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Suelen Callar: The Institutional Perceptions and Treatments of the Sexuality and Sexual Abuse of People with Intellectual and Psychological Disabilities in Guatemala

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Suelen Callar: The Institutional Perceptions and Treatments of the Sexuality and Sexual Abuse of People with Intellectual and Psychological Disabilities in Guatemala

by

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Dedication

To all of those fighting for the rights of people with disabilities in Guatemala. May they one day live in a world without barriers, and with justice, peace and equality.

Para todos los que luchan por los derechos de la gente con discapacidades en Guatemala. Que un día puedan vivir sin barreras, y con justicia, paz e igualdad.

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Abstract

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The understandings and treatments of the sexual rights of people with intellectual and psychological disabilities vary in different societies. However, one issue that is common in most societies is that this group of people experiences the highest rates of sexual violence and is regularly a-sexualized. Much attention has been paid to the increasingly visible issues of sexual violence in Latin America in a gendered and racial context, however recent scholarship has neglected to look at sexual violence in the context of people with disabilities. In this text, I aim to uncover how the human rights, and more specifically, sexual rights, are understood and treated for this highly marginalized group of people in Guatemala, a country that has endured heavy amounts of violence and trauma both contemporarily and historically.

Through ethnographic fieldwork conducted at institutions for disability services in urban Guatemala, I paint a picture of how the contemporary social and political climate involving violence, nearly complete impunity for crimes, culturally engrained patriarchal norms and neoliberal policies affect this group of people who are often depoliticized through patronizing portrayals in media and the public arena. Using in depth investigations of Guatemalan law and observational work and interviews conducted in public government-funded institutions, NGOs and non-profit organizations and human rights organizations, I seek to reveal the paradigms within the disparate types of institutions for understanding and treating people with disabilities. By questioning the institutional perceptions and treatments of the sexuality and sexual abuse of people with intellectual and psychological disabilities, I seek to examine the different ways cognitive disability has been socially constructed in Guatemala and the different reasons behind this group's social abandonment and high rates of sexual violence towards them. This work problematizes medical and charity models utilized for understanding disability that have been implemented through law, institutional and public policies, and societal misconceptions. This research also challenges Western disability policies and conceptions that have been imposed in developing countries like Guatemala, and questions the possibility to create spaces of local disability rights activism in spite of high risk factors for violence and neoliberal policies that limit political protest.

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INTRODUCTION

> “Over the clanking of the old jeep's motor as we trucked down the hill, I spoke with my escort from a domestic human rights organization about my sadness over the tales I had just heard in the national mental hospital. I wanted to know and continued to beg the question, what could be done by the staff there to end the constant sexual violence towards the 'patients' with intellectual and psychological disabilities? In a tone of exhaustion, my escort explained, 'They stay quiet. (*Suelen callar.*) What else can they do? (*¿Qué mas pueden hacer?*)'” - Fieldwork reflections, Serrano, July 2010

Intellectual and psychological disabilities, or different cognitive abilities, are human experiences and attributed characteristics that have been socially constructed, are historically diverse and have in turn become political issues (Oliver, 2001). Sexuality, while often thought of as a private issue, is a dimension of humanity that is socially constructed, historically diverse, and is in turn a profoundly political issue as well (Seidman, 1996). When the two taboo topics of sexuality and different cognitive ability meet in the political realm in any part of the world, many contentious issues over fundamental human rights emerge (Wilkerson, 2002). Questions of sterilization, eugenics, dependency, access, government funding, isolation, the definition of sexual violence and the definition of basic humanity unfold in the political convergence of sexuality and cognitive ability that would not otherwise come to light. The understandings and treatments of the sexual rights of people experiencing intellectual and psychological disabilities are divergent in different societies. One must consider how these controversial and taboo human rights are treated in a society already plagued by atrocities against humanity. This text takes aim to uncover how the human rights, and more specifically, sexual rights, are understood and treated for this highly marginalized group of people in Guatemala, a country that has endured heavy amounts of violence and trauma both contemporarily and historically.

The Guatemalan Civil War (often called the internal armed conflict), began with a CIA-backed invasion of the country in 1954 and did not officially end until 1996 with the signing of the Peace Accords. This left the country in need of healing after a genocide of over 200,000 Maya indigenous people and the disappearance of more than 50,000 others (Oettler, 2006). Guatemala's government is often considered corrupt, unstable, and dependent on foreign businesses and organizations for funding. The head of the United Nations-backed commission set up to combat impunity in Guatemala resigned in June of 2010 on the grounds that the Guatemalan government would not follow any anti-impunity measures suggested by the commission (“Head of UN anti-impunity panel,” 2010). Due to heavy violence from gangs and drug-traffickers, the average daily murder-toll, contemporarily in the capital city, Guatemala City, is higher than it was during the Guatemalan Civil War (“Crime and politics,” 2009). According to the Human Rights Procurator of Guatemala, in this Central American country with a population of about 14.35 million people, there were 5,437 murders reported in 2010 alone (Morales Alvaredo, 2011). The contemporary murder rate is double that of its neighbor, Mexico, and ten times greater than that found in the United States (“The tormented isthmus,” 2011). The country's population has a 43% prevalence rate of chronic malnutrition and 47% of the population does not have access to potable drinking water. 21.5% of people in Guatemala are living on less than $1 a day (“Humanitarian Appeal,” 2010).

The conditions in which people with different cognitive abilities and a large portion of the Guatemalan population live under in this Central American country, must be taken into context to begin to understand the treatment of a group like people with different cognitive abilities, who are considered "undesired," "unproductive," and "a societal burden." I utilize the term "people with different cognitive abilities" to refer to the group of people whose rights I am studying. I use this term not only because it relates to different ability levels of a psychological and intellectual nature, but also because it is difficult to fully promote the agency of a person with a different cognitive ability if one uses the term "disability" or "disabled" as being a defining aspect of a person. Disability means "without ability." To say someone is "cognitively disabled" can be interpreted as someone not having the ability for cognition. However, one can certainly experience an intellectual or psychological disability. Misconceptions and hegemonic societal values of what is normal[1] that have been imposed upon a person with different cognitive abilities can effectively create barriers in society and disable a person's ability to access the outside community or his or her rights (Oliver, 2001). I am advocating for the agency of people with different cognitive abilities or who are experiencing or have psychological or intellectual disabilities. They should be allowed to make their own choices in regards to their sexuality, receive assistance in making decisions if they wish to, and should have the same rights as people who do not have disabilities. In this argument, their education

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[1] In regards to "hegemonic societal values of what is normal" I refer to how people are taught to understand sanity and intelligence and how certain characteristics or habits that are not considered "normal" by the majority of society. These habits or characteristics do not necessarily cause complications or pose an actual burden on society, but have been socially constructed as scary, a liability or problematic. Some of these characteristics or habits are staring, difficulty in controlling tone of voice, learning difficulties, self-injuring, different understandings of personal space and difficulty gauging emotional reactions.

must be promoted and their sexual development nurtured in order to aid their understanding of the difference between both positive and negative sexual experience[2] and how to prevent and report sexual violence. Other words utilized for referring to different cognitive abilities including mental deficiency, mental retardation, intellectual incapability, mongoloid, psycho, crazy, loony, insane, mental, deranged, invalid, sick in the head and a number of other terms promote the social construction of cognitive disability as a deficiency that makes a person experiencing an intellectual or psychological disability seem less human or worth less.

To my knowledge, this is the first ethnographic research looking at the inner workings of the institution that provides services to people with disabilities in any Central American country. The original goal of this work was simply to chart risk factors for sexual violence for people with different cognitive abilities in Guatemala. However, this work paints a much larger picture of how the contemporary political climate involving violence, nearly complete impunity for crimes, culturally engrained patriarchal norms and neoliberal policies affect a group of people often depoliticized through patronizing portrayals in media and the public arena (Shakespeare, 1997). This is done through institutional ethnographic work, looking at the institutional perceptions and treatments of the sexuality and sexual abuse of people with intellectual and psychological disabilities.[3] While the human rights and justice for people with disabilities in general is an extremely

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[2] I use positive sexual experience to refer to any desired consensual act of a sexual nature. Negative sexual experience is any form of sexual violence.

[3] Some of the more common diagnoses I am referring to for intellectual disabilities are Down syndrome, fragile X syndrome, “mental retardation” and autism. Some more common diagnoses for psychological disabilities I refer to are schizophrenia, bipolar disorder, megalomania and psychosis.

important issue, focusing specifically on the realm of sexual rights and on sexual violence towards this group, allows for a case study that reveals the extent to which people with different cognitive abilities are understood as complete human beings with agency. By focusing on sexuality and sexual violence, an arena often considered taboo for people with different cognitive abilities, there is a space to discuss complete equal rights and justice, outside of those rights more likely to be considered basic, like food, water and shelter. There is also a space to discuss the number of risk factors for sexual violence often unidentified for people with different cognitive disabilities.

SEXUAL VIOLENCE FOR THE SOCIALLY ABANDONED

Within the sexual rights all people should be mandated, there is the right to live free of sexual violence. For the purposes of this study, I will borrow from the 2002 World Health Organization's definition of sexual violence, which is “any sexual act, attempt to obtain a sexual act, unwanted sexual comments or advances, or acts to traffic, or otherwise directed, against a person’s sexuality using coercion, by any person regardless of their relationship to the victim, in any setting, including but not limited to home and work.” (Jewkes et al., 2002, p.149)

According to one of the most relied upon studies of the sexual abuse of people with intellectual disabilities, 80% of the people with intellectual disabilities who were questioned had experienced sexual assault at least once in their lives and 49.6% of them had experienced sexual assault ten or more times (Sobsey and Doe, 1991). This study was conducted in Canada and the United States, where the situations for people with different cognitive abilities are obviously less than ideal, but there are still a greater number of resources and a much higher degree of enforcement of legislation promoting their human rights and preventing impunity in sexual violence. One could assume that because of this and other factors in Guatemala that the rate of sexual abuse is even higher than the rate found in Canada and the United States. There are, however, no reliable statistics on the rate of sexual abuse among people with intellectual or psychological disabilities in Guatemala. Within the statistics that are available, as of 2009, only 2% of reported sexually violent crimes in Guatemala made it to courts (Guatemalan Human Rights Commission, 2009). Besides nearly guaranteed impunity for sexual abusers in Guatemala, there are specific risk factors faced by people experiencing intellectual and psychological disabilities that increase the likelihood that they will experience sexual violence at some point in their lives.

Some of the specific risk factors faced by people with cognitive disabilities in regards to sexual abuse were highlighted in a study executed in Guatemala City and Quetzaltenango about the sexual abuse of children and adolescents with disabilities (ASCATED et al., 2004). The expansive list of risk factors noted includes:[4] a condition of submission and dependence often inculcated into people with different cognitive abilities; they often have low self esteems due to ostracization; they are not aware of what is sexual abuse and manners of avoiding it; due to physical limitations, they may have less strength to physically resist abuse; they are often accustomed to unequal treatment; they are often placed in large institutions where there is a large amount of

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[4] The study that this list of risk factors for sexual abuse comes from will be discussed more in later chapters.

workers who have isolated access to them;[5] in these institutions people with different cognitive abilities remain separated from society and reporting sexual abuse to someone on the outside is difficult or impossible; there is often a physical or affective dependence on the aggressor; they may lack the language ability to describe what has occurred; they may be convinced they are able to trust their victimizer and therefore any form of abuse is not considered as such; they may not note when the sexual abuse occurs and reoccurs because they are used to abuse from a young age; they may be scared to report the abuse because they are threatened with some form of violence if they tell anyone; they are able to confuse positive affection with sexual abuse, due to a lack of affection from family members or institutional workers; because of a necessity for assistance in bathing, toileting or dressing, some abusers may have extra opportunities for abuse; people with different cognitive abilities may feel a necessity to be valorized or accepted, placing them at risk for abuse; people often consider them unattractive and therefore it is assumed a person would not sexually abuse them; if people with different cognitive abilities do report abuse, it is often believed that they did not interpret the victimizer's actions correctly; actions that one would interpret as signs of abuse like aggression, changes in conduct or signs of terror are often attributed to the perceived disability; they are often isolated from society and don't have many people to tell in either their homes or institutions; there is little to no sexual education for the population; and a dehumanization

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[5] “Isolated access” refers to moments where these often untrained or under-qualified institutional workers are alone with clients with different cognitive abilities on a regular basis, or the workers are placed in a position in which they are the only people in charge of all of their clients' needs.

of people experiencing intellectual or psychological disabilities in institutions in which they live can result in authoritarianism and violence in their treatment.

Besides the extensive list of previously mentioned risks found in the Guatemalan study that only looked at children with disabilities, there are some other risk factors for sexual violence for people with intellectual and psychological disabilities that I have noted in my own research and experience in both the United States and Guatemala. Firstly, there is often a lack of positive sexual experience for people with different cognitive abilities. If a person does not have access to positive sexual experience, it may be difficult to identify when there is a negative sexual experience. According to my interlocutors in Guatemala, people with different cognitive abilities are highly stigmatized and are often considered curses for family member's sins or it is believed that the experienced psychological or intellectual disability did not come into fruition until someone decided to place a curse on the family. These beliefs that bring shame to family members, could make them want to hide the person with different cognitive abilities from the rest of the world. These stigmas can create violence in isolation due to resentment over the fact that the person with an intellectual or psychological disability is a perceived manifestation of the family's sins.

Adults with different cognitive abilities are often infantilized due to paternalistic ideas about behaviors and education of the group of people. These adults are also desexualized because it is assumed that people with “child-like mentalities” do not have “adult-like” sexual desires, even though, according to Anissa Ryland (personal communication, March 3, 2010) they experience for the most part “normal” hormonal development. A forgotten sexuality can mean that one deprives that person of sexual experience and sexual abuse of that person can occur without notice.

Another issue I have noted involves how the general public perceives family members and institutional workers that tolerate people with different cognitive abilities or provide services to them. Due to the fact that a discourse of charity surrounds this group of people, those who work with them or who are willing to spend extended amounts of time with them must be “good people.” Often times when I've told others what my research topic is or of past work that I have done with people with disabilities in the United States and in Guatemala, people have reacted by telling me that I am “an angel,” a “good Samaritan,” a “giver” or that I must be a “good Christian girl.” Aside from further promoting the patronization of people with different cognitive abilities, this common occurrence creates a lack of vigilance towards workers in the institution providing services to people with different cognitive abilities as well as their family members. It can be assumed that a “good person” who is willing to work with this “poor population” would not abuse them. The ASCATED et al. (2004) study also evidenced that family members, institutional workers and others close to individuals with disabilities are the most likely abusers.

POSITIONALITY

The study of the sexual rights of people with intellectual and psychological disabilities and the prevention of sexual violence in general are deeply personal issues for me. I feel my background both in my work and growing up with people with different cognitive abilities and my own experiences with sexual violence have helped me connect with this topic of study. I grew up with people with disabilities in my home because my mother worked as a Foster Mother in California for a branch of Foster Care called Respite.[6] Respite, in California, provided child care for parents trying to get back on their feet after regaining custody of their children who had previously been removed from what Child Protective Services deemed abusive or dangerous situations. This program provided short-term childcare for the parents while they took classes, attended meetings, went to work, went away on long weekends, sought refuge from domestic abuse, reformed relationships with other children, or attended to personal matters. My house also served as a transition home for children in the adoption process. Children would come to our house during the day, over long weekends, or for extended periods of time. This system was a method to both provide free child care for families in transition and to monitor the parents and children to assure that they were not in abusive situations. The majority of the children that were placed in our home were experiencing some form of disability because our house was accessible, my mother had grown up with a girl with an intellectual disability, and she was accepting of children with disabilities. There is also a highly disproportionate number of children experiencing disabilities in the Foster Care system when compared to the rest of the population (National Council on Disability, 2008).

When I was a young child, the "Respite kids" (as we referred to them) were my playmates. As the oldest of four daughters, when I grew older, it became part of my responsibilities, along with my two middle sisters' responsibilities, to help my mother

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[6] Respite no longer exists as a government program in California.

with the Respite kids. A number of the children in our home were survivors of sexual abuse, and although this was rarely spoken of in my household, I understood that I needed to avoid talking about certain topics and discussing certain people (their abusers) with the children.

While I was an undergraduate in college in 2006, I decided a good field for me to find work in was special education, due to my extensive background with children experiencing disabilities in my home. My first job outside of volunteer work with people with disabilities was as an instructional aide in a special abilities cluster in a high school in Southern California. While employed at the high school, I worked in both a low ratio integration classroom for people with profound intellectual disabilities and as an instructional aide in an Adaptive Physical Education classroom. In my time at the high school I heard countless stories of sexual abuse by family members of my students, found out about a teacher's sexual abuse of a student for disciplinary reasons, and saw the negation of the sexuality of my students on a regular basis. This experience was both shocking and eye opening.

I later went on to do volunteer work at an organization in Spain that promoted inclusion of people with disabilities in the community, while I studied abroad for a year in Madrid. Upon my return from Europe, in my last year as an undergraduate student, I worked as a tutor in a group home for six boys on varying levels of the autism spectrum. Several of my students had multiple diagnoses that included psychological disabilities like schizophrenia. In my time working one-on-one with the boys in the group home I gained a greater understanding of the dependence on the medicalization of disability in under-staffed institutions.

Upon finishing my undergraduate degrees in Spanish and Latin American Studies with a minor in Communications, I decided I wanted to continue to work with people with intellectual disabilities. I moved to Austin, Texas to carry on my studies in the Lozano Long Institute of Latin American Studies at the University of Texas at Austin, which is the institution that allowed me to conduct research for this ethnography. During my time in graduate school in Texas I have worked as an independence coach for an 11-year-old girl with a developmental disability and as a volunteer translator for an autism outreach program on the Mexico-Texas border. I did ethnographic fieldwork in Austin on the institutional perceptions and treatments of the sexuality and sexual abuse of people with intellectual disabilities as a preliminary investigation before conducting fieldwork in Guatemala. After closing my fieldwork in Guatemala in 2010, I observed sexuality and relationship classes as well as personal safety classes for adults with disabilities at a non-profit in Austin. I also taught a mind and body yoga class series to the adults at the non-profit.

In my work in Southern California, Spain and Texas, I have witnessed overt denials of the sexual abuse and sexual desires or needs of people with intellectual and psychological disabilities. My clients, students, and friends that have intellectual disabilities have confided in me about violence they have endured. I have felt helpless in attempts to report incidents of different types of abuse both because people do not feel that the abuse is understood by individuals with intellectual disabilities and because perceptions of what is and is not abuse for a person seem to change if the abused or abuser has a different cognitive ability. As a consequence of the inherent injustices and risk factors for sexual abuse for this group, incidents witnessed, and horror stories I have heard, I chose the sexual rights of people with intellectual and psychological disabilities for my research topic.

Sexual violence in general is an important issue to me for several reasons. A number of women in my family, including myself, are survivors of sexual violence. I felt the pressure and fears of destroying the fabric of my family if the secret of the abuse that my other female family members and I endured came to light. One older male cousin was able to violate a group of the younger females in my extended family. When we revealed the abuses, the other survivors and I still had to stomach his presence at family gatherings for almost a year. In order to keep the family together there were a series of biased therapy sessions, masked excuses, and false medical diagnoses of the rapist. After this process of denial, anger and grieving, most of the other victims and I were finally free from seeing our abuser.

In the years since my female family members and I escaped from the veil of the "wholesome American family," the majority of us have been able to tell our stories and steer clear of our abuser and those who tried to force us to continue seeing him. In this process, I have gained a greater understanding of how deeply sexual violence affects a person's mental state and sense of security. My experience revealed the desire to deny or excuse the taboo of incestuous sexual violence as well as the effects this type of violence has on a family and community.

I am also a survivor of dating violence. I was unaware of my survivor status until I was educated about what a person could and could not do to me in a romantic relationship without my permission or with my resistance. I blame my late identification of the sexual violence, in part, on my highly medicalized sexual education, a fear of a re-pathologization of my sexual experiences, and a lack of basis for understanding what is a truly positive sexual experience. As an undergraduate college student I was not socially equipped with the mental tools to comprehend, identify, and report the violence. While I demonstrated agency and resistance in all of my experiences with sexual violence, I still felt vulnerable and often helpless.

These experiences have steered my academic interests towards studies of the cultural scaffolding of sexual violence and methods of prevention and education. It is for this reason that I began my studies in Guatemala. In my final year as an undergraduate student at California State University of Fullerton, I was given the task of making a mini documentary as an independent studies project. I chose to look at a transnational feminist gender education project that was instigated by a Guatemalan-American woman, Lucia Muñoz, as a method of prevention for feminicide in Guatemala.[7] The organization called MIA, *Mujeres Iniciando en la Américas* (Women Pioneering in the Americas),[8] worked in promoting litigations with women's rights activists and teaching classes on gender equality in grade schools in Guatemala City. The idea was to work against future gender violence through education of young folks. As I worked with Guatemalan and

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[7] For more information on feminicide, refer to, Fregoso and Bejarano. (2010).

[8] For more information on MIA, refer to http://miamericas.info.

Guatemalan-American women for the documentary, while researching the topic of femincide, I became interested in the effects of culturally engrained patriarchal norms, the effects of neoliberalism in Latin America, and how quotidian public violence pervades into private domiciles through domestic and sexual abuse.

After my first semester at the Teresa Lozano Long Institute of Latin American Studies at the University of Texas at Austin, I opted to write my Master's thesis on the convergence of the three topics: cognitive disability, sexual violence and Guatemala. Upon further inquiry, I found little to no research conducted on sexual violence towards people with different cognitive abilities in Guatemala. A study of this nature would allow me to investigate the effects of high rates of violence and impunity, neoliberal policies, and culturally engrained patriarchal norms on the social construction of disability and sexual agency. The political, cultural, social and economic layers that are revealed in this study open up discussions about the effects of charity and medical discourses often surrounding people with disabilities while taking specific aim at challenging patriarchal norms imposed as forms of repression and exclusion.

Methodology

The original plan for this study was to focus singularly on the sexual rights of people with intellectual disabilities. However, when I began research in Guatemala City in 2010, I recognized that there were almost no resources for people with psychological disabilities. Within the few institutions that did work with people with psychological disabilities, there were a number of adults with intellectual disabilities. I came across confusion about the difference between the two forms of disability in the public arena and found out how the law often placed people with intellectual and psychological disabilities under the same restrictions. This led me to include institutions that work with people with psychological disabilities in the study as well.

In addition, I initially wanted to interview people diagnosed with intellectual disabilities themselves for this study. This would be a method to see how they perceived themselves, their basic human rights and their ability to exercise sexual agency. Interviewing the people with disabilities themselves would have been the ideal study in order to include their words and thoughts. However, the University of Texas Institutional Review Board (IRB) does not allow or instigates a difficult process to receive permissions to conduct a study of that nature because people with intellectual disabilities and psychological disabilities are considered a “vulnerable population” (Office of Research Report, 2011). This condition found in the guidelines of the University of Texas' Institutional Review Board in it self is an example of paternalistic ideas about adults with different cognitive abilities. It usurps their agency and their ability to decide whether or not they would like to participate in a study.

After learning about limitations regarding whom I would be able to work with for a study on the sexual rights of people with different cognitive abilities, I opted to do an institutional ethnography. I would interview those who work in and control the institutions that provide services to those with intellectual and psychological disabilities. As a person who has worked in several different fields within the institution that offers services to people with intellectual disabilities in the United States, I would have a common ground in regards to discussing issues that occur when working in disability services. By speaking with institutional workers and studying policies, publicity, and publications from Guatemala about people with intellectual and psychological disabilities, I could procure how the sexuality and sexual abuse of people with cognitive disabilities are understood and treated.

Due to the limited time I had to conduct fieldwork in Guatemala and because the majority of public institutions are located in the capital, my ethnographic fieldwork was limited to the greater Guatemala City area. The cities in which I conducted research were Guatemala City, Mixco and Antigua. I had not originally planned to do work in Antigua because it is located outside of the department of Guatemala in the department of Sacatepequez. However, Antigua is a short one-hour drive outside of Guatemala City and my interlocutors often told me that it is the most accessible city in all of Guatemala, due to the fact that there are a number of curb cuts and tiles in the sidewalk to designate handicap parking.[9] The small-town, safe(r), and international tourist-filled environment provided a significantly different viewpoint of how people with disabilities are understood and treated. There were substantially fewer international volunteers in institutions in Guatemala City and Mixco due to questions of safety and a lack of tourist attractions.

The institutional work my interlocutors did came from a wide range of arenas. The list of positions in institutions ranged from directors of hospitals providing medical

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[9] According to my interlocutors, very few people pay attention to the handicap parking tiles on curbs. These curb cuts and handicap parking tiles are mostly located in the center of Antigua. They are difficult to find once one leaves the more tourist-friendly areas of town. All of the roads are made of cobblestones, so although there are curb cuts it is still difficult to walk if one has certain physical or sensory impairments.

care to people with disabilities, to special education teachers, to psychologists, to human rights organization representatives, to rape crisis center representatives, to workers at non-profits and NGOs, to administrative workers at the National Council for Attention to Persons with Disabilities, to social workers, to religious vocational workers. The wide range of people working in the institution providing services to people experiencing disabilities gave me a cornucopia of ideas, policies, and opinions to sort through. Even though I came to Guatemala with only a few contacts, I was able to use the snowball method and ended up conducting official tape-recorded interviews with 30 different institutional workers.

Because sexuality is such a taboo topic in Guatemala, I felt it would be difficult to directly present my research as a study of my interlocutors' perceptions and treatments of the sexuality and sexual abuse of people experiencing intellectual and psychological disabilities. I would not have received a number of the interviews that I was granted and I would not have been permitted to enter a number of the institutions. After consultation with my advisers at the University of Texas and with friends in academia from Guatemala, I decided to present my study as an ethnographic work on the institutional perceptions of the state of life of people with different cognitive abilities. While this research topic title did not specifically highlight the topic of sexuality and sexual abuse, it did leave room for me to question my interlocutors about the sensitive issue. This is apparent when one considers the important role my interlocutors and their institutions played in the prevention of the sexual abuse (or any type of abuse for that matter) and the monitoring of their behaviors (sexual and non-sexual). The way I presented my research topic also allowed me to find out more about the general treatment of people with intellectual and psychological disabilities, while warming up to the topics of sexuality and abuse. These basic questions generated many fruitful observations and ideas in our conversations.

The majority of the appointments and initial contact made for interviews with my interlocutors were arranged via e-mail. At times, I was unable to converse with my interlocutors through e-mail and I utilized the telephone. I introduced myself as a Master's student from the University of Texas at Austin researching the human rights and state of life of people with different cognitive abilities. All of my formal interviews were tape-recorded, but several informal interviews were conducted as well while doing observations in institutions, which were not tape-recorded. I interviewed the majority of my interlocutors one time, but a few requested to speak with me on more than one occasion. The majority of my formal interviews lasted between one and one-and-a-half hours. The time range, however, was broad due to busy schedules of my interlocutors or multiple interviews requested by some of them. My shortest formal interview lasted seven minutes, and my longest interview, after adding up all three of our formal conversations, lasted seven hours. All interviews except for one were conducted one-on-one. At my interlocutors' requests, one interview was conducted in a restaurant with three people from a group that provides services to people on the autism spectrum. Most interviews were conducted in the institutions that my informants worked in, while a few were executed in restaurants or cafes if the institutions did not have formal establishments. I also did observations in two institutions without formally interviewing anyone. This occurred either because people working in them were too busy for an interview or they did not feel comfortable giving formal interviews. I was able to enter and conduct observations in 21 different institutional establishments.

For the purposes of the security of my interlocutors, I will use pseudo names for my informants. While I will use the real name of the majority of the public institutions, I will not state the exact job titles held by my interlocutors. I will only name these public institutions if I will be citing their publicity pieces or reports by them and publications about them. Private institutions will be given pseudo names to provide anonymity to both the workers and the organizations. For some of my interlocutors, anonymity was a much higher priority. One interlocutor who works in a public institution, Alex, requested that I not ever use gender in reference to him or her. I feel it necessary to respect all requests for heightened anonymity in this study.

I conducted all of the formal interviews for this study between June and August of 2010. I took the academic school year of fall of 2010 and spring of 2011 to process the information, and returned the following July of 2011 to discuss my results in a series of talks with interlocutors and community members. I received follow up information from a few of my interlocutors who knew of changes in the system during the year that I was away. The talks I gave discussed many of the basic findings of my thesis involving the lack of application of laws, scarcity of government support, and issues stemming from charity-driven and medicalized discourses within the institutions.

Although I invited all of my interlocutors whose contact information I had, only four interlocutors attended the three sessions. A total of 18 people attended the sessions.

The majority of the attendees were members of the institution providing services to people with intellectual disabilities whom I had not formally interviewed. I held two talks on weekend days, one on a Saturday and one on a Sunday. The last talk took place on a Wednesday evening. All three of them were held at the Casa Herrera, a house that is rented by the University of Texas at Austin in Antigua. A number of my interlocutors in Mixco and Guatemala City told me that they had a difficult time getting to Antigua for the talks due to the fact that it was the rainy season and it is often difficult to arrive in the rain. Others did not respond to the e-mails or phone messages I sent them and may not have been interested in the results, did not have time to come to the talks, had prior engagements, or for any other reasons. I spoke with three of my interlocutors who were unable to attend any of the talks informally at their request in July of 2011 as well.

Outside of interviews and observations in institutions, I also did research in three different libraries while in Guatemala City in 2010. I did research in the University of San Carlos's library of Psychology and in their library of Medicine.[10] I also did research in FLACSO's library in Guatemala City.[11] I searched databases and received assistance from librarians in every library. In the three libraries, I only found three different texts that discussed the sexuality of people with different cognitive abilities. Two were published theses from the University of San Carlos in Guatemala City from the school of Psychological Sciences. Both are manuals for sexual education that are geared towards parents of children and adolescents with intellectual disabilities. The first manual,

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[10] The University of San Carlos is the public university system of Guatemala. For more information on the university and its library system see, http://www.usac.edu.gt.

[11] FLACSO is the Latin America School of Social Sciences. For more information on the library FLACSO has in Guatemala City see, http://www.flacso.edu.gt/portal/?page_id=120.

“Sexual education directed towards parents of children with teachable mental retardation that attend the Neurological Institute of Guatemala” was written by Ardón Aguilar and Colomo Ortíz (1986). A second manual by Padilla Lechuga et al. (1993) is called “Elaboration of a manual of information directed towards parents of families, regarding the psychosexual development of the moderately mentally deficient adolescent.” They both discussed the reproductive system, methods of promoting personal hygiene, ways to avoid sexual violence from strangers, and stressed the importance of sexual education through parents of people with intellectual disabilities. The two studies are outdated, in regards to laws and the rights of people with disabilities. The manuals are both conservative in regards to ideas of sexual access for people with disabilities as well. The only empirical research conducted for the 1993 manual was a six-question survey given to parents in one special education school. The 1986 manual did not mention any form of original research or work with primary sources.

The other academic text that touches on the sexuality of people with different cognitive abilities is a book published by a Guatemalan doctor, Marco Antonio Acevedo (2007), about “caring” for people with Down syndrome, called “Down Syndrome in Guatemala.” There are several pieces of incorrect, unresearched, and heteronormative information included in the three pages that Dr. Acevedo dedicated to the sexuality of people with Down syndrome. This work will be further discussed later on in the text.

I also received the opportunity to conduct extended research in one institution. Early on in my research, in the summer of 2010, I received an invitation from a local non-profit organization to volunteer teach yoga. The non-profit is a school for children experiencing multiple disabilities that I will call SOFDAB (Schooling Organization for the Deaf and Blind). I will go much more into detail about my time at SOFDAB in later chapters.

LIMITATIONS

There are some limitations to this study that should be acknowledged. The first is that I only conducted work in institutions that provide services to people with disabilities. According to the director of SOFDAB, only 25% of people with disabilities in Guatemala have access to any form of services. This means, that in studying institutions and only interviewing people who work with these organizations, I am unable to research the conditions of the lives of people who do not receive services. People who do not receive services may not have access to them, may not be informed about services available, or may not trust or want them. According to many of my interlocutors, due to the fact that so few services are provided, many people with different cognitive abilities are jailed inside of their family homes at all times. It is this group of people whom, while I did hear stories about them, I am unable to know the situation that they live in.

The areas of Guatemala in which I conducted my investigations also limit my study. I remained in an entirely urban area of the country. When one considers that Guatemala has one of the lowest urban population percentages in Latin America, this is an extremely limiting factor (Lindstrom, 2003). People in rural communities live in distinctly different conditions. All major national governmental services for people with disabilities are based in Guatemala City and NGOs and non-profits that provide support for people experiencing disabilities are much scarcer in rural areas.

There are certain conditions of this study to consider when taking my positionality into account as well. In regards to my ethnic background, while I do have a Spanish surname, Serrano, I am not of Guatemalan descent. I have some Mexican heritage on my father's side. The Mexicans in my family are Criollo. My mother is of Western European decent, I was born in the United States, my hair is blonde and I have white skin. Although my last name and darker facial features (brown eyes and dark eyebrows) were often a topic of curiosity and interest during interviews with my interlocutors, it is clear that I am an outsider. In a country that still deals with several racial issues, as a white-skinned American woman, I live in a position of privilege. According to a number of my Guatemalan friends who conduct research in the country, as an American researcher, they believe I gained access to many institutions with much more facility and more quickly than Guatemalan researchers would.

For the vast majority of my interlocutors, I was the first international researcher who had interviewed them, even those in higher positions. As an outsider, some of my interlocutors may have viewed me as a threat or someone looking to criticize the services they provide. Other interlocutors confessed they felt more comfortable telling me stories that they would not talk to others about because I was not a part of the institution in Guatemala. A number of my interlocutors who worked for institutions that were dependent on international funding or who were working to attain it, viewed a visit from me as an opportunity to network for funding sources. While I did purchase the occasional chocolate bar made by “special children” in a few of the non-profits, I did not directly donate to any institutions. Since my return from Guatemala in 2010, three different non-profit institutions in which I conducted interviews and observations have asked me if I can network for them to find American philanthropists. This need to advertise to the potential foreign investor or link to international funding likely affected how my interlocutors responded to questions.

My white skin and American privilege also affected how people touched on racial issues in the country. Being Mayan (and with darker skin) in Guatemala, is often equated with being poor or from a rural area. None of my interlocutors self-identified as Mayan, which is a reflection of the lack of access to "professionalized jobs" and education for the Mayan population in Guatemala. To avoid the racial question, my interlocutors would often refer to the Maya as people from rural areas or the poor (*los pobres*). There were many stereotypes relayed to me about Mayan treatments and understandings of people with disabilities. Many of my interlocutors told me that people in "the rural areas" are uneducated and believe that people with disabilities are curses, punishments for sins, or are possessed by demons. This may be true for some people due to a lack of education, but this certainly does not only occur in rural areas and is not a belief limited only to Mayan Guatemalans. When I did speak with different people who had worked in a number of Mayan communities or were from Mayan communities, they all talked about how much more inclusive the rural indigenous communities are than urban ladino communities for people with disabilities. Some talked about how in Mayan communities there is an idea that everyone has a role in society, including those with disabilities. Others told me that while in urban areas, one would rarely see people with disabilities out in public (unless they are begging in the streets),[12] people with disabilities are often outside in small Mayan communities. Workers in the institution who had spent little or no time in Mayan communities themselves often relayed the aforementioned stereotypes about Mayan communities' treatments and perceptions of disabilities to me. In the institutions for people with cognitive disabilities that I entered, not a single person receiving services was dressed in Mayan *traje*,[13] spoke a Mayan language in my presence (England, 2003), or identified himself or herself to me as Mayan.

As a foreign researcher, I also have the luxury of distance and may be able to openly publish stories and opinions that workers in the institution cannot openly talk about for fear of loss of employment, resentment within the institution, or retaliation from people or groups inculcated in different incidences or situations. As I will discuss later on, the changing of political parties and governmental positions often signifies an attempt to fire workers that do not belong to a particular government official's political party. Therefore, making political statements openly can lead to a loss of employment.

I am also both limited and privileged due to the fact that I do not have a disability myself. I am limited because my understanding of disability is from an outsider's perspective. As an ally in the push for the rights and justice for people with disabilities, it is necessary for me to acknowledge that I can not speak for the group whose rights I am

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[12] According to a number of my interlocutors, people with physical and sensory disabilities are often seen in the streets begging because they do not have access to employment and it is the only method for them to make money. In Antigua, I saw three different mothers with children with disabilities who were using their children to ask for money from tourists. I also saw a number of men with physical disabilities and sensory disabilities asking for spare change or selling lottery tickets.

[13] Mayan women often wear *traje*, which is a specially designed shirt called a *huipil* and a skirt called a *corte*. The lack of *traje* worn by individuals who receive services could be due to institutions only dressing them in Western clothes.

advocating for, but rather, in solidarity with them. I am privileged, in Guatemala specifically, due to the extreme lack of accessibility in the country and pervasive presence of ableism. It would be tremendously difficult for people with certain impairments to conduct the same type of research that I did. A lack of ramps, elevators and accessible transportation would prevent those with different physical impairments from arriving at or entering establishments that I was able to enter. People with auditory or speech impairments would have a difficult time finding an interpreter in Guatemala, a country still divided on what form of sign language, if any, should be used (Fox Tree, 2009). I found physical barriers in nearly every institution I visited, but there were also attitudinal barriers in many institutions as well. The way individual workers understood people with disabilities also had an affect on access in the institutions in which they belonged. While all of the institutions in which I conducted research were apparently created to provide services for and to improve the lives of people with intellectual and psychological disabilities, a number of them promoted ableist policies and ideas.

ABLEISM AND UNDERSTANDING DISABILITY

Within the institutions that provide services to people with disabilities, in Guatemalan laws, and in society as a whole, ableist practices are promoted. Ableism, put simply, is the discrimination against people with disabilities based on their different impairments. However, similar to other forms of discrimination like sexism, racism, ageism and homophobia, there are institutionalized power inequalities that must be taken into account. Borrowing from Fiona AK Campbell (2001), ableism is, “a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human."

Ableism is a form of discrimination that favors those viewed as able-bodied or able-minded people. This carries the belief that any impairment a person may have is inherently negative and if granted the possibility, the disability must be mitigated, cured or disappeared. Exclusionary and repressive practices on a social, economic and cultural level are institutionalized, mandating which "abilities" are valued in society.

A large amount of the discrimination experienced by people with disabilities can be attributed to the paradigms utilized by different institutions, and more specifically the Guatemalan government, to understand and treat people with disabilities. The two models most often utilized to understand disability in the institutions and in the law in Guatemala are the charity model and the medical model. These paradigms, while executed on different levels, and not independently in institutions, allow for, and at times, mandate ableism. The use of these different paradigms in institutions further promotes ableist practices in society.

As mentioned before, disability is socially constructed. The impairments people may have, are the physical or mental features that prevent them from accessing the community and executing certain tasks in the same way as the majority of the population. The disability exists when there are barriers that prevent a person with an impairment from access in a community. This way of understanding disability is through the social model. This is the model I utilize to understand disability. Borrowing from the work of Mike Oliver (1996), by using this model, I do not wish to deny the very real presence of impairment, that may stem from personal restrictions, physical or psychological pain or specialized medical necessities, but rather, I wish to address "the social barriers of disability."

The medicalization of disability is seen as a method of social control. According to Peter Conrad (1992), "Medicalization occurs when a medical frame or definition has been applied to understand or manage a problem."(p.211) While some people with disabilities have recurrent health complications secondary to disability, the diagnosis or label of a disability does not inevitably mandate the need for ongoing medical surveillance (Hayes and Hannold, 2007). Michel Foucault (1989) charges that certain conditions or behaviors become distinguished through a "medical gaze" and that physicians may legitimately lay claim to all actions in regards to the condition. The medicalization of disability embraces the idea of able-bodiedness and able-mindedness, and reduces people with disabilities down to dysfunctional bodies and minds in need of medical treatment.

The medical model of disability relies heavily on the medicalization of people with disabilities, deemed sick. This is the paradigm most commonly used in the public institutions and by the Guatemalan government. This model looks at people with disabilities with pity and in a devaluing way, as the ill. People understanding disability through the medical model may either attempt to "cure" the disability or hide the person. Therefore, when people with intellectual disabilities cannot be cured of their "mental deficiency," they are placed in institutional settings away from the public or hidden in the home. People with different cognitive abilities in Guatemala are placed in public institutions through medical diagnosis, isolated from the outside community and controlled through pharmaceutical drugs.

An example of how the medical discourse is used to promote ableism in institutions is found in the most recent academic text I was able to find in Guatemala on disability that discusses sexuality. In the book, touched on earlier, titled "Down Syndrome in Guatemala," Acevedo (2007) speaks with an authoritative medical tone throughout the text, constantly referring to people with Down syndrome as "the patients" ("*los pacientes"*). As mentioned before, the book only dedicates three pages to the sexuality of people with Down syndrome. Those three pages are dedicated almost completely to limiting or denying the possibility that a person with Down syndrome would want access to positive sexual experience.

Under the heading, "Will they be able to marry when they are adults?" Acevedo (2007) wrote the following:

> "To facilitate things, nature has, in the majority of cases, diminished the libido of those patients, in the manner that they don't feel the same sexual appetite as normal people. Or there are very few of them, in a variable percentage, which instinctively and actually can decide to unite as a married couple. The man won't have erections and it is probable that he is sterile because of his low sperm count. Although the woman has all of her ovarian functions and her uterus is almost normal, she isn't going to feel an attraction to the opposite sex in a romantic manner either. Instead, what could happen for a woman is that she would be a victim of sexual abuse.
>
> Nevertheless there is a counterpoint as well. A normal man will not want to form a family with a woman that suffers from Down syndrome. Neither will a normal woman want to unite forever with a man that suffers from Down syndrome. For these reasons the possibility is very remote that the young people will be able to marry when they are adults. They will stay in their homes, forever accompanied by their parents until the parents are too old. That is when the brothers and sisters, who are 'healthy and normal' who are married in a home, integrate the patients into their families in an independent manner." (p. 234-235)

These two paragraphs riddled with personal moral judgments, assumptions, and fatalistic predictions paint a picture of how intellectual disability is often understood in Guatemala and many other parts of the world. People with intellectual disabilities are desexualized through medical "authorities" and other valuing systems that deem them abnormal and undeserving of the same rights as those labeled able-bodied or able-minded. It is unclear whether or not Acevedo was speaking from his own experience or without having conducted any research, but men with Down syndrome are able to have erections (they can father children), people with Down syndrome experience similar sexual desires to those without the genetic condition, and relationships between people without Down syndrome and with Down Syndrome have occurred (Pradhan et al., 2006).

Charity is another method used for understanding and treating people with disabilities. Through a charity paradigm, disability is declared a tragedy, or a misfortune, that must be alleviated or cured through generous giving. People with disabilities become passive and dependent objects of pity as opposed to people with agency who can make decisions for themselves (Tregaskis, 2000). Charity absolves the responsibility of the state to provide services to people with disabilities and places the responsibility on the church, NGOs and non-profit organizations, and people who feel sorry for and donate to organizations to help "the afflicted." In this model, the images of people with disabilities are exploited to receive charitable donations and services. This is similar to campaigns in "the Global North" for poor people of the developing world. Tom Shakespeare (1997) suggests that processes of colonization and imperialism are involved in both forms of charity campaigns.

Shakespeare (1997) also suggests that through the lens of charity, images of people with disabilities are fetishized, much like the objectification, eroticism and voyeurism often found in pornographic images. Shakespeare (1997) wrote the following:

> "The objectification of disabled people in charity advertising parallels the objectification of women in pornography. In each case the gaze focuses on the body, which is passive and available. In each case, particular aspects of the body are exaggerated: sexual parts, in pornography, or `flawed' parts in charity advertising. In each case, the viewer is manipulated into an emotional response: desire, in the case of pornography, fear and pity in the case of charity advertising." (p.7)[14]

Due to the constant necessity for funding in order to be able to provide services to people with disabilities, NGOs and non-profit institutions in Guatemala often use the charity model. According to Rosemarie Garland Thompson (2002), the charity model does not work against the medical model utilized by the state, but often works in tandem with it. The idea of people with disabilities as objects of pity, justifies institutionalization and segregation. Both paradigms are paternalistic and assume that people with disabilities are unproductive, passive, dependent, and cannot make decisions for themselves. It is their difference or "illness" that is to be pitied and possibly cured. Garland Thompson (2002) charges, "As charity campaigns and telethons repeatedly affirm, cure rather than adjustment or accommodation is the over-determined cultural response to disability." (p.14)

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[14] While some acts of "charity" may be done with intentions of challenging social and economic disparity issues, these charges are not meant to discount the many times well-meaning motives of acts of charity, but rather to challenge the need for the existence of charity and the hierarchy reproduced through it.

These social, medical and charity models are utilized in many different ways and for different reasons. Throughout this text, I will analyze how these paradigms are used or shift in urban Guatemala. After a chapter analyzing the law, I separate the chapters in this text by sectors of the institution that provide services to people with intellectual and psychological disabilities. I will often examine how these aforementioned paradigms and concepts affect or create risk factors for sexual violence and prevent or allow access to positive sexual experience for this group of people in the different institutions.

The first body chapter, as mentioned, is an analysis of Guatemalan law as applied to the rights of people with disabilities. More specifically, I focus on how these laws' application or lack of application affect their sexual rights and other fundamental human rights. Aside from specific Guatemalan legislation, I also analyze the outcome of policies implemented and the structure of CONADI, the National Council for Attention to Persons with Disabilities, an organization created and sustained by mandate of Guatemalan law. This portion of the analysis will also bring into discussion the policies and practices of certain non-profit organizations that are part of the institution that provides services to people with different cognitive abilities. While the Guatemalan government is not officially in control of the non-profit organizations, neoliberal Guatemalan laws and policies heavily affect how these institutions provide services and promote or deny human rights of people with intellectual and psychological disabilities.

The second body chapter is a specific case study of the Federico Mora National Hospital of Mental Health. The stories that come out of this institution and conditions within it paints an especially bleak picture of the social abandonment and medicalization experienced by people with different cognitive abilities. Through an examination of how the “patients” in this institution are treated and understood inside and outside of the hospital, I will detail how this group of people has become what João Biehl (2005) has deemed “ex-humans.” I will also focus on the effects violence on the outside of the institution has on those jailed inside of the mental hospital and how the current political, social and economic situation affects the understandings of a group deemed “unproductive.”

The following chapter delves further into the social abandonment on display in public institutions run by the Guatemalan government. There is an examination of the layers of paternalism in these public institutions, an inquiry into the social construction of people with disabilities as medical beings within the institutions, and a look at the insecurities and abuse workers in the public institutions endure that also affect people with different cognitive abilities who receive services from them. This chapter will delve into how charity and medicalization work in tandem in the way the Guatemalan government represents the images of the services they do provide for this group. This includes a look at how, although this group is often thought to be depoliticized, people with different cognitive abilities are heavily exploited and affected by political entities.

After an analysis of the government's role in disability services, I will examine how the workers in NGOs and non-profit institutions have come to understand and treat people with intellectual and psychological disabilities and how they have come to perceive themselves in the current neoliberal society. This entails charting the effects of neoliberal politics on the discourse and policies surrounding disability that strongly uphold ideals of charity and patriarchal norms. Through mapping out the different understandings and treatments of people with disabilities, I will detail resistance to those frameworks seemingly formed by the system. This will include an analysis of risk factors for sexual violence caused by systems that rely heavily on charitable donations from locals or on an international level. In addition, I detail some of the fear and real life traumas experienced in the public and private arena due to the situation of violence and impunity in contemporary Guatemala.

The last body chapter is dedicated to the work of human rights organizations and international aid organizations. I study the lack of power these human rights entities can exercise when they receive denouncements of violence, particularly sexual violence, and I detail the low rate of denouncements of abuse of people with disabilities due to insufficient confidence in the entities and fear of repercussions in reporting these episodes. By looking at international aid, I seek to chart how these organizations that "want to help" often fail to take into account the context of where their funding is going. This engenders problems with the way funding is spent because it does not necessarily reflect local needs. In this caveat for international funding organizations, I critique and analyze the effects of the one internationally funded piece of research on the sexual abuse of children with disabilities that I was able to find. I look specifically at how even these pieces of research in favor of the right to live without abuse reflect ableist ideals in regards to access to positive sexual experience for people with disabilities.

I will conclude this work with final observations about the institution providing services on a whole and a series of suggestions for further research. As mentioned in the many limitations of this study, there are a number of topics within this complicated and layered subject matter in Guatemala that should be further investigated. I hope to paint a picture for the reader that demonstrates, through a close study of sexual violence and access to positive sexual experience, how these layers including: patriarchal norms, neoliberal policies, dependence on charity, the medicalization of disability, violence and nearly complete impunity, and a lack of funding all leave people with intellectual and psychological disabilities in a state of nearly complete social abandonment in urban Guatemala.

Saving Face in a Neoliberal State: The Law and CONADI

> "The topic of disability in Guatemala continues to be driven by the idea of the person that cannot, the person that isn't capable, the person that doesn't think, the person that can't make decisions for him or herself, that can't assume responsibilities for him or herself or with others. So then with those ideas, they are the poor little things (*pobrecitos)*, they are the useless (*inútiles*), and they are expensive (*costosos*). They think all of that." - Alex, a worker in a Public Institution that provides services to people with intellectual disabilities[15]

Many of my interlocutors highlighted that people with disabilities in Guatemala have never experienced a time in which they were considered full citizens and had equal rights to those without disabilities. The age of neoliberal laws, policies and codes in Guatemala may not have necessarily worsened the situation for people with intellectual and psychological disabilities, but it certainly has altered society and created new understandings of what it means to be a productive citizen and what rights a person who is deemed unproductive or burdensome deserves. This individualistic system that has been imposed, creates new questions about how and why certain laws are created and why or why aren't they applied. Within the application of the law, how will the most marginal rights of a group of people deemed unproductive, sexual rights, be understood, treated, violated, hidden or ignored? This chapter questions how legislation passed at the intersection of the two stigmatized topics of sexuality and cognitive disability either purposely or inadvertently increases or decreases the risk factors for sexual abuse and increases or decreases the potential for people with different cognitive abilities to have access to positive sexual experience. I also examine how other laws, not necessarily intended to affect the sexual rights of people with different cognitive abilities, in fact

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[15] I will not indicate which public institution this interlocutor is connected with because the worker whom I call Alex claimed a very heightened need to maintain anonymity.

negatively impact their potentiality to access positive sexual experience while creating risk factors for sexual violence. The analysis in this chapter is two-fold and aside from specific Guatemalan legislation, I analyze the outcome of policies implemented by and the structure of CONADI, the National Council for Attention to Persons with Disabilities. As mentioned before, CONADI is an organization created and sustained by mandate of Guatemalan law. This portion of the analysis will also bring into discussion the policies and practices of certain non-profit organizations that are part of the institution that provides services to people with different cognitive abilities. While the Guatemalan government is not officially in control of the non-profit organizations, neoliberal Guatemalan laws and policies heavily affect how these institutions provide services and promote or deny human rights of people with intellectual and psychological disabilities.

DISABILITY LAWS AND CODES

Unlike the situation in the United States, there have not been court cases specifically touching on the sterilization or explicit reproductive or sexual rights of people with different cognitive abilities. While some laws touch on sexuality and sexual access for people with intellectual and psychological disabilities, there were not laws specifically written for that purpose. Although legislation is already in place to guarantee human rights to all people with disabilities, the lack of enforcement said laws and treaties, combined with contradictory legislation, hinders, if not stops, most people with disabilities, specifically those with different cognitive abilities, from claiming their freedoms and rights. One could argue that rather than work for the full inclusion of people with disabilities, the Guatemalan government actually seeks to specifically exclude people with intellectual and psychological disabilities from most of society while using the services they do provide for them as proof of the government's work for social welfare.

The Law of Attention to People with Disabilities or Decree 135-96 was passed in November of 1996, at the same time as the Peace Accords to end the Guatemalan Civil War. This law states "It is declared as a social benefit, the integral development of equality in conditions for participation in economic, social, cultural, and political development for people with physical, sensory and/or psychological (*mental*) disabilities in the country." (Decree 135-96, 1996)

While this act seems to guarantee equal participation on all fronts, it contains no penalties for non-compliance and is therefore unenforceable. The act (Decree 135-96, 1996) also contains Article 17, which distributes enforcement of the law to municipalities within the country. This decentralization of laws is a neoliberal approach to human rights that allows local and smaller entities to decide whether or not the application or guarantee of specific rights for different groups are of commercial, financial or cultural value in a specific area. This allows the interest of local businesses and commerce to win out over the promotion of accessibility and human rights for everyone. Decentralization of law application takes financial pressure away from the federal government and weighs private interests over public welfare.

The federal government does not even apply this law in its own institutions. As an example, during my visit to the building for the Secretariat of Social Welfare (*La Secretaría del Bienestar Social),* I noticed that it was not wheelchair accessible. This is the public entity that controls the majority of public services and resources for people with disabilities in Guatemala. The government does not follow its own mandates. Several other pieces of legislation and treaties have been passed to give people with disabilities equal rights, including the approval of the Protocol of San Salvador in 2000 and the Inter-American Convention on the Elimination of all Forms of Discrimination Against Persons with Disabilities in 2002 (International Disability Rights Monitor, 2004). But while both of these ordinances guarantee similar, if not the same, rights as those promised in the Protection of Persons with Disabilities Act of 1996 (Decree 135-96, 1996), little to no enforcement of these pieces of legislation have been enacted (United State Bureau of Democracy, 2009).

Within Decree 135-96, in Article 3 (1996), disability is defined as “Any physical, mental or sensory deficiency that is congenital or acquired, that substantially limits one or more activities that are considered normal for a person.” This definition, published in 1996, is the first explicit definition of disability I have been able to find in Guatemalan law. This nebulous definition allows the government to limit or expand what is considered a disability and what is not. Within this law there are no definitions of specific types of disabilities addressed in the section or what are considered “activities normal for a person.”

In Decree 59-2008 (2008), “The Convention about the Rights of People with Disabilities and its Facultative Protocol” states “The proposition of the present convention is to promote, protect, and assure the plain enjoyment of all fundamental human rights and liberties in conditions of equality for all people with disabilities and to promote the respect of their inherent dignity."

Decree 59-2008 (2008) defines "discrimination with motives of disability" as "an extension of any distinction, exclusion or restriction motivated by disability that proposes or has the effect of creating obstacles for or preventing the effect of the recognition, enjoyment or exercising of all of the fundamental human rights and liberties in political, economic, social, cultural, civil or any other type of environment in equal conditions. This includes all forms of discrimination and within that, the negation of any reasonable adjustments."

This law promises again to prevent any form of discrimination on the basis of one's disability. It also promises to promote adaptation to allow people experiencing disabilities to have greater access to the community. Although sexual rights are not detailed in the list of types of human rights, one could assume that they would be included in the vague portion of the definition stating that human rights and liberties could be expressed in "any other type of environment in equal conditions." Certain articles of this law explicitly guarantee specific sexual rights as well. In Article 23 (Decree-59-2008, 2008) people with disabilities are guaranteed the right to consent to marriage, the right to reproduce and choose the spacing between children, the right to sexual education and the right to maintain fertility. Article 25 guarantees them the explicit right to sexual and reproductive health. Once again there is no penalty assigned for non-compliance. People are only given the ability to denounce non-compliance to the

Secretary General of the United Nations. The denouncement will not come into effect until a year after the Secretary General actually receives the notification.

Within this supposed law, the republic's congress explicitly states that people with disabilities should have equal access to justice including declarations of testimonies, both direct and indirect. In an interview I conducted with a psychologist from one of the few domestic abuse and rape crisis centers in the country, Survivors (*Sobrevivientes*), whom I will call Leticia, she detailed an out-of-court testimony a woman with Down syndrome gave her. The woman with Down syndrome recounted a number of stories of rape and other forms of sexual abuse she survived by her father, that eventually ended with the discovery by her mother that her daughter was pregnant. The woman with Down syndrome drew pictures of her father inserting items into her vagina and her father chasing her around the house. She later explained the pictures to the psychologist in great detail. While the recounting and the pictures could be considered a form of adaptive testimony, the interview with the woman was not for an alternative form of testimony, but rather a mode of giving the woman a mental age. Mental aging is utilized to say that although a person is chronologically a certain age, they can have the mental capacity of a child. While this is used as a tool to increase the penalties of the sexual abuse of this group due to the fact that child abuse receives weighted penalties, the form of diagnosis is desexualizing to the person with different cognitive abilities as well (Benedet and Grant, 2007). Mental aging attempts to establish that people with intellectual disabilities are like children even when they are, in fact, adults. This process not only promotes the idea that adults with intellectual disabilities' sexual development is stunted, but it could also prevent them from accessing sexual liberties that many members of society as well as the law only grant to "adults." Mental aging not only further infantilizes people with different cognitive abilities, but also effectively desexualizes them.

In the woman with Down syndrome's case, her drawn and voiced recounting of abuse was not taken as a testimonial, but rather, was taken along with other tests as a mode of giving her a mental age. Instead of using the woman's claims to charge the father, they only used the medical fact of her pregnancy and her mother's testimony as evidence of the sexual violence. Thus, Decree 59-2008 was not applied, which should have granted the woman the right to testify for herself in an adaptive form.

Within Guatemalan legislation there are codes that completely contradict all of the previously mentioned rights guaranteed to people with disabilities. In the section of the Guatemalan Civil Code titled "Incapacity" (*Incapacidad*), (an already demeaning reference) Article 9 (Civil Code, 1964) of the code, in fact, incapacitates people with different cognitive abilities from accessing their civil liberties.

Article 9 (Civil Code, 1964) states:

> "Adults that suffer from mental illness that prevents them from discernment, should be declared in the state of interdiction. Those who may also be able to be declared in the state of interdiction can be people who abuse drugs or alcoholic beverages and those who expose themselves or their families to grave economic prejudices.
>
> The declaration of interdiction produces from the date that it is established in a firm sentence, absolute incapability of a person to exercise his or her rights; but acts prior to the declaration can be annulled if it is proven that the incapability existed notoriously at the time of the event's verification."

In other words, once an individual with a different cognitive ability has been declared in the state of interdiction, he or she will be dependent on and subject to acts performed by his or her representative. Article 9 of the Guatemalan Civil Code (1964) establishes that people experiencing psychological and intellectual disabilities need to be under "interdiction" and are therefore not allowed to exercise their rights, basically placing them under the category of "incapable."

Policies toward individuals with psychological and intellectual disabilities who are abandoned or whose families are no longer able to provide for them are even bleaker under the state of interdiction. According to Ana, a representative from the Human Rights Procurator's Office for the Defense of People with Disabilities, people with intellectual and psychological disabilities can be institutionalized on the basis of a court decision. They are declared legally incapable as well and are often subject to medical procedures, medication and psychiatric therapy without the right to refuse treatment. I visited both the Federico Mora National Hospital of Mental Health and the institution I will call the House of Psychiatry or the HOP, the only two public institutions in Guatemala for people with profound cognitive disabilities that are abandoned and legally placed under interdiction. The National Hospital of Mental Health, also known as the Federico Mora, is primarily for people experiencing psychological disabilities and the House of Psychiatry is primarily for children with profound intellectual disabilities. The "patients" in these two institutions live in extremely horrific conditions, which I will discuss in later chapters. Due to the fact that people placed in these two institutions are under interdiction by the government, they have no option to leave. When considering the imprisonment of this group entirely based on the diagnosis of a disability, one must question at what point are the extremely taboo sexual rights of people with different cognitive abilities even considered?

While article 9 of the Civil Code works to fully usurp the human rights that would have otherwise been granted to people with intellectual and psychological disabilities, it also works to place them in situations that already violate the rights that the supposed assigned guardians are expected to protect. This code is not only paternalistic and dehumanizing to people with different cognitive abilities, but it also contributes to their isolation in institutions and in the homes of their family members. If a family member is suddenly in charge of all of the actions of a person with different cognitive abilities, he or she may fear that that person's actions must be controlled and that can only be done in the privacy of the home. They also may feel authoritarian-like power over their family member. This privileges the desires and wants of the family member over the rights of the person with a psychological or intellectual disability. These instances of increased paternalistic attitudes, dehumanization and isolation are all noted as risk factors for sexual abuse (Save the Children Suecia et al., 2001).

In recent years, sexual violence, specifically against women, and sexual exploitation has received consideration in Guatemalan legislation. This is due, in part, to a large movement for women's rights as a reaction to the high rate of violent murders and violent rapes of women committed with nearly complete impunity in the Central American country (Musalo, Pellegrin and Roberts, 2010). The Law Against Sexual Violence, Exploitation and the Treatment of People (Decree 9-2009) was signed into effect in 2009 in response to this movement against sexual violence. Article 23 of the decree works to make special considerations for people with disabilities.

Article 23 (Decree 9-2009, 2009) states "Whosoever, through whichever action or omission provokes (exploitation or violence) against a minor or a person with a volatile, cognitive, physical or psychological incapacity or sickness or places a minor who is at great risk of suffering from any of those illnesses will be sanctioned to prison for two to five years, without first judging applicable sanctions for other crimes."

While this added time to a person's prison sentence for sexually violating or exploiting a person with a disability is meant to further prevent the sexual abuse of people with different cognitive abilities, it also promotes the perception that adults with different cognitive abilities have less sexual agency and do not have the same sexual rights or desires as adults who do not have psychological or intellectual disabilities. This increased penalty is a double-edged sword. It could help prevent the sexual abuse of a group of people with heightened risk factors from having that experience; however, it could also further marginalize them as sexual beings and stifle a call for them to be able to access their sexuality as adults. In regards to making charges for people with intellectual disabilities, I have not found a record of this added penalty's utilization. Rather, as exemplified earlier, people have utilized mental aging to add time to sentences by arguing that the violation of an adult with an intellectual disability is a crime against a child.[16]

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[16] The lack of application of this law could also be due to the fact that it was passed in 2009 and very few people are informed about the basics of new laws, let alone articles of specific laws.

Feminist scholar and queer theorist, Steven Angelides (2004), examines how laws and discourse in the 1970's that arose from the feminist movement in the United States against child abuse helped overturn the patriarchal myth of "stranger danger." The movement produced evidence that fathers, brothers, uncles and other family members were the most common perpetrators of sexual violence. This movement helped deny that children were in someway complicit in acts of sexual assault and helped promote an important critique of patriarchal family relations and adult/child power relations. However, he found negative side effects in this movement as well. Angelides notes that while the discourse surrounding child sexual abuse expanded, the discourse surrounding child sexuality was both repressed and denied. In this argument Angelides charges that the imaginary line created between age and sexuality is a failed attempt by the feminist movement to "hierarchize sexuality by way of a linear and sequential logic of age stratification." (Angelides, 2004, p.142).

While Angelides would not deny the importance of preventing child sexual abuse, he argues that establishing that children cannot be complicit in any sexual activity because they are not yet true sexual beings, usurps the child's agency and unnecessarily constricts and disempowers children. The same argument holds true in certain laws and codes passed, like the Guatemalan Law Against Sexual Violence, Exploitation and the Treatment of People (Decree 9-2009, 2009). The specific harsher penalties for people who abuse those with different cognitive abilities privileges the gravity of their abuse while it denies their status as developed sexual beings. The abuse of this group of people should hold the same weight as the abuse of people who do not experience disabilities so their positive sexual experience and sexuality can hold the same weight as well.

CONADI AND DECREE 135-96

Although there were a few laws and codes passed regarding access to rights for people experiencing disabilities before Decree 135-96, I was unable to find proof of enforcement of any laws or codes regarding disability outside of the section of the Civil Code that mandates interdiction over people with intellectual and psychological disabilities (Civil Code, 1964, Article 9). Most of the time this code was enforced without knowledge that the code existed. The vast majority of my 30 interlocutors had no knowledge that this code was real, but understood that people with intellectual and psychological disabilities were not to be granted decision-making powers. The only time this code seemed to be enforced via official mandate was when people were forced into public institutions like the Federico Mora.

One reason for this lack of application of laws, outside of enforcement of interdiction, could be the lack of government interest in promoting actual societal inclusion of people experiencing disabilities. This group, already deemed unproductive, societal burdens, and non-voting due to interdiction, could not be seen as contributors to the Guatemalan government's goals in the midst of a civil war. The transitions out of the Guatemalan Civil War, however, brought about a need to identify and acknowledge a demand for services to promote and understand diversity in Guatemala. With the world's eyes on the peace-keeping agreements in the Central American country, there were expectations that work would be done to promote human rights and to correct the atrocities that had been detailed in works by Rigoberta Menchu,[17] Guatemalan memoir writers, academics and other human rights advocates. However, this push for civil and human rights of different minority groups in Guatemala came during the ascendance of a neoliberal system in the country.

As discussed by anthropologist, Charles R. Hale (2002), in his work on the rights of indigenous peoples in Guatemala, neoliberalism, which is driven by the logic of transnational capitalism, works to strip down federal responsibilities for the social welfare of citizens, emphasizes individual responsibility and choice, and takes away restrictions in the world market on goods and capital. Hale details how in Guatemala, during the beginning of the Mayan movement and the transition to "peace" in the 1990's, proponents of the neoliberal doctrine actually promoted a significant, if limited, version of indigenous cultural rights, as a means to resolve their own problems and advance their own political agendas. Due to the fact that the Mayan movement was making ground and pushing for collective bargaining rights, the government needed to change its policies to assure the interests of transnational capitalism were kept. As Hale highlighted, "neoliberalism is predicated on recreating or recapturing the individualist essence, in danger of being lost." (Hale, 2002, p.496). As strange as it may sound, "this recuperation of the individual takes place primarily through strengthened ties with the non-state entities - communities, civic and voluntary organisations, churches, NGOs – that supposedly are the guardians of values lost." (Hale, 2002. p.496)

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[17] For works by Menchu that were published before the passage of Decree 135-96 (1996) see Menchu and Burgos-Debray (1994) and Menchu and Zurita (1993).

In the pursuit of expunging the state of social welfare responsibilities while actively promoting subject formation, the Guatemalan government began to purposely reinforce organizations of civil society that would serve these interests. By providing limited funding and support to organizations that did not push for “radical” collective rights but rather “basic cultural rights,” the Guatemalan government's cultural project was able to “harness and redirect the abundant political energy of cultural rights activism, rather than directly to oppose it.” (Hale, 2002, p. 498)

In 1996, at the time of the signing of the Guatemala Peace Accords, there was a motivating force to include and at least discuss all forms of minority rights outside of just indigenous rights. Along with the push of several different disability rights activists and the impetus of international and highly influential American laws like the Americans with Disabilities Act of 1990 in the United States (Jiménez, 2001), there was a need to create a government entity to advocate for the rights and accessibility for people with disabilities. Thus CONADI, the National Council for Attention to Persons with Disabilities (*El Consejo Nacional para la Atención a Personas con Discapacidad*) was created through Decree 135-96 (1996).

Utilizing Hale's analysis of the effects of neoliberal policies in Guatemala on the Mayan movement and the promotion of “neoliberal multiculturalism,” we can see how these ideas transfer to the disability rights movement by way of CONADI and through other details of Decree 135-96 already discussed. The government instigates a form of neoliberal ableism in the Central American country through CONADI as a sort of subject forming, neoliberal gatekeeper. Looking at the structure and funding provided by

CONADI demonstrates which groups the Guatemalan government feels are able and should be made into “proper subjects.” CONADI also reveals how the government is able to symbolically care for and advocate for accessibility for people with disabilities while providing minimal resources.

Although CONADI was created through the Attention to Persons with Disabilities Act of 1996 or Decree 135-96, it was not actually founded until 1997 (Decree 135-96, 1996). The creation of this entity was a huge advancement for acknowledging the existence of people with disabilities in Guatemala and a need for services. While there had been some NGOs, some non-profits (mostly in Guatemala City) and a few public centers, CONADI created a gathering point, or a council, for all of the organizations providing services to people with disabilities that fit its criteria. There is a board of directors that is made up of representatives from the different branches of the entity. These members of the board of directors meet semi-regularly. I have been in the CONADI building when one meeting was held but was unable to observe the meeting.

CONADI is separated into seven different civil social sectors or branches in which different organizations providing services for or advocating for people with disabilities are placed. These social sectors serve as the face of disability services. The seven civil social sectors include: Organizations of People with Visual Disabilities, Organizations of People with Auditory Disabilities, Associations of People with Physical Disabilities, Institutions that Provide Services to People with Disabilities, Institutions that Advocate in Favor of People with Disabilities, Organizations of People with Disabilities as a Result of Armed Conflict, and lastly the Federation of Parents and Friends of People with Disabilities (Escobar, 2007).

One may note that in this extensive list, not one of the sectors mentions intellectual or psychological disability. This is because organizations advocating and providing services for people with intellectual disabilities are all placed in the sector of "The Federation of Parents and Friends of People with Disabilities." There are no sectors of CONADI set up to promote services to people with psychological disabilities. When I questioned two separate officials from CONADI, they both explained that it is assumed that people with intellectual and psychological disabilities are unable to access services and support independently. It is necessary for someone else to advocate for them. Therefore, although the sector of CONADI provides services to people experiencing intellectual disabilities, it is really that group's family members who have access to the services. In a situation in which the dependency and incapability of people with different cognitive abilities is assumed, how can one argue for the sexual autonomy of people with intellectual disabilities? When I questioned what a person with different cognitive abilities could do if he or she was looking for resources to report abuse or to advocate for him or herself, one of CONADI's officials said that if a person with intellectual disabilities is able to do that, they can figure out that "The Federation of Parents and Friends of People with Disabilities" is the place they can go.

This lack of a sector named for people with intellectual disabilities and lack of any resources for people experiencing psychological disabilities, presents a hierarchy within the government's view of the disability community. It shows who is worth turning into a model citizen, and whom the government assumes can't be molded. The fact that parents and friends of people with intellectual disabilities have a sector as opposed to the people with disabilities themselves, demonstrates whom these services were created for. This could be due in part to the fact that under interdiction, people with different cognitive abilities cannot vote. People experiencing other forms of disabilities are and have actively pushed for collective rights and accessibility. Only the parents and friends of people with intellectual disabilities were able to lobby for the group's rights before the signing of the Peace Accords. Therefore those sets of people were, in Hale's words, the groups from whom it was needed to "harness and redirect the abundant political energy." (Hale, 2002, p. 498) Due to interdiction and possible mental impairments, people experiencing intellectual disabilities could not engage in political debate or voice their demands. According to my interlocutors, the lack of services for people with psychological disabilities could also be a consequence of the high rate of stigmatization of mental health in Guatemala and a lack of people willing to advocate for the group as a population.

The non-profits and councils that are a part of CONADI also receive the benefit of small amounts of funding. Non-profits often provide services that the government does not provide and through CONADI's funding, the Guatemalan government has a hand in how the entities are run. These services also work to begin to fill a gap left by a lack of government services and funding. They allow for the government to get away with not providing what it is supposed to provide, as mandated in the laws that they have passed. The majority of these non-profits not only provide higher quality services, but they also are used by CONADI as examples of the Guatemalan government's dedication to disability issues. For example, an image of the matron of one of on non-profit institution with her son, who has multiple disabilities, is one of the most common images seen in CONADI's building. The government can claim support of these institutions by dividing a portion of CONADI's funds to a few non-profit organizations. This money is a miniscule amount and is normally designated to pay for printing and promotional material for the non-profit institutions. In this manner, most pieces of printed material from the non-profits they support say “This material was realized thanks to the support of CONADI,” even though the printing of promotional materials is the only thing CONADI funds for a particular non-profit. The non-profits must work to secure the money for everything other than the printing of their promotional materials. CONADI does not fund the research to create the materials, only the printing. In this way, the non-profits do the lion's share of the work to provide services to people experiencing disabilities, but the government can claim some of the credit by having their representative emblem on all promotional material given to the outside public through the non-profits that they provide printing funds to.

Through printed materials of different non-profits and councils and divvying out other small amounts of funding, CONADI not only advertises which organizations the Guatemalan government deems fit to participate in subject making, it also has a hand in how organizations are run. According to a representative from CONADI, all of the organizations that CONADI provides funding to must meet a certain criteria and espouse certain values and ideas. They provide simple and non-inclusive services like separate special education and daycare, but do not promote full inclusion of people with disabilities in society or demand that the government provide the tools so that accessibility be promoted in public arenas. A few disability rights activists, one of them, a member of the board of CONADI, have formed an organization that does not fit CONADI's criteria and promotes independent living of adults with physical and sensory disabilities. The ideas are much more radical in regards to demands for accessibility and collective rights and this group does not receive CONADI's stamp of approval or funding. One of my interlocutors who pioneers the independent living group, Ana, told me she would not even think about including her work with the other organization in CONADI.

According to a number of my interlocutors, CONADI serves as the face of disability services, and although it does not provide much in the way of significant financial backing, it works to publicize their services. The national council also works as a legitimizing force for service-providing organizations. International organizations that work to promote philanthropy in “third-world countries” can use CONADI to find the right organization for their funding. An interlocutor that represents an association that works with people with Spina Bifida said neoliberal international funding and banking institutions also use CONADI to decide which organizations should receive funding from them.

CONADI is a complicated government entity to understand and to describe for several reasons. While it seems to have many functions and a number of members and contributors, very little is comparatively produced and important issues are ignored like psychological disabilities. According to Alex, an informant from a public institution "It (CONADI) isn't an institution that actually has a presence, it doesn't provoke anything." A friend of Alex's who works in a public institution that was in the room during the interview said, "CONADI is good for nothing! (*¡No sirve para nada!*)" [his emphasis].

As the national council on disability issues, CONADI is required to give recommendations yearly about methods of improving the lives of people with disabilities. The United States Annual Human Rights Report (2009) has pointed out that the Guatemalan government has rarely if never followed CONADI's recommendations. CONADI does not have power to make changes to government policy although it serves as an arm of the government.

When CONADI has been given specific tasks to consider law application, it has not produced. According to one member of the board of directors, CONADI was given the task of creating a plan of action to apply Decree 59-2008. This board member charged that meetings have yet to include discussion on how these laws should be applied. The frustration voiced by this board member, was voiced by a number of my interlocutors who were board members or who were a part of organizations that receive funding from CONADI.

Serving as the national council for all people with disabilities in Guatemala and the only public institution that works specifically for accessibility for people with disabilities, the funding for CONADI is mandated in Article 8 of Decree 135-96 (1996). It states that the Guatemalan Ministry of Public Finances must allocate a minimum of five million Quetzales or Q (about $625,000) each year.[18] Even though CONADI was established in 1996, according to Ana, it did not begin to receive a regular budget from the government until 2000. Rather than increase the budget for CONADI as the council has grown and inflation has taken hold, the Guatemalan government has actually decreased the budget from 6.5 million Q in 2007, to 5.5 million Q in 2008 and finally to 5 million Q in 2009 where it remained the same for 2010. As detailed above, this is the minimal amount of funding CONADI should receive annually. When one considers that CONADI has claimed that 12% of the population has some form of disability, this amounts to 1.72 million people in the country (Sarti, 2007). Taking all of that into account, this means that about 1/3 of one American dollar ($0.33), is granted annually for each citizen experiencing disabilities through CONADI. This is without discounting operation, capital and salary costs of the organization itself. The sparse amount of funding granted to the project exemplifies both the little amount of influence and funds needed to instigate controls on domestic non-profits in Guatemala, in addition to the lack of credibility the movement for the rights of people experiencing disabilities has received in the Central American country. Upon my return to Guatemala in July of 2011, one former board member told me that she believed that CONADI had their funds reduced because those running the institution did not know how to use the money. If this was the case, the government did not mandate a change in staff, but rather used the "poor" budgeting decisions as an excuse to cut funding. According to one interlocutor, Peter, from a non-profit for people with physical disabilities called Accessing Mobility, once

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[18] Quetzales or Q is the Guatemalan form of currency. Between 2010 and 2011, the Guatemalan Quetzal's exchange rate averaged at about 8 Q per American dollar.

the budget cuts happened, a change in staff and the board occurred. As of July of 2011, CONADI no longer had a website and one of my interlocutors on the staff left her position.

Within the several atrocities, inadequacies, discrepancies and repressive practices promulgated by the government through the law-mandated neoliberal entity of CONADI, there must be an examination of how this affects the application and understanding of the human rights of people with disabilities in Guatemala. Looking at how the sexual rights of people with different cognitive abilities are treated or understood through these policies in CONADI, allows for a case study of effects of neoliberal entities on perceptions and applications of important human rights. This also gives an example of abuses that are promoted in a system that overtly denies the personal agency of people with different cognitive abilities.

While both representatives from CONADI in July of 2010 that I interviewed demonstrated concern about the sexual abuse of people with different cognitive abilities, there was little to no concern for their access to their sexuality or positive sexual experience. An official in one of the highest positions in CONADI told me that if a person experiencing an intellectual disability masturbates, it is a sign that that person must have been sexually abused. He explained that a person with an intellectual disability could not possibly learn to masturbate autonomously.

This belief by my interlocutor from CONADI that people with different cognitive abilities could not learn to masturbate by themselves, demonstrates how people with different cognitive abilities are not understood as being natural sexual beings with sexual needs by key members of the institution, even by those who are supposed to work for their rights.[19] While it is important to be vigilant of signs of sexual abuse, a hyper-victimization of a group of people, as discussed by Angelides (2004), only usurps that groups' sexual agency. While the slogan of CONADI is “For total participation,” the workers in CONADI that I interviewed do not believe that people with different cognitive abilities can autonomously participate in sexual activities, even personal sexual stimulation.

One representative from CONADI told me that people with intellectual disabilities cannot have meaningful romantic relationships, but rather any romantic relationship they have will be a situation of “*novios de fulanito*” or “partners of whomever (in diminutive form).” This means it doesn't matter who their partner is in regards to personality, they will just form relationships with whoever is willing to be with them. This interlocutor went on to describe how they will treat each other like a prince or princess, but then impulsive conduct and aggression will take over, and the relationship will no longer function. This heteronormative assumption demonstrates one way institutional workers justify disallowing people with different cognitive abilities from forming relationships in the first place. Setting up the idea that any relationships formed are imagined or meaningless, chips away at the understanding of this group's humanity and in turn, the need to ensure all human rights.

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[19] It also must be noted that this official in a high position in CONADI does not have a disability and only officially worked to provide services to people experiencing disabilities for two years before he was appointed to his position. When questioned about how he found employment at CONADI in an interview I had with him in July of 2010, he told me the position was “*un puesto de confianza*.” The term in English basically means that he received the job because he was a friend of someone on the board that trusts him. He was not hired due to qualifications he had or his ability to perform the tasks the work entails. He is my interlocutor that still held a position in CONADI on my return trip in July of 2011.

The same interlocutor explained to me that she does not believe and discourages people with different cognitive abilities from having physical sexual relationships. She explained that this group only functions on impulsive behaviors and they are therefore unfit and not mature enough for sexual relationships, even as adults. These assumptions are not only generalizations that classify people with intellectual disabilities as a homogenous group, but they also animalize them and categorize them as primitive beings while attempting to prevent them from making choices in regards to their sexuality. This discourse of both infantilization and animalization is reinforced by the structure of CONADI and lack of a sector actually intended to provide services for people with intellectual disabilities. As discussed before, an overt denial of access to positive sexual experience is not only a form of abuse in itself, but also instigates the risk that if sexual violence occurs, it will not be understood as such.

While CONADI does not work directly with sexual violence or sexual access for people with different cognitive abilities, the non-profits it financially backs provide the face of disability services in Guatemala. Therefore, CONADI's criteria for non-profits to receive funds sets up how the non-profits can and often do understand and treat the sexuality and sexual abuse of this group. Most of the institutions that work directly with people experiencing intellectual disabilities under CONADI's influence work with children and claim it is not in their agenda to work with sexuality. My interlocutor in the only institution affiliated with CONADI that works with adults with intellectual disabilities still refers to the adults as "special children" or "*niños especiales*." When I asked this interlocutor if her students should have access to physical sexual experience, she responded, “They are very innocent and for that reason they don't need to get to that point. It's for that reason that they are children, children in adult bodies, but they're children.”

This is an example of the infantilizing beliefs that are cemented into CONADI's structure. These ideas underpin the measures taken to assure that people with intellectual disabilities will not gain real ground in receiving accessibility in Guatemalan society. Rather than supporting institutions that portray people experiencing intellectual disabilities as people with agency, CONADI supports and advertises institutions that paint people with disabilities as infants, objects of charity and pity, and beings unable to make decisions on their own or with assistance.

The Guatemalan government has only enforced laws and codes as applied to disability when it has worked in the interests of capitalism, neoliberal agendas, and other individualistic systems that came before neoliberalism. Rather than promoting social welfare and applying the laws and codes that would guarantee the human rights of people with intellectual and psychological disabilities, the only laws and codes actively applied are interdiction within the Civil Code and Decree 135-96. The Civil Code (Article 9, 1964) section titled “Incapacity” effectively removes abandoned people with different cognitive abilities from society and places them in dangerous institutions. It takes away the civil rights of people with different cognitive abilities who are not institutionalized as well. While Decree 135-96 (1996) seems to guarantee important human rights for all people experiencing disabilities, the decree immediately takes away any federal responsibility for enforcing these rights. This is done through Article 17, which divests all liability of enforcement of these rights onto municipalities, which do not have to comply with the requirements if it is not in their economic, political or cultural interests. Decree 135-96 also serves the neoliberal agenda of the Guatemalan state by creating CONADI to help control and disperse subject making responsibilities onto non-profit organizations that they deemed fit. CONADI works as an entity that shows the international human rights organizations as well as domestic disability rights advocates and sympathizers that the state at least symbolically cares about promoting the welfare of people with disabilities. Neoliberal policies not only create a wider disparity between the rich and the poor in any country by putting business interests above the interests of social welfare, but they also instigate grave human rights abuses such as those experienced by people with intellectual and psychological disabilities in Guatemala.

This Population Cannot Love: The Federico Mora National Hospital of Mental Health

> "As the jeep with my escorts and I rolled up the mountain in Zone 18 into the Federico Mora National Hospital of Mental Health in Guatemala City, we passed the unforgettable image and smell of an impromptu garbage dump that lined the side of the valley. This sight signified a tremendous and easily connected metaphor once we entered the hospital grounds. We were making our way into a dump for humans. As my escorts showed their badges for a domestic human rights organization to allow our entrance through the large gates, one noticed soiled hands reaching between the metal bars. When the gate opened, we drove by a throng of men and women with shaved heads in tattered, gray, unfitted, rag-like clothing. With sedated eyes and bare feet, a number of them walked near the jeep and stared into the open windows. In stark contrast to the seemingly abandoned group of men and women, a herd of police officers and security guards in sharp black uniforms and combat boots with AK-47-like guns watched the jeep with amusement. This isn't a hospital, I thought, it's an over-medicated prison." (S. Serrano, Field reflections, July 1, 2010)

This chapter is a case study of the previously mentioned Federico Mora National Hospital of Mental Health in Guatemala City. This institution is the only public institution of its kind in the country. It is considered a medical institution, although it becomes a permanent home for the majority of the patients housed there. The hospital does external consultation as well, but I will focus entirely on the live-in patients in the institution. The Federico Mora is government-funded through the Office of Public Health. I was granted a visit to the Federico Mora on June 29, 2010. While there, I was allowed three interviews. I spoke with a psychiatrist on the administrative staff, whom I will call Guillermo; a practicing psychiatrist, Astrid; and a resident surgeon, Cristina.

DISABILITY, CRIME AND PUNISHMENT

As mentioned in the previous chapter, the Federico Mora National Hospital of Mental Health is infamous in Guatemala due to the fact that while housing people with profound or severe intellectual and most often psychological disabilities, it also jails people who have been proclaimed “criminally insane.” Many journalists and all of my interlocutors in the Federico Mora, as well as in other institutions, said that these charged criminals placed in the Federico Mora often do not have intellectual or psychological disabilities. My interlocutors told me that these convicted criminals who do not have cognitive disabilities have either bribed or threatened a judge in order to be placed in the hospital as opposed to prison. According to Guillermo, Astrid and Cristina it is more desirable to be placed in the mental hospital for several reasons. Some of the reasons they gave me are: easy access to female patients and more vulnerable male patients for sex, more free walking and roaming area, drugs are circulated more easily through the establishment than in prison, and it is easier to escape from than a prison. According to *Nuestro Diario* (Equipo Investigativo, 2010) five to ten people escape from the hospital every year. By June 2010, three inmates had already escaped in the year. The same article claimed that psychiatrists in the hospital believe that about 80% of these charged criminals are do not have disabilities. The officers who are there to assure that they remain imprisoned are often suspected of helping these convicted criminals escape. In June of 2010, there were 325 medical patients housed in the Federico Mora and 80 men were jailed there as well (Equipo Investigativo, 2010). According to the Human Rights Procurator's report from March of 2009, there were 48 convicted criminals housed in the institution at that time. This means that in 15 months, the number of them increased by

40% (Procurador de los Derechos Humanos, 2009). This reported increase of charged criminals could be a reflection of the increased rate of extortions and threats reported in Guatemala over the past years (Martínez, 2010).

A number of the inmates in the institution were interned for violent acts. One man murdered his girlfriend out of jealousy. One inmate was charged with raping his mother and then murdering her. Another inmate was charged with the murder of his wife and three sons and for cutting off his sons' genitals (Martínez, 2010). Placing people who may or may not have a psychological disability but are charged with violent crimes in the same institution as people with psychological or intellectual disabilities who have not committed violent crimes, sends a message that the safety of that minority group is not of value to the government.

The convicted criminal portion of the population placed in the Federico Mora brings a large police staff onto the hospital grounds as well. According to Guillermo, it is difficult to decide which of the two groups, the police officers or the convicted criminals in the hospital, harass and abuse patients and medical staff more. The guards are notoriously corrupt and are cycled in and out of the hospital; this makes it difficult for a patient or staff member to identify abuse by guards unless charges are made right after the event has occurred. Immediate identification of abuse of a patient or medical staff by a guard is unlikely due to the fact that the guards carry very large guns that can cause intimidation.[20]

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[20] When I came out of the human rights organization's jeep, I followed my escort who was dressed in a uniform vest inside of the Federico Mora's grounds. After my escort passed, a group of the guards who were huddled together, with their guns in hand, stared at me for a moment and then whistled at me and

According to Guillermo, in recent years there was an issue with guards placing two holes at a time in the walls of one of the women's barracks. In one hole, the guards would place their penis and in the other hole, their gun. From there, the police would force the women in the barracks to perform fellatio on them at gunpoint. Although hospital staff installed video cameras around the barracks after the situation came to light, my interlocutor told me that nothing could be done to uncover which police officers sexually abused the female hospital patients. Guillermo explained that there is no way of knowing which guards did it due to the fact that the officers are cycled in and out of the facility so quickly and there is fear of retaliation if they file for an investigation. Even though the hospital staff has requested a change in the system that allows impunity for police officers' actions in the hospital, the government has done next to nothing to acknowledge those requests. I received a number of conflicting answers when questioning hospital staff and direction about these officers. While Astrid told me that officers receive a sensitization course about how to work with people with psychological disabilities, Guillermo and Cristina said that the officers receive no special training before working in the hospital.

Another discrepancy between answers given by my interlocutors in the Federico Mora involved questions of accessibility to sexual experience in the institution. There is often a demonization of people with psychological disabilities that makes any attempt to access positive sexual experience through self-stimulation, sexual advances, or

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asked for my number. This harassment seemed to be normal in the hospital. The guards were able to hit on an obvious outsider of the institution without fear of repercussions.

consensual sexual acts seem evil or malicious (Wilkerson, 2002). These issues along with a number of other false presumptions and stereotypes often prevent people with intellectual and psychological disabilities from accessing positive or consensual sexual experience in a safe manner and sometimes eliminate the possibility of ever accessing positive sexual experience. People interned in these facilities are often imprisoned in these hospitals for the majority of their lives and the denial of access to one's sexuality not only makes it less likely that one would be able to identify an abusive sexual experience, but also denies an essential facet of the human experience.

Guillermo and Cristina explicitly said that the hospital prevents access to sexuality but admit that sexual abuse does occur. Astrid gave a different response. When questioned if the patients experiencing intellectual or psychological disabilities were given access to positive and consensual sexual experience, the psychiatrist stated that she believes that they do. I questioned where and how do they receive access. Astrid explained that if patients could find a place in the field of the farm-style institution, hidden from guards and medical staff, they could probably have sexual intercourse. I asked if the institution provided any method to be able to have positive sexual experience in an indoor or private environment. The psychiatrist said that was not included in the hospital facilities. I then questioned if sexual education or protection were provided and my interlocutor responded that these were not granted either, even at a patient's request.

Hiding from guards and medical staff while having unprotected sex outside in a field does not seem to be a positive sexual experience. When one considers that a police officer with a large gun or a violent convicted criminal can interrupt the act at any point, the idea is more troubling. While discussing the scenario with Alex, a worker from another public institution, Alex responded that this scenario did not sound like a romantic rendezvous but rather a scene from a horror movie.[21]

According to my interlocutors, patients in the hospital are rarely given complete privacy, even when doing activities that would normally be considered private matters. A report by the Humans Rights Procurator for Disabilities (Procurador de los Derechos Humanos, 2009) said, "They did an inspection of the garden area where they offer occupational therapy to the patients. In the area there are some toilets and showers, which they find completely uncovered and in view for anyone to see. On top of that, in the moment of the inspection there was a person showering, completely nude; in the same way they disrespect the intimacy for those who use the toilets." (Procurador de los Derechos Humanos, 2009, p.5)

This lack of consideration for the privacy and safety of patients with cognitive disabilities promotes a dehumanization of the population. The fact that this is in an outside area that receives a large amount of traffic because it is where occupational therapy is conducted, signifies to the patients, medical staff, maintenance staff, and police officers that the patients do not have the right to decide who and who doesn't get to see the parts of their body that are normally deemed private in Guatemalan culture. People with intellectual and psychological disabilities are not granted agency over their bodies.

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[21] Alex has asked not to be identified by gender or institutional affiliation in this study.

According to Ana, one of the urgent issues caused by sexual violence and the denial of people with different cognitive abilities' sexuality in the Federico Mora is the increase in the number of residents and hospital staff who are HIV positive.[22] This is largely due to sexual violence, a lack of sexual education, and a scarcity of provisions of protective contraceptive options in the hospital. The Federico Mora does not have enough financial resources to prevent sexually transmitted diseases from being spread by the perpetrators to the hospitalized people with different cognitive abilities and between them (Procurador de los Derechos Humanos, 2009).

As one walks by patients in ragged clothes with no shoes and by a recreation area in which one cannot find materials for said recreational activities, the lack of resources is evident. The hospital is also understaffed although 90% of the yearly funding, which is 45 million Quetzales, goes to salary for hospital staff. The other 10%, which amounts to about $562,500 funds the expenses for the maintenance of the hospital grounds as well as the needs of the 405 (and counting) patients that live on the hospital grounds and maintenance of external patient service areas. The approximate $562,500 is spent on: food, medication, uniforms, bed sheets, hygiene products, recreational activities, cleaning supplies for the hospital grounds, record-keeping supplies and medical exams (Martínez, 2010). When one considers the high cost of psychiatric medications, there is little funding for attending to personal needs and desires of this group of people that will likely live in

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[22] An example of how the importance of the sexual health of “mental patients” in Guatemala was revealed in October of 2010. A person researching the Tuskegee cases in the United States explained that she found records that revealed that the United States government went into public institutions in Guatemala from 1946-1948 and deliberately infected “mental patients” with syphilis. It is unclear whether or not these patients were cured (McNeil Jr., 2010).

the institution until they die. This is a method of understanding the pecking order of basic human rights in institutions. It seems that so long as a roof, food, and clothing are provided, along with minimal psychiatric medical care, no matter the quality of these, the hospital has done its job. This population is not considered productive and funding is not provided to promote a change in the living conditions faced by the people imprisoned in the Federico Mora.

One method found in hospital policy that could be a result of difficulty in caring for the hundreds of live-in patients with limited funds is the number of psychiatrists that work in the hospital as opposed to psychologists. According to the Human Rights Procurator Report (2009) there were 32 psychiatrists in the hospital and only seven psychologists. Four out of seven of the psychologists were for external consultation only. The Human Rights Procurator Report (2009) points out the important distinction to be made between psychiatry and psychology. Psychiatrists in the Federico Mora make quick diagnoses and prescribe psycho-pharmaceutical drugs to depress symptoms or misperceived symptoms of psychological disability. These are often anti-depressant pills, anti-psychotic pills, sedatives and a number of other types of medications. Psychologists work as therapists to talk to patients and work with them to listen to issues, work on improving conduct and reducing stress. Therapy can also be used to create strategies for promoting a patient's social reintegration and personal development. While psycho-pharmaceuticals cover up a problem and are a quick fix for “handling” the large group of people with a small under-paid staff through sedation and over-medication, psychology could promote community access and help patient's state improve without dependency on medication.[23] According to Astrid, patients normally take between two to five different medications a day. The three psychologists that are designated to work with the more than 400 live-in patients are unable to create strategies for reintegration and likely unable to become familiar with patients' individual needs. Medication and psychiatry work cannot fill in the gaps where therapy could improve the mental health of the patients.

ANIMALS, CHILDREN OR PATIENTS?

One issue caused by the stress on psychiatry for this group as opposed to therapy is the medicalization of their sexuality. All three of my interlocutors within the institution told me that if patients in the institution verbally or physically express sexual desires in front of medical staff, they will be given medication that will suppress those sexual urges. The medical sexual repression not only signifies to hospital staff, medical staff, guards and patients that any sexual act from them is not desirable, but also that their sexuality is not normal and wrong. This literal desexualization not only denies the patients' rights to access positive sexual experience but also to have sexual and human feelings and desires. Cristina justified the desexualization of the patients through medication with claims that without repressing their "animal-like" urges, sexual violence would be common between patients. While this medicalized desexualization could prevent some sexual violence between the patients, it effectively denies that this group deserves or can have a sexual experience that is positive. This also hypersexualizes male hospital patients, who are often the people who receive these forms of medication, while hypervictimizing the

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[23] For more information on the dangers of nearly complete reliance on psychiatry and effects of over prescription of pharmaceutical drugs for people with psychological disabilities see Wyatt and Midkiff (2006).

female patients. This heteronormative binary removes sexual agency from the women while it denies men's ability to control their sexual desires and denies the idea that sexual violence or positive sexual experience can occur between patients of the same sex. This use of medication also carries the assumption that sexual violence is most likely to occur within the pool of patients in the hospital and not by medical staff, maintenance staff, or guards.

According to feminist disability theorist Abby Wilkerson (2002), this discourse surrounding the medicalization of the sexuality of people experiencing intellectual and psychological disabilities is pervasive throughout society and is detrimental to every aspect of the lives of people in this minority group. Medical discourse is presumed to be naturally objective and is henceforth a canonical fountainhead of truth, due in part to the fact that it poses as the health-giving light of science and technology. In turn, these truths and their employment are assumed to be completely altruistic. Therefore, this medical pathologization of intellectual and psychological disability, particularly as it manifests itself in negativism and denial regarding the sexuality of patients in the Federico Mora, is a weighty contributor to the sexual powerlessness and dehumanization of this group. According to Wilkerson, these problematic medical concepts, omissions, and emphases utilized, like those applied in the hospital, also reflect and reinforce broader cultural values, such as notions of sexuality based on a normative heterosexual male perspective, a penis-centered, intercourse-based, goal-oriented view of sex.

The employment of medical discourse when considering sexuality designates which bodies are valid and even what validity of a body is. This is more problematic due to the fact that the reliability of medical discourse is seldom questioned. As the experienced disabilities are constructed to be the only defining aspects of the patients in the Federico Mora, they are deemed less valid or completely invalid. This lower status seems to be irrefutable, owing to its medical certification (because medical evidence is viewed as completely unbiased, absolve of emotions, values and human interests) (Wilkerson, 2002).

While my interlocutors were deeply concerned with preventing the sexual abuse of people experiencing intellectual and psychological disabilities, when questioned about promoting access to positive sexual experience, my interlocutors were often more concerned with preventing the minority group from reproducing, due to the misconception that they will only produce more people experiencing intellectual and psychological disabilities. In fact, Cristina explained to me that if a woman in the mental hospital has a baby, she does not have any right to raise the baby and the child is immediately put up for adoption. Cristina explained that she would sterilize all of the patients if it were possible.

According to Cristina, any sexual urge people with different cognitive abilities have is animalistic. This interlocutor explained to me that people with psychological disabilities do not have needs beyond food and water: emotional health is not an issue. When I questioned the same interlocutor about a need for sexual experiences amongst her patients, Cristina said, “This population cannot love.” (“*Esta población no se puede amar*”). She later went on to detail how they are like small children or animals. The statement about people with psychological disabilities not being able to love insinuates both that positive sexual experience can only come with “love,” and also that they cannot form real emotional and human attachment. The denial of inherent human attributes dehumanizes people experiencing intellectual and psychological disabilities. A lack of humanity, again, infers a lack of human rights.

To understand the denial of the humanity of a group of people who are deemed unproductive and governed by medical discourse, João Biehl (2005) coined the term “ex-humans.” According to Biehl, a Medical Anthropologist from Brazil, the change of Brazil to a neoliberal state caused extreme changes in the lives of groups deemed unproductive by the state and society. In his ethnographic work on a woman named Caterina, who was assumed to be experiencing a psychological disability and was placed in a private religious institution to remove her from society, Biehl charted the woman's social abandonment and denial of humanity by the state, her family, and society at large.

Bodies deemed unproductive, when placed in institutions like the Federico Mora, experience a social death. While they receive minimal attention, the state can symbolically acknowledge that it has cared and society at large can forget about the issue or cleanse itself of any group deemed unproductive in a neoliberal state. The patients are “alive on the inside” of the institution, and dead to those outside of the hospital, unless questioned if the minority group exists or is cared for (Beihl, 2005, p.48-49).

In Beihl's words, “In the bodies of the abandoned... political and social forms of life and thereby subjectivity have literally entered into a symbiosis with death without those bodies belonging to the world of the deceased.” (Beihl, 2005, p.51)

It seems that removing these people from society is in the interest of both the state, and at times, the families and communities of people with intellectual and psychological disabilities. Their removal from society keeps the rest of society more productive because the people experiencing disabilities could serve as a distraction from capitalistic goals or create more work for their family members and the state. This removal from society to prevent deterrence from production is even state-sanctioned within the Guatemalan Civil Code (Código Civil, 1964) by placing people under interdiction.

People with intellectual and psychological disabilities are placed in the institution due to "interdiction." As detailed in the preceding chapter, once an individual with a different cognitive ability is declared in the state of interdiction, he or she will be dependent on and subject to acts performed by his or her representative. In the case of people who do not have relatives or someone else who will be their representative, people with different cognitive abilities can be placed in the Federico Mora. Article 9 of the Guatemalan Civil Code establishes that people with psychological and intellectual disabilities need to be under "interdiction" and are therefore not allowed to exercise their rights, placing them under the category of "incapable."

While this code is not frequently applied outside of the institution, any patient interned in the hospital is mandated to remain there under interdiction by law. With this code, people with intellectual and psychological disabilities lose all of their rights, including those to their body and decisions to be made about their futures. Interdiction seems to be a medicalized legal fusion. This code contradicts other laws and treaties signed stating that anyone with disabilities should fully enjoy all of the rights granted to people without disabilities (Decree 135-96, 1996; Decree 59-2008, 2008).

Owing to the fact that state-mandated murder and outright genocide of a group is taboo and may incite a call to action or for attention to the neglected population, the state does only enough to acknowledge they have “cared” (Biehl, 2005). This space, designated for providing services to people with different cognitive abilities, has increasingly served as a prison for both people who have committed violent crimes and have psychological or intellectual disabilities and even more so for people who are convicted criminals who are assessed as not having an impairment. These people, designated by the state as undeserving of basic rights, are removed from society through the Federico Mora. All of the patients in the facility are placed in dangerous conditions as a result of untrained and often corrupt police staff, over-medication, low surveillance of staff, and a lack of basic necessities, like shoes. June of 2010, the time period in which I visited the Federico Mora, was the first time I was able to find a bursting of publications about what was going on in the hospital. Both the *Prensa Libre* (Martínez, 2010) and *Nuestro Diario* (Equipo investigativo, 2010), some of Guatemala's most popular newspapers, published articles about the Federico Mora that month. These articles detailed the increase in violent convicted criminals placed in the institution. They were published, not specifically to speak of the horrors that people with intellectual and psychological disabilities live daily in the hospital, but to warn the public that three of the convicted criminals had escaped from the hospital/prison in the first six months of the year and that people who do not have disabilities are bribing or extorting their way into the hospital as opposed to prison. The concern was not primarily for the group on the inside of the hospital placed in dangerous conditions, but rather, for those on the outside of the hospital, the public, who would be exposed to those people that had been removed from society but escaped from the hospital. This resonates with the idea that the main purpose for the Federico Mora is not to provide services for people with psychological disabilities, but instead, to isolate them from the public. The patients' social death is apparent.

In order to answer the calls by the public to prevent more people from escaping from the hospital, the government has proposed a plan of action. As opposed to building a separate high-security prison facility for those proclaimed “criminally insane,” the Guatemalan federal government has proposed to build a taller wall around the hospital facilities (Equipo Investigativo, 2010). Instead of making the institution safer for the patients in the hospital that have not been charged with violent crimes, the government plans to provide funding to assure they remain contained and separate from the outside “productive” society. All of my interlocutors in the Federico Mora claimed they desire that a separate facility be built for the convicted criminals.

When the demands and desires for people who have not legally committed any crime to live in a separate, non-prison facility are deliberately ignored, where can sexual rights begin to be acknowledged? They are not acknowledged. People with different cognitive abilities in the Federico Mora are kept alive but are not given the opportunity to enjoy rights outside of food, drink, some “medical attention,” and shelter. The pecking order of human rights is revealed for this group of people that is not considered fully human or are “ex-humans” to some people working in the institution and greater society.

HOW THE OTHER HALF LIVES: COMPARATIVE SUFFERING

My understanding of the lack of attention to the humanity and the human rights of people living in the Federico Mora was not gained during my time in the hospital, but rather in my time in Guatemala City spent outside of the barbed wire. Very often, when I spoke about the atrocities found in the Federico Mora with people who lived in Guatemala City, I received similar responses. People were shocked, said how horrible the situation seemed, but they knew of another case that was worse in the city. Some responded by asking me how we can expect the government to take care of the "the crazies" or "*loquitos*" when they can't even take care of the "normal" people. The full rights of the privileged, "productive" people must be ensured before those who are not considered to be so can be touched upon. A number of other people I spoke to pointed out, "At least they have food and a bed; some people don't even have that."

Among my informants working for the rights of people with disabilities, the rights of those with intellectual and psychological disabilities seemed to be on the bottom of the list. First, the rights of people with physical and sensory disabilities, who have a "valid voice" (can legally vote and are not placed under interdiction) need to be assured before those with different cognitive abilities can be fully included in the conversation about disability rights. In conversations about inclusive special education, one of my interlocutors explained, "If they can't teach the blind, deaf, or kids in wheel chairs, how can they teach the retards '*los retrasados?*'" These dehumanizations in the institutions based on medical discourses, legal codes and misconceptions engrained in society, further demonstrate how the patients in the Federico Mora are, in fact, Biehl's "ex-humans," the categorization he reluctantly uses "to express the difficult truth that these persons have been de facto terminally excluded from what counts as reality." (Biehl, 2005, p.51)

The reality for most Guatemalans on the outside of the Federico Mora is a reflection of what goes on inside of the hospital. Located in a city that claims one of the highest murder rates in the Americas and nearly complete impunity in sexual violence, the conditions found in the local mental institution are not expected to be world class. Perhaps one of the most telling conversations I had with an interlocutor in the hospital was with Cristina. After she detailed to me about how the patients in the hospital could not leave if they wished, had to take medication to hinder sexual impulses, and often experienced sexual violence at the hands of police officers and custodial staff, I asked Cristina if she felt that the patients in the hospital were in need of any rights or if their human rights were acknowledged. She responded that the people housed in the institution have all of the rights "*todos los derechos*" that any other Guatemalan has.

This story is telling of how this interlocutor understands reality on the outside of the hospital and is an overt denial of the gravity of abuse people in the institution experience daily. The liminal reality that the medical staff of the Federico Mora lives in likely fosters an alternate understanding of the rights deserved, granted, and denied for different groups of people. They live between life in a city plagued by violence and trauma, and a world of "ex-humans," often corrupt police guards, and convicted criminals. My interlocutors are victims of the medical discourse and societal stigmatizations as well. The Federico Mora, unfortunately, is not the only public institution in which workers and “patients” experience such horrific realities.

“Unproductive” in a Neoliberal Era: The Public Institution

After weeks of phone calls, e-mails and desperate searches for connections, I was finally granted a visit to the public institution I will call the House of Psychiatry, or the HOP. I stepped out of the taxi unsure I was in the correct place, because I was told the HOP housed about 70 children with profound intellectual and psychological disabilities. I stood in front of a large painted metal gate in the middle of a street surrounded by small factories. I rang the doorbell several times and after a few minutes, a nervous seeming ladino man in a simple suit, Carlos, greeted me. As a door in the metal gate opened, the heavy stench of urine, feces and other bodily fluids wafted into the outside world's air. Screams and shouting, like I had never heard before, leaked through the cracks of the gates and left me uneasy, wishing I could leave as soon as possible. None of my years of experience in the institution providing services to people with disabilities in the United States or Spain left me prepared for what I was about to witness.

While I shook Carlos' hand, he explained to me how he did not normally allow visitors, but the connections I had made with other members of the public institution helped my case. As we began our interview, which was conducted in Carlos' office under a huge poster with a regal-looking image of the contemporary president of Guatemala, Álvaro Colom, I could not help but be distracted by the gut-wrenching screams coming from outside of the room. After the interview I would find the root of these piercing cries. Carlos offered me a short tour of the facility along with another interview with the only resident psychiatrist. I caught a glimpse of a large cement, block-shaped room, but Carlos insisted on showing me the rest of the institution first. After a tour of several areas including: the kitchen, the laundry area, two special education classrooms the size and shape of short hallways and a physical therapy room, I finally came to the cement block room that seemed to stand alone in a grassy area. Carlos introduced the cement cell as the "saddest part" of the HOP. A few windows with metal bars allowed for hands and young faces to peak through. The children and some adults were screaming, asking for things, shouting unintelligible words, moaning, or writhing in pain. As I gazed through the window, I attempted to count how many people were imprisoned in the area, but lost track quickly. There were at least 30 people. A few teenagers stood shirtless; with diapers falling off of them and fecal matter running down their legs. One boy that seemed to have a much milder intellectual disability than most of the others was asking me for money and laughing to himself. A young girl with Down syndrome sat in the middle of the room on the cement floor and cried as she hit herself on the forehead with her open palm. A young adult male was curled up in a ball in the corner. One boy screamed, "Look at the blonde girl!" ("*Mira la rubia!*") several times as he stared at me smiling. He reached out of the gate as far as he could, squishing his shoulder through the bars. I shook his hand through the openings and he pulled his hand away to hit himself in the face with the hand I had touched. Carlos laughed. A few people seemed catatonic while others were jumping about the room wildly. As soiled hands reached through the bars, only two women in nurse uniforms stood outside of two of the windows to tell the jailed group not to hurt one another or just to serve as some form of surveillance. Not a single staff member was in the room with the residents.

Carlos did not let me linger at the metal-barred window for very long. As he washed his hands vigorously because he had touched the hands of a few people in the cement cell, he explained to me that there was no other place for them to go during the day when class was not in session. Not all of the residents could attend classes either. Carlos walked me down an open-air hallway that was decorated by colored animal bodies with individualized paper printouts of names of residents, their favorite things, preferences and other fun-fact-sheet information of the sort. A photograph of the face of one of the residents was pasted on each animal to replace the creature's head. Besides questioning how they could possibly know residents' individual preferences when they were locked in a cage the majority of the day, I could not help but think that this "art project" reflected the real animalization of the children placed in a large cement cage, like dogs in a kennel.

Carlos then escorted me down another open-air hallway where I met Esperanza, the resident psychiatrist. She welcomed me in but warned me that she was busy. The HOP had a new arrival, a girl who was about nine years old from Xela. The HOP was the only public center of its' kind in the country where children with profound intellectual disabilities could be institutionalized if they were placed under interdiction. The girl seemed understandably confused and scared. Esperanza explained that she was testing a drug on the girl to see if it could calm her down; she needed to observe the girl for a while ("*un ratito*"). She thought her time observing the new resident would be the perfect time for me to interview her, since she was already stuck in the room. The girl, whose name I was never told, was sitting in a chair, breathing heavily and grunting as she rocked back and forth. Every now and then she would mumble something unintelligible, laugh or start to cry. Esperanza told me that the drug seemed to be working, but she would probably try a higher dosage the next round. Throughout the interview the girl screamed or walked around the room. At one point she came behind me in my chair and pulled on my ponytail. She then dug her unkept nails into my shoulder and let out a panicked moan. I felt the fear and confusion in her grasp. Esperanza lovingly guided her back to the chair and told her "Calm down, precious."

After speaking with Esperanza, Carlos pulled me aside to tell me that he understood my study but wanted me to know that if I had anything nice to say about the institution, I was allowed to use the HOP's real name. However, if I had anything negative to write, I could not mention the real name. He told me to remember that the institution does its best with the money it receives. I responded that I would not use the real name for any reason, but he again insisted I use the real name if something positive was to be said. I shook his hand after catching one last glimpse of the cement room with hands peeking out through the bars. As I stepped out of the door in the metal gate, the screams of the residents echoed and the scent of human waste permeated through my clothes. I got into my cab where my *taxista de confianza*,[24] Edwin, was waiting. As I collapsed into my seat, I stared out the taxi window at the large metal gate that isolated these children and adults experiencing disabilities from the rest of the world. This was social abandonment in one of its most extreme forms.

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[24] A t*axista de confianza* is a taxi driver who is known and can be trusted because of familiarity. My local friends told me that it is sometimes dangerous to take taxis with unknown drivers in Guatemala City.

PUBLIC CHARGES IN A FAILED STATE

Much like the Federico Mora, the HOP is the only institution of its kind in Guatemala. While the HOP is meant to be specifically for children with profound intellectual disabilities, there are many adults with intellectual disabilities housed there as well. This is because the only public institution in Guatemala for adults with different cognitive abilities is the Federico Mora, which is meant to be primarily for people with psychological disabilities. Although there are a number of people with intellectual disabilities in the mental institution, including a few people experiencing intellectual disabilities with very recognizable phenotypical characteristics, like Down syndrome, the hospital is hesitant to accept others with intellectual disabilities. Therefore, the adults with intellectual disabilities will remain in the children's institution as public charges without schooling opportunities and will likely be there until they die.

The HOP, is controlled and funded by the *Secretaría del Bienestar Social*, or the Secretariat of Social Welfare. The President of Guatemala’s wife at the time, Sandra Torres, ran the welfare system in Guatemala when I was conducting research between June and August of 2010. Since conducting my fieldwork, things have substantially changed for Sandra Torres and at least how the welfare programs are publicized. When I was conducting research from June through August of 2010, there were rumors circulating that Sandra Torres would campaign to be President of Guatemala in the elections in September of 2011. In March of 2011, those rumors became reality. She put in her bid for the presidential office (“Sandra Torres asegura,” 2011). Torres began using her experience managing the Secretariat of Social Welfare as evidence of her political background. At the time of my return to Guatemala in July of 2011, Sandra Torres had divorced her husband, Álvaro Colom, because there is a law in Guatemala that mandates that presidential candidates cannot be family members of current presidents of the country. The divorce between President Colom and Sandra Torres was not enough to convince some candidates and stirred a great amount of controversy in the country Rojas, 2011b). Sandra Torres was rejected as a presidential candidate in July of 2011, but continued her campaign while trying to overturn the ruling in the courts. During this time, she continued to use her work with the Secretariat as evidence of her political experience. On July 30th, 2011, the Guatemalan Supreme Courts decided Sandra Torres would not be on the ballot in the presidential election in September of 2011 (Rojas, 2011a).

The welfare system is in control of several arenas in Guatemala and is broken up into three different large branches. One branch is for family and community support, the second is for family rehabilitation, and the last is for reinsertion and re-socialization of children in conflict with the law. The program for people with disabilities is found in the branch for family and community support. The disability program is one of four programs within the branch. Within that disability program there are two separate lines of action, one for people experiencing intellectual disabilities and the other for people with other forms of disability.

On May 25th, 2011, upon an examination of the *Facebook* page of the welfare center, I noticed a disparity in images displayed in the photo section of the social networking space.[25] Seven out of twelve of the photo albums on the *Facebook* page include some pictures of children with intellectual disabilities. Five out of twelve of the albums were dedicated specifically to portraying children with intellectual disabilities (Secretaría de Bienestar Social Guatemala, 2011). Three of these albums were pictures of special events at the only public school for special education in the Guatemala City area, a place I will call the Special Education School of Guatemala, or SESOG. Two online photo albums were dedicated to excursions that residents of the HOP went on to places in Guatemala City. The other albums were pictures from excursions for a large orphanage that houses children without disabilities along with children experiencing mild to moderate intellectual disabilities. In one of those albums, an excursion to the circus, the boys with intellectual disabilities are distinguishable from the other children because they are all wearing Superman t-shirts while the children without disabilities are in white uniform shirts or plain blue smocks, according to age.

At the time I checked the Guatemalan welfare center's *Facebook* page, all of the albums with residents from the HOP in them were posted on the social networking site within the previous month (Secretaría de Bienestar Social Guatemala, 2011). Both albums contain photos from excursions. None of these photos were taken on the premises of the institution. In one large group photo there are only about 13 out of about 70 residents present. The excursions appear to have one attendant per HOP resident, which is very unlike the institution was during my visit. There were only two attendants for at least 30 residents. Esperanza told me that at night there are only two attendants for all 70

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[25] *Facebook* is a popular international social networking website.

residents. Both excursions seemed to be for a select group of residents. The residents all seem to be the most conventionally cute children with disabilities from the institution. The few close-up pictures in the two albums are of the same few children. The only close up pictures of HOP residents with attendants are of an American volunteer whom I met while at the HOP, and a conventionally attractive young female. These albums seemed like staged photo campaigns published to show that the Secretariat of Social Welfare is providing services above and beyond what is expected for groups of children otherwise deemed as public charges.

The disproportionate representation of images of children with intellectual disabilities must be highlighted as well. When one considers that services to that particular group make up one half of the disability program, which is one fourth of the family and community support branch, which makes up one third of the entire Secretariat of Social Welfare, we realize how disparate this representation is. Almost half of all of the photo albums were dedicated entirely to services for them. This over-representation highlights how people with intellectual disabilities, particularly children, have come to represent the greatest symbol of charity and goodwill in the system (Shakespeare, 1997). Work done for children with disabilities seems to be going above and beyond the call of public duty and must be documented for all to see. The welfare center is working to prove the good they are doing by displaying images of a few outings that a small number of HOP residents were taken out on. These images and publicity also reflect upon the image of current presidential candidate and former head of the Secretariat of Social Welfare, Sandra Torres.

These photos exclude the reality that the children and adults in the HOP and other institutions run by the public welfare system actually live in. There is no documentation of the cement cage or any other area of the HOP. By only documenting excursions, people are likely to see and imagine only the “good” the government does, without ever understanding the reality of the people living in these institutions. This exploitation of images of children with disabilities not only misinforms the public, but also further promotes this discourse of charity that allows the assumption that people with disabilities are objects of charity and services done for them are good deeds, as opposed to civil obligation. They are of a lower class or population and services given to them are extra and not mandatory or important. As Shakespeare (1997) charges, these charity campaign images portray people with disabilities as passive, vulnerable and dependent. In these photos it seems that the Secretariat of Social Welfare is promoting the happiness of these dependent and vulnerable people.

The fact that the Secretariat of Social Welfare’s website and *Facebook* have been updated and tweaked to help provide evidence of the work Torres has done to fuel her presidential campaign causes one to question what work she has actually done for or with people experiencing disabilities. When I visited the HOP, according to Esperanza, neither President Colom nor Sandra Torres had set foot in the institution. Esperanza told me there had been rumors in the past that they were in fact coming and there was even a scheduled visit at one point. Esperanza explained that when those who ran the HOP found out about the upcoming presidential visit, they worked to beautify the institution to a certain extent. That is when the animal art projects were placed in the open-air hallways. They bought several potted plants for the occupational therapy area. I saw the posters of President Colom and Sandra Torres that Esperanza said were made for the occasion. They were hung throughout the institution with faces of happy children with intellectual disabilities (mostly phenotypically Mayan) surrounding and below their central image.

Esperanza explained that before the scheduled presidential visit, there was an issue with open windows in the cement block-style bedrooms of the institution. While all of the windows had bars, they did not have curtains or glass plating. This not only allowed for bugs to enter the bedrooms freely, but also made it so raindrops would come in and fall on the residents' head when they were confined in their bedrooms to sleep. Guatemala City is in a tropical area of the world and has a distinct rainy season. With beds cemented into the wall, children and adult residents do not have a manner to move their beds away from the windows in these rooms filled with several beds. Although Esperanza had told those running the institution about the problem with the water hitting the residents when they were trying to sleep, nothing was done until the presidential visit was scheduled. They placed plastic sheets on the outside of the windows. Esperanza claimed that they did not put the plastic up to protect the residents from falling water, but rather because they freshly painted the bedrooms' walls on the inside and did not want water stains on the new coat of paint for when President Colom and Torres arrived. The HOP had received funding to make the institution presentable for photographs with the president and the future presidential candidate, rather than to improve the living conditions of the people in the institution. In this scenario, one sees a bleak picture of the necessity for ephemeral proof of services. Administrators at the HOP and in the welfare center show that they understand the conditions are poor in the HOP through their quick-fix work to beatify the institution before a presidential visit, and through sending the residents outside of the institution for photo opportunities. The actual living conditions are not addressed. Only the ephemeral image of the Secretariat of Social Welfare seems to matter. When referring to photos of the children with intellectual disabilities that are used for fundraising, Esperanza explained, “They love to put those up. Because the publicity in some way will attract funds that interest them, but 100% of those funds don't get to here (the HOP).”

These public institutions are not so much used to provide quality services for people with disabilities, but as a method for the state to show that it has symbolically cared. Private NGO, non-profit and for-profit institutions can provide services for the majority of the population that are able to receive services, while the Guatemalan government provides extremely limited services. According to Carlos and Esperanza, they only provide live-in services to about 70 people with profound intellectual disabilities at the HOP. These are 70 people whom the state could not find a private or non-profit institution to place them in under order of interdiction. The superficial images of outside excursions and what would have been freshly painted photo opportunities for the future presidential candidate, frame the overt denial of humanity and citizenship of people with disabilities in Guatemala. Seen as unproductive beings and objects of charity, there is not work or funding to improve their lives and promote access to important rights and individual needs. Instead, they are used for publicity and as proof that the

Guatemalan government may be complying with certain human rights treaties or laws, while people experiencing intellectual and psychological disabilities are socially abandoned in an institution that "cares" for them.

CARE, CORRUPTION OR CAUGHT IN THE SYSTEM?

The institution that I will call the WOGH (Workers of Guatemala Hospital) is the public hospital that provides discounted healthcare to people who are eligible for receiving Social Security benefits in Guatemala. I was given explicit instructions on exactly where to be dropped off at this institution, but upon telling my *taxista de confianza*, Edwin, that I was going to the WOGH he did not bother reading my instructions. He knew exactly where we were going. On the way, he warned me that the WOGH was a complicated and disorganized institution, and that it could not possibly serve the amount of people the institution was slated to provide services to. Edwin dropped me off in front of the institution that was intensely crowded with groups of people rushing in, out, and about the building. The white walls and chipped and age-stained tiles smelt of disinfectant and wet clothes from the crowd that had likely run for cover from the rain during the last downpour.

I felt people staring at me intensely, likely wondering why I was there. This is probably due to the fact that I am a pale blonde woman and I was in American-style clothes, with a large binder in hand. I walked through a small crowd that was sitting on the ground with their legs crossed in order to get to a reception desk. There, I asked where I could find the man I will call Dr. Zambrano. The woman looked relieved and said "Ah you're here for Dr. Zambrano," like it all made sense to her in that moment. I was on the wrong side of the hospital grounds. She told be to leave the building, and gave me a string of directions I knew I would not remember. I was told to go the rehabilitation center in the hospital. I walked outside, up a large grassy hill, down a long trail, and through another building so crowded that groups of people were sitting on the ground with children in their laps. After asking for directions a few more times, I arrived to find a beautiful building and a central plaza. There was a Japanese tranquility garden with a charming wooden bridge, an adaptive basketball court, an adaptive indoor soccer field, lush plant-life along the sidewalk paths and clean office hallways with only a few people at a time. I thought to myself that this building had to be where they normally sent researchers, journalists and important visitors. This was the face that the people who ran the WOGH wanted to be seen.

I was greeted by the kind and smiling face of Dr. Zambrano after waiting at the front desk of the rehabilitation center for only a few moments. Truly a charismatic and warm man, I had met him a few days earlier when in the building of CONADI. A representative from CONADI had introduced me to Dr. Zambrano and told me I needed to see the hospital for my research. Dr. Zambrano worked primarily with people with physical disabilities, but the rehabilitation hospital also had a number of patients experiencing psychological disabilities like Post Traumatic Stress Disorder, or PTSD and some heavy depression related disabilities. He would also introduce me to a psychiatrist in the rehabilitation center.

After a short tour of the rehabilitation center, I sat with two Ladino doctors, Dr. Zambrano and a psychiatrist, Dr. Chavez. While conducting one interview I saw another

Ladino man in a doctor's coat walk slowly by the glass window to the hallway of the room that I was sitting in. He looked in at me with a huge smile, turned around and knocked on the door to Dr. Zambrano's office. The man was a very high-ranking representative for the hospital, a man I will call Dr. Johnston. He entered the office and said something about needing to know who the beautiful blonde is. In between my interviews he sat and questioned me about my ethnicity. I told him how my mother was mostly Swedish and German and about my mixed heritage on my father's side that included Mexican and Spanish. His eyes lit up at the combination of Mexican and Swedish. "That explains the blonde hair and eyes made of honey." he pondered. I began to feel uncomfortable with the conversation centered on my appearance. After moving the conversation to other subjects with the three powerful doctors, Dr. Johnston would randomly chime in something to the effect of "What a beautiful mix!" ("*¡Pero que mezcla más bonita!*") referring to the outcome of my ethnic background. He told the other doctors to look at the color of my eyes a few more times and then as it was time to start my next interview he offered to be interviewed himself. The chance to interview one of the highest-ranking representatives of a public hospital was something I felt obligated to do as the opportunity presented itself.

At the close of my interviews with Dr. Zambrano and Dr. Chavez, Dr. Johnston brought me into his office. He made it clear and told me that he was not very familiar with the situation of people with disabilities in Guatemala, but he still responded profusely to all of my questions. He was unfamiliar with the majority of laws and policies and spoke several times about the innocence of people with disabilities. He made several broad and incorrect generalizations like, "Autistics don't know how to lie."

When I asked him what he thought were the causes of psychological disabilities, he first detailed congenital, hereditary, and trauma induced issues. He then explained that beautiful women could cause psychological disabilities as well. Pointing to me, he said "Exquisite women... they are the root of illnesses in men." or "*Mujeres divinas... son causantes de enfermadades en hombres*." He laughed to himself.

It seemed very strange to me that one of the highest-ranking personal in a hospital that worked with people with disabilities would be so unfamiliar with disability issues. At one point he explained to me about how women were the most important people in assuring that children experiencing disabilities get the services they need. Men don't know how to deal with it and are upset by their failure as a father and see the child with disabilities as a threat to their potency. It is mothers who have the capacity for unconditional love. This assumption or generalization not only re-imposes gender roles on both men and women, but also places blame on women if a child with a disability is not kept in the home or cared for "properly."[26] Men don't have the capacity to understand or tolerate disability, so they have an excuse. If a child with a disability is given to the state or a private institution for financial or other personal reasons, a mother is not properly performing her gender role and loving unconditionally and assuming all

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[26] For more information of the gendered service provision for people with disabilities, refer to Sousa (2011).

responsibilities for the child. The father cannot be blamed for his actions because of how disability naturally affects the family patriarch.

After about an hour and a half of conversation and questions, I turned off the tape recorder while I waited for my taxi. Although I said I could sit in the waiting area so he could get back to work, Dr. Johnston insisted that I wait for my taxi in his office. While sitting in his office he asked me if I was planning any trips or if I had been anywhere else in Guatemala. I told him that I had seen Antigua and I had recently come back from a weekend on Lake Atitilán. He asked if I liked the lake and then invited me to come with him to a place that he had on that lake for the weekend. He said it was beautiful and that I would have a great time with him. I politely told him I was busy over the weekend and was quite relieved when my taxi driver called to tell me he was outside shortly after that. Dr. Johnston insisted on walking me out to the taxi and at the car’s door, he gave me a hug goodbye and told me that I should reconsider going to the lake with him and to call him if I needed anything else.

Dr. Johnston's sexism, unprofessionalism and willingness to take advantage of his powerful position paints of a picture of the corrupt and hierarchical power systems in the public sector. His demeaning fetishization of my ethnic background in front of Dr. Chavez and Dr. Zambrano along with other active verbal flirtation that culminated in him trying to convince me to spend a weekend away with him, exemplifies the gendered patriarchal power structure found in these institutions. When one takes into account that I am an international researcher, from the United States, who was able to leave the WOGH at any point, I must question what forms of harassment might be endured by women not in my privileged position? What happens if nurses, secretaries, cleaning staff or other doctors who must be at the institution daily, experience similar or harsher forms of sexual harassment? Dr. Johnston did not take my position as a researcher seriously, and the interview seemed to be viewed more as an opportunity for him to flirt than to provide information about his work and view of the institution providing services to people with disabilities.

In nearly every public institution I worked in (CONADI, the WOGH, the HOP), the highest ranking member of the branch, division or institution that I interviewed seemed to be the least prepared to answer questions about the population that the institution catered to. They often had less education than those in positions below them and nearly all of the highest-ranking members of the institutions were ladino men. This is a reflection of the gender and racial hierarchy that is pervasive in most of Guatemala. It also shows the lack of care paid in hiring to assure that a knowledgeable person who keeps the best interests of the clients, patients, students or residents is employed. The highest positions seem to be figurehead positions in which people can exercise power to a certain degree, but are limited both by a scarcity of funds and lack of understanding to improve the situation of those receiving services from the institutions. Dr. Johnston, a man in nearly the highest position in the hospital, was able to take more than two hours out of his day to speak with me, a foreign researcher that was investigating a topic that he claimed that he was not very familiar with.

The disinterest in ensuring that the most qualified professionals work with people with disabilities is further emphasized in an incident that happened in the Secretariat of

Social Welfare at the time of the election of Álvaro Colom. According to Alex, after Colom was elected into the presidential office and Torres took over the welfare program, the Colom administration attempted to fire everyone in the administrative branch of the Secretariat of Social Welfare who was not a registered Colom supporter. This was to instigate a spoils system in the public sector. A domestic human rights surveillance office had to be called upon for help and the Colom Administration claimed that there was never an attempt to fire anyone. According to Alex, people were interrogated to find out who reported to the human rights organization and workers' e-mails were raided. By promoting a spoils system, the Colom Administration was not only attempting to prevent transparent democracy and to fire people who did not vote for Colom, but the administration also made it so, regardless of experience or work performance, people would have been terminated. This exemplifies how a political agenda and votes are more important than providing quality services to the group of people with disabilities for the Guatemalan government. According to a woman who works for an occupational therapy center run by the Secretariat of Social Welfare that attended one of my post-research talks in July of 2011, Avalon, the same situation that happened during the change to the Colom Administration will happen in this coming 2011 election. Former military general, Otto Pérez Molina, who is slated to win the Guatemalan presidential candidacy in September of 2011 ("El ex militar Otto Pérez," 2011), has warned the workers in the welfare center that if they are not registered for his political party, the Patriot Party (el *Partido Patriota*), they will be fired.

WORKING FOR THE STATE

“So then yeah, they tell you that your job doesn't need to exist. Because even though they (people with disabilities) have the same rights as anyone...but no, that isn't true. At a social level they are always marginalized, and in this type of situation you are marginalized as a psychiatrist, psychologist, or someone else who works with the people who the majority of the population that they call crazies (*locos*), you know? We are all discriminated against in some way.” - Esperanza

The effects on state workers of neoliberal policies and the isolation of people with cognitive disabilities must be taken into account to understand how the human rights of people with intellectual and psychological disabilities are understood and applied. As noted before, the public institutions are understaffed and short on resources. This leaves the workers in the public institutions over-worked, underpaid, overly stressed and often untrained. According to Alex, some public institutions try to have more unpaid interns from the local public and private universities working than the actual staff. For example, Alex explained that in July of 2010, SESOG provided 733 students with special education. There were 33 employees at the school but there were 42 interns. It does not seem to be in the government budget to assure that staff working directly with children and adults with disabilities will receive the best care possible from the institution.

According to Esperanza, caregivers at the HOP, during morning and night shifts, are not only in charge of watching over 35 children with profound intellectual disabilities each; they must also bathe them, clean up after them, prepare them for bed and get them ready for the day in the morning. I have worked with children experiencing similar grades of intellectual disabilities. I worked in a high school classroom in fall of 2006 in a class called Low Ratio Integration. In this class, I worked one-on-one with a teenager with a profound intellectual disability in a classroom and on excursions with other students who also had their own personal aid. Nearly every day I would leave work and would go to my university exhausted after a seven-hour shift that included a lunch break. While I do not wish to imply that all children with profound cognitive disabilities are the same, I do believe there are certain needs that are similar and providing quality services for them can be both trying and tiring. Assuring that 35 different children and adults with profound intellectual disabilities receive proper care over an eleven-hour shift, while cleaning up after them, seems to be an impossible task. On top of the stress of assuring that 35 people are washed, clothed, put to bed, woken up, fed, etcetera, there is also the issue of violence from the residents. Some intellectual impairments may cause someone to be more apt to resort to tactile force for stimulation or their impairment may hinder them from fully understanding the effects of their actions that could be seen as aggressive, especially without adequate service providing and behavior modification. In my experience, when my students have been victims of violence, they were also more likely to resort to physical aggression for a number of reasons. Others may use violence as a communication tool because they have not had the opportunity to learn otherwise. The caregivers are expected to understand how to cope with abuse from residents in this high stress and exhausting situation.

According to Esperanza, “So after they avoid some hits, sometimes they (caregivers) attack the residents because there isn't anyone who teaches them that, 'look you have to treat a patient who is agitated, violent, or aggressive this way.' So then caretakers can't touch them ever, but also they have to defend themselves in some way. However, they don't teach them that here. It's impressive that this area is not something that is taught. It is for that reason the caretakers' jobs are even more difficult."

This lack of training and consideration for the mental health and well-being of workers in the public institutions not only causes the caretakers to be unable to perform their jobs to the best of their ability, it elicits violence in the institution. The abuse of the patients and staff adds to the layers of adversity they experience and exemplifies how social abandonment and isolation in institutions can come with devastating results. The HOP is not working to integrate the group into society or even promote their well being, as photos on the welfare center's *Facebook* would indicate. It is the incarceration of a dependent population for the purpose of segregation. Institutions like the HOP become a practical system of disposal and work to draw the line between acceptable and unacceptable people in individualistic societies like the neoliberal one found in Guatemala. Rather than hire and train enough staff to meet the needs of all of the residents, the grave situation found in the HOP not only proves that this place painted as a "philanthropic institution" is nothing other than a government-mandated isolation zone. When placed under interdiction and into the HOP, the impairments and dependency of a number of the residents worsened. According to Esperanza, "Some residents went backwards. Before they were bathroom trained, and now they have to use a diaper."

Esperanza also explained how the HOP did not have a single psychologist or speech therapist on staff. These professionals would play key roles in working to reintegrate residents into society. According to Bill Hughes (2001), institutions like the HOP, which place people with disabilities "out of sight," amplify dependence and block people experiencing disabilities from participating in the public sphere in any consequential way.

Due to the fact that people with disabilities are removed from society and stigmatized by the public through a lack of knowledge of the groups' experiences, personalities, characteristics of their impairments, or what their impairments were caused by, those who work with them can be stigmatized as well. The workers can be labeled as those who work with "the crazies" ("l*os loquitos*") or "the idiots" ("*los tontitos*"). These reinforcements of negative labels both defame the workers when outside of the institution and dehumanize the residents in the eyes of the workers inside of the institution. The workers' stigmatization likely affects their treatment of the residents, while also disinsentivizing working for the HOP. Carlos said the turnover is high for nurses and caregivers there. Esperanza told me that the fact that she got a job at the HOP made people wonder if the psychiatry community was punishing her. Both she and Carlos said that if it weren't for the fact that unemployment is so high in Guatemala, they believe the turnover rate for employees of the HOP would be even faster. Outside of the stigmatization, low pay, lack of training, long work hours, and understaffing, there is a lack of job security as well.

Esperanza said, "We'll say in my case, I'm here working on a contract and the contract is until they decide when. If they say, no today, then no. So then, in that way, that's unstable, right? Because you don't feel that there is even a question about job stability here.... it doesn't exist." As mentioned before, the Colom Administration has tried to instigate the spoils system in employment with the Secretariat of Social Welfare. Esperanza indicated knowledge of this as well. A chat with Carlos about his prior knowledge of disability issues before coming to the HOP, revealed his little experience with people with disabilities. He was placed there to work in direction and administration by the Secretariat of Social Welfare, and did what he could without making any real changes to the institution.

During my return trip to Guatemala in 2011, I was able to speak with Alex again after one of my talks about my thesis results. Alex had connections to Carlos in the public institution and they had recently spoken. Carlos no longer worked for the HOP. Alex explained that the situation in the HOP over the year between August of 2010 and July of 2011 had gone from bad to worse. As mentioned earlier, the Secretariat of Social Welfare also controls a re-insertion program for youths who are in conflict with the law, juvenile delinquents. According to Alex the majority of them are gang members who are under 18 years old. The re-insertion program is like a prison for youth. After September, for some reason, administrators in the Secretariat of Social Welfare began to move male teens in the re-insertion program, who had misbehaved, to temporarily stay in the HOP. Alex did not know who made the decision to begin this disciplinary system.

Since then, the HOP has had several problems with the youth with criminal backgrounds in regards to abuse of the residents at the HOP with intellectual disabilities. Alex retold one account of violence to me. Teary-eyed, Alex explained how a daycare giver heard blood-curdling screaming from one of the bathrooms. The attendant ran to find a girl with Down syndrome being punched furiously in the face by one of the youths with a criminal background. The staff at the HOP found out that the young man was trying to rape her, and when she began to scream, he hit her so she would become unconscious and be quiet. The girl's face was broken.

Alex told me that after a number of incidents of abuse, Carlos complained to the Secretariat of Social Welfare that the system bringing charged criminals into an institution for people with profound intellectual disabilities was not right. Carlos was moved to another institution after that, so he could no longer complain about the system. Alex says he was not fired, likely do to the fact that he had been so closely connected with finances in the Secretariat of Social Welfare, which Alex stated was laundering money from the welfare center for Sandra Torres ' presidential campaign.

These layers of corruption, lack of job security, and abuse of staff found in the public institution providing services to people with disabilities is only over-shadowed by the abuse that is knowingly continued of people with disabilities jailed in these institutions. Placing youths charged with crimes in the same institutions as people with profound intellectual disabilities, exemplifies how intellectual differences are criminalized. This bio-politically problematic group is left on the outskirts of humanity when the government entities knowingly place them in situations of abuse, as if to discipline them for having a disability. Using living with people with intellectual disabilities as a punishment for youths charged as criminals signifies which group is lower in the hierarchy of citizenship. The punishment insinuates to the youth with criminal pasts that they could be in a place worse than a juvenile detention center and with people with less value in society.

Rather than take Carlos' recommendation to stop bringing juvenile delinquents into the HOP, he was removed from the institution. A valuable employee in the HOP seems to be one who does not complain. A person with different cognitive abilities is not valuable to the Secretariat of Social Welfare until his or her image can be used for harnessing charitable funds and votes in political campaigns or he or she can be used as a prop in a punishment for youths with criminal backgrounds (those who are considered more human).

SEX, DRUGS AND CHARITY

The philanthropic paradigms for understanding disability highlighted in the public relations of the Secretariat of Social Welfare are harmful to the sexual rights of people with different cognitive abilities, if not solely based on the fact that we have been conditioned to desexualize “objects of charity.” However, the medical discourse that seems to prevail inside of the public institutions both add to and reinforce the desexualization of this group while opening up spaces for more abuse. All of the representatives from the HOP and the staff of the WOGH agreed that it is necessary to medicalize their “patients” if they have different cognitive abilities and exhibit sexual urges. When trying to understand how the drugs work, I asked the psychiatrist from the WOGH, Dr. Chavez, if they were like “the opposite of Viagra” (*el opuesto de Viagra*) and he laughed and said that I was right. This form of medication seemed to be the answer to any sexual acts. He said the same type of pill must be used in the instance of a person with an intellectual or psychological disability masturbating in public as well.

While there seemed to be a hyper-vigilance towards limiting sexual activity and expression by people with intellectual and psychological disabilities, there weren't many precautions taken for preventing sexual violence. A number of my interlocutors explained that the main method for preventing sexual violence was the medication to reduce sexual urges of patients in institutions. This, once again, seems to indicate that there is a belief that the patients or residents themselves are the biggest perpetrators against the group. A number of my interlocutors in the public sector said that there was a higher rate of sexual violence for the group but they could not name an instance of it happening in their own institution. Both Esperanza and Carlos told me that people were sent to the HOP by court order because they had been sexually abused. Alex detailed stories of families that had committed sexual abuse in their homes but it was discovered in SESOG. Dr. Zambrano and Dr. Johnston both told tales of sexual violence against people with disabilities that they read about or watched on the news. A number of my interlocutors outside of the public sector that were from human rights organizations, non-profits and NGOs told me they had heard about sexual violence, specifically in the HOP.

My only interlocutor in the entire study who said that people with disabilities are possibly less likely to experience sexual violence than those who do not have disabilities was Dr. Chavez. When asked why he thought people with psychological disabilities are more vulnerable to sexual violence, Dr. Chavez responded, “Because of the disability itself.” He then went on to say they are sometimes less vulnerable to sexual violence.

Assuming that the only vulnerability to sexual violence is the impairment a person has, disregards any socio-cultural, political or economic circumstances people with disabilities endure. This exemplifies how people with disabilities are often seen only for their medical diagnosis and not as individuals or human beings. If one understands disability as a series of social barriers that limit a person's access to the community and their human rights, one can grow more sensitive to different risk factors that may arise for any form of abuse as barriers to access are taken into account. Dr. Chavez is a psychiatrist who manages his patients by way of pills and does not normally participate in therapy sessions to understand the root of issues that may occur in a person with psychological disabilities' life. Instead, the doctor prescribes pills to treat the surface issues or behaviors. This is exemplified in the case of Dr. Chavez's treatment of the public masturbation of his patients with different cognitive abilities. Rather than seeing his patients as agents with sexual needs, or people who have not learned exactly where or when it is socially appropriate to sexually stimulate him or herself, Dr. Chavez sees a person with a psychiatric disorder masturbating in public. There is a pill for that, so if the self-stimulating person is a man, he can no longer become erect, through temporary medical castration.

Both Carlos and Esperanza detailed to me how the largest portion of operating costs for the HOP was medication. While I will in no way deny (and have seen first-hand) some of the positive effects of medication for people with intellectual and psychological disabilities, the heavy stress on medication (along with isolation) limits the understanding of what disability is, both inside of the institution and in the pubic arena. As people with disabilities are confined to medical spaces, those in the medical profession run their lives. They are redefined as "sick bodies" and "sick minds" in need of internment and rehabilitation (Hughes, 2001). These bodies and minds, deemed unproductive in the neoliberal state, are biopolitically problematic and are forced into institutions organized to produce docile and dependent residents through medication and isolation (Foucault, 1978). Sexual agency does not pair well with docility and dependency.

While Dr. Chavez claimed that with medication, people experiencing psychological disabilities could be "normal" and have "normal" sex lives, he went on to say that, "I really don't know how someone can be with someone who is bipolar, but love is love." This statement effectively others people with psychological disabilities as well as those who form romantic relationships with them. While taking into account that he claims that medication is the normalizing factor for people experiencing psychological disabilities, why would it be strange or impossible in one's mind to be with a person who is bipolar? What would hinder this? The medical discourse does not allow a person to qualify as "normal" or a real "citizen" even while medicated. They simply become their diagnosis but medicated or controlled so they are deemed less "dangerous" or less biopolitically problematic. Despite adhering to the mandates of medical professionals, a person with a psychological disability only experiences greater dependency as opposed to greater independence as they continue to be treated and understood as their diagnosis, as opposed to individuals or full citizens, deserving of equal rights.

These ideas inside of the public institutions that medicalize disability seem to prevail over the sexuality of Guatemalans with different cognitive abilities. This occurs while the charity model is artfully executed in the public relations of the welfare center. A combination of the two paradigms filters out into the greater public. Because the welfare center is also in charge of removing children from reported abusive situations, those who receive the complaints in the welfare center can see the twisted result of the charity discourse in other isolated environments for people with disabilities.

According to Alex, the Secretariat of Social Welfare has received a number of reports about young girls with disabilities being sexually abused by their fathers. The reason a number of these girl's fathers claimed they raped their daughters was because if it weren't for them, their daughters would not have a sexual experience. This disgusting excuse re-appropriates the desexualizing discourse of charity used so eloquently by public and private institutions. In the fathers' minds, they morph the violation of rape into a philanthropic act. Somehow their daughters were lucky in the fathers' charges. As people with disabilities are desexualized in the public arena, in the private arena they become sexually victimized. While reinforcing the idea that people with disabilities should not have access to positive sexual experience, incestuous rape becomes a form of forced “access,” adding to the layers of risk factors and violence too often endured by people with disabilities. The fathers' claim of their daughters' sexuality also demonstrates the deeply culturally engrained patriarchal norms that hierarchize the desires, ideas and needs of the father over the daughter.

As the spaces close for sexual expression and positive sexual experience for people with intellectual and psychological disabilities, risk factors increase for sexual violence and a lack of vigilance to reduce those risk factors becomes pervasive. Denying this groups sexuality not only causes them to be “ex-humans” in institutions that deem them undeserving of fundamental human experiences (Biehl, 2005), it also creates dangerous situations that are not spoken about in the context of providing services in the public institution for people with disabilities. Instead of assuring a life free of abuse, people are sustained and controlled through medication. They cannot be cured, so they must be quieted and isolated. The medicalized bodies of people with intellectual and psychological disabilities inside of public institutions become objects of charity in the public arena as well. Although the services provided by the public institutions are often horrific, Guatemalan government exploits images of “charitable” acts for the group to gain headway in political campaigns, help fundraise for money that the institutions will not receive and show international and domestic human rights organizations that the government at least symbolically cares for the group. While the government symbolically cares, it becomes the work of non-profits and NGOs to fill the gap in services while actively participating in the government's work of proper subject making.

Bitter Charity: NGOs and Non-Profit Institutions

Private non-profit and non-governmental organizations make up an extremely diverse and necessary facet of service provision for people with intellectual and psychological disabilities. As mentioned before, according to SOFDAB data, only 25% of Guatemalans with disabilities receive any services at all.[27] Due to the scarcity of government-funded services mentioned in previous chapters, non-profits and NGOs are responsible for a large portion of those services. I would like to clarify from the outset that my intention in this chapter is not to vilify the workers and staff who dedicate their lives to ensuring access to services for people with disabilities, but rather to provide a critique of the larger system that relies on an over-burdened NGO and non-profit sector for the provision of disability services, as well as examine the social and political climate that causes dangerous and demeaning practices to prevail in these institutions.

During my fieldwork between June and August of 2010 I did observations in ten different sites belonging to the non-profit and non-governmental sector, interviewed representatives from ten different institutions, and conducted a total of seventeen official interviews with representatives from these groups. I also had several unofficial, unrecorded interviews with different service recipients and members of the non-profit and NGO sector. This sector can be divided into several different categories: religiously-affiliated organizations, schooling institutions, internationally-funded organizations, local community-based groups, research institutions, disability-specific organizations, age-specific service providers, and emotional support groups for parents and children. Several

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[27] In the interest of confidentiality and protecting SOFDAB's real name, I will not provide a citation here.

of the institutions fit into more than one of the categories. The diversity of purposes, goals, and the institutional makeup all reflect the lack of options provided by the public sector as well as the predominant opinion that public sector services are undesirable. According to some members of the non-profit and NGO sector, people are better off not receiving services in the public institutions.

Since non-profits and NGOs often fill a gap left by a lack of government services and funding, they allow for the government to get away with not providing what it is legally mandated to provide. The majority of these non-profits and NGOs not only provide higher quality services, but they also are used by government-funded agencies as examples of the Guatemalan government's dedication to disability issues. As touched on earlier, the photo of the matron of one of the non-profit institutions with her son who has multiple disabilities is one of the most common images seen at CONADI's headquarters. The government can claim support of these institutions by splitting a small portion of CONADI's funds between a few non-profit organizations. This minimal amount of money typically covers the costs of printing promotional material for the non-profit institutions. In this manner, most pieces of printed material from the non-profits contain CONADI's emblem even though the printing of promotional materials is often the only thing CONADI funds. The NGOs and non-profits do the lion's share of the work to provide services to people with disabilities, but the government can claim some of the credit by having their representative emblem on all of the promotional material distributed to the public. One of the organizations that CONADI grants funding for printing is SOFDAB.

SOFDAB is the one institution in Guatemala where I had an opportunity to do extensive observational work. The organization, SOFDAB (Schooling Organization For Deaf and Blind), is nestled in the mountains on the outskirts of the city. SOFDAB provides a beautiful, unique, and presumably safe environment for children with multiple disabilities and their parents or care providers. While the majority of students experience sensory disabilities, a number of students have different cognitive abilities as well. Perhaps the most unique aspect of this school is that it allows the parents to attend school with the children, giving them an opportunity to learn to effectively communicate with their children. The family incomes of people accessing services at SOFDAB vary immensely. Some families can be considered well off, while a larger portion have very scarce economic resources. The majority of SOFDAB students come with their mothers, while a few come with their grandmothers, one with a nun who works at an orphanage, one with a special paid attendant and one with his father.[28] Many children only come a few days a week due to their families' economic situations, their distance from the SOFDAB centers, or due to health-related issues.

My first day at SOFDAB began with a tour. I ended up at SOFDAB because many people recommended the institution for this study. For a number of people not involved in the disability services sector, this was the only institution they could refer me

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[28] SOFDAB's dedication to having parents attend school with the children is a major asset given that many families do not have the skills needed to communicate with their children at home. While the time and effort required to participate often means significant loss of family income, the school attempts to make up as much as possible for this situation by providing food, charging (often free) sliding-scale tuition, providing some transportation, and never requiring attendance or having a minimum amount of days students must attend to remain enrolled.

to or thought that I needed to see. SOFDAB had hosted several awareness campaigns at book fairs and in stores to sell chocolate for fundraising, making it more widely known in some parts of the outside community.

After contacting them by e-mail, I was invited to the non-profit on a Friday to go on a special tour of the facilities. A group of local artists had been invited to SOFDAB's facilities because they were working on a project that involved art for fundraising and they wanted the artists to donate their services. First, we were shown a series of well-produced videos about the institution and what it meant to the community. A staff member used simple terms to talk about how people are born with multiple disabilities, and then discussed SOFDAB's countrywide efforts to provide services to children experiencing multiple disabilities. SOFDAB has a total of three sites, including the site near the capital, and does outreach work in rural areas of Guatemala as well. We were then sent out on a walk with blindfolds and earplugs to simulate what life would be like with multiple sensory disabilities. This experience proved to be very enlightening for all of the artists and myself. Following the experiential (*sensibilización*) walk, we were taken back to the room where we had watched the videos to speak with the founder of SOFDAB. The founder, Adriana, is a fair-faced, relatively wealthy woman who started the school for her adopted son, a phenotypically Mayan man who is deaf-blind. Adriana explained how she had to do research on her own to find out methods to communicate with her son and find resources outside of the country. She decided she needed to start a school for children experiencing multiple disabilities because not everyone in her situation had the same opportunities or education as she did. Adriana seemed deeply passionate about the issue and was very gracious towards all of us for coming to the school. She had us go around the table and introduce ourselves and talk about what brought us to the non-profit.

When it was my turn to speak, I described the basics of my research and work I had done with people with disabilities in the past. One of the bits of experience that Adriana seemed to find most appealing was my experience teaching yoga to young adults on the autism spectrum. After the artists left, she requested that I speak with her in her office. Adriana excitedly asked me more about my experience with yoga. I explained that I had only ever taught adaptive yoga to promote a tranquil environment and allow my students to challenge themselves physically without competing with each other or using a lot of equipment. She beamed and asked if I thought that the students at her school would be able to learn these techniques. The Hindu tradition that was appropriated in the United States was gaining popularity in Guatemala and she wanted to see how her students would take to this exercise and meditation often reserved only for the wealthy there. I jumped at the chance to come back to the institution on more than one occasion and get to know the students, staff, and caretakers at the school. We decided that I would come twice a week to teach five sessions of yoga a day, one for each classroom.

My time at SOFDAB was a wonderful and worthwhile experience. The students at the school are some of the most fun-loving, and happy children I have met. The parents and caretakers were kind, compassionate, and loved to laugh. The staff members were some of the best trained, intelligent, and dedicated people I met during my fieldwork. For the most part, everyone at SOFDAB was welcoming, gracious, hard working and showed how much they cared about the promotion of education, acceptance, and inclusion of people with disabilities. I fell in love with the concept and values of the foundation quickly. In their brochure they stated, “SOFDAB is a private non-profit institution, dedicated to growing and strengthening bonds of communication for people who are deaf and blind and have multiple disabilities, through specialized methods applied with love, dignity, and respect, that support and involve their families in their development and incorporation into society.”

Two to three times a week I would arrive at the school in yoga gear at 8 a.m. and would leave the school at around noon. The sessions I taught consisted of basic yoga positions with different adaptations depending on the abilities of the students. The days I came to the school varied depending on the school activities schedule. SOFDAB never seemed understaffed and I was always greeted by a slew of students that appeared excited just to be around each other. At lunch, teachers, mothers, and grandmothers would chat together while they helped the children prepare their lunches and the children enjoyed each other's company. I always looked forward to sitting with the caretakers, teachers and children at lunch: learning words in Central American Sign Language, listening to stories of the students everyday lives, learning “*Chaupinismos*” or uniquely Guatemalan words from the students and caretakers as they laughed at my accented Spanish, and buying tostadas made by the students.

Being present at SOFDAB a few days out of the week allowed me to see what the staff had to do in order to provide the excellent services it offered. There is a back office with a number of staff members dedicated almost entirely to fundraising for the capital site as well as the outreach program and SOFDAB's two other sites in Guatemala. However, I learned the greatest lessons about their policies and needs for fundraising while I instructed yoga.

One of my first mornings teaching, I saw firsthand the spectacle of charity in a neoliberal and patriarchal society. I was with five students, a few mothers, a grandmother, and a teacher, and we were halfway through the session doing yoga on a grassy patch on a hilltop overlooking the city. In this serene moment we were in a yoga position called "cobra." With my eyes closed and giving adaptation instructions in Spanish, I suddenly heard a staff member above me saying something like, "This is Sam. She is an American who has come here to volunteer her time and teach the children yoga. She is a wonderful person and we are so happy to have her here to teach our angels this beautiful art."

While I was expecting her to be with a small group of people, like the group with the artists and I, I opened up my eyes while stretched in the snake-like position to find more than 50 Catholic schoolgirls and a few nuns staring down at my students and me. I was shocked because I had not been warned about the upcoming visits. I awkwardly smiled up at them, but I knew that my lesson needed to continue because I only had a limited time with these students. I continued to go through the positions with my students in a distracted manner, next came "child's pose." I heard the clicking of disposable cameras as the crowd watched our slow exercise that was supposed to be meditative. At that point the staff member began to pull the students one-by-one from the lesson to talk about him or her.

The staff member would say something to the effect of, “This is Angelina, she is blind and deaf and she was an orphan. The Catholic Church took her in and now she comes here during the week. She can now do yoga and she enjoys eating with her friends. She is a little angel and we are so happy to have her here.”

While the descriptions were spouted off and they puppeted demonstrations about how people who are deaf-blind communicate with their hands, I heard the adolescents say things like, “How cute!” (“*¡Que lindo*!”*)* or “Poor thing!” (“*¡Pobrecita*!”)*,* while they took pictures and whispered with their friends. I felt like I was in a zoo with the group walking by on a tour. The teacher present during my yoga class explained to me after the lesson that the schools would be allowed to visit SOFDAB in exchange for donations. A lot of religious schools came to SOFDAB because it was assumed that being in a safe environment around others who are “less fortunate” would make them grow as people. This is similar to the way the youths with criminal backgrounds in the HOP are punished by being forced to stay in an institution with people with intellectual disabilities. It is assumed that by being around those “less fortunate” they will begin to behave the way the Secretariat of Social Welfare-run facility wishes.

This practice of school visitations was a Wednesday tradition. In fact, there was a person in charge of booking the school for these Wednesday visits. After a few weeks they stopped having me come on Wednesdays because so many of my classes were interrupted and I would only be with the group for a few weeks more. While I was sitting in the office of the woman in charge of scheduling visits, Cecilia, to fill out some paper work, another woman from a school for children without disabilities entered the office.

She discussed with Cecilia all of the details of a day for her students to visit SOFDAB. She explained to Cecilia, first, that she wanted the students to have breakfast together and that she wanted one disabled student per non-disabled student. While they were working out the logistics of a visit to SOFDAB, I was called into another room, but it seemed that the schedule for visitors was quite full and this woman's school had to be penciled in. The woman wanted to get her charitable donations' worth of access to children with disabilities for her students.

The second Wednesday I was at SOFDAB, another group of students from a different school that I will call St. Mary's came to visit. Again my class was bombarded by a group of about 40 students during one of my lessons. My last session was cancelled so the students of St. Mary's could do a large group art project with all of the students at SOFDAB. The students at SOFDAB who were most able to interact with donating schools were all sent to the large sports court at St. Mary's staff request. It was the second time I had seen this exact art project carried out with the SOFDAB students during a school donation visit. The schools brought packages of powdered fruit punch, little bowls and coloring sheets. The students at SOFDAB were then surrounded by the St. Mary's students who did not have disabilities and instructed the SOFDAB students to finger paint with the fruit punch powder, which they had mixed with a small amount of water to make a solution that had the texture of a paint. One of the students from St. Mary's eagerly explained to me that they used the fruit punch in case the students tried to lick their fingers. The students at SOFDAB, however, normally use regular finger paint to make thank you cards for visitors. In the several instances I watched them make these cards, not a single student tried to lick the paint off of his or her hands.[29] During that time, the students from the other schools hovered around the SOFDAB students and instructed them in the ways of finger painting. They often placed their hands over the SOFDAB students' hands and guided them, even if some of the students could see and were only deaf. Throughout these sessions the students from other schools would chime "How cute!" ("¡*Que lindo*!") and "Aw what an angel!" ("*¡Ay! ¡Es un angelito!*").

One of the finger painting days, two of my yoga lessons were cancelled so they could fit donors into the school schedule. I sat against the chain link fence and watched the donating students, who I will call St. Francis students, with the SOFDAB students on the large play court normally designated for physical education. It was, again, the only area large enough to fit the large crowd. Attendance was very low that day at SOFDAB, and the school normally did not send students out who would be unresponsive or confuse volunteers. Only About ten SOFDAB students came down to the field. This made it so there were about six St. Francis students per SOFDAB student.

While watching the event, I chatted with one of the mothers that I had gotten to know through her participation in the yoga lessons. I asked her what she thought of these donation days. She said that she hated them. She thought they were demeaning and took the students away from actual learning. How could working with students who didn't know anything about them, who thought finger painting with fruit punch with them

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[29] I was given a thank you card with handprints in finger paint from one classroom on my last day teaching yoga at SOFDAB.

would be a fulfilling activity, and called them "poor things" positively impact her child? She continued describing her distress over the necessity for these days when the students were missing out on valuable class time. She said, by now, she and her son should be learning a word in Central American Sign Language per day, but she still doesn't have the ability to discuss the morning newspaper headlines yet. She admitted this was just something they had to deal with and she normally didn't like to go to the school on Wednesdays.

On this particular day, the St. Francis students brought baby wipes, although there were sinks nearby. After the SOFDAB students were finished finger painting, a number of the St. Francis students fought to be able to clean the SOFDAB students' hands off with the baby wipes, in spite of the fact that the students could have easily gotten up walked or been directed toward the sinks. As St. Francis students scrubbed every spot of fruit punch mix off of the SOFDAB students' fingertips, it became clear what a commodity this apparently charitable act of cleaning the SOFDAB children's hands was. It looked more like a competition to see who was the kindest and warmest person.

The fetishization of what are perceived to be "good deeds" for the SOFDAB children by the St. Francis students exemplifies the effects of the charity discourse surrounding disability in Guatemala. This particular case also exemplifies assistentialism caused by the charity discourse. People experiencing disabilities have been socially constructed to be objects of pity rather than humans with agency and rights. In this context, doing anything for these people who are seen as "poor things" or "little angels" is a kind and helpful act of generosity. While the SOFDAB staff may try to reconstruct how their students are seen in the public eye by also talking about what they can do, (like yoga, art, and conversing with friends) ultimately what is most visible or recognized by most in the public eye is what they can't do, or what they do differently. This is due in part to the very nature of this isolated institution. The children at SOFDAB must attend the school there because the public institutions, as well as the majority of private institutions, are not accessible to them.

The students from schools like St. Mary's or St. Francis' are conditioned to understand the relationship with the students of SOFDAB as a hierarchical relationship between they, who can, and the SOFDAB students, who they believe cannot. This resonates with the work of Michel Foucault (1978) with “Biopower,” which is a form of exercising power over other bodies. It is “an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations." (Foucault, 1978, p.140). This technology of power is employed to mark the higher social status of people who are not “disabled” over people with disabilities. While as Foucault would point out, Catholic school students do not actually posses power, they, and the rest of society, exercise it over the students with disabilities through isolation and exploitation. It is exercised through the existence of isolated philanthropic institutions, as opposed to the promotion of inclusion in greater society. This inclusion is an explicit goal of SOFDAB, but due to the necessity for charitable contributions like those of the other schools, SOFDAB is forced into these extremely demeaning and counterintuitive practices. The only option for them, as a non-profit institution, is charity.

Allowing the student visits does not promote inclusion in society for people with disabilities and in all actuality imposes ableism and assistentialism upon students at SOFDAB. They inhibit SOFDAB students from participating fully and receiving lessons one full school day a week and expose them to demeaning language and acts. Rather than focusing all efforts on teaching the students at SOFDAB methods of communication and taking down other barriers in society for them, a large portion of the administrative staff and time of both the students and teaching staff, are all dedicated to procuring funds for the continuing existence of the school. This not only hinders access to class-time for students, but also creates a constant tension between staff dedicated to fundraising and staff dedicated to teaching. Although there seemed to be a mutual understanding between both branches of SOFDAB staff, I heard several complaints from teachers about how fundraising efforts took time out of their day and how difficult it was to get through lessons. Foucault (1965) again points out how philanthropy is unstable, largely due to the fact that it covers up the origin of the problem that it addresses. However, in Foucault's analysis he seems to implicate the people promoting philanthropy instead of society at large as the culprits in this cover up. I believe that SOFDAB's staff and caretakers' resentment of these fundraising visits exemplify how these are not desires of those promoting philanthropy, but rather, they may often be effects of this charity discourse surrounding disability. The workers at SOFDAB do not necessarily forget these goals, but rather they have to set them aside in order to gain funding in a neoliberal society that a singular group is unable to resist against in order to provoke change. I would not argue that Foucault is wrong in every case in regards to those who cause this cover up of the root of social problems, but I feel his charges are not correct in SOFDAB's case.

In the context of disability in Guatemala, I refer to charity not only as money, goods or labor given for what is perceived to be a good cause, but also charity as a virtue for kindness or tolerant judgment. Tolerance is often mistaken for inclusion, due in part to this model of charity. People are often conditioned to believe that tolerance of a minority group allows for an equal society. Rosemarie Garland Thompson (1999) writes about how the real goal of the disability movement is not tolerance, it is accessibility and inclusion in society despite whatever form of impairment someone may have. Saying someone is allowed in a space and that they are tolerated does not necessarily mean they are able to access it, or that they are treated as full citizens or equals in that space.

The charity discourse surrounding disability has been something of a personal constant in my life. Growing up with children experiencing disabilities because of my mother's job, people would often tell me "Your mother is a saint." As I grew older and began working in the disability services sector myself, people would often tell me, "You're an angel!" or "You are such a kind and loving person." While I may or may not be what they labeled me as, I always found these categorizations problematic because people who spouted these compliments often did not know me, but only what their perception of my job was. I felt that they would have said this to anyone who worked in my field. A number of people I worked with in special education were not the "angels" that people might have assumed they were. One of my co-workers in the past sexually abused a student with the excuse that it was a disciplinary action, a number of my co-workers were negligent of our students' needs, and some taunted the students because of their disabilities. Charity allows for a group to be commodified as a source of good deeds and proof of kind-heartedness. The charity discourse is pervasive and not only affects people with disabilities, but also those who work with them, and society's perceptions and treatment of these groups.

ONE GOD, ONE COUNTRY, MULTIPLE PERCEPTIONS

The religious non-profit and NGOs are often the greatest proponents of the charity discourse. Guatemala is a deeply religious country and while it is predominantly Catholic, it has one of the fastest growing Protestant movements in Latin America (Garrard-Burnett, 1998). I was unable to find a single religious institution providing services for people with disabilities that was not run by people from a Christian faith group. Tim Stainton (2008) writes about how texts and teachings of the Bible have left many spaces for varying forms of religious interpretations of disability. Some religious teachings may imply that the person with disabilities is a manifestation of personal or family sin, while others believe that psychological or intellectual disabilities indicate demon possession. There are a plethora of Christian-based religious interpretations that could be deemed “positive” as well (or less outwardly dehumanizing). Some parents believe the child or children with disabilities are a “cross to bear” and that God would not give them that cross if he did not believe they could carry it. Others told me that they believe children with intellectual disabilities are angels sent down from heaven to teach us how to love. Others believe “We are all God's children.” and we all deserve to be treated fairly. All of these interpretations, positive and negative, manifest themselves in different forms of treatment of people with disabilities (Rogers-Dulan, 1998). Not surprisingly, to my knowledge, all of the NGOs and non-profit organizations where I did fieldwork in Guatemala held to these "positive" religious understandings of disabilities. It seems people who understand disability as a punishment for sins or the possession of the devil are unlikely to create or seek out the scarce amount of services available for people with disabilities in Guatemala.

I did fieldwork in one openly Protestant organization and two openly Catholic organizations. A number of organizations, while they claimed to be non-religious, very much imposed religious moral codes and often decorated the sites with religious items. One organization that said it was not religiously affiliated was located in a church. Another representative from the organization that I will call AWDAF (Adults with Disabilities and Friends) said that the group was not religious even though there was a sign reading, "AWDAF is Jesus Christ. Jesus Christ is AWDAF," in the room where I conducted an interview. According to Ana from the PDH, NGOs and non-profits often avoid specific religious affiliations in Guatemala because there are so many different sects of Protestantism and they don't want to be exclusionary of people who believe in the same God.

The Catholic organization whose policies I will discuss the most is the *Catholic Charity of Antigua,* or the CCA. I will call the Protestant organization *Protestants and Friends of Intellectual Disability* or PAFFID. While both of these organizations use religious doctrine both to validate and promote their causes, they utilize the Christian faiths to understand and treat disabilities in very different ways.

The Catholic Charity of Antigua, or the CCA, is a non-profit organization that provides medical services for the poor and serves as a live-in institution for abandoned populations like the elderly and people with disabilities. The CCA as an institution has existed for nearly 30 years. According to one of my interlocutors in the institution, an administrative staff member named Elena, 40% of people living in the institution have family members on the outside that are too poor to take care of them and 60% of people living there are abandoned. Many of the abandoned are placed there by court mandate, either under interdiction or because of removal from a dangerous family situation. There are around 200 people interned in the institution. The CCA also provides a significant amount of free and discounted external medical services to the public, as well as childcare and a drug and alcohol addiction recovery area.

The CCA works with very little funding compared to the services it is slated to provide. They receive about 20% of their funds from the government and their average monthly budget is 300,000 Q. The institution has around 300 employees, including administrative, maintenance, and health care professional staff. In order to cover the large amount of services the institution provides, medical doctors come from all over the world to volunteer at the hospital. The CCA also has between 700 and 750 lay volunteers work at the hospital annually.

According to Elena, on average, 90% of the volunteers are foreign. The largest number of volunteers comes from the United States and Canada, but many also come from Germany, France, Japan, Argentina and other parts of Europe as well. 10% of the volunteers are Guatemalan but most of the time they are there to receive certification for community service hours. Elena told me that all of these volunteers are necessary for the institution to exist. This is primarily because they are more likely to donate goods and money if they work in the institution and because they take pressure off of the nurses' work. There are only four nurses on staff per shift and nurses normally work 11 hour shifts, six days a week. Outside of people in the religious vocation, Elena told me that the turnover rate is very high for medical staff. A number of the surgeons, dentists and other medical staff are also international volunteers that come for short periods of time as well.

When one considers that the institution has over 300 employees, it seems strange that there are only four nurses working at a time and that each of them works six shifts a week for 11 hours at a time. Avalon, a woman who works for an occupational therapy center run by the Secretariat of Social Welfare, told me about a scenario that may explain the situation at the CCA. Avalon explained that within these large non-profit institutions as well as in public institutions, there is an issue with large administrative staffs and very small service provider staffs. Avalon claimed that this is due to corruption at the top of these institutions. Those in charge are given a certain amount of funding, and they often create jobs for their friends and family on the administrative end, because work directly with people with disabilities is not necessarily desirable. In this way, although the work of an institution is to provide services to people with disabilities, the majority of staff is dedicated to administrative work. While I cannot prove that this is the case in the CCA, the low number of nursing staff that works directly with people with disabilities could be a result of the situation Avalon detailed.

This CCA is much like the Brazilian Pentecostal institution in Porto Alegre, *Vita*, which was studied by João Biehl. Similar to Vita, within the CCA "words of salvation were everywhere." (Biehl, 2005, p.36). The CCA is dedicated to a male Catholic saint whom I will call Saint Marcos, who was Spanish-born. Painted on the arch over the entryway into the CCA, there is a larger-than-life image of Saint Marcos in a brown friar robe. With a halo and Anglo face he stands over a group of people who seem much smaller than him. Beneath his sheperding arms are: a phenotypically Mayan boy with crutches who looks sickly and is coughing; a small, frail and elderly Ladina woman looking up reverently at Saint Marcos; and a Ladino alter boy in a long white robe who is kneeling at Saint Marcos' feet.

The CCA's webpage holds a section titled "Nuestros Pobres" or "Our Poor," if one decides to view the site in English. Within the "Our Poor" section, one can find four musicalized photo slideshows.[30] The first slideshow is a series of images, mostly of solitary people in wheel chairs, alone. The tone of the music is heavy and somber and there are no vocal parts. The last three series are images of white Europeans and North Americans "helping" the different groups, including the elderly and children and adults with disabilities.

The last three videos carry even heavier messages of charity outside of the images of middle-aged Anglo tourists smiling and hovering over phenotypically Mayan children with disabilities. There are three separate vocalized praising songs that ring out in English

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[30] Due to confidentiality agreements, I cannot give the real name of any private non-profit institutions unless otherwise permitted.

along with each video. Some of the lyrics include, "The lord hears the cry of the poor, blessed be the lord." and in another video, "Christ has no body now but yours. No hands, no feet now, but yours. Yours are the eyes through which he moves compassion on this world. Christ has no body now but yours."

The lyrics that serve as the soundtrack for the promotional videos seem to insinuate that the Caucasian volunteers are doing their God's work by being in the presence of these abandoned populations. The song "The Lord hears the cry of the poor" accompanies images of a young Caucasian woman blowing bubbles for a phenotypically Mayan child, suggesting that anyone who does something positive for this group is a good Christian. This imagery also establishes a hierarchy of benevolence. The hierarchy is established along the division between aid givers and aid receivers, i.e. between who needs help and who can give it, between who has the privilege of paying to fly to another country to do volunteer work and those who have a disability in a country in which international funding and volunteers are necessary to receive essential services. Rather than painting a picture of interdependence or speaking to the reasons that residents at the CCA have been placed there, these promotional videos gloss over the social and economic issues perpetuating the position of complete dependence for people with disabilities in Guatemala (Foucault, 1965). Although the CCA provides important healthcare services, by promoting this image of people experiencing disabilities, the CCA serves as an oasis for philanthropic tourism.

Besides these musicalized slideshows of Caucasian people "saving" phenotypically Mayan children and adults with disabilities by hovering and smiling over them, there is a general sense of pity for the people interned in the hospital environment. Patronizing images and situations shone through in the language utilized by the CCA. This was one of the only organizations I found that still used the term *minusválidos* to refer to people with disabilities. According to many of my interlocutors, (such as SOFDAB, PAFFID, SADS, and Access Mobility) this term, while utilized often in the public arena, has become out-of-date among institutional workers. According to some of my interlocutors this is due to the fact that the term "*minusválido*" can be translated to mean "less valid" or "worth less." This type of language not only promotes the social construction of people experiencing disabilities as less deserving of rights, but also makes them seem less human. The only option for services for them becomes charity; it isn't a required and vital public service.

Much like Biehl's ex-humans, the people housed in the CCA's experiences and lives are devalued and reduced in language, practice and public acknowledgement. Both Vita and the CCA are caught in a perpetual fight for philanthropic funding due to neoliberal policies and overarching patriarchal ideas about people with disabilities. These large institutions not only serve as privatized spaces of social abandonment, but also institutionalize a patronizing and demeaning model for understanding disabilities on both a domestic and international level.

PAFFID, on the other hand, is a small, community-based NGO that is off the radar in regards to fame on both an international or domestic level. The aunt of two men with intellectual disabilities founded it. This woman, whom I will call Daniela, had a background in education and wanted to utilize it to find methods to promote inclusion for her nephews and people with similar diagnoses. It began with an inclusive youth group that allowed people with intellectual disabilities to lead the meetings and prayers. This group has expanded both into a parents' support group as well as a group to work to think of ways to create other arenas of inclusion. Members of the group with intellectual disabilities have: participated in a marathon alongside people without disabilities, took part in a graduation ceremony in a school with high school students without disabilities, took classes to learn job skills, and worked independently to plan their own events for the group.

It must be taken into account that members of PAFFID with intellectual disabilities and people with disabilities in the CCA are in extremely disparate situations. Members of PAFFID still live with their families, are of a higher socio-economic level, and are not limited to life in a large institution. PAFFID is also substantially smaller, is not as reliant on international volunteers, is not considered a medical institution, and is more community-based. The people housed in the CCA often experience more profound intellectual disabilities as well.[31] These differences allow for substantially more spaces for inclusion and allow for an entirely more humane treatment of people with intellectual disabilities.

As stated by Daniela, the main goal for PAFFID is credibility (*credibilidad*), in society. She wants people with intellectual disabilities to be understood as people who can do, as opposed to people who cannot do. Through different activities the group

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[31] According to Elena, the CCA used to house people with less severe intellectual disabilities, but they were moved to other institutions.

attempts to prove their worth in society by running their own events and creating spaces of inclusion. Daniela was knowledgeable about the social model of disability and talked about research she had conducted independently so she could work to ensure she was helping to promote the most inclusionary program possible. She spoke to me about difficulties she had in trying to create a special education classroom at a local school. She said that she did this so that administration at the school would eventually allow people with disabilities to experience full inclusion, (also known as mainstreaming) with the rest of the student body. This was done with the idea that exposure to people with disabilities is the key to making the public understand that this is a group that deserves inclusion into the rest of society. She talked about how people understood her, her students and the program she was running. According to Daniela, they would say, "the lady with her little school" (*"la señora con su escuelita"*), which she found demeaning to both her and her students with disabilities.

The social issues that prompted people to abase the group's efforts for inclusion are seen in the pervasive public use of the charity model of disability. Even when groups work to challenge these societal barriers that prevent people with disabilities from access to rights in society, the work is viewed as philanthropy. Daniela explained, "They think that I'm Mother Theresa." With these ideas, the special education class is not a learning institution, but rather a little school, a side project and a charity. Whatever is done for people with intellectual disabilities goes above and beyond what is necessary to provide in a society imprinted with neoliberal values.

While outside forces often limit the amount of activities and arenas that the group of people with intellectual disabilities is able to participate in in greater society, Daniela voiced resistance to paradigms that portray people with intellectual disabilities as objects of charity and medicalization. The CCA, on the other hand, models people with disabilities as sources of salvation for volunteers through philanthropy. The difference in interpretations of disability and how people should be treated and receive services translates to access to sexuality and prevention of sexual violence as well.

SEXUALITY AND CHARITY

In my research, I found that the way disability is perceived in an organization or by an individual tends to deeply affect how groups understand and treat the sexuality and sexual abuse of people with disabilities. Much like the study by Pamela Block (2002) of some service provider's feelings about sexual access for people with cognitive disabilities in Brazil, opinions and reactions varied greatly based on individual religious beliefs or past experiences. Continuing the comparison between PAFFID and the CCA, there were two distinct ways the groups, or individuals in the groups, understood and treated the sexuality of people with disabilities. In the case of Daniela, a person who treats disability as a series of social barriers that limit access in communities, she said, "Love is a reality that truly is not limited by cognitive capacity. And God is love. And if I come from a God of love I have to express my love. And love is expressed in sexuality and with a partner, right?"

She then spoke about how men and women with different cognitive abilities should be able to marry anyone with whom they are in a consensual relationship and have sexual relations. While this religious interpretation does not allow for sexual experience outside of the heteronormative paradigm, there is a space for some expression of sexuality for people with cognitive disabilities. This imposition of morals in a more egalitarian manner does allow for sexual access that is semi-equal to the rest of the population, but still very limited access. Christian-based religious teachings have historically been used to limit how people are allowed to express sexual desires as well as perform gender in society (Foucault, 1978). This is true of sexual restrictions for people with different cognitive abilities in Guatemala as well. Cognitive ability is often used as an arena to further limit access to sexual experience in religious institutions in Guatemala.

Due to the fact that there is a heteronormative view of sexuality in most Christian-based religious teachings in Guatemala, the Catholic organization, the CCA attempts to restrict access to sexual experience at the level of heterosexual partnerships. According to Elena, although everyone who resides at the CCA is required to receive the first four major Catholic sacraments (Baptism, Reconciliation, Communion and Confirmation), people with different cognitive abilities are not allowed to marry. Elena explained that they attempt to keep everyone residing in the institution from marrying. Creating separate areas for the men and women facilitates this. The only time they have regular access to the opposite sex is during church services or if they are children and are with volunteers in recreational areas.

When questioned if any of the “patients” at the CCA had married, Elena responded:

> “The patients, no. There is one particular case. One patient, from the area of men did marry a patient from the area of women. They were intellectually well (*estaban bien*). Their attitudes were normal. The young woman graduated from high school. They then got married. They did it that way and they now have two children. These are two children that are normal when the father can't walk and the mother has physical deficiencies. The two children are normal, so we let them be. However, we weren't looking for them to have a relationship with anyone. That's why we have the men and women separate.”

There are several layers to piece through in the above comment. The first layer is the position that hierarchizes levels and types of disability to limit sexual access. Working through the medical and charity model, people with disabilities of any form are to be pitied and to be put under surveillance. The CCA had to “let them” get married. It wasn't a natural right. One of the reasons they were allowed to marry was due to the fact that they were well or good in the mind (“*estaban bien”*). Saying someone is “good” or “*bien*” in the mind, indicates that a person with an intellectual disability or psychological disability is bad in the mind. There is something wrong with them. Since they are often born with intellectual or psychological disabilities, they will always and have always been “bad” in the mind. The other binary placed upon people with disabilities is normal versus abnormal. There is no space in between the two and the only determinant in the case of who is placed in the privileged category of “normal,” is not having a disability. There is also an attempt to limit consensual heterosexual activity no matter what form of disability a person has. One of the main reasons the above consensual relationship described seems to be permissible in the eyes of those who run the CCA, is the fact that both of the children produced by the couple are “normal.” Elena contended, “The two children are normal, so we let them be.”

The goal does not seem to be to promote a happy life for the couple, but to assure that the standards of "normal" are maintained, and to prevent the creation of more "disfunctional" or biopolitically problematic bodies. Several of my interlocutors (Alex, Cristina, Astrid, Dr. Chavez, Dr. Johnston and Elena) voiced that people with different cognitive abilities should not have sexual relations if it leads to them reproducing. Only one in my 30 interlocutors (Ana from the PDH) told me that people with intellectual disabilities should be allowed to reproduce. A few said people with "medically controlled" psychiatric disabilities should be allowed to reproduce, but they all said that they felt it was still risky and dangerous. My interlocutors often voiced two fears when it came to reproduction by people with disabilities (intellectual disabilities in particular). The first fear discussed was almost always that people with intellectual disabilities will only or are far more likely to produce more people with intellectual disabilities. This is untrue unless the disability is genetic (Irwin, 2011). Even if the disability is genetic, there is never a 100% chance that reproduction will result in a child with a disability. This worry is also problematic when one considers the long history of eugenic sterilization of women with disabilities and how this sterilization portrays people with disabilities as unwanted in society (Brady, 2001). The second fear my interlocutors often voiced was that if a couple produced a child, the person or persons would not be able to raise the child. It has been proven that people with intellectual disabilities have and can raise children when provided with the proper support, especially people with mild to moderate intellectual disabilities (Ehlers-Flint, 2002). In regards to sexual access, people often don't take into account that women with intellectual disabilities can choose not to have a child and a couple can use birth control if the pair chooses to and is given quality sexual education. A person with cognitive disabilities could also be homosexual or queer, and reproduction may not be a danger in consensual sexual acts.[32]

Elena said the staff at the CCA is also segregated between men and women. She said, "We prefer that male nurses attend to male patients, female nurses to female patients. That is also brought about by the influence of the Catholic religion. This includes when volunteers come."

Although I did see male and female volunteers with children in the same area, and I toured the facility with men and women and met with adult residents of the CCA with disabilities, most staff members in areas were segregated by sex. Elena pointed to me and told me that this separation of staff is for the good of the volunteers, not the residents. She said, Guatemalan men can be "bold" ("*atrevidos"*) and they don't want any of the foreign women to be harassed. This comment carries several charges within it. The first charge being that Guatemalan men cannot control themselves around foreign women. This creates a racial or nationalistic hierarchy and hypersexualizes Guatemalan men while hypervictimizing Anglo women. The reasons for the policies of the separation being for the sake of the volunteers and not the residents also carries the assumption that people would not sexually abuse or be "bold" towards the residents with disabilities. The reason for separating the patients by gender, they claim is to hinder sexual relationships

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[32] According to some of my Guatemalan friends, premarital sex is still highly taboo in Guatemala. Guatemalan Sociologist, Ana Silvia Monzón (personal communication, July 2010), told me that women, who want birth control, even if they are married, often get the birth control shot, which lasts six months. This is because it can be hidden more easily than pills or other methods. People with cognitive disabilities would not be able to access birth control methods independently due to interdiction.

between people with disabilities. The reason staff is separated is so foreign females will not be sexually harassed by Guatemalan men. This hierarchy or labeling of who deserves access to their sexuality, who is desired and who desires, limits how all of the groups are understood and how they understand one another within the institution.

A heteronormative approach to prevent access to heterosexual contact is seen in non-religious entities as well. In one non-profit school for special education that I will call the School for Attention to Down Syndrome, or SADS, the school is equipped with a swimming pool. However, after reaching the sixth or seventh grade, students are no longer allowed to go swimming. A psychologist from the school explained that this is because by that time, the students have adult bodies. The psychologist claimed that due to the infantile nature of people with Down syndrome, they fear the women or men will run out to the pool naked and the men and women will become curious about the other sex's bodies. This not only assumes that people with Down syndrome of the same sex would not be curious about each other's bodies, but it also hypersexualizes them and projects assumptions upon them that limit the amount of activities they are allowed to do. A center for adults with intellectual disabilities, that I will call AWDAF or Adults With Disabilities and Friends, goes on excursions to swimming pools on a regular basis. My interlocutor at AWDAF did not report any problems with sexual “deviance” or problematic conduct on these outings.

In regards to heteronormativity in institutions, I was able to ask a few of my interlocutors about what happened if a person expressed desires to be with someone of the same sex. In the CCA, Elena explained that if this was expressed, it meant the gay "tendencies" ("t*endencias"*) were part of the person's disability. This is seen as a deviant aspect of the person, and another reason to limit access to sexual contact. The Catholic institution, the CCA, is not supposed to provide services to people who are not heterosexual. By classifying the tendency as a part of the person's disability, they are able to reinforce that both homosexuality and disability should be cured, disappeared or hidden.

There were several contradictory understandings and treatments of the sexuality and sexual abuse of people with cognitive disabilities in a number of the NGO and non-profit institutions in which I conducted fieldwork. While speaking with a speech therapist whom I will call Pamela, at SADS, she told me that she believed people with intellectual disabilities deserve to enjoy all of the rights people without disabilities enjoy. We just need to find different methods of teaching them, and they can live "normal lives." However, she did not seem to consider sexual rights within the range of rights they should have or in the spectrum of a "normal life." When discussing access to sexual experience, Pamela said, "They (people with Down syndrome) live their romantic stage." She talked about how the relationships her students have are like dramatic soap operas. I then questioned her whether she believed these relationships should be physical. She asked, "Physical or romantic?"

I responded, "Well, what do relationships that are romantic look like if they cannot be physical?" We both laughed. Pamela then went on the say, "I believe that it (physical romance) is a little dangerous, it's true.... Of course no parent is okay to let it happen, right?... It's not allowed in this institution... But I feel like the children want it a lot and they express it openly. To me, it seems really conflictive, you know? Because no, because I don't want that to happen, right? ...The desire in the children is always there though. It's a high libido that the children have."

I then asked Pamela if there was a fear of sexual abuse between the students. She responded, "Abusive? No. In truth, it's really quite participatory." Pamela then went on to tell a story of how one of her students is actually the daughter of someone who attended the school herself. The woman with an intellectual disability ended up having sexual relations with someone and the child she produced also had an intellectual disability. This seemed reason enough to prevent physical sexual contact from happening for all of her students. This was common in the discourse of rights for people with intellectual disabilities. They did seem to deserve all other rights for many people working in NGOs and non-profits, but sexual rights needed to be limited. A few interlocutors told me that people with intellectual disabilities are too innocent for sexual contact. Others responded that they are like children, and children are not mature enough for sex. My interlocutor from AWDAF explained that her clients are children in adult bodies, so while their hormones may indicate otherwise, they are not and will never be ready for sexual contact.

While infantilization of people with intellectual disabilities further promotes societal and patriarchal restrictive barriers to sexual access, there is also a medicalization of the sexuality of people with different cognitive abilities to restrict actual physical sexual reactions. In the CCA, aside from imposing barriers between people of different genders from having contact, much like in the WOGH, the HOP and the Federico Mora, they create medical barriers that attempt to inhibit sexual desires in people with disabilities. Although they are already isolated from the rest of society, people with disabilities still need to be "normalized" or sedated. When asked if the "patients" could get away with not taking their medication if they chose not to, Elena replied, "They have to complete their work." ("*Ellos tienen que cumplir con su trabajo."*).

Due to the fact that medication is seen as the normalizing factor that creates docile and dependent bodies, which are less biopolitically problematic in isolation, it becomes the work of these bodies to take pills. As medical beings, people with different cognitive abilities are subject to medical prescriptions. As medical authorities have stated that reproduction would create more biolpolitically problematic people, several barriers must be created in order to prevent access to sexual experience. These "ex-humans'" jobs are to take pills and become docile bodies in isolation (Biehl, 2005).

VIOLENCE AT HOME

Besides the promotion of isolation due to restrictions on sexual access, a number of other societal issues in Guatemala serve as isolating factors. Violence and trauma deeply affect the disability community and service providers there. The increased rate of violence in Guatemala prevents institutions from providing all of the services they once did. A representative from AWDAF, whom I will call Amelia, explained to me that as an institution, they no longer take their students on excursions outside of swimming at a pool that is near AWDAF's center. Amelia said she feels unsafe even when they do that. She highlighted the fact that the last time they felt safe on an excursion was when some students received a scholarship and went to Colombia to perform a folkloric dance in a Latin American festival for people with disabilities. Amelia left Guatemala and went to a foreign country and felt safer. Considering she had a higher sense of security in Colombia, an unfamiliar country that is often considered dangerous as well, as opposed to her home city, is telling of the drastic effects that violence in Guatemala has had on Amelia and the vulnerability to violence she feels that she and her students experience in her home country.

The loss of these outside excursions in Guatemala for some NGOs and non-profits due to fears of violence has detrimental effects both on their clients experiencing disabilities and the public perceptions of people with disabilities. This fear of the public arena not only creates more isolation for people with different cognitive abilities, but it also prevents the outside community from exposure to the subgroup. Society as a whole cannot understand the social barriers created for them or work to remove those barriers if they are not exposed to the group to learn from them. Isolation from the rest of society not only creates a risk factor for abuse but also instigates a lack of general understanding of difference in society.

The isolation from society can often be justified by these NGOs and non-profits due to experiences their clients or students have in society. Of the four students that AWDAF decided were “mentally capable enough” to take the city bus to arrive at the school, three had experienced some form of violence in a year. One person was assaulted in the street at knifepoint and all of his belongings were robbed. Two students' families received phone calls for extortion by gang members who said they would kill the students if they did not receive a certain amount of money in exchange for the students' safety. These threats to their students' and clients' safety not only justifies isolating practices, but also effectively instigates more barriers and fear for people with disabilities to access the public arena in an area that is already extremely inaccessible. Fear of violence can be added to physical and other societal barriers found in Guatemala.

SEXUAL VIOLENCE AND HETERONORMATIVITY

Aside from violence and crime in greater society, these barriers of isolation and this lack of access to positive sexual experience, increase the risk factors for negative sexual experiences or sexual violence to occur for people with different cognitive abilities. Just as in the previous chapter about the public sector, not a single interlocutor working in the private sector stated that people with disabilities were abused in their institutions. While nearly all of my interlocutors in the non-profit and NGO sector claimed that no acts of sexual violence had occurred in the perimeter of their respective institutions, a number recalled tales from other centers (mostly public). Many also spoke about how some of their students, clients, patients or residents were victims of abuse in their own homes. I also was given reason to believe that one of my interlocutors came upon proof of abuse of one of the people receiving services in her institution, but she was unable to report the incident for fear of retaliation from the victim's perpetrator.

While preventing any form of access to sexual experience for people with intellectual and psychological disabilities is a form of abuse in itself, the methods used to prevent access create risk factors as well. These risk factors often lead to questions of whether or not it is possible that sexual abuse has not occurred inside of certain institutions. In institutions like the CCA, that separate people with disabilities as well as staff by gender, the gender segregation is often used as a tactic to prevent sexual violence.

This heteronormativity, however, comes with the assumption that people of the same sex would not sexually abuse each other. This also creates a general lack of vigilance towards possible perpetrators of sexual violence.

In the CCA this lack of vigilance is much more dangerous due to the amount of untrained and unpaid volunteers that come to the institution daily. This is particularly problematic due to the lack of background checks done for volunteers. According to Elena, “To volunteer, first they need to get to know the building, because often times the Spanish schools in Antigua inform them that they can volunteer there, but they don't know the impression they will get until they enter and see the patients... After that, they just need to bring two little photographs, an I.D., they have to fill out an application, and after that they are official volunteers.” The lack of background checks is more troubling when one understands the extent to which volunteers have access to the “patients” at the CCA. Elena detailed, “The work of the volunteers is to help the nurses with stimulation for the patients, feeding the patients, changing clothes, brushing teeth...”

As touched on earlier by Elena, there are only four nurses on staff at a time and they work six, eleven-hour shifts per week. These nurses cannot possibly provide surveillance for all of the volunteers inside of the institution. When one considers the amount of access the volunteers have to the bodies of the “patients” at the CCA, one must wonder how much agency these “patients” have over their bodies. They don't have authority. The CCA decides who can come and change the clothes and brush the teeth of these people with disabilities. The “patients” do not have a choice and the CCA does not work to assure that the volunteers are qualified for the work, outside of their willingness to be in the institution. The volunteers don't even have to be fluent or proficient in Spanish.[33] This makes it so they are not always able to ask for permission or describe what they will do for the "patients." This would negatively affect the people with disabilities' understandings of the agency they have over their bodies, as strangers come daily to undress and dress them without their consent. A lack of body agency not only lowers a person's self-esteem, but could also create a lack of understanding of what sexual violence looks like for a person with an intellectual or psychological disability. If strangers are able to touch one's body on a regular basis, in intimate acts like changing one's clothes, how could one recognize when his or her body is being touched inappropriately?

When I asked Elena if she thought that volunteers for the CCA might be given a space to abuse the "patients," she replied that people don't become volunteers to abuse people with disabilities. This assumption follows the belief that anyone willing to work with people with disabilities is a naturally "good person," just as the promotional videos of the CCA indicate. This also trails the idea that people with disabilities cannot be sexually abused because they are not seen as sexual beings. When one considers the comparatively higher rates of sexual abuse, particularly for people experiencing intellectual disabilities, these risk factors have to be brought into question.

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[33] I took a tour of the CCA with people who wanted to be volunteers, and the tour had to be in English because five out of eleven of them said they would not understand the Spanish.

A large portion of the risk factors that are present for people with intellectual and psychological disabilities in NGOs and non-profits are partially due to the neoliberal system instigated by the Guatemalan government. The heavy focus on charity that is the only option for institutions like SOFDAB and the CCA in order to provide services helps model and reinforce how society understands people with disabilities. It is difficult to perceive objects of charity as people with sexual agency. As a group deemed unproductive and burdensome in a state that does not provide services for citizens who are deemed productive, NGOs and non-profits must fill in the gap of services not provided. The policies for NGOs and non-profits often reflect the values imposed upon them in society. They also portray the personal values and ideas of workers in the institutions. These personal values and ideas can be conservative religious or moral beliefs, or fears or hopes brought on by the contemporary situation of violence and socioeconomic disparity in Guatemala. Personal ideas of the workers also reflect upon culturally engrained patriarchal norms found in Guatemalan society. Even when some workers in NGOs and non-profits challenge the overwhelmingly medicalized, patriarchal and charity driven view of people with disabilities, as exemplified in the case of SOFDAB, they often must cater to societal misconceptions in order to garner funding. In this way, the NGOs and non-profits that are considered the safer and more desirable option as opposed to public institutions often create dangerous circumstances for understanding and promoting the human rights of people with intellectual and psychological disabilities. The NGOs and non-profits do not challenge the state, but rather, reinforce its ability to ignore the lack of services for this group of people. As explained by the friend of one of my informant's, it is easier for the NGOs and non-profits to ask the general public for support, instead of challenging the government.

On my return trip to Guatemala in July of 2011, an informant whom I will call Andrea and a friend of hers, Victoria, asked me if I would go to breakfast with them after they attended one of my talks. Andrea is the head of a school for children with Down syndrome that I will call FIDS (For Inclusion of Down Syndrome). FIDS is different from other schools in which I did observations, because at the younger grade levels, they have begun to create a full inclusion classroom in which half of the students have Down syndrome and half of the students do not have disabilities. It is an encouraging project and Andrea says they have had great results in the classroom in regards to academic and social achievements for students with and without disabilities. Andrea and her husband created the school when Andrea gave birth to a boy with Down syndrome, and she has dedicated her life to the school since then. Victoria became involved with FIDS because she read a newspaper article about the organization and she was passionate about inclusionary education because she has two sons that are diagnosed with ADHD.[34] Victoria is an admittedly wealthy woman, and decided she wanted to dedicate her spare time to garnering donations and support for FIDS. Unbeknownst to me, they had extended the invitation for breakfast because they wanted me to create a donation network for them at the University of Texas at Austin. I had to let them know that I would

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[34] ADHD stands for Attention Deficit Hyperactivity Disorder.

unfortunately no longer be a student at the university in less than a month because I was about to graduate in August of 2011.

After telling me about other methods they had found to find funding, they began to talk to me more about the presentation I had given that they attended a few days before. In my presentation I talked about how NGOs and non-profits had to fill the gap in services that the government had left and how this had caused people with disabilities to be understood as objects of charity in society. Victoria said it was interesting how I talked about disability and said that NGOs and non-profits "fill the gap" ("*llenar el vacio*") that the public sector should cover. She said the way to fill the gap was to get the Guatemalan people to open up their hearts and just donate. Victoria explained that people don't know how to open up their hearts, that is the problem with society today. I then asked her if she thought the state needed to be challenged as well. Victoria then explained to me that NGOs and non-profits can't challenge the state but maybe they can get more people to open up their hearts.

Rather than challenge the system that the state imposes, NGOs and non-profits simply grant an alternative that bandages the situation but does not work to actively ensure that the government allocates proper resources to people with disabilities. Creating alternative services and constantly working for funding is not an easy option, but it is easier in comparison to working to hold the state accountable for providing the services that are necessary to take down barriers that prevent access for people with disabilities in society. Filling the gap in services becomes the job of civil society, both through funding and the creation of NGOs and non-profits. As the gap is filled, pressure to change is removed from the government. Because that lack of government support implies that all services for people with disabilities are charitable, these services provided by the NGOs and non-profits are often considered unquestionably good and positive for those receiving services from them. However, these NGOs and non-profits are heavily influenced by personal religious and moral beliefs in regards to sexual and other forms of expression, along with patriarchal ideas imposed by the state and society upon people with disabilities. NGOs and non-profits also often work like businesses to get funds, and doing good deeds for those "less fortunate" is the product being sold. This often causes exploitation of people with disabilities that is demeaning, reinforces their image as objects of charity, and places them in situations in which they are vulnerable to abuse. In this respect NGOs and non-profits often inadvertently reinforce the system that deem people with disabilities less valuable in society or "ex-humans."

Human Rights for "Ex-Humans"

> "Well this, we'll say, is the case of Dorita. This case happened in, if I'm not wrong, in 2003. It finally arrived in court in 2006. She was chronologically 18 years old, but mentally she was the age of a seven-year-old girl. She had spinal issues but despite that, she was able to walk. She lived here, more or less about an hour outside of the city in an eastern community. One day, a group of men and women broke into the house. They beat up and tortured the mother and they raped her. They went and threw the mother in the ravine and then went on to do the same to the girl. It was then that they raped her (Dorita), killed her, and set her on fire. She is a girl who died charred, as ashes." - Norma Cruz, director and founder of Survivors or *Sobrevivientes*, the largest rape crisis center, domestic abuse shelter, and women's justice center in Guatemala[35]

Stories, like the one recounted above, of extreme violence against people with intellectual and psychiatric disabilities, were told to me often while conducting fieldwork for this study. There is, however, one aspect of this story that is different from the majority of the other narratives of violence against people with different cognitive abilities that I heard. This case went to the Guatemalan courts. People were charged for the atrocity. Offenses against people with cognitive disabilities often go unnoticed, and if others realize that crimes have occurred, in the opinion of many of my interlocutors, they go unreported.

According to Norma Cruz, there are specific factors and societal misconceptions that prevent people or cause them to not report the sexual abuse of people with different cognitive abilities. "There the impunity is much greater and many times, I am sure that many times, the parents don't notice. The cases that we have received (at Sobrevivientes)

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[35] I am including Norma Cruz's real name because during our interview she encouraged me to use her real name. She claimed that she is a public figure and would prefer to be named in publications that I produce.

have come because the victims have died or have been impregnated. Until then, the parents don't notice that their daughters have been sexually violated for some time. That is that they are angels, they are angels and that is it. For them the whole world is their friend, right? So then that makes them really vulnerable."

The Human Rights Procurator's Defense for People with Disabilities (*La Procuraduría de Derechos Humanos: Defensoría de las Personas con Discapacidad*) is an entity that is supposed to receive denouncements of acts of violence against the minority group. Ana, the representative from this entity, also known as the PDH, told me that she received very few reports entailing sexual abuse. When I asked about why I heard so many stories of sexual violence that she had not received word of, she responded, "There are very few (denouncements of violence) that arrive here. Many people don't want to denounce, or I believe they are afraid, or are not confident in the institutions... We live in a country in which it is very risky to denounce acts of violence, acts against human rights, and yes there is really a lot of insecurity."

In the case of sexual violence, Ana mentioned there were often more specific circumstances that inhibited people from reporting violence as well. "It (sexual abuse) is closer to people than they wish to admit. If I interview people from organizations, it's possible that they themselves are living experiences of abuse... because really, acts of sexual abuse are much more common than the way they are talked about, right? It's talked about very rarely, but it happens all of the time... In truth, the majority of the time, the aggressor is part of the family, so people won't say anything. They're not going to denounce their father. So then, people prefer not to say anything. Furthermore it is shameful to admit that a family member of yours is a sexual abuser. It is a huge taboo."

What makes denouncing violations of human rights in Guatemala more difficult is partially due to the lack of credibility human rights organizations receive. When people do make denouncements of violations of human rights of people with different cognitive abilities or of other groups, they are often in danger themselves. While many human rights organizations in other countries can offer forms of protection for people in danger after denouncing human rights violations, the PDH cannot. According to Ana, "It's the police that provide those measures, not the PDH.... so if the person is the victim of a criminal network, at times, they have connections with the police, in reality. So then that causes a lot of insecurity, right?"

When abuse does occur for people with disabilities (particularly sexual abuse), one problem that transpires is that there are multiple organizations to which one could report the crime. If a person has an intellectual or psychological disability and is a victim of sexual abuse, one may report to the PDH, CALDH or the Center for Legal Action in Human Rights (*Centro de Acción Legal en Derechos Humanos*), the Ministry of Public Health, the Secretariat of Social Welfare, a local rape crisis center like Sobevivientes, and if the victim is under 18 years old, CONACMI or the National Commission Against Child Abuse (*La Comisión Nacional contra el Maltrato Infantil*). One organization may be better than the other for bringing a denouncement to court. There is not a guide to decide which organization would be the best for preventing impunity in an act of violence and there is no central recording center for acts of sexual violence. Furthermore, simply denouncing a case does not mean an abuser or the abused will be taken before a judge. Many times, the institutions don't have the power or the initiative to actively pursue a case. According to the representative I met with from CONACMI, Nicolás, “The cases have been left abandoned. They have been left in a state of impunity. The denouncements are presented but there is no follow up.”

Nicolás charged that even if the case does arrive at the courts, the testimony of people with disabilities, especially intellectual and psychological disabilities, are not considered viable and are often dismissed. They are not believed to be reliable witnesses. Due to the probability that the testimony will not be taken seriously, Nicolás commented that bringing the case to the courts is not and often cannot be CONACMI's greatest concern. He said, “Then, the big problem, and what really worries us is not that the cases remain with complete impunity or the persecution of the aggressor, but principally that the child remains in a situation of a complete lack of protection.”

Within the private sector, there seemed to be a general distrust in organizations like CONACMI and the PDH. This was not because they did not believe that workers at the human rights organizations did their jobs, but they could not work to truly enforce the rights that the Guatemalan government was supposed to guarantee. Institutional workers seemed to know and assume that at least the workers at the PDH truly try to promote the human rights of this group. More than ten of my interlocutors in both the public and private sectors asked me if I had yet spoken with Ana from the PDH, because she would be the best person in Guatemala to speak with about the human rights of people with disabilities. A person who has a disability herself, Ana worked her way into the PDH and has written a number of blogs and reports about disability rights and is active in work with a number of non-profit and NGO institutions. Ana is from a well-off family and her disability is non-congenital. She openly admitted to me that she had many advantages that the majority of people with disabilities do not have. She actively works to promote the employment of people with disabilities in institutions that provide services to and create policies for people with disabilities. She is involved in the promotion of independent living, research on disability, and actively protesting the structures and policies of a number of public entities that provide services for people with disabilities.

Ana referred me to a number of people in the institution and was well informed about issues involving sexuality and sexual violence towards people with disabilities. She, in fact, was the person who referred me to the only study I was able to find focusing on sexual abuse and disability in Guatemala. To my knowledge, outside of a few publications that work to talk about the sexual education of people with intellectual disabilities, it is the only study that has attempted to procure statistics on sexual violence towards any group of people with disabilities in Guatemala.

PREVENTION, DETECTION, ATTENTION AND DENOUNCING: INTERNATIONAL FUNDING AND AN UNKNOWN STUDY

The study that Ana referred me to is titled, “Between shadows and silence... the sun and the moon in open terrain: The sexual abuse of children and adolescents with disabilities- Guatemala City and Quetzaltenango” (Save the Children Suecia et al., 2001) It was realized in 2001 in a joint effort with a number of human rights organizations and research institutions including: CALDH, ASCATED or Association for Capacitation and

Technical Assistance in Education and Disability (*Asociación de Capacitación y Asistencia Técnica en Educación y Discapacidad*), CONACMI, Save the Children Sweden (*Suecia*), and CENDEP or The Center for Studies for the Development of Pueblos (*Centro de Estudios para el Desarrollo de los Pueblos*).[36]

The study, "Between shadows and silence..." was used to help produce a series of guides directed towards parents and teachers of children with disabilities, without the assistance of CENDEP. Each guide covers a different concept to follow up on the study and lower the rate of sexual abuse and impunity for sexual aggressors of children experiencing disabilities. The four guides, in order, are titled: "We Prevent" (*Prevengamos*), "Detection" (*Detección*), "Attention" (*Atención*), and "Denouncement and Registry" (*Denuncia y Registro*) (ASCATED et al., 2004a, 2004b, 2004c, 2004d). Another set of publications arising from the original was a series of workbooks/ instruction manuals on sexual education for children with disabilities. There are three units in this series called "System of Capacitation: Better Parents, Better Sons and Daughters" ("*Sistema de Capacitación: Mejores Padres, Mejores Hijos"*) (ASCATED, 2004a, 2004b, 2004c). The three units of the study are titled "Sexual Education," "Adolescence" and "Sexuality and People with Disabilities."

ASCATED is a non-profit civil association located in Guatemala City. This is the only private non-profit disability services organization for which I will use the real name. This is because in my interview with an ASCATED representative, in which I was given their publications on sexual abuse of children with disabilities, I was specifically told to

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[36] CENDEP no longer exists as an organization.

assure that I cite all of their hard work at ASCATED properly. The organization does projects specifically involving Special Education by producing teaching materials. CALDH is a human rights organization that has a number of different programs within it to promote the rights of certain groups in Guatemala. In 2001 there was a program for people with disabilities, however, CALDH has condensed in the last decade and chose to cut the disability program. I interviewed a representative from CALDH, whom I will call Sergio, and he explained that it was assumed that people with disabilities could still be served within the other four programs due to their intersectional identities. The current programs are Women's Rights, Youth Rights, Indigenous Rights and the Program of Justice and Reconciliation. Sergio worked for CALDH when they had a program for Disability Rights and he continues to work there.

The project began because Save the Children Sweden decided to fund a research project to procure information about the sexual abuse of children with disabilities in Central America. They contracted representatives from Guatemala, Nicaragua and El Salvador to conduct research in the two cities with the highest populations in each country. The chosen organizations did research in four specific institutional sectors- Education and Special Education, Healthcare, Protective Care, and the Judicial and Penal System (Save the Children Suecia et al., 2001).

The conclusions of the study were in line with many other studies about sexual abuse of children with disabilities in countries outside of Guatemala. The aggressor in acts of sexual violence is someone known to the victims the majority of the time. They claim that children with disabilities are much more vulnerable to sexual violence than children without disabilities. Children with intellectual and psychological disabilities are the most vulnerable to sexual violence out of the group of children with different forms of disabilities.

While I have no doubt that the study was conducted with intentions to promote change and instigate conversation about the topic in the public arena, there are a few issues that need to be highlighted about the original study itself. The first being the fact that those conducting the study had very little to work with in regards to statistics about people with disabilities at the time.[37] I this period, only 0.8% of youth in the city was registered as having any form of disability (Save the Children Suecia et al., 2001, p.v). In the early 2000s, the World Health Organization (1976) (as cited in United Nations Human Rights et al., 2009) claimed that at least 10% of the world had some form of a disability, and contemporarily they claim that 15% of people in the world have some form of a disability (World Health Organization, 2011). The issues involving a lack of information and reliable statistics are not identified. Another issue is, while they took care to work with experts on disability and experts in researching, none of the researching entities worked with sexual violence. The study also seems to have been put together in a hurry and was not fully edited. The index does not correspond with page numbers and CENDEP was accidentally typed twice in a row on the cover of the study that lists the authors.

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[37] In my research, I have found that there are still very few reliable statistics to work with regarding disability contemporarily.

The four guides directed towards teachers and parents of children with disabilities contain useful pieces of information, but do not seem to have direct connection with communities in Guatemala. In fact there is a picture on nearly every page in the guides, and not a single picture looks like a phenotypically Guatemalan child (ASCATED et al., 2004a, 2004b, 2004c, 2004d). The pictures are black-and-white lined drawings of children that seem phenotypically Western European, dressed in clothes from the first half of the 1900's. None of the children portrayed in the guides have visible disabilities either. Most of the activities being done in the pictures do not correspond with what is being said on the pages. For example, on the page that begins with “To whom do I present a denouncement (of sexual abuse) in the capital city?” there is a picture of a girl with what seems to be blonde hair in ringlets, running in a field with butterflies. (ASCATED et al., 2004d, p.13). In a section titled “Segregation makes them vulnerable to sexual abuse,” there is a picture of two girls taking cookies off a cookie sheet that an adult woman is holding, and a little girl in a sundress bending over to sweep the ground with a child-sized broom (ASCATED et al., 2004c, p.9-10).

The units that ASCATED wrote on sexual education and training for adults and children with disabilities again have pictures of people who appear to be phenotypically Western European. There are no pictures of people with disabilities or discussion of people with disabilities until the last three pages in the unit titled, “Sexuality and People with Disabilities.” In this unit there is a picture of a blind man holding the hand of a woman in a wheel chair. Next to the picture, there is a text box that says “Remember: It is common for people with disabilities to form couples amongst each other, although they have different disabilities." (ASCATED, 2004c, p.16)

There is no mention of the fact that people without disabilities can and do form romantic relationships with people experiencing disabilities. The next section details how people with children with intellectual disabilities prevent their offspring from marrying because they are afraid they will have to take care of a second person (their son or daughter's partner). The text further explains that it is for that reason that people with intellectual disabilities "are seen to be obligated to be permanently anchored in (*anclados*) masturbatory practices." (ASCATED, 2004c, p.17). The idea that the entire population of people with intellectual disabilities is condemned to masturbation as a tool for sexual stimulation for the entirety of their lives is not problematized.

While I would not argue that people did not do research on the topic of sexuality and disability, there are a number of charges not cited or fully explained. At the end of the unit titled, "Sexual Education" there is an awkwardly Freudian explanation of childhood sexuality in which Sigmund Freud is not cited.[38] The section, titled "Phases of Infant Sexuality" has a small block of text and a picture dedicated to each of the phases Freud named in the beginning of the 20th century. ASCATED highlights the oral stage, the anal stage, the genital stage, the Oedipal complex and the lactation stage. Just like in the other units, there is a text box next to the Oedipal complex section that charges, "Remember: This is a phase that all children go through. It is a transition without erotic

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[38] For more information on Freud's work that should have been cited, see Freud (1962).

content. For a boy, his girlfriend is his mommy, and for a girl, her boyfriend is her daddy." (ASCATED, 2004a, p.18).

This heteronormative statement and entire section are problematic in a number of ways. Firstly, the aforementioned statement about boys believing their mothers are their girlfriends and girls that their fathers are their boyfriends denies the possibility of having a child who is gay, lesbian, bisexual, transsexual or queer. Freud has been proven wrong in regards to his phases in infant sexuality. While Freud's work on sexuality was functional in promoting the idea of child sexuality, feminist scholars like Judith Herman have worked to dismantle his theories on phases of sexuality (Herman, 1992). This is because his idea of the Oedipal complex was used to deny childhood sexual trauma of women. Rather than talking about the reality and epidemic of sexual violence toward women in their homes, Freud used the Oedipal complex to explain away memories of rape and sexual molestation that were recounted to him by women that had been diagnosed with hysteria at the turn of the 20th century. Instead, Freud theorized that women were speaking of unfulfilled childhood fantasies during their Oedipal stages. The explanation used in this unit of sexual education for people with disabilities to prevent sexual abuse was actually used by Freud to deny childhood sexual trauma.

While I do wish to heavily critique the materials produced from the original study, the original research itself is very useful for drawing attention to the problem of sexual violence towards children with disabilities (Save the Children Suecia et al., 2001). The guides produced also serves a purpose (excluding the pictures) for giving basic (mostly non-culture specific) guidelines for preventing, detecting and denouncing acts of sexual violence (ASCATED et al., 2004a, 2004b, 2004c, 2004d). However, few people had knowledge that a study of this nature existed. I came across one example of the lack of diffusion of this study in my time at SOFDAB.

Although I was not open about the specific nature of my research, (how within the field of human rights I was focusing specifically on sexuality and sexual abuse of people with different cognitive abilities) the focused goals of my study became more apparent to SOFDAB staff as weeks went by. Rumors circulating through a few well-connected institutions providing services to people with disabilities, including SOFDAB, made my focus on sexuality and sexual violence more apparent.[39] On my last day teaching yoga at SOFDAB I was pulled into an office to speak with one of the program's coordinators, Susana. She asked me about methods of talking about sexuality with the students, resources for educating the parents about talking about sexuality with their children, and how to treat the students as sexual beings. It seemed she felt the need to address the fact that SOFDAB, as an organization, was concerned about the sexual education and health of their students. I told her I thought they do a great job of promoting a form of surveillance to prevent abuse.[40] However, I was not trained in giving sexual education and could not truly give advice on methods of teaching for the staff of SOFDAB. I asked Susana if she knew about the study and manuals that ASCATED had published. She said that she had never heard of them. Both ASCATED and SOFDAB had members on the

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[39] A number of my interlocutors were closely connected and likely chatted with each other about interviews with me. I questioned all of them to a great extent about the sexuality and sexual abuse of people with intellectual and psychological disabilities. It seems unlikely they would not notice the focus at the end of the interview.

[40] Due to SOFDAB's constant contact with the community, sufficient and trained teaching staff and inclusion of parents and family members in activities, I truly believe in that statement.

board of directors in CONADI. I also know that a representative from ASCATED is a colleague of a staff member from SOFDAB at a local university due to an event I attended. After reviewing my field notes and interviews, I found that none of my interlocutors outside of the organizations that participated in the study and Ana ever mentioned the research to me.

The lack of diffusion of this research seems strange when one considers how many organizations were involved in its publication. I received some of the last distributable copies of the main study and the proceeding publications from ASATED and CONACMI, and I was unable to obtain original copies of the units for training of children and adults. The results of the study are not published on the Internet and are not available for purchase. One must question where these copies of the study have ended up. Who has access to them outside of international researchers and human rights organizations? If the materials created following the study were created for training and as guides for parents, teachers, and children with disabilities, why didn't my interlocutors outside of human rights organizations have copies or even knowledge of the study? How can a study promote change if the groups affected are not informed of its existence?

One of the reasons for the lack of publicity is likely due to the fact that funding was not granted for the diffusion of the study. This lack of funding for diffusion, editing, and Guatemala-specific materials could also be explained because this study was mandated through international entities and funding. Save the Children Sweden instigated the study following the line of conclusions made in “The World Congress Against the Commercial Sexual Exploitation of Children” in Stockholm, Sweden in

1996. As an organization, Save the Children Sweden decided this study was important "to integrate the study of sexual abuse of children with disability as an alternative theme to commercial sexual exploitation and as part of the global context that the child exists and develops in." (Save the Children Suecia et al., 2001, p.i). They then decided to conduct research in the three Central American countries in which the organization had a presence.

Save the Children Sweden mandated the methods, research questions, and arenas in which this investigation would be conducted, after deciding which entities in Guatemala, Nicaragua and El Salvador that they would work with. The plan was to look at reports from hospitals, schools, the court system, NGOs and non-profits and child protective services. Looking at the research funded and controlled by Save the Children Sweden, important details found in Guatemala were not considered, specifically involving the lack of reporting of sexual abuse and the scarcity of previous research involving disability in general in the area. Save the Children Sweden did not take into account that they were working in countries with high rates of impunity and very low reporting rates for crimes. While the study identified the fact that people rarely note whether or not a person has a disability, they did not mention that reports of abuse are rarely made (Save the Children Suecia et al., 2001).

In the area discussing limits of the study, if interviews were not allowed by specific entities they wished to access, blame was placed on the entities themselves. In the list of reasons given why entities would not want to participate in a study that openly focuses on sexual violence towards children with disabilities, those mentioned included:

"institutional jealousy," "lack of interest in the topic," "lack of credibility or confidence in the investigation as a tool for knowledge, on par with a lack of confidence in both national and international non-governmental organizations," and methodological limitations due to the lack of registration of certain entities (Save the Children Suecia et al., 2001, p.x). This list did not take into account societal, structural or individuals' limitations in Guatemala that may hinder a group's ability for participation, including the consideration that the topic of sexuality is taboo, uncomfortable or forbidden to talk about for some individuals; there is a fear of exploitation or violence if they talk about the issue; people working in the institution may be experiencing violence themselves and the topic is sensitive for them; there is a lack of funding that will allow personal the time to work with researchers; they may have anxiety over possible gossip in the often close-knit institution providing services to people with disabilities; or they may have had poor experiences before with international or domestic researchers.

International organizations often do not necessarily take into account unique situations in other countries.[41] This is apparent in the study funded and controlled by Save the Children Sweden. There are also other issues with international funding outside of research often experienced by local organizations in Guatemala.

On my return to Guatemala in July of 2011, I was invited to visit an internationally funded foundation that I will call Access Mobility. A man who became paraplegic due to a gunshot wound from a local gang, whom I will call Guillermo started

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[41] For another case of international humanitarian organizations that do not take into account local conditions in the developing world when providing services or conducting research, see Hemment (2004).

the charity organization, Access Mobility. The organization, which is based in Antigua, works to have people with physical disabilities build wheel chairs that they give to Guatemalans “in need” in exchange for some form services. They also help pay for medical services for people with disabilities, build prosthetic limbs, work a print shop and run an independent living center for people with physical disabilities. More than 80% of the staff members in the center have a disability and many of them speak English although they were all born and raised in Guatemala. They speak English largely due to the fact that a great number of English speaking volunteers and personal from donating entities come through the foundation on a regular basis.

The director of Access Mobility is a middle-aged white American man, whom I will call Peter. As a special educator and disability policy maker in the U.S., he had worked with people with disabilities for many years. Peter originally went to Guatemala to learn Spanish, but then he met Guillermo. He brought Guillermo back to the United States to get special treatment when he discovered that Guillermo was extremely ill due to a deficiency of proper care in Guatemala. They later returned to Antigua to form Access Mobility and create a center for independent living and medical attention for people with disabilities. After a short time trying to work with domestic entities like CONADI, Guillermo and Peter opted to have Access Mobility run almost entirely on international funding. In Peter's words, they believed this would allow them to keep out of the “whole corrupt and stupid system.” However, Access Mobility found that there were still a number of challenges to be dealt with when considering foreign aid. Peter explained that there were always pre-existing conditions for receiving funding from international entities. These conditions do not always allow them to use the money for what the people at Access Mobility need, but what the international donators say is needed.

Peter explained to me that international entities that have funds to donate become fixated on certain "buzz words" that are terms that are popular in the foreign aid industry. These words are Western terms that the groups from Europe, the United States, Canada and Japan have come to be familiar with and try to directly apply in the "Global South." Peter explained that words and concepts like "sustainable," "capacity building" and "independence" are the current favorites. He said he has been asked to try to prove to one foreign aid organization that by giving a wheelchair to a man with a physical disability, that person and his family can become financially independent. This is nearly impossible when one considers the lack of accessibility in Antigua due to unmanaged cobblestone roads, a lack of curb cuts, and small doorframes often found in older buildings. If society as a whole is not accessible and jobs are scarce for people with and without disabilities, how can just a wheelchair make a man and his entire family financially independent?

Another instance in which Access Mobility came across an international funding organization that felt the need to apply Western buzz words, came about when an American women from a foreign funding entity came to help write grants and to assess the wheel chair making shop at Access Mobility. Peter noted that the woman seemed obsessed with the idea of capacity building. He said every recommendation she made seemed to include that phrase. Guillermo and other workers in the shop tried to stress to her that they knew how to build the chairs and work, but rather they needed supplies to build the chairs. They often received donations of old wheelchairs from the United States but many times could not salvage usable parts from them. They needed new wheels, industrial quality fabric for cushions, welding supplies and safety equipment. The American foreign aid worker still claimed that capacity building was the need, so the money that would be granted needed to be utilized for “capacity building,” rather than essential supplies.

In Save the Children Sweden's case, the organization funded a study that did not take into account local circumstances in Guatemala. Because of this they were unable to provide real numbers due to issues with investigation methods, they did not assure or hire someone to make sure the study was properly edited, and they did not take into account the necessity to fund the diffusion of the study. Although the investigations did prove a heightened vulnerability to sexual violence for children with disabilities, the study and follow-up guides that could have served the institution providing services to people with disabilities, do not serve local needs and in general, have not reached the hands of workers in the institution.

CAPITALISM AND DISABILITY: NOT A LOVE STORY

While with Sergio from CALDH, I asked him why the state had not promoted specific programs to prevent sexual violence against people with disabilities if there was, in fact, a study that proved they are at a heightened risk for being victims of this form of abuse. When one considers so many human rights organizations were involved, why wasn't a branch of one of the organizations added or why weren't further studies ordered by the government or by these human rights organizations? After explaining to me that human rights organizations did not often receive designated funding for research of such a specific nature, he moved on to the issue of the lack of government interest in the topic. Sergio claimed, “Now in such a specific topic, like the attention to people with disabilities, what the state has is minimal. It's almost offensive to the dignity of this group or population of people with disabilities. So then we have an absolute deficiency. And here the big complaint that really hurts is that this is a state that doesn't lack resources. But it comes that it is a state that has been incapable of adequately administrating, in a transparent manner, the public resources they take in is apart from indirect taxes. That is, furthermore, we have an indirect fiscal system. That is that one pays more the less one has, one pays less the more one has, understand? So then the redistribution of resources has not been done in an adequate manner and in the process of redistribution there are many acts of corruption. So then those funds don't arrive at, or that is, it isn't possible to do better redistributions of funds to people with disabilities, right? So then you aren't going to find an established public institution with credibility that is really focused in a right that is very specific or on a group of people of a type that is very specialized. It isn't easy. But you will find organizations that are trying to cover that space that the state generates.”

Following the line of resources generated, to resources allocated, to those redistributed in the corrupt and neoliberal system in Guatemala, explains why such scant resources arrive to assure the wellbeing of people experiencing disabilities. As Norma Cruz commented, “I believe that in Guatemala one has to understand that those who own and run the country don't give them (people with different cognitive abilities) importance.

That is, if they don't attend to the necessities of the people that are 'healthy' that represent income for the country through productive activity, what can we hope for these people that society and the state consider a burden?”

Aside from not being able to vote in a country in which services are often provided in a very populist manner,[42] the population is not seen as productive. If one cannot produce to satisfy the business-focused capitalist desires of the Guatemalan government, that person is no longer a valuable member of society. Therefore NGOs and non-profit organizations and international entities like Save the Children Sweden, are the only option for services for them. The non-profit organizations of SOFDAB, AWDAF, PAFFID, Access Mobility, and SADS all expressly highlight that one of their organization's missions if to make people with disabilities productive. Productivity is often stressed before basic education, physical health, self-esteem, or fostering interpersonal relationships. Sergio, Ana, Norma and Nicolás all charged that people with different cognitive abilities are on the bottom of the hierarchy of people who deserve human rights because they are not seen as productive. Productivity is the buzzword for Guatemalan non-profit organization and human rights organization. This focus reinforces the idea that in order to be deserving of basic rights, one must be productive first. Until they are what the government deems “productive,” it does not seem their human rights, and in turn, their humanity, will be considered in the public sphere.

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[42] For more information on populism in Guatemala, see Copeland (2007) and Seligson (2007).

Conclusions

No happy ending or anecdotal hope-filled story can be told to round out this work detailing the desperate situation that people with intellectual and psychological disabilities live in in Guatemala. During conferences and in classrooms when I talk about this topic, I'm often questioned if I can say anything positive about the situation for people with different cognitive abilities in Guatemala. I normally respond with something to the effect of, "There are family members, friends, disability rights activists and many well-intentioned and hard working people in all types of institutions promoting the human rights and justice of people with different cognitive abilities there." However, I have to add the unfortunate number of physical, attitudinal, economic and societal barriers that severally limit, hinder and at times stop their work.

People with different cognitive abilities themselves are banned from accessing their civil rights by law and are often imprisoned in their families' homes or institutions by court order, due to shame felt by family members or because of a lack of resources. This does not allow for them to promote and fight for their own rights in the public arena. The government-run institutions are scant, under-funded, under-staffed, dependent on medicalization, corrupt and in horrible conditions. Workers in the institutions are affected both by violence outside of these public centers and on the inside, which creates risk factors for abuse towards the group to whom they are providing services. Images of ephemeral services granted to people with different cognitive abilities, specifically children with intellectual disabilities, are exploited by the government entities. They are utilized to portray the image that government is going above and beyond the call of duty to assure the well being of this "unproductive" group of people. This is done to improve the government's, political parties' and individual candidates' images on an international and domestic level. These campaigns hide the inhumane conditions lived in institutions and cause the public to assume they are "well taken care of."

The NGOs and non-profit institutions are meant to fill the gap left by the lack of public services, but are not given the resources or funding to do so. They are often forced into using dehumanizing charity paradigms to understand and treat people with disabilities in order to gain funds. In their charity campaigns and pursuits they often reproduce the social constructions of people with different cognitive abilities in the public arena as victims of tragedy that are dependent, passive, and need to be pitied. This social construction creates a cycle that continues to leave NGOs and non-profits that provide services to them dependent on charity paradigms because the public has come to understand people with different cognitive abilities as vessels for philanthropic acts. The charity discourse surrounding disability does not leave a space to talk about taboo topics like sexual rights. Many NGOs and non-profits are also limited in scope, services and ideas they are able to promote through the neoliberal entity CONADI. For the non-profits that are under the umbrella of CONADI, their ability to promote radical political change is diminished. CONADI harnesses the political energy of some activists to funnel it into less radical forms of services like segregated special education, receiving denouncements of human rights violations and basic job skills training.

While there are many human rights organizations that try to work in favor of justice for people with different cognitive abilities, they are not granted the funding, protection or power exercising abilities to actively prevent risk factors for violence or to pursue justice in crimes against this group. More often than not, they serve as figureheads that occasionally publish about the atrocities that go on against people with disabilities, but can do little to prevent the continuation of their abuse. They can record denouncements, but if they are able to bring cases to the Guatemalan courts, the judges often will not believe the testimony of people with different cognitive abilities. In this way, the work of the human rights organizations seldom leads to justice. Internationally funded projects and research for the human rights of people with disabilities often do not take into account specific circumstances and conditions found in Guatemala and do not work with a non-Western frame when mandating how funding should be spent by entities in research or in providing services. This renders many internationally funded services and pieces of research less useful and at times wastes the time and energy of local institutions that could be providing more valuable services or research.

There are culturally engrained patriarchal norms found in all of the types of institutions providing services to people with intellectual and psychological disabilities. Patriarchy instigates the beliefs both inside of the institutions and in the public arenas, that people with disabilities are unable to decide what is best for they themselves and that they cannot or should not access certain rights. These patriarchal ideas existed long before neoliberal policies were imposed in Guatemala. They have historically justified the segregation, isolation, and the condemnation to charity of people with disabilities as well as the denial of this group's agency and at times their humanity. This is exemplified through the existence of laws, policies, and institutions promulgating patriarchal ideas long before the rise of neoliberalism in Guatemala in the 1990's. Neoliberalism, however, does reinforce these ideas through a stress on production that deems those viewed as unproductive (people with disabilities) as less valuable in society and in turn, less human (or Ex-Humans) and undeserving of government funding that should be used to promote capitalistic goals in society. In neoliberal societies, people with intellectual and psychological disabilities are "cared for" by being removed from or prevented from entering greater society. The majority of services are then relegated to the NGOs and non-profits; while public institutions work on the surface level to show that the government has at most symbolically cared for the abandoned group.

The conditions found in the different types of institutions involving: medicalization, charity, isolation, segregation, insecure and undesirable employment, low funding and stigmatization all create risk factors for sexual violence for people with different cognitive abilities. Combine these risk factors with high rates of violence in society as a whole, and barriers in making charges of sexual violence against this group, advances impunity in their abuse and allows for it to continue. In sum, there is nearly complete impunity for crimes against people with intellectual and psychological disabilities, tremendous vulnerability to violence, scarce economic resources, and laws and government policies that allow different forms of abuse. Keeping those conditions in mind, ideas about disability and forms of resistance to the current system need to be reframed to fit the Guatemalan context.

Other Western models used for fighting for the rights (specifically sexual rights) of people with disabilities have assumed a certain degree of independence of activists and an ability to protest without fear of extreme violence.[43] Unfortunately in the case of Guatemala, this fear and reality of hostility exists. This is exemplified in the cases of the students at AWDAF, who experienced violence when out in their own in city; in the case Carlos from the HOP, who was moved to another institution when he complained about horrific institutional conditions; and in the heightened need for anonymity of a number of my interlocutors for fear of repercussions. In these instances the symbolic power and real-life terrorism found in the system must be taken into account when seeking out

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[43] See Wilkerson (2002) for some Western examples of models used to push for the sexual rights of people with disabilities.

methods of resistance. People cannot resist in a society when they are not considered human in said community. Workers cannot protest if they fear that they will no longer be employed in the institution that allows them to work with people with cognitive disabilities. They could also become victims of different forms of violence. Others cannot resist when they do not have access to the outside community themselves due to a fear of violence or because of physical barriers. All of these realities must be taken into account.

There are a number of arenas for future studies that could be considered to help find and create spaces for resistance and change to current paradigms used for understanding and treating people with different cognitive disabilities contemporarily. First and foremost, work should be done with people with intellectual and psychological disabilities as the main interlocutors. This not only promotes the public's understanding of people with different cognitive abilities as a group with agency, but also ensures that this normally marginalized group is a part of and continuously involved in decisions about what changes should be made in the system and how they would like to be portrayed in studies. Including them in research as active participants could bring to light forms of resistance that they themselves have used in institutions or in their homes to create change on an individual level as well. People with intellectual and psychological disabilities should also be encouraged to conduct research on their own at the level they feel they are capable of and with assistance if they so choose.

Comparative work should be done to look at the difference between Mayan understandings and treatments of disability alongside Ladino perceptions and treatments. As mentioned in the introduction of this work, all of my official interlocutors for this study are Ladino. There are distinct cultural differences between Mayan and Ladino groups that could seriously alter how people with intellectual and psychological disabilities are perceived and treated. The same form of comparative work should be done between rural and urban areas, considering this study only took place in urban areas.

Other studies should be conducted about the connection of gender to the perceptions of the sexuality and sexual abuse of people with different cognitive abilities. As mentioned before, there seems to be a hypervictimization of women with disabilities and a hypersexualization of men with disabilities. This plays out in various ways, but normally tends to lead to heteronormative forms of isolation and segregation. By studying gender norms and the social construction of gender for people with intellectual and psychological disabilities in Guatemala, a conversation could open up about the negative effects of hegemonic, heteronormative and patriarchal systems forced upon people with different cognitive abilities and in society as a whole.

Lastly, more work needs to be done to uncover the stories of extreme violence towards people with disabilities both inside of and outside of the institutions. These stories that go un-denounced and often untold, must surface in popular media and on an international scale in order to create a discussion of the issues of abuse in the public arena. Conversations need to open up about the effects of the severe marginalization and isolation of this minority in order to instigate questions on a more public level about the lack of support for this group.

In the documentary "Examined Life" (Taylor, 2009), Judith Butler and Sunaura Taylor, a person with a physical disability, take a walk to discuss disability as a political issue. They discuss how through using the social model, disability becomes a topic to promote rethinking "the human as a site of interdependency." Embodied impairments create differences in how people are able to access certain things, perform certain actions or understand certain topics or concepts. Sometimes these actions or access may require assistance. Butler asks, "Do we or do we not help each other with basic needs? Are basic needs there to be decided on as a social issue and not just my personal, individual issue, or your personal, individual issue?" In other words, disability, as a social issue, is a challenge to individualism. The individualism challenged is not individualism with respect to personal preferences including style, profession or pastime. The individualism challenged is the idea posed by neoliberalism and liberalism before that. This is the individualism that charges that the human is an independent being and should be independent without support from other people. This interdependency posed by Butler and Taylor proposes that as humans we all have certain dependencies, and we should recognize that we live in a world in which human beings need other human beings in order to address basic needs. Butler argues that the world should be reorganized on a social and political level on the basis of that recognition.

Rethinking the human being as a site of interdependency necessitates that a person does not lose value because of different forms of dependency, and furthermore that work be done on a social level to assure complete access in communities for everyone. As highlighted earlier, this interdependency challenges the individualistic ideas of the current neoliberal system in place. Keeping this in mind, along with the heavy effects of patriarchal norms, charity and medical paradigms, and culturally engrained violence, a number of systems of exclusion outside of neoliberalism must be done away with in order to allow for full inclusion in society. Other systems of exclusion like ableism, sexism, homophobia, erotophobia, racism, ageism and capitalism must cease to exist to fully remove barriers to access in society. As it does not seem that these systems will be done away with in the near future, further studies and activism work must be executed urgently. Work should be done to highlight the often hidden quotidian horrors that occur in the lives of people with intellectual and psychological disabilities and the stigmatization and abuse of those working with them and fighting for their rights and justice.

My interview with Ana from the PDH was the first interview I conducted for this research. While sitting with her in the PDH's office in June of 2010, I asked her how I should respond to people when they question why it is important to advocate for the sexual rights of people with different cognitive abilities when egregious violations of other human rights are committed on a daily basis. She responded that sexuality is an intricate part of our humanity and once it is established that a person is a sexual being with sexual needs there is no denial of one's humanity. As both sexuality and cognitive disability have been socially and historically constructed as taboos, they must be reconstructed together to occupy a larger part of the discussion of the human experience and equal rights and justice in Guatemala, Latin America and the rest of the world.

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