Needs Assessment

Perspectives of Community Mental Health Services and Resources Available to Parents of Children Living with Disabilities in the Municipality of Antigua, Guatemala

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543-A: Community Population Needs & Health I

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August 1, 2025

Introduction

The purpose of this needs assessment is to explore the physical and mental health needs of parents who have children with disabilities in Antigua, Guatemala. General research was conducted to find previous information on mental health services in Guatemala and studies found on the topic of mental health were limited. Research was further collected through virtual interviews led by Morgan Villano, an occupational therapist who specializes in mental health and is a professor at Sacred Heart University. The interviews were conducted with staff members from Iglesia Del Camino, a church that leads missions in Antigua, Guatemala to gather information on the experience of parents living with a child with disabilities. Further research is needed to understand what services are currently offered for parents and what resources parents need to access these resources.

The research conducted provides a baseline for our needs assessment that will be used to complete a community health assessment in Antigua, Guatemala. The data collection from the needs assessment will occur in October 2025, in Antigua, Guatemala, by Morgan Villano. Professor Villano will use a semi-structured interview process. The needs assessment will inform the program development team about the necessary information to create resources that will be most beneficial to parents living with children who have developmental disabilities in Antigua, Guatemala.

Community/Population Description

Citizens of Guatemala typically maintain strong ties to their cultural heritage through language, music, food, religion, and community celebrations, demonstrating a deep respect for Indigenous and Spanish traditions (McNeill, 2021). Religion plays a central role in daily life,

with many Guatemalans practicing a unique blend of Catholicism and Mayan spiritual beliefs which are especially evident in widely celebrated festivals such as Holy Week, the Day of the Dead, and Independence Day (McNeill, 2021). However, according to McNeill (2021), despite their vibrant culture and celebrations, Guatemala is a country facing significant sociocultural and socioeconomic challenges, including having one of the highest homicide rates in Latin America, corruption, and a lack of trust in the government by its citizens. Gender inequity is also prevalent, with women frequently facing violence, harassment, and limited protection. There is also high poverty, illiteracy, inequality, and malnutrition rates, especially among the Indigenous population who make up around 42% of the population (McNeill, 2021).

The target population of this study are caregivers raising children with disabilities in Antigua, Guatemala. These caregivers often lack access to diagnostic services, therapeutic interventions, and educational support due to limited disability awareness and community resources (De Leon, 2020). Families facing poverty are particularly vulnerable, focusing on immediate survival needs over long-term developmental goals and future planning for their children (Saetermoe, et al., 2004). Efforts to increase disability awareness and develop culturally appropriate interventions are essential for promoting equity and inclusion for Guatemalan caregivers.

Environment Description

Guatemala, a Central American country covering about 42,000 square miles, has a population of around 18 million and is home to a blend of Spanish and Mayan cultures (McNeill, 2021). While Spanish is the official language, over 20 languages are spoken throughout the country. Guatemala's culture is deeply shaped by its indigenous heritage and Spanish colonial

history, creating a unique blend of long-standing traditions and historical influences. Catholicism is the predominant religion in Guatemala, but Guatemalans typically practice a combination of both Catholic and Mayan beliefs (McNeill, 2021). According to McNeill (2021), throughout the year Guatemalans celebrate many holidays and festivals, including Independence Day, the Day of the Dead, and Holy Week, which is considered the most notable celebration.

One of the providers for children living with special needs is Brillo del Sol. Brillo del Sol is a school run by a non-governmental organization (NGO) in San Gasper Vivar, which is near Antigua, Guatemala, that has grown to educate 85 students there. It helps kids and teenagers with various disabilities such as learning difficulties, developmental issues, emotional challenges, and physical conditions. Brillo del Sol provides education opportunities and extra services like "speech therapy, psychology, teacher training, parent education, and other academic support services" (*Brillo Del Sol*, 2013, para. 17). The school's focus uses an inclusive pedagogy, encouraging creativity, and helping students grow in all areas by providing both academic lessons and vocational training. Its mission is both education and healing. This approach helps students by using personal methods that boost their self-confidence, independence, and ability to interact with others (*Brillo Del Sol*, 2013). Iglesia Del Camino (IDC) is a friendly religious community where you can grow in your faith. Iglesia Del Camino provides practical Bible-based teachings and lasting friendships in a relaxed and welcoming environment (*Iglesia Del Camino*, 2025). Beeline Wheelchairs is a nonprofit organization in Guatemala that creates and shares unique wheelchairs. These wheelchairs are designed to be strong, easy to move, and simple to transport (B*eeline Wheelchairs*, 2020).

In contrast, regular public schools in rural Guatemala usually struggle with a lack of resources, limited teaching time, and not enough qualified teachers (Marshall, 2009). These

schools often face challenges, for example, teachers not showing up regularly to class (Marshall, 2009). These issues can make it more difficult for students to do well in their learning environment. Even though public schools use a national curriculum, they often don't provide special services, especially for students with disabilities or learning difficulties. Indigenous students who represent a significant part of the rural school population often achieve lower academic results because of language difficulties and wider social inequalities in their communities (Marshall, 2009). Brillo del Sol takes a complete and welcoming approach to education, while most regular public schools usually do not provide services like speech therapy, mental health support, or vocational training.

Literature Review

The literature review was conducted to gather data and information that informed the researchers on current, as well as historical, needs and resources for parents whose children are living with disabilities in Antigua, Guatemala. The literature review encompassed information gathering about caregivers of children living with disabilities in Guatemala, Central and South America, as well as other Latino Caribbean geographical areas. Given the lens of the needs assessment is specific to occupational therapy, the literature review includes occupational therapy models, frames of references, and associated theories.

Models and Theories

Models and frames of references support occupational therapy assessments and treatments. When looking at the potential mental and physical health of caregivers of children living with disabilities in Antigua, Guatemala, Occupational Justice, the Model of Human Occupation (MOHO), and the Person, Environment, Occupation, and Performance (PEOP) model are necessary to consider when creating supports for the community of Antigua.

Occupational justice, the right for people to engage in meaningful occupations that contribute to their quality of life, is imperative for creating a more inclusive and healthier world, as it promotes well-being and removes various barriers (World Federation of Occupational Therapists, 2019). The MOHO is a framework that helps therapists make decisions during their practice and in research. This model highlights an individual's values and interests, roles and routines, and performance skills (Kielhofner & Burke, 1980). The PEOP model is holistic, and client centered, it focuses on how an individual's environment, performance level, and the activities they participate in interact to influence how they engage in daily occupations (Bass, Marchant, de Sam Lazaro, Baum, 2024).

The MOHO and PEOP models connect to the understanding of occupational justice by providing a lens to the practitioner to gain a holistic understanding of clients and patients. If a practitioner considers occupational justice and promotion of equity through the participation in occupations, the practitioner must assess and potentially treat the whole person, the whole community, and the whole population. By using the PEOP model, practitioners can gather information to understand the various client factors and contexts that impact an individual as well as how their environment can interact with their habits and roles. Caregivers of children with disabilities may face occupational injustices due to the stigmas surrounding mental health conditions, lack of community support, financial hardships, and limited resources. Using the PEOP model as a lens to better explore potential challenges that impact successful engagement in occupations for caregivers of children living with disabilities is recommended. Similarly, the Model of Human Occupation can help practitioners pinpoint client barriers to occupational engagement and success, specifically related to performance patterns.

Antigua, Guatemala, Socioeconomic Status, and Culture

According to McNeill (2021), the indigenous people in Guatemala make up over the 40% of the population. As descendants of the Mayan civilization, they play a large role in the culture and traditions Guatemala has today. They speak Spanish, their native language, and still practice traditions that have been passed down for generations such wearing traditional dress with vibrant colors, listening and dancing to traditional marimba music, using masks in folk art, and by cooking the same dishes for generations, especially maize (McNeill, 2021).

Recently, Guatemala has been experiencing steady economic growth, having a gross domestic product growth rate of 5.5% in 2019. However, regarding Guatemala's healthcare system, basic services are greatly limited for the indigenous people. Additionally, poverty rates are still high, leading to challenges for Guatemalan's surrounding inequality, malnutrition, and illiteracy (McNeill, 2021). According to 2021–2022 data, only 50% of Guatemalan children aged 24–59 months are developmentally on track in health, learning, and psychosocial well-being, based on the Early Childhood Development Index (ECDI) and the United Nation's Sustainable Development Goals (SDG) indicator 4.2.1 (International Congress of Infant Studies, 2025). According to the International Congress of Infant Studies (2025), developmental outcomes vary by group, with 57.9 percent of non-Indigenous children showing adequate development compared to just 45 percent of Indigenous children. Undernutrition, especially among children, is a significant concern in Guatemala, as nearly half of the child population suffer from insufficient growth and development due to their lack of nutrients consumption. Undernourished children have weakened immune systems and delayed cognitive development (International Congress of Infant Studies, 2025). This leads to long-term disadvantages which can be passed down to future generations (Ostvig, 2023). Food insecurity in Guatemala as well as the country's vulnerability to natural disasters, worsens the issue and can even cause premature death.

Undernutrition has been linked to approximately 45% of child deaths in Guatemala under the age of 5 (Ostvig, 2023).

Although Guatemala has a large population of individuals with disabilities, access to educational and rehabilitation programs remains limited, largely due to poverty, as explained by Rodriguez, Luterbach, and Gaitan (2014). In response to these limitations, disability laws introduced in the 1990s and early 2000s aimed to reduce discrimination and promote inclusion in both education and rehabilitation. These laws identified three primary disability categories: physical, sensory, and intellectual. According to the same source, most services are concentrated in the capital city, which results in rural communities, where a significant portion of the population lives, receiving inadequate support. The study also found that many children with special needs are still unable to attend school. To begin addressing the lack of trained professionals, the Guatemalan government collaborated with U.S. universities in the 1980s to develop support plans and provide training for educators. Despite these efforts, Rodriguez, Luterbach, and Gaitan (2014) concluded that special education in Guatemala continues to face major challenges.

School attendance among children in Guatemala differs significantly based on disability status, as reported by Dionicio et al. (2016). The study found that while 83 percent of children without disabilities attend school, only 76 percent of children with disabilities do. The same source explains that this gap is even wider in rural areas, where just 61 percent of children with disabilities are enrolled in school, compared to 82 percent of children without disabilities. According to the study, urban areas show higher and more equal attendance rates, with over 80 percent of both groups attending school. Overall, the findings from Dionicio et al. (2016) suggest

that children with disabilities, particularly those living in rural areas, continue to experience unequal access to education.

Latin American Culture and Disability Stigma

Stigma applied directly to an individual or community can negatively affect people's physical, spiritual, and mental health (Paul et al., 2022). The topic of disabilities in Latin American culture is often avoided due to the stigma that exists around certain physical and mental conditions (Figueroa et al., 2020). Findings from studies conducted in Guatemala show the impact stigma has on children born with physical or intellectual disabilities and their families (Paul et al., 2022). Parents and caregivers associate having a child with disabilities as a punishment from God for having been too self-absorbed (Saetermoe et al., 2004). People in Guatemala have less information on physical and mental disabilities and often are not provided adequate education on the cause or symptoms of these disabilities. This results in people developing implicit bias that leads to judgement of those with disabilities, which limits their opportunities. Someone with a disability would not be given employment or educational opportunities because people in society create a negative view of these conditions and the families feel ashamed putting their disabled child in a school or in a job (Saetermoe et al., 2004).

Although there is shame around having a child with disabilities, that does not mean families do not want the best for their children. Research has shown that caregivers have "a strong desire to see their adolescents able to read and write," (Saetermoe et al., 2004, p 1038). Unfortunately, there are not many resources available to parents and caregivers to help their children achieve developmental and social milestones, which further enhances the stigma around mental and physical disabilities. Therefore, parents and caregivers default to wishing that their

child will become more independent so they can conform to society (Saetermoe et al., 2004). Caregivers want to see their child be able to ambulate independently, feed themselves, develop higher cognitive processes, and be able to hold a job (Saetermoe et al., 2004). Each of these basic functional skills can be challenging for someone with a disability and limits their ability to participate in society, which is why some parents feel they must hide their child from others to avoid being stigmatized and shamed (Saetermoe et al., 2004).

Another challenge families face if they have a child with a disability is their own personal stigmas (Paul et al., 2020). Research using interviews with siblings who had a brother or sister with an intellectual disability found that stigma existed within each family member (Paul et al., 2020). Each family member has their own personal level of bias towards people with disabilities, and it is hard for them to get past their own biases to help the child in their family with the disability (Paul et al., 2020). There are many barriers for family members when trying to understand a child with a disability, for example, communication can be a challenge (Paul et al., 2020). Oftentimes, people with disabilities have trouble communicating their wants and needs with their family members and this can be frustrating for both parties if neither side is able to understand one another (Paul et al., 2020). Some family members cannot get past their personal stigma and find understanding the child to be too much of a challenge and they can abandon the child (Paul et al., 2020). Unfortunately, stigma against individuals with disabilities is ingrained into the Guatemalan culture and there are not that many resources that exist for parents and caregivers to get the help they need to ensure their child has a good quality of life.

Services, Resouces, and Supports for Parents of Children Living with Disabilities

In Guatemala, parents of children with disabilities face significant challenges in accessing services, resources, and support due to socioeconomic difficulties and systemic issues.

(Saetermoe et al., 2004) point out that families in Guatemala, especially those with limited resources, face many struggles in seeking regular medical care, education, and support services for their children with disabilities. Many caregivers depend on nonprofit, governmental, or private organizations for help. However, these resources often do not meet all their long-term needs for growth and their goals. This emphasizes the need for personalized planning that considers each family's situation, cultural practices, and available resources. (Manasyan et al., 2023) also stated that they support this idea. It was also highlighted that affordable screening tools such as the Ages and Stages Questionnaire (ASQ) work well for detecting early signs of neurodevelopmental delays. Trained healthcare workers also use this in places with limited resources like Guatemala. Using straightforward and culturally accepted tools like the Ages and Stages Questionnaire (ASQ) can help recognize neurodevelopmental delays early in places with limited resources. When trained healthcare workers use the ASQ, it allows for a practical and affordable method to check how children are developing, as well as implementing the right treatments if needed. This method can help caregivers recognize and find support services more easily in areas where there aren't many healthcare facilities.

Key Questions

In collaboration with Professor Morgan Villano the following key questions were developed. Are there mental health needs for the parents or caregivers of children and young adults living with neurodevelopmental disabilities (NDD) and/or developmental disabilities (DD)? Are there physical health needs for the parents or caregivers of children and young adults living with neurodevelopmental disabilities (NDD) and or developmental disabilities (DD)? What resources are available to these specific Guatemalan parents or caregivers if they have any of the above needs?

Current Programming in Place

There are several organizations and schools in the Antigua, Guatemala area including Hermano Pedro de San Gaspar, Beeline Wheelchairs, and Brillo de Sol school, that provide services to children young adults, and adults with disabilities.

Stakeholders provided the information that caregivers of children at Brillo del Sol have a few options for support, but most of these are informal and come from the community rather than being part of a formal program. The school helps children between the ages of five and sixteen who have different physical, emotional, and developmental challenges. It offers classes all year round.

Iglesia Del Camino (IDC) provides programs like Celebrate Recovery and Alcoholics Anonymous as well as hosts missions to support the Antiguan community. However, many people attend these programs quietly because they worry about what others might think. Iglesia Del Camino offers support groups for young mothers who have children living with disabilities.

Data Collection Methods

Our data was obtained through semi-structured interviews with key stakeholders at Iglesia Del Camino. We reached out to the stakeholders via email and introduced ourselves, our project, and then requested meetings. The interviews were conducted on Google Meets or Zoom and lasted about an hour in length. The interview on Zoom was recorded and the transcript from the recording was retrieved from Tactiq transcription. The transcript was then converted to a Word document and then coded using NVivo and descriptive approaches. Field notes were also taken at each interview and used to help in the coding process. It is anticipated, pending email responses, that at least two more semi-structured interviews will occur before October 2025, one with the Principal of Brillo del Sol, and the other with a staff member from IDC who spends

most of their time in the Antiguan municipalities supporting the more vulnerable community members.

Data Analysis

Qualitative data was collected and analyzed by coding each interview transcript. Microsoft Word was used to code all of our data and highlight themes that stood out to us in the transcripts. Line-by-line coding, descriptive coding, and NVivo coding approaches were used to analyze the data that most accurately represented the themes presented in each transcript. Each researcher coded each transcript to improve the reliability of the coding method. The student researchers then assessed for themes from the coding data and created broad categories that housed specific descriptive codes or quotes from the NVivo process.

Results

The primary themes identified from the two coding processes informed the researchers on the following: there is informal rather than formal programming for mental health in Antigua, Guatemala, there is a lack of resources especially health related and financial, more health and education services are provided in urban areas compared to rural areas in Guatemala, and there is an overall lack of mental health services in general.

Invivo and descriptive paragraphs

After coding the two interviews using NVivo and descriptive techniques we gathered information and key words from the transcript, with the intention to highlight common themes and categories. These themes include shame and stigma, impacts of socioeconomic status, guilt, challenges, and perspectives. We also recognize that there is a cyclical nature to support systems in this area.

We analyzed the IC A interview, where our coding highlighted challenges, guilt, socioeconomic status, and shame. We connected the similarities between the NVivo and descriptive coding, where words such as "ashamed and taboo" regarding children with disabilities were noticed in both.

In the IC B interview the descriptive and NVivo coding were slightly different. The main categories in the descriptive coding were challenges and perspectives, whereas the NVivo categories were culture and socioeconomic status. For NVivo the culture category highlighted adolescent pregnancy, alcoholism, and where the majority of people living in villages work; the socioeconomic status category included the difference between villages and the city. The two categories created from the descriptive coding noted lack of time, rural communities, costs of sending children to school which were placed in the challenges that parents face. Social status, guilt, stigma, prenatal care was placed in the category of perspectives.

These two interviews had many similarities in the information that was gathered. There is a large emotional piece that comes with being a caretaker of a child or young adult with disability, whether that is a feeling of guilt or shame due to the lack of education regarding disability. The culture of people living in Antigua, Guatemala also plays a role in the livelihood of caretakers and their ability to take care of their disabled child, as many of them are farmers and work long hours.

Discussion

There is limited research that has been conducted on this topic and very few studies to help supplement our data. The limitation of our data is that we only had two interviews and only one of them had a transcript. The data collected from the transcript could have recorded inaccurate statements from our interviewee. Another limitation is that we must conduct our

interviews virtually as cannot travel to Guatemala at this time. More qualitative data is needed to interpret our findings to find the priority needs of our population. There are some services in place to help parents in Guatemala who have children with disabilities, but it is possible mental health concerns are not being addressed. Despite these challenges, the connections made by IDC and Brillo del Sol open up chances for future programs that focus on caregivers. This will be especially effective through trusted leaders and outreach efforts based on faith.

Recommendations and Conclusion

The limited data collected revealed that there are limited resources for parents with children who have disabilities. There is also stigma that exists around having a child with a disability and mental health is not a widely addressed topic in Antigua, Guatemala. There is a need for an ongoing assessment to continue to find resources that will be beneficial for families. Our recommendation is to create a support group through IDC for parents, to provide a safe space to offer mental health resources and assist parents in obtaining resources for their children and young adults with disabilities. Another recommendation is to increase mental health education for parents in Antigua, Guatemala to help caregivers become advocates.

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Appendix A

Semi-Structured Interview Questions

Interview with Isaí Méndez

- Where do students who attend Brillo de Sol live? How far do they travel to come to the school?

- What are the physical, spiritual, and mental health needs of parents whose children attend Brillo de Sol?

- Do people find addiction to be taboo?

- What resources do people have that live in the town versus in the villages?

- What is the best option to find parents that we can interview?

- What religion is practiced in the church?

Appendix B

Semi-Structured Interview Questions

Interview with Allan Mejía

- Are most students living with physical disabilities, emotional disabilities, or a combination of both?

- Is the school all year round, or is it closed during the summer?

- How do Guatemalans perceive people living with disabilities? Are they open to caring for them? Is it something they don't want to talk about?

- Is there a level of guilt parents feel if they can't provide these resources financially for their children?

- How does cultural stigma impact the care of children with disabilities? Are children taken care of or ignored?

- Do you think the families don't want people to know about their children with disabilities? Do you feel that this causes stress to them?

- Why do parents not want to accept a diagnosis like Autism?

- What about the children that are physically affected by whatever condition they have? Do you feel that those parents also struggle to understand how this occurred?

- What are your thoughts about mental illness in the Guatemalan culture?

- Do people talk about mental health?

- As a culture, do Guatemalan's talk and discuss about mental health with other people outside of their family or internally within their family?

- Are there resources for young mothers?

- Is it typical to have children in the culture that young?

- Are there two different churches? Is it a catholic church?

- What should I bring for them? What do they need, these parents?