

Northwest University

Las Estrellas Fugaces (The Shooting Stars):
Toward Equipping Lenca Parents of Children with Disabilities to Dream Bigger

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Introduction

Throughout human history, the experiences of poverty and disability have been faced by people worldwide. While some have lived with only one of these challenges, many experience both simultaneously. An estimated eighty percent of people with disabilities (PwD) also live in poverty, and among this demographic are children with disabilities (CwD) in the minority Lenca communities of Honduras (“Factsheet”). The research findings below demonstrate that for Lenca CwD to realize their fullest potential, their parents need improved access to resources and relationships. Parents experience increased hope when their access to practical resources improves, as it means they are better equipped to meet their child's unique needs. Additionally, parents experience increased levels of encouragement when their access to supportive relationships increases, which can provide both friendship and practical support. As a result, parents can then dream more ambitious dreams for their children, causing CwD to experience an increased likelihood of growing up in an environment where they can reach their full potential.

From the DRC to Honduras

In October 2019, as part of my job at the Christian humanitarian organization World Vision (WV), I led a group of donors on a trip to Gemena in the Sud-Ubangi province of the Democratic Republic of Congo (DRC). While in DRC, my team visited a group of adults living with physical disabilities who were part of a project supported by WV. I had worked for WV for nearly a decade and visited our work in DRC and other countries, but this trip was the first time I encountered a WV project focused on supporting PwD. I was deeply moved by the people I met and the stories I heard that day.

Upon arriving, we were welcomed by around ten people of various ages, who greeted us warmly with singing and clapping. The singing was led by a woman named Constantine.

Constantine's body prevented her from standing up entirely straight, but she stood straighter in her strong spirit, leading the group in a powerful, passionate chant: "Take your destiny and move forward! No begging! No violence! No discrimination! No injustice! We want to be considered, to be respected. We want to be integrated. We want equality of chance!" Many of the individuals in this group could not walk and moved on their hands and knees. I met one man who was blind and later learned from WV staff that he was the group's official leader. WV staff also informed me that additional group members could not attend the meeting that day due to the heavy rain, which made the red, muddy Gemena roads inaccessible. Even our group had struggled to reach the meeting location in the rugged WV Land Rovers; travel for those without vehicles or with physical disabilities was even more arduous.

During the hour we spent together, these Congolese group members shared stories of how participating in this WV husbandry project had positively impacted their lives. Through this project, they received agricultural training, learned to raise goats and chickens, built a community with one another, and acquired an income to support their families by selling the milk and eggs from the animals at the local market. The group members shared about their improved senses of dignity and humanity through the resources and relationships acquired from participation. Inspired, I returned home to Seattle, Washington with a newfound personal calling to respond to what I had seen.

It was three years later when I would learn that while Constantine and these group members were navigating their own stories in DRC, a different community in another region of the world, the Lenca people in Honduras, were navigating similar but unique challenges. With a population of 450 thousand, the Lenca are the largest of eight ethnic groups in Honduras. While specific estimates are unavailable for the Lenca, it is estimated that ten percent of all Hondurans

live with some form of disability (“Disability Information”). Paired with the simultaneous challenges of poverty throughout their communities, life is difficult for Lenca living with disabilities, and in August 2022, I found my journey as a graduate student at Northwest University leading me to Honduras to better understand these challenges.

The following research was focused specifically on Lenca CwD but inspired by Constantine and the group members I met in DRC, who first opened my eyes to the challenges faced by people experiencing poverty and disabilities simultaneously. The data was collected over the course of a three-week-long qualitative research study conducted in the southwestern region of Honduras. It was focused on understanding the question: What is daily life like for Lenca children with disabilities and their families? Below, an overview is presented of the research context and design, followed by a presentation of key themes in the data. I then outline the research’s limitations along with recommendations for future research. Finally, I provide a proposal for Las Estrellas Fugaces (LEF), a project model I have designed that could be implemented by non-governmental organizations (NGOs) or community organizations who desire to better equip parents to support CwD.

Research Context

This research took place at the intersection of three key challenges faced by Lenca CwD: disability, poverty, and the experience of living as part of an ethnic minority group. Understanding these challenges' context and interconnectedness was critical in conducting my research and interpreting the findings.

What is Disability?

Numbers are difficult to assess because of definitional disagreements and data collection challenges, but the World Health Organization (WHO) estimates that approximately 1.3 billion

people globally live with a disability. This number represents one in six people or about sixteen percent of the global population (“Disability”). Disability is often used as an umbrella term for impairments, activity limitations, and participation restrictions. It refers to the negative aspects of the interaction between an individual and their surrounding environment and context (Willis 178).

Disability can be understood in two categories, which are visible and invisible disabilities. As its name suggests, visible disabilities are impairments that can be seen quickly by others, often noticed through visible markers such as one’s use of a wheelchair or guide dog, facial scarring, absent limbs, or a strikingly different physical appearance. Invisible disabilities are impairments not visible from the outside, such as hearing loss, mental illness, or chronic pain. Research suggests that people are treated differently based on whether their disability is visible or not and that a person can live with a visible and invisible disability simultaneously (Olkin et al. 758-781; Lingsom 3).

Another way of understanding disability can be through the lens of these three dimensions offered by the WHO:

Impairment in a person’s body structure or function or mental functioning; examples of impairments include loss of a limb, loss of vision, or memory loss.

Activity limitations include difficulty seeing, hearing, walking, or problem-solving.

Participation restrictions in normal daily activities include working, engaging in social and recreational activities, and obtaining health care and preventive services.

Despite the exact language one may choose to define disability, evidence indicates that serious challenges exist for those with disabilities. Some risk dying up to twenty times earlier than those without disabilities, while others have a more than doubled risk of developing comorbid

conditions such as depression, asthma, diabetes, stroke, obesity, or poor oral health. Statistics also indicate that those with disabilities find inaccessible health facilities up to six times more challenging and are up to fifteen times more limited by inaccessible and unaffordable transportation (World Vision, “Programming Guidance 4”).

What is Poverty?

Various definitions and theories exist of poverty, each bringing to light different aspects of a complex topic. In his book *Walking with the Poor: Principles and Practices of Transformational Development*, author Bryant Myers defines the poor as a group of people experiencing a deficit. Through Myers’ view, the poor are understood to be those missing tangible necessities like food, water for drinking and irrigation, and affordable housing. Myers’ deficit perspective also frames the poor as lacking access, including access to land, health systems, credit, or other necessities. He explains that those who seek to understand poverty from a Christian worldview often add a spiritual dimension to their understanding, believing that the poor also lack knowledge of God and the good news of Jesus (113-114). It is worth noting that the research informing this thesis was conducted alongside a Christian organization and through the lens of my own Christian faith.

Other community development practitioners have brought forth different definitions of poverty. Development scholar Robert Chambers, for example, describes the poor as “being entangled in a cluster of disadvantage” and discusses a “poverty trap” in which the poor are caught (See Appendix A). When examining the poor through the lens of this trap, they are seen as being tangled up amidst the challenges of material poverty, physical weakness, isolation, vulnerability, and powerlessness (115-116). Other views of poverty that could be examined are those of scholars like John Friedmann, who views poverty as a lack of access to

social power, and Isaac Prilleltensky, who suggests that poverty is the reality of diminished personal and relational well-being (118-121). Every view's strengths and weaknesses could be discussed and debated, but each adds to the depth of one's understanding, which then has implications for which approaches are utilized to address poverty.

The Disability-Poverty Cycle

The relationship between poverty and disability is cyclical and can be compounded by stigma and negative attitudes, assumptions, discrimination, and lack of equitable access to services, facilities, and systems. Those who are poor are more likely to become disabled, and those who are disabled are much more likely to be poor (World Vision, "Programming Guidance 4"). Author and development practitioner Katie Willis discusses this disability-poverty cycle in her book *Theories and Practices of Development*, explaining that disability can act as both an outcome and a cause of poverty. As an example, she explains that issues caused by poverty, such as malnutrition or an infectious disease, can cause one to experience a new disability they were not born with. Conversely, living with a disability can prevent someone from accessing a job and providing a financial income (Willis 179).

Another example of this cycle in action is highlighted in David Pellow's book *Resisting Global Toxics: Transnational Movements for Environmental Justice*. Pellow discusses the complex effects of pesticide exposure, which tend to cause the most harm in less developed countries in the global south, including Latin America. Women, children, migrant farmworkers, poor populations, and indigenous populations are part of those most affected. Because work options are limited, working in these harmful conditions is often required to generate income. Unfortunately, being around toxic pesticides can cause significant risks to women's reproductive health, and this type of exposure has been shown to increase the likelihood of children being

born with a disability. Because of their disabilities, these children may someday have difficulty finding employment or accessing a job, meaning they cannot bring in an income as an adult. Additionally, mothers may need to stay home as caregivers for their CwD, which means they cannot return to work themselves. In this situation, it can be seen that the disability-poverty cycle is perpetuated (151). A chart showing this cycle can be viewed in Appendix B.

Current Approaches for Combating Disability and Poverty

The number of PwD is increasing globally due to factors like increased numbers of wars and conflicts, natural disasters, extreme poverty, traffic accidents, and growing numbers of chronic health conditions associated with disability globally (World Vision, “Programming Guidance” 1). International collaborative efforts have led to the development of various frameworks aiming to unite countries and organizations around approaches to addressing issues that contribute toward the disability-poverty cycle. Three key frameworks worth noting are the United Nations Convention on the Rights of the Child (CRC), the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and the Sustainable Development Goals (SDGs). The CRC is a historic human rights treaty created by the United Nations. It sets out children's civil, political, economic, social, health, and cultural rights and includes provisions advocating for the well-being of CwD (“Convention, United Nations”). The CRPD is an international human rights convention that sets out the fundamental human rights of people with disabilities of all ages (United Nations). Finally, the SDGs are seventeen goals formed in 2015 by the United Nations General Assembly. The SDGs are a set of seventeen commitments that 191 member states united around to create a better world for humanity. Of the seventeen SDGs, disability is explicitly mentioned in goals related to education, growth and employment, inequality,

accessibility of human settlements, and data collection and monitoring of the SDGs (“SDGs and Disability”; London International Development).

Individuals and groups working in the development sector have historically taken one of three primary approaches to disability: the medical approach, the charity approach, and the social model (inclusive) approach:

The medical approach defines a person with disabilities as a patient with special needs and seeks to ‘cure’ or ‘improve’ individuals to ‘fit’ them into society without considering barriers to participation.

The charity approach predominantly regards persons with disabilities as ‘unfortunate,’ ‘dependent,’ or ‘helpless’ and as needy recipients of welfare and support, and therefore sees charity as the only way to support persons with disabilities.

The social model (inclusive) approach focuses on society & family as the problem, not the individuals with disabilities themselves. It sees disability as a social consequence of having an impairment. It seeks to identify and remove attitudinal, environmental, and institutional barriers that prevent those with impairments from equal inclusion in development programs and their own societies (World Vision, “Programming Guidance” 2).

World Vision Honduras (WVH), the organization my research was conducted alongside, adheres to the social model (inclusive) approach and aligns with the goals and recommendations of the CRC and CRPD. They also align their global programming with targets mentioned in the SDGs (World Vision, “Programming Guidance” 2; “Convention” WVI; “Sustainable Development Goals” WVI).

República de Honduras

My research took place in Honduras, more formally known in Spanish as the República de Honduras. Honduras is located in Central America, with Guatemala and El Salvador on its west and Nicaragua to its south and east (Honduras). Hondurans experience a unique and rich culture of their own, which sets the backdrop for my research. Hofstede et al. defines culture as “the collective programming of the mind distinguishing the members of one group or category of people from others” (334). Hofstede’s research presents a model in which six cultural dimensions are examined; according to his research, Honduran culture scores particularly high in a dimension called *power distance* and low in a dimension called *individualism*. These scores suggest several noteworthy hallmarks of Honduran culture. First, the power distance score indicates that Hondurans tend to accept that everyone has a place in society and that some things cannot be changed and are simply the way they are. Second, the low individualism score indicates that Honduran culture is collectivist, meaning that everyone takes responsibility for fellow members of their group and a high value is placed on community (“Country Comparison Tool”). I observed these cultural characteristics throughout my time in Honduras, and they were helpful as I analyzed my research findings.

Metrics like the Human Development Index score, which has generally increased since 1990, indicate a positive trajectory toward human flourishing in Honduras (“Human Development Index”). However, these numbers only tell part of the story, as other evidence demonstrates that the disability-poverty cycle is prevalent and the most vulnerable are still suffering. With a population of approximately 9,449,000 people living in rural and urban areas, it is estimated that 64.5 percent of Hondurans live in poverty, and 42.6 percent live in extreme poverty, defined as living on less than 2.5 dollars a day (World Bank). Violence is also

widespread in Honduras. As the second most violent country in the Americas, violence in certain areas is a significant cause of injury that can contribute to death and disability, particularly in young individuals (Yacoub et al. 428-32). Those disabled through violent injury and those with a disability they were born with contribute toward the estimated ten percent of Hondurans living with a disability (“Disability Information”). Other challenges in Honduras are caused by its agricultural terrain, which makes the country especially vulnerable to natural disasters. Natural disasters like the devastating Hurricane Mitch of 1998 can cause the most harm to vulnerable populations, especially children and their mental and physical health (Kousky 74-5). Additional challenges faced by Hondurans are weak governance, systemic corruption, and food insecurity (“U.S. Relations”).

The Honduran Government and Disabilities

Understanding the government’s approach to addressing disability was critical to designing my research approach and understanding the results. Currently, national policies exist to advocate for PwD in general life and related to education (Weissman 66). However, despite the existence of laws, they are not consistently being enforced. This is recognized by the Honduran Ministry of Justice and Human Rights, who have previously offered their commitment to addressing issues but acknowledge the significant challenges in implementing their commitments:

Honduras demonstrates its commitment to and responsibility for efforts to construct a better world for persons with disabilities toward supporting PwD...[the government]...recognize[s] the serious structural situation affecting the enjoyment of their [PwD] rights. Although worthwhile, the current measures are clearly insufficient and cannot be assessed in the short term. There must be further progress based on a

dynamic of responsiveness, intersectoral dialogue, and commitment by the current Government and its successors (“Committee on the Rights” 5-6).

Before my trip to Honduras, I had the opportunity to discuss the Honduran government’s current strategies for supporting PwD with Rider Calix, the Director of Strategy and External Cooperation at the Ministry of Social Development of Honduras. Calix shared that PwD have been “historically forgotten and not taken into consideration in Honduras.” His job is focused on managing the government’s strategic partnerships with external corporations and NGOs to fund various projects around the country to support PwD. Calix told me that the government is trying to prioritize programs and projects that support minority groups like the Lenca and the Garifuna, another ethnic minority group located in northern Honduras. Calix also shared that the government has plans to acquire updated statistics on the number of PwD because the most recent estimates and data were collected about ten years ago and may not have included all types of disabilities; he suggested that the number of Hondurans with disabilities is likely much higher than ten percent. Overall, Calix indicated that he had hope for the future of PwD in Honduras based on his experience working for the government, telling me: “We’re breaking the rules, we’re breaking the stigma. We’re breaking the way we’ve been working.”

Lenca Culture

Within Honduras, the Lenca experience their own culture, derived from Chibcha-speaking Indians from Colombia and Venezuela more than three thousand years ago (“Things to Do”). As the largest of eight ethnic minority groups in Honduras, approximately 100,000 Lenca reside in Honduras, with an estimated 40,000 in El Salvador. Most Lenca communities, about 612, are in hard-to-reach mountainous areas. The Lenca traditionally live in small villages

known as *pueblos*, surrounded by satellite villages called *aldeas* and clusters of isolated houses called *caserios*. The primary crops grown by Lenca are corn and beans (Quattrocchi 127).

A lack of infrastructure and discriminatory government policies have caused precarious social, political, and economic living conditions for Lenca ("Things to Do"; "Strengthening of the Indigenous"). Amidst these challenges, the Lenca are struggling to maintain their cultural traditions while modern influences come into their communities, especially through younger generations. In some cases, they are caused to adapt. For example, crafts like basketry and pottery are historically, economically, and spiritually significant to the Lenca. Pottery makers, however, who once created pieces primarily for utilitarian purposes, have shifted to the creation of more aesthetic pieces favored by tourists (Toombs 141). Another example of the struggle the Lenca are caught in can be seen in their efforts to maintain their language and culture. The establishment of Lenca radio stations has been one way the community is trying to address this concern. These stations are a critical tool for organizing and political awareness while also helping preserve their language ("Strengthening of the Indigenous").

My research was conducted along *La Ruta Lenca*, or in English, the Lenca Route. The Lenca Route is a grassroots tourism initiative developed to support Lenca communities. My hotel, *Huella Lenca*, was owned and operated as a tourism and job training project that WVH had started. In English, the name *Huella Lenca* means "The Lenca Fingerprint," which is an ode to the rich Lenca history in the area. I conducted my research primarily in the communities of Yarula, Santa Elena, San Miguelito, Dolores, and San Juan. These communities were all part of the Lenca Area Program (AP), the name of WVH's larger project in the Lenca communities (See Appendix C). One interview was conducted in Gracias, Lempira, with a small nonprofit

organization called FHD Honduras. Gracias had previously been part of WVH's Lenca AP, but its programming had closed the year prior due to WVH reaching its goals in the area.

Research Design

The decision to focus my research on Lenca CwD was made after an intentional networking period with personal and professional contacts. Securing an organization willing to accommodate my research with a vulnerable population during the lingering COVID-19 pandemic was a task that I anticipated to be difficult, and for this reason, I committed to remain open-minded to the types of opportunities that would arise. As an employee of WV's US office (WVUS), I had hoped to partner with my employer in my research, but the possibility of this was initially unknown due to rapidly evolving pandemic-related travel restrictions. After a series of fruitful conversations with Edward Winter, WVUS's Senior Technical Advisor for Gender Equality and Social Inclusion (GESI), and Karina Aquino, Gender Equality and Social Inclusion Specialist for WVH, I was grateful to be invited by WVH to partner with their office for my research. WVH has a reputation within WVUS for being a high-capacity country with an innovative, creative staff. They expressed enthusiasm for partnering with me and we agreed that the opportunity would be mutually beneficial.

Recognizing that the topic of disabilities and poverty is broad, my goal was to narrow my focus to a more specific topic that would interest me as a researcher while also contributing to WVH's existing strategy. Through a series of exploratory discussions with Aquino and a review of WVH's 2022-2024 three-year strategy, it became evident that studying the Lenca population would meet these objectives. According to WVH's strategy, supporting Lenca CwD was an important part of WVH's goal to make a "relevant and sustainable footprint" in Honduras (World Vision, Field Office Strategy 1-3). I chose to focus specifically on understanding the

lives of children because I knew that they are more deeply affected by poverty than other ages and I wanted to focus my research on the most vulnerable individuals in the population (Boyden et al. 11). WVH's existing presence in the community also meant that I could leverage their existing trust and relationships to enhance the depth of my research. My research focus was finalized after a thorough literature review revealed little information specific to what life was like for CwD in Lenca communities.

Research Methodology

Research was conducted over the course of a three-week-long qualitative ethnographic study between August and September 2022. Data was collected using semi-structured interviews, focus groups, and group interviews. Many spontaneous conversations with community members also occurred, as well as hours of observation at community events (such as a community bakery inauguration I was spontaneously invited to), schools, and shopping centers. Multiple documents and artifacts were also collected for analysis. An intentional effort was made to interview a wide variety of informants, resulting in fifteen group interviews, seven focus groups, and twenty-five pre-scheduled interviews.

Arriving in Honduras

On Saturday, August 13, 2022, I arrived in Comayagua at Palmerola International Airport. Upon my arrival, I was warmly welcomed by Patricia Fajardo, a long-time staff member on WVH's GESI team, who spent a few hours of her Saturday helping me settle in. Our first stop was Mall Premier Comayagua, where I was able to exchange my US dollars for Honduran Lempiras at a bank and purchased a SIM card from a CLARO kiosk. I took note of a middle-aged man sitting on a bench with crutches leaning up next to him. Over the next few days in Comayagua, I spent time preparing for my interviews and having my first experiences with

Honduran culture. On my first morning, I experienced my inaugural taste of the traditional *plato tipico*, a breakfast comprised of queso seco (a white cheese), Honduran beans, and eggs. This meal became a staple throughout my time in Honduras. On Monday morning, I was picked up by a WVH driver and we drove three hours into the winding mountains. It was in the chilly, rainy mountain community of Yamaranguila that I would remain based for the next three weeks.

On Interviewing Methodology

This research focused on understanding the lives of Lenca CwD, but only informants over eighteen years old were interviewed. Throughout my research, I spoke with Lenca parents, educators, mayors, community leaders, healthcare workers, and NGO staff from multiple organizations (WVH, the Special Olympics of San Juan, FHD Honduras, and Honduras Compassion Partners). Some young adults with disabilities who were eighteen or older were interviewed. The questioning methodology I used was semi-structured and rotated between open and closed questions. As I actively listened and facilitated discussions, intersubjectivity played a crucial role in my process, and I was careful to observe for patterns. I also acknowledged my own interpretation of what was shared with me as I formed questions and led conversations (Mind Tools; Sunstein and Chiseri-Strater 11). A list with a sample of the questions used to guide my discussions is available in Appendix D. All questions sought to understand the primary research question: What is daily life like for Lenca children with disabilities and their families?

To establish rapport, I added in times of casual conversation before and as needed throughout interviews. This was especially helpful with parents when I could sense them grow emotional while discussing their child's condition or daily challenges. In these moments, I let the conversation err on the side of empathetic and casual, stepping away from my role as a researcher and into the role of a compassionate listener. It was a priority of mine in all interviews

to be cautious that informants did not feel weighed down by rehashing parts of their lives that were difficult or traumatizing (Sunstein and Chiseri-Strater 219-221). Because I was partnered with WVH, whose Christian identity is widely known in the communities, and knowing that many Lenca embrace Christian and Catholic beliefs, I offered to close many of my interviews with a prayer. This gesture was always warmly welcomed and became a helpful method of ending heavy discussions with a positive tone.

Interviews and focus groups occurred in informants' homes, WVH offices, government offices, schools, and clinics. The sounds of roosters, dogs barking, and school children playing were typically heard in the background, later reminding me as I transcribed interview recordings that despite the difficulty of the topics we were discussing, Lenca communities were active and full of life. All data collected was coded utilizing a qualitative data coding software called Quirkos. Additionally, thematic analysis was used to identify, analyze, and discover themes within the data (Braun and Clarke 79).

On Being a Learner

With the goal of approaching my research as a learner, I made intentional efforts to separate my role as a researcher from that of my role as a WVUS employee, although this separation sometimes proved to have blurry lines for myself, informants, and WVH staff. I was well aware that previous extensive travel as a staff member and eleven years working for WVUS naturally gave me an advantageous understanding of WV's development work. Still, I attempted to keep these roles separate when possible by emphasizing my role as a researcher to informants and sharing that I was in Honduras to learn from them. Myers discusses the importance of development practitioners being "ruthlessly self-aware" and understanding our goals as practitioners and researchers. He also cautions against the potential urge to "succumb to the

temptation to play god in the lives of the poor, thus adding to their captivity to the god complexes of the non-poor” (227-228). This was a spirit I attempted to be aware of and embody throughout my research. For this reason, I was also mindful of my position as an outsider, being a white American who is not a parent, and someone who possessed minimal experience working with the disability community before my research (Merriam and Tisdell 130). I knew this lens would be critical and relevant to how I would see and interpret all data.

On Keeping a Notebook (and a Recorder)

In her essay “On Keeping a Notebook,” author Joan Didion discusses the importance of taking notes, suggesting that one write everything down, whether or not it makes sense. She writes herself, for example, potentially unimportant and specific details she once observed about “cracked crab, a woman in a dirty crepe-de-Chine wrapper; a New York Blizzard” (Sinstein Chiseri-Strater 66). Inspired by Didion’s detailed notes and with the goal of using best practices in ethnographic notetaking, I kept a notebook detailing my observations. My notebook became a valuable source of ensuring details were being recorded and observed (70). In addition to this paper notebook, I recorded all interviews and conversations using a small audio recorder, with permission from those I spoke with, to access them for later analysis (Merriam and Tisdell 131). Many photos were taken of informants, always with the informant’s permission, and of sites around me. Various reports and artifacts I reviewed also provided rich insight into the research, supplementing my notes and observations (Stringer and Ortiz Aragon 141).

On Navigating Language Barriers

Although I had studied Spanish for many years and understood enough language to hold a basic conversation, I knew that having an interpreter would be critical for the success of my research. Before my trip, I worked with the WVH team to identify an interpreter to join me for

the entire three weeks. Upon learning that the cost of a professional interpreter was not feasible for my budget, WVH connected me with a more affordable local bilingual woman who was also a volunteer letter translator for WVH's child sponsorship program. Because this was her first time working as an interpreter, having her join me proved mutually beneficial for us both, offering a professional growth opportunity for her and much-needed assistance for my travel and research. Due to the interpreter's English level, it ought to be noted that many phrases were interpreted using general thoughts, not word-for-word. Quotes included in this paper are at times reflective of this reality. When nuanced information was needed during the coding process, I utilized the help of additional fluent Spanish speaking colleagues I knew for added accuracy.

On Language Choices

Language choices are important and help form the reality that we live in. In *The Thin Book of Appreciative Inquiry*, author Sue Annis Hammond discusses the ways that some words carry certain emotions behind them. For example, she explains that words like stress, depressed, and dysfunctional "can carry negative emotions or be the language of deficit." Knowing that deficit language can lead to deficit thinking, I ensured that the language I used to form my questions was framed positively whenever possible (19).

After returning from Honduras, I discussed my research with my friend Natalie Higashiyama, who is the mother of a daughter with a disability and has served in leadership positions with several local disability-focused non-profit organizations. Higashiyama informed me that from her experience, those in the disability community have various perspectives on what language is considered acceptable (Higashiyama, Personal Interview). The language I have chosen throughout this thesis is generally drawn from recommendations in the Disability Terminology Chart created by the State of California (Appendix E).

Research Findings

While not all community members shared homogenous concerns and experiences, clear themes emerged from the data, all pointing toward the need that parents have for resources and relationships to better support them in caring for their children. I have outlined these themes in the following sections: Disability Statistics, Healthcare, Self-Esteem, Community Attitudes, Partnerships, Local Government, Education, Transportation, and Hopes and Dreams. Together, these findings paint a picture of the daily challenges commonly experienced by Lenca CwD and their families and demonstrate that the disability-poverty cycle is prevalent in the Lenca communities. While these findings highlight the existence of significant challenges faced by Lenca CwD, parents also shared their hopes and dreams for their children. The first eight sections below can be viewed as a presentation of challenges, while the final section, Hopes and Dreams, outlines the spirit of hope and joy that was observed. Important to note is that not all CwD live with their parents, and some lived with another relative; when parents' perspectives are discussed, this should be understood more broadly as the child's primary caregiver. All informant's names have been changed for privacy purposes.

Disability Statistics

During my conversations, it quickly became apparent that quantitative data around disabilities was challenging to find. While various clinics and municipal offices spoke of piecemeal efforts to collect data in their communities (typically through door-to-door surveys), informants often spoke to me about statistics from their own personal observations. Some communities did share more formal reports with me, such as the municipal office in San Miguelito, which had developed a thorough document outlining disability data in their community (Several pages of this report can be viewed in Appendix F). The Santa Elena

municipal office had also been working hard to understand disability statistics in their community. In Santa Elena, I met Osman, who was living with a physical disability himself and had been hired by the local mayor to support their disability strategy. Osman was well respected by the local government staff and spoke with pride about his work going door to door to collect data on the number of PwD in the community (Asociación de Discapacitados).

Common Disabilities

The most frequently mentioned categories of disabilities were Down syndrome, learning disabilities, and cerebral palsy. A broader fourth category also emerged from the data, which included all undiagnosed conditions. Down syndrome was the most common, being mentioned in eight interviews and focus groups. Various types of learning disabilities were mentioned in seven conversations I had, although these typically did not have a formal diagnosis from a medical professional. Some parents spoke about a teacher diagnosing their student with learning disabilities, and teachers mentioned diagnosing students. When asked how she knew that several of her students had learning disabilities, one teacher named Sandra mentioned that she had diagnosed them herself through her personal observation in the classroom. Cerebral palsy in children was observed or mentioned specifically in five interviews. Undiagnosed conditions were typically undiagnosed because a doctor did not know the condition's name or the family had not visited a healthcare facility to receive a formal diagnosis (Adolescent Clinic Staff, Santa Elena Community).

While Down syndrome, learning disabilities, and cerebral palsy were mentioned most frequently, other disabilities mentioned more than once included microcephaly, the inability to walk, and cleft palates. I was invited to spend one morning observing an elementary school where WVH staff informed me that many children had cleft palates, but I was not able to identify

from observation which students had this condition because of masks being worn due to the COVID-19 pandemic. In a conversation with the mother of one of those children, it became evident that a lack of financial resources was a key obstacle she faced in obtaining the multiple surgeries recommended by medical professionals necessary for a cleft palate repair (Patria y Libertad; Berkowitz 127-28).

Healthcare

Two primary observations were made regarding the healthcare experiences of Lenca CwD and their families. First, it was apparent that healthcare workers were enthusiastic about their work and desired to help CwD, but were under-resourced. Second, parents of CwD indicated varying levels of involvement with official healthcare systems. For these two reasons, some families received the care they needed while others did not.

Resources and Training for Healthcare Workers

Healthcare workers informed me they lacked the necessary resources and supplies to support CwD properly. Resources they mentioned needing were items like specialized medicines, medical equipment, and wheelchairs. Sitting in the lobby of the Dolores adolescent clinic, four female doctors and nurses shared extensively about their desire to help the teenagers with disabilities who visited their clinic but highlighted the challenge of having limited resources and serving the large population in their area. Their clinic is part of a larger medical facility serving twenty-three communities in San Juan, with a population of ten thousand. In addition to healthcare workers mentioning the need for resources, families also mentioned sometimes being unable to access the resources they needed from clinics. The grandma and uncle of a teenager named Danny were an example of this, who told me that Danny needed a better wheelchair, but they were unable to get one from the local clinic (Adolescent Clinic Staff; Lucia and Pedro).

A need for training of healthcare workers was also observed. Not only was this mentioned in multiple focus groups as something that they would find helpful, but on multiple occasions, I heard healthcare workers provide conflicting information. For example, when asked why they believed Down syndrome was common in Lenca communities, San Miguelito healthcare workers told me about a campaign they were designing to help prevent teenage pregnancies in the community and told me it would be helpful in preventing Down syndrome (San Miguelito). However, doctors from San Juan disagreed upon hearing this and informed me that Down syndrome was caused primarily by pregnancies of mothers who are “more than thirty-five years old” (Adolescent Clinic Staff). Later, I heard a WVH staff speculate during a card ride that Down syndrome may occur because of heavy alcohol use in certain families. Doctors and nurses frequently mentioned wanting to be better equipped to support CwD and their parents.

Family Experiences with Healthcare Facilities

Some families of CwD utilized healthcare clinics and hospitals often, while others did not. Various reasons were mentioned for not visiting, including inaccessible or expensive transportation to clinics, lack of trust in healthcare workers, or financial reasons. Twenty-one-year-old Andrea has been using a wheelchair since childhood. Andrea discussed positive experiences with the healthcare system in San Juan, sharing that in “times that she has gotten sick, her doctor attended to her very well.” Andrea’s family, however, is more financially stable. Both of her parents have steady jobs, which allows them to live in town in a custom-built house that is wheelchair accessible. These factors make it easier for her to access a doctor when needed.

For Lenca residing in more rural communities, health clinics are much more difficult to access due to challenging roads, the distance of clinics from their homes, and the lack of a way to

transport children with mobility challenges. In a conversation with the lawyer in San Juan, I learned it is common for Lenca to travel at least five kilometers to access a healthcare center, and many people take buses for several hours to access medical services. For Lenca families of CwD, this can create a tremendous barrier to accessing supportive healthcare (Alma). Other families, like Juana's, have found ways to save up the financial resources necessary to visit far-away clinics. Juana told me about an upcoming surgery that she was taking her daughter to by bus at a children's hospital in Tegucigalpa. I also learned from doctors that some families were resorting to taking their CwD to small, unofficial clinics called *parcheros*. This was mentioned as a concern to some doctors who said that these clinics are even less resourced than regular healthcare centers (Adolescent Clinic Staff).

Specialized Services and Therapy

Existing research suggests that there is a need for an increase in rehabilitation resources in rural, remote Honduran communities; this appeared to also be the case with rehabilitation and specialized therapy services in the Lenca communities (Umaefulam et al. 11). Although not always easily accessible, specialized care and therapy for CwD is available and utilized by some Lenca who can find transportation and the money to pay for services. One organization, Teletón, was mentioned frequently. Teletón did not reply to my inquiry for an interview, but according to their website is a private non-profit focused on comprehensive rehabilitation services focused on improving the lives of PwD in Honduras ("Quienes Somos"). Lenca families who had used Teletón's services shared positive results, though some could not continue services due to the cost and distance. "Economic resources are a challenge," explained one mother. She told me that her daughter attended Teletón in Santa Rosa recently but could not continue because of finances "Teletón helped her a lot" (Special Olympics Families). Another mother shared a similar

experience about her son: “He attended Teletón for sixteen years, and Teletón helped him one hundred percent.” She went on to explain that at Teletón, he had access to specialized doctors, psychologists, and teachers who could offer language therapy (Special Olympics Families).

While most of my interviews were done in partnership with WVH, I was able to spend one afternoon with Greg and Jean Hines, the directors of a small nonprofit called FHD Honduras (FHD). FHD supports various disaster relief and medical projects in Gracias and the surrounding area. FHD launched its *Casa de Reuben* project after the Hines, originally from the United States, observed a need for more physical therapy services for PwD. Casa de Reuben offers what the Hines call the “missing link,” a place for PwD to do physical therapy work between visiting facilities like Teletón. Casa de Reuben employs several staff, including two pediatric nurses, and has space for some PwD to live on-site as needed (Hines).

Self-Esteem

While giving me a tour of Casa de Reuben, Greg Hines told me, “A big thing for people with disabilities is to feel like they have a purpose.” This topic of purpose and self-esteem emerged frequently in conversations, and two common themes emerged. First, low self-esteem was a common challenge for Lenca CwD. Second, those who had received support from psychologists experienced an increase in their self-esteem.

Parents and community members indicated that CwD children struggled with low self-esteem. A community leader named Mario, who was passionate about supporting PwD in Lenca communities, shared that self-esteem can be a problem for all PwD in the Lenca community and that efforts are often made to connect them with psychologists (Asociación de Discapacitados). Self-esteem was also highlighted as a challenge by teachers at the 15 de Septiembre high school, who told me that low self-esteem was why many CwD stopped attending school. Self-esteem

was often mentioned in relation to bullying at schools, which is elaborated on in the Student Attitudes subsection of this paper.

Unfortunately, not all families could access psychologists due to location or transportation, but parents who could take their children to one spoke about noticeable improvements in their child's confidence. Families accessed psychologists at the local municipal offices and specialized facilities like Teletón. I met several psychologists in the Lenca communities, all passionate about their work. A psychologist in Dolores spoke about her love for her job and the improvements she had seen in CwD: "The results encourage me because I love to work with children and feel so happy to be here" (Dolores Municipalidad).

Community Attitudes

In his book *Unclean: Meditations on Purity, Hospitality, and Mortality*, Richard Beck examines the psychological dynamics of social exclusion, suggesting that the dynamics of disgust and dehumanization foster exclusion and expulsion. He writes that hospitality welcomes the outcast and stranger as full members of the human community (124). While evidence showed that many Lenca leaders desired an inclusive community free from this type of exclusion, discrimination still existed in certain areas. When community members were asked how PwD are treated in the community, informants described various observations. Some adamantly shared that there was no discrimination in their communities, but others told specific stories of discrimination they or their children had experienced. A summary of findings in this area is categorized below in the areas of General Community Attitudes, Parent Attitudes, and Student Attitudes.

General Community Attitudes

Of those suggesting that discrimination does not exist was the lawyer I spoke with in San Juan, who said that “they do not have discrimination from anybody” (Alma). During one focus group, a community leader told me that attitudes are positive toward the disability community and that “...it is a nice experience to learn together with people experiencing disabilities because they have so many things to teach us” (Santa Elena Community). PwD had different perspectives, however. A twenty-one-year-old wheelchair user I spoke with told me that “people are not educated or polite, and there is discrimination...of course, it’s so complicated to talk to them.” She said those beliefs are passed on from adults to children (Andrea). Other community members in Santa Elena echoed this, sharing that “children grow up with this feeling of discrimination” (Santa Elena Community). Leaders at the San Juan municipal office also acknowledged that discrimination exists in their community (San Juan Municipalidad).

Parent Attitudes

While parents I met and observed appeared to be loving and accepting of their children, the existence of negative treatment and superstitious beliefs were mentioned by some community members. One doctor in Santa Elena shared that mothers are sometimes known to hide their CwD at home. Although the reason for this was unclear, the doctor explained that this creates challenges for doctors who desire to provide the necessary care to those children. My conversation with these doctors echoed my earlier conversation with Calix, who had told me that “people do not understand these abilities in a proper way.” Calix had informed me that in rural areas, parents may think disability is a punishment, causing them to lock up their children or hide them in their houses (Calix). The doctors in Dolores said that parents with many children may not give their CwD the needed care. They suggested that part of this may be neglect and

mentioned that often, they have seen CwD malnourished and with poor teeth. “Parents do not care about their disabled children,” explained one doctor. “This is the reason they do not take care of the children” (Adolescent Clinic Staff).

At the adolescent clinic in Dolores, healthcare workers spoke extensively about their experiences navigating parental beliefs about the cause of disabilities. Many Lenca mothers believe that if their pregnancy is exposed to a solar or lunar eclipse, the unborn baby will be born with a disability. Many Lenca women also believe that wearing something red on their stomachs while pregnant, such as a belt, will protect the child. This belief is not exclusive to the Lenca but is heavily present in Lenca communities. Moreover, it carries similarities to beliefs in other areas of Honduras, like the northern island outside of Roatán, in which it was reported that pregnant women were expected to be careful during a lunar eclipse and wear red to avoid a child being born disabled (Schneider 13). Similar beliefs were also highlighted in an Italian research study, which found that Lenca midwives of La Campa believed that the “moon takes away while the sun gives.” In this study, Lenca women were found to believe that if exposed to a lunar eclipse, they would specifically give birth to a child with a cleft lip, and those exposed to the sun would have a child with six fingers (Quattrocchi 132). The healthcare workers I spoke with discussed the challenges of changing deeply held but not scientifically proven beliefs (Adolescent Clinic Staff).

Student Attitudes

Not all CwD could attend school, but those who did had a wide variety of experiences with how other students treated them. For children who had negative experiences, bullying from other students was often the reason. Multiple parents shared that their children had stopped attending school after being bullied, which caused low self-esteem. In one case, a father shared a

story about his teenage daughter who stopped attending school because another student physically hit her. He said that “they felt bad because the teacher didn’t take care of her” (Special Olympics Families; Porfirio).

Not all Lenca CwD, however, had negative experiences at school. A number of teachers spoke to me about the improved progression of positive attitudes among students toward CwD over time. One Yarula teacher shared the story of a student at her school who had surgery for a cleft palate. She said that “in the beginning, the other children looked at him strangely,” but went on to explain that over time, she saw improvement in their interactions as she encouraged other children to treat the boy like everyone else. Another teacher in this group shared the story of a first-grade boy at her school with a disability and said that he is not discriminated against and is “taught like normal children.” Teachers all shared similar thoughts around the idea that it is important for adults to teach children to treat others kindly (15 de Septiembre; INPOFACE).

Partnerships

I observed a wide range of community organizations collaborating and noticed a desire between groups to partner in new ways to support CwD. These partnerships were observed on an official level and grassroots, more organic levels. Organizations I observed included secular groups and faith-based groups all seeming to partner together for the sake of a more equitable and sustainable society (Moe-Lobeda 7; Collective Impact Forum).

Because I spent most of my time with WVH staff, I was able to learn about WVH’s existing partnerships with groups like the Special Olympics of San Juan, local municipal offices, and schools. WVH was observed to be a key player in facilitating interactions between these groups to implement solutions. Community leaders and mayors often spoke highly of WVH’s work; the mayor’s representative Santa Elena said that “it’s a blessing to have World Vision in

Santa Elena.” WVH’s presence was seen as they partnered with different groups to implement solutions in the community. When at the adolescent clinic in Dolores, I was shown a restroom for PwD that I was told was “not supported by the government, but...[it] is by World Vision” (San Juan Municipalidad; Alma; Adolescent Clinic Staff).

Through my earlier connection with Calix, I was connected with Jonathan Zelaya during my time in Honduras. Zelaya is the President of Honduras Compassion Partners (HCP), a nonprofit in Honduras that implements clean water, safe housing, and education projects for the people of the La Paz community. Zelaya also serves as the Assistant Governor for the Rotary District 4250 and is the founding president of the Rotary Club of La Paz, which partners closely with HCP. HCP places a high value on partnerships with other organizations. Zelaya talked with me about the importance of organizations working together to make an impact for Lenca CwD:

I always say that everything is about relationships. And it’s so important in order to keep supporting children with disabilities, especially in Lenca communities... it’s [important to] work together with other nonprofits and the local government and corporations that are private, because we have to unite efforts in order to do that. That’s important, and it’s one of the key priorities because when we do things alone, it’s not the same impact as when we do it together (Zelaya).

HCP partners closely with Rotary International, which has also engaged in projects that support CwD in Honduras, such as “creating ramps to increase accessibility at schools and providing children with equipment like wheelchairs, canes, and walkers” (Zelaya).

Organic partnerships were also observed being formed. Several days before I visited Gracias to meet with Greg and Jean Hines at FHD, I learned that one of my WVH colleagues, Fernando, had run into Greg at a random gas station. Recognizing the WVH logo on the vehicle,

he approached Fernando, they exchanged phone numbers, and agreed to talk about collaboration in the future. I also observed organic relationships forming after one of the focus groups I led in Santa Elena. The group was comprised of community members representing various local ministries and sectors. Partway through the focus group, I noticed a side conversation had broken out between several people; my interpreter told me that the healthcare workers and teachers were exchanging phone numbers because they wanted to keep in touch to collaborate after the group.

After that same focus group, the representative of the mayor of Santa Elena approached me to share about an upcoming program that the city municipal office was hosting for adults with disabilities. She explained that before the focus group, her office had only focused on programming for adults. However, after hearing about the challenges of CwD from teachers and doctors in the focus group, she was compelled to revisit the event plans and add in programming for CwD (Santa Elena Mayor's Representative). It was evident that many community members recognized the value of partnership and were eager to work together to address challenges for CwD.

Local Government

The municipal offices in all communities I visited welcomed me for an interview and appeared eager to discuss my research. Mayors and their staff members shared that their buildings were frequently visited by PwD or their family members requesting help, but their offices were under-resourced and unable to assist as much as they wanted. Some offices discussed strategies, partnerships, and programs they had in place to support PwD in their communities.

At the municipal office in San Miguelito, I was told that weekly, many people “come here to ask for help because they do not have work...” San Miguelito staff spoke of having

difficult conversations with PwD to inform them they cannot help. Usually, their requests are for “...specialized medicine, and [they] come here to look for money for the expensive medicine they do not find in public health. And that happens daily.” The Yarula municipal office mentioned that they sometimes provide money and economic resources when people need to visit the doctor or hospital (Yarula Community Leaders).

Some offices had strategies or programs in place to support PwD. For example, the staff in Santa Elena had hired Osman, a PwD, to support their strategy. “They are working with him because he has many abilities,” explained the mayor’s representative, saying that he gives workshops in the community for other PwD. The San Juan mayor also shared about a future program they were planning to implement specifically for children with learning disabilities. He said:

...they will be working together with the youth and children office and with the psychologist to identify at school children who have learning problems...and in that program, they will have a focus area to teach those children to improve their learning problems, and they will look for strategies with specialized people to teach them.

This program had not yet been started at the time of my visit, and World Vision was working with them to support the project.

Education

Through my conversations, it was evident that the effects of the COVID-19 pandemic still had a lingering hold on the education system. Teachers spoke about students who were now behind in grade levels because they could not attend school and recalled how the pandemic caused much of the world to move toward virtual education. They reminded me that in their poor and rural areas, the lack of infrastructure and resources prevented them from benefitting from

virtual education, which has been proven to be helpful in other areas of Central America (Amado-Salvatierra et al. 158-168; INPOFACE). My overall findings around education had similar themes as those mentioned in a study by Amanda Weissman, who explains that the four commonly identified reasons for poor access and quality of learning for students with disabilities are “social stigma and discrimination, lack of resources and infrastructure, inadequate pre-service training, and lack of knowledge among in-service teachers” (68). I have categorized my findings related to education in the following categories: Social Stigma, Resources and Infrastructure, and Transportation.

Social Stigma

Social stigma and discrimination in the school setting were evident in many conversations. Because many students experience bullying, some drop out and no longer attend school. Social stigma was a consistent theme related to education and is further elaborated on in the Student Attitudes section.

Resources and Infrastructure

Despite many teachers wanting to support CwD, Honduran schools were generally not set up to accommodate children with special needs. Wheelchair ramps, accessible restrooms, and specialized materials like books in braille were existent in some schools, but scarce. At one school, I was shown a restroom for CwD, and the principal shared that there were laws requiring restrooms for PwD (INPOFAC). In some cases, parents were educating children at home to the best of their abilities. I met a mother named Alejandra, who explained that teaching her son at home was best for him because of his learning challenges.

Teachers held differing views on how to best support CwD. While some teachers recommended that their school hire a specialist staff member to teach a class just for CwD,

others argued strongly against this, stating that CwD should be integrated into regular classrooms. Those teachers advocating for integration believed that this would help reduce discrimination. This echoes Gordon Allport's Contact Hypothesis, which suggests: "Contact is of utmost importance in reducing prejudice and promoting a more tolerant and integrated society..." (Everett). Whether or not teachers desired a specialist to be brought in or believed in an integrated approach, all agreed that they needed additional training in how to work with CwD. Studies have found that Honduran teachers who participated in professional development and inclusive education strategies perceived it beneficial to teach students with disabilities, however, no teachers I spoke with mentioned receiving special training related to CwD (Pfortner 78; Weissman 78; 15 de Septiembre).

Transportation to School

According to many parents I spoke with, transportation challenges were often a reason their children could not attend school. For children who are unable to walk, some parents mentioned carrying them to school. Unfortunately, this was not always possible due to distance or the size of the child. Most Lenca families do not have a car, and while a few are fortunate enough to have a motorcycle, walking is their primary mode of transportation. For those who could not get to a school, several stories were shared of teachers who would do home visits to teach CwD in their houses. Danny's grandma and uncle told me how thankful they were for his teacher, who regularly stopped by their house to teach Danny after he had to stop attending (Lucia and Pedro).

Transportation

In addition to the challenges of transportation to and from school and healthcare facilities, transportation challenges are a broader challenge faced by Lenca CwD and their families.

Speaking specifically about CwD, one community leader summed up the issue this way: “It is difficult to go to school, to go to health centers, and to go to important places that they need to go” (Association de Discapacitados de Santa Elena). Zelaya echoed this, saying rough streets create “zero accessibility” for Lenca CwD. Overall, my conversations found that transportation is challenging for multiple reasons, including poor road conditions, lack of access to vehicles, and lack of finances to pay for public transportation.

Roads in most Lenca communities are in poor condition, bumpy, and laden with potholes. Even for WVH staff with four-wheel drive vehicles and motorcycles, it was challenging to navigate the road conditions. During the rainy season, roads can become completely inaccessible. WVH staff advised me that we had to depart several of my interviews early because of expected rain and concern that we may get stuck at the homes we were visiting. Road conditions in town centers like La Esperanza or San Juan are slightly better, but there is still a general lack of accessibility and sidewalks are rare. One wheelchair user mentioned that in the cities, “structures of the places are not curved to be able to enter... this means people sometimes cannot attend an event in the community they want to go to” (Andrea).

In cases of families of CwD, transporting a child with a disability, especially those who cannot walk, can be a difficult task. Parents spoke of carrying their children on their backs or relying on other stronger relatives to help. One mother spoke to me about her twelve-year-old daughter Margarita, who cannot walk much due to pain in her feet: “Sometimes her cousin takes her [to school] and carries her on his back” (Maria Cristina). Even for those fortunate to have cars or motorcycles, transporting children with certain disabilities can be impossible, dangerous, or difficult.

Public transportation is an option for some who can find the money to pay for it, as there are opportunities for utilizing the bus or motor taxis (Juana). Margarita sometimes takes a motor taxi with her mother to places like the Special Olympics meetings (Maria Cristina). Public transportation can be difficult depending on one's disability, however, and buses are not accessible for wheelchair users (Andrea). Lack of ability to take the bus prevents many Lenca CwD from receiving access necessary access to critical resources, doctors, nurses, and resources like Teletón (Special Olympics Families).

Hopes and Dreams

Understanding the hopes and dreams of parents and children was a theme that became central to all my conversations with families. While not originally on my list of questions to ask, I quickly realized the heaviness of our conversations and began ending conversations (before my prayer) by asking parents what their hopes and dreams were for their children. This question was another helpful way of lightening the mood while also providing valuable insight into how life at the intersection of disability, poverty, and in a minority community may affect or limit parents' abilities to dream for their children. The hopes and dreams shared varied in size and scale and primarily fell into the categories of physical healing or future and career dreams.

Dreams for Healing

The desire for their children to be physically healed was typically mentioned first when I asked parents what their dreams were for their child. The specific dream of their children being able to walk was mentioned the most frequently. While most parents seemed to light up with hope when discussing the future, a few became emotional as they seemed to reflect on the difficulty of their situation. For example, Daniela became emotional and teared up when she told me: "... I ask God to someday see him walk." Gerardo's mother, however, had a more hopeful

reaction when talking about her son, who experiences challenges with walking but was thriving as a runner in the Special Olympics. She smiled widely as she shared that her dream for him was that “he improves.” Similarly, a father I spoke with shared that he aspired to see his teenage daughter walk someday (Porfirio). Gerson’s mother also shared that she hopes that “he could walk someday,” although she explained that this did not seem realistic due to a necessary expensive surgery that could help him walk (Laura). Diana’s aunt smiled when asked about her dream for her niece Diana, telling me that “her dream for the girl is that the girl one day can walk and can move on her hands...to write and to learn.” Elaborating on the importance of education, she explained that “if the girl can one day do that, she will get her to school” (Carmen). Finally, Danny’s grandmother’s dream is “physical and for the future...to go make a miracle and Danny stand from that wheelchair...and Danny to get a job. I will feel joy if Danny stands up from that wheelchair. It is my faith” (Lucia and Pedro).

Dreams for the Future

While physical healing and walking appeared to be at the forefront of parents’ minds, longer-term dreams, including those related to careers and relationships, were also brought up. Margarita’s mother, for example, said that she wants her daughter to fulfill her own dream of becoming a nurse (Maria Cristina). Gerardo’s parents told me he dreams of traveling, visiting the United States, and using the computer skills that he already has to work with computers (Milagro). Blanca’s mother smiled as she reflected on this question and shared that “[my] hopes and dreams are a lot... I do not feel good because my other children are studying, and Blanca is not studying, and I feel bad. I want my daughter to be professionally something.” At the Special Olympics group, one twenty-three-year-old man with cerebral palsy smiled widely and lit up with joy as he sat next to his mother and told me about his dream to own both a specific type of

Toyota sports car and a horse. He and another young man in his thirties with Down syndrome also shared with me that they dream to get married in the future (Special Olympics Families).

Perseverance and Joy Amidst Hardship

Despite their challenges, a spirit of perseverance and joy was evident in many families I met. Daniela spoke of the joy in their home as she told our focus group about her son: “Despite special needs at home, he spends [time] smiling... He is not a sad boy.” Another mother from the Special Olympics focus group spoke about her son in this way: “he is a blessing from God, and I feel proud to be his mother.” Another mother responded by acknowledging her unique role: “God gives special children to special parents” (Special Olympics Families).

As a researcher, I was forced to grapple with the reality that many parents of CwD must delicately balance the tension of living with joy and grief simultaneously. The focus group I conducted with five mothers whose children are part of the Special Olympics was a clear picture to me of this joy-grief tension. Gathered at an outdoor restaurant over coffee and *baleadas* (a traditional tortilla and bean dish), I listened as mothers discussed the challenges they experienced while also laughing hysterically and building camaraderie with one another. One mother endearingly shared with the group about her daughter with Down syndrome amidst tears of laughter: “She likes everything! Playing eating, she eats more than her sister! She likes to play with dolls. Playing ball and even doing the dishes! She even likes to clean, too! She mops and sweeps and receives her mother with coffee!” Also laughing, another mother shared that her daughter likes to “give orders!” and the mothers all laughed together (Special Olympics Families). These mothers told me they were encouraged by simply being around mothers with similar experiences, and this focus group later became central to my inspiration for the LEF project model I developed.

Andrea's Story

Throughout my conversations in the Lenca community, it became clear that parents were experiencing a lack of practical physical resources and beneficial relationships with others. On my last day of research, I had the opportunity to meet a young woman named Andrea, whose story is worth highlighting because it exemplifies what can happen when parents have resources and relationships to support their CwD.

Andrea, mentioned and quoted previously throughout this paper, is twenty-one years old and studying to be a lawyer in a five-year program. Andrea is also a leader in various youth leadership clubs and organizations in the community. One of these is a local evangelism club. As we sat together in her living room over coffee and bread, she shared with me her passion for using her future law degree to advocate for other youth with disabilities. When asked about her dreams for her life, she shared this:

[My dream] first of all, it is to achieve my purpose. That is to talk about Jesus. To share the Salvation message and to help each other find purpose in life, so they get out of depression and low self-esteem. Because I live with those things. And I want others to find the exit. And the other one is to graduate from the university, be able to work, and be able to return to my family and help with the town's development. To be able to travel, to meet places, to meet countries and cultures... that is what I love.

Author Parker J. Palmer discusses the concept of pilgrimages, saying that “Most of us arrive at a sense of self and vocation only after a long journey through alien lands. Going on, he explains that before we “come into the light” we must travel in the dark. Hardships are not accidental but integral to the journey (17–18). Andrea embodied this text as she openly shared her struggle with depression and how she found a sense of purpose and vocation through it. After meeting

Andrea's parents, I learned they both had good jobs that helped provide them with resources to support Andrea, such as medical equipment and the wheelchair ramp at the entrance of their home. They also had strong relationships with community members who could support their family and encourage Andrea to reach her potential. With her parent's support, Andrea was on the path to making an exponentially positive impact on the world.

Limitations

This research had a few limitations that should be acknowledged. First, as the researcher, I was not fluent in Spanish. Because all translations were made through an interpreter, there was a risk of specific nuances being lost in conversations. Additionally, being an outsider may have affected how comfortable informants felt being honest in our interviews; "insider" role status frequently allows researchers more complete acceptance by their participants (Merriam and Tisdell 130-131). It should also be noted that many interviews with parents were conducted while their child was sitting next to them. It is plausible that this affected the answers that parents gave me. Finally, this study was only three weeks long. A longer, more complete ethnographic study would likely yield additional findings (Merriam and Tisdell 29).

Future Research Recommendations

A few areas are recommended for future research. First, a more extensive exploration could be made into understanding the experiences of Lenca children with specific types of disabilities. My research focused on children with a broad range of disabilities, but the experiences of those with specific disabilities are unique. A second recommendation for further research would be to further understand the beliefs of parents about solar and lunar eclipses in relation to the birth of CwD. These beliefs have appeared to exist in Honduran culture for many years, but it is unclear if or how they may be evolving with time. Finally, a topic that also

deserves further research is a community that I was informed has a high population of young people becoming blind. According to the former mayor of San Miguelito, a small neighborhood near San Miguelito is known to have large numbers of people losing their eyesight at early ages, most “between the ages of twenty to forty.” World Vision is aware of the issue, but it was unclear from my conversations if any research or programs were being conducted to address the situation (San Miguelito Municipalidad).

Recommendations for Other Contexts

This research focuses on the Lenca community, but many of the principles span globally and could be used to inform similar contexts in which disability and poverty are being experienced by an ethnic minority group. The Las Estrellas Fugaces project model, outlined below, could also be considered for adaptation in similar contexts. In these cases, any references to Lenca culture could be changed, as well as the model’s Spanish name, if used in a non-Spanish-speaking context. Adaptations should be made carefully, as no two contexts are the same. The research included in this thesis and the LEF project model are only recommended as starting points; expansion on this research and the project model is encouraged.

One Proposed Solution: Las Estrellas Fugaces

Based on the findings presented above, I have developed a proposed project model called Las Estrellas Fugaces (LEF). LEF is a one-year-long program that can be implemented by NGOs or local community organizations that desire to equip parents to support CwD. LEF aims to create a hospitable setting for parents to find support through connection and resources, which Beck says has a “remedial function and can help abandoned people socially or economically” (124). Because parents and other relatives are often the most enduring and important source of support for individuals with disabilities, the goal of LEF is to provide parents with practical tools

and friendships in the community (Carter). This model will not meet every single tangible need of every parent, but the model is designed to address parents' common needs, no matter what disability their child has (Pinilla-Roncancio 114).

The model's name, *Las Estrellas Fugaces*, translates into English as The Shooting Stars. From a scientific perspective, shooting stars are caused by tiny bits of dust and rock called meteoroids falling into the earth's atmosphere and burning up, which creates streaks of light that light up the night sky ("Meteors and Meteorites"). Shooting stars are often associated with dreaming and hope for the future, and across cultures, many people will make a wish when they see one. The name of this model is intended to represent that every child has unlimited potential to be a bright light in the world when those around them are able to support and dream alongside them.

The Model

At the heart of the LEF model are four workshops. Each workshop is three and a half hours long and broken into a large group session, a small group breakout time, and a closing large group session. While the large group times are focused on offering practical information through a guest speaker with expertise in that session's topic, small group times are designed to allow parents to discuss what they learned while building friendships. The closing large group session will offer additional group discussion and a time of reflection. LEF workshops are designed to take place quarterly over the course of twelve months with the goal of parents being empowered to continue to meet on their own after the year is over.

Over the course of the year, LEF walks parents through the process of Appreciative Inquiry (AI), which has been built into the LEF methodology. AI is a philosophy for change that focuses on asking groups to identify what is working in their community and determining how to

repeat those behaviors and actions (Hammond 3; Mathie and Cunningham 474-486). This means that in addition to simply learning about practical resources and building relationships, parents will engage in discussions that align with the five AI phases: Define, Discover, Dream, Design, and Destiny. I have considered the first phase, Define, to have been completed through the research I collected during this study, and the four workshops will each align with the four remaining phases of AI. Because AI is a process meant to be ongoing, the Define phase then evolves into reDefine as the AI cycle is repeated. Appendix G provides an LEF curriculum cover page, a welcome page from a child community leader, an outline of the LEF model, and four high-level workshop outlines. These resources are intended to be a proposal and should be added and expanded upon if LEF is implemented.

Large Group Sessions

Each opening large group session is structured to equip parents with practical tools and resources to address tangible needs. Guest speakers with expertise in relevant topics should be brought in to teach these sessions, such as psychologists, doctors, NGO staff, and educators. Sessions will cover practical topics like nutrition, understanding rights and disability laws, navigating healthcare systems, self-care for parents, and supporting their child's education. I have added suggested topics to four workshop outlines I created. Because these documents are a proposal and the full LEF curriculum is not developed, these are only suggested topics. If LEF is to be implemented, the hosting NGO should work with local experts to refine exact session titles as necessary.

LEF Small Groups

Based on the number of parents participating, an attempt should be made by the workshop facilitators to group parents together who have children with similar disabilities or

ages, although this is not a requirement. It also is recommended that each small group be composed of three to five parents or caregivers to ensure groups are not too large and allow for easier relationship building. Each group will be led by a trained facilitator. Facilitators will use the questions in the discussion guides to walk participants through the AI process but are encouraged to adapt questions as necessary to draw out answers from participants. Facilitators should encourage parents to stay in relationship between workshops through methods like WhatsApp to provide encouragement and support.

Nothing About Them Without Them

LEF incorporates values from Nothing About Us Without Us, a concept that originated from the disability community, suggesting that no decision should be made about PwD without PwD being included in the conversation (Kubenz and Kiwan 32). While children will not be participating actively in the workshops, LEF facilitators are encouraged to find ways for CwD to be involved when possible, such as being asked to say a closing prayer at the large group session. Including the voices of those with disabilities is important, as the three universal human needs are to have a voice and be heard, be seen as essential to a group, and be seen as unique and exceptional (Cooperrider). It is recommended that the hosting organization have a special daycare area with trained caregivers on the site who can care for the children whose parents are in the workshops. This will allow parents who are often full-time caregivers a break and allow them to focus fully on participating in the workshop.

Sustainability

The final workshop is focused on the Destiny phase of AI, and on moving parents into the reDefine phase. In the final workshop, parents are asked to reflect on what they have learned and think about how to continue making a difference longer-term. In this workshop, they will

discuss how to live into the ideas they have discussed throughout the AI process with their new knowledge and relationships. This final large group session will include a special ceremony to celebrate the parents and children, and each person who completes the ceremony will be awarded a special certificate of completion. A signup sheet will be available for any parent interested in continuing to meet, which will be highly encouraged so that parents can enter into the reDefine phase and continue the work of supporting Lenca CwD.

While the new group should be led by parents, it is recommended that the hosting organization be available for consulting from the group if needed. According to Zelaya, it is critical that parents take ownership of the efforts around CwD moving forward to ensure sustainability. Zelaya has seen success in the La Paz community of parents of CwD leading a group called the Asociación de Padres de Hijos con Discapacidad de La Paz Adephanes (Zelaya). Additionally, in other parts of Honduras, like the north in Roatan, there is another small organization formed by the parents of CwD to address needs of CwD in the community. The Roatan group conducts awareness-raising activities, including a march for the World Day of Autism and the sale of goods produced by the parents as a fundraiser (Schneider 19). If feasible, parents from existing group like these can be brought into the closing ceremony of LEF to share about their experience and inspire Lenca parents.

Expanding LEF

The LEF model is designed to be implemented within the Lenca culture but may, with careful consideration, be considered for adaptation and implementation in other locations similar contexts. Online parent workshops have been proven to have a high rate of success in places like Australia and Canada, building build strong levels of family empowerment and parent confidence (Miller et al. 1-12). While the context in Honduras is significantly different and the

lack of internet is a significant challenge, some creative development practitioners may be inspired to explore ways to develop LEF into an online or hybrid model.

Conclusion

My goal as a researcher was to act as a gatherer of information and a steward of the stories graciously entrusted to me. Throughout my research process, I was often reminded of these words from Higashiyama, who once wrote that "...disability is not about what is missing, but what is abundant in the expressions that make us human (Higashiyama). Whenever I reflect on those words, I cannot help but remember Melissa, another mother I met back in Honduras. Looking at her son, unable to speak or walk, Melissa told me: "I hope to fight for him." While I hope that this research will contribute to the wider body of knowledge on CwD, I hope that, even more so, it will compel people to act. Whether in DRC, Seattle, or Honduras, may the world rise up and join parents as they fight for their children's dreams and the abundance of expressions that make us all human.

Works Cited

- Adolescent Clinic Staff Focus Group in Dolores. Personal Interview. 25 August 2022.
- Alejandra. Personal Interview. 24 August 2022.
- Alma. Personal Interview. 25 August 2022.
- Amado-Salvatierra, Hector R., and Jose R. Hilera. "Towards an approach for an accessible and inclusive virtual education using ESVI-AL project results." *Interactive Technology and Smart Education* 12.3 (2015): 158-168. doi:10.1108/ITSE-04-2015-0005.
- Andrea. Personal Interview. 26 August 2022.
- Aquino, Karina. Video Interview. 14 February 2022.
- . Video Interview. 29 February 2022.
- Asociación de Discapacitados. Focus Group. 16 August 2022.
- Association de Discapacitados de Santa Elena (Focus Group) Personal Interview. 16 Aug. 2022.
- Beck, Richard. *Unclean: Meditations on Purity, Hospitality, and Mortality*. Eugene, OR: Wipf and Stock Publishers, 2011.
- Berkowitz, Samuel. "Parents' Satisfaction with Repair of Pediatric Cleft Lip/Palate in Honduras." *Pediatrics & International Child Health*, vol. 33, no. 3, Aug. 2013, pp. 127–28. doi:10.1179/2046905513Y.0000000067.
- Boyden, Jo, et al. *Tracing the Consequences of Child Poverty*. Policy Press, 2019.
doi:10.2307/j.ctvkjb390.
- Braun, Virginia, and Victoria Clarke. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3.2 (2006): 77–101. doi:10.1191/1478088706qp063oa.
- Calix, Rider. Personal Interview. 5 August 2022.
- Carmen. Personal Interview. 18 August 2022.

Carter, Erik W. "Supporting Families." Erik W. Carter,

www.erikwcarter.com/writing#/supporting-families/. Accessed 12 Jan 2023.

Collective Impact Forum. "Tackling Complex Social Problems through Collective Impact."

YouTube. December 1, 2014,

www.youtube.com/watch?v=pzmMk63ihNM&feature=youtu.be. Accessed 12 Nov. 2022.

"Committee on the Rights of Persons with Disabilities Considers the Initial Report of Honduras."

OHCHR, 31 Mar. 2017, www.ohchr.org/en/press-releases/2017/03/committee-rights-persons-disabilities-considers-initial-report-honduras.

"Convention on the Rights of the Child." United Nations Human Rights Office of the High

Commissioner, Convention on the Rights of the Child, www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child. Accessed 1 Sep. 2022.

"Convention on the Rights of the Child." World Vision International. www.wvi.org/crc.

Accessed 16 Dec. 2022.

Cooperrider, David. "Why Appreciative Inquiry" Lessons from the Field: Applying

Appreciative Inquiry, Thin Book Publishing, 2002.

"Country Comparison Tool." Hofstede Insights, www.hofstede-insights.com/country-comparison-tool?countries=honduras*.

Accessed 13 Nov. 2022.

"Disability Information and Statistics for Central America and Mexico." Disabled World,

Disabled World, 23 Dec. 2017, [www.disabled-](http://www.disabled-world.com/news/america/camstats.php)

[world.com/news/america/camstats.php](http://www.disabled-world.com/news/america/camstats.php). Accessed 15 Jan. 2023.

"Disability." World Health Organization, World Health Organization,

Dolores Municipalidad Focus Group. Personal Interview. 26 August 2022.

Everett, Jim A.C. "Intergroup Contact Theory: Past, Present, and Future." *The Inquisitive Mind*, 2013, www.in-mind.org/article/intergroup-contact-theory-past-present-and-future.

Accessed 2 Dec. 2022.

"Factsheet on Persons with Disabilities." United Nations,

www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html. Accessed 2 Feb. 2023.

15 de Septiembre School Focus Group. Personal Interview. 17 August 2022.

Hammond, Sue. *The Thin Book of Appreciative Inquiry*. 3rd ed. Bend, OR: Thin Book Publishing, 2013.

Higashiyama, Natalie. "Tonight." Received by Annie Martin, 28 January 2023.

---. Personal Interview. 22 March 2022.

Hines, Greg, and Jean. Personal Interview. 1 September 2022.

Hofstede, Geert, et al. *Cultures and Organizations: Software of the Mind*. McGraw-Hill, 2010.

"Human Development Index." Human Development Reports, hdr.undp.org/data-center/human-development-index#/indicies/HDI. Accessed 23 Sep 2022.

INPOFACE School Educators Focus Group. Personal Interview. 23 August 2022.

Juana. Personal Interview. 24 August 2022.

Kubenz, Vera, and Dina Kiwan. "'Vulnerable' or Systematically Excluded? The Impact of Covid-19 on Disabled People in Low-and Middle-Income Countries." *Social Inclusion* 11.1 (2023): 26-37. doi: <https://doi.org/10.17645/si.v11i1.5671>.

Kousky, Carolyn. "Impacts of Natural Disasters on Children." *The Future of Children* (2016): 73–92. doi:10.1353/foc.2016.0004.

Laura. Personal Interview. 16 Aug 2022.

Lingsom, Susan. "Invisible impairments: Dilemmas of concealment and disclosure."

Scandinavian Journal of Disability Research 10.1 (2008): 2-16.

doi:10.1080/15017410701391567.

London International Development Centre. "The Sustainable Development Goals (SDGs)

Explained," YouTube. 15 June 2015, www.youtube.com/watch?v=NkAv9L1_r1M.

Lucia and Pedro. Personal Interview. 24 August 2022.

Maria Cristina. Personal Interview. 25 August 2022.

Mathie, Alison and Cunningham, Gord. From Clients to Citizens: Asset-based Community

Development as a Strategy for Community-driven Development. *Development in*

Practice. Volume 13, Number 5. November 2003. doi:10.1080/0961452032000125857.

Melissa. Personal Interview. 24 August 2022.

Merriam, Sharan B. and Elizabeth J. Tisdell. *Qualitative Research: A Guide to Design and*

Implementation. 4th ed. San Francisco: Jossey-Bass, 2016.

"Meteors & Meteorites." NASA Solar System Exploration, National Aeronautics, and Space

Administration, 25 Jan. 2019, [solarsystem.nasa.gov/asteroids-comets-and-](http://solarsystem.nasa.gov/asteroids-comets-and-meteors/meteors-and-meteorites/overview/?page=0&per_page=40&order=id+asc&search=&condition_1=meteor_shower%3Abody_type)

[meteors/meteors-and-](http://solarsystem.nasa.gov/asteroids-comets-and-meteors/meteors-and-meteorites/overview/?page=0&per_page=40&order=id+asc&search=&condition_1=meteor_shower%3Abody_type)

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[or_shower%3Abody_type](http://solarsystem.nasa.gov/asteroids-comets-and-meteors/meteors-and-meteorites/overview/?page=0&per_page=40&order=id+asc&search=&condition_1=meteor_shower%3Abody_type). Accessed 13 Nov. 2022.

Milagro. Personal Interview. 23 August 2022.

Miller, L., et al. "Impact of "early intervention" Parent Workshops on Outcomes for Caregivers

of Children with Neurodisabilities: A Mixed-Methods Study." *Disability and*

Rehabilitation (2022): 1–12. doi:10.1080/09638288.2022.2143579.

Mind Tools. "Active Listening: Hear What People are Really Saying". Mindtools.com. Accessed 13 Jul. 2019, www.mindtools.com/CommSkill/ActiveListening.htm.

Moe-Lobeda, Cynthia. *Resisting Structural Evil: Love as an Ecological-Economic Vocation*. Minneapolis, MN: Fortress Press, 2013.

Myers, Bryant. *Walking with the Poor: Principles and Practices of Transformational Development*. Maryknoll, NY: Orbis, 2011. Oaks, CA: SAGE Publications, 2020.

Olkin, Rhoda, et al. "The Experiences of Microaggressions against Women with Visible and Invisible Disabilities." *Journal of Social Issues*, vol. 75, no. 3, Sept. 2019, pp. 757– 85. doi:10.1111/josi.12342.

Palmer, Parker. *Let Your Life Speak: Listening for the Voice of Vocation*. San Francisco, CA: Jossey-Bass, 1999.

Patria y Libertad School. Observation. 22 August 2022.

Pellow, David Naguib. *Resisting Global Toxics: Transnational Movements for Environmental Justice*. MIT Press, 2007.

Pförtner, Katharina. "Community-Based Inclusive Education: Best Practices from Nicaragua, El Salvador, Guatemala and Honduras." *Disability, CBR & Inclusive Development*, vol. 25, no.1, Mar. 2014, pp. 72–81. doi:10.5463/dcid.v25i1.321.

Pinilla-Roncancio, Mónica. "Disability and poverty: two related conditions. A review of the literature." *Revista de la Facultad de Medicina* 63 (2015), 113-123. doi:10.15446/revfacmed.v63n3sup.50132.

Porfirio. Personal Interview. 24 August 2022.

Quattrocchi, Patrizia. “‘Parteras Gracias a Dios’. Il Sistema Di Nascita Lenca (Honduras) Fra Tradizione e Modernità.” *La Ricerca Folklorica*, no. 44, Oct. 2001, pp. 127–38.

doi:10.2307/1480023.

“Quienes Somos.” Teletón Honduras, teleton.org.hn/quienes-somos/. Accessed 16 Sep. 2022.

“Strengthening of the Indigenous Popular Communication Project of the Lenca People Radio ‘the Voice of Lenca,’” WACC, 27 Aug. 2014, waccglobal.org/strengthening-of-the-indigenous-popular-communication-project-of-the-lenca-people-radio-the-voice-of-lenca/. Accessed 5 Jan. 2023.

San Juan Municipalidad Mayor and Staff group. Personal Interview. 23 August 2022.

San Miguelito Municipalidad Mayor and Staff group. Personal Interview. 24 August 2022.

Sandra. Personal Interview. 18 August 2022.

Santa Elena Mayor’s Representative. Personal Interview. 17 August 2022.

Schneider, C. “Teachers’ Perceptions of Disabilities on the Island of Roatán, Honduras.”

Disability, CBR and Inclusive Development, vol. 28, no. 2, 2017, p. 5–22.

doi:10.5463/dcid.v28i2.573.

Special Olympics Families Focus Group. Personal Interview. 25 August 2022.

Stringer, Ernest T. and Alfredo Ortiz Aragon. *Action Research*. 5th ed. Thousand Oaks, CA:

SAGE Publications, 2020.

Sunstein, Bonnie Stone, and Elizabeth Chiseri-Strater. *Fieldworking: Reading and Writing*

Research, 4th edition. Boston: Bedford/St. Martin’s, 2011.

“Sustainable Development Goals (SDGs) and Disability | Division for Inclusive Social

Development (DISD).” United Nations, United Nations,

social.desa.un.org/issues/disability/sustainable-development-goals-sdgs-and-disability.

“Sustainable Development Goals”. World Vision International. www.wvi.org/SDGs. Accessed 17 Nov. 2022.

"Things to Do in La Ruta Lenca." www.Frommers.Com/Destinations/La-ruta-lenca, www.frommers.com/destinations/la-ruta-lenca. Accessed 11 Mar. 2023.

Toombs, Hannah. "Indigenous tradition, change, and uncertainty in western Honduras: how Lenca potters maintain craft production livelihoods in the face of socioeconomic development." *Latin American and Caribbean Ethnic Studies* (2022): 1–14. doi:10.1080/17442222.2022.2130669.

Umaefulam, Valerie, et al. "Critical perspectives on rehabilitation education, practice, and process: northern Honduras case study." *BMC Health Services Research* 22.1 (2022):1-12. doi:10.1186/s12913-022-08875-6.

United Nations. “United Nations Convention on the Rights of Persons with Disabilities.” 6 December 2006. www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf. Accessed 17 Jan 2022.

“U.S. Relations with Honduras - United States Department of State.” U.S. Department of State, 1 Mar. 2023, www.state.gov/u-s-relations-with-honduras/.

Weissman, Amanda Ketner. "Striving to Include the Excluded: A Case Study of a Special Education Initiative in Rural Honduras." *FIRE: Forum for International Research in Education*. Vol. 6. No. 1. Lehigh University Library and Technology Services. 8A East Packer Avenue, Fairchild Martindale Library Room 514, Bethlehem, PA 18015, 2020.

Willis, Katie. *Theories and Practices of Development*. 2nd ed. New York: Routledge, 2011.

Winter, Edward. Video Interview. 3 February 2022.

World Vision. "Programming Guidance for the Inclusion of Children & Adults with Disabilities." 22 January 2021. www.who.int/health-topics/disability#tab=tab_2.

---. World Vision Honduras Field Office Strategy FY22-FY24. June 2021.

Yacoub, Sophie, Sergio Arellano, and Dennis Padgett-Moncada. "Violence related injuries, deaths and disabilities in the capital of Honduras." *Injury* 37.5 (2006): 428–434. doi:10.1016/j.injury.2005.12.001.

Yeo, Rebecca. "Chronic poverty and disability." *Chronic Poverty Research Centre Working Paper* 4 (2001).

Yarula Community Leaders Focus Group. Personal Interview. 18 August 2022.

Zelaya, Jonathan. Personal Interview. 4 April 2023.

Appendices A-G

Appendix A

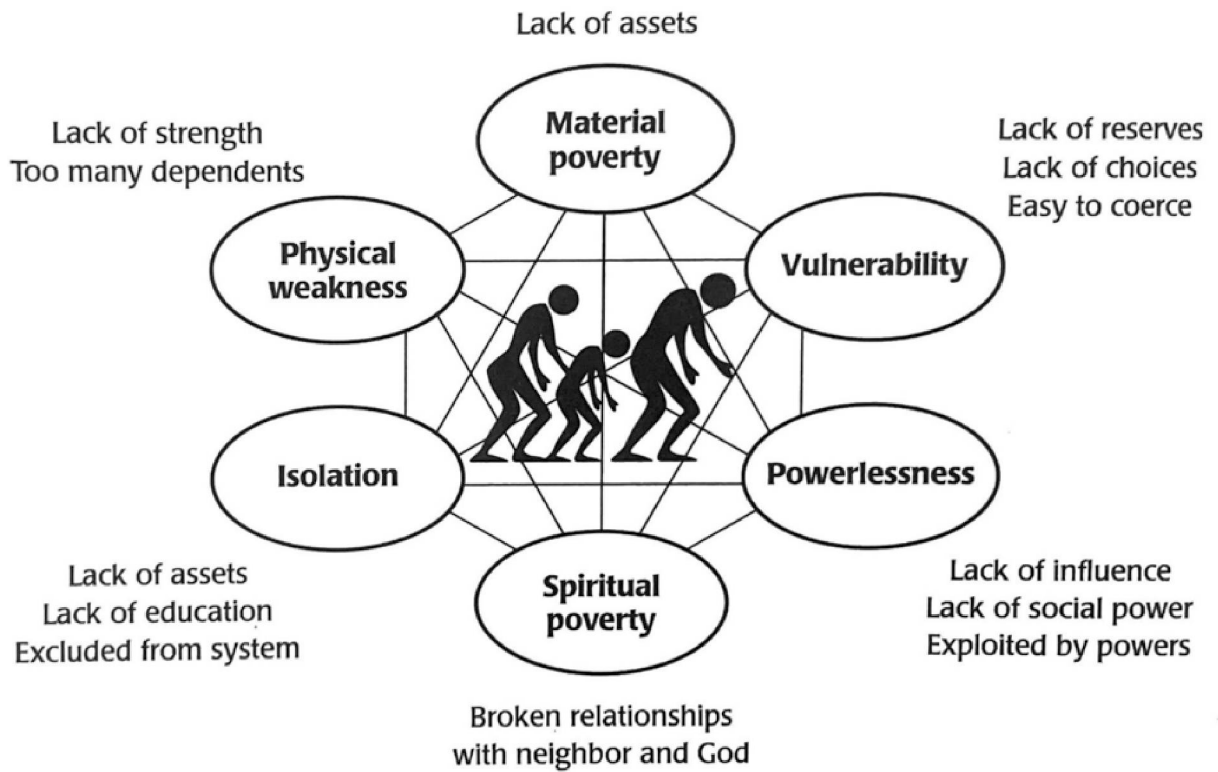
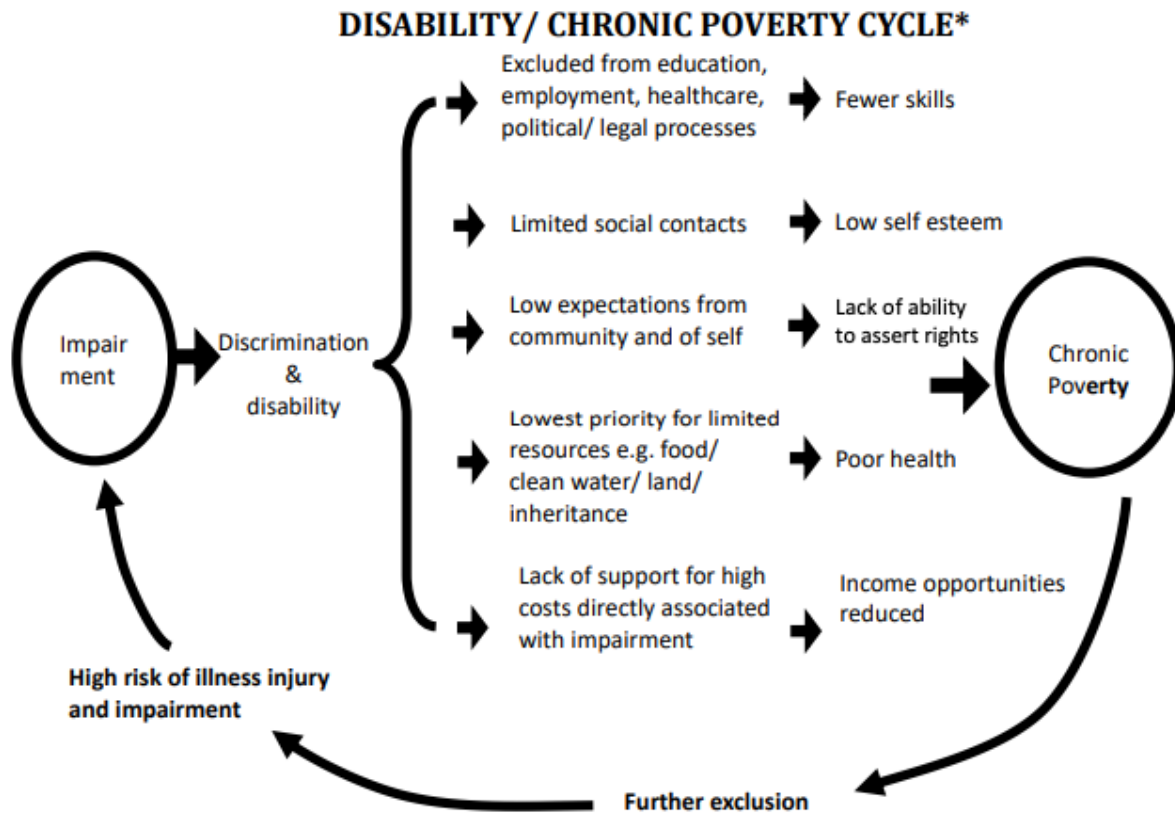


Figure 4-2: The entanglement of the household.
(Adapted from Chambers 1983, 110)

Appendix B

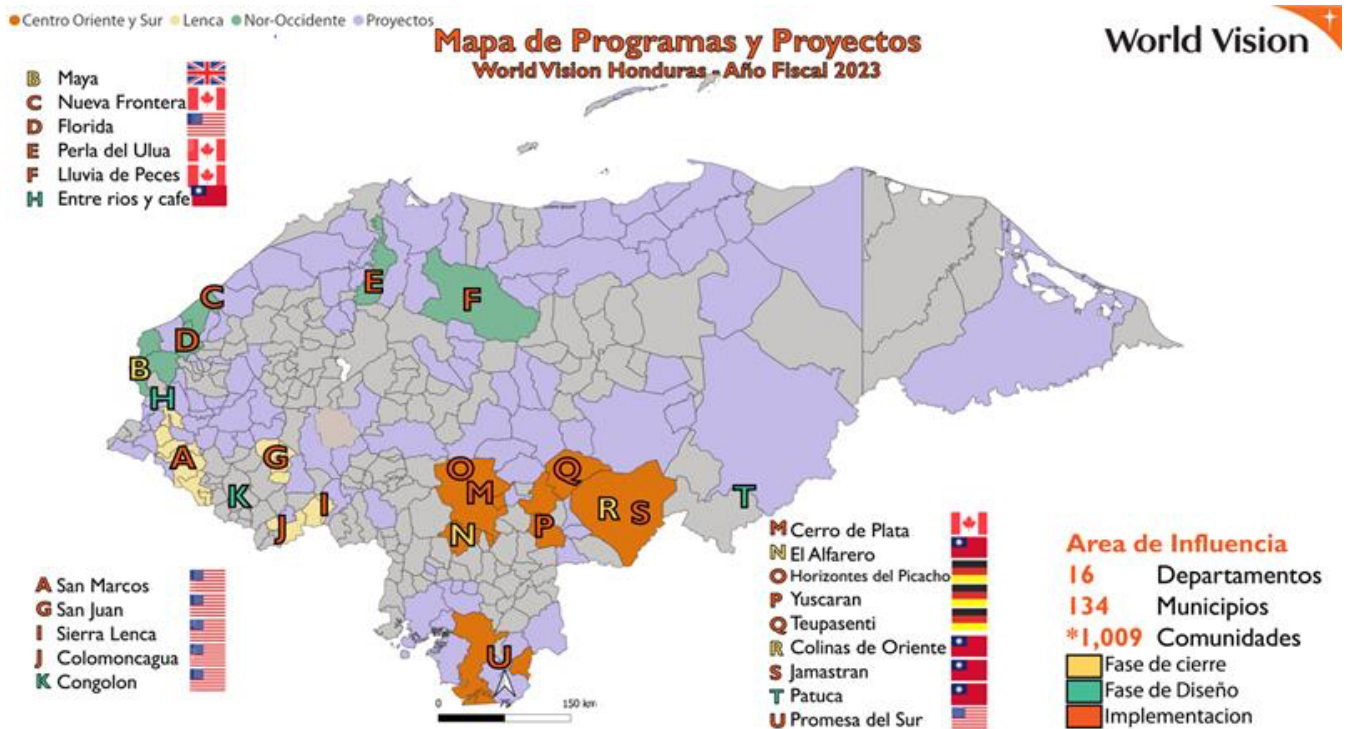
This chart has been copied from World Vision’s “Programming Guidance for the Inclusion of Children & Adults with Disabilities” document. It is adapted from the research of R. Yeo: Chronic Poverty and Disability Cycles.



*based on R. Yeo: Chronic Poverty and Disability Cycles

Appendix C

Map of World Vision Honduras' programming locations in FY23 (October 1, 2022 – September 30, 2023). Country flags indicate the World Vision Support Office funding each project. Research informing this thesis took place primarily within various communities in G (San Juan) and I (Sierra Lenca).



Appendix D

Sample Interview Questions

Parents and Caregivers

1. Tell me about your family and your child.
2. What is a typical day like for your family?
3. What was your experience like when you learned about your child's condition?
4. Did you ever receive a formal diagnosis for their condition?
5. What are some challenges you face when caring for a child with disabilities?
6. Are you in a relationship with any other parents whose children have disabilities?
7. How do you deal with difficult days?
8. What brings you joy?
9. Tell me about your child's favorite activities.
10. Does your child have friends?
11. What are your dreams and hopes for your child?

Healthcare Workers

1. Tell me about your job.
2. Can you share about your clinic/hospital?
3. What are some of the most common disabilities you see here?

Mayors and Government Officials

1. Tell me about your community.
2. Can you talk about the laws that are in place to support PwD?
3. Does your office have any programs to support people with disabilities?

Teachers

1. Tell me about your school.
2. Why did you decide to become a teacher?
3. Are there students with disabilities in your school?
4. Tell me about your experience teaching students with disabilities.
5. How do other students in the school treat students with disabilities?
6. What types of resources do you think would be helpful for you as a teacher to support students with disabilities?

All Groups

1. How did COVID-19 affect your community?
2. Are there challenges for PwD that are unique to the Lenca communities and may differ for PwD in more urban areas?
3. If you could dream of any resources in the community to improve the lives of Lenca PwD, what would you like to see or imagine?

Appendix E

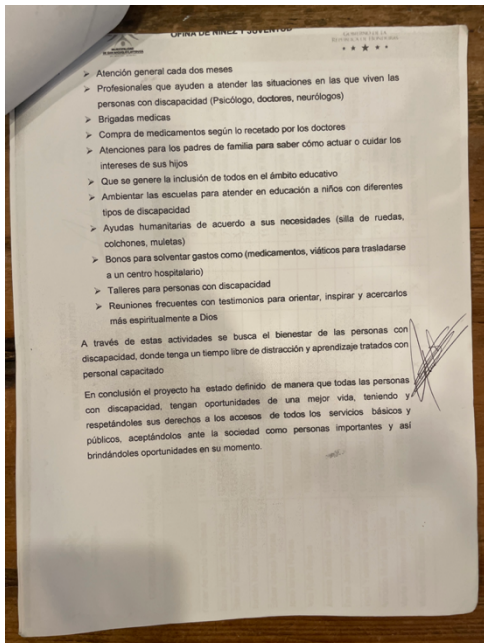
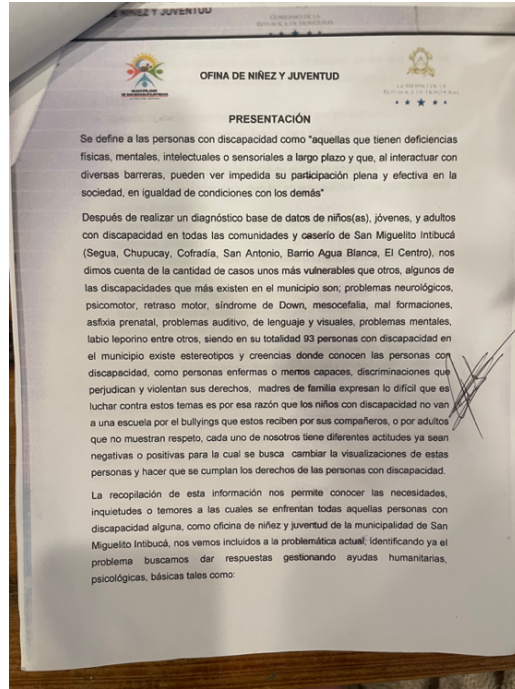
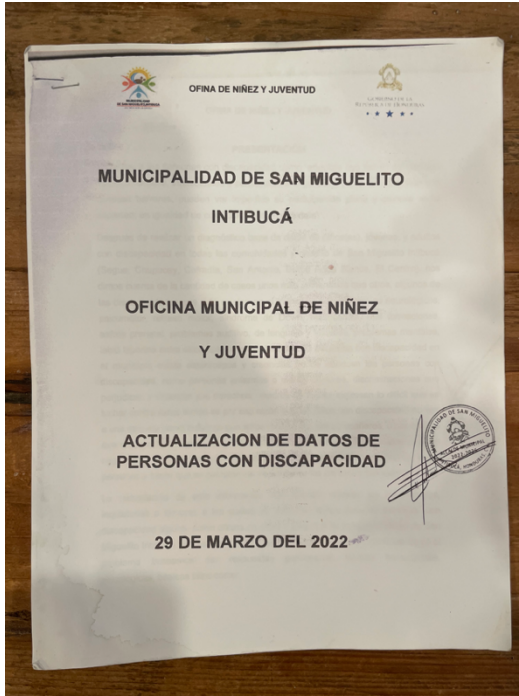
DISABILITY TERMINOLOGY CHART

When referring to people with disabilities, choose words that reflect dignity and respect. Use language that describes the person's disability without defining the individual as his or her disability. The following are just some examples.

INAPPROPRIATE	APPROPRIATE
The disabled, the handicapped	People with disabilities, the disability community
Crippled, suffers from, afflicted with, stricken with, victim of, invalid	Has a disability, is a person with a disability
Normal person, healthy, whole	People without disabilities, able-bodied, person who is able to walk, person who can see, etc.
The blind, the deaf	Person who is blind, person who is deaf or hard of hearing
Wheelchair bound, confined or restricted to a wheelchair	Person who uses a wheelchair, wheelchair user
Handicap parking	Accessible parking, parking for people with disabilities
Dumb, mute	Person who cannot speak, has difficulty speaking, uses synthetic speech, is non-vocal, non-verbal
Stutterer, tongue-tied	Person with a speech impairment, who has a speech disability, speech disorder, or communication disability
CP victim, spastic	Person with cerebral palsy
Crippled, lame, deformed	Person with a disability, walks with a cane, uses leg braces
Epileptic	Person with epilepsy, person with seizure disorder
Fit, attack	Seizure, epileptic episode or event
Crazy, maniac, lunatic, insane, nuts, deranged, psycho, demented	People with emotional disorders, mental illness, mental health disability, psychiatric disability
Retard, mentally defective, moron, idiot, slow, imbecile, feeble-minded, Down's person, mongoloid	Person with a developmental disability, person with mental retardation, person with a developmental delay, person with Down syndrome or person who is brain injured, has traumatic brain injury, is brain damaged, with a closed head injury
Slow learner, retarded	Person who has a learning disability
Dwarf, midget	Short stature, little person
Paraplegic, quadriplegic	Person with spinal cord injury, man with paraplegia, woman who is paralyzed
Birth defect	Congenital disability, birth anomaly
A post-polio, suffered from polio	Has had polio, experienced polio
Homebound	Stay-at-home, hard for the person to get out
Senile, demented	Person with Alzheimer's disease, person who has dementia

Appendix F

These images show several pages of a report created by the Municipality of San Miguelito, Intibucá in 2022 outlining disability statistics in San Miguelito.



Appendix G



LAS ESTRELLAS FUGACES

A Project Model for Equipping Lenca Parents of Children with Disabilities to Dream Bigger



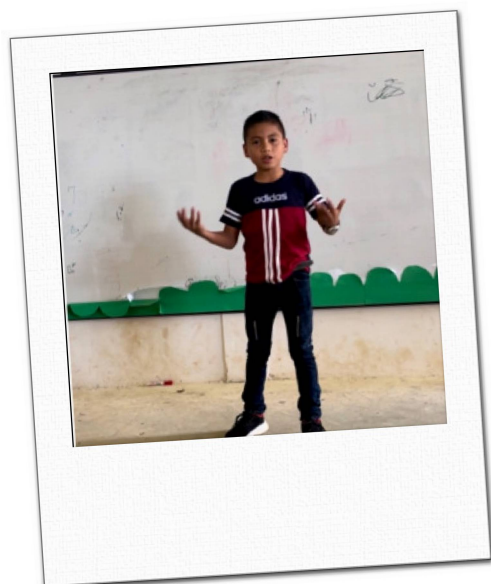


¡BIENVENIDOS, NGO STAFF!

Thank you for your solidarity, interest and commitment to children with disabilities in this municipality. **People with disabilities are human beings with rights, obligations and desires.**

They want to work for their families and for societies. They have the capacities to be able to participate fully and effectively in each of the aspects of political, social, economic and cultural life, **but it is necessary to have adequate conditions that allow people with disabilities to enjoy their rights under a framework of equality** with the rest of the people.

Likewise, solid steps need to be taken so that our children with disabilities can be respected and recognized as full members of society today we can renew our commitment to ensure that all children's rights can be fully and equitably fulfilled, and I remind you that **disability is not contagious** but discrimination, yes!



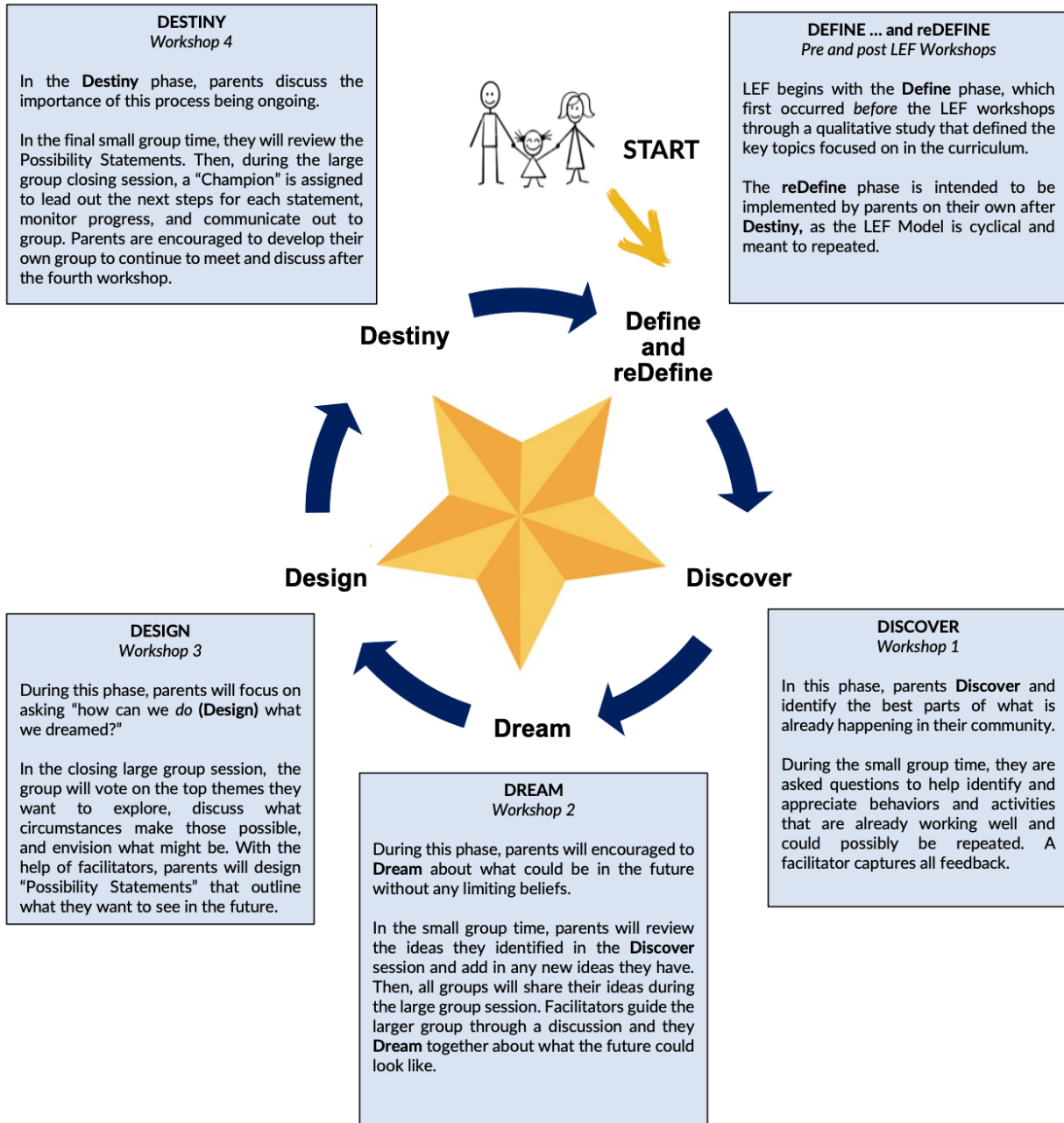
Muchas gracias,

Javier

Javier
President of the Lenca Children's Club



The Las Estrellas Fugaces Model



In addition to large and small group sessions designed to equip parents with practical resources and relationships, this model demonstrates how LEF walks parents through the phases of Appreciative Inquiry.



TALLER #1

(Workshop #1)

TIME	ACTIVITY	DESCRIPTION	FACILITATOR
30 Minutes	Families arrive	-Families arrive (<i>On their own or transported by NGO staff in NGO vehicles</i>) -Children dropped off in daycare area with trained caregivers -Parents enjoy refreshments, coffee, and mingle	Hosting NGO Staff
1 Hour	Large Group Session	<u>Large Group Session Topics:</u> -Welcome and vision casting for the year -Presentation: <i>What is LEF?</i> -Presentation: <i>Created in the Image of God: What is disability?</i>	Hosting NGO Staff + Guest Speaker
15 Minutes	Break		
1 Hour	Small Group Session	- <i>"Get to Know You"</i> Icebreaker Activity -Debrief the Large Group session -Discuss " Discover " questions	Hosting NGO Staff
15 Minutes	Break		
30 Minutes	Closing Large Group Session	-Closing Session: <i>Staying encouraged on difficult days</i>	Hosting NGO Staff

Small Group Discussion Guide | **Discover**

(The facilitator may also introduce supplementary questions aimed at uncovering successful activities and behaviors that can be replicated in their parenting approaches and in the community)

1. What was something new that you learned during the Large Group session?
2. Describe a time when you felt proud to be your child's parent.
3. Share a time you felt that you succeeded as a parent and describe what made that possible.
4. Talk about a time you saw your child make progress. What do you think made that possible?
5. Tell us about a time you felt well-supported as a parent. Where did you receive that support and what was the experience like?


TALLER #2
 (Workshop #2)

TIME	ACTIVITY	DESCRIPTION	FACILITATOR
30 Minutes	Families arrive	-Families arrive (<i>On their own or transported by NGO staff in NGO vehicles</i>) -Children dropped off in daycare area with trained caregivers -Parents enjoy refreshments, coffee, and mingle	Hosting NGO Staff
1 Hour	Opening Large Group Session	<u>Large Group Session Topic:</u> -Presentation: <i>Education for children with disabilities/supporting children's self-esteem</i>	Hosting NGO Staff + Guest Speaker
15 Minutes	Break		
1 Hour	Small Group	-Icebreaker Activity -Debrief Large group session -Discuss " Dream " questions	Hosting NGO Staff
15 Minutes	Break		
30 Minutes	Closing Large Group Session	-Group Discussion: <i>Dreaming about the Future</i>	Hosting NGO Staff

Small Group Discussion Guide + Questions | **Dream**

(Questions this week focus on revisiting questions from Workshop 1 small group)

1. What was something new that you learned during the Large Group session?
2. Describe a time when you felt proud to be your child's parent.
3. Share a time you felt you succeeded as a parent and describe what made that possible.
4. Talk about a time you saw your child make progress. What do you think made that possible?
5. Talk about a time you felt well-supported as a parent. Where did you receive that support?



TALLER #3
(Workshop #3)

TIME	ACTIVITY	DESCRIPTION	FACILITATOR
30 Minutes	Families Arrive	-Families arrive (<i>On their own or transported by NGO staff in NGO vehicles</i>) -Children dropped off in daycare area with trained caregivers -Parents enjoy refreshments, coffee, and mingle	Hosting NGO Staff
1 Hour	Opening Large Group Session	<u>Large Group Session Topics:</u> -Presentation: <i>Overview of child rights, disability laws, resources available in the community (Government resources, local NGO resources)</i>	Hosting NGO Staff + Guest Speaker
15 Minutes	Break		
1 Hour	Small Group	-Icebreaker Activity -Debrief Large group session -Discuss " Design " questions	Hosting NGO Staff
15 Minutes	Break		
30 Minutes	Closing Large Group Session	-Group discussion: <i>Sticky dot voting activity and designing Possibility Statements</i>	Hosting NGO Staff Parent Leader

Small Group Discussion Guide + Questions | **Design**

1. What was something new that you learned during the Large Group session?
2. Are you aware of any resources that have helped you that should have been mentioned?
3. When you think about the future of this community and your child, what do you want to see, and what steps do you think are needed to get there?



TALLER #4
(Workshop #4)

TIME	ACTIVITY	DESCRIPTION	FACILITATOR
30 Minutes	Families Arrive	-Families arrive (<i>On their own or transported by NGO staff in NGO vehicles</i>) -Children dropped off in daycare area with trained caregivers -Parents enjoy refreshments, coffee, and mingle	Hosting NGO Staff
1 Hour	Opening Large Group Session	<u>Large Group Session Topic:</u> -Presentation: <i>Self-Care and Finding Respite</i>	Hosting NGO Staff + Guest Speaker
15 Minutes	Break		
1 Hour	Small Group	-Debrief Large group session -Discuss " Destiny " questions	Hosting NGO Staff
15 Minutes	Break		
30 Minutes	Closing Large Group Session	-Closing Celebration Ceremony -Next Steps: <i>NGO staff discuss opportunity for parents to start their own association</i>	Hosting NGO Staff

Small Group Discussion Guide + Questions | **Destiny**

1. What was something new that you learned during the Large Group session?
2. What are two takeaways you have from participating in LEF?
3. In what ways have your dreams about your child's future changed since participating in LEF?
4. Are you interested in participating in a future association of parents and continuing to meet?
5. How do you think parents could continue to support one another and children with disabilities in the community? (*Facilitator to provide sign-up form to parents if interested in joining group to continuing to meet*)