Policy and Practice of Disability in Rural Zones of Southern Peru and Coastal Ecuador

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ABSTRACT

This study investigates the sociopolitical realities for individuals with disabilities in rural zones of Ecuador and Peru. Chapter One defines disability within global, national, and local contexts with regards to La Ley Orgánica de Discapacidades of Ecuador and Law No. 29973 of Peru, laws enacted to protect individuals with disabilities in each respective country. Chapter Two describes two case studies based on short term ethnographic fieldwork in 2017 and 2018 among disabled populations in San Migos, Ecuador. These narratives contribute to a general understanding of how access to medical professionals and quality diagnoses are determined by geographic situation, economic ability, and familial situation. This inequitable system contributes to the lack of political support for individuals in rural zones, such as San Migos, Ecuador. Chapter Three focuses on case studies taken in 2018 from Rio Mar, Peru and discusses structural limitations, such as education, familial support, and economic abilities, that make it difficult for individuals with disabilities to claim rights and recognition by the Peruvian government. Chapter Four compares case studies in Ecuador and Peru and makes suggestions for disability practices in each respective country. The situation for people with disabilities in rural areas of Rio Mar, Peru and San Migos, Ecuador is neither equitable nor efficient. We must increase research in this area to improve the system.

CHAPTER I: INTRODUCTION
DEFINING AND EXPERIENCING PHYSICAL DISABILITY: CASE STUDIES OF RURAL ECUADOR AND PERU

Physical disability may seem apparent and easy to define. It is not. At the global level, institutions such as the World Health Organization seek to define physical disability. At the country level and around the world, policy makers do the same. At the local level, care providers have to consider policy guidelines handed down to them from above and manage scarce resources to address needs. At the most personal level, people with physical disabilities and their families and friends experience everyday living and its challenges within different socioeconomic contexts.

In this paper, I first describe my findings from fieldwork experiences in Ecuador (Chapter II) followed by those from Peru (Chapter III). I then offer comparative comments from the two case studies, followed by some conclusions and thoughts for future research on the subject of physical disability, particularly people’s lived experiences, specifically in low income contexts (Chapter IV).

HISTORICAL TIES

As bordering neighbors, Ecuador and Peru have historical ties that date back to the Inca empire of the 15th century. The Inca empire was well known for advanced agriculture, government structure, and military (Burkholder & Johnson, 1990).

Both countries were dominated by Spain from the 16th century until the beginning of the 19th century. Historical records show years of oppression of the native people of Ecuador and Peru. The Spanish conquerors used indigenous peoples as indentured servants and generally treated them more like animals than people. There were striking contrasts among power dynamics of Europeans, mestizos, creoles, and natives.

After Ecuador and Peru achieved independence from Spain, in 1822 and 1821 respectively, territorial disputes between the two countries persisted until the late 20th century. On May 13, 1999, Ecuador and Peru agreed to the Brasilia Presidential Act which formally demarcated borders after nearly a century of dispute. This agreement also rejects the use of war and violence against each other (Witt & Fujimori, 1998).
CONTEMPORARY SOCIO-POLITICAL CONTEXT IN ECUADOR AND PERU

Ecuador's politics are marked by many years of unfulfilled presidential terms. Rafael Correa, President of Ecuador from 2007-2017, was the first president since the 1990's to complete his entire term. Correa led Ecuador into a new phase of politics and leadership as a more liberal leader who was praised for decreasing poverty rates, increasing GDP, and increasing overall equality within Ecuador (Monitoring, 2017). While in office, his vice president, Lenin Moreno, did much work advocating for individuals with disabilities. The Guardian claimed that Ecuador became one of the “most progressive nations in Latin America” during Correa's presidency in terms of assisting those with disabilities (Watts, 2013, para. 10).

Lenín Moreno assumed the office of presidency in 2017. He was nominated for a Nobel Peace Prize in 2012 for the stark increase in registrations for disabled individuals. In only 4 years, over 50,000 people have been able to access a disability registration (Astudillo, 2017, para. 4). He created a system of “guaranteed medical and social care” for individuals with disabilities through the Manuela Espejo Program (Astudillo, 2017, para. 4). At the time of his nomination for the Nobel Peace Prize, he said that he had only accomplished 20% of what he wanted because he realizes the necessity of “structural change” (Watts, 2013, para. 14).

Peru, conversely, has a long history of political corruption and instability. Many of Peru's presidents have either been impeached or imprisoned due to their involvement in various political schemes. This political disruption contributes to a larger system of unenforced laws in Peru. There are laws in place to protect disabled people and the land of indigenous communities, yet the individuals in power have not done their part to ensure these laws are fulfilled within communities in Peru.

It was not until President Ollanta Humala in 2011 that rhetoric for the social inclusion of vulnerable populations became apparent. Humala established the Ministry of Development and Social Inclusion (MIES) in Peru (RPP Noticias, 2011) and was president during the passing of Law 29973. While I was in Peru, Humala was impeached and later arrested as a recipient of a bribe from a Brazilian construction company (Post, 2016).

DEFINING PHYSICAL DISABILITY AT THE NATIONAL LEVEL

Ecuador

In Ecuador, La Ley Orgánica de Discapacidades, Natural Law of Disabled Individuals, promotes the inclusion and security of individuals with disabilities in Ecuador. According to an October 2018 report by the Ministry of Public Health, 449,169 Ecuadorians were registered as having a disability. This excludes the number of individuals who have yet to register their disability (Ministerio de Salud Publico Ecuador, 2018).

The purpose of this Law is to ensure the prevention, timely detection, habilitation and rehabilitation of disability and guarantee the full validity, dissemination and exercise of the rights of persons with disabilities, established in the Constitution of the Republic, treaties and international instruments; as well as those that derive from related laws, with a gender, generational and intercultural focus... This Law protects Ecuadorian or foreign persons with disabilities who are in the Ecuadorian territory; as well as, to Ecuadorians abroad; his relatives within the fourth degree of consanguinity and second of affinity, his spouse, partner in de facto union and/or legal representative and public, semi-public and private non-profit legal persons, dedicated to the care, protection and care of the People with disabilities...The scope of application of this Law covers the public and private sectors. Persons with disabilities or disabling conditions are covered by this Law, as pertinent (Ley General de la Persona con Discapacidad, 2012, p. 6).

In Ecuador, a person with a disability is considered:

any person who, as a result of one or more physical, mental, intellectual or sensory deficiencies, independent of the cause, is permanently restricted in its biological, psychological and associative to exercise one or more essential activities of daily life, in the proportion established by the Regulation (Ley Orgánica de Discapacidades, 2012, p. 8).

Ecuador maintains el Registro Nacional de Personas con Discapacidad (a National Registry of Disabled Persons). La autoridad sanitaria (the National Health Authority), is responsible for maintaining the National Registry of Persons with Disabilities and Deficiency or Disabling Conditions. Additionally, public, semi-public, and private legal entities that are dedicated to providing care to individuals with disabilities or living conditions that are disabling, are legally bound to maintain a registry that will become part of the National Public Data System. These public, semi-public, and private entities must “maintain proper interconnection with the agencies of the public administration and private institution” in order to ensure that information is streamlined and transmitted in a timely manner (Ley Orgánica de Discapacidades, 2010, p. 25). Individuals are also administered a disability card that is transmitted through el Consejo Nacional para la Igualdad de Discapacidades (The National Council for the Equality of Disabled Individuals), CONADIS (Ley Orgánica de Discapacidades, 2010, p. 25).

In Ecuador, patients must find a doctor who is certified in evaluating disability. These doctors go through extra
courses and exams to be deemed eligible to evaluate disability. These certified medical officials work directly with el Ministerio de Salud Publico (the Ministry of Public Health) and are placed in varying cantons at local medical facilities and larger hospitals. Medical officials have a codified way of diagnosing disability - or they all follow the same book, “Valoración de las Situaciones de Menusvalia.” This book has charts and instructions detailing how medical officials should evaluate disability.

Disabilities are categorized as: Fisico (Physical), Motriz (Motor Skills), Auditivo (Ability to speak), Visual (Visual), and Intelectual o Mental (Intellectual or Mental). Once the doctor has made their assessment, they assign a percentage that is reflective of how disabled a patient is. The doctor will then register the disability through an online system monitored by The Ministry of Economic and Social Inclusion (MIES). MIES is directly connected with CONADIS, an agency responsible for processing disability cards. If patients are at a hospital with printing capabilities, patients will receive their card the same day as their appointment. If not, their card usually takes two days to process.

Peru

The situation is quite similar in Peru. In 2017, the National Institute of Statistics and Information conducted a census in which 1,637,407 people were identified with a disability in Peru (Instituto Nacional de Estadistica e Informatica, 2017). According to Law No. 29973 of Peru, individuals with disabilities have the same rights as the rest of the population. People with disabilities have protection against discrimination in employment and in public spaces. They can also receive benefits from the Ministry of Health that guarantees and promotes the entry of the disabled person into a system of universal insurance. In addition,

Social Health Insurance (ESSALUD) guarantees and promotes access of people with disabilities to ensure affordable health benefits, rehabilitation and support mechanisms, including home care, assistance staff, intermediate care facilities and residential centers, according to the needs of the insured (Ley General de la Persona con Discapacidad, 2012, p. 6).

The law states that the State of Peru is obliged to have specialized services and perform preventive actions according to the types of disabilities (Ley General de la Persona con Discapacidad, 2012, p. 7).

El Registro Nacional de la Personas con Discapacidad (National Registry of Disabled Persons) is a nationwide instrument used in Peru to register individuals who have a disability. This registration grants individuals the right to be recognized as having a disability, a recognition that makes individuals qualified to receive government aid. Individuals may also receive a disability card from a certified medical official. This card documents an individual's disability and may be presented at public and private institutions as recognition that the individual is protected under the law. More officially, an un certificado de discapacidad (Disability Certificate), is a legal medical document that certifies the condition of a person with a disability. It is granted by the health establishments of the Ministry of Health, Ministry of Defense, Ministry of the Interior, Social Health Insurance - EsSalud, INPE and authorized private entities (Ministerio De Salud Peru, 2016).

People with disabilities can be protected under the disability law if they have a disability certificate. Certification is in the form of a card. The process for obtaining the card is free, and includes evaluation, qualification, and certification (RESOLUCION MINISTERIAL, 2009). If people do not register their disability with the Ministry of Health, then they can not receive social protection, be considered for social health insurance, or apply for other benefits that the law promotes. In 2014, the National Council for the Integration of Persons with Disabilities (CONADIS) in Peru, a sector of the Ministry of Women and Vulnerable Populations, published a national survey that said of the 45,067 people with disabilities in Cusco, only 11.8% had a certified disability. 74.9% of individuals were not registered with CONADIS (Departamento de Cusco, 2014, p. 171). It was not until 2017 that the question was included in the census. This leaves the question, how many people have a disability but have not yet had it registered?

According to the Ministry of Health Peru, a person with disability is:

one who has one or more deficiencies evidenced by the significant loss of some of their physical, mental or sensory functions, which imply the decrease or absence of the ability to perform an activity within forms or margins considered normal limiting it in the performance of a role, function or exercise of activities and opportunities to participate equitably within society (RESOLUCION MINISTERIAL , 2009).

In Peru, individuals need to coordinate with the Municipal Office of Attention to Persons with Disabilities (OMAPED) to find a Traveling Disability Qualifying Brigade (BICAD) or a group of specialists who travel to evaluate, qualify, and certify their disability (Resolucion Ministerial, 2009). The evaluation process is a codified method where the doctor analyzes the capacity of the person. Doctors must submit their evaluations, through means of an online form that is more than 50 pages long, to the Ministry of Health. Individuals will be assigned a percentage that represents the gravity of their disability.
Disabilities are divided in three levels, low, moderate, and severe. Classifications are divided as follows: Física (Physical), Auditiva (Ability to Speak), Visual (Visual), Intelectual (Intellectual), and Psiquica (Psychological).

The Ministry of Health then transmits the information to CONADIS, where the process of transmitting a disability card begins. This process usually takes two to three months.

METHODOLOGY AND ETHICS

Methodology

**Ecuador**

My methodology differed somewhat between my work in Ecuador and Peru. In Ecuador, I had already conducted previous field research with Florida Atlantic University's Ethnographic Field School in a town I will refer to as San Migos. My fieldwork location was predetermined prior to the start of my field research. My pre-established contacts in the area, which included local government officials, medical professionals, leaders of non-governmental organizations, educators, and disabled individuals, were helpful in connecting me with local individuals to interview.

My research population was men and women of differing age groups who are currently living with a physical disability. For five weeks I investigated three age groups of adults as determined by the Ministry of Health in Ecuador.

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*Table 1. Research Population Ecuador*

My fieldwork also included interviews with local professionals working in various fields related to disability. In San Migos, this includes the doctor responsible for diagnosing disability in the canton of San Migos and four individuals working for organizations in support of disabled persons. I interviewed two educators from Ana Sol, a local public school for children with disabilities, as well as the directors of the local primary school, high school, and private school in San Migos.

In San Migos, a tape recorder was used to document interviews. This information was guarded by password on my computer and was analyzed in a field journal with pseudonyms used to protect the identity of interviewees. All interviews were conducted in Spanish and later transcribed into English.

**Peru**

In Peru I was bound by the requirement of my study abroad program, SIT Peru: Indigenous Peoples and Globalization. I utilized the help of my research advisor in Peru, Deisy Moscoso, to locate an appropriate location to carry out my field work.

I was connected with Asociación ARARIWA, a local non-profit organization with development projects across Peru. ARARIWA has an ongoing project aiding children with disabilities in a community three hours outside of Cusco. Already having pre-established contacts in the area, ARARIWA suggested that I conduct my research in an indigenous community that has a large population of

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*Table 2. Research Population Peru*
disabled persons and has a local OMAPED office. I will refer to this location under the pseudonym Rio Mar.

ARARIWA and OMAPED scheduled my interviews with local individuals with physical disabilities. These interviews were mainly done in Quechua, a language native to Ecuador. Jaime Huaman from ARARIWA and Carlos Garcia from OMAPED assisted my efforts in Rio Mar by acting as translators between myself and research participants. The initial translation was done from Quechua to Spanish and the interviews were later transcribed into English. In Rio Mar, a video camera was used to record interviews. This footage was taken with formal, written consent to produce a video documentary.

Due to the amount of time spent in each community-San Migos for 5 weeks, and Rio Mar for 4 days- the size of my research population in Ecuador greatly outnumbered my research population in Peru.

As in Ecuador, my research population in Peru were men and women of differing age groups who are currently living with a physical disability. I investigated three age groups of adults as determined by the Ministry of Health Peru.

Furthermore, I conducted research with two public school educators in Rio Mar who work specifically with children with disabilities. I also interviewed one doctor from the local clinic, or Centro de Salud de Rio Mar, who is qualified to diagnose disability, and two authorities working with organizations fighting for the rights of individuals with disabilities.

Ethics

All research was conducted under the advisement and approval of the George Washington University Institutional Review Board, 051841 “Diagnosing Physical Disability in Coastal Ecuador: The Policy and Practice of Disability.” Research conducted in Ecuador was approved prior to entrance in the field. In Peru, research was approved by SIT Peru’s internal Institutional Review Board by means equivalent to the George Washington University Institutional Review Board. The research conducted in Peru was later retroactively approved by the GW Institutional Review Board through a modification request.

Necessary precautions were taken to ensure the privacy of all individuals participating in my study. Working directly with a vulnerable population, individuals with physical disabilities, I have no written record of the names of individuals participating in my study, except for individuals who chose to be identified for my documentary in Rio Mar, Peru.

Verbal consent was acquired before the start of all interviews and was preceded by a detailed explanation of my project. A copy of the project description was provided to each participant. Interviews were taken in private spaces, the majority being in the homes of the interviewees, upon their invitation.

RELEVANCE OF THE STUDY

The findings presented in this study draw from and contribute to the social science literature on physical disability, particularly related to definitions and policies, services, and most importantly disabled peoples’ lived experiences, with specific reference to two case studies in rural, low-income communities.

Some studies, such as Mont (2007), have addressed cross-cultural patterns of physical disabilities. Mont has found inconsistencies in identifying disability on the global scale, as many countries rely on individuals to report their disability through census or surveys (Mont, 2007, pp. 1-35). Trotter et al. (2001) presents a model that attempts to create an international classification for disability that accounts for cross-cultural interpretations. However, this model tends to be a problem for some, due to the ever evolving nature of the rhetoric surrounding disability (Trotter II, Rehm, Chatterji, Room, & Ustun, 2001, p. 37).

Without a codified method for identifying disability, there is great variation in what functional limitations constitutes a disability, which leads to inaccurate data at the global scale. A related study by Prince et al. (2011), examined the relationship between physical impairments and dementia in low and middle income countries such as Peru. Chronic physical comorbidty is common in dementia. While some countries may denote this as a disability, others may record this physical impairment as a result of malnutrition and lack of treatment for dementia, and would not consider the individual to have a disability (Prince, et al., 2011, pp. 511-519). Imrie (2004) describes the shortcomings of the International Classification of Functioning, Disability and Health (ICF), as created by the World Health Organization, in failing to specify the nature of a disability. The paper argues for further clarification and development in defining the nature of an impairment and clarifying the implications of universalization as a principle for guiding disability policies (Imrie, 2004, pp. 287-305).

Several scholars have addressed the question of whether disability law and policy should be universally defined and applied. For example, Zola (1989) suggests that universal policy towards disability is in the best interest of an entire society. Zola states that recognizing individuals with disabilities as a minority pits them against the rest of the population in terms of their needs, wants, and rights. Further, social, medical, economic, and political impairments are not exclusive, but universal to individuals with disability. Therefore, an exclusive special needs approach to disability is a short-run approach (Zola, 1989, pp. 401-428).

Kanter (2003) acknowledges that more than 10% of the world’s population has a disability, and this number...
continues to grow as a result of war and violence, inadequate medical care, and natural and other disasters. A 1991 UN Report found that people with disabilities live a marginal life, deprived of their rights due to the deplorable conditions in which they live and the segregation they face from the rest of the world. Kanter continues to note how conditions of poverty have the potential to add to the risk of disability. The World Bank thereby called for the integration and economic participation of disabled individuals within society (Kanter, 2003, pp. 241-269).

Unfortunately, this integration has been overshadowed by the stigmas associated with disability. Zola reviews the universal stigmatization of disability, citing Disability Rag (1984), which expresses that individuals avoid using wheelchairs, even temporarily, because of its perceived stigma and association to frail individuals.

A study of college students in Manabi Province, Ecuador, (Macias, et al., 2018) found that while individuals may differ in social support and in how they contracted their disability, whether by birth or in an accident, the lack of resilience in an individual to cope and make due of their life serves as a potential obstacle in obtaining proper attention, care, and/or treatment (Diaz, Macias, Tarazona Meza, Bumnila Garcia, and Tola Bozada, 2018, pp. 1-8). Stuecher et al. (2000), analyzes how economic challenges can negatively impact the health, education, and welfare of individuals with disabilities in Ecuador. Often, children with disabilities are only identified with regard to their educational needs and not formally recognized as disabled. Special education centers have opened to provide opportunities for physical and intellectual growth as well as general education. However, these models may not prove to be sustainable due to the economic challenges faced by families with a disabled person (Stuecher & Suarez, 2000, pp. 289-298).

Exploring the lived experience of physical disability and stigma are key to this paper. Stigma and social exclusion emerge as prevalent themes. In their cross-country study of Ecuador, Ethiopia, and Kenya, DeBoer et al. (2008) found that disabled persons with epilepsy are disadvantaged in their ability to maintain relationships and participate in society as students and part of the workforce. In Peru, less than 25% of adults with disabilities are gainfully employed, and 51.4% of disabled children do not attend school (Campoverde, 2003, p. 5; Redko & Hunt, 2015, p. 24).

Given their tendency to focus on local populations, several sociocultural anthropologists have provided insights into the lived experiences of those with various physical disabilities, including blindness. Ingstad and Whyte offer some of the earliest studies in sociocultural anthropology of disability in their 1995 book (Ingstad & Whyte, 1995). Staples et al. (2016) confirms that there are relatively few ethnographic studies on disability. Disability studies tend to document and analyze disability, but fail to configure disability cross-culturally. Across several decades, many anthropologists have shifted away from engaging with this topic due to disinterest or finding it irrelevant. Staples criticizes Ingstad and Whyte for failing to reference the works related to disability studies.

The capacity of anthropology to understand disability cross-culturally and the “deep hanging out” (Staples & Mehrotra, 2016, pp. 35-50) of participant observation allows us to situate a complex web of identities, social relations, and historical circumstances of individuals with disability. I should note that “deep hanging out”, or rather, increased time spent within a given community, can lead to emotional participation that begins to blur the lines of research and personal connection or relationships to the given community in which you are living. Fabos (1999) recalls her dilemma in delineating boundaries between research and personal life (Fabos, 1999, pp. 98-118).

Shuttleworth (2004) credits Joan Ablon to the establishment of an anthropological focus on social stigma. Shuttleworth says that Ablon’s research contributed to, if not established, the notion of stigma in an attempt to understand community despite physical differences (Shuttleworth, 2004, pp. 139-161). Mirana-Galarza (2015) underpins this stigma as a result of the lack of understanding of disability among Ecuadorian families and calls for more ethnographic research to understand the impact of global definitions on disabled families (Miranda-Galarza, 2016, pp. 260-288).

I have found few studies about the lived experiences of those with physical disabilities in Ecuador and Peru that would be more closely related to this paper. Rattray (2013), however, conducted an ethnographic field project in the highlands of Ecuador where he attempted to understand how cultural differences of bodily difference and spatial forms of exclusion shape the marginalization of people with disabilities. His work was informative and the most relevant to mine in terms of portraying lived experiences of people with physical disabilities. Within the Ecuadorian social system, individuals with disabilities struggle with their ability to access medical care, jobs, and an education because of the spatial order of an urban neighborhood, such as Cuenca (Rattray, 2013). More often than not, individuals in Ecuador and Peru encounter difficulties with public transportation in urban areas where they must seek alternative ways of entering and maneuvering through inaccessible spaces. As I will explore later, this inaccessibility is an enormous barrier in individuals’ ability to register their disability and receive protection from the government.

Rojas (2012) published an article about the inclusion of people with disabilities in Peru. However, terminology associated with disability is constantly evolving. During my field work both in Ecuador and Peru, I was told that the term discapacitado/a (disabled person) is offensive and outdated, and that instead individuals are personas con discapacidades (people with disabilities). It is important to note that, although published in 2012, “La
situción de los discapacitados en el Perú: Exclusión/
inclusión de las personas con discapacidad,” repeatedly
uses outdated references when addressing people with
disabilities (Rojas, 2012, pp. 242-259). This shows how
quickly terminology and knowledge fluctuates among
these groups of individuals.

According to Rojas, vulnerable populations in Peru,
such as young children, women, older populations,
and individuals with disability, are highly excluded
in the Peruvian social system. There are economic
incentives that the government offers that allow
vulnerable populations to live a life more closely related
to non-vulnerable populations, but unfortunately these
incentives have not been implemented fairly. According
to Rojas, 43% of people with disabilities live with less
than $1 per day. Keeping this in mind, individuals’ access
to medical and political protection may largely be based
on economic ability to access resources (Rojas, 2012, pp.
242-259).

In summary, the social science literature on physical
disability provides some insights into the topics of the
worldwide distribution of physical disabilities, the laws
and policies addressing it, and the lived experiences
of people with physical disabilities. However, there is
little research on disability in low-income countries,
and especially on the lived experiences of people with
physical disabilities in those countries. This study
therefore provides a comprehensive, cross-cultural
approach to understanding disability in such populations.
This literature will contribute by identifying policy
gaps for those with disabilities, stigmas surrounding
individuals with disabilities, and the ability of those
in rural communities to apply for disability support.
It is important to raise awareness for marginalized
communities, as they are often those who most need
support, yet are not receiving it. The paper recognizes
the needs of people with disabilities in both political and
cultural contexts and the additional difficulties they face
in two rural communities, one in Ecuador and one in Peru.

PURPOSE OF THE STUDY

Given the scarce sociocultural academic research on
the lived experiences of people with physical disabilities
in low-income countries, I have yet to find studies that
address state processes in labeling individuals as disabled.
Individuals are marginalized in rural zones due to their
inability to register their disability. This marginalization
contributes to larger forms of systemic oppression.
Without the registration, individuals are not entitled to
receive protection under certain disability laws, because
this law only applies to individuals who are registered as
having a disability. The principle question I will address
is: What types of barriers are present in rural zones
of Ecuador and Peru that limit disabled people from
receiving protection under their given laws?

By living and conducting anthropological fieldwork
within two communities, whose names will be protected
based on recommendations of the George Washington
University Institutional Review Board, I will be able to:
• Identify systemic limitations in receiving political
recognition for disabled individuals
• Analyze how geographic location, economic situation,
familial support, and societal norms affect the ability
to live as an individual with a recognized disability
• Analyze how cultural beliefs affect the lives of
individuals with disabilities

My research will be presented in the way I conducted
my fieldwork. I will first present my findings on Ecuador
to determine the barriers that limit individuals from
receiving protection under given Ecuadorian laws. I will
then explore the situation in Peru to understand how they
have come to practice disability policies and how they are
working towards the inclusion of disabled individuals in
mainstream society. Finally, I will conclude with a brief
comparative analysis on Ecuador and Peru and how each
country is influencing the other as models for disability
practices in Latin America.

CHAPTER II: CASE STUDY: SAN MIGOS,
ECUADOR

In this chapter I describe the context of my fieldwork
in a small, rural town in Ecuador and my research findings
about policies and experiences of physical disability
there. I was fortunate to be able to spend the summers of
2017 and 2018 there.

REFLECTIONS ON FIELDWORK IN SAN MIGOS

In my first fieldwork experience in San Migos, I lived
there as a visiting student for 6 weeks. I was a participant
in an Anthropological Field School run by Dr. Michael
Harris and Professor Valentina Martinez from Florida
Atlantic University. For 21 years, Harris and Martinez
have conducted a summer field school for students of
ethnography and archeology to live in the community and
conduct short-term research projects, with permission
from the community.

The town is familiar with outside researchers and
welcomes them, as San Migos has been a site for
archaeological projects for years. Archaeologist Presley
Norton established an archaeological museum in San
Migos and has contributed greatly to the prestige of the
town as a tourist hub and archeological land mine.

The town benefits economically during the weeks of
the anthropology field school because it brings an influx
of money to local tiendas (stores) and families who host
visitors and are paid through the program. The field
school also creates jobs - four local women cook three
meals a day for the students at the Museo, Norton's
archeological museum which also serves as a hostel for
the field school. Dr. Harris and the local president of
the Comuna, the local governing body responsible for overseeing land negotiations, as well as operations at the Museo, manage the network of individuals employed by the field school to ensure that no family is the primary receiver of all economic gain.

THE TOWN OF SAN MIGOS

How would I describe San Migos in three words? First, **tranquillo** (calm) is the word of choice for locals and my fellow researchers for this small, coastal fishing village of around 2,000 people. As I will describe in this section, it is a town based around **familia** (family), **chisme** (jokes) y **chiste** (gossip).

In my two visits, I found that in general, people are willing to help, feed, and support one another. My fellow students and I often commented that everyone in San Migos seemed to be related. For example, I taught English at a local high school and my class roster had some variation of last names. Individuals will take the surnames of both their mother and father. It would be common to see “Macias Pincay” or “Pincay Aguilar”.

Long standing family histories and ties underlie the town. It has been built and maintained by people who treasure and cherish family, friends, and community. Although these individuals do not identify as being indigenous, they are natives to Ecuador, whose families have been in San Migos for centuries. For the few individuals without family, such as my friend Zoilo, who passed away shortly after my last visit, there is no question that someone in town will be ready and willing to offer him a seat at the dinner table or play him in a game of cards.

It was not until my second visit to San Migos in 2018 that I realized the depth and degree of tensions that existed between and within families. My first year in San Migos, I was blinded to the potential for difference, or the potential that the interfunctions of a town and relationships within it can differ in the presence of foreigners. I was overwhelmed by the kindness that everyone showed me, and I was shocked that everyone seemed to be friends. My inability to see this could have been because I was living bounded in the walls of Museo San Migos. It could have been that my Spanish skills were not as advanced at the time and there was a disconnect between what I wanted to know from locals and what I could actually ask. I was very much a student, going into this town for a study abroad experience, and to practice being a researcher.

My second visit to San Migos was very different, and I began realizing the potential for difference. In 2018, I was an independent researcher instead of being a student. Unlike my 2017 visit, I spent more time engaging with locals and I rented a home within the community. By living within the community and through more advanced conversations with locals, I realized that there is a large potential for difference among a community when researchers enter and disrupt normal social patterns.

According to locals, the members of the town normally keep to themselves and remain within their friend and family groups. There is no intermixing and individuals do habitual daily tasks. The potential for difference occurs when a community shifts in terms of social dynamics with the entrance of foreigners, giving foreign researchers a somewhat false impression of the true interworking of a society.

Town Demographics

As complex as relationships can be within San Migos and as quickly as news spreads around this town, laughter erupts from the majority of the 2,600 inhabitants. Walking during the daytime along the malecon, the sidewalk directly parallel to the sea, you hear the laughter of forty or fifty-year-old men relaxing before heading out to sea. In the evening you hear the chatter and laughter of younger children playing soccer and volleyball in the street. The friendship built in this community is fueled by chiste as every other breath of a conversation seems to be a spurt of laughter.

I remember being taken back by the grey clouds, light mist, and somewhat cool weather. The town seemed to be closed and there was not much movement. I took a walk around town where I observed ten men pulling a boat with a red bottom, white sides, and blue interior, onto the sand of the beach. It looked as if they were playing tug of war with the middle sized boat, or fibra.

Looking into the ocean, there were about 90-100 fishing boats consisting of three different sizes - barcos (the largest), fibras (midsized), and bongos (smallest). The fishing industry is the main source of income for families in San Migos. Almost every household will have or has had a family member who is a fisher. Unfortunately, the fishing industry is too inconsistent to promote livelihood and security for some families, especially if the family member works on a smaller boat and relies solely on fishing for their income. Other families may run tourism agencies that will take tourists whale watching or snorkeling to an island that is a five-minute boat ride from the mainland, or local tiendas where they sell snacks and household products. While the field school offers an annual economic boost, for the rest of the year families depend on their own agriculture such as poultry and vegetables.

There is a clear local gender division of labor, the fishing industry is dominated by men, whereas women are mainly involved in the domestic domain, taking care of children and carrying out household duties. Most men leave around 6pm every evening and return in the early morning with fish that is either consumed by their household, given to friends, or sold at markets in Guayaquil, a larger town about 300 miles away by car.

Close kin typically live together in a nuclear or
extended household, but also have wider ties in the town. It is common to find these families living within the same block. If one needed to get the attention of an extended family member across the street or in the house next door, a simple whistle would suffice, and every person has a distinct whistle. For example, as one woman explained to me, her husband has a specific whistle to call her and a different one to call his best friend, or mother. This method is more efficient for a town with spotty cell phone coverage and minimal internet.

RESULTS

Disability Narratives

I had an accident. I was working in the sierra near Quito because there were not that many jobs here and I wanted to work there because there was more opportunity. I worked there for 2.5 years, but then I had to come back. I was with a friend and we went out and were passing time and my friend was driving and he wrecked the motorcycle and he died. I lost my leg. I wanted to die. I was very sad. My life changed. The doctors had to motivate me to keep living and I had to live for my daughters because I was losing faith. I really wanted my daughters. They were my only hope to keep living - I want to be there to see get married. I want them to be with me and see me. They are my reason to live.

-Jonny, July 2018

I often saw Jonny lounging in a hammock in the center of town. During my first visit to San Migos, I would pass him day to day and we would exchange a simple greeting. But there was a sadness that surrounded his body, a sadness that I felt uncomfortable approaching. It was clear that something traumatic had happened to Jonny - he was missing a leg. Yet that did not stop him from walking around town with his crutches, passing time with his friends, or being surprised by his youngest daughter looking for money for ice cream.

Belen and Danny, my friends and research assistants, played vital roles in my research in San Migos. Both Belen and Danny had been working for Dr. Harris for over eight years after asking if he would be willing to hire them as field assistants. Like many individuals involved with the field school, Belen and Danny are paid for their work. I used part of my grant to pay for their help in the field.

They accompanied me to homes of individuals who they thought would be willing to talk to me about their disability and introduced me to those I would have never met. For example, Belen suggested that I speak to Jonny during my second year. I remember being hesitant at first because there was a cloud that seemed to loom over him whenever I would see him. I realized upon later reflection that this perception was likely influenced by my personal bias, my way of stigmatizing disability and individuals living with disability.

Jonny was warm and welcoming. It turned out he is the ex-husband of one of my friends in the town, something that she had never mentioned to me in 2017. He is also the father of three daughters, one who I knew well. It was interesting that I did not know about the familial connection. This gap in my knowledge prompted me to question familial ties and how support is necessary following a disabling trauma for a family member.

Nonetheless, I was fortunate in that, in 2018, Jonny shared with me his experiences of what happened to be the 4th anniversary of his accident. Something was raw about how Jonny described what happened when he lost his leg. He spoke slowly, taking pauses, his shoulders were hunched, eyes watery, but not crying. Although the town was aware that both Jonny and the driver were intoxicated at the time of the accident, Jonny never confirmed this himself. I had the feeling that he still holds a lot of internal pain and shame based on the inflections of his voice and rubbing of his eyes. He said that he did not understand why his friend died and he did not. He went through heavy moments of depression and suicidal thoughts after the accident, but eventually he found something to live for.

As I noted earlier, everyone, or almost everyone, in San Migos has kinship ties, that are more or less close with everyone else. I could probably connect all my case studies through familial ties. For example, another woman I met, Somona, was the mother of the man who died in the accident with Jonny. Now in her late 70’s, Somona was disabled in an accident nearly thirty years ago.

I was normal before. There was one time when I was at the corner of the highway and I wanted to go buy something. A car came and I wanted to buy the food that they were selling- so I went to go buy the food and I told him I would pay later but then a car from Machalia came- they passed two times and they were drunk. They passed around the curve and they crashed into the car that was selling fruit. Two of my kids were with me. There were so many kids around. So many kids. I told the [medics] to attend to the kids before me. So she attended to them first.

-Somona, July 2018

Somona recalls an accident that had left her knee forever damaged, even after surgery, and had killed one of her other sons. There was an enormous amount of pain in Somona’s eyes when she discussed how automobile accidents had taken the lives of two of her sons and left her handicapped. She now uses a slab of wood as a crutch as she has no formal cane. As she recalled the accident, she wiped away tears as she pointed to pictures of her sons hanging on the wall.

Car accidents are a common thread in disability stories in San Migos. Jonny’s ex-mother in law was involved in
They still deal with pain on a daily basis, but the two of them were able to confidently recollect the accident and deal with the pain associated from two physical disabilities. Senora Laura Marie, who I consider to be one of my closest friends and mother-like figures in San Migos, frequently recalls living with her discapacidad (disability), which she developed at the age of three after having contracted polio. She remembers having a number of treatments that were supposed to help her regain mobility in her legs, but she still remained disabled from the pelvis down, unable to walk without crutches. I will discuss her story in greater detail later.

In addition to my two research assistants, my access to research participants was greatly facilitated by Freddy Pincay, the former President of Parroquia San Migos, the governmental branch that reports directly to the Ecuadorian government. Freddy, who lives in San Migos and now works with his organization, Unidad San Migos, introduced me to several disabled people who were participants in my study. As a community leader, Freddy has begun mobilizing local individuals with disabilities to demand access to medical attention and financial support. He is fighting to ensure that the government recognizes individuals with disabilities as equal members of society.

Freddy wanted to ensure that I learned about local people's experience of disability from a variety of perspectives. He wanted me to have a well-rounded view of the lives of physically disabled people in San Migos and how their situation as a rural zone constrained their access to government aid. For example, he took me to the home of a man who was no longer able to talk effectively because of an aneurysm that ruptured. Although mentally handicapped as well, he is given the label of physically disabled because he is bed ridden and unable to move. His mother spoke with me on his behalf, because he was not able to give consent and was not able to hold or process conversations.

His head was inflating and so they brought him to Puerto Viejo to attend to his problem. We were there for 8 days. The doctors had to make a decision quickly, and so we had a very quick family meeting to figure out how to pay to get him to Guayaquil quickly so he wouldn't die...

...During the operation he lost feeling, he lost the ability to move...

...He had another operation to remove a water-like tumor that was growing in his head - he was losing a lot of liquid from his head. They had to remove parts of his head. It was like deflating a balloon...

...A doctor who was a specialist helped him during the operation. My son couldn't talk. He could only stare blankly...

...The doctor told me that he would have problems with his memory. He couldn't remember his daughters. We were in the hospital for 3 months. The doctors would visit us and the other doctor said that he was absolutely non responsive. I said to him, “I am your mom,” and he still didn't understand...

...For three months we were there and we were just waiting for him to get better - for three months in the
intensive care unit.

-Ana, July 2018

His mother was in tears, crying as she sat at the foot of her son’s bed, holding on to his foot. Her body was hunched over and she was rocking back and forth with one hand on her face, wiping back her sadness. Three little girls were running in and out of the room, curious as to who the strangers were in their father’s room. Their father lay there, paralyzed. He asked his mother, repeatedly, what he could eat, but his mother was too struck with sadness to respond. I will later explore how his situation and disability has not only left him paralyzed, but has caused his friends and loved one to abandon him. His mother’s pain was coming from a place of sadness as she saw her son lying in bed, helpless, but also came from pain as she realized no one else was around to take care of her son once she was gone.

Process of Registering a Disability

Before going into the barriers faced by individuals in certifying their disability, I must first explain the process to obtain a certification. A major goal of my research was trying to understand how one individual could be considered more or less disabled than another. What is the process? Is there a table that differentiates symptoms and indicates the correct numeration?

As mentioned previously, those who have been diagnosed with a disability are eligible to apply for a disability card that provides disabled people, regardless of age, with an identification marker to receive health benefits and financial aid from the government. Carla Rivera explained the process for obtaining a card.

The process for a person to obtain a card - if you are born with it, you are given it right away. There are medical doctors to qualify cards. Doctor Havillas is the person in our canton who is qualified, people will go to him and he will decide what percentage to give, what the disability is, etcetera....

...There is only one doctor that has the ability to qualify people for their disabilities. He is the only person allowed and trained to do so. In Ecuador there are different doctors for people in different places. There are many doctors who are qualified to do so in Ecuador...

...When people go to the doctor, the doctor assigns a percentage but they don’t always accept it because sometimes the people will want a higher percentage.

- Carla Rivera, July 2018

Although the process for obtaining a card seems somewhat regulated, multiple interviews with different people indicated that the process is much more difficult than it sounds. The medical doctors who are qualified to diagnose disabilities follow a list of qualifiers and use that list to designate percentages. From what I understand, if a family has enough money to travel to other places to receive a card, they can receive a second opinion from another doctor in their province. Once the doctor assigns a percentage to a patient, the patient must then apply for their card. The process can take up to 6 months to a year.

Evaluation Process:

1. Individuals in the canton call to schedule an appointment with Dr. Havillas. They can either go to the local clinic where he works, or he can make house calls, but they must have transportation to pick him up.
2. Dr. Havillas evaluates whether or not an individual is considered disabled. He uses his book “Valoración de las Situaciones de Minusvalía” (“Diagnosing Situations of Deficiencies”).
3. Dr. Havillas refers to recommendations from specialists and his own diagnosis to decide if individuals qualify as being disabled.
4. Dr. Havillas gives the certification to the patient to bring to Jipijapa, a nearby city, to receive an official card. If the patient can’t travel, he will transmit the information to CONADIS over the computer. However, MIES is slowly starting to become the main actor for processing cards.
5. The card will be printed in Jipijapa and will be delivered to the local clinic within 3 days. If the patient can travel to Jipijapa, they can get it on the same day.

Systematic Method among Medical Professionals

Dr. Havillas believes that the system is fair and equitable to all people. All medical doctors that are responsible for diagnosing disability must follow the same charts and book – there is very little room for interpretation. These medical doctors must complete an extra five years of training before they are considered qualified to diagnose disability. In their practice, they must evaluate 30 patients to decide whether or not the patient should receive a disability card.

We have a book – it is an international book that helps us diagnose disability. There is also this summary that shows the range of disability. In their practice, they must evaluate 30 patients to decide whether or not the patient should receive a disability card.

...All doctors in Ecuador use the books to diagnose disability. If you are amputated it is a certain percentage. There are ranges of disability and you have to have at least 30% disability to receive a card – if you need to use a crutch or something else to move to function....

...There is leve, moderado, and grave (slightly disabled, moderate, greatly)....

...I am very busy because I am also a generalist. Not only disability. Other things, too, but we don't need another doctor...
...in the Canton of San Migos there are about 350 people with disabilities. There are an equal amount of women and men. 
-Dr. Havillas, July 2018

There are only 20 doctors responsible for diagnosing disability in Manabi Province. A few years prior, there were only three. Due to the increase in medical staff, Dr. Havillas believes that the system is highly accessible for individuals. As a doctor, he finds himself to be available and willing to help individuals with disabilities as soon as they call him. He says that the transmission of information from consultation to certification is fast and easy. Dr. Havillas will offer to take a photo of the patient, send it over WhatsApp, and then the office in Jipijapa will transmit the information quickly.

Dr. Havillas finds it absolutely vital that individuals have a disability card. He notes that the majority of his patients are not embarrassed by their disability, but instead are looking for financial assistance from the government and need a disability card in order to receive it.

It is necessary that people have a card because they will receive a government stipend. They receive government assistance. People are not embarrassed about their disability because they want a card. They will do all they can to receive a card but sometimes they just don’t qualify. There is no corruption with the system. The process is more complicated because I have to look and figure out if the person qualifies. I have a huge responsibility to ensure that the person has a disability. Because people receive a lot of help if they have a disability. They can get a new house if they have 40% or more they qualify. 
-Dr. Havillas, July 2018

According to Dr. Havillas, Ecuador has encouraged countries such as Bolivia, Paraguay, and Peru to follow similar classification systems that will provide support to individuals with disability. He nonetheless sees the flaws in the system that patients in Ecuador perceive as well.

An Inequitable System: Limitations in the Process of Registering a Disability

Unfortunately, individuals in rural communities in Ecuador are disenfranchised from their ability to register a disability due to geographic seclusion, lack of knowledge “about” the process, financial hardship, and lack of familial support.

Geographic Situation

As discussed previously, individuals in the Canton of San Migos are guaranteed a free consultation from Dr. Havillas. Dr. Havillas has an office located in the middle of the canton, but individuals still have trouble making it to his office. For individuals with physical disabilities, it becomes difficult to use transportation because they must lay flat, or they require large pieces of equipment, such as a wheelchair.

Luckily for them, Dr. Havillas will make house calls, but these individuals must provide him with transportation. Unfortunately, within the canton, which is a rural zone, there is no way of finding specific homes by using Google Maps or other navigation applications. Individuals do not have specific addresses and therefore it is necessary that an individual pick up Dr. Havillas so he is not searching for an individual for hours on end.

I accompanied Dr. Havillas as he went to a house call for an elderly woman. This woman waited months for him to finally come to her home. The delay was due to his need for medical records and recommendations from other specialists, as well as the need of the family to locate transportation.

Dr. Havillas, his assistant, Danny, two family members of the patient, and myself rode in a pickup truck to travel for 30 minutes to get from the clinic to the patient’s home. Dr. Havillas traded his white lab coat for a navy vest and he had his books in hand that help him determine whether or not the patient is disabled.

The patient laid still in her bed – she could not sit up or eat. She was in her 70's, had diabetes, and had suffered from a fall that left her bed ridden. The woman had fractured two sides of her hips and was not able to support her own weight, so she would have to lay in bed for the majority of her days. Her family said that they were no longer able to work because they were busy caring for their mother. The work that they could do as fishers could support the cost of pills or the cost of surgery, which would be $400. Dr. Havillas explained to the family that diet could largely impact her recovery and be an indication of strength, or lack thereof. He addressed his concerns with her not having much movement and said that her condition was worsening because the family is not exercising her.

As the woman lay there helplessly, her children stood around her with tears forming in their eyes. Dr. Havillas told them that she does not qualify as being disabled because she is an older woman whose accident caused her disability, and that there is a way to fix it, through surgery, but the family has not pursued that option.

Once the consultation concluded, my companions and I returned to the pickup truck and drove back to the clinic. For this family in particular, their geographic situation seriously limits their consultations with other medical professionals. Some individuals, such as Freddy Pincay, have had the opportunity to travel to nearby cantons to receive diagnoses from other doctors. Unfortunately, due to the immobility of this woman, it will not be possible to pursue a second opinion. Dr. Havillas is the only professional responsible for making house calls to where
this woman lives, and she is not located in a place where she could easily be transported to a clinic.

**Frustrations with Designated Medical Professionals**

Many individuals have expressed their dissatisfaction with Dr. Havillas. Some people have said that they received a lower percentage from Dr. Havillas, but then traveled to Jipijapa and received a few percentage points higher. These points were not enough for the patient to qualify for the next level of government stipend, but it was enough for the patient to feel validated and equal. Others have said that Dr. Havillas has been helpful, that he frequents San Migos to check on certain individuals, and has provided a fair percentage to patients.

According to Freddy Pincay, most individuals are waiting and hoping that one day Dr. Havillas will come around to help them. Alberto, who went blind at age 60 after an open heart procedure, has lost hope and does not know what the future holds.

The constitution guarantees equality for all people and at certain clinics they accept the insurance. There is more help at the national level. When I went to the local clinic to ask for help, a lot of times I don’t receive help because the model is changing. I have to have a meeting. But to do that, I have to call... ...In a small town, in the Parroquia, we are not receiving the same services as bigger cities. The attention that you receive in bigger cities is much better... ...Everything is difficult, when I try to leave, when I eat, when I have to bathe. I haven’t accepted my disability. I am still fighting... ...But how can I be? I am not yet dead. My body is fine. The feeling is worse than being dead. Now I can feel more sensitive. I can sense more for my family. I feel useless. I can’t do what I want or what I need to do... ...Rafael Correa and Lenin Moreno have been very helpful for changing policy in the Republic of Ecuador... ...But to be alone, to be in the dark, without anyone to help me. It is depressing and it is hard. No one can help me. There is no one to help.

- Alberto, July 2018.

**Economic Ability**

Financial barriers proved to be an ongoing problem amongst participants in my study. Freddy Pincay, the former president of the Parroquia and leader of United San Migos, shared that when he was president of the Parroquia, he coordinated a system to speed up the process of obtaining a card. From his own experience, he traveled more than three times to cities that were about two hours away, trying to find other doctors that could diagnose and assign percentages. Not all families have the ability to travel, as travel can be very difficult and expensive. For that reason, he coordinated with those who needed cards, giving them lodging and food so that they could receive a diagnosis and then apply for a card.

According to Senora Laura Marie, the cost of obtaining a card is free because all people deserve the right to a diagnosis.

We deserve to have a life with respect. We deserve education, a calm life, these are the rights that we have. We have privilege. For example, if a person can’t hear or talk or walk – they have the right to a diagnosis. –Senora Laura Marie, July 2018

In reality, there is a gap in the way that individuals receive a diagnosis. The system is not equitable for those in rural zones, and therefore these individuals continue to be treated as second class beings. For many patients, Dr. Havillas first requires that they visit a specialist who will give a preliminary diagnosis. Dr. Havillas will then use these recommendations as a factor in considering if an individual does in fact have a disability. Seeing a specialist is often expensive, requires travel to a city, and takes individuals away from their kids and or jobs. Many times, it is financially irresponsible or impossible to schedule a meeting with a specialist because the process of finding and obtaining a meeting with the right person can take months.

**Familial Situation and Knowledge of Process as a Barrier to Registration**

For one family, my explanation of how to obtain a disability card for their father was the most detailed information they had ever received. While other individuals with disabilities do not have family to help them with the process, completely. Familial support is helpful in a variety of ways. For some, the support of family is attached to the means necessary to persevere in wake of an accident that leads to a life-altering disability. For others, it is the knowledge and financial investment from family members that allows for rehabilitation and access to medical professionals, and even an education. Interviewing individuals with disabilities also meant interviewing family members who are the caretakers for these individuals.

Jonny mentioned that he would have probably ended his life if not for his ex-wife. Although their relationship was severed at the time of the accident, Jonny mentioned that his ex-wife, Carolina, stayed with him in the hospital for three months, helped him relearn how to walk and use crutches. He recalls how amazing she was and how her motivation and support was a reminder of his need to persevere for their daughters.

For others, family members serve as the individuals who actively seek rehabilitation and medical doctors who are certified in diagnosing disability and assigning
percentages for individuals’ disability. I was able to speak frankly with three daughters and the wife of Luis, an individual who has trouble walking because of tumors that were growing in his knees. These tumors have since been removed, but he is left with a limp and severe pain. These women care for their father and are trying their best to learn about different medical doctors who have the potential to help their father as he continues working.

Senora Laura Marie recalls how helpful her family was when she was a young girl in Guayaquil. She remembers being lucky that her family had the ability to move to Guayaquil where she would receive treatments for her disability. She remembers being in therapeutic pools where her family would watch through a window nearby. She recalls how her siblings, who were very close in age, helped her assimilate with classmates and would take her to parties, even though she did not have the ability to dance or participate.

Once she reached adulthood, Laura Marie would live in Guayaquil and San Migos, depending on her father's work schedule. Laura Marie eventually found out that she was pregnant at 21 years old, relatively older compared to other mothers in San Migos.

I was 21 years old when I had Pedro. It was difficult. It was hard later to carry the baby. I fell in the museum on the cement to go to the bathroom—I was walking with another friend and we fell. I was 2 months pregnant. The doctor told me I needed to be careful because I was small...

...I had to make the decision to have the baby or not have the baby, because I also wanted to work and because the doctors told me it was dangerous with my condition. I decided to have the kid. I continued working— but I had to be careful....

...The baby was not at fault.
~Laura Marie, July 2018

Laura Marie told me the story of having to choose whether or not to give birth to her son, Pedro. Pedro sat in the room as she told this story and his face was frozen, actively listening to what his mother was saying. She thinks back to having had to make that decision and how happy she is that she did not abort the baby.

She is very grateful for how helpful her husband, who is the brother of Pedro’s father, and Pedro have been in helping her walk through town or helping her complete tasks, such as cooking and cleaning, around the house. She walks with crutches and has a hard time moving through town if the terrain is wet or if she has a lot of things to carry. At one point I remember Pedro, her son, leaving lunch (he was one of my good friends), to assist his mom to ensure she could adequately make her way to a community support meeting for individuals with disability. She made continuous mentions of her gratitude towards her spouse and son for helping her, because without them she would have a much harder time.

Other cases require that family members be present to help their family members at any and all hours of the day. For the gentleman with the aneurism, his mother was crying at the thought of who would have to take care of her son once she no longer could. For family members caring for individuals with autism and other mental disabilities, the stakes become higher.

(Crying) I still think about who will care for my son if one day I die. I really don't know to be honest. It has to be someone with a lot of love for my son. It has to be someone who has the patience to attend to my son. Because sometimes I have to use diapers with him, sometimes I have to bathe him. There are a lot of things I have to do and a lot of things he has to have help with. It is hard. And he gets annoyed.
~Denise, June 2018

Sisters of Ximena, a young girl with Down syndrome, mentioned how right now their mother is her caretaker, but that it will likely be them one their mother passes away. However, they are still worried about what this means for their sister.

There are 10 years between me and my sister. My sister is more accustomed to my mom - I left and went somewhere when I was young so now my sister is more accustomed to my mom. And my sister would go everywhere with my mom so now she doesn't prefer to be with us...

...If something happens, I assume my sister will stay with us. She probably won't understand what happened but she will also probably cry a lot.
~Juliana, June 2018

Familial support is a large determinant in the ability of an individual with a disability to continue living a fruitful life with government, medical, and educational aid that makes them equal to their able-bodied counterparts. Freddy Pincay brought me to the house of an older man who suffered from a stroke and is now left with minimal movement in half of his body. This man has 12 children, but none of them have been present to care for their father. According to Freddy, it is a custom, somewhat expected and required, that children care for their parents in Ecuador, especially in San Migos. According to Pincay, this man will not receive help in the form of government monetary assistance until he has caretakers. This older man sat outside of his house among three stray dogs. He sat hunched over, unable to move or communicate. He had a gash on his head and smelt like a mixture of urine and an unbathed body.

Walking inside his home, I saw that a neighbor was washing some of his clothing. She explained how sometimes he has nothing to eat, he has fallen multiple
times and has no one with him to care for him or support him. It made me think: what did this man do to his children that would put him in a situation where he was essentially rotting away? Regardless, it was such a notable difference in those who have familial support and those who do not. Generally speaking, those without family to support them do not have the slightest knowledge of how to register their disability and apply for financial aid from the government. On a smaller scale, familial and household levels, family has the ability to help maintain the personal well-being of their family members with disabilities. Although it is hard work, family can be a crucial determinant in the livelihood and future of individuals with disability.

Inability to register disability due to barriers associated with geographic seclusion, financial constraints, familial support, and lack of knowledge in the process are real and persistent among individuals in rural zones. Without registering their disability, these individuals are excluded from the possibility of receiving support and protection from the government.

ANALYSIS

Political Support for the Inclusion and Protection of Individuals with Disabilities

Once the state has identified and registered an individual as having a disability, they are entitled to certain laws that attempt to make them equal to able-bodied individuals. Equity is achieved through inclusion laws in school, stipends to cover medical bills and care, and guaranteed ease of access to public and private spaces.

Although Ecuador is an exemplary model for Latin America in their inclusion of disabled individuals in public and private spaces, the cultural tendencies, geographic location, and lack of general public knowledge of the Law of Disability lessens the likelihood that these individuals will receive the protections stated in the law.

Statistics on Disabled Population according to Ecuadorian Government

Ecuador has an impressive online system that monitors the number of individuals who have registered their disability and how many people are reported as having a disability. The online system is public record and is regularly updated by CONADIS with the information provided to them from the Ministry of Public Health. This development allows anyone to see disability data based on province, canton, gender (LGBTI included), percentage disabled, age, and type of disability. It truly shows how Ecuador places a strong emphasis on policy and knowledge supporting disability (Ministerio de Salud Publico Ecuador, 2018).

There are currently 357 individuals between the ages of 18–65+ who have registered themselves as having either a physical or visual disability. The majority of individuals who have registered their disability are adults. Only 114 of these individuals have qualified for a government financial stipend. Depending on a multitude of factors, such as type of disability, age, and socioeconomic situation, patients will be considered for a specific financial stipend. Of the 357 individuals with disability, only 35 are employed.

Financial Assistance for Individuals with Disabilities

The Ecuadorian government has recognized the importance of individuals with disability and has tried their best to ensure that individuals with disability are living a life that makes them equal to their able-bodied counterparts.

Once a person is diagnosed with a disability and given a percentage, they must register at the national level and the state will decide what benefits the person will receive. According to a law passed by the Ecuadorian government, if a disabled person has a card and is registered in the National Registry, they are considered as an equal person to those who do not have a disability. In order to make this equality become reality, individuals are given financial stipends in order to alleviate the financial burden of living with a disability.

Once registered, the state will decide how much help a person needs in order to make their lives equivalent to a person who does not have a disability. The money given is a way to supplement the costs required to care for disabled persons. The money comes from a government foundation, MIES, and payments are typically as follows:

- Basic Stipend: Below 75% disabled, $50/month
- 75% and above physical disability, 65% and above intellectual/mental disability: $240/month
- 40% and above: Pay half of their light and electricity bills
- All with cards: Pay half of the bus fare (with documentation, ex: disability card)
- Public healthcare is free; discounts will be given based on percentages if an individual goes to a private medical specialist

This financial support comes from three different sources that are overseen by the government and banking institutions: the general Joaquín Gallegos Lara pension, Joaquín Gallegos Lara pension for disability, and a general pension for disabled individuals. MIES is responsible for evaluating disabilities, then individuals must meet with a MIES representative to fill out online documentation that will then determine if they are qualified to receive a government stipend.

Limitations in Who Receives Financial Aid

MIES asks individuals petitioning for financial assistance to meet with administrators to fill out an online
There are some people who actually need the money but from MIES visit the homes of individuals receiving document that determines whether or not an individual is qualified to receive a government stipend. Stipends are based on the economic situation of a family and whether or not they have caretakers. Questions range from how many individuals live in the home, what type of home an individual lives in, sources of income, and whether or not an individual has material items that could indicate socioeconomic wellbeing, such as a refrigerator or television.

These government stipends are only for physical and intellectual disabilities. Individuals with disabilities related to visual and oral ailments rely on other foundations for outside support. Policy reflects an understanding that these individuals will not be made equal to able-bodied individuals with financial support. Instead, there are associations that help individuals learn how to use braille or other forms of technology to help their functionality with their condition. However, the government has not been very supportive in the opening of facilities where these services are offered for a decent price.

I began to question how honest this system of petitioning for financial assistance is. Representatives from MIES visit the homes of individuals receiving government stipends to determine the necessity of the assistance and to monitor what the money is being used for. Most of the time, money is needed to travel outside of San Migos in an attempt to find a doctor that is reputable and well trained. Other times, the money is used to pay for medications that would not be affordable without financial assistance from the government.

Senora Laura Marie indicated that the system is flawed. There are some people who actually need the money but lack the resources to leave their town to obtain a card or register with the state to receive benefits, while others are receiving more than they need.

Yes. It is a problem. It is false. They can lie to receive more benefits. I think it is a problem in Ecuador. For example, I visited many people but ultimately the government will update the system and the records. I see people that really need help but others take advantage...

...El bono is the money people receive from the government. If someone recovers from their disability, their money is taken away. There are people from the government who will come and scope out the house and if you have a laundry machine, a kitchen, TV, computer...

...There are people who have cars and motorcycles and receive the money - these people are lying about the facts. There are people who don’t eat and drink. There are people who need it but they won’t get it...

...I use my money to help others and to help organizations with disabilities. For example, there are two men in Puerto Loto that live alone and they are adults, the spouse has diabetes and can not walk - others visit them and help the men by bringing doctors and they are qualified to receive $240, but they don’t receive it...

...It is very difficult because they don’t have much money and therefore they don’t receive money.

-Senora Laura Marie, July 2018

Financial and Medical Aid from Private Foundations

Nevertheless, according to Carla Rivera, a representative from MIES and a social worker for Jose Eugenio Rivera Chonillo, a foundation dedicated to aiding disabled adults, foundations were created to regulate the problems associated with disabled people. These organizations make aid available to individuals who can not afford to pay for things such as electricity because of other medical expenses. Under this private foundation, all disabled people are entitled to receiving aid, and it is not solely for people who are impoverished or with physical and intellectual disabilities.

It is more than common to find foreign foundations that will set up offices in Ecuador to help families who can’t afford specialty procedures. As stated earlier, the medical care in and around San Migos is less than sufficient to meet the medical needs of those with handicaps. Most families will travel to bigger cities and hospitals twice a month to receive care if they can afford it. One family explained how they are currently saving up for their grandson to receive a procedure that would cost $20 in transportation and $10 for a consultation (this number comes after the discount that he receives for being disabled). Luckily for the family, their grandchild was chosen to receive a free procedure from a NGO. What I learned is that it is more than common to find foreign medical specialists working around Ecuador. However, the cost of transportation may still be too expensive for the family to afford and the NGO may not stay around long enough to finish their work or provide the remaining procedures that the child may need.

Government Housing Programs

In addition to government financial aid, those who are registered with the state as having a disability also enjoy benefits, such as the time it takes to receive a government home, or Miduvis and Manuela Espejos. These are part of a governmental project to aid families by building them homes. Manuela Espejos are homes specially designed for those with disabilities, are larger than Miduvis, and include ramps or other accommodations that a family may need. If a family with a disabled person were to apply for either type of home, the process becomes quicker than for those without disabilities. The government will look into a family’s economic status prior to granting them a home.

I spoke with a representative that meets with families and helps them fill out an online form that asks
different questions which gather an idea of the family's socioeconomic wellbeing. Based on these results, families may be considered qualified to receive government assistance, including stipends or a home.

Lady Toala, an individual who used to work for MIES and a government non-profit organization supporting individuals with disabilities, provided me with helpful knowledge of the Miduví and Manuela Espejo process. As a researcher, I visited homes of individuals with disabilities who did and did not qualify for a home or stipend. I was confused. Some of the individuals lived in a home with a dirt floor and bamboo walls, yet did not qualify for a stipend. Other individuals lived in gorgeous, painted homes, with ceramic tile and light, and these individuals did qualify for a stipend.

I later learned that it is essential to not only consider an individual's living situation to determine if he or she is considered 12% below the poverty line. Being 12% under the poverty line means that individuals are entitled to receiving a Miduví or Manuela Espejo. As Elizabeth Rojo, former Vice President of the Parroquia, informed me, many times individuals will put their incomes towards alcohol instead of fixing up their homes. She believes that people are responsible for their own financial situation and a lot of times they use their money irresponsibly.

Lady Toala said that Miduvís are only for individuals who do not have many resources. Individuals with disability can receive the home, which is worth $10,000, for free, but other individuals typically have to pay $200-$300. She does believe the situation is starting to change. After conducting a census, the government realized that the homes that they are building are not always going to who they are intended for. For example, many families will be awarded a Miduví or Manuela Espejo, but then relatives will be the ones who live and benefit from the home, not the person who the government intended to receive it.

**Government Housing Limitations**

For some, the process of receiving a Miduví or Manuela Espejo can take years. At the start of the program, beginning during the Correa administration, individuals were not required to show the titles of their land and construction could begin immediately. Now, before you receive a home you must show that you are the owner of the land. These individuals must have notarized proof of ownership. This process can take months to years.

Cirilio Macias, the president of the Comuna San Migos, is responsible for overseeing ownership of land and sales. The Comuna of San Migos has a deed that gives them 2536 hectares of land to oversee. 95% of this land is owned, but sometimes ownership is based on word of mouth or familial history. When individuals are ready to build a Miduví or Manuela Espejo, they must get proof of ownership from the Comuna. Problems arise when individuals petition for a certificate of land ownership, but then are contested by other individuals who also claim ownership of the land. At the end of every month, the town holds meetings where they negotiate land disputes and vote in favor of a specific individual. If the situation is not resolved at that meeting, conversation is continued the following month.

With all of this being said, the process of building a Miduví or Manuela Espejo can take months to years. Typically, the Comuna will charge $200 to give papers to individuals certifying that they own the land, but for individuals with disabilities it is free or discounted.

**White Flag: A Call for Attention**

When Lenin Moreno took office, representatives from La Manuela Espejo program made visits to the homes of individuals with disability. Lenin Moreno has a disability himself and has been a global influence in the equality for individuals with disabilities. Representatives came to San Migos multiple times to develop a census and question individuals on their needs. Freddy Pincay has instructed individuals with disability to demarcate their house with a white flag so that the government knows that they are there.

In a rural community without direct addresses, the white flag represents a marker of identity and petition for help. There is no community center in San Migos, Ecuador, and it is fairly difficult to grab the attention of the government and medical professionals. The white flag is a signal for hope and a representation of the need for attention from these people.

I think that there are problems in every part of the country. But there are people who sometimes need a lot of help but they are just waiting and waiting - they don't really fight hard for what they need or want - so they don't receive what they need because people aren't being forceful with what they want or need... Sometimes people don't believe that people will help them- they don't believe them, so they just give up and don't receive anything...

... There are people who are waiting for things to materialize- but they don't consider how helpful technical activities could be. They just want beds and crutches, etc. ...

...There is a law for people with disabilities. The disability law lays out all of the obligations and everything else for people with disability.

-Freddy Pincay, July 2018

At this point, individuals have become accustomed to Freddy and different organizations visiting their homes, asking what they need and offering help and aid for applying for a government home or government stipends. However, all of these are simply false promises that lead
Stigmatization of Disability based on Cultural Beliefs and Non-Inclusion

Some prevailing beliefs in San Migos seek to explain the presence of physical disability. These beliefs are non-scientific and have been passed down through generations. I argue that failure to include individuals with disabilities in mainstream schools contributes to the persistence of these beliefs. The non-inclusion of individuals reinforces tendencies to discriminate against those with disabilities, which then leads to a general stigmatization within the community.

Cultural Beliefs on Disability

There are multiple beliefs that, while antiquated, still exist and still are assumed to have power. Some individuals think that the prevalence of individuals with disabilities is high because individuals are giving birth at the age of 15. Others feel that physical disability could be related to a genetic mutation of some sort. While some beliefs are driven by science, others are not. There is a belief that if you make fun of a child with a disability, there will be reciprocity involved and your future child will have a disability. There is a belief that if rape was involved and the dad was highly intoxicated, the baby will be born with a disability. Some individuals have said that children are affected in the fetal stage because of women trying to abort their pregnancy by drinking “bad water.”

As a student researcher who was trying my best to form and retain relationships with the community, I was hesitant to bring up the question of disability due to a lack of genetic variety. I was afraid the insinuation of incest would be taboo. However, in San Migos, as is common throughout the world, individuals take the last name of their father and mother. Many people in the town share the last name “Aguilar” but claim that there is no relationship between them and the Aguilar next door. In one family specifically, there were three instances of mental disability among cousins of the same generation, causing me to question whether or not they believed genetic makeup to be relevant.

Inclusion of Individuals in Education

School is an influential medium in the inclusion of individuals in mainstream society and in the breaking down of cultural stigmas associated with disability. If individuals are accustomed to going to school and interacting with individuals with disabilities, they are more accustomed to understanding these differences. Inclusion policies are put in place for a reason: to end the segregation of individuals based on capacity. In one year, there were dramatic changes in the number of individuals who are now being included in mainstream schools.

Within San Migos there is a primary school, a private school (La Escuela Particular), and a high school (where I spent a decent amount of time teaching English). Where a child attends school is dependent upon the needs of the child, the preference of the parents, and most of all, the financial ability of the family as the private school requires the family to pay for schooling.

The primary school is the largest school in San Migos, the property stretching down the main road in San Migos. Yellow cement walls border the school with paintings of children and the names of the founders painted nicely on the sides. In order to enter the school one must knock, or yell “a ver,” in order to grab the attention of the guards or administrators working at the school to open the giant metal door at the entrance. Walking in is a courtyard directly to the front and classrooms to the left and to the right. The school is two stories high with at least 20 classrooms in total, and classes are divided based on age.

The director of the school, Esteban, greeted me at the entrance and we continued to his office. Esteban is a middle aged gentleman with a mixture of grey and black hair. His office was quite large, larger than some of the homes in San Migos. The floors were made out of ceramic and his desk sat in the back corner of the room, facing diagonally towards the door.

My interview with Esteban led me to the realization that there are about six students with disabilities who study at the primary school, a school for children aged 6-10 years old. The disabilities present at the school ranged anywhere from physical disabilities to mental disabilities. Esteban educated me on the new inclusion law that had passed, reforming education in Ecuador for children with special needs. Government schools are required to take all means necessary to integrate disabled children; however, it still proves to be quite difficult for the teachers and unfortunately, not all cases work out the way they were planned.

Now with the reform of integration, parents will go to the school district and will tell them what the disability is and they will find a way to accommodate the student. The district will decide which level....

...There exists a school only for children with special needs. For example, [Chico] studied here in the first level for two years. He had a cleft lip. But he also had hyperactivity. He would leave the school without permission. The mom took him out of the school and tried the private school. The mom studied in this school. I helped [Chico’s] mom, but this situation is completely different. She went to the district to find help, and [Chico] was sent to the special school. He goes 2-3 times a week.

-Esteban at La Escuela Primaria, July 2018

As indicated in the transcription above, although the government made it law to include children in mainstream
school, there are situations where it becomes too difficult to manage and the family is forced to seek other options. Although Ecuador is trying to integrate children into normal government schools, there is only so much they can do to accommodate these children because teaching a class with a child with special needs is quite difficult for some teachers.

The professors here have multiple lesson plans. They work with two classes in one classroom - it is complicated. The system is put in place by the district, not me. It is difficult to include all students.

- Esteban at La Escuela Primaria, July 2018

At the primary school, the teachers who handle students with special needs have only the basic education that is required to be a teacher. Although they may have previous experience with disabled children in primary school, they do not need to pursue further education to teach these children.

When children with special needs are integrated into normal classrooms, they are given books that are 2-3 years below what the rest of the class is learning, depending on the child and their learning capabilities.

Spatially, students are completely integrated with each other, but academically they differ. The teacher explains the lower-level materials and assignments to individuals with disabilities but then they must proceed to teaching the rest of the class completely different material.

Based on my observations, although the school is abiding by government regulations by spatially “integrating” disabled children into the normal school, these students are still segregated intellectually.

It is a little complicated because she is not the same as the other children. I have to make a different plan for her and others. I teach other children. I have to explain and repeat myself multiple times when I work with [Sarita]...

...For example, when I write everything, she understands- but doesn’t understand when I explain it. She writes but she doesn’t write well and writes other words. It is a difficulty of hers...

...I spend the same time working with her as I do the others because she is a different level. She is in the first level...

...She will understand in the moment, but after she will not. I have to repeat myself multiple times and she does not understand anything...

...She has other problems and there are other children. She does not understand everything, practically a different language. It is a problem with the girl, with [Sarita]. I would love help. She could use language therapy. Right now she can not talk...

She needs language therapy. It is necessary because in order to teach she needs to learn the language. [Sarita] likes to paint but she paints in other colors, not the one we told her.

She needs language therapy but doesn’t get it. Her mother doesn’t teach much. [Sarita] needs to be taught by her mom. There are words that she understands and I explain it to the mom, and I try to teach her. She speaks some words. She practices so that she can be better. The mom doesn’t worry about her child. It is necessary to have language therapy.

- Teacher at La Escuela Primaria, July 2018

Freddy Pincay and Unidad San Migos are working to improve the resources available for families in San Migos and surrounding areas. Their goal is to have a school that children with disabilities can go to that is not two hours away. At the least, he is fighting for transportation that can take children from San Migos to Jipijapa for free because every child and every person deserves access to an adequate education.

**An Excerpt from a Previous Report: “Living with Disabilities 2017”**

At the beginning of my 2017 report, I mentioned that the stigmatization of a seven-year-old in San Migos prompted my research on disability. During my first visit to San Migos, I carried out a small scale research project for the Florida Atlantic University field school that researched the stigmatization of children with disabilities in the community. This research allowed me to interact with children and their families under the advisement of Dr. Harris, but without approval from the Institutional Review Board as it was a “class activity.” Nevertheless, here I cite a finding from my 2017 project report about how the non-inclusion of individuals in mainstream schools contributes to the general stigmas against individuals with disabilities.

My research started and ended con mi amigo (with my friend) from the amphitheater, “Chico.” Locals like to call “Chico” el terror, loco y malo, (a terror, crazy, bad) but from what I have observed, “Chico” is a seven-year-old kid who has been brought up in a home with a mother who is intellectually disabled and a town that may not understand the behaviors and actions of the child. His grandmother cares for him, his mother, his two-year-old brother (who does not have a disability), and watches over the rest of her grandchildren with the help of her other daughter.

I had the opportunity to follow the family closely through interviews, ’playdates’ in the amphitheater with “Chico” and his cousins, and even in Jipijapa where “Chico” attends a school for children with disabilities.

Unfortunately, the financial status of the family is not
strong enough to send “Chico” to school on a daily basis, he attends school three times a week, if the money is available. When I asked his ten-year-old cousin why “Chico” wasn’t at school on a day that he normally is, he responded “Porque no hay plata.” There was no money to pay for the 2-hour bus ride that would bring “Chico” and his grandmother to the special school in Jipijapa and another 2-hour bus ride back to San Migos. For two people, the roundtrip to Jipijapa from San Migos is about $10.

For Senora Epi, the grandmother of “Chico,” her pauses in speech and changes in inflections indicated that raising a daughter who is 60% intellectually disabled and a grandson who is 50% physically disabled, along with taking care of household duties and the rest of her grandchildren, takes a toll on her life.

“For me it is difficult because I want to take [Chico] to school and keep the other child with his mother. But she is not a parent and can’t take care of the baby. For example, before [my daughter] washed the baby in hot water. But I have to go with [Chico] because God wants me to and I want to go and I have to take him, but I am still worried about leaving the other baby. About leaving and leaving. But [Chico] is too important.” -Sra. Epi, July 12, 2017, 3:00pm, J. Scolapio

Senora Epifania shared that “Chico” was born prematurely, weighing only three and half pounds, and so small that he could “fit in a shoe box”; doctors projected that he would not survive past the first month.

Town gossip indicated that he was born to a disabled mother as a result of a rape. In Ecuador this situation does not permit an abortion. The father is unknown; and completely out of the picture. During an interview I had with Senora Laura Marie, an adult who is physically disabled and a leader in the local organization for those with disabilities, Unidad San Migos, she shared that this is a huge problem. Disabled women in this area wind up pregnant, sometimes due to rape, and end up with a child that they are unable to raise.

In an interview with a representative of MIES, an outreach organization aiding those with disabilities, I was told that there are recognizable trends of mothers with intellectual disabilities giving birth to children with cleft lips, the condition of “Chico.”

Along with a cleft lip, “Chico” was born with a heart condition and a hernia. Once he made it to one month of age, doctors operated on his lip for the first time. It was not until the age of six that “Chico” began to speak. The speech delay has proven to be a deficit in the learning ability of “Chico” and his ability to communicate with others.

Today, “Chico” is still waiting to receive ten more surgeries for his lip. Due to financial restraints and the severity of the procedures on his weak heart, they are waiting for until a later date to perform the remaining procedures (Scolapi, 2017).

Stigmatization as a Result of Non-inclusion

When I returned in 2018, “Chico” was no longer traveling to Jipijapa because transportation became too much of a financial burden on the family. I was happy to see that he had been reintegrated into the local private elementary school where he was surrounded by peers. His situation has changed dramatically. Families welcomed him into their homes, fed him, and played soccer with him. He is now seen as less like an other and instead is valued as an equal member of society.

This situation contrasted starkly from the summer of 2017 when community members I spoke with viewed “Chico” to be un terror (a terror). They did not recognize that his separation from peers, lack of education, and lack of opportunity in learning proper ways to behave within the community, were a function of his lack of inclusion within mainstream schools. Instead, beliefs and town gossip persisted and reinforced ideas of the causes of disability. The general consensus of the town was that “Chico” was crazy because he was brought into the world in an inhumane way. Individual understanding circulated through the community and created a place where “Chico” was somewhat seen as dangerous and something to be avoided.

My comparative findings, from visits in 2017 and 2018, suggest that much has changed in the general understanding of disability among members in the community. Notably, the work that Freddy Pincay has done locally with Unidad San Migos and the example that President Moreno has set for all individuals with disabilities, is a strong foundation for promoting the inclusion of physically disabled individuals in public and private spaces in rural Ecuador.

CHAPTER III. CASE STUDY: RIO MAR, PERU

ENTERING THE FIELD: PERSONAL EXPERIENCE

Inspired by my research and time in Ecuador, I found myself moving to Cusco, Peru for four months to participate in a semester abroad with the School of International Training. The title of the program was “Indigenous People and Globalization” and we spent our semester living with indigenous families, learning about the history of Peru, and becoming culturally acclimated to our home base, Cusco. At the very beginning of my research in Peru, ARARIWA made the recommendation to conduct my fieldwork in Rio Mar.

My home in Rio Mar was nestled behind the main cathedral of town. It had wooden floors with a layer of dirt on top, a small kitchen table with six chairs, and four beds covered with sheets to prevent dust and spiders
from entering. The home was comparable to a studio apartment but without accommodations like clean water, Wi-Fi, or even telephone signal. I found myself at the local market where I bought a carrot, mangoes, raw chicken, and rice. It was my every intention to cook a world class meal on the portable, two-burner gas stove. Unfortunately, that was not the case and I was left with a stomach virus that cut my research from two weeks to five days.

Living in the community for only a few days, I hardly had time to establish meaningful relationships with the community and did not get a good scope of life in Rio Mar, placing extreme limitations on what I could learn about physical disability there.

Prior to entering the field, Jaime Huaman, from ARARIWA, warned me that some individuals may not be willing to talk to me. He made sure that I understood my position as una extranjera (foreigner). He mentioned that individuals with disabilities in Rio Mar, Peru may feel unsettled talking to foreigners because of a history of false hopes and promises from foreign organizations. According to ARARIWA, many foreign organizations will visit communities, like Rio Mar, to offer free medical care, medical equipment like crutches or wheelchairs, and, in some cases, will even provide a home for disabled individuals who have been abandoned by their families. These organizations assist selected individuals, those who they deem as most in need. After a few months or maybe a couple of years, these organizations leave these communities with their unfulfilled promises. All things considered, I made sure to maintain the role of student researcher while in the field with no promises made.

Jaime Huaman, ARARIWA, and Carlos Quispe, OMAPED, accompanied me to my interviews and selected participants that they had pre-established relationships with. These individuals were actually willing to share their stories and often thanked me for having a conversation with them about the challenges they face as physically disabled individuals. Since Rio Mar, Peru is an indigenous community, interviews were done in Quechua and Spanish. Interviewees were often shocked at my ability to communicate in Spanish and were even more intrigued when I knew basic lines of Quechua. Needless to say, my linguistic capabilities were certainly a way to build repertoire in the community. With the help of ARARIWA and OMAPED, I was able to gather enough data to feel comfortable with my decision to return to Cusco.

The remainder of the month was spent finalizing my research project, written in Spanish, Las Barreras que enfrentan Personas Indígenas con Discapacidades en una Comunidad Rural (The Barriers faced by Indigenous People with Disabilities in a Rural Zone). This chapter describes my experiences in doing research in Rio Mar and my findings such as they are.

CONSIDERATIONS AND LIMITATIONS TO MY STUDY

According to the census of CONADIS in 2014, 11.8% of people in the Cusco region have registered their disabilities with the government. There is a great possibility that statistics have changed since 2014 because now there are significant changes to improve the ability of people with disabilities to receive a certificate. In 2016, there was an extreme increase in the number of doctors who may qualify a persons' disability. I imagine that more people can now receive a certificate because doctors do not need to travel because doctors are distributed everywhere in the region to certify people.

One limitation of my study is that we have no recent statistics. At the time of carrying out my research, the census of 2017 was still not available. This particular census is very important because it is the first official document on which people could report if they have a disability and have their disability registered. In my interviews with medical professionals, the OMAPED officer, and an officer of ARARIWA, they all agreed that the situation and the number of people who are registered with the government is improving. They said the increase in physicians is a big reason for the change because now doctors are more accessible and people do not need to travel because doctors are distributed everywhere in the region to certify people.

TOWN DEMOGRAPHICS AND LIVELIHOODS

About 11,000 people live in Rio Mar, Peru. While some live in homes directly adjacent to the main plaza in town, others live alongside a long, inclined hill that is only accessible by stairs.

Rio Mar is a Quechua community, meaning that the majority of individuals who live there are indigenous. Most individuals in the town speak Spanish as a second language, which they learn in school. The main market in town, known for a specific type of bread that is circular in form with a hole on the top, as well as a variety of potatoes, takes up the equivalent of one small block. It is typical to see middle to older-aged women sitting in their traditional dress selling produce. Typically, a pig would be roasting on the street and people would stop to make their purchases. Many families are self sustainable as they use their land to produce crops later used for cooking within the home. One of the women at the market told me that she travels to Cusco to buy produce that she then sells at the market. Other families maintain their household by owning small stores where they sell paper products, medicine, or other household supplies.

The town itself appeared to me as somewhat barren. There were empty streets with many dogs rummaging through trash cans. The town has no wireless internet and hardly any phone signal. Because of this limitation, when my research ended for the day, I found myself at a
TABLE 3. Overview of Disabled Interviewees

<table>
<thead>
<tr>
<th>NAME</th>
<th>AGE</th>
<th>GENDER</th>
<th>MARITAL STATUS</th>
<th>DISABILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Milagros</td>
<td>22</td>
<td>F</td>
<td>Single</td>
<td>Physical (ankle limp)</td>
</tr>
<tr>
<td>David</td>
<td>29</td>
<td>M</td>
<td>Single</td>
<td>Physical (needs crutches, minimal lower body mobility)</td>
</tr>
<tr>
<td>Marleny</td>
<td>37</td>
<td>F</td>
<td>Single</td>
<td>Physical (Feet)</td>
</tr>
<tr>
<td>Carlos</td>
<td>33</td>
<td>M</td>
<td>Single</td>
<td>Physical (Accident, paralyzed)</td>
</tr>
<tr>
<td>Felipe</td>
<td>76</td>
<td>M</td>
<td>Widow</td>
<td>Physical (Wheelchair bound, knee)</td>
</tr>
<tr>
<td>Maria</td>
<td>55</td>
<td>F</td>
<td>Married</td>
<td>Physical (accident: hip &amp; back)</td>
</tr>
</tbody>
</table>

However, many people told me that during the popular festival in Rio Mar celebrating the Virgin Carmen in July, the town is packed with people who come to Cusco and surrounding rural areas, with all available lodging booked one year prior. The festival, a religious celebration, also includes public dancing and singing.

RESULTS

According to records held by OMAPED and ARARWA, 284 people in Rio Mar have registered their disability with the government, but the majority have yet to receive their disability card. This documentation is vital to receiving benefits promised through the La Ley General de la Persona con Discapacidad. OMAPED and ARARWA only retain a record of individuals who have made an initiative to see a doctor and register their disability. With that being said, for my study they were only able to locate individuals who had already registered their disability with the government. Fortunately, I was able to connect with and interview one woman who has yet to register her disability because she was not aware of the ability to do so.

Key Research Participants

Of my six interviewees - three women and three men - three have had their physical disability since birth. For the others, it was either developed over time or was caused by an accident.

Carlos offers an example of someone who became disabled in an accident. He was nineteen when he was in a car accident that paralyzed him from the waist down. He recalls moments of severe depression because his life changed forever with no hope of regaining mobility. Carlos went from being an independent young man with hopes of going to college to a bedridden individual who was being cared for by his mother and siblings. He remembers having to relearn how to shower and how to do tasks that were once so simple, such as brushing his teeth and changing his clothes. Slowly he regained confidence, but was constantly reminded of his disability when people would stare or say: “ooof qué pena” or “pobrecito” (“how terrible” or “you poor thing”).

For other individuals, like Marleny, disability is often associated with familial abandonment at birth. Marleny has a difficult time conversing and comprehending dialogue. She assumes that her family was either ashamed of her learning disability or that it was too much of a financial burden. For about fifteen years, an Italian non-profit organization that was working on sustainable development projects in Rio Mar, Peru, offered Marleny room and board at their facility. Unfortunately, this organization closed their office in Peru and Marleny was left alone. For seventeen years now, Marleny has had to search for clothes and food, and has no job or family. The town of Rio Mar does what they can to help her but Marleny still refers to her family as the volunteers who were part of the organization.

Structural Limitations to Gaining Recognition

This section discusses several structural constraints limiting the recognition of individuals with disabilities under the law that emerged from my interviews. These include lack of popular awareness of Law 29973, access to general education, familial traditions and support, access to medical care, and economic ability.
Popular Awareness of Law 29973

As mentioned in the introduction, Law 29973 of Peru (2012) protects individuals with disabilities by guaranteeing them the same rights as the rest of the population. People with disabilities have protection against discrimination in employment and in public spaces. They can also receive benefits from the Ministry of Health that guarantees and promotes the entry of the disabled person into a system of universal insurance.

Most of my disabled interviewees said they are familiar with and understand the law for people with disabilities in Peru. OMAPED and other officials have held public meetings for people with disabilities in Rio Mar, where they can be educated on their rights as disabled persons. These meetings teach the community about what it means to be a person with a disability and informs them on the process of registering their disability with the government, receiving a disability card, and receiving state protection.

We have meetings every three or four months to sensitize the community about disability and teach people about their rights.
- Carlos, administrator OMAPED Rio Mar, May 2018

The reality is that these meetings have not been largely accessible to the majority of individuals in Rio Mar. Therefore, the majority of the population neither receives help from OMAPED nor is educated about their rights. Additionally, there is a belief among people in Rio Mar that only people from Cusco, the closest city, and people who have family from Cusco, are familiar with the laws and government benefits.

Organizations do not help all people in Rio Mar. It is an inequality because some do not go to meetings and some do not understand their rights because they have no knowledge of the meetings.
- Maria, translated from Quechua, May 2018

My fieldwork revealed the lack of programs to educate people with disabilities about all parts of Law 29973. Even disabled people in Rio Mar who considered themselves to be knowledgeable about the law conveyed a lack of understanding about each protection they are guaranteed to receive. As a result, many institutions, such as restaurants and government offices, are not being held accountable for their non-compliance with the law, as I explore below. If physically disabled people in the area were better informed and fully understood their rights, they would be empowered to claim them and fight for them.

Discrimination in Education

Discrimination is highly present throughout childhood for individuals with disabilities, especially in terms of education. As mentioned previously, under the law individuals are guaranteed an education without discrimination towards their disability. But there are problems when teachers do not think that students have the ability to learn and when teachers believe that they are distractions to other students.

My interviews support these generalizations. Two of my interviewees, Milagros and Marleny, did not attend school during their childhood because their teachers were not equipped to deal with their personalized needs. Both individuals have a physical disability, but also have some intellectual delays. According to her teachers, Marleny did not know how to interact with other students and teachers did not have time to give her preferential attention, so she was left out of the education system. It was not until adulthood that Marleny was welcomed into a school, this time a school specifically for individuals with disabilities.

... every student receives an individualized education here. Each student is different with different limitations. We can not teach everything at once. You can not teach people with intellectual limitations in regular schools because there is no time, there are other students without limitations.
- Katrina Davila and Mariamela Villalbe, teachers of Virgin del Rosario in Rio Mar, a school for individuals with disabilities, May 2018

According to the teachers of Virgin del Rosario, many families choose to keep their children out of the school system due to discrimination among students and students with disabilities. When people do not understand disability and the laws that protect people with disabilities, there is discrimination, and people choose to hide from society.

There’s always discrimination. The lack of knowledge on the laws. People don’t understand that the law makes us equal to them.
- Carlos, administrator OMAPED Rio Mar, May 2018

Within mainstream schools, able-bodied and able-minded students tend to bully those who have a disability. Sometimes it is hard to go to school and focus because there is discrimination and teachers do not have the time to support them. Many parents hide their children for that reason.

Yes, in elementary school the other students teased me. Always. I did not want to go to school because they did not understand me, but high school was
better.
-David, physical disability, Administrator Ministry of Education Peru, May 2018

Even when parents want a disabled child to stay in school and get educated, other factors arise to prevent school attendance. Schools are not always accessible to people with physical disabilities. For example, one of the local high schools I visited in Rio Mar is situated atop a large hill, making it difficult for wheelchairs to travel up the incline, and nearly impossible for someone on crutches to make the hike. Inside the school, there are two levels with no elevator and very minimal ramps. Schools may lack the proper equipment to adequately serve physically disabled students and make them feel welcome as equal participants in the education process.

Familial Traditions and Support
To start, Rio Mar is a Quechua community and traditional beliefs are still present in the community and within families. Andean worldview is the belief that nature has important power and spirits have influence on the lives of people. There is a belief that disability is associated with nature and the work of spirits. Quechua communities blame the devil for infecting individuals with their disability. With strong beliefs, parents have shame if their children have disabilities and choose to keep them hidden. While each situation is different for people with disabilities, some people have large families to support their disability, while others have no one due to the stigmatization of disability that could be a result of traditional discourse.

It is a serious problem in Rio Mar that parents of children with disabilities leave them after birth. Or parents hide their children and children do not leave the house. They do not go to parties, school, or play with other children.
-Katrina Davila and Mariamela Villalbe, teachers at the Virgin of the Rosary in Rio Mar, May 2018

There are cases where parents leave their children who have a disability and these children grow up without a family. Sometimes NGOs from Italy and other countries come to Cusco to support children. They provide a home, food, clothing, and a family. But eventually they return to their countries and children are abandoned again.

She does not have a family. It is a special case. She needs to look for her clothes, food and other things.
-Katrina Davila and Mariamela Villalbe, May 2018

Most of my interviewees told me that they have no help or live alone in the house. In cases where they have support at home, they also have many resources and are registered with the National Registry of disabled persons. For most people with family, the family helps them receive support from OMAPED and family will seek rehabilitation services and medical care.

Some received support from their relatives when they were children. Parents helped them around the house with bathing, getting out of bed, eating, and cooking. Especially in cases involving an accident where the individual lost the ability to walk, parents helped a lot. But now, as adults, most live alone and do not get much help. However, when they had the support of family, they received certificates and identity cards for their disabilities. The family could travel to Cusco and wait with them in the process to certify their disabilities.

Lack of Medical Services
Before, I was the only doctor in Rio Mar. We could not help many people with disabilities ... once or twice each year doctors came here to certify disability. Earlier in the district of Cusco, there were only three doctors to certify disability. There are now more than 50 doctors. So people in Rio Mar do not need to travel to the cities to receive certificates because doctors come here.
-Dr. Degarra, Medical Professional, Rio Mar, May 2018

There were only three doctors to qualify and certify disability in the Cusco region before 2016. The region is composed of thirteen provinces, Rio Mar included. People from Rio Mar needed to travel to find doctors in the city to qualify their disability. Seeking medical attention was very difficult and, most of the time, people did not have the patience or resources to receive a certificate, because in order to do so, they needed to know where the doctor was and how to make an appointment with them.

According to Dr. Degarra, it was very difficult for patients to find the only three doctors in the region of Cusco that could certify disability. For people living in rural communities, including many districts in the province of Rio Mar, they sought transportation to travel to cities or locations where doctors were certified to diagnose disability.

They use farmers’ transportation to travel to locations for medical attention. Many times when farmers are carrying agricultural products to cities or in places where there are doctors, disabled people travel with them because it is the only opportunity to receive medical care.
-Dr. Degarra, Medical Rio Mar, May 2018

Further, with a shortage of doctors in Rio Mar, every appointment was thirty minutes. Doctors did not have the time to care for people with disabilities. Thirty minutes was neither enough to qualify a disability nor sufficient
enough to cater to people with disabilities.

I had the desire to search for people with disabilities to help them. But I had no time.
-Dr. Degarra, Medico Rio Mar, May 2018

There are now more than 50 doctors who are qualified to certify disability in the region of Cusco. With more doctors they are available to travel to the provinces to assist people with disabilities. OMAPED works with doctors to have one day each year to certify people with disabilities.

Now there are three doctors in Rio Mar, but there are no specialists.
-Dr. Degarra, Medical Rio Mar, May 2018

Rio Mar still lacks rehabilitation treatments for people with disabilities. Now there are more doctors to certify disabilities, but still no treatments to help people recover from disabilities in Rio Mar. There are only three general practitioners in the medical post with no education to care for disabilities.

It is a huge inequality in Rio Mar. We need specialists but they all are in Cusco and I can not leave, I do not have help.
-Felipe, May 2018

Sometimes doctors offer services to people with disabilities who were abandoned. Most told me they had no insurance or insurance only helped when they had the flu or a similar disease. But the post still offers contraception to mature women with intellectual disabilities in the event that they were abandoned, who receive an implant in their arm to prevent pregnancy. Doctors believe it is better to prevent pregnancy when they are living alone and do not have the ability to be cared for by someone else.

Economic Situation

There are opportunities to accelerate the certification process and to receive a card if a person travels to Cusco or Lima. There are also opportunities to receive physical therapy or special medical care. But most of the time, a person needs to invest a lot of money for treatments to travel and receive medical care.

Yes. If I received physical therapy or rehabilitation, I could heal faster. But rehabilitation is in Lima and is not in my financial situation to receive treatments.
-Carlos, physical disability, administrator Office OMAPED Rio Mar, May 2018

People do not travel to Cusco or Lima to certify their disability because transportation is very expensive, and they still need to pay for a hotel. Furthermore, people with disabilities still can not travel to Lima or other urban places because within the city, accessibility is not easy. For example, for some there is no special transportation that will accommodate their wheelchairs. Combis (public buses) are not accessible to people with physical conditions. Individuals would have to pay for private transportation. Therefore, for most, their economic situations do not allow access to resources outside Rio Mar.

Most people want financial assistance from the government for their disabilities. Only people with severe disabilities and living in poverty can receive government benefits or stipends, although the majority have yet to see the money. For people who do not receive a pension and are not in the position to work, the situation to buy clothes and food is difficult. They do not have the means to make money and live a comfortable life.

Discrimination in Employment

Even if individuals wanted to work towards an economic situation that would enable them to pursue care, there are still limitations within the labor market. In terms of the labor market, public companies must reserve 5% of the jobs for people with any type of registered disability, while for private companies, it is 3%. There are specific points that employees use to hire someone. Curriculum, 50 points, 50 points Education. People with disabilities receive 10–15 more points.

My interview with Jaime Huaman of ARARIWA Cusco revealed that people with disabilities received 10–15 points more than people without disabilities to take into consideration interviewer discrimination or lack of education or curriculum.

In spite of this provision, I learned that companies often do not comply with the laws; thus, discrimination still exists and people with disabilities face barriers in finding employment. CONADIS has the responsibility to ensure that the institutions are complying with the law, but it cannot follow the activities of all companies. So most of the time, according to my interviews, laws protecting disabled job-seekers have no teeth.

The law is only 10% effective.
-Carlos, physical disability, administrator OMAPED Rio Mar, May 2018

Obtaining Disability Recognition: The Government as a Threat

In Peru, obtaining a certificate of disability with a qualified physician is the first step in registering a disability with the government. But the reality is that
there are many steps before a meeting with a doctor that the government has the power to control.

Five out of the six participants in my study could not get their disability acknowledged until they were 18 years old or older. The process of obtaining a card is slow, but compared to years past, it is actually must faster. Before, people were not allowed to register for a certificate of disability until they had the identification card administered to all citizens of Peru. Until recently, this card was only administered to individuals once they turned 16. Now the law has changed and people can apply for a license when they are children.

I guess now more people have disability certificates because now we do not need to wait until 16 to get an ID. Now children can register for an ID. It is a huge change because now people can register for a certificate of disability earlier in their lives.

-Jaime Huaman, ARARIWA Cusco, May 2018

CONADIS now has the responsibility to monitor whether the law and the process of registering a disability is working. But most say the process for people with disabilities is very slow in Rio Mar. First you need an ID, then you need to wait for the one available day of the year (or sometimes two days depending on the number of people who want a grade) when OMAPED and the medical post in Rio Mar work together to qualify and certify people with disabilities. From there, medical professionals will transmit the disability certificates to CONADIS in Cusco and will wait for the information to arrive in the capital, Lima, to then be processed into a card.

This process may take anywhere from six months to two years. The government controls most of the process and because of the many regulations, the process is slow. For people who do not understand the process or do not have the help of OMAPED, the post or CONADIS, the process may be especially difficult or even unattainable.

There is no help. I have no one.

-Felipe, May 2018

The Lack of Data on Disabled People in Peru

There is a lack of accurate statistics on the number of people with disabilities in Peru, and therefore, the Peruvian government can not ensure that all are registered or receiving benefits. Until 2017, Peruvian censuses failed to ask if an individual considered themselves disabled. At the time of my research, the results had not yet been released, but other censuses estimate that 1,637,407 people can be identified as having a disability in Peru. This information could help CONADIS to develop a national survey that reflects what percentage of people with disabilities in Peru have registered their disability. But the fact that the census has not considered disabilities until 2017 demonstrates that there was no accurate data for disability at the national level until very recently.

Although its policies and programs are flawed, the Peruvian government can and does help people with disabilities in serious situations. For example, when parents abandon their children or in situations of extreme poverty, Municipal Rio Mar may step in to provide some support.

She [municipal] brings me food and clothes and DVDs.

-Marleny, May 2018

ANALYSIS: ACHIEVING RIGHTS THROUGH RECOGNITION

The potential for individuals with disability to live a life with dignity, in which they are acknowledged and protected by the government, as well as their rights, is called into question in the absence of education, familial support, and a general understanding of Law 22973 that protects them.

The law has greatly contributed to the improvement of social and political protections for individuals with disability. Peru’s adaptation of Ecuador’s system for diagnosing and registering disability has dramatically increased the number of physicians who are qualified to certify disability and has improved individuals' access to special schools for people with disabilities, as well as employment opportunities. Although there is improvement, the system is still not equitable. Individuals who live in rural areas are excluded from receiving the protection of the state and benefits provided by the law because of cultural stigmatization and the lack of opportunity that comes with being so far from the city.

The process to register and obtain a certificate which acknowledges the rights of individuals with disability is expensive and not widely accessible. The transmission of information from rural zones to cities and back again is inefficient and non-supportive of individuals disenfranchised by the system.

Education of Law and Familial Support in Registering a Disability

Law No. 29973 should promote equality and protection of persons with disabilities, but unfortunately, structural barriers exclude individuals in rural areas from educating themselves on the law and educating themselves on the resources available to them.

In Rio Mar, there is no clear and universal information about the process to obtain a certificate of disability. People with disabilities need help from government organizations to give them instructions, but information is scarce and people with disabilities and families do not know how to find information or how to seek help.

Within the law, there are directions to obtain a
certificate and be recognized as a disabled person. However, the law is only available in Spanish and is only accessible by internet or government offices. For example, OMAPED in Rio Mar has information about the law. For people with disabilities in rural areas without internet, without interest or knowledge to go to the offices such as OMAPED, and without Spanish education to help them understand the law, the process for obtaining a certificate becomes difficult and undesirable.

For individuals with disabilities who have family to help them through the process, there is an increased opportunity that these individuals will understand and receive protection under the law. Family members have the ability to learn and visit institutions that promote resources and rights for people with disabilities. For individuals without family, or without family members who are willing to help, there are various limitations and barriers to receiving a certificate. Without help, people with disabilities are alone. They have no one.

People with physical disabilities can not leave the house or have trouble getting around the community. Without mobility, people do not have the opportunity to search for organizations to educate them about the laws and protections for people with disabilities. In cases of intellectual disabilities, people do not have the ability to understand the laws or do not understand that the laws exist. In situations of abandonment, they have no one to protect them. Therefore, the presence of family could determine the ability of an individual to receive protection according to the law and register with the National Register.

Laws can only guarantee protections for people who have knowledge of the laws. For people in an indigenous community where the main language is Quechua, a law produced in Spanish is not useful. In addition, if they were abandoned or have no help from others, it is very common that they will not receive government protection for their disabilities. The reality is that these people long face barriers to obtain the certificate and passport. Therefore, they will live a life of inequality.

Persistence of Traditional Beliefs as a Result of Insufficient Resources

With the increase in the number of doctors to certify disability in the district of Cusco, people in Rio Mar theoretically should receive more medical care, but this is not the reality. Doctors who are authorized to certify disabilities only visit Rio Mar once or twice a year. With infrequent visits, people in Rio Mar are not getting the help they deserve under the law. For people in cities, the process to get certified is easier because all of the necessary resources are at the patient’s disposal. But again, indigenous people with disabilities face a serious barrier to the lack in medical care. The law guarantees free and accessible medical care in terms of diagnosing disability, then in receiving rehabilitation services. There should be a clause that clarifies these opportunities to be solely in cities, because within indigenous communities, there are no doctors who can certify and rehabilitate disability.

The government has tried to promote the inclusion of persons with disabilities in the labor market, but there are still discrepancies and discriminations in the process. There are not many companies in Rio Mar to recruit people for employment; therefore, there is a lack of awareness of the law that promotes jobs for people with disabilities. The law protects people in cities, such as Cusco, because they have access to jobs in the public and private industries. But in Rio Mar, people face a barrier to employment and thus depend on traditional jobs in the chakra (farm) or at home. But most of the time, jobs are not accessible to people with physical disabilities and therefore they do not have the opportunity to earn income. Trends to exclude specific populations reinforce discriminatory tendencies in Rio Mar and in Peru. When people grow up without the freedom to achieve something, or without equal opportunity that people without disabilities have, then they lose hope for receiving help.

The law promotes alternative schools for people with disabilities. It was interesting to see that there is a special school for people with disabilities in Rio Mar. Schools are important for the education of children with disabilities because they have the opportunity to learn in a more personal way. When children have the ability to learn from others with similar abilities and with teachers who give them special attention, there are more opportunities for children to make academic and social progress.

Unfortunately, there are still problems with a school structure that only includes people with disabilities because it shows that there is a lack of inclusion in mainstream schools. Many times students were asked to leave mainstream schooling for another school that was more suited to their special needs. By not including people with disabilities in mainstream schools, there is more stigmatization of disability, which strengthens a system that excludes people with disabilities.

Cultural beliefs largely play a role in the interpretation of disability in Quechua people in Rio Mar. In Rio Mar, the presence of the Andean world is strong and still has an impact on the way in which people view and understand disability. If indigenous people with disabilities are excluded from health care, education and/or employment, they tend to adhere to cultural traditions for guidance. These traditions inform understanding of disability, and can even include traditional medicine. Although the law is intended to protect all, when not understood, it is easier for these individuals to rely on beliefs and traditions that have long been practiced in the lives of people in Rio Mar.

Traditional beliefs are not troublesome but they still pose extreme barriers to the ability to record a disability with the National Registry. It is normal to hide a disability
because the Andean worldview says that disability is the effect of extreme nature or the devil. People are afraid to share their disabilities with the world. When a person does not have the opportunity to leave the house, there is no evidence that the person exists. For example, it is very common in Rio Mar that children are born in homes. Often people who practice Andean worldview never allow children born in the house with a disability to leave the house. In other words, they are hidden at birth. When someone is forced to hide for all of their life, it is very difficult to go out and find support because they have no idea where help is available.

A Difficult Process Unrewarded

The process to register and obtain a certificate and/or a card is long, expensive, and not widely accessible; therefore, people with disabilities are unable to find tangible benefits to exercise their rights.

There are many steps to obtain a certificate of disability and sometimes the process is not possible for everyone. For starters, there was a fundamental barrier when people with disabilities could not certify their disabilities because the age for receiving an ID. Most people rely on familial support to help them through the process of obtaining and exercising their rights.

Individuals in Rio Mar have minimal access to Cusco. There are private cars to travel to Cusco, but this transport is not accessible to people with physical disabilities. It is very uncommon, maybe impossible, for physically disabled to leave Rio Mar. If they leave Rio Mar, the transportation within the city is not accessible to people with physical disabilities. Within cities, institutions are not complying with the laws and individuals have a difficult time walking around and entering public spaces. While the law promotes free public transportation, it is an empty promise because it only applies to people who already have a disability card and who can physically use the public transportation available.

Many people with disabilities cannot work and are therefore left in poor economic situations. Although the process to obtain a certificate is free, people in Rio Mar would have to pay more to travel to areas with more medical staff and support. Instead, they wait for doctors in Rio Mar and never receive attention.

There is no tangible benefit for those in Rio Mar to exercise their rights. A certificate does not have much value in Rio Mar because there are no forms of rehabilitation and other benefits, such as free transportation, which is only available in cities. Therefore, there is no incentive to certify disability in Rio Mar.

People are not going to register their disabilities if they are not receiving the benefits or rights they should receive. In theory, people could live a life equal to those without disability if they have a certificate, but discrimination is present and strong in Peru. Individuals have trouble finding jobs or do not have the ability to work with their disability. The law promotes assistance to individuals in finding jobs, but there are not that many jobs in Rio Mar; therefore, it does not matter. Individuals are technically guaranteed to receive financial assistance from the government if they are living in poverty with severe disability; but again, people have yet to receive this money.

It is a serious problem that people do not understand the laws and do not understand their rights. It is another problem that people understand their rights but still do not believe that it applies to them in Rio Mar.

In conclusion, the process of obtaining a license is not accessible to everyone in Rio Mar. There are extreme gaps for people in rural places because the process is long and expensive to access cities. The benefits that people with disabilities receive do not apply in the district of Rio Mar, because there are not many resources. In reality, there is no reason to register a disability in Rio Mar because there is no opportunity to exercise rights.

CHAPTER IV: SUMMARY OF RESEARCH FINDINGS AND IMPLICATIONS FOR FUTURE POLICY AND RESEARCH

This chapter presents major findings from my visits to San Migos, Ecuador, and Rio Mar, Peru, from two perspectives. First, I describe the importance of long-term research, including a return trip, versus very short-term research and the impact it has on the quality of the findings. Second, I discuss what I learned about disability policy in Ecuador and Peru and how such policy has been implemented in each respective country. In the last section I will share closing thoughts and recommendations for future studies.

THE VALUE OF LONG-TERM RESEARCH

The quality of my findings were deeply affected by two key factors: the length of time of my visits and my role as a student researcher. Long-term research meant that I was able to return to San Migos for a second visit.

As described earlier in this study, I spent much more time in San Migos than in Rio Mar. Every social anthropologist knows that rapport is essential to building trust with local people and gaining better insights into the social context, institutional processes, as well as everyday lived experiences of disabled people and their families.

My role as a student researcher had a great impact on the willingness of individuals to participate in my study. While people in San Migos, Ecuador are accustomed to the annual summer arrival of American students, individuals in Rio Mar, Peru remain isolated and cautious of foreign visitors. In each setting, my role as a student researcher had a positive effect of providing me with a harmless identity and role. That is, no one misperceived
me as an outsider with intent to to change disability politics and practice. Frequently, social anthropologists have to cope with false role assignments when they enter the field. I did not have that problem.

My research in Ecuador was conducted in a way that I, as a student researcher following the recommendations of the George Washington University Institutional Review Board, was at liberty to decide. My research in Peru was completed under strict requirements for an Independent Study Course. Throughout this study it is clear that the information I collected in Ecuador is denser and more descriptive than the information I collected in Peru due to community involvement, length of stay, and research structure. Thus, the many differences in my fieldwork experiences, and the amount and quality of information I gathered differed dramatically and, in turn, made any rigorous comparative findings difficult if not impossible.

Regardless, in the following section, I attempt to draw some comparative findings from the two research sites in relation to disability policy, practices, and experiences.

COMPARING DISABILITY POLICIES, PRACTICES AND EXPERIENCES IN TWO RURAL SITES IN SAN MIGOS, ECUADOR AND RIO MAR, PERU

During the summer of 2017 in San Migos, Ecuador, I was taken aback at the concept of assigning a numerical value to a human. Ecuador’s disability policies and practices assign a score to a disabled person which determines the benefits he or she will supposedly receive. Such a numerical value had so much power in offering financial assistance and a chance at a more equal life, but such a numerical value was also clouded in an unknown, subjective process. My field experience in San Migos indicates that one medical professional is responsible for assigning an individual’s disability score and thus totally shaping that person’s quality of life. My research in Rio Mar, Peru in spring 2018, however, revealed that it is a privilege of the local individuals to have the knowledge that programs for disabled people exist. Most disabled people had no inkling that a certificate of disability was a possibility and what it could provide for them.

Ecuador and Peru have passed policies to promote the inclusion of individuals with disabilities into mainstream society. As mentioned in an earlier section, these laws are in an effort to make individuals with disabilities somewhat equal to their able-bodied counterparts. The law outlines the process by which individuals must register their disability in order to be considered a disabled individual under the law. Once people are recognized as disabled individuals, they are guaranteed basic human rights, such as inclusion in public spaces, anti-discrimination in the workplace and school, and access to affordable medical care in their given communities.

Although there is always room for improvement in the enforcement of these laws, Ecuador has been fairly progressive and liberal in their social policies. Ecuador has been a pioneer and example for the social protection of indigenous communities and has been an exemplary model for how governmental programs can aid disabled populations. According to the World Bank, five countries attended a conference led by Ecuador, at which Ecuador promoted their Manuela Espejo Program and discussed useful measures to include disabled populations in general areas.

In the area of disabilities, Ecuador is becoming a true laboratory for Latin America.

–Cristhian Córdova, budget and planning manager of the Peruvian National Council for the Integration of People with Disabilities

Previous laws have been placed to protect disabled populations in Ecuador. In 2012, President Rafael Correa passed a law that called for the inclusion and social protections of disabled people in public and private spaces. These changes have slowly been coming to fruition. Within one year, I noticed more inclusivity among children with disabilities in San Migos, Ecuador. Children who were previously suspended from local schools were re-enrolled and representatives from Manuela Espejo were visiting the community to record the needs of individuals with disabilities. There was an additional sense of pride that was more present. Individuals with disabilities are excited to be part of a country where their president is just like them.

Even in rural zones, at least as far as my research in San Migos suggests, Ecuador has managed to streamline the process of registering a disability. With new technology and an increasing number of medical doctors who can diagnose disability, the process has become efficient systematically. However, as discussed previously, there are still barriers to reaching this point.

Conversely, Peru has struggled in their ability to adopt a similar system. The transmission of data is often slow and the reward is not high enough for individuals to want to wait for their registration to process. While Peru has prided itself on being one of the first countries to adopt a law that protects individuals with disabilities, according to people with whom I spoke in rural Peru, laws in Peru are simply not enforced. There is a long history of political corruption in contemporary times, and although the law promotes the inclusion of individuals with disabilities, the likelihood of it being enforced is slim. Individuals, from what I have gathered, have lost hope in politics and are waiting for a more stabilized form of government and representation.

The most updated version of the law for disabled people in Peru was passed in 2012. However, the law is not as ironclad and descriptive as the law in Ecuador. Ecuador passed a very comprehensive law that would take hours to read, line by line, whereas Peru passed a
law which attempted to say the same things that Ecuador said, but in a much more lackadaisical way.

To support disabled individuals in Peru, there is pressure to follow in Ecuador's footsteps by including individuals with disabilities into mainstream society. Unfortunately, Peru is not yet in a political state that allows for such laws to be fulfilled and complied with. When there is political unrest and corruption involved at the head of state, there is no room for the voices of the most vulnerable to be heard. Ecuador has faced extreme pressure from vulnerable populations to change the sociopolitical climate and increase protections, whereas Peru has either ignored the concerns of their people or have not yet faced the determination of the masses to change the system.

Neither country has had success in providing services that meet its disability policy goals. It is up to citizen-led initiatives to advocate for the political protection and social inclusion of individuals with disabilities. While it is unknown if the current legislature in Ecuador and Peru will be effective long-term, until individuals with disabilities are living in a more equitable system, there will always be room for sociopolitical improvements.

CLOSING THOUGHTS ON PHYSICAL DISABILITY POLICIES AND PRACTICE

Although the situation is improving in Ecuador, there is still work to be done. Individuals with disability are taken seriously by the community and government so long as there is pressure to improve the lives of these individuals. President Correa and Moreno have increased protective policies for individuals with disabilities and are in the stage of making processes to obtain a certificate more efficient.

At the community level, individuals like Freddy Pincay and Unidad San Mígos are raising their voices to bring attention to the medical, educational, and economic inequities that present themselves within rural zones of Ecuador.

Although resources may not be present at this time, there is hope on the horizon that change and progress will come under the leadership of the newly elected president, Lenin Moreno. Many families are hopeful that, with his leadership, there will be an increase in benefits for those with disabilities.

The situation for indigenous people with disabilities in a rural area of Río Mar, Peru is not easy and is not fair. The Peruvian government passed a law to protect people with disabilities, but only if they have registered their disabilities with the government.

It is clear that the process of recording disability is not easy for those living in a community outside the city, a rural area, or an indigenous community, such as Río Mar. There are barriers that people with disabilities face in Río Mar that do not allow them to receive a certificate and therefore do not allow them to receive their rights.

In reality, the law is only a document. Río Mar indigenous people with disabilities are not protected because there are structural barriers that prevent them from understanding their rights. It is a serious situation and one in which needs more attention to improve life for each indigenous person with a disability in a rural area. Access to the National Registry of Persons with Disabilities is access to a life with equal rights. But still, indigenous people in Río Mar are excluded from the process at the beginning of their lives.

Suggestions for Peru, Ecuador, and the Academic World

While Lenin Moreno has done substantial work for individuals with disabilities in Ecuador, there is still plenty of work to be done when it comes to implementing and aiding policy across the board in both Ecuador and Peru.

The government needs to enforce the laws that have been passed specifically for people with disabilities. The rhetoric changes country to country, but the general consensus is that there is always room for improvement when it comes to the compliance with laws. In Peru, it is the general consensus that there is no help or aid because of the political unrest, that the law consists of written promises that will never be fulfilled. In Ecuador, the rhetoric is filled with hope. Individuals know that there are protections and they have seen the good that has come out of their current president, but individuals in rural communities are still waiting for their concerns to be addressed.

Lenin Moreno is absolutely correct. The issue concerning the wellbeing of individuals with disabilities is all created within the structural framework of a given community. The rhetoric surrounding disability must change. The exclusion of individuals from school based on disability is not progressive. There must be dynamic shifts in the understanding of disability and that all begins with inclusion.

Due to exclusionary practices towards rural zones and indigenous communities, individuals are not getting much support and do not have access to knowledge of disability and laws. Most individuals in rural zones are disenfranchised by the system due to the inaccessibility of materials. There, individuals do not have internet on a day to day basis and are living paycheck to paycheck, so it is the least of their concerns to educate themselves lineby-line on laws for individuals with disabilities. There must be organizations present who understand this reality. The state has an obligation to protect individuals with disability and to support individual needs.

These laws need to be made more visible through mainstream media and within public schools so individuals and family members can have a better understanding of their rights as human beings. Once individuals are aware
of their rights, they will feel more empowered to press the government to comply with the promises granted to them in law. The government should respond by holding both public and private spaces accountable to protecting the laws of individuals with disabilities.

While education and enforcement would be helpful, there is still not enough medical staff readily available to diagnose and certify all individuals with disabilities. Many of these doctors are also general practitioners and must attend to the needs of general patients as well. Universities for physicians and government programs should offer incentives for physicians if they specialize and receive training to be qualified to certify disability. With more doctors, it is more likely that some will travel to serve vulnerable populations in rural areas. With that, disabled people would not need to travel or wait for long to receive a certificate of disability.

To conclude, there is an extreme lack of academic research on disability in Ecuador and Peru. There are no prior studies on the process of certifying disabilities. Research has yet to be published on how individuals are left out of the system before they even realize it, before they even have the title, “being disabled.” How do we understand that we need to improve the system without having research that describes the realities?

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Julia Scolapio is a 2019-2020 Fulbright Scholar to Ecuador. Scolapio graduated summa cum laude from the George Washington University ('19) with double honors in Dance and International Affairs, with a minor in sociocultural Anthropology. In 2018 she received the George Washington University Undergraduate Research award which allowed her to carry out field research on the policy and practice of disability in a rural zone of Ecuador. Scolapio carried out similar research while studying abroad in Peru. Her project received special recognition in GW Research Days 2019 as a special prize winner in Equity, Diversity, and Inclusion.

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**Mentor Details**

This paper was written with mentorship from Professor Barbara Miller.

Professor Barbara Miller received her B.A., M.A., and Ph.D. in anthropology from Syracuse University. She joined the Elliott School in 1993 as a specialist in the anthropology of international development. Most of her research has focused on gender and health in India and South Asia more generally. Professor Miller served as the Director of GW's Women's Studies Program from 1994-1999; as Associate Dean of the Elliott School from 1999-2002 and 2009-2012; as founding director of the Elliott School's Global Gender Research and Policy Program from 2010 to 2016; and as director of the Elliott School's Institute for Global and International Studies from 2012-2016.