 2010). While in some cases this may include setting up alternative or parallel specialist rehabilitation services, many contemporary CBR programs focus on supporting and enhancing existing mainstream health provision to become more inclusive, specifically in the areas of PHC services, recognizing it's essential role in the areas of health promotion, prevention, and medical care (CBM, 2016a; Iemmi, Kuper & Blanchett et. al., 2016; WHO, 2010). PHC is recognized as a whole society approach to health, extending beyond primary care, which is the first level of care provision and a component of the primary healthcare approach, although the two terms are often used interchangeably (Global Report on Health Equity for Persons with Disabilities, 2022). While there are a number of studies and reports on CBR and its use across LMICs, limited research has focused on access to PHC, particularly in Latin America (Bachfischer et al., 2023; Besoain-Saldaña et al., 2020; Grech, 2015).

Despite having the largest economy in Central America, Guatemala, which is home to 17 million people, continues to face the highest rates of poverty and inequality in the region (The World Bank, 2020). Government healthcare spending in Guatemala is the lowest in Central America at 5.82% of GDP in 2022 (Guatemala, n.d.). What is more, it has the highest coverage gaps in basic healthcare with the lowest healthcare to inhabitant ratio in the region (International Monetary Fund, n.d.). The country is administratively divided into 22 departments, with a centralized healthcare system and a constitution that states that every citizen has the right to universal healthcare (The World Bank, 2020). The public healthcare sector, however, is highly underfunded, with funding gaps resulting in the lack

of basic medicine and equipment (Samuel et al., 2020). These system inadequacies are even more marked in rural areas, which often have large indigenous populations (Pan American Health Organization, n.d.; Samuel et al., 2020). The International Monetary Fund recommends that the short-term goal for Guatemala should be to enhance its primary healthcare coverage (International Monetary Fund, n.d.).

According to a national disability survey conducted in Guatemala in 2016, it was estimated that Guatemala's all-age prevalence of disability was 10.2% with the greatest prevalence of limitation amongst adults being anxiety and depression (9.3%), followed by mobility (8%), vision (4.2%) and hearing impairments (4%), with 44% of adults with disabilities experiencing significant limitations in more than one functional domain (CBM, 2016a). The results also indicated that about 31% of all households have at least one person with a disability and that families including people with disabilities were more likely to be in the lower socio-economic status groups, have larger household sizes, and a higher dependency ratio with a lower proportion of household members who were working compared to households without a family member with a disability (CBM, 2016b). This places these families at greater risk of financial hardship and will affect how they seek and access healthcare services.

The aim of this paper is to explore the perspectives of the various stakeholders, including people with disabilities and service providers, on a pilot project aimed at improving access to health services, specifically primary healthcare for people with disabilities as part of a larger CBR program in Santiago Atitlán, Guatemala.

METHODS

Study Setting

Santiago Atitlán, located in the southwest region of Guatemala, in the Department of Sololá, is a municipality divided into 10 districts called "Cantones" (Kondo et al., 2014). Five of these are designated as urban, two as semi-urban and three as rural (Kondo et al., 2014). According to the census conducted by the municipality in 2017, Santiago Atitlán had a population of 49,631 (Consejo Municipal de Santiago Atitlán, Solola, 2020). The majority of the population is of indigenous Mayan descent, and Santiago Atitlán is recognized as the capital of the Tz'utujil people, with most speaking Tz'utujil and having strong traditional beliefs. PHC services, provided by the Ministry of Health (MOH) in the region, are delivered through a central health center called the Centro de Salud and respective smaller health posts, puesto de salud, located in the various cantones. They are staffed primarily by nurses at the central health center and auxiliary nurses in the health posts and in the community.

Santiago Atitlán is also home to an organization of people with disabilities (OPD) known as ADISA (Asociación de padres y amigos de personas con discapacidad de Santiago Atitlán). Although ADISA was legally established as a nonprofit and non-governmental organization in 2013, it started working with the community in 1998 with a mission to assist, defend and further the rights of people with disabilities using community-based inclusive development strategies informed by the WHO CBR guidelines (ADISA, n.d.). Their CBR program includes a range of projects targeting the different pillars of the CBR matrix, including health. Under the health pillar their services normally include access to assistive devices, rehabilitation, and access to medical care, supporting people with disabilities to access specialized services and diagnostics.

In 2018, ADISA started a 3-year pilot project under its CBR health program, in collaboration with the local division of the MOH, to improve access to healthcare, including primary healthcare for people with disabilities in Santiago Atitlán. The aim of the project was to establish an Inclusive Health Model involving inclusion and mainstreaming of care for people with disabilities at the individual, family and community level in collaboration

with the local MOH, focusing on the right to health of persons with disabilities. As part of this program and parallel to the provision of rehabilitation services, ADISA's CBR team worked in close collaboration with the local MOH, including both staff and healthcare practitioners at the different levels and posts, and traditional healers in the community, to support people with disabilities to access healthcare. The program consisted of several components as listed below:

Increasing understanding of disability from the Mayan worldview of the Tz'utujil people of Santiago Atitlán through conversations with community leaders and midwives

Identification of people with disabilities and supporting them to access healthcare with an emphasis on children and adolescents through support of the healthcare team of each territory by ADISA's technical staff/CBR team

Monthly community meetings to increase awareness and education on disability

Bimonthly community visits to provide comprehensive care in remote areas

Advocacy and dissemination of results of the work carried out to the municipal authorities and other bodies as relevant.

Study design

A qualitative approach was used to explore the perspectives of the CBR program's stakeholders. This involved conducting in-depth interviews with both people with disabilities and key informants. Key informants consisted of CBR workers and administrative staff from ADISA, healthcare practitioners from the community, and staff from different levels of the local division of MOH.

Interviews were conducted in October 2019 by Goli Hashemi, the principal investigator, with the support of a Spanish interpreter and research assistant from Guatemala. The research assistant was trained in qualitative interview techniques, and the importance of confidentiality and direct translation to minimize changes or misinterpretation during the translation process. While most interviews were completed in Spanish, two were conducted in English with occasional support from the interpreter, and four were completed in Tz'utujil, using an additional interpreter and requiring double translation.

Interviews with people with disabilities took place either at their homes or at ADISA, and interviews with the healthcare stakeholders took place at their place of employment or their home. Each interview lasted between 60-80 minutes. With the permission of the participants, all interviews were audio-recorded. They were then transcribed, anonymized and uploaded to NVivo 12 for data management and analysis. Data were thematically analyzed according to Braun and Clarke's (2006) process.

Ethical approval was received from the Ethics Board at the London School of Hygiene and Tropical Medicine in the United Kingdom, and the Comité Institucional de Ética-INCAP (Instituto de Nutrición de Centro América y Panama) in Guatemala. An information and consent sheet in Spanish was provided and reviewed item by item with each of the participants prior to the beginning of interviews. All participants who were approached consented and signed the consent forms. No incentives were provided for participation in the study.

Study Sample

Participants were selected through purposive and snowball sampling with support from ADISA, based on the primary author's request to include people with disabilities with a range of ages and impairments and key informants from the community who held various roles related to the pilot project. A total of 27 participants (15 people with disabilities and 12 healthcare stakeholders) were interviewed. Participants with disabilities consisted of 8 men and 7 women, representing an age range between 21 to 99 years. Participants had a range of impairments (Table 1). None of the people with disabilities had access to any health insurance. Key informants consisted of 8 women, 6 staff from the MOH, 5

staff from ADISA, and 1 independent practitioner (Table 2). Their experience in their respective positions at the time of the interviews ranged from 1- 15 years, with eight of them providing direct clinical care.

Table 1: Characteristics of participants with disability

Characteristics	Total, N
Gender	
Male	8
Female	7
Age (years)	
18-30	2
31-40	2
41-50	5
51-60	2
>60	4
Type of impairment	
Mobility	2
Visual	1
Hearing	1
Mobility and Sensory	6
Psychiatric/mental illness	3
cognitive	2

Table 2: Characteristics of key informants

Characteristics	Total, N
Gender	
Male	4
Female	8
Position	
Administrative	4
Physical therapy	2
Nurse	2
Auxiliary Nurse	2
Health assistant	1
midwife	1
Years in position	
0-10	9
11-20	0
>20	3

RESULTS

At the start of the pilot project, to support the initiative, ADISA provided six intensive training sessions to community healthcare workers and nursing staff from the MOH on disability, to which community leaders and midwives were also invited. The topics ranged from causes of disability and prevention, identification of disability, differences between acquired and congenital disability and human rights of people with disability. In addition, ADISA staffed this program with three physical therapy technicians, a minimum of two interns and two volunteers at any given time to work closely with the

community health workers from the local division of MOH to assist with community outreach and home visits.

Four primary themes were identified from the interviews: program challenges, program facilitators, program impact, and sustainability of the program.

1 Program challenges

Two of the program challenges identified were cultural beliefs and language barriers.

Cultural beliefs

Both people with disabilities and key informants stated that, according to the Mayan culture in the region, disability is perceived as a punishment from God or a higher power presenting itself as a form of possession by a spiritual being that would either resolve on its own or with appropriate treatment from a traditional healer. As a result of such beliefs, people with disabilities would often be hidden by their family members or may avoid coming out and interact with the community due to fear of stigma. Similarly, this belief would at times leads healthcare providers to avoid treatment of a person with a disability. The following quote demonstrates that perception:

> *"… the second thing, the cultural situation again…Sometimes they (the health professionals) feel that they (people with disabilities) are under a spell or something, that they (the patients) have received some kind of witchcraft over their bodies, so they prefer not to treat this kind of people." Male CBR worker*

Many members of the Tz'utujil community lacked trust in governmental institutions particularly MOH and healthcare professionals. This distrust was particularly strong as it is related to disability, resulting from fear that people with disabilities might be taken away and subjected to harm. Given this lack of trust, people with disabilities and their family members tend to only consider sources of support that they trust, such as traditional healers and community midwives, who incorporated familiar cultural practices, including traditional prayers, into their care.

> *"…the staff from the Centro de Salud have tried to reach the homes but they are rejected -they (families) are not allowing access into the house. It is not necessarily a person with a mental disorder or a disability – it may happen sometimes with any other family without any condition. Sometimes, general families reject the attention from Centro de Salud. For example there are children that do not receive their vaccinations. They trust more in the midwives and the historic culture." Female MOH staff*

As a result of the above, many people with disabilities would often not receive any medical attention for their disability-related or general healthcare needs, including preventive medicine/services.

Language Barrier

Language differences also posed a significant challenge. Some CBR workers, specifically physical therapy technicians who were not from the local area, had to rely on the nurses for interpretation as they did not speak Tz'utujil. The need to interpret for the CBR workers impacted the efficiency of the nurses' home visits, as they were required to meet daily visit quotas. Thus, doing visits with the CBR workers appeared to be a burden as shared by one of the CBR workers:

> *"……The other situation that I was telling you about is the situation of the nurses, that they have to fulfill their daily agenda and sometimes they are in a rush because they need to complete in a certain time. When I ask for a translation that takes more than 10, 15 minutes*

over their time, they get upset. They don't want to continue translating for me because they have to continue with their own job. So that has been the biggest limitation that I have faced…" Male CBR worker

2 Program facilitators

Program facilitators included the extensive disability trainings provided by ADISA (described above) and the partnership between the CBR workers and the community nurses.

Training

All participant groups, including the CBR workers themselves, saw the benefits of the training provided by ADISA and wished for more. For some, specifically the midwives, this was the first time they had received training on disability. Unlike the short training they received while in school, the nurses felt that the training provided by ADISA prepared them for interactions and treatment of people with disabilities, taking into account their impairments and abilities. The nurses also expressed a desire for more training. This is reflected in the following quote:

"I would like to learn more about people with cerebral paralysis- sometimes I have to be honest- I don't know what to do with them… I had an experience when I visited a person and I remember the caregiver said that since you are a nurse feed that person. ….I was scared. I did not know what to do…" Female Nurse

Partnership between CBR workers and community nurses

The partnership between the CBR workers and the community nurses resulted in improved acceptance of the nurses during household visits. This enabled the nurses to not only meet some of their community visit quotas but also provided them with the opportunity to educate and advocate for people with disability to their family members on the benefits of using healthcare services and going to health centers.

3 Program impact

Despite the challenges discussed, participants reported that there has been a positive impact on access to and quality of primary healthcare at the health centers because of the pilot program, specifically in relation to the program facilitators, namely the training and partnership between ADISA and the community nurses. One such impact is that people with disabilities and their families had started to have more trust in the health centers and were more receptive to the use of primary healthcare services. In fact, several key informants reported more people with disabilities were going directly to the health centers rather than going to ADISA for all their healthcare needs as demonstrated by the following example:

"the lady I told you about, the one with diabetes and that at the beginning didn't accept….with continued talking to her she changed her mind. She is no longer taking only natural medicine, she is already taking the prescriptions that we provide over here, and she is coming by herself to the regular consultation..." Female auxiliary nurse

Key informants also reported that there has been an increased sense of empowerment among nurses and midwives to take a more holistic approach to patient care and to identify people with disabilities, resulting in greater numbers of referrals to ADISA for disability specific concerns.

While the perceptions of people with disabilities about health services remained mixed due to limited use of the primary healthcare services, those who had used primary

healthcare services during that time frame reported notable improvements. The majority reported an improvement in access and quality of care at health centers and health posts. According to them, people with disabilities were no longer being turned away and were receiving the same attention as people without disabilities.

4 Sustainability of the program

When asked about the sustainability of the program, participants expressed mixed views. While a few were very optimistic, given ADISA's reputation within the community and success with programming, others, specifically CBR workers and the staff from the MOH, recognized that the sustainability and continuity of the program was very much dependent on government priorities and future funding. Despite the partnership with ADISA, some MOH community nurses expressed concerns about the fact that disability remains a low priority within the MOH, expressing that this was demonstrated by the MOH's budget, and the lack of data management/entry related to disability by the MOH, implying limited monitoring of the program by MOH. They also expressed concern with corruption and lack of funds when it came to the government and MOH, particularly with upcoming elections.

> *"We cannot say because currently it will depend on the government. They are working on a model that allows to work with other organizations but in January we will change our government and the new government will always bring new ideas and new models. Ideally, they would stay with this model we have now because the strengthening we have received from them, ADISA, is very good." Female Nurse*

DISCUSSION

The results of the study identified four primary themes from interviews with both people with disabilities and key informants involved in the pilot project implemented by ADISA and the MOH in Santiago Atitlan: program challenges, program facilitators, program impact, and sustainability of the program. These themes suggest that, despite the research being conducted midway through the duration of the pilot project, there appeared to be a positive impact on both access and quality of primary healthcare provided to people with disabilities. This was demonstrated by reported increases in the utilization of local health centers by people with disabilities for their primary healthcare needs and increased referrals to ADISA for disability services through increased identifications of people with disabilities. However, there were also ongoing challenges that impacted the program's efficacy.

One of the primary challenges was the influence of cultural beliefs. This is consistent with findings from past research indicating that cultural beliefs and attitudes act as a barrier to both accessing and receiving quality healthcare services amongst people with disabilities (Grech, 2016; Hashemi et al., 2020). Cultural beliefs, lack of trust and secrecy not only limit people with disabilities and their families in accessing public healthcare services but also hinder the identification of people with disabilities, resulting in large numbers of unidentified people with disabilities with untreated health conditions in the community. The findings indicate that people with disabilities accessed services either through traditional healers or went to ADISA with whom they had developed trust, for all their disability related concerns including healthcare needs. While research shows that including people with disabilities in the healthcare intervention planning is often missing (George et al., 2015; Grech, 2016), CBR can play a significant role in empowering people with disabilities and their family members by addressing cultural beliefs and fostering trust.

Through the CBR approach, ADISA was able to help people with disabilities and their families gain trust and feel comfortable with the public healthcare services,

encouraging them to go directly to the health centers for their healthcare needs. This is important as healthcare decision-making starts within the home when an illness is identified and depends on several factors that make this decision-making both complex and unique for everyone, ranging from severity of illness to socioeconomic factors (Grech, 2016; Hashemi et al., 2023). CBR programming can not only help with some of the factors that influence decision-making, including awareness of rights of persons with a disability, but can also empower people with disabilities by providing them with choices they may have not have previously considered and increase their engagement through empowerment strategies (Biggeri et al., 2014; Magnusson et al., 2017).

Another challenge identified was the contrasting reputations of ADISA and the MOH. This not only impacted how services were perceived of and sought by people with disabilities but also how participants felt about the sustainability of the program. Some participants, particularly the key informants, seemed to have more faith in the sustainability of the program if it was managed by ADISA due to its good reputation in the community, success of past programming to date, political instability and the absence of monitoring and evaluation by the MOH for the disability inclusive program.

Given that regular monitoring and evaluation are integral to the success of CBR programs, ADISA could work more closely with the MOH and other healthcare providers to not only monitor the number of visits to and referrals of people with disabilities but also share their progress reports with the various stakeholders, including members of the disability community. This would increase transparency, potentially increase commitment to the program and demonstrate their continuous adjustments to the evolving needs of individuals with disabilities and the broader community as they focus on mainstreaming healthcare services.

Another key finding of the study highlighted the value of disability-specific education and training provided to the healthcare providers. It appears that the primary positive outcomes of the study were a direct result of the training provided by ADISA on disability. This finding aligns with the benefits associated with healthcare provider training on disability as part of in-service updates, enabling them to apply their learning in real time (Rotenberg et al., 2021). Providing comprehensive training to local community members, including healthcare workers, volunteers, and families is a cornerstone of CBR (Khasnabis et al., 2010). This capacity-building approach ensures that communities possess the required knowledge and skills to address the specific healthcare needs of individuals with disabilities not only at the healthcare service delivery level but also at the household level where initial healthcare decisions are made by people with disabilities and their families.

Finally, it is important to note that this paper focused only on access to PHC as part of the health component of the CBR strategies used by ADISA and not on the overall CBR programming and success. Given that CBR adopts a holistic approach that extends beyond addressing health needs to encompass social, economic, and environmental factors, this may have impacted the results of the study. By considering the broader context of individuals' lives, CBR programs contribute to the creation of a supportive environment that enhances overall well-being. This holistic framework further emphasizes the need for a multisectoral approach to CBR. Through working with the various sectors, CBR can increase the inclusion of people with disabilities in not only healthcare but also other aspects of community life.

Limitations

One key limitation of the study is related to potential losses in the double translation (for 4 interviews), which involved translating from Tz'utujil to Spanish and then to English, where there may have been discrepancies in translation due to limited training of

Tz'utijil interpreters. At times, extended conversation were observed between the study participant and the Tz'utujil interpreter, which was explained to be due to the lack of certain expressions related to disability in the Tz'utujil language. This necessitated the use of alternative expressions in describing certain concepts related to disability.

Lastly, while not exactly a limitation, it is worth noting that this study took place before the COVID-19 pandemic. It is anticipated that the pandemic must have had a major influence on the pilot project and its potential outcomes over the 2nd half of the pilot project, given the impact it had on the Guatemalan healthcare sector, exacerbating an already strained system (WHO, n.d.).

CONCLUSIONS

Access to primary healthcare for individuals with disabilities remains a critical concern, with various barriers impeding their ability to obtain essential health services. This paper contends that programming through community-based rehabilitation (CBR) programs or approaches offer a promising avenue for overcoming these challenges and fostering inclusivity within the mainstream healthcare systems. The study supports that while more work need to done to address cultural beliefs and attitude, a CBR approach can have a positive impact in facilitating improved access to mainstream primary healthcare for people with disabilities.

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