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A Cross Cultural Study of Disability in the United States and Brazil
By
Emily K. Stortz

A Thesis Submitted in Partial Fulfillment of the Requirements for
A Master of Science in Sociocultural Anthropology

Minnesota State University, Mankato
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This thesis was made possible through the ongoing support of my parents. My father introduced me to Santarém as a small child and I was able to see it for myself in 2005. He traveled with me for my fieldwork and his friendships and ongoing rapport with the Brazilian women running the institution allowed me access and knowledge I otherwise never would have gained. I would also like to thank Daniela and Nedy for being such wonderful hostesses. Tia Alba Rosa and Dr. Emmanuel Silva were also instrumental in making the Brazilian fieldwork happen.

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Abstract

A Cross Cultural Study of Disability in the United States and Brazil

Emily Stortz M.S. in Sociocultural Anthropology Minnesota State University, Mankato in Mankato, MN 2010.

Disability is not only a biological issue, it is an inherently social one. People are only as disabled as their society allows them to be. Enhancing our understanding of the social processes affecting the disabled will allow for their increased participation within society.

The researcher employed qualitative methods including semi-structured interviews and participant observation to perform case studies at fieldwork sites providing care to the disabled in Chicago, IL, USA and Santarém, Pará, Brazil. The researcher spent two consecutive weeks in each location. The former location is a residential facility for people with developmental disabilities and the latter is a school for people with mental and physical disabilities.

The results showed that cultural phenomena such as social inequalities, gender roles, and intolerance for difference affected the experience of those living with disabilities. Social inequalities account for many disabilities found in Brazil such as those caused by preventable infectious diseases or by inadequate living conditions. The results suggest that the greatest obstacle for the disabled is the strained social interaction they have with the able-bodied. The prevalence of stigma against the disabled is a product of human discomfort with liminality and ambiguous status. People with disabilities are viewed as not fully human. Exposure and increased education, especially among children, can reduce discrimination allow people with disabilities to function within society and develop an identity therein.

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Chapter One: Introduction

Introduction

One of the most well known and widely read anthropologists of all time, Margaret Mead, believed that all cultures exist somewhere along an arc (Mead, 1935). There is a broad spectrum of human beliefs, understandings, faiths, morals, and norms. This arc encompasses all the human behaviors found across the globe. No individual culture accepts all the different ways human beings, as a group, can choose to conduct themselves. Each individual culture chooses merely a small segment along this arc. Each culture deems their particular segment the 'norm' and often considers the lifestyle of their segment superior to the lifestyles of other segments. Of course not everyone within a culture blindly accepts the norms and rules that their society chose. The people who consciously question why certain things in their lives must be done one way and not another are rebellious. These are the outliers. In a world where everyone has more access to different cultures and lifestyles, it is only natural that more people should start to question their particular culture's way of living. Thanks to technological innovations, including television, air travel, and the Internet, people are now exposed to more segments along Margaret Mead's arc. The purpose of this study is to bring to the readers a glimpse of the cultural issues surrounding people with disabilities living along different segments of the arc of human existence. Disability is not a highly visible part of society.

Movies and television shows seldom chronicle the plight of people with disabilities. Through experiencing and learning about different lifestyles and perceptions, people can better understand their own attitudes and lifestyles. Ultimately, a more global perspective allows us to understand human nature at a superior level and can help to improve the lives of people living with disabilities by tackling the social aspects of this condition that can so often be more paralyzing than the medical condition itself.

Disability existed in all parts of the world and at all times. The reactions to disability and perceptions of disability by the general public greatly influence the condition of life for those living with disabilities. In an ever globalizing world, it is essential that people understand disability as a partial product of cultural institutions to be able to better serve those living with impairments of various degrees. The United States is a multicultural nation where people from numerous cultural backgrounds must interact effectively to provide the optimal care for people with disabilities. This thesis will demonstrate that disability is, at core, a *social* condition. This qualitative, ethnographic case study examines two cultures from different segments of Mead's arc to demonstrate the effect of culture on disability.

To illustrate the effect culture has on disability, it is helpful to examine case studies comparing disability in two different cultures. Like the U.S., Brazil is also a multicultural nation. These two nations have comparable populations and geographic areas (Levine, 1999). Brazil is a world economic power and a contender on the international scene but is still considered a "Third World" country by many people. These two countries could benefit from understanding each others' perspectives towards disability. According to the U.S. Department of Health and Human Services, there are

currently about 54 million Americans (about 17.4% of the population) with a disability (US Dept. of HHS, 2010). The newest study in Brazil on disability was carried out by the Instituto Brasileiro de Geografia e Estatística and dates back to 2000. This survey suggests that about 24.5 million Brazilians-14.5% of the population-are living with disabilities (IDBG, 2010). Based on these numbers there is clearly a great need in both countries to better understand how society and culture impact those living with disabilities, both in positive and negative ways. Attitudes and perceptions towards disability are continually evolving along with culture.

Cultural differences have an immense effect on how people within societies view people living with disabilities. The very definition of disability varies cross culturally, making statistics next to impossible to collect. Just as a person could be considered to have black skin in America, but white skin in Brazil, a person could also be considered disabled under one culture's definition of disability, but fully abled under another's. Stigmas and myths attached to people with disabilities vary cross culturally and affect their level of acceptance into the community.

Statement of the Problem

While there are obviously severe disabilities that are quite physically and mentally limiting, the degree to which the people living with disabilities are ostracized or accepted is culturally dependent. The core values and beliefs in a society about what is morally right or wrong and what constitutes a 'person' determine how people and the law will react to disability. To have a disability is to deviate from the prescribed norm. The number of standard deviations one moves away from the norm, the more difficult their

lives become (Davis, 1995). Human nature has an inherent discomfort with undefinable or marginal states. A person with a disability creates a problem for the able bodied because they are viewed as occupying a marginal space, somewhere between fully human and not fully human. The more severe the disability, and therefore the more standard deviations away from the norm, the more stigma is attached to that individual. Another common phenomena occurs depending on the level of visibility. A highly visible disability is more stigmatizing than a barely visible one (Murphy, 1990).

The social beliefs and norms prescribed in a given society affects how people react and respond to disability. If the public had more exposure to disability and a greater understanding, the crippling effect of social stigma could be lessened and the lives of those with disabilities less constrained. By taking a global perspective on disability, people can see where their cultural norms and biases impact disability more clearly. A case study of two quite different cultures allows us to see how culture is a major determining factor in the lives of people with disabilities.

Background and Need

Pioneering ethnographic social observers like Ann Fadiman have tried to bridge the gap between cultures through ethnographies focused on the clash between American medical beliefs and other cultures' belief systems about health and disease (Fadiman, 1998). In an ever globalizing world where different cultures are coming into contact for perhaps the first time in large numbers, it is important to have as good an understanding of each other as possible to cohabitate successfully. With something as intimate and precarious as health and disease, it is imperative that doctors and patients are able to

communicate. Aside from frequent language barriers, there are often cultural barriers that prevent the best care possible from being provided. The United States and Brazil are both multicultural nations with people from many different backgrounds. The United States has many new immigrants arriving each year, and as Brazil's economy continues to expand, they too can expect more immigrants and an integration with other parts of the world. People with disabilities are not a homogenous group; they have different life histories and unique cultural backgrounds and experiences. Therefore, people are not all approaching their disability with the same mindset. Anthropologists play a significant role in continuing, brick by brick, to build a foundation for multicultural medical care. Research of this kind is also necessary to take a more global perspective on disability and look at the sociocultural aspects that impact those living with disabilities. If we can understand why people feel the way they do towards people with disabilities, we can better understand why they treat them in certain ways, and eventually work to improve the lives of the impaired. This ethnography aims to contribute to a much larger dialogue on the power of culture over our lives in general, and our medical systems in particular.

Purpose of the Study

The purpose of this study is to compare attitudes towards disability in two cultures. It aims to dismantle the social barriers that exist for people living with various mental and physical disabilities in all parts of the world. Four weeks were spent in participant observation at two different institutions. In the United States, two weeks were spent at a large residential facility for people with developmental disabilities in Chicago, Illinois. The researcher also spent two weeks at a school for children and adults in

Santarém, Brazil. These research sites are both premiere institutions of their kind in their region. Santarém is situated in the Northeastern region of Brazil, an area with the highest rate of disability in the country. The disability rate is about 16.8% of the population there compared to the national rate of 14.5% (IDRM Publications, 2004) Along with participant observation, the researcher conducted interviews with the staff and caretakers at both locations. The researcher sought answers to questions regarding an individual's definitions of the word 'disability.' Participants were questioned about society's attitudes towards people with disability, their level of understanding or ignorance, and any stigmas or myths attached to the disabled. Also researched were perceived causes of disability, parents' reactions, and the particular goals of both institutions. Interviewees were asked what the major obstacles disabled people face in their culture and how well public spaces are equipped to allow accessibility. The researcher overall wanted the interviewees' opinions about the role people with disabilities played in their society and how accepted or marginalized they are and why this was so.

Based on her literature review, the researcher expected to find that deeply rooted cultural beliefs and norms would greatly influence the lives of people with disabilities. A culture's location along the arc described by Margaret Mead shapes members' definition of personhood, the role of religion, beliefs about causality, and the degree to which 'others' are accepted and given a place within the larger society. This is a qualitative study designed to explore what cultural factors affect public opinions towards disability and to aide the ongoing effort in the United States and Brazil to firmly establish and enforce laws aimed to integrate people with disabilities as active citizens.

The sub-discipline of medical anthropology views medical systems as a cultural institution that reflects the cultural beliefs and norms a particular society. Humans around the world and throughout time have encountered many of the same diseases, health problems, and disabilities, yet have viewed them very differently. Cultures attribute different causes and treatments for the same issues, and often employ different justifications for their presence. When members of disparate cultures interact with different medical systems, conflict can ensue. Western societies have adopted a biomedical approach to healing patients, whereas in other parts of the world religion and taboo play a much larger role.

Significance to the Field

Broader Impact

The potential significance of this research is to raise awareness of the sociocultural side of disability in order to further alleviate the burdens felt by people with disabilities. Through education, knowledge, and acceptance, the disabled can be freed from the social constraints that hinder their full participation in society. Some of the lessons from this research can be applied to other cultural settings and medical issues.

Local Impact

This work will create a better understanding of disability in both cultures to help with improvements or alterations to the treatment of people with disabilities. Knowledge of another culture's understanding and how they care for their members with disabilities

can give Americans and Brazilians insight into their own norms and practices and perhaps ways to improve the system.

Definitions

Participant Observation: A research method employed by social scientists producing an ethnography where the researcher observes people in their natural environment over a (generally long) period of time; the researcher must also become involved in the setting and not just observe from a distance. This method allows researchers to gain access to emic perspectives (Bernard, 2002).

Ethnography: A write up or the story of a researcher's fieldwork and immersion into another culture providing detailed description of that culture's beliefs and lifestyle (Bernard, 2002).

Case Study: A data collection method that involves in-depth studies of specific cases or projects within a program. The method itself is made up of one or more data collection methods (such as interviews and file review). (www.cdc.gov/getsmart/program-planner/Glossary-Eval-Res.html)

Emic perspective: The "insider's" view of a culture (Bernard, 2002).

Etic perspective: The "outsider's" sound, scientific view of a culture (Bernard, 2002).

Quantitative research: Follows a deductive research process and involves the collection and analysis of quantitative (i.e. numerical) data to identify statistical relations of variables. (www.utexas.edu/academic/diia/assessment/iar/glossary.php)

Qualitative research: Follows an inductive research process and involves the collection and analysis of qualitative (ie, non-numerical) data to search for patterns, themes, and holistic features. (i.e. observations, interviews, focus groups) (www.utexas.edu/academic/diia/assessment/iar/glossary.php)

Disability: A complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives. (WHO, 2010.)

Cerebral Palsy: A general term for a group of disorders that appear during the first few years of life and affect a child's ability to coordinate body movements. Cerebral palsy can cause muscles to be weak and floppy, or rigid and stiff. (<http://www.mayoclinic.com/health/cerebral-palsy/DS00302>)

Microcephaly: A rare, untreatable, neurological condition in which a newborn's head is significantly smaller than it should be. Microcephaly can be caused by a variety of genetic and environmental factors. Children with microcephaly have severe developmental issues. (adapted from <http://www.mayoclinic.com/health/microcephaly/DS01169> with help from Dr. Dennis J. Gates, M.D.)

Hydrocephalus: A condition that occurs when excess fluid builds up in the brain, most often because of an obstruction preventing proper fluid drainage. The excess fluid can compress surrounding, brain tissue, causing brain damage. Left untreated, hydrocephalus can be fatal. (adapted <http://www.mayoclinic.com/health/hydrocephalus/DS00393> with help from Dr. Dennis J. Gates, M.D.)

Down's Syndrome: A genetic condition that causes abnormal physical and intellectual development. It occurs in approximately one in every 800 live births. Individuals with Down syndrome have 47 chromosomes instead of the usual 46. (adapted from http://www.nads.org/pages_new/facts.html with help from Dr. Dennis J. Gates, M.D.)

Phenotype: This is the outward, physical manifestation of the organism. (<http://www.brooklyn.cuny.edu/bc/ahp/BioInfo/GP/Definition.html>)

Genotype: This is the internally coded, inheritable information carried by all living organisms. (<http://www.brooklyn.cuny.edu/bc/ahp/BioInfo/GP/Definition.html>)

Righting reflex/ Righting reaction: Movements that restore the body to normal positions against forces that have displaced the body from these positions (<http://medical-dictionary.thefreedictionary.com/righting+reflex>)

Hypertonic: Having extreme muscular or arterial tension; spastic (<http://medical-dictionary.thefreedictionary.com/hypertonic>)

Research Questions

- 1) How does the culture individuals live in affect their experience of disability?
- 2) What specific aspects of culture affect people with disabilities and the perception of the public about disabilities?
- 3) How can information about the social dimension of disability be used to enhance the lives of people living with disabilities?

Limitations

All studies and research have limitations which should be addressed to make the reader cognizant of the weaknesses and constraints under which the researcher worked. The foremost difficulty for any research conducted on disability, much less disability cross culturally, is that the very term “disability” is difficult to define. There are many different definitions, some more and some less inclusive. Under some definitions, a particular person might be disabled, while under a different definition, that same person would be considered able-bodied. Legal definitions of disability set qualifying standards for who is considered to be living with a disability. However, there are many people affected by disability who do not technically, under the legal definition, qualify as living with a disability.

The word “disability” is an umbrella term that encompasses a wide range of mental and physical impairments that affect the lives of those living with them. Disabilities range from mild to severe, and the level of functionality of people living with disabilities varies greatly. The degree to which a disability limits a person’s functionality is context dependent. If a person comes from a family with a long line of scholars with white collar jobs, a mental disability could be more difficult to cope with. On the other hand, a person from a farming family might find a physical disability more difficult to deal with than a mild mental disability. Who is living with a disability, and who considers themselves as living with a disability?

The external validity of the study lies in the general idea that culture impacts the experience of those living with disabilities as well as who is categorized as a person with a disability. The idea that disability is a social problem can be generalized to other

cultures and locations whereas the specific ways in which culture affects disability in this study's particular sites may not be transferable to other locales. Simply, the broader ideas of this thesis are applicable to other situations, whereas the specifics are not necessarily transplantable.

Another limitation could be the researcher's nondiscriminatory method of examining any and all disabilities that could be accessed. The researcher did not choose one or two particular disabilities to examine, but kept the topic generalized. Of course, disabilities vary greatly and this could be considered a limitation. However, by looking at disability as a social problem, the researcher was more interested in the stigmas (or lack thereof) and perceptions and attitudes of society at large, more so than in the particular etiology of various disabilities. By including all disabilities seen at these institutions, the researcher was better able to compare perceptions of different types and severities of disability.

The study included interviews with people who work with people with disabilities. This includes people in the health care professions or who work at the administrative level. Members of the general public were not interviewed for their opinions on disability. People might change their perceptions when directly questioned about them for fear of "looking bad" to the researcher. By asking people who work with the people with disabilities about the perceptions of the general public, it is plausible the researcher gathered more honest answers.

The final limitations of the research were time and funding constraints. Fieldwork at each site preferably would have lasted about a month. Safety considerations needed to be taken into account at the Brazilian location. The researcher, a young American female,

was advised against traveling alone to Santarém, and therefore was accompanied by her father who had visited the region many times over the last 25 years. The trip was self-funded by the researcher and her father, both of whom had other commitments in the United States, and therefore could not take unlimited time to collect data. Fortunately, the researcher had visited the city of Santarém five years prior, as well as the school where fieldwork was conducted. Therefore, the researcher had an overall idea of the feel and layout of the area prior to arrival. The culture shock was mitigated by previous experience and the researcher was able to more easily transition into fieldwork.

Ethical Considerations

The researcher followed the Institutional Review Board's (IRB) process for informed consent for research involving human subjects. The researcher ensured the IRB that no children or people with disabilities would be interviewed because they are considered part of a vulnerable population. Prior to data collection, informed consent was obtained from both institutions. (A copy of the institutional consent forms can be found in Appendix B.) Before interviewing, participants were given a consent form to read and sign that explained the purpose of the study, the procedure that would be followed, and the risks and benefits of their participation. The consent form also explicitly stated that participation was voluntary and that the participant could withdraw from any part of the research or the research entirely at any point without penalty. The participants would be kept anonymous. Only the primary and secondary investigators had access to the audio-recordings and transcriptions of interviews. (A copy of the interview consent form can be found in Appendix C in Portuguese and English.)

The researcher obtained permission to take photographs of the institution, without people in them, at the Brazilian location. Consent was received from all individual's pictured. For pictures of minors under 18 years of age, consent was obtained from their legal guardian or parent (The photography consent form can be found in Appendix D.)

For any participants who were not able to read or write, or simply were not comfortable signing their name to forms, the researcher had permission from the IRB to record the consent form being read out loud to the participant and to record the participant stating that they understood the meaning and were willing to participate either in an interview or in photographs.

The researcher minimized risks to participants by understanding the sensitive nature of the topic. Disability can be difficult for people to talk about if they are personally involved in the issue either through work or through family or friends living with disabilities. Therefore, the questions remained impersonal and were delivered in a sensitive manner. If a participant declined a question, the researcher understood and moved on to the next (An outline of the interview questions is available in Appendix A)

Participants appeared eager to be involved and contribute their thoughts and opinions in order to improve the condition of people with disabilities. The benefits of this study include greater understanding of disability at a multicultural level and an increased understanding of the social aspects of any given culture that make life difficult for those living with disabilities.

Chapter Two: Literature Review

Introduction

Physical and mental disabilities are undeniably biological processes at work on the human body. However, the degree to which a disability actually disables a person and limits their functionality is dependent on the culture in which the person resides. Disability is a biological problem with social solutions. A person is only as limited as their culture allows them to be. According to the World Health Organization, about 10% of the world's population lives with disabilities. In the United States alone there are over 54 million people with disabilities (U.S. Dept. of Health and Human Services, 2009). Through increased understanding of the social nature of disability, professionals and families can provide better care for people living with disabilities and their marginalized status within society can be changed to allow them greater acceptance. This study compares the experience of disability as well as the social perceptions and attitudes towards disability in two very different cultures. Case studies were carried out at a residential facility for people with developmental disabilities in Chicago, Illinois, USA and at a school for people with intellectual and physical disabilities in Santarém, Pará, Brazil. The comparison between a developed large city in the United States and a smaller, developing city in the Amazon Rainforest of Brazil allows for a better understanding of how cultures affect disability. These two cultures are quite different and so too are their perceptions of disability. Societal norms and expectations are relative and often people subconsciously abide by them. Only when members of a culture are aware of their biases

and their adherence to norms can they be more accepting of people who deviate from the prescribed norm.

The researcher in this study employed the grounded theory method where theory is derived from the qualitative data of interviews and observations. However, an extensive literature search was performed before data collection. Key concepts and issues identified in the literature on disability studies helped the researcher design the interview questions and to take note of certain things during observations.

The following review of the literature will address several areas related to the experience of disability in different cultural contexts and how culture affects those experiences. First, this literature review will address the foundational texts that make a case for the social construction of disability. These are some of the texts that inspired the researcher's design for this thesis.

Second, the literature review will discuss other case studies that helped inform the case studies performed for this thesis. The breadth of these case studies extend from the United Arab Emirates, to China, Cape Verde, and Brazil. They include topics such as quality of life, the role of sex and gender, and prenatal care.

Third, the literature review focuses on the complex ways in which pressing social issues and disability are intertwined. The aging of the population is a foremost concern in the United States and other nations around the world and this section will discuss the complications that are occurring as people with disabilities live longer than ever before. While Alzheimer's and dementia are biological processes, society's inability to cope with the combination of developmental disabilities and such disease processes of old age is cultural. The United States in particular is guilty of age-ism and stigma against people

with disabilities. Next, infectious diseases continue to plague all human populations, albeit to varying degrees, and this section will discuss how infectious diseases affect the rate and prevalence of disability within a given culture. The environment, and toxins found within, it are a major concern around the globe as the pressure of limited resources and human destruction of the environment make international headlines every day. The role of human/environment interaction and environmental toxins in disability discourse is discussed in this section of the literature review. Finally, the idea of personhood and its varying cross-cultural definition is discussed due to the overwhelming response from participants in the researcher's study that people with disabilities are first, and foremost, people. The debate over defining personhood appears in national and international discussions of abortion, war, and religion. The literature review shows how this debate directly relates to disability.

Lastly, the literature review will focus on issues of genetics, genetic counseling, and the legal status of abortion in Brazil. Genetic counseling provides parents with information on the health and condition of their unborn child. The abortion debate is related to genetic counseling and disability in general because in some instances fetuses with severe disabilities can be legally aborted and the mother's right to choose abortion or not affects her perception of the pregnancy and her children. Genetics, or genetic abnormalities more specifically, are also an important part of the literature review. Genetic abnormalities that are the result of genetic inbreeding leave people with various degrees of disabilities. Genetic inbreeding is either condoned or tabooed by societal standards. A culture where genetic inbreeding is accepted or where it is unconsciously practiced, will experience greater levels of severe disabilities. All three of these concepts

are social in that a society decides whether or not genetic counseling is viable, whether or not abortion is legal, and who receives prenatal care and to what extent as well as the quality of that care.

Body of the Review

Foundations: Social constructivism and disability

Cultural perceptions of disability have changed over time. The euphoria of eugenicists ill-fated plans in culminating in the Holocaust and the cultural revolutions, including the Civil Rights Movement and Women's Movement, in the United States helped form the trajectory of disability studies and accentuate the social nature of disability. The following literary studies illustrate how social change affects the lives of people living with disabilities, especially in terms of the degree to which they are stigmatized or accepted.

Disabilities themselves are not the natural creator of social stigma. Since all societies choose one segment along an arc encompassing all human behaviors and beliefs, 'normal' is a social creation. The terms "normal," "normalcy," and "norm" entered European vocabulary and society in the mid-nineteenth century. Once the terms were popularized, the stigma against anyone deviating from the norm was enhanced. Lennard Davis, in his book Enforcing Normalcy: Disability, Deafness, and the Body (1995) explains, "I would like to focus not so much on the construction of disability as on the construction of normalcy. I do this because the 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (Davis, p.9, 1995). According to Davis, the problem with people

with disabilities is not inherent within them; the problem lies in their deviation from the accepted norm for human existence. Thus disability is not only biological, but also social. Varying definitions of “normal” affect social views of disability.

Statistics became an area of popular academic pursuit in the 1830s and interestingly many of the first statisticians were eugenicists. Sir Francis Galton, the founder of eugenics and Charles Darwin’s cousin, was a statistician. The French statistician Adolphe Quetelet applied the concept of a norm, or ‘normal’ to humans with his theory of the *l’homme moyen physique* and *l’homme moyen morale*- physically and morally average man. (Davis, p.11, 1995). There is a natural connection between eugenics and statistics because statistics is the science of normalizing populations and dividing populations into norms and non-norms and calculating how deviant a particular population is from the norm. It calculates how a specific data point or individual deviates from the norm of their population. By creating a norm, statisticians and eugenicists alike created the abnormal as well. People with disabilities fit into the ‘abnormal’ category along with others considered “unfit’ by eugenicists. People with disabilities were associated with all those who deviated from the new narrow definition of the ‘norm’- criminals, prostitutes, the insane, alcoholics, and people with tuberculosis (Davis, 1995). The more standard deviations from a prescribed norm a person is by some measure, the more undesirable and burdensome they appear to society. The eugenics movement, which came to a head with extremist groups like the Nazis, sought to eliminate all the ‘undesirables’ (including those with disabilities) in an attempt to normalize the population. Davis points out that this runs counter to the laws of statistics in which “all phenomena will always conform to a bell curve” (Davis,1995).

The recent history of extreme discrimination against people with disabilities still looms over their existence. Generational differences seem to have made younger people more accepting, but stigmas still exist and greatly hinder the lives of those with disabilities, at times more so than their actual disability. Many people with disabilities still living today remember times when they would have been shipped off to an institution and their condition not spoken about. These times, especially in America, are more or less in the past, but the memory of institutionalization and forced sterilization is still fresh. Knowledge of the historical contexts of disability in any culture is vital to understanding the social construction of disability in the present.

Building on this foundation, Pamela Block used a historical particularist approach to examine the evolution of the discourse of intellectual disability (ID) in the United States, Brazil, and Europe during the twentieth century. She determined that Brazil's support system for people with disabilities is *not* simply evolving along the same progressive line but at a slower pace than in the United States and elsewhere. Brazil's support systems for disability have a unique history and have followed their own trajectory, that has, at times, been more humane and progressive than in other nations. Brazil did not have the forced sterilizations found in the United States or the genocide of Nazi Germany. Brazil's eugenics movement was not homogeneous with eugenics movements in other parts of the world. This affected Brazilians view of disability and the support systems they have had in place over the last century.

The purpose of Pamela Block's 2007 study, "Institutional Utopias, Eugenics, and Intellectual Disability in Brazil," was to outline how cultural beliefs and practices influence the ideology of disability discourse. She believed that cultural survivals from

the eugenics period were maintained and influenced people's attitudes towards disability in the United States. She aimed to compare and contrast this notion in Brazil. An understanding of the historical contexts surrounding disability set the stage for the current situation, attitudes, and legislation.

Block's study focused on the work of Helena Antipoff in Brazil. She was an educator who helped replace the biomedical pedagogy aimed towards people with disabilities in Brazil with an educational one at the same time, she promoted a healthy teaching model that did not involve competition but was based on dignity, respect, and community (Block, 2007). Antipoff was against institutionalization and large facilities. She changed the terminology used to describe people with disabilities from the derogatory "abnormal" or "subnormal" and coined the term "exceptional" (Block). Antipoff viewed people with disabilities as humans and believed in their basic goodness and the common humanity of all people regardless of their abilities. Her model led to the creation of several institutions, including the Association of Parents and Friends of Exceptionals (APAE) which is one of the research sites in this thesis. Her study discusses the criticisms of her theory and of institutions such as APAE. Some argue that they are self-perpetuating and should be a means to an end, not an end in themselves. However, most everyone acknowledges that Brazil experiences higher rates of intellectual disabilities than the United States and that institutions such as APAE cannot even begin to meet the demand for services because the need is so great. There are over 1000 APAEs located throughout Brazil today (Block).

Block examined some of the history of the discourse on disability throughout the twentieth century and provides the context for the current status of people with

disabilities in the United States and Brazil. The eugenics movements in both countries were sparked by social problems that needed to have scapegoats and be alleviated. The cultural responses were different. Brazilians were more concerned with environmental causes of degeneration than with genetic causes. They believed more in the Lamarckian theory that transmutations could occur (Block, p.8, 2007). They thought that the environment could alter individuals physically and that offspring would have these newly developed characteristics. Therefore, discrimination and forced sterilization were less commonplace than during the eugenics movements in the United States and Europe. Cultural beliefs altered the course of Brazilian eugenics. By offering a critical examination of the ideological changes over time in how disability is perceived, students and researchers can better understand the plight of those with disabilities now and recognize that they are not a homogenous group. Unique historical contexts must be considered in order to understand modern attitudes and perceptions of disability.

In her article, "Sexuality, Parenthood, and Cognitive Disability in Brazil," Pamela Block discussed how historical contexts and cultural beliefs affect the extent and form of social control over the sexuality and fertility of Brazilians with cognitive disabilities (CDs). Women with CD in Brazil have been vulnerable to the repressive means of control that common to all Brazilian women at different times. Past cultural conceptions that the sexuality and fertility of Brazilian women with CD must be controlled and protected color modern perceptions. Since the eugenics movement took a unique trajectory in Brazil, people with CD were not segregated from the larger community (Block, 2002). Brazil adopted the motto "to sanitize is to eugenize" based on their Lamarckian inspired beliefs that the environment causes abnormalities like disability

(Block). Brazilians blamed lack of hygiene, insufficient medical care, and dirty water as causes of disabilities. Better health was equated with better genes. If the environmental and sanitary conditions are improved, there will be less disease and genetic problems for them and the next generation. Though a debate raged on the topic, the government did not support forced sterilization like other governments in the first half of the twentieth century.

After the decline of the eugenics movement, sexuality and fertility among people with CD were not discussed at great length in Brazil or in the United States until the 1960s and 70s. The ongoing belief until this time had been that people with CD were asexual and childlike. A book entitled “Menino Sempre” [Perpetual Child] was even published in Brazil by a parent, Yara de Oliveira Celentano¹ (Block, 2002).

Sexuality and race are intimately linked in Brazil with white women’s sexuality being historically repressed and the sexuality of white men and black women being more public and open. Brazil’s seemingly open sexuality contrasts with the extreme control parents of children with CD practiced. Parents reacted strongly and negatively towards signs of sexuality in their children with CD. A fear of vulnerability of sexual abuse is prevalent as well as a fear of procreation where the individual would not be fully aware of the implications of pregnancy or be able to care for their offspring.

Block’s study resonates with the larger theme of this thesis because it discusses the unique ways in which historical contexts and cultural beliefs can affect one aspect of disability. Sexuality, marriage, and parenthood are difficult topics for people dealing with CD in all cultures because it raises not only economic and financial issues, but also

¹ Celentano, YO (1977). *Menino Sempre*. Sao Paulo: Published by Author.

human rights and moral issues. Cultural attitudes towards sexuality intertwine with race, status, and disability to create the standard for sexuality and fertility for people living with physical and cognitive disabilities.

Sexuality and women's issues took center stage in the United States in the 1960s and 1970s. Birth control pills and the legalization of abortion permanently changed women's sexual lives in this country. This time period included several cultural revolutions including the Civil Rights Movement and the Women's Movement. During this time, Americans seemed to be questioning the prescribed norms handed down to them from previous generations. The norms were changing and those who deviated from the norm were given a voice for the first time. Erving Goffman's seminal book, "Stigma: Notes on the Management of a Spoiled Identity" (1963), questioned social norms and the marginalization of anyone considered to be different, and was a part of this cultural revolution. He used case studies and autobiographies to explore the lives of people who cannot meet the standards society has set for "normal." This includes ex-mental patients, prostitutes, criminals, drug addicts, people with disabilities, etc. Tension surrounds their social life because normal interactions are impossible between them and the non-stigmatized because those with stigmas carry what Goffman calls "uncertainty of status" (Goffman, 1963).

People with disabilities are ostracized because of their ambivalent social position. They are considered to be somewhere between fully human and not fully human. They are marked by their disability and their condition causes anxiety for those who encounter them. People with less severe or with less visible disabilities can partake in "passing" as Goffman calls it. This is when a person hides their stigma from others as much as they

can. The stigmatized in general can almost take on the role of the anthropologist because they become acutely aware of the social mechanisms that control all human encounters and interactions. They become excellent at managing encounters to alleviate the tension for the non-stigmatized. People with stigmas understand the social complexities of 'normal' versus 'abnormal' and the human tendency to rely on neat categorization. Humans are dependent on prescribed norms to guide their behavior and when a stigmatized individual upsets this normal routine, the non-stigmatized do not have instinctual responses to lean back on. Social norms and standards create deviants. And the stigmas that those who deviate from the norm experience prohibit their full participation in society.

Multicultural Case Studies

An important aim of this thesis is to contribute to improved care for people with disabilities living in culturally plural societies. The United States is home to people of many different cultural backgrounds and our healthcare system is grounded in a biomedical model. Miscommunication and misunderstandings due to cultural differences are common between patients and medical practitioners. In order to provide optimum care, it is imperative that people understand that disability is not a uniform experience and that people living with disabilities are not homogeneous. Unique cultural backgrounds create differences in experience and understanding of disability. The treatments and beliefs of the medical community do not consistently align with those of ethnic minority communities and problems arise out of this discrepancy for both patients and medical practitioners.

A good example of a culturally constructed experience of disability within a multi-ethnic society can be found in Dawna M. Thomas' 2009 study, "Culture and Disability: A Cape Verdean Perspective." The Cape Verdean (CV) community within the United States perceives health behaviors and disability in a different way from the mainstream American culture. Service providers do not understand their perceptions and therefore cultural differences act as a barrier to providing adequate care. This leaves the CV community's health needs unserved or under-served. The attempts made by service providers to understand their subculture have been inadequate (Thomas, 178).

The purpose of Thomas' study was to provide information about the CV culture. The author tried to explain the Cape Verdean perception of disability and how it differs from mainstream American perceptions. She also wanted to explain why past attempts at understanding their culture have not been successful. Finally, the purpose was to make recommendations for improved service provision.

What is today called the Republic of Cape Verde, is an island located about 300-400 miles off the West coast of Africa that was colonized by the Portuguese in the fifteenth century. The island declared independence and took its modern name in 1975 (Thomas, 2009). Cape Verdeans immigrated to the United States to avoid poverty in their homeland and many settled in the New England area. These immigrants experienced difficulty with racial classification because Cape Verde is very multicultural and there are no specific physical features that define Cape Verdeans. People from Cape Verde now living in the United States can identify themselves as Black, White, American, African, Portuguese, or Other (Thomas). This racial issue permeates the health provision system and creates misunderstandings and prevents the best care from reaching them.

The researcher's analysis was based on fieldwork from a study called "Understanding the Cape Verdean Community: An Analysis of Race and Disability in Massachusetts" which employed individual interviews and focus groups. The researcher drew conclusions from these data. The first conclusion was that Cape Verdeans saw the word 'disability' as something very negative that creates stigma and they preferred the word "quitodo" which translates to "poor things" (Thomas). Although the participants claimed that having a disability did not stigmatize an individual, all agreed that it was best kept as a private matter and hidden as well as possible. Physical disabilities were more easily dealt with than intellectual disabilities because physical disabilities, while creating obstacles, can often be accommodated for whereas intellectual disabilities are not as easily accommodated in this community.

Another conclusion the researcher drew from the data was that males' social status was hurt more by disabilities than females' social status. In Cape Verdean culture there are clearly defined gender roles that place the male as the "breadwinner." If a male's disability prohibits him from taking care of his family, his status is hurt. It is more acceptable for women to need help. However, women with disabilities deal with the dual discrimination of being female *and* disabled (Thomas, 182).

Finally, Cape Verdeans have strong family ties to the extended family beyond just the nuclear family. They believe that the extended family should care for a person with disabilities and protect their family member from institutionalization. The American ideal of independence from family is not compatible with the Cape Verdean cultural belief system.

Thomas recommends that service providers recognize that the goals they laid out for Cape Verdeans with disabilities were in direct conflict with their cultural beliefs. Service providers would be better off having direct knowledge of Cape Verdean culture and historical background rather than receiving general “diversity training.” Service providers should understand that interdependence is valued over independence. Finally, it is best to promote better care for the disabled *within* the Cape Verdean community because they have a strong network of community organizations.

This study is an example of the cultural construction of disability and how societal beliefs affect a person’s experience of disability. Attempting to assimilate a culture within the United States into the American biomedical community’s belief does not work. Service providers need to understand how cultural beliefs affect perceptions of disability. This requires experts who understand how a culture views disability and why it is viewed that way. Which social norms form their opinions and attitudes? Once the cultural perceptions are understood, service providers can offer care that meets the needs and desires of the families and people with disabilities in a culturally appropriate way

A major cross-cultural issue encountered by anyone attempting to study disability in different countries are the many different definitions of the word. The definition of disability varies cross culturally and even within cultures. While there are often legal and medical definitions associated with the word, these too can vary. Also, a person may feel he or she has a disability without fitting these definitions, or a person might be categorized as having a disability without feeling as though they have one. It is crucial for any research involving disability to have participants clearly state how they define the term. All measurement instruments for any study must be reliable and produce valid data.

In terms of disability, a common concept is Quality of Life (QOL). This term is subject to the same ambiguity as the term disability. Many participants in this thesis' research discussed QOL and the idea of living a full life. Because of the fluid meanings of the terms, the researcher decided to explore studies testing the reliability and validity of using these terms across cultural borders.

In order to gather reliable data for this thesis, the researcher had all interview participants define the term 'disability' at the beginning of the interview. This way, the researcher knew precisely what she was comparing when discussing this topic. As long as terms are clearly defined, cross cultural comparison is possible. When terms are not defined or not applicable in different cultures, a significant comparison cannot be made.

Quality of life (QOL) could be defined differently in various societies based on particular cultural beliefs and ideals. Internationally recognized QOL indicators need to be compared to cultural indicators of a high quality life. A study conducted by J. Xu, M. Wang, Y. Xiang, and X. Hu (2005) compared Chinese indicators of happiness with the recognized QOL scale to ensure the latter's level of appropriateness (Xu, Wang, & Hu, 2005). The study looked at the belief in Chinese culture in "FU, LU, SHOU, XI." These are indicators of life happiness. FU represents good fortune, LU represents financial well being, SHOU represents longevity and health, and XI overall happiness (Xu, Wang, & Hu, 2005). The purpose included a continued study of QOL concepts to inquire about the emic and etic elements in relation to Chinese culture.

The study included 87 people with mild intellectual disabilities (ID), 58 parents of people with ID, and 210 professionals who worked with people with ID as teachers or in rehabilitation settings. The Cross-Cultural Survey of Quality of Life Indicators was

translated into Chinese and back-translated to ensure reliability. It was administered in three forms to the three different groups of participants. The results were statistically analyzed (Xu et al., 2005).

The results showed that the recognized international measure of QOL was an appropriate measure to use in Chinese culture. The researchers reached three conclusions from their quantitative data. First, they found that seven out of eight indicators of QOL were appropriate measurement tools. (Xu et al., 2005) Second, all three groups of participants ranked different categories of QOL in the same way. Finally, QOL concepts enhance opportunities for social life and employment for people with ID in China through education and rehabilitation models as well as through school curriculum and employment possibilities (Xu et al.).

Quality of life for people with disabilities is culturally relative. What one society might consider a high quality of life could vary greatly from another society's standards. Therefore, researchers need to be cautious when applying international measurement scales. Happiness is a difficult concept to quantify and it seems appropriate for qualitative measurement tools to be employed in order to understand the quality of life for people living with disabilities of all kinds in different cultures.

When comparing social issues in different cultures, it is essential to consider gender and sex roles. Gender is socially constructed and is a strong determining characteristic of individuals lives. Women are often associated with the domestic and caregiving spheres. It seemed pertinent to examine gender in relation to disability for this thesis. A person's sex is biologically determined, but a person's gender is socially determined. The researcher performed a literature review of materials discussing the role

males and females play in providing care for people with disabilities. She also examined how the gender roles of a particular society affect the experience of people living with disabilities and the role mothers, fathers, and other family members play in providing care for someone with a disability.

Gender roles vary cross-culturally and can determine which family members provide care to a member of the family with a disability. In cultures where disability is highly stigmatized and women are discriminated against, it can be hypothesized that females will provide a majority of the care for the disabled. A qualitative, ethnographic study was performed using intensive interviews in the United Arab Emirates (UAE) with a focus on the affect of culture and gender norms on the roles parents play in providing care for children with developmental disabilities.

The purpose of the study conducted by Sara Ashencaen Crabtree, “Maternal Perceptions of Care-Giving of Children with Developmental Disabilities in the United Arab Emirates” (2007), was to examine family care-giving to children with disabilities in order to explore areas of concern and understand how society perceives the effects of disability on the child’s life. The study also aimed to increase families’ resilience to the difficulties of caring for a disabled child. This study was conducted with attention to Islamic ideals.

Islamic principles state that people with disabilities should not be discriminated against and should be provided with care by all. In UAE, people with disabilities have full legal status. However, there is a widespread stigma against people with disabilities and they are regarded as something worthy of shame and guilt on the part of their parents. It is shameful to have a family member with a disability (Crabtree, 2007).

Gender roles in the Middle East designate women as nurturers and the providers of care to the young, ill, and elderly. Women also provide care to disabled family members. In the Middle East, as opposed to in the West, the roles of mother and nurturer come with a degree of prestige and status. It is important to note that in the UAE, a politically stable and medically advanced nation, women are encouraged to seek an education and be full members of society more so than in any other Arab nation.

This qualitative study employed observations and interviews. Fifteen families were observed and interviews performed predominantly with the mothers. Participants were chosen through a local semi-government run organization for people with disabilities. Of these fifteen families with children with disabilities, twelve of the children had Down's Syndrome, one had microcephaly, and the rest were labeled "mentally retarded" (Crabtree, 2007).

This study found that mothers provided the majority of the care and turned to service organizations for help. Mothers also looked for help from daughters and grandmothers while fathers, sons, and grandfathers were not expected to provide any direct care, only financial help. Sons were only expected to play with the disabled child. This holds with the cultural norm of women as caregivers and males as providers (Crabtree, 2007). Interestingly, it did not seem that male help was even desired aside from emotional support because their help was too much of a break from traditional gender roles.

The data showed that while females with disabilities experienced the dual discrimination of sexism and the shame of disability, the affect of having a son with disabilities was more serious for the family (Crabtree, 2007). Fathers, and sometimes

mothers, will deny that their son has a disability, refuse to have the medical testing done to confirm the disability, or minimize the extent of the disability. The cultural norm maintains that males should marry, reproduce, and provide financially for the family. Disabilities could prohibit their ability to do this, and this creates the tension surrounding male disability. For both sexes, parenthood holds great importance, because based on cultural values, a person becomes an adult through parenthood.

Mothers could not employ male help because that would bring their sexual virtue into question. Cultural norms also deterred mothers from hiring female help to care for their sons with disabilities (Crabtree, 2007). Therefore, mothers described the great emotional and physical toll caregiving took on them. This study recommends more familial support and a reduction of the stigma and shame carried by parents of children with disabilities. The UAE needs more options for respite care for the mothers.

This study clearly demonstrates the power of culture over the perception of disability and the experience of men and women living with disabilities and providing care for those with disabilities. Islamic gender roles affect how males and females with disabilities are viewed and the goals that parents have for their children with disabilities. Males with disabilities bring more distress to the family because there are higher expectations for their adult life. The providers of care and lack of respite care are also affected by cultural norms that see women as nurturers and make male-female, female-male caregiving situations taboo outside of the family.

Gender roles and sexual mores, both of which are socially constructed influence how people view pregnancy. Sexual liberation and sexual taboo create the stigmas or acceptance associated with sexual intercourse and marriage. Social norms dictate the

expectations for males who are about to become fathers. In Brazil, as shown by the data from this thesis, it is quite acceptable for males to take on little to no responsibility for their progeny. In a culture where machismo rules and males feel no obligation, women can have strongly negative feelings towards their pregnancies. The literature review showed that attitudes surrounding a pregnancy correlate with disability because the more comfortable and positive a woman is with her pregnancy, the more likely she is to receive adequate prenatal care. Adequate prenatal care, as opposed to inadequate or no care, helps prevent the occurrence of disability.

Prenatal care is highly affected by maternal attitudes towards their pregnancy. The way women view their pregnancy and their socioeconomic and demographic variables are related to whether or not they receive care and how adequate the care is that they receive. Diego G. Bassani, Pamela J. Surkan, and Maria Teresa A. Olinto undertook a study in southern Brazil to collect data from postpartum mothers in Porto Alegre, “Inadequate Use of Prenatal Services Among Brazilian Women” (2009). They looked at social and demographic variables, prenatal care, the mothers’ relationship with the father, abortion attempts, whether the pregnancy was planned or accidental, and the levels of satisfaction with the pregnancy. These variables were compared as to whether the women had adequate, partially inadequate, or inadequate prenatal care to determine if a correlation existed.

The researchers used 611 participants from three local public maternity hospitals in Porto Alegre. All women signed consent forms. The researchers employed interviews using structured questionnaires to interview the women within 24 hours of giving birth. The interviewee asked about their income, education, age, race, whether they lived with

the father, and how many children they had (Bassani, Surkan, & Olinto, 2009). The researchers also gathered data on what point during the pregnancy women began receiving prenatal care and how many visits to the doctor they made during their pregnancy. “Adequate care” was defined as beginning care in the first trimester and visiting the doctor at least six times during pregnancy. “Partially inadequate care” was defined as either beginning prenatal care later than the first trimester or visiting the doctor less than six times during the pregnancy. “Inadequate care” was defined as both beginning prenatal care after the first trimester *and* coming in for less than six visits. The number of visits was adjusted for women who gave birth earlier than 37 weeks (Bassani Surkan, & Olinto, 2009).

The researchers analyzed the data statistically using a computer system which they cross-checked. They found that the mean age of participants was 25.5 years old with a mean monthly income of \$63.30 USD. The average length of education was 8.2 years. Of the 611, 40% were first time mothers, 15% did not live with the father, 64% had not planned the pregnancy, and 27% were dissatisfied with their pregnancy. In total, only 4% attempted abortion. The results showed that 61% of the participants received adequate prenatal care, 21% had partially inadequate care, and 4% had no prenatal care (Bassani Surkan, & Olinto, 2009).

According to this study, many of the socioeconomic and demographic variables had correlations with prenatal care. Higher education levels were positively correlated with better prenatal care. Being nonwhite was correlated with poor prenatal care. Women who were giving birth for the first time were more likely than women who were giving birth for the third or fourth times to report adequate prenatal care. The women living with

the father were less likely to report inadequate prenatal care. The lower a woman's income level, the more likely she was to have inadequate prenatal care. Finally, researchers found that planned and wanted pregnancies were correlated with better prenatal care (Bassani Surkan, & Olinto, 2009).

This shows how societal constraints on women's right to choose whether to continue or terminate a pregnancy affects the health of the fetus. The government plays a role in this study through the illegal status of abortion and through the maintenance of socioeconomic variables that affect prenatal care. Women with less education and lower incomes receive less prenatal care and therefore carry higher risks of having children with health issues. This exemplifies the cyclical nature of socioeconomic inequality.

Social Issues

The binary categories of 'dead and alive' and 'subject and object' are challenged when people in chronically liminal positions are considered. People in permanent vegetative states (PVS), people with severe dementia and Alzheimer's, and people with severe developmental disabilities are an example of chronic liminality due to their lack of self awareness, self consciousness, or awareness of their environment. They create confusion for the people around them who are uncomfortable with the ambiguity of their position somewhere between dead and alive and between subject and object. The question of their personhood, or status as a person, is raised and needs to be dealt with. Are they people with rights just like everyone else?

Nurit Bird-David and Tal Israeli performed an ethnographic case study of people in permanent vegetative states in an Israeli hospital. The researchers wanted to learn how

the professional care these patients received every day helped to construct them as people (Bird-David and Tal Israeli, 2010). They argue that the biomedical system strips the patients of their former “persons” upon entering the hospital but that new, fluid personhoods emerged during their time there. The fieldwork consisted of participant observation and interviews with family members and personnel who cared for people in PVS. Between 30 and 40 patients were cared for in the hospital unit where research was conducted and 80% of these patients were male. All patients were between 17 and 79 years of age and most had traumatic head injuries from army service or car accidents (Bird-David and Israeli, 2010). The objective of the hospital unit was to keep the PVS patients ‘alive’ as long as possible. Discussion of their personhood, life or death, and object or subject, was not considered by caregivers or families because they operated under the social idea that life lasts until the last breath. The futility or purpose behind extending the patient’s current condition to hold off that last breath as long as possible was not discussed among the families or personnel.

The researcher found that caregivers personified the PVS patients and were attuned to their most minute changes. The personnel discussed the personalities and ‘mood changes’ of their patients, attributing them with actions and intentions that the biomedical community would otherwise claim them incapable of doing. The caregivers even re-personified their patients and created identities for them based on how challenging they were as patients. An easy patient, one who required less help and stress and rarely became sick, would be re-personified as a good person. Conversely, a difficult patient to care for was re-personified as having been a difficult person to deal with in life before they ended up in PVS (Bird-David and Israeli, 2010).

This study exemplifies the challenges of personhood that come with liminal states. When a person does not have full consciousness or awareness, it can be difficult for others to view them as persons. However, those who work closely with people considered to have no ‘person’ left in them can often notice the most minute details that restore personhood. The slightest change in patterns, movements, or moans can be interpreted as an expression of personhood from the PVS patient. The difficulty of personhood and defining a ‘person’ is important for the disabled community. Recognizing people with disabilities as fully human could restore the enforcement of their rights. A reduction of the tension created by liminality could also alleviate some of the stigma against people with disabilities. The definitions of personhood and ‘person’ become ambiguous and incoherent when trying to apply them to people with developmental disabilities. A greater understanding of the changed way in which a person with disabilities or in PVS maintains their personhood and expresses *something* that makes them a *someone* helps restore their humanity.

Environmental Toxins

Health care professionals are seeing developmental and learning disabilities with unknown origins. They are seeing processes at work that do not fall under one disease process. Professionals attribute these cases to exposure to environmental toxins such as pesticides, lead, and mercury. These neurotoxicants, toxins that have adverse affects on the nervous system, can be quite dangerous to vulnerable young brains in children and for fetuses in utero. The developing brain is exposed to these toxins and is ill-equipped to battle their side effects. Children are much more susceptible because they have a rapid

rate of brain development whereas adults have reached their maximum brain capacity as of age twenty (Antoniadis, 2006).

An article by Anastasia Antoniadis, Steven Gilbert, and Michelle Wagner from the American Speech-Language-Hearing Association as published in the ASHA Leader discussed sources of lead, pesticide, and mercury. Lead exposure comes from old paint, during home renovations, or in water fountains with very old piping systems (Antoniadis, 2006). Pesticides are often used in schools to kill pests without thought for the effects on the students' neurodevelopment (Antoniadis, 2006). Finally, elemental mercury accidents in school leave children exposed to its adverse affects as well. The authors stress that prevention is key. These neurotoxicants can be avoided and their dangerous side affects, including developmental disabilities, could be prevented through education. A program called Integrated Pest Management has already begun where schools try to avoid using pesticides by preventing their pest problem in the first place. Schools remove access to any food, water, or hiding places for rodents and pests to thrive in their school. This reduces the need for pesticide use. When pesticides must be used, schools opt for less dangerous ones in smaller doses (Antoniadis, 2006).

The article by Antoniadis et al. pertains to the research discussed in this thesis because environmental causes were a major problem in both research sites. Toxins found in the environment, and lack of awareness and education regarding these toxins, leave people with incurable, preventable developmental disabilities. An increased understanding of the side effects of toxins could help eliminate some of the threat.

Infectious Diseases

The Amazon region of Brazil is endemic with malaria. A large city, Manaus, situated about 500 miles from this thesis' research site of Santarem, accounts for 22.5% of all malaria cases reported in Brazil each year (Chegas et al., 2009). Pregnant women seem to be more susceptible than non-pregnant women to the malaria infection. While only about 0.8% of non-pregnant women are infected at any time with malaria, about 4.3% of pregnant women are infected with malaria (Chegas et al., 2009). Malaria is passed from mother to fetus through the placenta and can lead to many complications with the pregnancy. Malaria during pregnancy can cause developmental disabilities, spontaneous abortion, premature birth, and even death for the fetus.

The purpose of a study, "Impact of Malaria During Pregnancy in the Amazon Region" (2009) performed by four Brazilian researchers was to determine the effects malaria had on the developing fetus and attempt to identify predispositions or risk factors for pregnant women to avoid contracting malaria. The researchers observed and interviewed 417 pregnant women who had been diagnosed with malaria and were being treated at the Fundação de Medicina Tropical do Amazonas. The results of the study showed that changes were detected in 26.2% of the pregnancies. The threat of abortion was present in 25.5% of cases but abortion occurred in only 1.0% of cases. Similarly, the threat of premature birth existed for 25.1% of cases, but only occurred in 1.0%. The study also found that mothers under the age of 20 experienced a significantly higher risk of the threat of abortion and premature birth (Chegas et al., 2009).

This study is interesting because, while malaria is endemic in Brazil, it has more or less been eliminated in the United States. Malaria is responsible for about 10,000

maternal deaths and about 20,000 deaths among children in their first year of life (Chegas et al., 2009). Because malarial infections are preventable, this is clearly a social cause of disability and death in Brazil. If they had access to malaria vaccines, they would not be faced with this issue.

Aging

Research and experience have repeatedly found that people with Down's Syndrome (DS) experience an increased risk of developing dementia and Alzheimer's disease (AD) as they age. As people with DS live longer due to earlier intervention, better lifelong care, and improved medical technology, the community of people with disabilities is experiencing an influx of people dealing with the dual processes of AD and DS. Caregivers for people with developmental disabilities do not know how to care properly for AD and dementia patients, while caregivers trained to deal with AD and dementia do not know how to properly care for people with DS. AD is one of the leading causes of mortality and morbidity in elderly DS patients.

Seven Dutch researchers conducted the largest population-based study to examine the instance of dementia and AD in people with DS as they age (Coppus et al., 2006). In this longitudinal study, researchers reported on 506 DS patients over the age of 45, some of whom were institutionalized and some of whom were not. They were physically examined and checked for dementia and then followed up through their deaths (Coppus et al.). The researchers studied the prevalence of dementia and AD and compared the mortality rates. All participants were tested for degree of intellectual disability using a standardized test from the World Health Organization and their previous and unrelated health concerns were taken into consideration. Interviews were conducted and more

standardized measurements of dementia and social competence were administered. Laboratory examinations of plasma were conducted to screen biochemical, hematological, and thyroid functions with samples saved for later research (Coppus et al.). The patients with dementia or AD, or possible dementia and AD, were followed and examined on a yearly basis for functional, social, and cognitive decline as well as physical examinations tracking their progression. One hundred and three people were followed for one year, 130 people for two years, 160 people for three years, 76 people for four years, 30 people for five years, and ten people died within the first year of the study. Participation ended through either censorship (leaving the study) or death. The data were statistically analyzed using chi-square tests and one way analysis of variance. Statistical significance was set at the 0.05 level (Coppus et al.).

The results showed that up to the age of 59, the rate of dementia doubled for every five year period. Between 45 and 49 years of age, the rate of dementia was 8.9% while the rate for those between 50 and 54 was 17.7%. From the ages of 55-59, the rate was 32.1%, but from 60 years of age and older there did not seem to be an increase with the rate remaining steadily around 25.6%. This could be accounted for by the high mortality rate of people with DS by the age of 60 and above. After the age of 60, it appeared that people with DS with and without dementia or AD had similar mortality rates. The overall prevalence of dementia among the participants was 16.8% (Coppus et al., 2006). These findings were consistent with the literature.

The limitations of this research included the validity of the diagnosis of dementia or AD- both of which can be difficult to diagnose correctly. Another limitation was that symptoms of depression and dementia can often overlap and that that depression is

strongly associated with AD. A final limitation is the high rate of hearing and vision problems among people with DS. These difficulties could negatively affect their cognitive, social, and functioning levels and either cause them to appear more demented than they really are or to have a more severe intellectual disability than they do. Therefore, these variables could skew the results of this study.

The aging of people with disabilities as a population is cited as an issue of great concern in the United States. The dual issues of disability and age related processes is uncharted territory. Care providers in the United States specifically cited AD and dementia among people with DS as a cause for concern. Committees have been formed to deal with this new issue, an issue that reflects greater life-long care and increased technology. This study, while educational and informative, offered no insight into why people with DS are more susceptible to dementia and AD than other populations. If AD and dementia are great concerns for the mortality rate of people with DS, it seems more causal knowledge is required. As people with DS age and are living higher quality lives, it would be optimal to try to prevent the onset of these conditions.

Genetics, genetic counseling, and abortion

Abortion remains a controversial topic in the United States. Although abortion is currently legal, the moral arguments against it hold the media's attention and it appears as an issue for many political candidates' platforms. Abortion relates to this thesis in several ways. First of all, the abortion debate revolves around the definition of human life. This concept parallels the repeated assertion that people with disabilities are still human and therefore deserve the care and respect shown to the able-bodied. The second way that

abortion relates to disability is through genetic screening and the legal right to choose to end a pregnancy if the fetus has a disability.

As the following research studies show, abortion is illegal in Brazil except in the cases of rape and an immediate threat to the mother's life. However, obtaining legal abortions in these cases is quite difficult. An understanding of abortion can help clarify some of the attitudes surrounding disability in Brazil and might even account for the shame of parenting a child with disability found among men.

Abortion is seen as a crime against the life of the fetus in Brazil and therefore remains illegal except in the instance of rape or if the mother's life is in immediate peril. Brazil is a predominantly Catholic nation and the arguments for the fetus' right to life clashes with the argument of women's autonomy in this ongoing debate (Diniz, 2007). The legal status of abortion is intimately intertwined with disability. Thanks to the technology of ultrasounds and modern medicine, women often know in advance that the fetus has developmental disabilities. Given the option, some women, especially those in financial or social constraints, might choose to abort.

In 2004 the Brazilian Supreme Court ruled that abortion would also be allowed in cases of anencephaly (Dinis, 2007). Anencephaly is a condition, sometimes caused by environmental toxins, where a large part of the brain and skull are missing (<http://www.nlm.nih.gov/medlineplus/ency/article/001580.htm>). Fetuses with anencephaly will not survive more than a few hours. The diagnostic process is simple and the existence of anencephaly is clear even to a layperson. The legal definition of 'alive' in Brazil is defined as having cerebral activity (Diniz). With a large part of the cerebrum missing and therefore no capacity for cerebral activity, fetuses with anencephaly do not

meet the legal definition of 'alive.' The mother's right not to be subjected to torture is important to this topic. Forcing a woman to bear a severely deformed child that with certainty will not survive more than a few hours of life after birth can be considered torture. The Brazilian Supreme Court considered these conditions and ruled that anencephalic fetuses can be legally aborted.

The discussion of the legal status of abortion in Brazil is important because it highlights one way in which culture can directly affect disability. In the United States and other nations in which technology can inform parents that their child has a disability while still in the womb and in which abortion is legal, parents can opt to end the pregnancy and avoid caring for a child with a disability. If parents know they are ill-equipped or incapable of caring for a disabled child, they might also choose to terminate the pregnancy or give the child up for adoption. Disability is regarded as shameful in some developing parts of Brazil and this could in part be accounted for by the lack of options when learning a fetus has a disability. If parents learn that a fetus has a disability and choose to continue with the pregnancy without being forced by their government, their feelings of shame appear to be less strong or even nonexistent.

However, it is important to note that while abortions are illegal, women can procure abortions illegally in very high numbers. It does not appear too difficult to obtain an abortion through illegal means, but it is a dangerous procedure and many women suffer medical and legal consequences. Failed, illicit abortion attempts can even cause some disabilities.

The corruption of the Brazilian government is no secret. The power of laws lies in their enforcement, and in many cases in Brazil, laws are not enforced. Abortion is legal in

Brazil in only two instances-in cases of rape or when the life of the mother is threatened. While this may be the written law, women who seek legal abortions must fight their way through the red tape to acquire one. The cultural norms have not changed to meet the standard the law has set. Therefore, women who are eligible for legal abortions often are turned away and carry the fetus to term against their wishes. Women do not know the laws well enough to know when their rights are being violated.

Emma Sokoloff-Rubin, a Yale University student, wrote about her recent research on abortion in Northeastern Brazil for *The Nation*. Sokoloff-Rubin performed a case study of a young woman, Adriana, who had been raped by a gang member and sought an abortion. Sokoloff-Rubin chronicled Adriana's struggle and eventual denial. Adriana was turned away from the hospital when she sought an abortion because they claimed the pregnancy was too far along. Legally, Adriana was still eligible at that time to receive an abortion. She was at 19 weeks gestation and the law states a woman needs to be 22 weeks or less to receive an abortion. The hospital required documentation of the rape and the pregnancy (Sokoloff-Rubin, 2009). By the time Adriana obtained the proper paperwork, the hospital claimed that the fetus was too large to abort. Adriana made five trips to the hospital and five trips to the police station and worked with a women's support organization, but was still denied her right to an abortion. She carried the unwanted fetus to term and delivered the baby of her rapist.

Women are vulnerable to the machismo culture of Brazil and their legal and human rights are sometimes denied. Between 1 and 2 million Brazilian women seek illegal abortions every year in Brazil and many end up in the hospital with complications (Sokoloff-Rubin, 2009). In a society where men set the standard and women are

marginalized and gender inequalities prevail, women are forced to bend to the will of men. An uneducated public and poorly enforced laws prevent women from legally obtaining abortions in the case of rape and a threat to their lives.

Illegal abortions are prevalent and unsafe abortion attempts are the third largest cause of maternal death (Guilhem & Azevedo, 2007). Reproductive health needs to be conceived of as a human rights issue. Sixty-five percent of Brazilian women are in their reproductive years (between 10 and 49) and feel the combined affect of social inequality as represented through economic indicators, morbidity, mortality, rates of sexually transmitted diseases, race and gender discrimination, along with violence (Guilhem & Azevedo).

Public policies towards women's rights and sexual and reproductive health are inherently entangled in social inequalities faced by Brazilian women. Women suffer significantly as a result of social inequality; a fact which is made clear through women's unequal pay, higher morbidity and mortality rate, violence against women, and rates of cervical and breast cancer. Sexual and reproductive rights are part of human dignity issues and in order for women to exercise their human rights, they must be viewed as autonomous individuals.

Researchers Dirce Guilhem and Anamaria Ferreira Azevedo delved into the issue of public policies regarding women's reproductive and sexual health in their study, "Brazilian Public Policies for Reproductive Health" (2007) in which they discussed the lack of implementation of otherwise progressive ideas. They performed an in-depth analysis of the public policies in place in Brazil and conducted interviews with health officials. They looked at family planning, the perinatal period, and abortion.

The results of their study show that while family planning is advocated for, most places do not offer contraceptives other than the Pill or condoms. Also, family planning services are not readily available and many people are unaware of policies and their rights regarding family planning. Funding is not made available where it should be and doctors' attitudes do not promote autonomy for couples seeking their help with family planning (Guilhem & Azevedo, 2007). In terms of abortion, the results of this study show that, while abortion is a crime in most cases, about 1.4 million women have abortions in Brazil each year. About 300,000 of these women experience complications that require them to be hospitalized and their care paid for by government programs. An estimated 31% of pregnancies in Brazil end in abortion (Guilhem & Azevedo). In the legal cases of abortion, where rape occurred or the mother's life is on the line, some professionals cite conscientious objection and claim that their moral or religious beliefs prevent them from performing abortions. Women are forced into unsafe abortions by the restrictive abortion laws in their nation. The implementation of legal abortions is quite difficult and this represents an infringement of women's legal and human rights. Finally, the results show that prenatal care greatly affects maternal morbidity and that it is positively correlated with socioeconomic status. Brazil has made strides to help reduce the maternal mortality rate. However, how well implemented these plans are is questionable due to the fact that the majority of maternal deaths are directly related to obstetric care. National and international standards are already outlined to prevent these kinds of deaths (Guilhem & Azevedo).

Family planning, abortion laws, and prenatal care all affect disability rates. Many disabilities, especially those found in Brazil, are preventable with education and quality

prenatal care. Through family planning, women over a certain age, who are at higher risk for bearing children with developmental disabilities, can prevent pregnancy if they so wish. If women had the right to abort a pregnancy due to severe anomalies in the fetus, perhaps the shame of having a child with disabilities would be less because the women exercised a right to choose to keep the fetus. Women's reproductive and sexual health are intimately intertwined with their social status. When women suffer fewer social inequalities, they will also experience improved sexual and reproductive health.

Genetic counseling is not common in Brazil. This is probably due to the illegal status of abortion. Genetic counseling is therefore limited to preparing parents and medical personnel for the birth of a malformed child and for the prevention of future anomalous fetuses (Correa & Guilam, 2007). The later is done through autopsying the fetus. Because abortion is illegal, genetic counselors often do not bring up the possibility of terminating the pregnancy except for in extremely anomalous fetuses where a court order could be obtained allowing for an abortion. Cases of anencephaly-where large parts of the brain or skull are absent-or other conditions where the fetus could not live outside of the womb and therefore not experience human life are sometimes granted exceptions to the abortion law. Therefore, genetic counselors need to determine in which cases a court appeal should be suggested to parents.

Marilena C.D.V Correa and Maria Cristina R. Guilam performed a case study at a large public hospital in Rio de Janeiro, Brazil studying the genetic counseling offered there. It is one of only three hospitals throughout Brazil that offer genetic counseling. They found that geneticists and doctors offer information in a quantitative form while parents' seek qualitative answers to questions such as "will he/she walk?" and "will

he/she attend school?"(Correa & Guilam, 2007). Parents seek answers about the quality of life of their future child and the hospital staff provides information about risks and biomedical explanations that are incongruent with the parents concerns.

A contradictory problem exists in genetic counseling in Brazil. Women are provided with as much information as possible but their choices as to what to do with that information are limited. Women's autonomy cannot be granted while the law forces women to carry non-viable fetuses to term. Women's human rights and psychological welfare are violated when courts deny their appeals for termination of pregnancies of fetuses that, with certainty, cannot survive outside of the womb. Another discrepancy exists in genetic counseling. The parents' concerns differ from the doctors' and geneticists', but the latter have a position of power and prestige over the parents in many cases. Genetic counseling has a long way to go in Brazil and cannot ever reach its true potential while abortion is eliminated as an option for most women.

Genetic inbreeding allows recessive traits to appear in the phenotype of offspring. When parents share genetic traits and therefore variability is reduced, their offspring have an increased likelihood of experiencing negative consequences of recessive traits.

Eight researchers conducted a study in a Muslim Arab Israeli town of about 10,500 inhabitants known to have high rates of mental retardation and genetic inbreeding (Basal-Vanagaite, et al., 2007). About twenty clans make up the population of this town. Married couples, both of whom were born in the town, were asked to participate in this study to do genetic screening for the G408fsX437 mutation in the CC2D1A gene that is known to lead to mental retardation. Carrier couples were provided with free genetic counseling and free prenatal testing (Basal-Vanagaite et al., 2007).

Out of the 540 people involved in this study, 28% of the marriages had genetic inbreeding with 58% (or 16.5 % of the total number of participants) being first cousins. In total, 524 women received genetic testing and 14 of their husbands were tested as well. Out of the 14 total couples tested, eight were carriers of the gene mutation. Out of these eight carrier couples, six (75%) had children with developmental disabilities (Basal-Vanagaite et al., 2007).

The researchers concluded that the high rates of mental retardation in this village can be accounted for by genetic inbreeding. The lack of variety in the gene pool causes recessive genes to manifest themselves in the phenotype of offspring. Another cause is that two families that have high rates of mental retardation are scorned by the rest of the town as unsuitable marriage partners. Therefore, these families must intermarry and risk even higher rates of mental retardation in future generations.

This study provided the participants with genetic screening, genetic counseling, and prenatal testing in order to help alleviate the problem of high rates of mental retardation in the town. The attitudes and perceptions of disability were not discussed, but the town's scorn for the two families with the highest rates of disability suggest a stigma against it. It is suggested that a reduction in the rate of disability could alleviate the strain on the community to care for these individuals, but this seems to assume that the disabled are in fact a great burden. Without a qualitative follow up on the attitudes and perceptions, as well as caregiving for people with disabilities, the researchers cannot know how burdensome or not people with disabilities are perceived to be. Perhaps because of the high rates of disability, it is more accepted.

This study offers insight into the relationship between isolated populations leading to genetic inbreeding and the rate of disability. While the study has limitations, it does offer solutions if they are sought to prevent these high rates of disability through science and knowledge. This study seems to tow the ethical line and is reminiscent of the eugenic euphoria of the early twentieth century.

Genetic inbreeding can lead to severe genetic abnormalities that do not necessarily fit the etiology of any one disease process. The genetic conditions and their manifestation in an individual due to inbreeding can be quite puzzling to scientists and do not always align with any other instances of genetic abnormalities. Variety is most often sought in a reproductive partner so that the offspring have a larger gene pool to select from and should therefore be healthier and more likely to survive.

The case study of a Brazilian family performed by Gilberto de Limas and Maria de Graca Martino Roth (2007) focused on four siblings (two males and two females) born to genetically related parents who all presented with very similar conditions including severe mental retardation, coarse facial characteristics, small stature, lack of speech, small hands and feet, strabismus, hirsutism, and a quadrupedal gait. Strabismus is more commonly known as cross-eyed and hirsutism is a condition where women have male-pattern hair growth. Someone with a quadrupedal gait walks on all fours using both hands and feet. The parents of these patients are first cousins but the mother had another child from a relationship without genetic inbreeding who has no genetic abnormalities. All four of the children with genetic problems were born vaginally and appeared to have no issues until they reached the age when they should be crawling and failed to do so.

Not all of their symptoms could be categorized together as belonging to the same genetic abnormality process. It is interesting to note that all four presented with such similar symptoms. It was believed that the siblings had Coffin-Lowry syndrome, a form of mental disability, which accounts for their coarse facial features, small stature, and bone alterations but does not account for the quadrupedal gait. Several of the main symptoms of Coffin-Lowry syndrome such as tapering digits and degenerative issues in the vertebrae were not exhibited by the siblings (Garcias & Roth, 2007).

This study is quite interesting because the Brazilian participants in the research done for this thesis discussed how some of the students there presented with many symptoms with no apparent correlation. This research suggests that if a child is the offspring of genetic inbreeding, the child's genetic conditions cannot be neatly categorized into specific processes. Cultures with higher levels of genetic inbreeding are going to see more complex genetic problems that do not fit with well any single genetic anomaly.

Chapter Summary

There has been an abundance of research on disability in the last two decades. Seminal pieces such as Erving Goffman's "Stigma: Notes on the Management of Spoiled Identity" (1963) set the tone for understanding disability as more than a biological problem. The social side of disability includes the stigmatization and marginalization that people with disabilities face. Disability can even be caused by societal rules, norms, and laws. The research shows that genetic inbreeding and environmental toxins affect the

prevalence of disability. Abortion laws also affect disability because they limit women's right to choose to carry fetuses to term. When abortion is illegal, women seek illicit means to terminate pregnancies and failed attempts can lead to disabled children.

The way a culture perceives disability, and therefore how they treat the people with disabilities, is dependent upon their cultural norms and values which are formed through unique historical contexts. The eugenics' movements that swept the world in the twentieth century have greatly affected the lives of people with disabilities to this day. The different trajectories of these eugenic movements in different countries color modern day perceptions of difference. The creation of statistics by eugenicists in the twentieth century allowed for discriminatory beliefs to negate the personhood of the disabled and force sterilization, and sometimes death, upon them in the United States and Europe. Examining the historical contexts of the perceptions of people with disabilities shows that Brazil is not simply following the same path as the United States. Brazil has followed its own trajectory in terms of dealing with and understanding disability. The articles discussed in this literature review exemplify some of the main concepts and issues in the field of cross-cultural disability studies. People with disabilities are not a homogeneous group and the problems faced by them vary cross culturally. This seminal and current literature helped set the stage for this research project and enhanced the researcher's understanding of the data collected. The unique themes and issues that emerged from the data required a more extensive literature review than had previously been done because the researcher relied on inductive reasoning and let the data from observations and interviews guide the research.

This research project contributes to social scientific knowledge of disability by analyzing two comparative case studies that illuminate many of the key concepts discussed above including genetics, environmental causes of disability, social perceptions and stigmas, cross cultural definitions of disability, and gender roles. This research contributes to a larger dialogue aimed at improving understanding of disability in different contexts in order to provide appropriate and adequate care that allows people with disabilities to be limited as little as possible in their lives. People with disabilities are only as limited as their society allows them to be, and understanding the causes and perceptions of disability helps to bring the disabled to the forefront of political and moral concerns.

Chapter Three: Methodology

Introduction

This qualitative case study describes the affect of culture on perceptions and attitudes towards people living with disabilities. In this instance, the researcher employed E.B. Tylor's 1871 definition of culture as, "that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society" (Tylor 1924 [orig. 1871]:1) The hypothesis that perceptions of disability are directly influenced by culture was tested through case studies in a large midwestern American city and a small northeastern Brazilian city. The study began with an extensive literature review and then utilized participant observation and interviews. Narrative data on the definition of disability and attitudes surrounding it were collected and the data were transcribed, coded, and divided into categories based on the research questions.

The research questions of this study included the following:

- 1) How does the culture people live in affect their experience of disability?
- 2) What aspects of culture affect people with disabilities and the perception of the public about disabilities?
- 3) How can information about the social dimension of disability be used to enhance the lives of people living with disabilities?

Setting

Description of the Regions

The researcher performed fieldwork in a school for people with intellectual and physical disabilities in Santarém, Pará, Brazil and at a residential facility for people with

developmental disabilities in Chicago, Illinois, U.S.A. The following is a description of the regions in general and of the fieldwork sites specifically.

Santarém is a city in the state of Pará in Northeastern Brazil. It sits at two degrees South latitude and 54 degrees West latitude in the Amazon, at the meeting point of the Tapajós River and the Amazon River (SEMPLAN, 2008). The climate is tropical, characterized by hot and humid conditions. The average temperatures range from about 25-28 °C (75-82.4 ° F). During the rainy season from about December to May, an average of 170-300 millimeters (6.7-11.8 inches) of rain falls each month (SEMPLAN). During the dry season, from June to November, an average of only 60 millimeters (2.4 inches) of rain fall in a month. The terrain, in part due to the presence of the Amazon Plain in Pará, is at times subjected to the flooding of the Amazon River (SEMPLAN).

The urban portion of Santarém consists of about 47 square miles, with an additional 14,000 square miles including the rural areas that surround the city. According to the 2007 census, the combined population of the rural and urban areas of Santarém consisted of 274,285 people (SEMPLAN). As anyone who travels to the region knows, Santarém is quite isolated. Santarém is nestled in the lower Amazon and surrounded by dense rain forest. The nearest large cities are Manaus to the West and Belém to the East. These cities can be reached via a one hour flight either way, or a two day boat trip down the river. A very rough and difficult road exists between Santarém and Manaus, but generally only large trucks are capable of maneuvering the terrain (Prefeitura de Santarém, 2008).

Chicago is a large midwestern city with a population of over 2.8 million people according to the U.S. Census Bureau of 2008. It is an urban area covering 227 square

miles of the northeastern part of the state of Illinois, bordering Lake Michigan. Illinois is a plain with a continental climate. The average temperatures range from 21.3° F in January to 73.4° F in July. There is an average of 35.82 inches of rainfall each year (City-Data.com, 2008).

The settings of the two institutions that served as the basis for this research are quite different. Environmental determinists of the past argued that people from similar environments have evolved over the course of many generations in similar ways under similar constraints. Following this antiquated line of reasoning, people from Santarém would have a very different culture than those from Chicago due to the environment. Anthropologists such as Alfred Kroeber have been attacking this line of thought for many years and it has now lost all credibility. However, the stark contrast between the two fieldwork sites is still worthy of note because although culture may not be a product of the environment, lifestyle and accessibility are certainly affected by the extreme climate in Santarém. The dense rainforest surrounding the city will be a major factor in this study on disability, a point that will be further developed in a later chapter.

At this point it is essential that the reader understand that the region of Brazil discussed in this research is not representative of Brazil in general. There are vast economic, developmental, and cultural differences that exist throughout Brazil. While the United States is considered a developed nation, Brazil is still ranked as a *developing* nation and Santarém is less developed than the larger cities of Brazil such as Rio de Janeiro or São Paulo. This comparison cannot be generalized to include all of Brazil. The experiences of people living with disabilities in São Paulo as compared to Santarém could be as varied as the experiences between Chicago and Santarém or Chicago and

somewhere like Greencastle, Indiana. This study compared the difference between a developed and a developing cultural setting.

Description of Fieldwork Sites

Fieldwork took place at a residential facility in Chicago, Illinois, U.S.A for people of all ages with developmental disabilities. It serves about 550 people. This site is a Catholic organization with a mission to support the disabled by giving them as much independence as possible in a place enhancing the quality of their life through personal dignity, respect, and work ethic. They offer residential placement, daily care, job training, physical therapy, speech therapy, occupational therapy, health and fitness guidance, and spirituality to their residents. This institution attempts to raise community awareness, to educate the public on issues of disability, and to advocate for better lives for those with disabilities. This institution also provides recreational activities such as sports, psychological support, a spiritual life, and much more. It is one of the premier institutions of its kind and researchers from all over the world are interested in this facility. The large majority of the residents are from Chicago and the surrounding areas, better enabling families to frequently visit and remain a part of their loved one's life.

The second fieldwork location, in Santarém, Pará, Brazil, is a school for people with disabilities. This institution was founded to provide better health, education, and overall welfare for those living with disabilities. This school promotes prevention, rehabilitation, and education for people with mental disabilities who may also have physical disabilities. They offer physical therapy, speech therapy, counseling, support, and an education for people with disabilities. The administration strives to teach people

their rights and to push for the enforcement of protective laws. The school serves about 300 people total, with 264 students. The ages range from infants to 40 years old. A person must have a mental disability to receive help from this institution. Many people travel great distances to come to this school because it is the only institution of its kind in the region. People who are provided with services other than schooling that live a long distance away travel to Santarém for one week of every month. Usually mothers travel with their child with a disability. The means of travel is often by boat. Mothers and their children will take a bus ride to the river if they live in the interior, and then take a boat ride down the Amazon River or up the Tapajós River to Santarém. These boats are often small and the average time spent on the boat was between six and twelve hours. Some of the cities served by this institution include Obidos, Oriximina, Juruti, Alenquer, and Itaituba, as well as their surrounding areas.

Sample/Participants

The fieldwork sites were selected based on accessibility and rapport. The researcher had previous contact and volunteer experience at both locations that enabled her to gain access for fieldwork. The researcher used a non-random sample. Individual participants were selected from the broader population based on their connection to these two fieldwork sites. The researcher used a purposive sample in which individuals are selected because they meet the criteria to be considered representative of a certain population. The participants in this study were all people who worked with and for people with disabilities, either providing health care or working at the administrative level. Therefore, they were people who represented the best interests of people with

disabilities in both countries and had insiders' knowledge into the conditions of life for people with disabilities. Most of the participants have been involved with people with disabilities for several decades with only a few exceptions. Both fieldwork sites had many employees so the researcher used a convenience sample to select interview participants. The researcher chose to interview people who were willing and accessible during the duration of her fieldwork at each site. The researcher also tried to gain access to a variety of employees in both locations. This included medical personnel as well as administrators.

The researcher also interviewed four participants who were not employed by either fieldwork site. One of these participants was an American physical therapist who has volunteered at the Santarém fieldwork site on six different occasions for the last 25 years. He was the chief of physical therapy at the Rehabilitation Institute of Chicago. Another unaffiliated interviewee was an American orthopedic surgeon who has volunteered his services to the local hospitals and clinics in Santarém over the last 25 years.

A Brazilian oncology surgeon was also interviewed. He was selected through convenience. Finally, a Brazilian professional woman was interviewed as well since she worked as the interpreter and her family has been highly involved in the health care and administrative care of people with disabilities throughout her life.

All of the interview participants for this study were over the age of eighteen and all but one worked either in the health care or administrative care of people with disabilities. In total, fifteen people were interviewed, six (40%) of these interviewees were male and nine (60%) were female. The following is a list of the titles of each

interview participant and an indication of their sex marked with an (M) for male and an (F) for female and their country of expertise delineated by a (B) for Brazil, a (US) for the United States and (B/US) for those with knowledge in both regions:

- Physical Therapist (M) (B/US)
- Physical Therapist (F) (B)
- Physical Therapist (F) (B)
- Orthopedic Surgeon (M) (B/US)
- Oncology Surgeon (M) (B)
- Director of the Center of Education and Professor of Clinical Psychology (F) (B)
- Director of Fundraising, Director of Marketing (F) (B)
- Businesswoman (F) (B/US)
- Administrative Assistant at U.S. residential facility (F) (US)
- Nurse and Relief Supervisor “Q” (F) (US)
- 3rd Shift Relief Supervisor (F) (US)
- Intern- Therapeutic Recreational Therapy in the Recreation and Leisure Department (M) (US)
- Instructor of Theater and the Heartbreakers (M) (US)
- Direct Support Person working with children (F) (US)
- Recreation and Leisure Instructor (M) (US)

Measurement Instruments

Description of Instruments

- 1) Semi-structured Interviews
- 2) Participant Observation

Semi-structured interviews

Interview questions and topics were submitted to the Institutional Review Board for approval prior to the commencement of research. Due to the nature of the study, semi-

structured interviews were conducted to avoid limiting participants to narrowly defined questions with limited ways to respond. The questions were open ended and open to interpretation by the participant. The interview questions were formed based on the literature review and overall research questions. (A copy of the interview questions can be found in Appendix D.1 English and D.2 in Portuguese). Because the research was qualitative and the researcher used the grounded theory method, hypotheses were deduced *from* the data rather than the data testing pre-formed hypotheses. The study began without clear hypotheses to test; the data formed the hypotheses. Questions were designed in a way to avoid leading the participants to certain answers.

Interview participants were selected based on the criteria described above and presented with a consent form explaining the purpose of the study, risks and benefits, procedure of the interview, the confidential and voluntary nature of their participation, and the contact information for the principal and secondary investigators. (A copy of the consent form is available in Appendix B.1 for American participants and B.2 for Brazilian participants.) Participants read and signed the form authorizing their consent to participate and have their answers used in this study.

The interviews were administered in a casual, conversational manner to ensure the comfort of the interviewees. This strategy was effective at putting interviewers at ease and ultimately allowed them to share more without fear of providing “wrong” answers. The interviewer began each interview by asking about the job position held by the person and the number of years he/she have worked in the field and his/her motivation for entering this particular field. After collecting this preliminary information, the interviewer moved on to the interview questions focused on disability.

The interview question format was designed to start out with less difficult questions that eased into the more difficult ones. The interview consisted of twenty-two official questions but, as necessary and appropriate, they were adjusted. The additional questions were for clarity or for further explanation on a topic the interviewee brought up that was not necessarily part of the interview format. None of these additional questions were of a personal nature. Every interview opened with the question “How do you define disability?”. The researcher explained that she was familiar with the textbook and legal definitions of this word, but would like the informant’s personal definition. The next question, for those affiliated with one of the two fieldwork sites, asked “What are the goals of your institution?”. This question was followed by a series of questions designed to understand the participants’ feelings on attitudes and perceptions in their culture about people with disabilities. These focused on the behavior of the non-disabled towards people with disabilities as well as stigmas and myths.

The next series of questions dealt with the expectations for people living with disabilities and their role within society as active or marginalized citizens. The researcher also sought information regarding how well equipped public spaces were for people with disabilities to access. After this series, the next set of questions sought answers regarding care for people with disabilities and whether this occurred on the familial or professional level.

The final set of questions focused on parents’ reactions to learning their child had a disability as well as perceived causes and justifications for disability. The researcher also sought a definition of personhood in the participants’ society, a question that proved quite difficult for many to answer. This section also introduced the topic of religion.

Two important questions dealt with aging among people with disabilities and the difference between the experience of men versus women living with disabilities. These questions were important to include because age and gender are two defining characteristics of any person's identity and these impact almost all aspects of human life.

The interview portion of this study was designed to measure the perception and attitudes that are culturally specific regarding disability in both of the fieldwork regions. By interviewing people with an expertise and experience working with people with disabilities, the researcher was able to gain expert opinion on how people in that culture regard disability and those living with impairments.

Participant Observation

The researcher carried a notebook at all times to record as many details as possible on the surroundings and the interactions of people. The 'participant' aspect involved volunteering at the Chicago location during 'Camp Week' and volunteering as a physical therapy aide in Brazil. The researcher had previous experience as an aide.

An important component of the observations at the Santarém fieldwork site was the presence of mothers. Most of the children brought to physical therapy were brought by their mothers and they formed their own kind of support group. Therefore, the interactions between the mothers and their children were noted as well as the interaction between mothers and employees, but especially the interactions among the mothers. The researcher took note of the signs and bulletins posted around the fieldwork site. At both sites the researcher reflected and provided commentary on the observations. This way the researcher was able to recall her state of mind and own biases when the notes are reviewed at a later point.

A major limitation for the researcher doing participant observation was the language barrier. The researcher has an intermediate comprehension of Brazilian Portuguese, and found conversations difficult to follow that were not directed at her. The mothers at the Brazilians institution were aware that the researcher spoke some Portuguese and seemed shy about speaking in front of her. The natural flow of conversation may have been altered by the researcher's presence. Therefore, many of the observations focused on actions rather than words.

Validity and Reliability-Trustworthiness

According to Yvonne N. Bui (2008), the validity of research is determined by how well the measurement instruments measure what they are intended to measure, while the reliability of research is determined by how consistently the measurement instruments measure what they are intended to measure. Validity and reliability are determined in a different way in qualitative data than in quantitative data due to the nature of the data collected. Qualitative data is non-numerical, and therefore mathematical formulas cannot be effectively used to determine validity or reliability. However, these are still very important in order for the research to be replicated and trusted by other researchers and readers. In order to ensure both validity and reliability, the researcher in this study took detailed records and employed multiple methods of data collection to measure the same thing. In this case, the researcher employed both participant observation and interviews in order to answer the same research questions. This worked as a sort of check and balance system within the research. The researcher observed phenomena and then interviewed participants about the same phenomena. The goal was not only to combine the data from

both measurement instruments, but also to compare and contrast for validity and reliability of results. If the data from both measurement instruments were conflicting, the researcher's data would not be valid or reliable.

Participant observation is based on the rapport of the anthropologist and the research subjects. The researcher attempts to avoid affecting the behaviors and interactions of the people studied. The subjects grew accustomed to the researcher's presence. This reduces what H. Russell Bernard (2002) refers to as "reactivity." Participants do not change themselves because they know they are being watched and recorded when they are accustomed to the researcher's presence. The less reactive the research participants, the more valid are the data.

Data Collection/Procedures

The first measurement instrument was interviews. All interviews were conducted in a private setting where others were not able to overhear the responses of the interviewee. The interviewer sought written permission from the interviewees to audio-record the entire interview to transcribe and code later. The interviewer also took notes as the interviewee responded to questions. The duration of the interviews was dependent on the participant. The average time of interviews was about one hour with the shortest lasting only about 30 minutes and the longest lasting two hours. The translator was present for all interviews where the Brazilian participant did not speak any English.

The second measurement instrument was participant observation. The purpose of the observations was to collect data on how the fieldwork institutions went about achieving their goals and missions. During observations the researcher tried to be as

attentive to as many details and actions as possible. Humans have taught themselves to be selective in what they pay attention to in every day life because they cannot pay attention to everything all at once. The researcher attempted to employ Clifford Geertz' method of thick description where the observer records more than the simple actions of humans. The observer also records the *context* of the behavior or action. Geertz simplified this theory with the example of winking. If one only described the action of a "wink" the only information would be that someone rapidly closed one eyelid while the deeper meaning of perhaps flirtation or deception that often accompanies a wink would have been missed (Geertz, 1973). The researcher kept a fieldwork journal on her at all times and recorded grand tour observations as well as mini-tour observations (Bernard, 2002). Grand tour observations included the general setting and events that were being observed which includes where the events are happening, who is involved, what is happening, what emotions or feelings were involved, etc. Mini tour observations deal with smaller scale observations that go into greater detail about the same parts of an event listed above. The researcher used two of the four types of fieldwork notes- jotting and a diary (Bernard). Jottings were recorded in an omnipresent journal and were the facts of a situation to aid memory. At a later time, away from the immediate setting, the researcher recorded more personal facts as well as went into greater detail about the jottings. The researcher tried to write these diary-type entries each night to avoid a changed perception or foggy memory that comes with a night's sleep.

The researcher performed observations at the Chicago location for two consecutive weeks between July 19, 2010 and August 1, 2010. Observation totaled 48.5 hours with observation periods lasting between 2.5 hours and seven hours at a time with

an average length of 4.4 hours. The researcher observed and recorded in a private notebook all significant details and her own reactions in order to identify her biases. The researcher took note on the lifestyles and activities as well as the interactions between staff members, between residents, and between residents and the staff. The researcher took detailed notes on the resources available at this institution and the lay-out designed to maximize the potential of the residents and to make life as easy as possible for them. The researcher was able to observe physical therapy, the wheelchair clinic, theater practice, social activities in the arts and crafts room, the operation of the bakery, the residents at work in the laundry facilities, as well as tour the institution's different buildings designed to care for different types and degrees of disability. During the first week of observations, the researcher observed a performance by the dance group from this institution at the Americans with Disabilities Act 20th Anniversary Celebration in downtown Chicago. The researcher took note of all the celebratory activities and informational booths at this event.

Observations took place at the Santarém site between August 23, 2010 and September 3, 2010. The researcher planned to be at this location for "Semana Nacional da Pessoa com Deficiencia Intelectual e Multipla" (The National Week of People with Intellectual and Multiple Disabilities). The researcher observed at this school between the hours of 8 a.m. and 11 a.m. and again from 2 p.m. until 5 p.m. Monday through Friday for two consecutive weeks. These hours were selected because these are the hours of operation for the institution and the only times that students are present. Between the hours of 11 a.m. and 2 p.m., all students return home for long lunches, showers, and naps. Therefore, the researcher performed a total of 60 hours of observations at this location.

This amount of time is about 25% more than the time spent at the American location. This time discrepancy is due to the fact that the researcher had greater prior experience with disability in the United States and more time was needed to gain an equal understanding of disability in Brazil. The researcher observed a ceremony celebrating the *Semana Nacional da Pessoa com Deficiencia Intelectual e Multipla* which included several performances by students as well as speeches by members of the board of the institution. The performance included two groups of dancers. A mother and her daughter, a wheelchair bound student at this institution, performed a ballet dance together with the mother maneuvering the daughter's body.

The researcher toured the facility and observed the lunchroom, the recreational gymnasium, the arts and crafts room, classrooms, a playroom, the physical therapy room, several kitchens, a cafeteria, a wheelchair room, a woodworking room, and a room where prosthetic limbs were made. The researcher spent a majority of her time observing the physical therapy department where mothers brought their children twice a week for care. The ages of people receiving treatment ranged from one year of age to 16 years old. The average and modal age were both three years old. The researcher again observed the interactions of the employees with the students and people receiving care.

Both in Chicago and in Santarém the researcher engaged as a *participant* observer. At the Chicago location the researcher was involved with what the institution referred to as "Camp Week." This is an annual event every year during the week when most residents leave the facility to return home with their families or go on a vacation with their families. The residents that are not able to go home or on a trip remain at the facility and are treated to a variety of leisure and recreation activities throughout the

week. Of the approximately 600 residents, about 150 remained on campus. The researcher was directly involved in carrying out the activities this week. The researcher aided residents in tie-dyeing scarves, helped set up and supervise a circus themed dance, played 'boardwalk games' with the residents such as bean bag toss, and did arts and crafts projects. The facility was greatly in need of volunteers for this week and the researcher was able to give something back to the institution by participating in these activities. The researcher's presence did not disrupt the participant's or residents' normal, daily activities.

In Santarém, the researcher also practiced participant observation by working directly with the children receiving physical therapy. The researcher acted as an interpreter between English and Brazilian Portuguese speakers in the physical therapy room and assisted the physical therapists. The researcher had previous experience working as a physical therapy aide in the United States.

The researcher's presence altered the regular activity of the physical therapy department of the school. The parents of the children at the school were aware that Americans were on campus and wanted their children to be seen by the Americans. Therefore, parents whose children do not normally receive physical therapy requested they be seen by the Americans. The administration denied these requests at the recommendation of the physical therapists employed there.

Data Analysis

The data collected from interviews and participant observation were in narrative form. The analysis of the interviews began with transcribing them from the audio-

recordings for accuracy and completeness. Specific interview questions were then matched to specific research questions. The researcher went through 96 pages of transcribed interviews and selected the data relevant to the research questions. This reduced the data to 52 pages with the remaining 44 pages of data saved for use in later research. Grounded theory text analysis was employed to expose major themes and ideas. After reading through the data, the researcher coded them into ten categories using a color scheme, boldfacing, underlining and italics. Each category was assigned a color and some were made bold-faced, underlined, or italicized to distinguish between codes. This technique of visual changes to the text was employed because the researcher believed it made it abundantly clear just upon looking at the data what categories related to specific questions during the interviews. The ten categories were as follows: (1) the notion that people with disabilities are still 'people'; (2) expression of shame, denial, or blaming for a person's disability; (3) legal rights and equality for people with disabilities; (4) the desire for people with disabilities to have 'full participation' in society; (5) the difference between mental disability and mentally ill; (6) normalizing disability and the current lack of education and exposure to it; (7) the role of money and funding; (8) the male role and machismo attitude; (9) the belief that people with disabilities are a "gift" and have hidden abilities and; (10) an appeal against pitying people with disabilities. Once the data were divided into significant categories, the themes of the data were more evident. The researcher used memoing, which is the act of going through the data and adding notes and thoughts as they come during reading (Bernard, 2002). Verbatim exemplar quotations from the interviews that highlighted these themes were then chosen.

Analyzing two notebooks full of participant observation field notes began with an ocular scan. The researcher read through the notes several times before marking anything in them to get a feel for emerging categories and themes. The researcher then coded the data in the same way that the interview transcriptions were coded with a visual technique making the relationship between specific categories and observational settings or times clear. The ten coded categories were again connected into larger themes and memoing helped create a theoretical analysis.

Chapter Four: Results

Introduction

The researcher analyzed the data through a social constructivist theoretical framework and the belief that although disability undeniably is a biomedical construct it is also, to an extent, a social construct. The researcher hypothesized that the society in which a person with a disability lives defines the term and the way the public perceives people with disabilities. The ways that people with disabilities are perceived and in turn perceive themselves are specific to their particular culture. The culture or society that a person lives in determines whether or not they are considered to have a disability and to what degree their disability limits their full functioning within society. In order to progress our understanding of disability we need to comprehend how culture and the particular society in which a person lives affects their impairment. Two people with the same diagnosis living in different cultures can have very different experiences.

The results of the study that follows are presented in two ways. In the first section, the results of interview questions and key observations are discussed in detail. The second section discusses emergent themes from the data that pertain to the research questions. All of these themes are culturally dependent and illustrate the ways in which disability is socially bound. The idea that people with disabilities are “still people, just like you or me” is culture dependent, because what makes a person a person varies cross culturally. For example, among the Kenya Maasai, to be considered a person, one must live communally, marry, and have children. Aud Talle, author of “A Child is a Child: Disability and Inequality among the Kenya Maasai,” explained, “Being ‘human’ - being a

person (*oltungani*) - among the Maasai is to live communally with other people (i.e. be “social”) in extended residence groups where sharing, generosity, and cooperation are virtues of highest degree... In order to live a full life as a Maasai it is imperative to marry and beget children. Maasai elders who have been blessed (“lucky”) by old age and high fertility in children and animals embody the image of the good life (*enkishon*)” (Talle, 1995). In the abortion controversy, people debate whether or not a fetus constitutes a life. The theme of “full participation” in life depends on culture, because cultures define what they mean by “full participation.” A typical American might describe a “full” life as someone having a family, children, a good job, a nice house, a car, and annual vacations. A person living in Santarém could hold a very different opinion of a full life. “A full life” is culturally relative.

This is a short summary of the themes found in the data which will be elaborated on in the next sections. There are many instances where social beliefs and norms make life more difficult for people with disabilities. This is the case when people with mental disabilities are wrongfully mistaken for being mentally ill and stigmatized as a result. This is an example of social beliefs creating more barriers through stigmatization and the public’s lack of education. The next theme, funding, is not biological in any way. Money is entirely a creation of culture. Politicians decide how best to allocate money, and unfortunately, people with disabilities are not typically high priority when it comes to funds. Next, the cultural phenomenon in Santarém of machismo and the role of males consistently emerged as a theme explaining the lack of male presence not only at the fieldwork institution, but in the lives of children with disabilities at large. While sex roles are more biologically determined, gender roles vary cross culturally. In some places

women have much more power and authority in relation to men than in other parts of the world. In Santarém, the male role is still heavily dominant. The final themes, which include a plea not to pity the disabled as well as a plea for increased exposure and education about disabilities can also be tied to culture. If the public were well educated and more frequently exposed to disabilities, people with disabilities would not be as stigmatized and marginalized because they would be more mainstreamed. Discomfort and fear of the unknown is a human universal; if this fear and discomfort could be alleviated, people with disabilities would feel less adverse affects. Because people are not familiar with disabilities, there is a tendency to pity the ‘poor dears’ rather than recognize their abilities and see them as a gift. When a society does not understand disabilities and pities people with disabilities rather than advocates for and accepts them, living with a disability is made more difficult.

Interview and Observation Results

Defining Disability

The term ‘disability’ has many different definitions that vary across cultures and through time. Legal definitions and medical definitions of the term exist, but for the purpose of this study, the researcher wanted to know exactly how the participants defined the term. This was important to do at the onset of the interview because throughout the interview the researcher would be asking questions about disability and it was imperative that the researcher knew what the participant meant by the term. A common answer at both research sites was that disability is something that everyone deals with on some level. Participants in Brazil and America both seemed to think that everyone has a

disability to a degree, and some people simply have greater needs or more visible disabilities.

American participants defined disability primarily as a 'difference' that prevents a person from fully participating in life without the assistance of others or technology. In Brazil, the answers also described 'differences' that led to difficulty performing a task. In both places, participants recognized that disability is a social problem.

Institutional Goals

The researcher asked all interview participants about the goals of the fieldwork institutions. After coding the data using a color system, it was overwhelmingly clear that many of the answers for this question centered around providing a full life, or full participation in life, and also about the legal aspects of law and equality. In the United States, the goal repeatedly expressed was to provide people living with disabilities with a fulfilling life where they reach their full potential and have a high quality of life. Participants described reaching maximum potential and as much independence as possible, based on the limitations of their disability. Others included living with dignity, providing normality, and providing an enjoyable life with self expression.

The Brazilian respondents working in the administrative realm of disability said their number one goal was to fight for equality and legal rights for people with disabilities, as well as to inform them and their families of those rights to help them utilize them to the best of their abilities. The physical therapists at the Brazilian institution both stated that the number one goal was to get children to walk and talk. One

therapist explained that she also wanted them to reach maximum potential and have a good quality of life, but that the mothers pushed walking and talking as goals.

The issue of walking and talking was apparent through observations as well. Mothers, rather than fathers or other family members, primarily brought their children to physical therapy. Many of the mothers were pleased that a male, American physical therapist would treat their child and considered his opinion as superior to the female, Brazilian physical therapists' opinions. Most mothers, with very few exceptions, asked whether or not the American therapist thought that their child would walk or talk one day. The American physical therapist did not rule out the possibility for any child. The next question that followed from the mothers was "When?". It was very clear that walking and talking were imperative concerns for these mothers. The next chapter provides a discussion of this result.

Male v. Female

All across the board in both locations, participants claimed that they did not think that one's gender affected one's experience of disability. However, a Brazilian informant did point out that in some cases, people live in such dire situations that they are already so discriminated against, it would be impossible to discriminate against them further based on gender.

Public Knowledge

People that work with and care for people with disabilities undeniably recognize common misconceptions of the general public about the disabled. The researcher wanted

to provide an opportunity for participants to vocalize what they wished society knew about people with disabilities. In both locations, the participants wished that others understood that those living with disabilities are still people and that they are people capable of many things and not just limited people. Brazilians wished the public would respect them as people with rights and opinions who understood when they were being treated poorly by their society.

The American participants thought the public should view people with disabilities as a gift, not a burden, and as capable of more than they are given credit for. They are not mentally ill and people should have hope for them, not feel sad. One informant pointed out that the disabled have most likely accepted their disability and are comfortable with it so they do not view themselves as a “disabled person.”

General Public's Attitude and Understanding

A major component of this study was to discern the general public's attitude towards people with disability and their level of understanding of different disabilities. This was achieved by talking with the people who provide care for those with disabilities and are informed and understanding about the issue. In the United States, the answers were more optimistic, with many participants claiming that, although there is a broad spectrum, most people are at least compassionate enough to try to understand and be accepting. People who are intolerant of people with disabilities also tend to be intolerant of any sort of difference, whether it be race, socioeconomic status, religious beliefs, etc. Their prejudice and lack of acceptance tends not to be aimed only at people with disabilities. Many participants mentioned that the general public's attitude and

understanding are changing for the better. An important way of facilitating this change is through exposure and education. The more visible people with disabilities are in society, the more accepting the general population appears to be. One participant found that people are more accepting in larger cities than in smaller ones, and this could be due to a higher level of exposure in large cities where facilities are better equipped for physical needs. The American informants even described the general public's desire to get involved and make a difference.

The Brazilian participants painted a very different picture of the general public's attitude and level of understanding. While the Brazilians and Americans alike saw the public as rather uninformed and needing more education and exposure regarding disability, the Brazilians also described a more widespread and profound intolerance towards disability. The public can, at times, be rudely curious and question parents about 'what is wrong' with their child. About half of the Brazilian participants believed that the public was 'afraid' of people with disabilities, whereas the closest comparison to this sentiment among the American participants was that the public is 'nervous' due to lack of education and exposure. Finally, Brazilians discussed how the public was very pitying towards people with disabilities which seemed counter to the other statements of 'fear' and intolerance.

Stigmas

Erving Goffman's 1963 book, "Stigma: Notes on the Management of Spoiled Identity," is a classic work in disability studies. He described how stigmas deny a person their status as a human being and reduces them to something lesser. In regard to the

stigmatized Goffman writes, “He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap” (Goffman, 65, 1963). Goffman writes about the debilitating stigma people experience due to different characterizations, such being a former drug addict, a prostitute, an ex-mental patient, or having a disability. He believes the ostracization of stigma is caused by these people’s deviation from the ‘norm’ their society has set. He discusses stigmatized people’s feelings about their stigmas and what they do to compensate for or manage them. Inspired by Goffman’s work, the researcher wanted to know what stigmas existed about people with disabilities in both locations.

Brazilian respondents described the major stigma against people with disabilities as being that they are mentally ill, or ‘loco.’ The distinction between mental disabilities and mental illnesses has not permeated the general public’s knowledge in Santarém. The bus that drives the local students to the school every day is referred to as the “crazy bus.” The stigmas are so strong against people with disabilities that often the father of a child with a disability will abandon the mother and child, claiming that this could not possibly be his child.

According to U.S. participants, the stigma that people with mental disabilities are mentally ill still exists in the United States, but was much more pervasive in the past. The stigmas that exist today are that people with disabilities cannot understand anything or do anything. People stigmatize them by thinking that they are not deserving because they are not capable of anything. According to participants, stigmas in the United States also include the idea that people with disabilities are defective or that the disability is a

punishment for the family or for the individual themselves. Participants explained that there is often a stigma against the unknown, and that people need more exposure to disability. When asked whether stigmas against the disabled exist, one interviewee responded, “Yes, absolutely and they’re terrible. But I think as a species we are inherently flawed... it’s interesting because, as a species, we are capable of the great things and these horrible things... So this place [Chicago facility] is just a microcosm of that” (Personal Communication, Emily Stortz with John, 7/25/10).

Interestingly, the American participants described intra-discrimination among the residents of the American institution. Some of the higher functioning residents believe they do not belong here with people with more severe disabilities. There is also some discrimination between those residents who have lived their entire lives at this institution versus those who have come to the facility later in life. Residents like to tell how long they have lived at the institution and those who have lived there for many years enjoy enforcing the rules.

Expectations

When dealing with any kind of disease or disability, people often talk about how prognoses and expectations can be a self-fulfilling prophecies. Greater outcomes can be the result of higher expectations. The researcher wanted to know what expectations the individual participants and society had for people with disabilities. The American participants explained that people with disabilities are expected to have social lives and work a job that is at their skill level. They are expected to maximize their abilities and

engage in sports and relationships with others. At the American institution, marriage and intimate relationships were not allowed, but legally in the United States people with disabilities can marry. A final expectation was that they would be unique individuals.

In Brazil the expectations mentioned included, once again, walking and talking. There are laws in place to provide employment opportunities and they can legally marry. One participant said that her expectations were that if an individual was capable of something, they would do whatever it was. Other participants pointed out that more often now than in the past, people with disabilities are getting more involved in the community and are out in public. They referenced three flute players who perform at a church. However, they explained that there are families who still are not comfortable with going to public places with their relative with a disability.

Fieldwork observations confirmed that despite people with disabilities being legally able to marry, such marriages seldom actually occur. The key Brazilian informant did not know of any people with disabilities who were married and she had worked in the field for about 30 years. At the American site the residents are not allowed to marry while living there. One of the first interactions the researcher had with residents at the facility in Chicago involved them showing their engagement rings and introducing the researcher to their girlfriends, boyfriends, or fiancés. These relationships are officially not recognized. However, measures are taken to prevent intimacy and staff tries to distract residents from these relationships through other recreational activities. These relationships were prevented to in order to avoid legal and emotional issues that could ensue if the couples were to want to divorce or have children they would be incapable of raising on their own.

Myths

At both field work locations people talked about how people in general lack exposure to and understanding towards people with disabilities. To explain the unknown, cultures will turn to myths. However, sometimes these myths can be misleading. When asked about myths regarding disability, Brazilians explained again that the myth that people with disabilities are crazy people is prevalent. They also described myths about what causes disabilities. Some of these myths include that a person with a disability came to the family as a punishment for something, or that certain foods and behaviors on the part of the mother during pregnancy caused a particular disability. Clef lips are believed to result from the mother having a key in her pocket during pregnancy and birth marks can be from the baby killing a fish or other animal. The informant explained that only uneducated, or “simple” people believe these kinds of myths now.

When asked about myths regarding disability, none of the American informants spoke about legends or tales. They described myths more as misconceptions. One informant told the researcher that there is a myth that people with disabilities have uncontrolled sexuality. Another explained that a myth exists that people with disabilities are somehow less than human. A final, debilitating myth is that people will think that a person with a disability will never be capable of a certain task or skill or behavior so they never try to enable them to do it.

Active or marginalized citizens

While myths, stigmas, and lack of understanding or exposure can prevent people with disabilities from being full members of society, there are often laws in place to

ensure their legal rights. In both countries laws are in place to protect the citizenship of people with disabilities. These laws are not always enforced in either country, which makes their status as citizens ambiguous. This study sought participants' perceptions of whether or not people with disabilities are active citizens or if they are marginalized in the legal and political arenas as well.

Brazilians perceived the disabled as marginalized citizens who, although they have the right to vote, often do not exercise this right. Americans also saw people with disabilities as marginalized citizens, but noted that the situation is improving. If they are capable of comprehending politics and voting, they can take it very seriously. However, many of the residents of the American institution do not exercise their rights as active citizens because they are not capable of doing so because of the severity of their mental impairment.

The researcher observed the Americans With Disabilities Act 20th Anniversary Celebration at the Thompson center in downtown Chicago on July 22, 2010. This event provided information on resources for people with disabilities as well as an educational experience promoting awareness and understanding. People with disabilities performed for a crowd and artwork done by people with disabilities was on display. Many government agencies had representatives in attendance. Some of these agencies included the Mayor's Office, Social Security Department, the Department of Health and Human Services, the CTA and Pace buses, the Chicago Public Library, and the Regional Transportation Authority. Although people with disabilities may be perceived by some as marginalized, these observations show that the government is making an effort to mainstream their lives and is interested in their welfare. Despite their legal status as full

citizens, observations also show the reality that they remained marginalized when laws are not enforced or applied.

Accessing Public Spaces

The researcher asked the participants how well equipped public spaces are for meeting the needs of people with disabilities. How well equipped places are reflect how well enforced laws are and how well lawmakers are informed about the needs of people with disabilities. If a society is well equipped for people with disabilities, they have less functional limitations. If a disability is a difference or a limitation, then eliminating obstacles allows people with disabilities to live ‘normal’ lives with able-bodied citizens.

Every Brazilian participant stated that public spaces are not well equipped for people with disabilities. One cited regional differences around Brazil, claiming that the Northern region is especially poorly equipped. Although there are laws regarding equipping public spaces to be handicap accessible, these laws are not enforced. There are not the appropriate ramps to allow for wheelchair access to many places, and bathrooms are not designed to allow people with disabilities to use them. It is next to impossible to get around Santarém in a wheelchair.

Observing the conditions of roads and sidewalks in Santarém validates these responses. Many roads are made of dirt, and the paved roads are in various stages of disrepair. Sidewalks are very uneven and curbs are quite high. Many streets are very steep and sidewalks often get quite narrow. Photographic evidence was taken of the peril a person with a physical disability could face trying to get around this city. No handicap accessible bathrooms were seen throughout the duration of fieldwork.

The American participants stated that public spaces are better equipped now than in the past and they continue to improve. There are laws in place that are enforced. New buildings are built to a standard that makes them handicap accessible and older buildings have been retrofitted for things like wheelchair access. The United States seems well equipped for dealing with physical disabilities, and the Americans take “equipped” to the next level by describing ways to equip public places to deal with mental disabilities as well as physical disabilities. One described how a church provided First Holy Communion to a communicant in his home because the echo in the large church was disturbing to the child who has a mental disability. Another informed the researcher of a movie theater that has a special viewing each week for children with autism. The degree to which each location was equipped for allowing access to public places for people with disabilities was one of the most striking distinctions between the two places.

Obstacles

To help improve the condition of life for people with disabilities it is imperative that people know what major obstacles lie in their way. Obstacles come in two forms- day-to-day ones that hinder getting through daily activities, and large-scale obstacles that affect the bigger picture of their lives. The researcher asked participants what they saw as the day-to-day obstacles and the large-scale obstacles that people with disability face.

Day-to-day obstacles faced by people with disabilities in both locations revolved around self care. Simple activities such as feeding oneself or bathing oneself can be impossible for someone with a disability. The frustration with complete dependence on others leads to emotional distress. Communication for the non-verbal or those with

speech impediments is another day to day obstacle. These daily obstacles seem to describe the situation of people with severe or profound disabilities. People who function at a much higher level face obstacles that are quite different. A person who is mildly disabled, especially mildly mentally disabled, faces the obstacle of recognizing what they are perhaps missing out on. They are cognizant of the difference between themselves and the so called 'able bodied' and struggle with being left out of the rites of passage such as marriage and parenthood.

The large scale obstacles in both the U.S. and Brazil were comparable. The number one obstacle cited was acceptance. Dealing with the public and the public's perception of people with disabilities as inferior or incapable is an obstacle that creates barriers legally, in their educational lives, and in their professional lives. An interviewee from the United States stated that 'humans' were the worst obstacle faced.

Provision of Care

This study asked interviewees who provide a majority of the care for people with disabilities about whether family members or professionals were more involved in their care. In the United States and in Brazil the government provides some care. The problem with government aid in both places is that families do not know how to utilize the aid to maximize benefits. The systems are too complex for many people, especially those with little education or the illiterate, to comprehend. In Brazil, more people with disabilities are cared for by their family members than by professionals because there are not enough professional resources to provide care to the disabled. Also, people with disabilities may live in regions where no professional care is available at all. The family members

providing care tend to be the mothers, sisters, and grandmothers. Single mothers with a child with disabilities commonly move in with their mothers for help. Fathers will provide care, but there is a trend for fathers to abandon a child with a disability.

The majority of the American participants believed that more people are cared for by family members than by professionals in the United States as well. They acknowledged that both the level of government aid and degree of professional involvement are dependent on where a person lives and their family background. The sources noted that people with disabilities are living longer than in the past and that therefore they are cared for by their family members, especially parents, until the family members are too old to provide care. At this point, more professional help is required.

Aging and Disability: Dual Concerns

Aging is an issue in many countries around the world where the population's average age is steadily climbing. Thanks to the epidemiological transition, which gave humans a degree of control over infectious diseases through medicine, and overall improved medical technology and intervention, people are living to older ages in larger numbers than ever before. The researcher hypothesized that with this increased longevity, there would be more people living with disabilities. However, this research shows that the major problem is that people with long term disabilities are living to old age in greater numbers than ever before. At the American fieldwork site, aging is considered a major concern and planning committees have been formed to address the issue. People with disabilities have taken medicines for many years with unknown long-term effects. People with disabilities also experience greater rates and faster declines of certain progressive

diseases such as Alzheimer's and dementia. The informants described situations where a person with a disability also experiences issues related to the aging of the body systems and not many people are equipped to care for both. Nursing homes know how to care for elders, but not necessarily for people with disabilities such as cerebral palsy or Downs Syndrome. The caregivers of people with disabilities conversely do not know how to deal with the issues of old age in their patients with disabilities. The American institution is flooded with requests for people to enter the facility once their parents have passed away and there is no one else to care for them. The combination of things like cerebral palsy and Alzheimer's is a new frontier for all the caregivers involved and extremely concerning.

While the aging of people with disabilities is a foremost concern in the United States, it is almost a nonexistent issue in Brazil. The Brazilian informants told the researcher that people with disabilities generally do not live to old age. If they do, it is the exception, not the rule. People with disabilities succumb to medical problems before old age because of inadequate medical care and lack of access to doctors and medicine. There are not enough doctors in the region to properly care for the population. Socioeconomic status and the quality of one's life greatly affects their chances of living to old age. One informant described the future for people with disabilities as they age as "com sombra" or "shady" (Personal communication, Emily Stortz with Ana, 8/30/10). The prognosis is not good, but not terrible either. The fieldwork site in Santarém began a program called the Health Maturity Program for people 33 years of age and older. While informants said people were not living to old age, they do seem to think that people with disabilities are living longer than before.

The researcher noticed the general trend of median ages in both locations. At the American site the majority of residents were adults. Many were in their 30s and 40s. On the other hand, in Santarém, there were mainly children. This is, of course, in part due to the fact that the Santarém location is a school and children generally attend school. However, in talking with the staff there, they expressed that there are many more children with disabilities than adults with disabilities in Santarém. They questioned whether this was the trend in the United States as well. It seems that the reason there are few adults at the Santarém site is because there are not adults with disabilities seeking help from them. The demand does not exist so the services are not supplied.

Parents' Reaction

Disability can occur in any family for any number of reasons. Families with no previous knowledge or exposure to disability can suddenly find themselves with a handicapped child or sibling. Their reaction to this situation is culturally bound. Their perception of disability within their culture colors how they will perceive disability in their own child. In a way, the parents' reaction is a reflection of how society views disability. The researcher hypothesized that the more accepting the culture, the less negative the parent's reaction to learning their child has a disability.

The reaction of the parents' also reflects their degree of understanding of disability. There is no one reaction. Reactions are entirely dependent on the individual parents. A broad spectrum of reactions exist, but informants from both countries described disappointment and fear as common reactions along with sadness and anger. Two American informants believed that the reaction mirrored the process of mourning

with stages of denial, bargaining, anger, and finally acceptance. The American informants described that once the parents' initial shock wore off they formulated plans and accepted their fate. One said she believed it was a cultural thing to just continue on and take care of the child. Another informant said that most people, especially those with children at the American site, ultimately saw their child as wonderful gift to the family.

The reactions described by Brazilian informants were decidedly more negative. Aside from fear and disappointment, they have seen parents deny paternity. They may accuse the hospital of switching their child with another in the nursery. Fathers commonly will leave the child completely. Acceptance may come with time, but families often first look for someone or something to blame and hope to transform the child into a 'normal' child. Parents also commonly do not want their child with disabilities and give the child up for adoption. Unfortunately, the informants explain that very few children with disabilities are ever adopted.

The Role of Religion

Religion is always a difficult subject to broach, but it seemed imperative that this study give the participants an opportunity to explain the role of religion in disability if it exists. The results varied greatly from informants in both locations with some claiming religion played no role whatsoever and others saying it played a huge role. The American site is a Catholic institution so the American informants pointed out that it was inspired by Catholic nuns seeing a need amongst people and reaching out to help. The Catholic perspective that every life has value and all human life is of equal value is carried out by the employees there even if they do not view it in religious terms. One informant stated

that faith, not necessarily religion, was important in the United States. This informant related faith to the idea that everything happens for a reason and people have to make the best situation possible with what they are given.

Brazilians were as divided on the topic as the Americans. While some said religion played no role, another said that it was very important because it gave people something to believe in and provided comfort. One informant said that religion played a role because people with little self confidence would turn to God to beg for help in their unfortunate situations.

Defining 'Personhood'

A common theme in the data brought forth by the participants was that people with disabilities are still 'people.' The informants described them as "people, too" and 'humans just like you or me.' This prompted the researcher to pose the question "What is a person? What makes a person a person?" later in the interview. Interestingly, many participants were not able to answer this question, or their responses contradicted their statement that people with disabilities are still people. Many people with profound disabilities did not match the criteria they listed for being a human or person.

Some of the characteristics of a 'person' listed by the American informants include: the ability to follow the golden rule, being mentally strong and able to overcome barriers, having intellect and free will, the ability to see life and love in others, the capacity to love, the ability to communicate desires, and the ability to abstract and view society in relation to something other than oneself. Part of an answer was having a heart, soul, and brain. The informants seemed to reiterate the idea that everyone is equally

human regardless of their abilities. One informant explained that a person is what they get from society and what they give to society.

The Brazilian informants explained that a person is defined by their identity and relation to society. When someone has made a place for themselves in society, they are a person. Another Brazilian informant indicated that a person is what he or she represents to his or her family. A Brazilian physical therapist explained what makes a person a person by saying, “What the child represents to the family makes them a person. Being part of a family makes them a person. Even when it appears that there is no consciousness, when medical tests say there’s nothing there- mom might still think and believe and be able to get a response” (Personal communication, Emily Stortz with Susan, 8/25/10). This idea was manifested in particular by one mother-daughter pair the researcher observed in physical therapy in Brazil. This will be discussed further in the following chapter.

Causes of Disability

The perceived causes of disability are important for this research because an understanding of what causes disabilities could lead to the prevention of some disabilities. Causal beliefs also influence the way the public views people with disabilities. The researcher hypothesized that in both countries people would cite biological, medical causes for disability, but that these causes would be combined with other beliefs as well. The researcher asked her participants what they believed caused various disabilities as well as how they explained the presence of disability in some people and not in others. Participants in both locations explained that genetics and

problems during pregnancy or childbirth will often lead to disabilities. Otherwise, unfortunate accidents can cause disabilities. Other causes cited included nutrition and environmental hazards including toxins and pollution. American participants agreed that some disabilities are preventable.

Some American informants believed that only God knew why disabilities existed and what caused them, and several expressed that there is no way to explain disabilities. They seemed to believe that it is 'just how life is.' Disability is a part of life and everything happens for a reason so the causes do not matter- the conditions are set and humans must just deal with it.

The Brazilian informants referenced more behavioral and cultural causes for disabilities. Aside from genetics and congenital problems, they believed that lifestyle caused disability. Smoking and drinking causes disability. They also said that lack of health conditions, lack of hygiene, and lack of running water are factors in causing disability. Nutrition was a cause, especially in the Northern region of Brazil, among the poor. They cannot afford fruit and vegetables and eat a diet laden with fish and farofa (a regional dish of toasted manioc flour). A cultural issue believed to contribute to the rate of disabilities is genetic inbreeding. A belief exists in some areas of the less developed Northern region that a woman should have intercourse with a man from her family before she goes to her husband.

Santarém's remote location contributes to genetic inbreeding and related disabilities. Santarém is located about 500 miles from two other large cities- Manaus to the West and Belém to the East. There are two ways for people to travel from Santarém to one of these cities. They can travel by air or by boat. The boat rides take about two

days and costs approximately \$70-\$180 US dollars. The flight is only one hour long but can cost about \$350 U.S. dollars. For perspective, the maid that worked at the home the researcher stayed at during fieldwork earned about that amount working from 7 am-4:30 p.m. six days a week. With that money she had to support her three children. Therefore, the cost of a flight prohibits many people from traveling from Santarém. The pool of potential mates for residents is limited due to the isolated geography of the region and the prohibitive costs of traveling by boat or plane. Therefore, the population is unknowingly engaged in genetic inbreeding.

The population of Santarém has grown rapidly in the last 30 years. As of 1980, according to the CIA Factbook, the total population of the urban and rural areas of Santarém totaled 191,950 (CIA Factbook, 2010). According to the same source, the population as of 2007 was 274,285. This is equal to a 43% percent population growth. If the population steadily increased over the 27 years between 1980 and 2007, then the average yearly population growth rate was about 1.6%. In comparison, Brazil as a nation grew only 1.199% from 2009 to 2010 (CIA Factbook, 2010). This growth rate shows that although there is limited pool of mating partners, the population continues to expand quickly. This suggests the genetic inbreeding is occurring because people are not reproducing less although the genetic relationships in the city are stronger because few new genes are added to the pool by outsiders.

Problems of genetic inbreeding have plagued the human population throughout our existence. The problem lies in the fact that ‘variety is the spice of life.’ Organisms prosper the best when they have a variety of genes pools to choose from. In incestuous pairings, the gene pool is limited because the partners share some genes. Organisms that

share genes share dominant and recessive traits. Recessive traits can be present in an organism's genotype, but not made apparent in their phenotype and therefore have no adverse affects on the organism. In incestuous relationships the male and female share some genes and therefore have an increased chance of sharing the same recessive alleles. Their offspring then have an increased chance of these recessive traits appearing in their phenotype- the observable component of one's genotype- and having adverse affects on their health. Genetic abnormalities and problems that have been dormant for generations as recessive traits, appear in greater numbers in the offspring of incestuous pairings. Taking into consideration that when offspring lack genetic variety, they have less resistance to disease contributes to the overall idea that genetic inbreeding and disability are positively correlated.

Conversations with the Brazilian physical therapists as well as observing the disabilities seen in the children in Brazil both indicate that there are some unusual problems that cannot be categorized into a certain disease process. The physical therapists explained that the children they see seem to have several different processes working against them with no apparent correlation. For example, one five-year-old boy had the developmental level of a one-month-old but was also blind and partially deaf. The only explanation offered was that his mother had rubella, which she contracted during her seventh month of pregnancy. The resulting problems that her son faced did not match with the diagnosis, especially since she became ill with rubella so late in gestation. Another young boy, also age five, was diagnosed as having severe cerebral palsy and "Syndrome of the West." He weighed only about 20 pounds and had extreme respiratory difficulty. Further research in Syndrome of the West, showed that this is an epileptic

disorder in infants. This young boy did not manifest the typical symptoms of epileptic seizures at an early age. As noted earlier, a Brazilian informant noted that they seemed to have more children with disabilities than adults in Santarém. This could be explained through the rapid population growth that is not accompanied by much infiltration by outsiders bringing new genes into the pool. Each generation could expect to have a greater amount of genetic inbreeding, and therefore a greater amount of disabilities like those mentioned here.

The data seem to show that there are greater numbers of children with unusual and severe disabilities that cannot be categorized into one distinct disease process due to genetic inbreeding and the genetic abnormalities that correspond with genetic inbreeding. The combination of an isolated geographic location and a rapidly growing population has led to devastating and unusual genetic abnormalities that leave people with developmental, physical, and mental disabilities. Notice that this region of Brazil, the Northeast, has a decidedly higher rate of disability (16.8%) than other regions. Overall the data suggest that genetic issues are a result of Santarém's isolation.

According to the World Health Organization's 2010 Statistics, certain infectious and damaging diseases exist in Brazil that have no reported cases in the United States in the same year. In 2008, there were 315,914 reported cases of Malaria; 2,029 cases of Rubella; and 37,697 cases of tuberculosis (WHO, 2010). The United States reported no cases of any of these. This is of interest because Brazilians listed infectious diseases as a cause of disability, whereas Americans did not ever mention infectious diseases as a cause. The Brazilians even listed specific infections, such as rubella and syphilis, as common causes of disability. The researcher was even told upon meeting some of the

children receiving therapy in Santarém that their diagnoses included “infection during pregnancy.” The Americans focused more on genetics and accidents or problems with the birth and pregnancy than infections. One patient at the Brazilian site was a victim of rubella during his gestation.

Emergent Themes

Ten major themes emerged from interview and observational data. What follows is a discussion of these themes in a larger context, connecting them to the different interview questions and observational settings.

In both settings, the theme emerged that people with disabilities are still ‘people’ or ‘humans.’ The care providers in both places were adamant that the people they took care of were just as human as everyone else and simply experienced life in a different way. One direct care staffer in the United States, when asked what she wished people understood about disability responded that, “They’re human beings just like anyone else, just another person. And I think we stop and look at different quirks that people have and, ya know with physical disabilities, the sounds, or the lack of sounds that come out of somebody, or the gestures and some people are so quick to judge” (Personal communication, Emily Stortz with Maria, 7/22/10). Caretakers were adamant that the lives of people with disabilities were just as valuable as anyone else’s. Some staff at the American site, a Catholic run institution, explained that every human life is valuable and has meaning. Participants at both sites stressed individuality. They did not view the residents or students as one large group, but recognized their individual preferences and

needs. Observations revealed how both places treated people with disabilities as humans. In Chicago, the researcher joined the physical therapist for a morning of evaluations. The researcher accompanied the physical therapist to see a resident who was aging rapidly and whose level of functioning had greatly decreased in the last year. The most recent concern was that the staff was finding his limbs so stiff in the morning that they were having great difficulty transferring him out of his bed. The physical therapist and several direct staffers gathered to meet and discuss that problem along with several other, minor problems. At one point there were six people all in the resident's room, respectfully discussing all aspects of his care and addressing this problem to alleviate the issue. The staff did not talk around him, the researcher noticed they were addressing him even though he was non-verbal. They would look directly in his eyes and tell him what they were planning for him. They would pat his back and the researcher took note of how 'humanely' they treated him before any interviews had been performed discussing the treatment of residents as full humans.

A second theme that emerged from the Brazilian data was one of shame, denial, or blame. This sentiment was not expressed in interviews or manifested in observations in the United States. However, it was talked about in terms of the past among the American informants. In Santarém, a common emotion regarding disability is still shame. Parents will deny that a child is theirs or look to blame others and place responsibility somewhere else. At the same time that interviews revealed that fathers will commonly abandon their children and the mother of the child when the child is revealed to have a disability, this was also observed at the school. Throughout the fieldwork there, the researcher witnessed only one father bring his child to physical therapy. Otherwise, every single child in

therapy was brought in by a mother, other than one child that was brought in by a grandmother, and one young boy who was brought by a male employee of the government housing the boy lived in. A Brazilian physical therapist responded to the researcher's question, "How do parents react upon learning their child has a disability?", in the following way: "It is very difficult. They'll ask 'who is guilty? who is responsible?' and are always looking for ways to transform the child to normal. Acceptance only comes with time" (Personal communication, Emily Stortz with Sylvia, 8/25/10). When the researcher asked who or what they will blame, she responded, "It depends. Between the mom and the dad they'll say, 'You have this in your family, not mine!'" The other physical therapist, when asked the same question about parents' reaction explained that, "They [the parents] feel that the child was changed for another- that they were given the wrong child. They will say, 'My child is gone, my child died, they gave me another child- it is a gift but it is not mine.' They are disappointed. Some fathers go away" (Personal communication, Emily Stortz with Diane, 8/30/10). No comparable data were found in the United States in this case study.

This attitude of denial, blame, and shame relates to the third theme that emerged from the Brazilian data. This is the theme of male machismo and the male role in Santarém in general. Informants explained that the role of males, especially in this particular region, is quite different from the role of women. Male machismo is quite common and men see a child with a disability as an insult to their masculinity. One Brazilian informant explained stigmas against people with disabilities that contributes to this machismo theme. The informant explained, "...mothers will care for the baby with problems but the father is not involved. Frequently the fathers don't get involved.

Machismo! 'I wouldn't have a son with problems! I am a strong, perfect man.' In the Amazon, the men are very macho, they are much more so here than in other parts of Brazil" (Personal communication, Emily Stortz with Diane, 8/30/10). Another informant explained that often it is the mothers who provide care for the child with disabilities and that fathers take off. When the researcher asked why this is the case, the informant laughed as if to say, 'Need you really ask?'. This informant told the researcher the men left, "Ah...Because men are not prepared for frustration, especially in certain cultures here. The man has a different position from the woman. Males come first. When he gets a family and has a child with a disability, it is difficult for him to understand. They leave quickly" (Personal communication, Emily Stortz with Ana, 8/30/10). This reflects the same idea shared by other Brazilian informants who explained that it is a cultural phenomenon that men leave families, with or without disabilities. They will leave for many other reasons and this is considered a cultural norm. Therefore, when there is the added burden, in his eyes, of a disability, it is all the more likely that the father will run away from the family.

Shame, denial, or blame could also be a reflection of the myth that people with mental disabilities are mentally ill. This idea has been reduced to a relic in the United States, only believed by a minority, but is still a widespread belief among the public in Santarém. A theme throughout the data was the stigma of being "crazy." The Brazilian informants described how the public will say that the children at the school are 'crazy' and that while this idea is less prevalent today than in the past, it is still a commonly cited stigma against people with disabilities. Because they are different, they are considered

mentally ill. This leads to a fear that people with disabilities will act aggressively towards others.

Aside from fear, informants in both locations told the researcher that they wished the public would not feel sad for the disabled or pity them. Unnecessary hopelessness and sadness emerged as a theme throughout the data. People often expect to enter these kinds of facilities and feel depressed, but the researcher did not experience that emotion in either place. This theme directly relates to the fifth theme- that people with disabilities have skills people do not expect and that their lives are often viewed a gift. During observations the researcher in this study was astonished by the skill and strength of some of the performances witnessed. The courage to perform dances or music in front of a group impressed the audiences. The researcher saw performances at the ADA convention as well as at the Semana da Pessoa Com Deficiencia ceremony in Brazil. These skills sometimes need encouragement to develop. The mission at both places was to continue pushing and not give up when at first a skill or activity seemed too difficult for a particular person to accomplish.

Full participation in life emerged as a theme in the United States. Full participation was the goal, and this appears to be how the special skills and abilities mentioned above developed. The researcher volunteered to help with 'boardwalk games' one evening during Camp Week at the Chicago site. At first, it seemed the games were much too difficult for many of the residents to partake in. After about an hour, it became apparent that this was the embodiment of the ideal to provide full participation in life. Residents would never be able to partake in games like 'bean bag toss' or 'ring toss' if no one ever tried to play these games with them. The more the researcher worked with the

residents at games, the more she learned about what parts of the game they were capable of. Although a resident may not be capable of actually throwing the bean bag in bean bag toss, they could get enjoyment out of the game. During a tie-dying adventure, a resident might not be able to do every part of tie-dying a scarf, but they could pick which colors. Almost every American informant brought up the idea of 'full participation in life' while this theme was not mentioned at all by Brazilian informants. This was most commonly mentioned by the Americans when the researcher asked about the goal of the institution or the definition of disability during the interview. One informant explained that the goal was as follows: "To give the people that live here the opportunity to live their life to the fullest, in a respectful and dignified environment that allows them to meet goals that other people might not think they were capable of" (Personal communication, Emily Stortz with Julie, 7/20/10). 'Full participation in life' is a multi-faceted term that could mean very different things to different people. Only one informant elaborated on the meaning of 'full participation' without being prompted by the researcher. Explaining the goal of the American site, this informant said that, "harmony and quality of life and full participation without defining what that is... there's not the mentality of 'He can or he can't' and even in the Chicago public schools they are still saying the word 'plateaued'. There is no plateau here" (Personal communication, Emily Stortz with Kate, 7/23/10). The quest for full participation in life is the driving force behind the many activities and opportunities provided by this institution and allows for abilities to develop that might otherwise have been neglected and never realized.

Two themes with a strong correlation emerged. These include financial aspects of disability and the legal rights and equality of people with disabilities. Funding and the

fiscal decisions that impact the daily lives of people with disabilities are dependent on the legal system. Both institutions receive funding from the government and people with disabilities in both countries qualify for financial aid from the government. However, in both places there is a discrepancy between the amount the government provides and the need that exists.

An American informant explained that funding is always limited for groups like people with disabilities and that programs and funding for them are usually cut first when budget restraints are necessary. The same informant also explained that these programs and benefits that the government provides can be quite difficult to obtain because of the difficulties of utilizing the complicated system. The informant explained “Funding can always be a problem and also I think it’s a matter of who your family is, and what they expect of your life. And also trying to deal with state funding and trying to get your child into state programs takes a lot of tenacity and I think you have to be an educated person to understand how to get your child into these programs and how to get your child the most out of the government” (Personal communication, Emily Stortz with Julie, 7/20/10). Similarly, the Brazilian informants told the researcher that although laws and programs are in place and that benefits are available, often families do not know that they exist or do not know how to go about obtaining them. Therefore, a goal in Santarém is to help educate family members on how to seek the benefits they qualify for from the government. This includes financial aid. However, this financial aid can end up being split among an entire family that is in need rather than being used specifically for the family member with a disability.

The administrative interviewees in Brazil both stated the number one goal was to secure legal rights and equality for people with disabilities and to inform the students of these rights. There are laws requiring ramps. There are laws requiring companies of 100 employees or more to hire at least one person with a disability. And there are laws requiring schools to accept children with disabilities. There are even laws that allow families to report harassment against people with disabilities and the offender can be punished. However, these laws are not enforced and that is the ultimate goal of the institution- to fight for the enforcement of these laws. It appears that the two major obstacles to enforcement are: (1) people's attitudes against those with disabilities and; (2) lack of funding.

In both locations participants explained how the general public sometimes scoffs at the government's spending on people with disabilities or their placement in jobs. An American participant explained this problem: "A lot of people think they [people with disabilities] don't have the same rights as everybody else... some people think 'Why are we letting them have that job when somebody else could benefit from it?'" (Personal communication, Emily Stortz with Molly 7/20/10). Laws to protect and serve people with disabilities cannot be enforced until funding is available to enforce them and until attitudes like this are changed.

A final theme that emerged from the data is the overall lack of education and exposure that the general public has with regard to disability. Through education and exposure, people with disabilities can be normalized and seen more as a part of mainstream culture rather remaining marginalized. Many informants discussed educating the public and making disability a more visible part of our culture throughout their

interviews. They talked about these issues when asked about the general public's attitudes, when asked what they wish the public knew, and when speaking about the goals of their institution. The literature made this theme apparent as well before the fieldwork commenced. Observation validated what informants said about their attempts to normalize and spread understanding and exposure. Residents in Chicago and students in Santarém are getting more involved in their communities. Several students now play the flute at church on Sundays. Other students work at the local grocery store chain called 'CR.' The American institution has an extensive job placement system and residents hold a variety of paid jobs. Some work at local grocery stores and others even work at the international airport in Chicago taking computers apart. They have two performing groups that dance and sing for local events. They also have a popular bakery, restaurant, and gift shop on campus run by residents. Both places receive many volunteers, and this serves as another means through which people can gain exposure and educate themselves about people with disabilities while contributing to these institutions. Informants explained that this lack of exposure and education contributes to the myths and stigmas against people with disabilities. The general public does not know what to expect from people with disabilities and people are generally uncomfortable and dislike the unknown. When people do not understand why a person with a disability is doing what they are doing or the way they are doing it, it leads to acceptance issues and discomfort. A staffer working with children with profoundly disabled children in Chicago explained, "I mean the first time you see someone, lets say a grown up walking around drooling and holding a towel, it can be unnerving for some people, or if they can't feed themselves properly or the sounds they make. Some people are taken aback by that. I think its a lack of

education” (Personal communication, Emily Stortz with Maria, 7/22/10). A goal for both institutions is to work on gaining visibility for people with disabilities so that the general public’s discomfort is eased. Interestingly, the researcher experienced the attitude of discomfort during the course of fieldwork from peers. Peers inquired into the research and expressed that they would be too uncomfortable to go to these fieldwork sites. They questioned how the researcher dealt with being around people with disabilities. Fears such as not understanding what the residents are saying, being grabbed by a resident, or witnessing ‘gross’ things like drooling, or ‘disturbing’ things like yelling were quite common.

The literature on disability discusses how highly invisible disability used to be in the United States and remains in many regions of the world. People with disabilities are not generally depicted in films or on television nor in magazines or advertisements. American informants explained again and again that this was ‘changing’ and that the United States is a more disability friendly country than it used to be. Many talked about how in ‘the old days’ people with disabilities in the United States were shipped off to institutions and the problem was never talked about. Family members now keep people with disabilities at home and are vocal advocates for their cause. The Chicago site has been featured prominently in newspapers, People Magazine, and even in an evening television news segment focused on them.

Chapter Five: Discussion

Introduction

Emile Durkheim observed that ‘social facts’ are real because they have very real effects. Repercussions exist for those who break with the accepted social behaviors and beliefs. These repercussions can be severe (i.e. prison sentences) or mild (i.e. gossip) (Durkheim, 1895). Similarly, the social side of disability is real because it has very real effects. A society’s beliefs about disability impact how people with disabilities are treated.

This qualitative ethnographic case study attempted to understand the social side of living with a disability and the many ways in which a person’s culture affects his or her experience of disability. The research explored how the public perceived disability and how culture colored these perceptions. The research sought to enhance understanding of how society affects disability in order to help alleviate some of the cultural burden of being disabled. In doing this, the quality of life for people with disabilities living in any culture can be improved. The researcher employed participant observation and semi-structured interviews to gather data at a fieldwork location in Chicago, Illinois, U.S.A and in Santarém, Pará, Brazil in order to compare and contrast perceptions and experiences of disability in two very different cultures. These data were coded and emergent themes were analyzed. Previous research of this nature was quite limited. This study contributes to a larger discourse in medical anthropology and disability studies,

with an aim to enhance the quality of life for all those living with disabilities by raising recognition that although disability is a biological process, it also is a strongly social one.

Discussion

When anthropologist Robert Murphy's health declined due to a tumor in his spinal column, he learned through experience that the most difficult part of living with a disability, for many people, is the social reaction (Murphy, 1990). The data from this research support Murphy's assertions. The participants stated that other people are the number one obstacle faced by people with disabilities on a large scale. While day-to-day obstacles are more physical, the pressing and exhausting obstacles that weigh heavily on the spirits of people with disabilities deal with other humans.

Liminality

The stigma of disability exists because people with a disability deviate from the norm. Human nature causes us to be wary of the unknown and uncomfortable with it. People with disabilities find themselves in a liminal position somewhere between fully human and not fully human. Humans are more comfortable with neat, concise categories, and ambiguity is generally not well tolerated. The ambiguous role of people with disabilities creates the social tension directed against them. This discomfort is a product of the disruption of the basic instincts humans turn to whenever meeting someone new. Almost unconsciously humans size up the new person and make determinations about the relationship between them. The non-disabled, upon encountering a person with a disability, do not know how to categorize the person and, in turn, the person with a

disability does not know how he or she will be categorized. Erving Goffman refers to this phenomenon as “uncertainty of status” (Goffman, 1963). The relationship is strained upon first meeting. Often, people with disabilities must be highly skilled in dealing with the discomfort they create for the able-bodied. One informant touched on this idea when asked about what he wished the general public knew about disability. He responded, “In many cases that person with the disability has dealt with it and integrated it into their persons, their selfhood, probably better than we can imagine immediately and are perhaps more comfortable with their difference than we are initially...that the disabled person, in many ways thinks of themselves as being whole, just with a level of inconvenience” (Personal communication, Emily Stortz with Gordon, 09/05/2010).

Humans consistently display their ongoing discomfort with liminality. This universal discomfort seems to characterize human nature. Few phenomena appear in cross cultural studies as commonly as the distaste for “in-between” stages and ambiguity. Humans often engage in rituals to move out of liminal stages and into clearly defined categories. Many examples of human attempts to avoid liminality exist. For example, many funerary rituals exist to move a recently deceased person from this world into an afterworld and to prevent the deceased from remaining in the in-between stage of not fully alive or dead (Rakita et al., 2008). The concepts of haunting and ghosts show a fear of the liminal position between dead and alive. As another example, in many Western countries, if a baby is born with ambiguous sexual organs, doctors often immediately perform surgery to assign the child to one sex regardless of what his or her future sex and gender preferences might be. Victor Turner described this liminality with the phrase “betwixt and between” in his seminal piece on rituals among the Ndembu (Turner, 1967).

Because humans are more comfortable with definitive categories, and spend a great deal of energy dividing the world into these distinct categories, an inherent discomfort exists whenever the boundaries are blurred. All rites of passage involve three stages-separation, transition, and re-incorporation. The second stage, transition, represents the liminal period when a person is neither what they used to be, and not yet what they are about to become (Turner, 1967). For people of ambiguous status, it is as if they are stuck in this transitional period. This betwixt and between state leaves them discriminated against and creates tension between them and those easily categorized.

This betwixt and between state can be devastating when a person is cognizant of their liminal position. One American informant described this kind of recognition when asked what major obstacles people with disabilities face. She was familiar with a young woman who had a mild disability and had lived at home with her family and siblings and attended regular high school. She was acutely aware of her siblings leaving home, marrying, and starting families and struggled with the fact that she was not engaging in the same life experiences. The participant described this young woman as living in an “in between place” (Personal Communication, Emily Stortz with Julie, 7/20/10). Her awareness of her liminal position somewhere between severely disabled and completely able-bodied was difficult for her. The awareness that came with being mildly disabled was a blessing, but also a curse because she was able to recognize the position she held in society and almost mourn for what she might be missing out on had she been fully abled.

Susan and Sammy: An Example of Humanity

Many informants found the interview question, “What makes a person a person?”, quite difficult to answer. The adamant insistence by participants that people with

disabilities are “still people” necessitated this troublesome question. A definition of a “person” clarified what everyone meant by the former statement. The most striking answer was given by a Brazilian physical therapist. She said:

What the child represents to the family makes them a person. Being a part of a family makes them a person. Even when it appears that there is no consciousness, when medical tests say there is nothing there-the mom might still think and believe and be able to get a response... So families learn subtle clues to know what the child wants and is responsive in a way. They are not brain dead to the family (Personal communication, Emily Stortz with Sylvia, 08/25/2010).

A mother-daughter pair that the researcher spent a significant amount of time with highlighted this response. The daughter, Sammy, and her mother, Susan, spent one week of each month, rather than the usual two days of each week, at the school in Santarém because they lived 74 kilometers (46 miles) away in the Interior of the Amazon Rainforest. To get to Santarém, they had to travel by bus on unpaved roads for two to two and half hours to arrive in the city of Óbidos. From there, they boarded a small boat and rode for six hours to arrive in Santarém. They stayed with friends throughout the week. Sammy and Sandra happened to be in Santarém for longer while the researcher was present due to a doctor’s appointment. Therefore, the researcher was able to see them every day during fieldwork.

Sammy is sixteen months old and diagnosed with microcephaly-a genetic or congenital condition where the volume of the head is smaller than normal. It results in severe developmental difficulties and no treatment exists aside from physical therapy to help improve quality of life and encourage development. Sammy is categorized as having severe and profound disabilities. She spends most of her time sleeping and is non-responsive. Sammy does not roll, sit, crawl, cry, make sounds, hold up her head, or even

move her limbs apart from reflexes. She is dominated by primitive reflexes and maintains a primitive pose such as archer's posture (with one arm extended and the opposite arm bent at the elbow). Archer's posture, also known as asymmetric tonic neck reflex, suggests a severely damaged or undeveloped central nervous system. These reflexes exist in all children but would slowly disappear as they develop and are integrated into normal movement. Because of her disability, Sammy's central nervous system is not developing so these primitive reflexes remain. She has no righting reactions or equilibrium and is also hypertonic. Hypertonicity is an increase in muscle tone characteristic of central nervous system disorder that leaves limbs rigid. Sammy does not attend to sound or visual stimulation. Fortunately there are no indications of pain behaviors. At only sixteen months, Sammy weighs 12.5 kilograms (27.5 pounds).

From the first encounter, the researcher recognized something special in Sammy and Susan. She took note of the mother's complete devotion to her daughter and the eagerness with which she approached the physical therapy session with the American. The researcher noted "very energetic and excited and super in love with daughter. Dedicated. Giving her kisses. She [Susan] pointed out everything her daughter could do to us [the researcher and physical therapist] and shook our hands when she left (unusual)." She was the only mother throughout the fieldwork who shook our hands. Sammy, like all the children, was very well cared for. Sammy's clothes were always clean and her hair styled. Both the researcher and the physical therapist marveled at how clean and cared for the children were. It can be quite difficult to maintain cleanliness in children, much less children with developmental disabilities living in an extreme climate. The arduous journey they made each month to come to Santarém exemplifies the

mother's dedication. Each day Susan was determined to get Sammy into the hands of the Americans, even if it was the researcher and not the physical therapist.

After establishing rapport and mutual respect, the researcher was able to learn more about Sammy and Susan's lives outside of the school. They live outside of the city of Óbidos, Pará, Brazil. Sammy is an only child, but she has many cousins, aunts, uncles, and her grandparents close by. They even have a dog named Bingo. Susan responded positively when asked if Sammy was the center of life for the whole family. Susan stated "Ela é minha vida." This means "She is my life" in Portuguese. These sentiments show how intuitive the Brazilian physical therapist is who stated that a person is what they are to their family. Although Sammy may not be conscious or may technically be considered brain-dead, she maintains her humanity through the joy that she brings to her family. Informants discussed viewing the disabled as a 'gift' and the researcher saw how Sammy was a gift to her mother and her extended family.

Earlier it was noted that Sammy weighed 27.5 pounds at only sixteen months. Eating is one of the only things that Sammy is capable of even if she is not aware of what is happening or does not necessarily take pleasure from eating. Her mother probably enjoys feeding her because it is the one way she can get a reaction out of Sammy. If one puts food to Sammy's mouth, she will eat it. The mother probably likes to feed her because it connects them. It bridges the gap between mother and daughter and overcomes Sammy's non-responsiveness.

There is a great lesson with the Sammy/Susan example. This lesson is that people with disabilities can contribute to society and are not a burden. People with severe disabilities, who may seem non-responsive, represent a purity or innocence that can stir

great amounts of love and compassion in humans. Several American informants explained how the residents seem incapable of cruelty or teasing. Sammy and many others with severe and profound disabilities can contribute to all societies through their purity and the joy they can bring others.

The eloquent answer that a person is “what they represent to their families” was an exception in the responses to this question. Understandably, this question was quite difficult to answer. The most common responses were discussed in the previous chapter. Most participants explained that a major myth, stigma, or misconception about people with disabilities is that they are not ‘fully human.’ These participants remained adamant that people with disabilities *are* fully human, a point with which the researcher agrees. However, when pressed to explain “what makes a person a person” their answers often contradicted their statements that those with disabilities are people or they simply were not able to define what makes a person. This confusion or ambiguity could be a part of the problem with the public’s view of people with disabilities as less than fully human. What makes any of us fully human? Society in general has a problem accepting anything different or unique. The existence of racism, sexism, agism, classism and homophobia prove that humans are generally uncomfortable with and hostile towards what is different from themselves. Discrimination is often the result of one group viewing themselves as superior to another group and more fully human and deserving of life. There is no simple answer to the question of “what makes a person a person” and this ambiguity contributes to the public’s distaste for the range of human variation that exists and enables discrimination against any “others.” Of course, “other” is relative. In the case of Susan and Sammy, Sammy’s humanity was maintained by her role in society and the joy she

brought her family. If more people could be exposed to children and mothers like Sammy and Susan, perhaps people would be more understanding and see the contribution and humanness of people with disabilities of all degrees.

Intolerance for Intolerance

“The moral test of government is how it treats those who are in the dawn of life, the children; those who are in the twilight of life, the aged; and those who are in the shadows of life, the sick, the needy and the handicapped. - Hubert H. Humphrey”
(Source: <http://www.ssas.com/main.htm>)

Former Vice President under Lyndon B. Johnson, Hubert H. Humphrey made this observation four decades ago. This concept could be applied to society in general. The treatment of the weak and vulnerable reflects a society's norms and values. It also represents their economic and political realities. The powerful need to have compassion and advocate for the vulnerable. Society needs to agree and keep these advocates in positions of power. Change often comes from the bottom. If people in both the United States and Brazil were intolerant of injustices and cruelty aimed at people with varying degrees of disability, the government may follow suit. It is not that people are necessarily immoral, it is more so that people are unaware or not informed. The United States has seen a series of cultural revolutions in the last few generations including the Women's Rights Movement and the Civil Rights Movement. This general attitude of intolerance towards intolerance has promoted the laws and the enforcement of laws protecting the citizenship and humanity of people with disabilities.

Intra-discrimination

Intra-discrimination exists among people with disabilities. They are not a homogeneous group and therefore there is discrimination against people with different kinds of disabilities or different levels of impairment between people with disabilities. This phenomena was not discussed or observed in Santarém but it was in Chicago. High functioning residents will claim they “don’t belong” at the institution with “those” people. The truth is, if a person did not require the care that this institution offers, they would not be there because there are many others who would like to enter the facility and are on a long waiting list. This attitude is not prevalent nor is it a characterization of any person or institution. This attitude seems to be the exception and not the rule, but its existence is worth noting because it speaks to the capacity of humans to discriminate against others even when they themselves are being discriminated against.

Sex and Gender

Sex and gender bear weight on an individual’s identity in all cultures. From the literature review, it became clear that sex and gender also affect a person’s experience with disability. The literature discussed the increased vulnerability for sexual exploitation that women with mental and physical disabilities face. The inability to fight off unwanted advances, the inability to recognize exploitation or abuse, or the inability to report and prevent or stop further abuse are all great concerns.

Women with disabilities are often viewed as unfit mothers. People either think they are incapable of bearing children, or that they are at least incapable of properly raising children. For both sexes, the public tends to view men and women with disabilities as either asexual or hyper-sexual with little ability to control their impulses.

The latter is more focused on males with disabilities and leads to discrimination and myths.

Males with disabilities experience unique circumstances in terms of their relationship with women and their gendered roles. Anthropologist Robert Murphy described how his relationship with women was altered by his disability. Women became friendlier with him once he was in a wheelchair because the threat of physical attack was removed. Women that had not acknowledged him in the past now waved and greeted him. Men have the added burden of the 'breadwinner' standard. Males with disabilities could suffer from more emotional distress due to their disability if it impairs their ability to work and earn a living. They feel as though their masculinity is attacked if they cannot provide for a wife and family.

Women face the added burden of unrealistic beauty ideals, particularly in the United States. The ideal body for men and women is to be toned, fit, and tan in America. While men with disabilities deal with this problem, women are generally held to a higher standard than males and the range of acceptable appearances is much narrower for women (Wolf, 1992). Therefore, women with disabilities often feel that their beauty and desirability are negatively affected by their disability. In a society that worships health and vigor, it is difficult to live with a disability and have great confidence in one's appearance.

Interestingly, no participants in either nation thought that there was much of a difference between males' and females' experience of disability. Only one American informant brought up the issue of sexuality. Otherwise, the majority stated that there was no difference. Sex and gender are such definitive characteristics of a person's identity

that it was surprising to the researcher that no participants immediately thought of any of the differences described above.

Gender roles are a human universal. In Santarém, the machismo culture maintains that males take precedence over females. Informants discussed this attitude and its manifestation in culture was observed to an extent. The researcher might argue that among the lower classes, male machismo is stronger. The women that the researcher lived with and spent recreational time were all empowered, strong-willed, single women. They were financially and personally independent. They were educated and had knowledge of the world and other cultures besides their own. Perhaps they were an exception to the rule, but they ran counter to the idea of machismo. However, the lack of male presence at the fieldwork institution coincided with the idea that fathers often abandon disabled children. Abortion is illegal in Brazil, so women do not have a choice (unless they obtain a dangerous, illegal abortion) as to whether or not to have the child when they learn they are pregnant. Until recently, males had the legal right to completely walk away from their children and have no personal or financial obligations to the child or the child's mother (Personal communication, Emily Stortz with Nadia, 9/5/10). Fortunately, this law has changed and men can be taken to court if they refuse to financially aid their children.

Since the United States experienced the Sexual Revolution and Women's Rights' Movement, females have improved their status. Not coincidentally, as women gained rights, so too did other minority groups-whether they be racial groups, religious groups, or people with disabilities. A general atmosphere of tolerance took hold. An attitude of inequality contributes to stigmas against people with disabilities within a society. If males

take precedence over females, why not let the able-bodied take precedence over those with disabilities? People with disabilities represent their own minority group, and in a culture where minorities are discriminated against, it seems to follow that the disabled would be discriminated against as well. Male machismo among the lower classes in Santarém represent an unfounded tolerance for inequality and discrimination.

Public Spaces

The discrepancy between how well equipped public spaces are in Chicago as compared to Santarém ultimately comes down to economics. Laws exist in both places calling for retrofitting and handicap accessibility, but if the funding is not available, this will not happen. In Chicago, accessibility is much less of an issue because large amounts of money have been invested to make public spaces accessible to people with disabilities. Ramps at the appropriate incline allow wheelchairs access to more places. Handicap doors and bathrooms allow wheelchairs access as well. In Santarém the entire infrastructure of the city would have to be overhauled to make it even somewhat handicap accessible. The sidewalks are in such stages of disrepair that it seems not only likely that they could not be repaired, but also unlikely that they could be retrofitted with ramps and widened to allow wheelchairs to use them. Public restrooms are often haphazardly attached to buildings as afterthoughts and in cramped quarters. The city of Santarém would have to be completely redesigned and the infrastructure changed to even begin to make the city equipped to any degree for people with disabilities. The major issue is funding, but other obstacles lie in the way as well. Currently in Santarém, public authorities are trying to pave more of the streets and have put aside the money to do this. However, the project is taking much longer than expected because there is only one piece

of machinery in all of Santarém that can pave the roads. The isolated geography of the region prevents more equipment from arriving in town. A city in which it is not uncommon to see a horse and cart seems many steps away from ramps, automatically opening doors, and wheelchair-accessible public bathrooms.

Abortion

Abortion is considered a crime against life in Brazil in all but two instances- in the case of rape or when the mother's life is immediately threatened by the pregnancy (Diniz, 2007). The only other exception is when a fetus is known to have a severe genetic anomaly, such as anencephaly, where it will be incapable of life outside of the uterus. In cases like this, the fetus does not meet the Brazilian legal definition of 'alive' (Diniz, 2007). Genetic counseling is not common in Brazil, most likely related to the lack of options available for those who learn that their child will have severe disabilities. Parents undergoing genetic counseling and testing may learn that their child will have a disability but not be able to terminate the pregnancy if they know they cannot adequately care for that child. It would be reasonable to assume that some of the shame associated with having a child with a disability is related to the parents' lack of choice. Parents in the United States and other places where abortion is legal have the right to terminate a pregnancy when they learn the fetus will have disabilities. Whether that choice is morally correct is beyond the scope of this paper. If parents learn that their child is going to have disabilities and proceed with the pregnancy, they most likely will not feel ashamed of their child. They loved the child regardless and chose to carry on with his or her life. However, when parents do not have the right to exercise choice, they may feel forced to bear a child they otherwise would not carry to term. The legal status of abortion is

relevant to disability because the abortion debate is entangled in arguments over the definition of 'life' in the same way that disability is intertwined with this same definition.

Brazil is a predominantly Catholic nation, a fact that explains the triumph of the pro-life party. Often, the abortion debate is entangled in the definition of 'life' and whether it begins at conception, at first breath out of the uterus, or somewhere in between. It is interesting to note that when asked about "what makes a person" no Brazilian informants' answers mirrored the kinds of responses pro-lifers might use. This can reflect several things, one of which may be that religiously inspired laws do not match people's secular beliefs. It could also reflect that the concept of 'life' as argued by pro-life supporters has not yet been applied in arguments supporting concern for people with disabilities. If Brazilian legislation argues that, 'life' is defined as cerebral activity, then even people with severe disabilities would be and are considered alive. It is hypocritical to protect the life of a fetus, but not adequately protect the humanity and citizenship of those with disabilities.

Aging

The researcher originally formulated the interview questions on aging and disability based on the fact that many nations have rapidly aging populations where people are living longer than ever before. People who live far into old age tend to be living with disabilities they have developed over the years. The researcher was expecting to hear about how more people are living with disabilities now but discovered that the pressing problem in terms of aging and disability is that the people with disabilities are living longer than ever before. This caught the researcher off guard and almost constitutes its own research project based on the gravity of the situation. There are few experts in

disability who also understand the biological and psychological aspects of aging. Because of the overwhelming concern and discussion about the aging of people with disabilities in America, the researcher decided to ask about aging and disability in Santarém. The participants almost seemed confused by the question. This confusion most likely arose from the fact that, as the researcher discovered, people with disabilities do not reach old age in Santarém. Asking about their predictions for people with disabilities as they reach old age did not make sense to the Brazilian participants because its a nonexistent phenomenon and the question irrelevant.

According to the World Health Statistics of 2010, as of 2008 the average life expectancy at birth for a Brazilian man was 70 and for a Brazilian woman it was 77. In the United States these numbers were slightly higher with men having an expectancy of 76 and women an expectancy of 81. These numbers are all higher than the global life expectancy of 66 for males and 70 for females in 2008 (WHO, 2010). These data show that the life expectancy discrepancy between the disabled living in Santarém versus Chicago is not accounted for by an overall life expectancy discrepancy between the two nations. Brazilians in general are living about as long as Americans. This means that there is something particular to the life experience of people with disabilities in a remote, less developed region of Brazil that is preventing them from reaching old age as people with disabilities are in the United States.

One Brazilian informant believed that, although no data support or refute it, people with disabilities are overall living longer even if not until old age. She said that the reason they are not reaching old age is because they have difficult lives and very limited access to medical care and intervention (Interview by Emily Stortz, Nadia,

9/5/10). They live in environmental situations that are not conducive to long lives. They have dirty water and cannot afford fresh food, medicine, or medical care. This informant specifically stated that low social class directly and negatively affected people's ability to live long lives. People need better diet and more overall concern with their health because eventually years of poor health and living conditions leads to their death. She complained that people with disabilities are "treated like everyone else" and do not get special privileges or aid because they have disabilities (Interview by Emily Stortz, Nadia, 9/5/10). This sentiment is in contrast to the battle cry throughout the research that people with disabilities "should be treated like everyone else." This informant clearly saw the low life expectancy of people with disabilities as a direct result of social conditions. Their low socioeconomic status and the lifestyle and lack of healthcare that comes with it promotes short lives and succumbing to complications earlier in life than necessary.

Over the last four decades in the United States, people with disabilities have experienced earlier medical intervention as well as improved ongoing medical care throughout their lives. Control of infectious diseases that improved public health measures allowed the general population to live longer, and medical advancements in the understanding of the etiology of disabilities has allowed people with disabilities to live longer as well. A barrier in Brazil to longer lives for people with disabilities is a lack of doctors to provide this early intervention and ongoing care. As several Brazilian informants explained, there are not nearly enough doctors in Santarém to serve the population. The new Regional Hospital, as impressive as it is, could be filled with cancer patients alone, according to the head of surgical oncology.

Santarém has a population of about 275,000 people. However, the Regional Hospital serves the entire population of the region, which totals about 1.5 million people from nineteen different cities in West Pará. The Regional Hospital only has about 100 doctors and there are a total of only 150 doctors in all of Santarém. Therefore, the waiting time to see a doctor or have surgery can be extensive. The ideal ratio of patients to doctors would be one doctor for every 1,000 people. In Santarém alone the ratio is more like one doctor for every 2,000 people. Once the regional population of 1.5 million people is considered, the ratio plummets to about one doctor for every 10,000 people. One informant explained that the wait can be four to six months just for a consultation with a doctor. The entire time a person waits, he or she is going without treatment. The school where fieldwork took place strives to help their students get treatment quickly. The researcher saw the issue of extensive waiting played out in the observations of the physical therapy patients in Santarém. Some of the children needed surgeries and told the researcher and the American therapist that they were going to have the surgery done. The researcher would ask “When will you have the surgery?” and the most common response was “We do not know, we are waiting.” No one seemed to know how long the wait would be. This problem is another example of how the isolating geography affects people living with disabilities and their life expectancy. It also demonstrates an inadequate number of resources available for an abundant problem. Not only elders, but people with disabilities as well are affected by lack of access to medical care.

Infectious Diseases

The rates of certain infectious diseases in the United States and Brazil were discussed in the previous chapter. Malaria, rubella, and tuberculosis were non-existent in

the United States in 2007 (WHO 2010 Statistics). It seems that infections play a serious role in the rate of disability in Santarém. These disease processes that do not affect the United States today are still creating complications during and immediately after pregnancy for Brazilians. This result was surprising because the question regarding what causes disability was more grounded in the researcher's hypothesis that people would *perceive* different causes for disability, not that there would *actual* different causes for disability. However, the presence of these curable, infectious diseases again speaks to society. Although data on the distribution of these diseases across classes could not be found, it is reasonable to expect that the lower classes have higher rates. This biological problem is the result of social inequality. The vaccines and immunizations are available for a price. Paul Farmer's book, "Infections and Inequalities: The Modern Plagues," delves into the topic of the distribution of health care and the unequal access given to the poor around the world (Farmer, 2001). The results from the Brazilian site in this research support Farmer's ideas.

The United States considers Rubella an eliminated disease because it is highly preventable thanks to the MMR (Measles, Mumps, Rubella) vaccine, generally given to children twice before they attend school. Pregnant women are advised to make sure they have their Rubella vaccination because contracting Rubella during pregnancy can lead to serious birth defects and developmental delays in the fetus. The greatest risk is during the first trimester. About 85% of babies born to mothers with Rubella suffer from Congenital Rubella Syndrome (CRS) (NIH, 2010). In Brazil in 2007 there were 30 reported cases of this. The symptoms include growth retardation, vision problems, developmental delays, deafness, mental retardation, heart defects, and defects in other organs (NIH, 2010). A

five-year-old boy in Santarém was introduced with the diagnosis that his mother had had Rubella during the seventh month of his gestation. He appeared to have CRS based on his blindness, deafness, and mental retardation. He was, however, extremely large for his age which runs counter to the normal symptoms of CRS. However, there seem to be other processes at work with respect to this young boy, judging from his large size and severe developmental delays beyond mental retardation. These could be accounted for by genetic issues, as discussed earlier. The importance of these data in the research project lies in the fact that CRS is a vaccine-preventable disease. It can be avoided if a society requires and enforces vaccinations for all people (NIH, 2010). Therefore, CRS, while obviously a biomedical problem, is also a social problem that leads to disabilities. Society fails to prevent these disabilities by not distributing the vaccine, and then society harshly judges those with disabilities caused by CRS. This biological problem could be socially solved.

According to the World Health Organization, about 10% of the world's population have disabilities. If disabilities were evenly distributed throughout the world, one would expect to find that within any given nation, about 10% of the population had disabilities (WHO 2010 Statistics). About 14.5% of the Brazilian population lives with disabilities. This number varies across regions with the highest rate in the Northeast, the location of Santarém, where 16.8% of the population is disabled (IDRMP, 2004). This high rate of disability can be accounted for, as discussed earlier, by the isolated location of Santarém and certain cultural beliefs. One Brazilian informant explained that the rate is much higher than it should be. She explained that about 60% of the disabilities seen at the fieldwork site are preventable (Interview by Emily Stortz, Nadia, 9/5/10). The

informant explained that the big difference between disabilities in the United States and Brazil is that Brazilian disabilities are caused by one's social surroundings. Mothers have poor diets during pregnancy and problems at birth coupled with non-hygienic home environments. Women are often unaware of the medical care that prevents disabilities in their children or do not have access to such care. This informant sees disability as a social problem because such a large percentage of disabilities could be prevented.

Walking and Talking

The results showed that one of the goals of the Brazilian fieldwork site, particularly in physical therapy, was to enable children to walk and talk. These physical goals were interesting because none of the American informants talked about physical goals. The Americans focused on quality of life, dignity, and providing a full life. While the overall goals of the Brazilian institution were more in line with the American ones, the goal of walking and talking seemed so simple yet so significant. The physical therapists explained that they had this goal because they felt pressure from the mothers to fulfill them. Many of the mothers asked if their child would walk or talk and, if so, when? Walking and talking were of utmost importance to these mothers for several reasons. The first of these reasons is most likely the physical burden a non-mobile child places on a mother. As the child grows, the mother has a more difficult time transporting him or her. The ability to speak allows children to tell what they need or want and makes the mothers' lives much easier than if a child can only cry and the mother does not know if the child is hungry, tired, in pain, etc. When a child can speak, they can also tell when they are being mistreated. Communication problems create much frustration for the non-verbal and the overall quality of life can be improved through the ability to speak.

Technical problems of existence are made easier when a person can express their thoughts, feelings, needs, and desires. Socially, life is much easier when a person can walk and talk. The social stigma against a person with a disability who can walk and talk is much less than for a person who cannot do these things. Walking allows for much greater mobility in Santarém, where the use of wheelchairs is just about impossible. Walking and talking give a person with disabilities a greater chance of procuring work and blending in more with the general population. A nonverbal, non-walking person in Santarém is subject to cruelty because his or her disability is so visible. In this culture where disability is seen as shameful and stigmatized, it is only natural that mothers would desire for their children to gain the skills that allow them to seem more 'normal.' It seems that the mothers wanted these skills for their children for their children's sake.

Physical v. Mental Disabilities

This study did not distinguish between physical and mental disabilities or the level of severity of disabilities. Therefore, the researcher was able to study the experiences of people with all kinds of disability and levels of functioning. Obviously, in both cultures, the higher functioning a person is, the more accepted they are. However, it appears that it is easier to live with a physical disability in the United States than it is in Brazil. Conversely, one could argue that it could be easier to live with a mental disability in Brazil than it is in the United States. The United States is retrofitted to allow for great accessibility to public spaces for people with physical disabilities. As a culture, Americans seem to have developed a level of tolerance and understanding for physical disabilities, as long as they are not too severe. In Santarém, it is impossible to be mobile if a person has a physical disability. The infrastructure and technology do not

accommodate physical disabilities. In America, people not only can use wheelchairs, but the technology for wheelchairs has expanded to the point where quadriplegics can use their own breathing to propel their power wheelchairs. Nothing like this exists in Santarém. Physical disabilities tend to be highly visible. When a person has a visible, physical disability it is almost impossible to try to blend in. A person in a wheelchair cannot blend in and “pretend” to be “normal.” On the other hand, people with mental disabilities may be able to pass as “normal” more easily if their disability is not too severe. The average person is not immediately alerted that something is “wrong” with a person with a mild mental disability.

Limitations of the Research

Although this study was successful and yielded revealing results that add to the discourse of medical anthropology and disabilities study, there were several limitations. The limitations of the design of the study were addressed in the introductory chapter, and now additional limitations will be discussed. The first limitation perceived by the researcher was her own lack of medical training and knowledge. This project required detailed understanding of the biological and anatomical processes at work for many different disabilities. Fortunately, the researcher was accompanied by medical experts that could explain the biological aspects. This was a limitation because the researcher would have preferred immediate knowledge rather than depending on the experts’ opinions after the fact.

After reviewing the data from interview questions, the researcher noticed a limitation in her research questions. Many participants described how the goal of their

institution was to provide a “full” life for participants, or a “fulfilling life,” or to provide “full” participation in life for the disabled. A limitation was the researcher’s lack of a follow up question to these responses asking them to clarify what they meant by “full.” If the participants could have qualified these statements, more revealing data could have been collected. This was a limitation because these answers were difficult to interpret. The researcher did not know what participants considered a full life, or what they considered full participation, so she could not compare their responses or say something larger and meaningful about them as well as she could have with further explanations. Without the context of the surrounding conversation, it was not plausible to request further explanation on this matter from the participants at a later date and collect reliable answers.

The final limitation was completely beyond the researcher’s control. A few days into the fieldwork portion in Brazil, the researcher started to experience symptoms of a cold. The researcher had brought medicines from America including a general antibiotic. As the symptoms became worse, the researcher tried self medicating with antibiotics and over the counter cold medicines from the local pharmacy. Unfortunately, she developed a sinus infection including a cough. Eventually, she had to visit a Brazilian doctor who prescribed a different antibiotic and steroids. Many of the children at the fieldwork location have compromised immune systems. Their respiratory systems struggled the most and some will eventually succumb to respiratory issues such as pneumonia. Therefore, the researcher became wary of getting too close to the children and possibly spreading her sinus infection to them. This clearly became a limitation to the research. The researcher even missed an afternoon of fieldwork because she was too ill. This

limitation was unavoidable and unfortunate, but the researcher had to make the best of the situation and continue on with the work without jeopardizing anyone's health.

Recommendations for Future Research

This study is built on the foundation laid by other researchers in medical anthropology and disability studies. It contributes to a larger dialogue in the hopes of creating a discourse that allows for the spreading of knowledge and exposure that improves the quality of life and care for people living with disabilities in all cultures. Disability is a broad term that can intersect with many other areas of study. Some of these that are significant to this study include the intersection of disability and sex or gender and the intersection of disability and gerontology. Recommendations for future research include more in-depth analysis of how disability intersects with sex, gender, and aging. The latter is especially pressing in the United States, where aging was cited as a major concern among the health care community that deals with disability. Aging concerns are gaining more attention in the world and in the United States as Americans face the reality of an aging population and the health, economic, and social implications of these changing demographics.

Gerontologists would serve people with disabilities well by providing more insight into how to deal with the combination of developmental disabilities and the progressive diseases of old age, including but not limited to Alzheimer's disease and dementia. The American fieldwork site has taken great steps, including forming an aging committee, to meet this new challenge and supplementary research and aid could be greatly helpful.

Future research in gender studies as it relates to disability could offer more education and understanding on how one's gender affects one's overall identity and experience of disability. Sex and gender are such all encompassing identity characteristics that it seems impossible they do not affect a person's experience of disability. The effects of gender on disability were discussed briefly above, but a more in-depth look could improve quality of care for all genders. Deviance from gender norms and disability are both targets for discrimination. It would be interesting to look at not only how the experience of males versus females differ, but how people from all along the gender and sexuality spectrum deal with disability. This study did not have permission to discuss sexuality, but studying sexuality, along with sexual preference among people with disabilities could be enlightening with regard to an issue that has long been tabooed in societies in general, much less among a population whose sexuality is often ignored or misconstrued.

Conclusion

This research blossomed in 2006 when the researcher visited Santarém for the first time and witnessed a need and felt a desire to contribute to the facility. Having grown up around disabilities due to her parents' profession, the researcher felt a unique sense of comfort with disability. She had been exposed to various physical and mental disabilities at her parents' practice from a very young age. She was also able to ask open and honest questions and receive answers to all of her inquiries. As she grew, she became acutely aware that other people in her culture did not necessarily have the same view of disability. After her first trip to Brazil, when she visited her future fieldwork site, she

realized that things were quite different there from what she had witnessed for many years at her parents' offices. Five years later, armed with the ammunition of anthropology, it became clear that the difference could be accounted for by cultural variety in beliefs and perceptions about disability. Santarém fell along a different segment of the arc that Margaret Mead described. The major conclusions of this research project supported that theory. The male machismo still existent in Santarém led to an overall guilt towards disability and abandonment of children with disabilities. Socioeconomic conditions and lack of education create about 60% of the disabilities seen in Santarém. Children are suffering the consequences of preventable, curable infectious diseases. The physical conditions of the city and surrounding areas inhibit people with disabilities from entering the public arena, and their absence makes them all the more stigmatized. Visibility, exposure, and education are intimately related to acceptance. The more visible and exposed any sort of "other" is, and the more education the public has about their differences, the more they are accepted.

The researcher's prescriptions for improvement are already in action. People with disabilities, and all minority groups, in Santarém need advocating voices that demand their rights be enacted and encourage public education so that those without disabilities know that people with disabilities are "still people" and not "crazy." This could be done through news segments on disability, portraying the skills and abilities of people with disabilities rather than their downfalls, or newspaper and magazine articles highlighting the accomplishments of the Brazilian school and its students. Tolerance seminars could be required at work. The most important group to educate is the children. Children are impressionable and open to new ideas. If schools would welcome children with

disabilities and discuss people with disabilities so that they did not seem so mysterious, it could greatly improve future social attitudes towards people with disabilities.

Discrimination is a learned behavior.

This study contributes to a larger discourse on disability and anthropology. The more people who are interested in the topic and conduct studies, the closer humans will be to accepting differences and perhaps even recognizing the similarities between themselves and 'others.' Change often comes from the bottom. The more people discuss an issue and show compassion for a cause, the more likely it is that negative attitudes will be transformed into more positive ones. The findings of this study contribute to a greater understanding of the social side of disability. While humans can never prevent all disabilities, or cure them, we can cure the social failures that make life with a disability more difficult than it needs to be. The unanimous opinion expressed by informants in this study is that the lack of social acceptance is one of the most difficult parts of being disabled. This study is an attempt to alleviate some of that social intolerance by joining the dialogue about which aspects of culture affect disability and how. Recognizing the social side of disability can improve the quality of life for people with disabilities and help them recapture their status as "fully human." A person is only as limited by their physical condition as their society allows.

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Appendix

- Appendix A: Institution Consent Forms
 - A.1: Misericórdia
 - A.2: Associação de Pais e Amigos dos Excepcionais

- Appendix B: Interview Consent Form
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Appendix A

Institution Consent Form

A.1: Misericordia Heart of Mercy

Misericordia Heart of Mercy **Consent Form**

Your institution is invited to participate in a cultural analysis of disability. The research is being conducted by Professor Kathryn Elliott and a graduate student, Emily Stortz, both from the Anthropology department of Minnesota State University, Mankato. We ask that you read this form before agreeing to participate.

Purpose

The purpose of this research is to compare and contrast the concept of disability in Brazil and America, including but not limited to the treatment or management, attitudes surrounding, and expectations for those with disability in the hopes of providing useful ideas and tools as well as a better understanding for health care workers and families of the disabled.

Procedure

Misericordia's agreement to participate will involve interviews with employees and family member's of residents as well as allowing a researcher, Emily Stortz, to observe and participate as instructed for two weeks at your facility. There is also a survey component to the research to supplement the interviews if people are more willing and able to fill out surveys at their convenience. The interviews should last about 30-45 minutes and will have about twenty questions on the interviewees perception and understanding of disability. All interviews will be audio-taped and every individual interviewed will be asked to sign a consent form detailing the purpose and procedure.

Risks and Benefits

Although I will not be asking any personal questions during interviews, the sensitive nature of this topic could cause some emotional discomfort for some. If at any point throughout the interview the participant would like to withdraw either from a particular question or topic or from the entire research project, they are able to do so. The benefits of this study include contributing to a greater understanding towards disability.

Confidentiality

The information gathered at Misericordia will be kept private and confidential. No information will be included at any point that identifies individual research participants.

We do not ask for any contact information from you. The audio-tapes and transcripts of interviews will be kept in a locked file only accessible to the researchers of this study.

Voluntary Nature of this Study

Participation in this research is voluntary and involves no penalties should you decline to participate. Participants may withdraw at any time with no penalty.

Contact

If you have any questions or concerns at any point you may contact the primary investigator, Dr. Kathryn Elliot, or the secondary investigator, Emily Stortz. Dr. Elliott can be reached at the University by calling (507) 389-6590 and Emily Stortz can be reached (773)-519-9926. If you would like to talk to someone other than the researchers contact: MSU IRB Administrator Minnesota State University, Mankato, Institutional Review Board, 115 Alumni Foundation, (507) 389-2321.

By signing here I am indicating that I read the above information and understand that Misericordia's participation is voluntary and the institution may withdraw at any time. I consent to Misericordia's participation in this research.

Signature: _____

Date: _____

Researcher's Signatures: _____ Date: _____

_____ Date: _____

____ Mark an "X" if participant received a copy.

A.2: Associação de Pais e Amigos dos Excepcionais

APAE Consentimento

Sua instituição é convidado a ser um participante de um estudo da deficiência. O estudo está sendo feito pelo Dr. Kathryn Elliott e Emily Stortz, uma estudante, de Minnesota State University, em Mankato, Minnesota, U.S.A. Por favor leia isto antes de participar.

Objetivo

Este estudo vai comparar deficiência nos Estados Unidos e no Brasil.

Procedimento

Seu contrato de participação inclui um pesquisador, Emily Stortz, observando-se durante duas semanas. Envolve também entre dez e quinze entrevistas com funcionários e membros da família do aluno. As entrevistas vão durar cerca de trinta minutos e serão gravados.

O risco e a Vantagem

Eu não vou fazer as perguntas pessoais em entrevistas, mas este é um tema sensível. Os participantes podem terminar a sua participação a qualquer momento. Eles podem recusar qualquer pergunta. A vantagem deste estudo é melhorar a compreensão da deficiência

Confidencialidade

Esta informação vai ser privado e confidencial. Os participantes serão anônimos. Nós não pedimos para informações de contato. A gravação e transcrição da entrevista será em um arquivo bloqueado e só os pesquisadores terão acesso a ele.

Voluntário

A participação das instituições e da participação dos indivíduos é voluntária e não há penalidades se alguém se recusar a participar. Os participantes podem se recusar a participar em qualquer momento, sem penalidade.

Minhas informações de contato

Se você tiver alguma dúvida pode contactar o investigador principal, Dr. Kathryn Elliot, e do investigador secundário, Emily Stortz. Dr. Elliott pode ser contactado na Universidade pelo telefone 00-1-507-389-6590 e Emily Stortz pode ser alcançado 00-1-773 -519-9926. Se você gostaria de falar com alguém que não seja o contacto entre investigadores: MSU IRB Administrador Minnesota State University, Mankato, Institutional Review Board, 115 alunos da Fundação, Mankato, MN, E.U.A. ou pelo telefone 00-1-507-389-2321.

Minha assinatura ou marca representa a minha concordância em participar. Também representa o meu entendimento de que a minha participação é voluntária e posso retirar a qualquer momento.

Assinatura ou marca do participante: _____

Data: _____

Assinatura ou marca do pesquisador: _____

Data: _____

Appendix B:
Interview Consent Form

B.1: English

Interview- Consent Form

You are invited to be a participant in a cultural analysis of disability. The research is being conducted by Professor Kathryn Elliott and a graduate student, Emily Stortz, both from the Anthropology department of Minnesota State University, Mankato. We ask that you read this form before agreeing to participate.

Purpose

The purpose of this research is to compare and contrast the concept of disability in Brazil and America, including but not limited to the treatment or management, attitudes surrounding, and expectations for those with disability in the hopes of providing useful ideas and tools as well as a better understanding for health care workers and families of the disabled.

Procedure

If you agree to participate, your participation will involve 30-45 minutes of your time in a semi-structured interview. I will ask you open ended questions about your understanding of disability in your culture. The interview will be audio-taped.

Risks and Benefits

Although I will not be asking any personal questions, the sensitive nature of this topic could cause some emotional discomfort for some. If at any point throughout the interview you would like to withdraw your participation either from a particular question or topic or from the entire research project, you are able to do so. The benefits of this study include contributing to a greater understanding towards disability.

Confidentiality

The information recorded will be kept private and confidential. No information will be included at any point that identifies you. We do not ask for any contact information from you. The audio-tapes and transcripts of this interview will be kept in a locked file only accessible to the researchers of this study.

Voluntary Nature of this Study

Participation in this research is voluntary and involves no penalties should you decline to participate. Participants may withdraw at any time with no penalty.

Contact

If you have any questions or concerns at any point you may contact the primary investigator, Dr. Kathryn Elliot, or the secondary investigator, Emily Stortz. Dr. Elliott can be reached at the University by calling (507) 389-6590 and Emily Stortz can be

reached (773)-519-9926. If you would like to talk to someone other than the researchers contact: MSU IRB Administrator Minnesota State University, Mankato, Institutional Review Board, 115 Alumni Foundation, (507) 389-2321.

By signing here I am indicating that I read the above information and understand my participation is voluntary and I may withdraw at any time. I consent to participate in this research.

Signature: _____ Date: _____

Researcher's Signatures: _____ Date: _____

_____ Date: _____

B.2: Portuguese

Entrevista Consentimento

Você está convidado a ser um participante de um estudo da deficiência. O estudo está sendo feito pelo Dr. Kathryn Elliott e Emily Stortz, uma estudante, de Minnesota State University, em Mankato, Minnesota, U.S.A.

Por favor leia isto antes de participar.

Objetivo

Este estudo vai comparar deficiência nos Estados Unidos e no Brasil.

Procedimento

Se você concorda, eu vou te fazer perguntas sobre deficiência. A entrevista vai durar trinta para a quarenta minutos e será gravado.

O risco e a Vantagem

Eu não vou fazer as perguntas pessoais, mas este é um tema sensível. Você pode terminar a entrevista a qualquer momento. Você pode recusar qualquer pergunta. A vantagem deste estudo é melhorar a compreensão da deficiência

Confidencialidade

Esta informação vai ser privado e confidencial. Você vai ser anônimo. Nós não pedimos para informações de contato. A gravação e transcrição da entrevista será em um arquivo bloqueado e só os pesquisadores terão acesso a ele.

Voluntário

Sua participação é voluntária e não há penalidades se você se recusar a participar. Os participantes podem se recusar a participar em qualquer momento, sem penalidade.

Minhas informações de contato

Se você tiver alguma dúvida pode contactar o investigador principal, Dr. Kathryn Elliot, e do investigador secundário, Emily Stortz. Dr. Elliott pode ser contactado na Universidade pelo telefone 00-1-507-389-6590 e Emily Stortz pode ser alcançado 00-1-773 -519-9926. Se você gostaria de falar com alguém que não seja o contacto entre investigadores: MSU IRB Administrador Minnesota State University, Mankato, Institutional Review Board, 115 alunos da Fundação, Mankato, MN, E.U.A. ou pelo telefone 00-1-507-389-2321.

Minha assinatura ou marca representa a minha concordância em participar. Também representa o meu entendimento de que a minha participação é voluntária e posso retirar a qualquer momento.

Assinatura ou marca do participante: _____

Data: _____

Assinatura ou marca do pesquisador: _____

Data: _____

Data: _____

Appendix C
Photography Consent Form

C.1: APAE

Fotografia Consentimento

Sua instituição é convidado a ser um participante de um estudo da deficiência. O estudo está sendo feito pelo Dr. Kathryn Elliott e Emily Stortz, uma estudante, de Minnesota State University, em Mankato, Minnesota, U.S.A. Por favor leia isto antes de participar.

Objetivo

Este estudo vai comparar deficiência nos Estados Unidos e no Brasil.

Procedimento

Se você concorda, eu vou tirar fotos para ser usado para melhorar a minha pesquisa para os meus leitores.

O risco e a Vantagem

Não há riscos envolvidos. A vantagem deste estudo é melhorar a compreensão da deficiência

Confidencialidade

As pessoas não serão identificadas em todas as fotos e os seus nomes não serão utilizados.

Voluntário

A participação das instituições e da participação dos indivíduos é voluntária e não há penalidades se alguém se recusar a participar. Os participantes podem se recusar a participar em qualquer momento, sem penalidade.

Minhas informações de contato

Se você tiver alguma dúvida pode contactar o investigador principal, Dr. Kathryn Elliot, e do investigador secundário, Emily Stortz. Dr. Elliott pode ser contactado na Universidade pelo telefone 00-1-507-389-6590 e Emily Stortz pode ser alcançado 00-1-773 -519-9926. Se você gostaria de falar com alguém que não seja o contacto entre investigadores: MSU IRB Administrador Minnesota State University, Mankato, Institutional Review Board, 115 alunos da Fundação, Mankato, MN, E.U.A. ou pelo telefone 00-1-507-389-2321.

Minha assinatura ou marca representa a minha concordância em participar. Também representa o meu entendimento de que a minha participação é voluntária e posso retirar a qualquer momento.

Assinatura ou marca do participante: _____

Data: _____

Assinatura ou marca do pesquisador: _____ Data:

Data: _____

C.2: Individual-Portuguese

Fotografia Consentimento

Você está convidado a ser um participante de um estudo da deficiência. O estudo está sendo feito pelo Dr. Kathryn Elliott e Emily Stortz, uma estudante, de Minnesota State University, em Mankato, Minnesota, U.S.A.

Por favor leia isto antes de participar.

Objetivo

Este estudo vai comparar deficiência nos Estados Unidos e no Brasil.

Procedimento

Se você concorda, eu vou tirar fotos para ser usado para melhorar a minha pesquisa para os meus leitores.

O risco e a Vantagem

Não há riscos envolvidos. A vantagem deste estudo é melhorar a compreensão da deficiência

Confidencialidade

As pessoas não serão identificadas em todas as fotos e os seus nomes não serão utilizados.

Voluntário

Sua participação é voluntária e não há penalidades se você se recusar a participar. Os participantes podem se recusar a participar em qualquer momento, sem penalidade.

Minhas informações de contato

Se você tiver alguma dúvida pode contactar o investigador principal, Dr. Kathryn Elliot, e do investigador secundário, Emily Stortz. Dr. Elliott pode ser contactado na Universidade pelo telefone 00-1-507-389-6590 e Emily Stortz pode ser alcançado 00-1-773 -519-9926. Se você gostaria de falar com alguém que não seja o contacto entre investigadores: MSU IRB Administrador Minnesota State University, Mankato, Institutional Review Board, 115 alunos da Fundação, Mankato, MN, E.U.A. ou pelo telefone 00-1-507-389-2321.

Minha assinatura ou marca representa a minha concordância em participar. Também representa o meu entendimento de que a minha participação é voluntária e posso retirar a qualquer momento.

Assinatura ou marca do participante: _____

Data: _____

Assinatura ou marca do pesquisador: _____

Data: _____

Data: _____

APPENDIX D
Semi-Structured Interview Questions

D.1: English

How do you define “disability”?

What is the goal of your institution for your clients? Rehabilitation? Work with them so that they are able to be gainfully employed? Care for themselves? Live independently?

Are the experiences of men and women living with disabilities different? If yes, how?

What is one thing you wish society in general understood or knew about people living with disabilities?

How understanding are people outside of the field and without a disabled loved one about people with disabilities?

Patient? Sympathetic? Frustrated? Curious?

What is the general public’s attitude in your society towards those with disabilities?

Inclusive/exclusive

Understanding or ignorance

Are there stigmas attached to people with disabilities? If so, please describe.

What expectations are there for people with various degrees of mental and physical disabilities?

Employment/career? Marriage/intimate relationship? Parenthood?

Inclusion in social life/friendship? Independent living?

Are there any major myths you wish to dispel regarding people with disabilities?

Are the disabled active citizens or marginalized? How?

(Re)Integration into society? Is this even a goal?

How well equipped are public spaces for meeting the needs of the disabled?

What are major obstacles for those with disabilities? Large scale and in day-to-day life?

Who provides a majority of the care for the disabled?

How much are professionals involved in the care of disabled?

What do you predict for people living with disabilities as they reach old age in higher rates than ever before?

How do parent's react when they learn their child is disabled?

Does religion play a role in this topic? If so, explain.

What are the traits necessary to be considered a person? How do you define personhood in your culture?

Based on the disability(s) you are familiar with, what is responsible for them? What causes that particular disability(s)? Preventable? Supernatural? Natural? In utero? Accidents?

How do you explain the presence of disability in some and not others?

D.2: Portuguese

Como você define a deficiência?

Quais são os objetivos de sua instituição?

Os homens e mulheres deficiência experiência diferente? Se sim, como?

O que você deseja que o público sabe as pessoas com deficiência?

Como entendendo são as pessoas que não trabalham com as pessoas com inabilidades e sem parentes com deficiência?

Paciente? Simpática? Frustrado? Curioso?

O que o atitudes das pessoas em direção as pessoas com deficiência?

Inclusive? Exclusivo?

Entendimento? Ignorante?

Há estigmas contra as pessoas com deficiência? Se sim, por favor descreva.

O que expectativas estão para as pessoas com deficiência de varios níveis de mental e físico deficiências?

Trabalhar? Casamento ou namorado(a)? Paternidade ou maternidade? Vida social?

Independencia?

Existem quaisquer grandes mitos que você gostaria de dissipar sobre as pessoas com deficiências?

São as pessoas com deficiências marginalizados? Ou são cidadãos activos? Como?

Se marginalizados, a reintegração é desejado?

Como bem equipados são espaços públicos para satisfazer as necessidade das pessoas com deficiências?

Quais são as maiores obstuculos para as pessoas com deficiências? Na vida em geral e no dia a dia?

Que prove a maioria dos cuidados para as pessoas com deficiências?

Como envolvidos são profissionais?

O que voce prognostico para as pessoas com deficiências no deles velhice?

Como os pais reagem quando eles aprendem que seu filho tem deficiências?

E a religião importante para este topico? Se sim, como?

Quais são as características necessarias para ser considerado um pessoa? O que faz um pessoa uma pessoa? Como as pessoas sao diferente dos animais? Plants? Terra? Deuses? Espiritos?

O que causa deficiências? Você pode responder sobre a deficiência você sabe bem, ou você pode responder sobre a deficiência em geral. Sobrenatural? Natural? No utero? Alguma coisa durante a gravidez? Acidentes?

Como você explica ou entende a presença de deficiência em algumas pessoas e não em outras pessoas?

