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### Quicksand, Handcuffs and Duct Tape: a Life with Disabilities

Amy Lynn Nicola  
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**QUICKSAND, HANDCUFFS AND DUCT TAPE: A LIFE WITH DISABILITIES**

**A thesis submitted to  
Regis College  
The Honors Program  
in partial fulfillment of the requirements  
for Graduation with Honors**

**by**

Amy Lynn Nicola

**May 2008**

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**REGIS UNIVERSITY**

**Regis College Honors Program**  
**Honors Thesis**

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## **I. Quicksand, Handcuffs and Duct Tape: An Introduction**

Close your eyes and imagine that you are standing on an open highway with nothing in your way. Except, your legs are sinking in quicksand. Your hands that have toiled endlessly at paper writing, piano practices, and have brought you many achievements are being put into handcuffs. And your mouth that has allowed you to converse with people, build relationships, and share your deepest thoughts is being duct-taped shut. You stand there with the use of your legs slowly fading beneath you on this open highway that once had no obstacles. You have lost the use of your hands and your means of communication. Find a way to start moving, to enjoy the open highway, to live. It is possible. With a little creative innovation and support from the people around us, it is possible to live with quicksand, handcuffs, and duct tape. People with disabilities do it every day.

My first frustration with the injustice that a person with a disability faces occurred three and a half years ago in the Omaha Amtrak train station. I had just arrived from Denver for my winter break and was waiting for my ride. I watched a man in his thirties fumble with his suitcase and a large Omaha metro area telephone book. He sat in an electric wheelchair while his one good limb balanced the awkward luggage and flipped through the yellow pages. After no luck with his search, the man steered his chair to the ticket window and asked the Amtrak employee if there was an accessible transportation service available. The man behind the counter phoned several companies, none of which

could meet the man's needs. He apologized but the man replied, "It's okay. I knew what I was getting into when I decided to come here." Clearly frustrated, the man made his way out the door. My ride finally arrived and a few blocks from the train station I saw the disabled man making his way up a hill, his suitcase tucked underneath his good arm while his good hand operated the chair. My heart dropped. Was there nobody who could give this man a ride? How far did he have to go? Was his battery going to run out before he got where he was going? The man faded away into cold December air as I drove away. There was nothing I could offer him. I do not know exactly why the taxi companies could not accommodate this man. I later researched accessible services in the Omaha metro area and there were available options. What I do know is that witnessing this episode gave me a little idea of what people with disabilities have to encounter every day.

People with cerebral disorders, severed limbs and paralyzing brain injuries live in every community throughout the world. Their struggles differ as societies differ, but the injustice of this world greatly impacts the life of a disabled person, despite where that person lives. In congruence with my Neuroscience studies, I have had the privilege of working with people with disabilities and brain disorders in both the United States and in the Dominican Republic. I have witnessed the quicksand that swallows their dreams. I have seen the handcuffs that are put on by false cultural perceptions. I have tried to remove the duct tape that binds people with disabilities from living the life they deserve. This thesis is a collection of my experiences, of stories that have been shared with me,

and of research that has helped me learn how we can eliminate the quicksand, handcuffs and duct tape that unjustly burden people with disabilities.

## **II. Americans with Disabilities**

### History of Disability

Our country has a long history of disability injustice. In the late nineteenth and early twentieth centuries, laws were passed in several major cities banning from the public eye anyone “diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object” (Schweik 59). The first known ordinance that shunned people with disabilities was in San Francisco in 1867. Chicago passed a similar law in 1911. It came to be known as the “ugly law.” Some claim that this is only an urban legend, but legal archives show proof of its existence and its true ugliness. In 1911, George Gray, the “legless newsboy of Times Square,” was arrested and sued. It was assumed he was a runaway who lost his legs after he became a tramp (59). In 1924, Virginia passed a law that forced mentally handicapped women to be sterilized in order to protect society from overwhelming populations of “imbeciles” (Reilly 303). The “ugly law” violated citizens’ liberty and restrained their rights and opportunities (Connor and Bejoian 54; Schweik 59). What makes this law even more disgusting is another law passed in the early twentieth century which stated that property, no matter how “unsightly and disfiguring,” “unpleasant to the eye and in violation of the rules of property and good taste,” would not be considered a nuisance. “The law does not cater to men’s tastes nor consult their convenience merely” (Schweik 64). Yet the “ugly law” deemed humans with disabilities as nuisances due to distaste to the public eye. Despite the injustice of

these laws, there is no evidence of resistance against them. Nobody seemed to notice just how ugly it really was. Schweik suggests that this discrimination hinged on the definition of a citizen as an able-bodied individual. Disability, then, was understood as the “literal opposite of liberty, privilege, and immunity” (60).

### Disability and Homelessness

There are 49.7 million people with physical and mental disabilities in our country (Catchpole and Miller 1333). Many of these people are hidden on the streets. It is estimated that approximately one-fourth of homeless people seeking shelter are people with mental and physical disabilities. This does not include those who are living on the streets, not seeking shelter (Koch A1). Disability has long been associated with poverty and homelessness. The “ugly laws” pertained to the disabled as well as to poor beggars. The public supposedly should not have had to tolerate either on the streets. In 1877, a 10-year-old boy named Frank Haller was arrested for begging in the sidewalk of down town New York. During his trial, Haller said, “I’m just a harmless cripple.” The reply was, “That’s the point exactly” (Schweik 66). Philadelphia, in 1887, recognized the unconstitutionality of the law and added that the prohibited mendicancy did not apply “to any blind, deaf, or dumb person, nor shall it be applicable to any maimed or crippled person who is unable to perform manual labor” (62). However, as Schweik notes, this consigned disabled people to the role of beggar. Society classified them as incapable of normal life. The Constitution does not offer disabled beggars protection and courts allow restriction on mendicancy. Perhaps this is because begging confronts the more privileged members of society (66).

Laws now prohibit panhandling, suppress aid from urban social justice groups, and keep people with disabilities away from institutions. Don Mitchell, a professor at Syracuse University, stated, “By redefining what is acceptable in public space, by in effect annihilating the spaces in which homeless people *must* live, these laws seek simply to annihilate homeless people themselves” (qtd. in Schweik 67). To help these homeless individuals in need of medical attention, Stacy suggests that medical education begins addressing issues of homelessness through case studies or community work (844). The school curricula should include teaching information about “routes into homelessness, prevalence statistics, legal and social aspects, and health care provision” (Stacy 844). With more knowledge of homelessness, medical care will be able to reach out to people with disabilities living on the streets.

### Disability and War

One may ask why the numbers of disabled people on the streets are increasing. A true and serious answer is war. Over 30,000 American men and women have been injured in Iraq, Afghanistan, and the war on terror (Schumer). An untold number of these veterans will be permanently disabled. With more troops being deployed to fight a ceaseless war, more disabled will return to lives that will never be what they were. More people will be denied government help and more people will struggle to find sustainable life on the streets. A commandment among soldiers is that a fallen comrade is never left behind (Mulrine 10). Yet our disabled veterans returning from war are forgotten. Priest and Hull revealed this sad reality at the Walter Reed Army Medical Center in Washington, D.C. in 2007 (A1). As the major clearing house for returning soldiers, this



facility is supposed to be among the best. Yet in the outpatient buildings, doors are torn off their hinges and mold has painted the walls. Almost 700 recovering soldiers sleep with mice and cockroaches. The average stay is ten months and some stay as long as two years, suffering from post-traumatic stress, amputated limbs, brain injuries, and internal damage. Not only are the facility conditions unbearable and overcrowded, there are not enough doctors, nurses, or therapists. Priest and Hull discovered that soldiers with the use of their hands are feeding their fellow comrades who lost their hands and soldiers with psychological problems are counseling those who are suicidal. Morale at Walter Reed is low and depression is high. Our veterans are not getting the psychological and physical attention they need. One soldier commented that it was worse at Walter Reed than it was in Iraq (Priest and Hull A1). War has only increased the numbers of people with disabilities; the number of people to be neglected. The disabled cannot be hidden on street corners or in homeless shelters and a war resulting in a nightmare like Walter Reed cannot be ignored.

#### Disability from a Cultural Perspective

Yet why are these injustices overlooked? Societal prejudices toward people with disabilities are a prominent factor. In addition to the “ugly law,” people have long believed that deaf people could not hear the word of God and therefore not enter the kingdom of heaven and that epileptic people were possessed by demons (Connor and Bejoian 54). The media also portrays negative associations with disabilities. In 2005, best film Academy Award winner, *Million Dollar Baby*, and best foreign film Academy Award winner, *The Sea Inside*, both told stories of courageous, accomplished characters

who chose death rather than life with disabilities. In other words, these movies show their audiences that “life with a disability is simply not worth living” (Connor and Bejoian 53). It should come as no surprise that society has such a negative connotation of people with disabilities. Phrases such as “that’s retarded,” “what a lame idea” and “are you deaf?” are regularly used. Every time a remark such as these is made, it reinforces the harmful association of disability. It labels people with disabilities as inferior, incompetent, unwanted, and different (Connor and Bejoian 52; Dinerstein 40).

Pat, a client at the King Adult Day Enrichment Program (KADEP) where I volunteer in Denver, said the one thing that bothers her the most is that “I’m automatically deaf.” People talk extra slow and loud simply because Pat is in a wheel chair. She has a physical and respiratory disability but hears just fine. When Pat talks on the phone with her housing manager, he asks her to hand the phone to someone else so that he can explain the issue. Pat can clearly hear and understand every word. Able-bodied people assume that people with disabilities cannot fend for themselves (Pat). Discrimination, however, is only one obstacle that needs to be overcome.

### Disability in the Law

In 1990, the Congress passed the Americans with Disabilities Act (ADA). President George H.W. Bush strongly declared, “And now I sign legislation which takes a sledgehammer to another wall, one which has, for too many generations, separated Americans with disabilities from the freedom they could glimpse, but not grasp” (qtd. in Johnson 30). This law serves the 49.7 million people with physical and mental disabilities by addressing issues such as intentional exclusion and discriminatory effects of

employment, architectural, transportation and communication barriers (Catchpole and Miller 1333). The law guarantees “antidiscrimination protection for disabled individuals—defined as those having physical or mental impairments that substantially limit one or more major life activities” (1334). The ADA was passed to eliminate discrimination, to protect people with disabilities, and to ensure justice for *all*. The law holds to the boundless American dream, to what the Preamble of the Constitution promises. However, the law is ambiguous and open for a wide range of interpretation.

The ADA protects people with disabilities from discrimination in employment, compensation, and accommodating facilities. The Equal Employment Opportunity Commission (EEOC) enforces the ADA in the work place. The EEOC clarifies the vagueness of the ADA, further defining “disabled individuals,” “substantially limits,” and “major life activities” (Catchpole and Miller 1338). They determine if an individual is substantially limited in a major life activity by the severity of the impairment, the duration of the impairment, and the long-term impact. These regulations are applied on a case-by-case basis (1342). Despite the ADA’s good intentions, the law is often ineffective. Congress was vague in defining disability so that it would be inclusive as new disabilities arise. However, this ambiguity leaves many people with disabilities in the dark. The courts interpret the standards too conservatively, and ultimately not many people benefit from the ADA (Hartman and Techner). The ADA was passed so that people with disabilities could more fully participate in economic and social life (Catchpole and Miller 1343) and to keep people in the work force (Johnson 33). Yet, when courts view the ADA regulations too narrowly and neglect very limiting

disabilities, they keep people out. President Bush's sledgehammer has not exactly broken down many walls.

### Medicaid

People with disabilities are eligible to receive Medicaid, a program designed in 1965 as part of Lyndon Johnson's Great Society (Wright 30). As of February 2006, approximately 13 million elderly and disabled people receive Medicaid (Goodwin 20). However, as with the ADA, problems with Medicaid greatly limit people with disabilities. Each state has different eligibility requirements. In Colorado, a person with disabilities must earn less than \$2,000 per month and have basically no assets, such as savings or property (Hartman and Techner). One initial problem with the system is that many people cannot complete the application without assistance, due to physical or mental handicaps. At KADEP, three of the 135 clients are illiterate. Without help, these people with disabilities cannot apply for Medicaid benefits. Another issue is that Medicaid cannot provide consistent services. The state sub-contracts services such as transportation and home health care agencies. However, there is tremendous turnover because the employees are under-trained and underpaid (Hartman and Techner).

Nancy is one of the clients at KADEP. She was in a car accident eighteen years ago that left her quadriplegic. She has a personal aid come to her home in the morning to bathe and dress her for the day and in the evening to put her to bed. One Friday I noticed that she was not at KADEP. She later told me that a personal aid did not come from the agency. This meant that Nancy spent the entire day in bed with no food and no bathroom, until the evening aid could relieve her. New care providers are continually being hired

and quitting. People like Nancy barely have time to get to know the person bathing them. Steve, another client at KADEP, was a pedestrian caught in the middle of a car accident. He lost the use of his left side, including his vision, mouth, arm, and leg. Steve receives \$260 per month from Social Security. However, because he owns his own house, he does not qualify for Medicaid (Steve).

Many of the problems with Medicaid are due to the huge financial cuts that states are making.<sup>1</sup> Yet, in the last ten years, Medicaid has tripled its spending. Larger numbers of people are applying, health care bills are increasing, and prescription drug costs are rising. According to Kristine Goodwin in *State Legislatures*, “Medicaid will not be sustainable in the long run” (20). This tragedy has not escaped the notice of public officials. Some states are proposing reforms. Others are making cuts. In Missouri, the state cut millions of dollars from Medicaid and left 90,000 people without coverage (Wright 30). For Wayne Fry, this massive cut left him without his home health aid that provided care twelve hours a day and his twenty-five different daily medications. Missouri cut eligibility requirements from \$1,300 per month to \$300 per month. The state also cut a special program that allowed Fry to earn money working for a nonprofit organization. His only income is \$1,175 per month from a Social Security disability check that does not cover his numerous bills (Wright 31). The “solutions” that Missouri had to fix the problem of Medicaid spending left Fry without care, medicine, work, and an opportunity to have a social life. Fry is only one of the 90,000 people that were left

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<sup>1</sup> Financial cuts are made for numerous reasons and differ in each state. One reason for the major Medicaid cuts in many states is to fund state prisons. Cuts hurt not only Medicaid, but also prescription drug coverage, rehabilitation therapy, and Medicare (Wright 31).

without coverage in Missouri. Wright notes that this new policy is going to force more people into nursing homes, which, long-term, will cost more than cuts in Medicaid save (31).

### Transportation

Transportation is another major limitation for people with disabilities. There are plenty of options that are accessible, but the road is not easy. In Denver, the Regional Transportation District (RTD) has lifts for wheel chairs. However, RTD is not an option for many people with disabilities. Too many people assume that the disabled can remember bus schedules or have the use of their hands to write it down. People with disabilities are vulnerable to being mugged. Many are scared to wait at a bus stop. They have no protection and no defense. RTD access-a-ride provides transportation to people who qualify under ADA regulations. It is \$6 roundtrip. For many of the clients at KADEP, transportation costs more than attending the program (Hartman and Techner). As with home health care aids, drivers do not offer consistent service. People with disabilities do not always have control over what happens. Nancy's aid did not come, the taxi could not give her a ride, and the driver did not get paid. Scott, another client at KADEP, has been pleased with his transportation agency which Medicaid covers. However, he has to give a three day notice when he is going to need a ride which can obviously be very limiting. Scott cannot simply make a trip to the grocery store for a loaf of bread or to the pharmacy for a prescription (Scott).

## Housing

Housing is another issue. Many people with disabilities live with aid services. However, these are only general and do not address specific needs. Government housing is available through a lottery. Often people will be approved but then are unable to get there to verify it because of their disability. Accessible housing is not profitable and therefore is in shortage. The ADA sets guidelines and regulations to make facilities accessible, but there is no follow through. Just because a wheel chair can fit through the door does not make it accessible. People with disabilities may need showers that a chair can roll into or lower kitchen counters (Hartman and Techner). Another KADEP client, Jim, is a man that is very satisfied with ADA. The law has allowed him independence and has saved him from being recluse. However, the one thing he cannot do is cook. He does not trust himself at the hot stove (Jim). If this stove were lowered so that Jim could maneuver his chair around it easily, he would be able to cook.

## Where We Go From Here

It is these basic necessities of life that people with disabilities struggle to obtain. Food, adequate shelter, being clothed by a personal care aid, and getting from point A to point B are inherent things that the disabled community needs and the able-bodied community neglects. Another basic need is love. Many people who acquire disabilities are abandoned by their families. Approximately 30 to 50 percent of the clients at KADEP are divorced for reasons attributable to their disability. It is an easy assumption that all people have family that would care for them. But the reality is that many people with disabilities have no one. They are left alone, some illiterate and some without the use of

their limbs. Many suffer from loneliness and lack of socialization, among many other emotional problems (Hartman and Techner).

People with disabilities face an ugliness of which able-bodied people are so ignorant and unaware. Our society must change. As this war on terrorism continues we will have more and more people with disabilities living in the shadows of our society. Additionally, as the baby boomer generation grows older, more and more people are going to suffer from disabling disorders such as Parkinson's, Alzheimer's, multiple sclerosis, stroke, and Huntington's. However, there are solutions that we can achieve if we are willing to make our society a more just society. Walk in someone else's shoes and then you will understand their walk of life.

Part of solving the problem is to understand the problem. In 1990, the ADA passed almost unanimously; no one is against helping the disabled (Johnson 30). Yet, the disabled are mistreated and neglected. A primary reason for the discrimination toward people with disabilities is fear. People are afraid of what they do not know. Fear brought about the "ugly laws" and pervasive superstitions associating disability with contamination and infection (Connor and Bejoian 54). The negative connotations connected with disability give people reason to fear it. Movies like *Million Dollar Baby* and *The Sea Inside* lead people to fear. This, in turn, leads to discrimination. Our society has made it taboo to talk about disability in public for fear of offending, but people with disabilities will not typically be offended. Their disability defines who they are. At KADEP, employees and volunteers encourage physical contact with the clients. Because fear of disability is so strong, many people with disabilities are never touched. Whether it



is a hug, and handshake, or simply a hand on a shoulder, physical touch creates a personal connection and fulfills a natural human need. One KADEP client once told a bank teller, “I don’t have leprosy you know” (Hartman and Techner).

Awareness and personal interaction with disability can eliminate the fear and discrimination. People need to be more educated with the way of life of people with disabilities. More able-bodied people need to work closely with disabled people (Dinerstein 53). I spent one summer working as a counselor at a camp for people with physical disabilities. The first week I was afraid. I did not know how to treat a person in a wheel chair. I did not want to offend anybody. I talked slowly and loudly. I was nervous pushing people in their chairs. However, it did not take me long to learn exactly how to interact with a person in a chair or a person with only one arm: treat them like you would treat anybody else. By the end of the week my new friends and I were playing chair-tag, sneaking into the kitchen for a midnight snack, and laughing for hours about the talent show earlier in the week. Everyone is guilty of the discrimination, even if unintentional. But if we take a few minutes of our time to get to know someone who might have wheels rather than legs, our similarities soon eclipse our differences.

Disability is a “natural part of human diversity,” simply another bodily feature like race or gender (Connor and Bejoian 52). It is not a medical category. The answer to these issues is not a cure. It is acceptance of difference. While a lot of movies and media portray negative implications of disabilities, some show that diversity does not matter. In the Disney favorite, *Finding Nemo*, the clownfish Nemo has a “gimpy” fin that is not a tragedy or disability: “It just is.” Other characters also have disabilities. Dory has short-

term memory loss. Nemo's classmates are "H<sub>2</sub>O intolerant" and "obnoxious" and the octopus has uneven tentacles. Gill is the fish from the ocean trapped in the fish tank that tells Nemo, "I have a bad fin...it never stopped me" (Connor and Bejoian 55). This movie demonstrates to children and adults alike that disabilities and diversity are normal.

While people with disabilities need to be treated just like everyone else, we also must be aware that people with disabilities live different lives. Able-bodied people must understand that disability is a way of life. After being paralyzed, Christopher Reeve believed that disabilities should be considered as a "temporary setback" (Johnson 32). Most people understood this. People wanted the disabled to continue with life as if they had no disabilities. But the solution is not to deny that they have a disability. And miracles do not happen for all people. Disability is rarely temporary. Yet, Reeve declared he was going to walk again. "Some people are able to accept living with a severe disability. I am not one of them" (33). Reeve did not accomplish his goal of walking by the time he died and apparently places the blame on "opposition to stem cell research" (33). While everyone should have hope and set goals for themselves, we also need to realize that disability is a way of life. It is a good way of life. I met hundreds of people at the camp where I worked and a hundred more at KADEP. The people are satisfied with their lives. They would not trade their disability in for a "normal" body and a "normal" life. Their disability has made them who they are and they are grateful for what they do have.

Changes need to take place on the political level as well. A few states have proposed reforms with intentions to fix problems in Medicaid. Florida wants to contract

private companies that will set their own regulations on eligibility and benefits (Goodwin 20). ADA qualifiers will choose a plan that fits their needs. All will provide a risk-adjusted premium and will cover the mandated services. The details will vary in amount and duration of benefits offered (21). There is both support and opposition to the reform. Currently, the government has no incentive to ensure efficiency of the Medicaid program. Supporters believe that privatization of Medicaid will improve service care and organization through free market competition. Others feel that competition between companies will cause inflation and once again leave the disabled with no coverage (22). Handing Medicaid service over to the private sector will further reduce the distribution of wealth and those at the top of the capitalistic ladder will gain more power. Despite the opposition, it is important that we at least attempt to improve the Medicaid deficiency, one way or another. This way people like Jim can continue to have the independence that the ADA enables and people like Fry can have the aid he needs 12 hours a day and a job to enable him a social life.

Disabilities Cross Coalition is a group of organizations that have combined their efforts and lobby to get laws passed at the state and federal levels. They have had much success and continue to work hard to get more legislation supported (Hartman and Techner). The general public views of disability must change. Techner suggested the possibility of making public service campaigns addressing disability biases to increase awareness. Whether the answer lies in the hands of the media, political campaigns, or personal interaction, we need to be proactive in creating awareness and serving justice to people with disabilities.

### **III. Living with Disability in a Poverty-Stricken World**

While life with disability in the United States has many problems that need to be addressed and obstacles to be overcome, disability in the developing world has even more problems and more obstacles. They bear the heavy burden of poverty, corrupt governments and absence of quality health care in addition to problems of prejudice, transportation, housing and insurance. The drastic difference between disability in the first-world and disability in the third-world can be seen in opportunities for handicapped children: In the summer of 2006, I worked at Camp Courage in Minnesota for adults and children with physical disabilities. We worked with every degree of impairment and ages six to 65. Some people were quadriplegic without the ability to talk or eat. Some were deaf. Some used walkers, some used wheelchairs and some used nothing at all. Despite each person's disability, everyone participated in the fun camp activities. Even if a person had total paralysis, he or she got to ride a horse, play basketball, go canoeing and build a campfire. We had adaptive devices that allowed people with disabilities to ski behind a boat and knock down bowling pins. In the evenings we bathed the campers, administered their medications and completed their physical therapy exercises. Nothing was impossible at this camp.

In the fall of 2007, I worked at Hogar Luby, an orphanage for children with disabilities in the Dominican Republic. Crippled, malnourished bodies lie on a hard tile floor. There are no wheelchairs specially made for each child. There is no physical

therapy to stretch their stiff spastic muscles or medication to prevent spasticity and improve their muscle tone. There is no speech therapy to develop a form of communication for each individual that cannot speak. There are no activities to entertain the children. No assessment is done to measure how bright these children are. Nothing is being done to improve their quality of life or prolong their lives. Camp Courage is proof that disability does not mean limitation or hopelessness or impossibility. But at Hogar Luby, nobody knows the potential that a child with a disability has. These children will never have the life they could.

### Disability in the Developing World

Six hundred million people in our world live with a physical or mental disability. While causes range from chronic disease, injury, violence, infectious disease and malnutrition, eighty percent of people with a disability live in a low-income country. They suffer from poverty with little or no access to basic health care or therapeutic rehabilitation (WHO, "Disability" 2007). No matter where a person lives in our world, disability is a challenge, but the third world redefines what it means to suffer with a physical or mental impairment. Disabled life is heavily influenced by the culture, the laws and mostly the poverty of the developing world.

Despite the numerous biological, environmental, and economic causes of disability, there are many cultural ideas that attempt to explain the reasoning behind physical and mental impairments. Many of these beliefs are born of poverty from inadequacies such as lack of education or unavailable medical treatments. These cultural explanations of disability determine the way disabled individuals are accepted and treated

within their societies. Before modern science began to define causation, peoples believed physical and mental disabilities were punishments or the result of wrong doing (Groce 7; Miller 95). Perhaps a parent committed infidelity or the mother had evil thoughts during pregnancy. Some cultures believed disability was a sign of divine displeasure or bad family blood possessed by evil spirits. The disability could simply be bad luck or fate (Groce 7). Whatever the cultural belief behind the impairment, the individual was not considered an innocent victim. They were blamed for what they suffered. Others in the society avoided the individuals with a disability for fear of “catching” the deficiency (Groce 7). Not only was the disabled individual blamed, but a disability reflected badly upon the entire family (Sotnik and Jezewski 27). Both individuals and families of disability were an embarrassment to the society (Groce 7).

### Disability in the Law

In many poor countries, laws to protect people with disabilities do not even exist. In other governments, the legislation has been made only to collect dust on the shelf. Policies and programs ensuring quality of life to those with disability are rarely implemented or enforced. Many of the disabled in the third world experience social, economic and political disadvantages as well as denial of human rights. The Dominican Republic is a small Caribbean country in the Greater Antilles archipelago with a 500-year history of afflicted economy and corrupt politics. Of its almost 8.6 million people, 25 percent live below the Dominican poverty line (CIA 2007) and the majority of the population lives below the American poverty line. Those who live with a registered disability number 358,341 (One 2007). Many more have undocumented mental or

physical impairments of which the government is unaware. Two million Dominicans, almost one-fourth of the population, do not have birth certificates and are therefore excluded from the system (Wooding and Moseley-Williams 50).

There is good legislation protecting the rights of people with disabilities in the Dominican Republic. Law 1494, passed in April of 1994, applies to all children with temporary or permanent sensory, physical or mental disability (Suero 166). It assures equal opportunities to education, employment, marriage, parenthood, political rights, privacy and property. The law guarantees health and medical care, rehabilitation, counseling, financial security and independent living (López-De Fede and Haeussler-Fiore 193). Full respect for human dignity and opportunity to enjoy the privileges and benefits that the law permits are assured. The law ensures there will be actions taken to prevention, detection, education, treatment, rehabilitation and investigation to the fields of disability (Suero 167). However, despite the solid foundation of Law 1494, the legislation is not applied because of “limited fiscal resources, shortages of trained personnel, accessibility barriers, cost associated with assistive devices and prescriptions, and lack of rehabilitation facilities” (López-De Fede and Haeussler-Fiore 193). Neither government officials nor the general public recognize the law. Many Dominicans are simply unaware that the disability protection exists.

### Public Health

Similar to the lack of enforced legislation, public health in much of the third world is either nonexistent or not implemented (O’Hara 373; WHO, “Disability”). The United States began taking public health measures as early as the 1870s simply by

purifying water, controlling sewage and waste, giving immunizations and employing pasteurization (Fedder, Desai and Maciunskaitė 330). Unfortunately, countries such as the Dominican Republic have still not taken the correct measures to address these basic health needs. In fact, according to the World Bank Report, during the 1990s, the Dominican Republic spent only two percent of their gross domestic product on health-related services. World Bank recommends that governments should offer their people prenatal and intrapartum care, childhood immunization, clean water and sanitation (Carman and Scott 28). Even more, in many countries, disability is excluded from public health leaving no protection or support for people with impairments. Poverty further limits their access to health and rehabilitation (WHO, “Disability”).

### Poverty

Disability can be “both a cause and a consequence of poverty” (WHO, “Disability”). It is a continuous cycle, as shown in Figure 1. Socioeconomic and political instability can lead to malnutrition which causes disability or impaired development. This can compromise immunity which causes infection and disease. With bad health comes reduced economic productivity and therefore poverty. In an economically and politically unstable society, there is a lack of education and health systems, which reignites the cycle of poverty, leading to an economically and politically unstable society (Schaible and Kaufmann 806). Disability impacts the productivity of the community and its already limited resources (Carman and Scott 31).



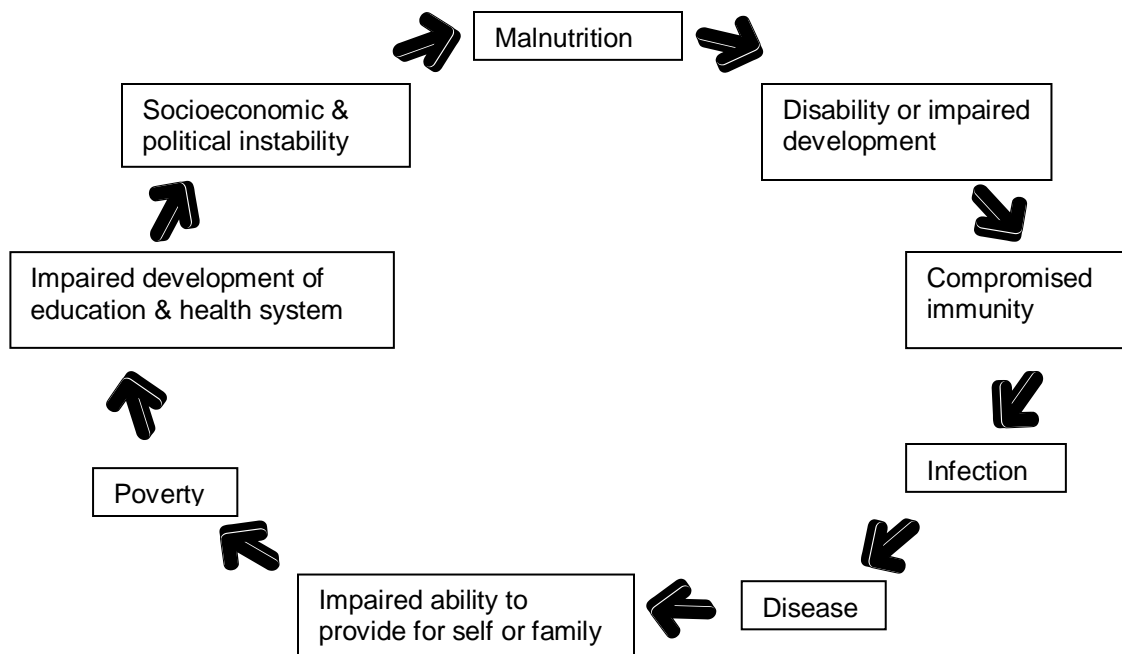


Figure 1. The Cycle of Poverty

Adapted from Schaible, Ulrich E. and Kaufmann, Stefan H.E. “Malnutrition and Infection: Complex Mechanisms and Global Impacts.” *PLoS Medicine* 4.5, May 2007: 806.

According to the bioecological model of development theorized by psychologist Urie Bronfenbrenner in 1979, an individual is a reflection of his or her environment (Figure 2). The individual is the center of this model, enveloped in multiple levels of environmental factors that influence his or her development (Bronfenbrenner and Morris 1002; Siegler, Deloache and Eisenberg 346). The cycle of poverty weaves through each of these levels, affecting each environmental factor and its influence on the individual.

The first layer in which the individual is embedded is the microsystem which is comprised of factors with which he or she has direct contact, such as activities, roles and relationships. Each factor in the microsystem is bidirectional, meaning that the environmental factor can influence the individual and the individual can impact the

environmental factor. The second layer is the mesosystem (not shown in Figure 2). This level represents the connections among different microsystem factors. The exosystem is the third layer, defining the larger social system in which the individual does not function directly but still has influence in development (Siegler, Deloache and Eisenberg 346). The outermost layer is the macrosystem, comprised of cultural attitudes, laws and customs. The final component of Bronfenbrenner's model is the chronosystem which takes into consideration changes over time. For example, social values change, technology changes, people pass and the individual grows (348).

In poverty-stricken societies, where the cycle of poverty intertwines this bioecological model of development, the individual is strangled by socioeconomic and political instability, by impaired development of education and health systems, by malnutrition. The environmental factors of the micro-, exo- and macrosystems negatively influence the individual and lead to impaired development or disability.

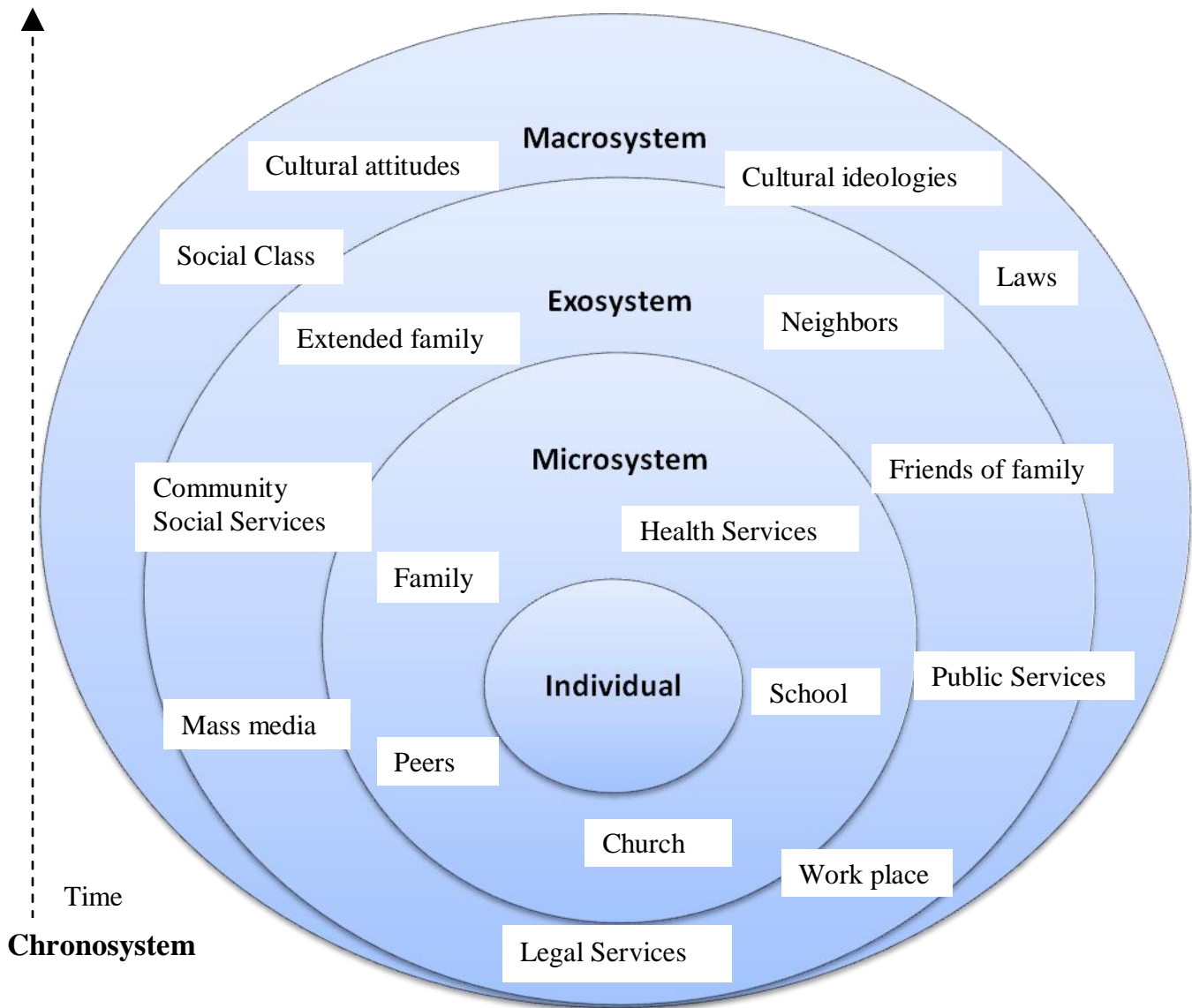


Figure 2. The Bioecological Model of Development  
 Adapted from Bronfenbrenner, Urie., & Morris, P. A. "The Ecology of Developmental Processes." *Handbook of Child Psychology, 1*. New York: Wiley, 1998: 993-1028.

With the lack of public health to guarantee people their basic health needs, the cycle of poverty continues its hopeless devastation generation after generation on each bioecological layer. Over 1.1 billion people in our world do not have access to purified water. Approximately 2.6 billion people do not have access to safe sanitation (WHO,

“Water”). Sixty-one percent of child mortality in the Dominican Republic is caused by communicable diseases that surface from contaminated water and poor sanitation (Carman and Scott 28). Nutritional and energy deficiencies can inhibit childhood development and lead to mental impairments and retardation. Maternal and early childhood malnutrition can also cause chronic disease (31). The cycle continues: Under-nourished girls with greater susceptibility to health problems will have low birth weight babies who “are unable to catch up in an environment where the water is contaminated” and the sanitation is unsafe (31).

Malnourished children are predisposed to respiratory infections, diarrheal diseases, measles and malaria. These illnesses are typically prolonged and exacerbated with a lack of nutrients in the body (Schaible and Kaufmann 808). Furthermore, third world countries cannot provide for their sick. During one weekend in September a hospital in the capital city of the Dominican Republic had eighty registered cases of respiratory infections in children age one to five. Fifty percent of the cases were pneumonia, according to the newspaper *Listin Diario*. Doctor Cruz Jiminián attributed at least eight of the respiratory infections to the environmental contamination. The director of the hospital, Luisa Lafontanine, believes the illness is a result of bad hygiene of the children and recommended that families clean their houses of spider webs and mice (Feliz A11). This is the harsh reality of health in the third world.

#### Environmental Toxins Influence Disability

Environmental toxins are another major cause of birth defect and disability in developing countries due to poverty and inadequate laws. Poverty is highly correlated

with excessive exposure to harmful environmental toxins such as pollution and pesticides. Economic factors limit choice and too often leave the poor living in high risk areas of toxic exposure (Dilworth-Bart and Moore 247). Substances from pesticides and other environmental toxins poison victims in many ways. They are present in the workplace as well as in a family's home and they are difficult to control. The pollutants are in the air from crop dusting and spray drifting. Workers bring contaminants home on clothing, skin and hair. People also consume the pollutants in their water and food (Dilworth-Bart and Moore 253-4).

Environmental toxins have the greatest harm on fetuses and infants. These victims are more sensitive to organophosphorous and polycyclic aromatic hydrocarbons, both major chemicals used in pesticides, because of lower levels of cellular enzyme activity (Laviola *et al.* 332; Perera *et al.* 1287). Prenatal exposure to pesticides correlates with adverse neurodevelopment. Results can lead to impaired fetal growth from DNA damage, growth retardation, reflex failure and disrupted neural sensorimotor circuitry (Laviola *et al.* 340; Perera *et al.* 1290). In research conducted with rodents, pesticides were shown to cause behavioral effects such as hyperactivity, learning and memory problems and altered habituation. The Environmental Protection Agency set pesticide regulations based on results from animal research that has shown gross malformations, fetal loss and tumor formation from acute and chronic exposures to these chemicals (Dilworth-Bart and Moore 253). Furthermore, children are at risk for performance deficits in cognitive domains such as language, reading and math (Perera *et al.* 1290). Behavioral disturbances and neuropsychiatric disorders can also be a result of environmental toxins. Laviola and

his colleagues found that pesticides can alter cholinergic concentrations characteristic of both schizophrenia and autism (332).

Sabana Rey is a small campo in the Cibao Valley of northern Dominican Republic. The main occupation and source of income for the people of Sabana Rey comes during harvest season of the hundreds of acres of rice fields. For generations, the agricultural workers have been using pesticides that have contaminated the water, soil and produce of the fields. In the United States since 1991, the Department of Agriculture, Food and Drug Administration and Environmental Protection Agency have monitored and regulated the use of pesticides and residues found in foods (Dilworth-Bart and Moore 254). However, the Dominican Republic and most of the third world has no laws concerning these harmful pesticides. The effects of pesticides are very apparent walking through the dirt roads of Sabana Rey. Several people have malformed faces, extra appendages and uneven pigmentation. Children with twelve fingers play dominoes on the sidewalk. These victims are most likely being exposed to nitrates in the pesticides used in the rice fields. They are breathing in the toxins from the air and from the workers' clothes. They are consuming the foods grown in contaminated ground. Furthermore, there is rarely clean, running water to wash foods, clothes or hands. Much disability results from environmental toxins as well as from unjust poverty.

#### Disability from a Cultural Perspective

Culture, like inadequate laws and third world socioeconomic situations, also unmistakably affects how people with disabilities are received in their own societies. Even with modern science that today can biologically explain why people are born with

impairments, much of the third world continues to employ false cultural ideas. According to López-De Fede and Haeussler-Fiore who have studied the culture of disability in the Dominican Republic, the people believe illness to be the result of three different circumstances: psychological states such as envy, anger, embarrassment, worry or guilt; environmental or natural phenomena like germs, bad air, excess cold or heat or bad food; or uncontrollable supernatural reasons (192). The small country of Haiti occupies the western third of the island shared with the Dominican Republic. It is the poorest country in the Western Hemisphere with destroyed land, destroyed economy and 80 percent of its people living in poverty (Jacobson 142; Wooding and Moseley-Williams 25). In the Haitian culture, disability is not discussed. It is considered mysterious and dangerous. Their ideas are rooted in the Haitian religion, Voodoo, a combination of African tribal religious practices and Catholicism. Rather than disability being a medical issue, it is considered a curse, punishment, or a spell cast by an enemy. Parents of a disabled child show love to the individual, but regard the child as worthless (Jacobson 147). A person with disability is considered crazy, stupid or possessed and is treated as an animal by society. Others avoid contact in fear of displeased spirits. Haitians believe disability is contagious and therefore avoid touching any object that has been touched by a disabled person. The disabled are also kept from the public eye (Jacobson 148).

While these cultural beliefs are still widely alluded to, acceptance of people with disabilities has improved with a scientific understanding of causation (Miller 100). People accept impairments if they know why the impairments exist, rather than blame the cause on a curse or evil spirit. Physical disability is generally more accepted than mental

disability. In the same way, acquired disability is more accepted than congenital disability (Zhang Liu 70). If someone is paralyzed as a result of a motorcycle wreck, it is recognized as simply an accident rather than a curse from evil spirits. When a child is born with cerebral palsy as a result of complications during birth, it is harder to see it as simply an accident.

The cultural acceptance of physical compared to mental disability is very apparent in Sonador, a small campo in the northern mountain range of the Dominican Republic. There are two individuals with a disability in the community. Rafael is a forty-year-old man with mental retardation and scoliosis. While his disability is only slightly physical, it is the mental handicap that is most noticeable upon meeting Rafael. Jimmy is a sixteen-year-old deaf and mute boy with what appears to be mild cerebral palsy affecting only the lower half of his body. His feet and ankles have mild spasticity which causes an imbalanced, shuffled gait. Jimmy's mind is perfectly intact and he can communicate clearly through his very animated system of sign language. While neither Rafael nor Jimmy is ostracized by Sonador, there are evident differences in how each are treated by their family and friends. Jimmy, even with his handicapped hearing, speech and gait, is able to associate with the other teenage boys from the community. He plays baseball and helps with the physical labor in Sondaor. If people pick on him, he can hold his own. He communicates his intelligence and plays his part in the community. Rafael, on the other hand, is not as respected. He lives with his parents and does not typically venture far from the house. When he speaks to people they often shrug him off. One of his nieces admitted that she does not like to call him her uncle because she is embarrassed. Rafael is never



mistreated, but also is not seen as an essential member of Sonador. In many third world cultures, mental impairment is the most stigmatizing disability (Miller 98), as visible in Sonador with Rafael and Jimmy.

### Public Awareness of Life with Disability

The problem of having no role in society, as Rafael and many others with disabilities, is intensified by stigma and discrimination that prevent full acceptance and involvement in a community (Groce 9; Who, "Disability"). The stigma and discrimination exist because there is no public awareness of life with disability. Too often children with disabilities are excluded from the public eye. Parents try to keep secret their family's deficiency. From the start, the child is labeled as incompetent. He or she is kept from helping, working and leading an independent life. With the lack of education in developing countries, parents as well as community members are unaware of a child's potential. Information and education about management of disabled life is almost nonexistent. Parents are not acting out of cruelty by keeping their children away from society; rather they simply do not know of available and possible resources (Miller 99). For example, Emi is an eight-year-old girl at the orphanage Hogar Luby. She has cerebral palsy, is quadriplegic and cannot speak. However, her mind seems to be very intact. She finds ways to communicate with her eyes. She laughs at jokes and stories. The potential of Emi's mind is overlooked because of her profound physical disability. If she were given a computerized assistive device offered by speech therapy programs in the United States, Emi would be able to use the computer as her voice. She could participate in intellectual conversations and even receive an education. However, Emi's potential will

never be fully reached simply because her caretakers are unaware of possible opportunities for people with disabilities and because these technologies are unaffordable and unavailable in the Dominican Republic.

Not only are people unaware of worthy life with disability, the cultural depiction and grave poverty are limiting factors in helping an individual reach his or her full potential. Because of the cultural beliefs or restraints due to economic situations, basic measures are not taken. For example, according to Miller, a Jamaican woman gave birth to a baby with a facial abnormality and refused to even touch her child. The baby was left abandoned at the hospital (98). The woman obviously felt extreme shame and embarrassment and wanted no association with a “contaminated” child. This appalling incident is the cultural reality in many developing countries. Many of the Dominican children at Hogar Luby have been abandoned in parks and on the doorsteps of the orphanage. In Haiti, because of the cultural stigma of disability, when a child is born with impairment, many times the father will impregnate another woman in hopes of having a normal child to prove that the disability was not his fault (150-1). Other parents, however, may react in the opposite way, being very nurturing but also overprotective, sometimes to the point of hindering the ability of becoming independent (Miller 98). If the parents of children with a facial abnormality, Down’s syndrome or cerebral palsy knew how to manage the disability and understood that their child could still lead a normal life, there would be a lot fewer kids left parentless in orphanages or in the hands of a single mother.

#### Economic Influences on Disability

The economic struggle of the third world prohibits many people with disabilities from reaching their full potential. For one, there is very limited access to health services. Transportation is often difficult and costly. According to physical therapist Nick Greer, about 75 percent of Dominicans use medical services less than two kilometers from their home. Unfortunately, there are rarely services this close to the majority of the Dominican population, especially in rural areas. Even when there are services available, medical professionals are often not. In Haiti, with a population of eight million, there is only one doctor for every 4,000 people (Jacobson 142). Many people do not seek medical help to avoid financial embarrassment (Miller 106). Others cannot afford time off from work to travel into the city, take a number at the clinic and wait eight hours only to be denied help and start over again the next day, hoping to get a lower number. Another problem in seeking medical aid is confronted by machismo culture. Many men simply believe they can fend for themselves and therefore do not seek help for themselves or their children (Greer; Miller 106). Illiteracy is yet another barricade in receiving health services. Many parents or caretakers of disabled people cannot read or write and consequently struggle more with understanding disability and available resources.

Trudy Bekker is a physical therapist from the Netherlands that has spent the last 14 years working with disabled people in the Dominican Republic. She believes that social economics is the biggest problem faced by Dominican families that have a child with a disability. The families Bekker works with do not have the financial resources to receive health services. They are poor before having to pay medical bills. If they choose to spend money on health care, then they lose their dinner for a week. Many times a

medication will cost more than the family has to live on for one month (Bekker). Pat Malone is a Jesuit priest who spent two years with an African tribe in Mali. He witnessed communities encouraging parents to do away with a child when he or she was born with a disability. This was meant as an act of mercy (Malone). The sacrifice required to raise a disabled child would result in killing the rest of the family. It was better to lose one life than to starve several.

### Health Care Inadequacies

The cycle of poverty continues (Figure 1). Economic instability leads to poverty, which leads to impaired development of educational and health systems. Most of the third world suffers from some level of health care inadequacy. First of all, below par medical education is the standard. In the Dominican Republic, there is no undergraduate prerequisite preceding medical school. Students enter into the six-year medical program directly after high school. Angelina from the campo of Sonador is eighteen-years-old in her second year of medical studies. When Dutch physical therapist Trudy Bekker was asked what she thought about the level of doctor education in the Dominican Republic, she replied that it is “lower than my own training” (Bekker). I also came to a similar conclusion after meeting two medical students at a private hospital in Santiago. They were the same age as me but already doing independent clinical rotations. We were discussing the dengue epidemic in the Caribbean and while they were very educated on the infectious disease, they could not tell me the neural effects of dengue. I seemed to know more than these medical students with my undergraduate neuroscience studies and questioned if they would even know what to do if the hemorrhagic infection caused

cerebral bleeding. Greer commented that neurological disorders frequently go undiagnosed because they are not covered in the medical text books or course material (Greer). As a result of substandard medical education, malpractice is common. One of the primary disabilities in the Dominican Republic is cerebral palsy (Bekker; Greer). This disease results from disruption of cerebral oxygen supply during the birthing process and can lead to a number of physical or mental impairments depending on which part of the brain is affected. The uneducated doctors do not know what actions to take when complications arise at birth and therefore many children live with the permanent, progressive deficits of cerebral palsy.

Another area of health care inadequacy includes the absence of medical documentation. Individuals' medical histories are unknown because prior health records are unavailable (Carman and Scott 31). If a man goes to the emergency room complaining of balance loss, numbness of the right side and slurred speech, all clear signs of a stroke, doctors cannot look at his nor his family's history of high blood pressure, heart problems or diabetes because no health records have been kept. Some of the reason for the absence of medical documentation is that most people living in poverty do not have a primary physician nor have annual check-ups (Greer). According to Greer, over half of the medical visits in the Dominican Republic are emergency visits. People do not practice preventative health. Women in particular are at high risk of health problems because they do not receive routine gynecological examinations or pre- and postnatal care (Bochenek and Delgado 697).

These health care inadequacies are rooted in the poverty. They affect not only the medical education and the health care given, but also the modern technology with which is available to practice medicine. The third world constantly struggles to balance and integrate new and old scientific knowledge because they simply lack many of the modern resources and must continue to depend on dated technologies. Even when doctors do have access, familiarity with the science and technology are limited (Sotnik and Jezewski 23). Luis is a three-year-old Haitian boy living at Hogar Luby. He is a very bright child. He understands three languages: Haitian Kreyol, Spanish and English, but he also has vision, neck and leg impairments due to untreated jaundice. In the United States, eye surgery would correct his vision problems which would also fix his neck impairment that only exists because he cranks his neck to focus his eyes. He would have access to ankle-foot orthoses and leg braces that would enable him to walk. In the Dominican Republic, none of these technologies are available or even known. A normal life for Luis would be easily attainable in the United States but in the Dominican Republic he will grow up in an orphanage never learning to walk. Fortunately, there is an American couple trying to adopt Luis and offer him the medical attention he needs, but most disabled child victims of poverty never receive this miracle.

Modern assistive devices are hard to find in developing countries. Most are constructed by hand, purchased secondhand or donated by international organizations (López-De Fede and Haeussler-Fiore 193). In many poor areas, a “great deal of creativity in crafting appliances that foster independence” has been observed (193). I have seen this with Luis at Hogar Luby. He cannot walk, but he can crawl up a plastic chair and scoot it

along the floor, using it as a walker. This innovativeness allows Luis to explore the whole facility rather than be confined to one room. The creativity and manual skills utilized by many cultures give people with disabilities some degree of assistance even in economies that cannot afford assistive medical devices.

### Cultural Influences in Seeking Medical Care

Because of the relentless poverty, indifferent skepticism prevails when the necessity to seek medical help arises (O'Hara 374). Some cultures believe a physical or mental condition should not be altered. Health is considered predetermined and cannot be solved with human intervention or modified with adaptive technology devices (Sotnik and Jezewski 23). Similarly, self-sacrifice is valued and respected. Living with a disability is considered surrender to the will of God (23). As Greer commented, Dominicans do not believe they have control of their health or disability. It is simply in God's hands (Greer). A saying used in everyday conversation in the Dominican Republic is "Si Dios quiere" or "If God wills it." After centuries of economic destruction and overwhelming poverty, perhaps putting life in God's hands is the only way of finding hope. Answers to health problems are sought by prayer and rosaries offered to the Virgin Mother (López-De Fede and Haeussler-Fiore 196; Zhang Liu 69-70). In Haiti, disability is considered a failure and therefore Haitians see no point in seeking treatment or rehabilitation (Jacobson 148). Often third world cultures will self-medicate or use home remedies passed through generations before pursuing medical help (Miller 97). Many developing countries are not future oriented. This is another way that culture influences the motivation to obtain health care. Treatment and rehab require time and commitment.

People who live in poverty cannot look too far into the future. In order to survive, they must worry about today. As a result, people find it hard to see the benefit of working toward a goal that cannot be immediately met. In the same way, they fail to find purpose in taking medications that do not have immediate effects (Greer; Jacobson 152; Sotnik and Jezewski 61). Also, because of high illiteracy, many people fail to continue and complete rehab and regular evaluations (Miller 89).

The substandard health care system due to poverty and cultural influence affects the opportunities offered for people with disabilities. The World Health Organization and United Nations publish recommendations to reduce functional limitations of disability by promoting community awareness, public accessibility and access to education and employment (WHO, "Disability"; United Nations). However, while laws do guarantee basic human rights and equal opportunities, third world governments simply cannot and do not offer these opportunities. Laws promising the disabled equal rights and access to basic health care are not enforced.

### Government Facilities

Many people with disabilities are imprisoned in meager government facilities. Culturally, putting a child in an institution is not accepted. It is considered neglect from the family whose role should be to provide and care for its children (Groce 10; Miller 107). Similarly, Dominican Law 1494, Article 163 makes the responsibility of a disabled individual the priority of the family (Suero 167). However, as discussed before, many disabled children are abandoned because of social embarrassment or inability to afford the special care.



There are ten Hogar Luby facilities throughout the Dominican Republic. They are government-run homes for children with disabilities under age 18. The facility in the capital, Santo Domingo, is understaffed and overburdened with 140 kids. The immobile children lay in bed 24 hours a day. There are no activities, toys or interaction with the kids to stimulate them physically and mentally. There is constant screaming and children running wild because there is nobody there to give them the attention that any child needs. There is no physical therapy or medications offered for the children's disabilities. The biggest problem is the lack of personnel which is also the largest cost. While a private organization, Foundation for Dominican Child Care, spends approximately 60,000 Dominican pesos each year and helps on average 300 children, Hogar Luby in Santo Domingo spends about 60,000 pesos each month providing for only 140 children (Bekker). Hogar Luby in the smaller city of Santiago is not quite such a horrible scene. There are only 38 children and there is more space for immobile individuals to be moved from their beds a couple of times a day. However, there is still no therapy, stimulation or medication for the children. Hogar Luby offers a home for children only until they turn 18. After this, they are placed away in a public health home, according to the law. However, there are no public health homes in the Dominican Republic. When a child "placed away," he or she is sent to the top floor of a public hospital and will lay there for the remainder of his or her life (Bekker). Fortunately, many of the children in the orphanages do not have birth certificates and their age cannot be proven. Many times the caregivers will intentionally forget to inform the government when a disabled individual turns 18.

In the government facilities, there is nobody following up with the regulations to insure the needs of the children are being met. Government jobs in the Dominican Republic are typically given to friends of the president. A person employed by the government is guaranteed a stable job for at least that presidential term. With the high rates of unemployment in the country, securing a job is very important, regardless of a person's skill. Many employees at Hogar Luby are there for the paycheck, not to care and love the hundreds of children with disabilities. The children are often neglected. At Hogar Luby, the employees are often mopping floors rather than changing soiled pants. The sister of the current Dominican president is the head of child services. She should be the one regulating the government homes, when in reality she is not aware or educated in the needs of children with disabilities (Bekker).

### Accessibility

Opportunities for people with disabilities are very limited in developing countries, whether one lives with a family or in an institution. Accessibility is major obstacle in achieving quality of life and participating in society. Dominican Law 1494 Article 167 ensures public access for people with disabilities. It reports that construction companies will not be able to obtain a building license if the blueprints do not comply with the guidelines (Suero 168). A building code is set by the Colegio Dominicano de Ingenieros, Arquitectos y Agrimensores (Dominican School of Engineers, Architects and Surveyors) (Bekker). However, like many laws protecting the disabled, the building code is rarely enforced. Even Hogar Luby is not accessible. The home is located up a steep flight of stairs with no elevators in the building. The only way for the children to get outside is to

be carried down the stairs, which never happens. They cannot get down the stairs to enjoy the outdoors, let alone in the case of a fire, earthquake, or hurricane.

### Quality of Life

In the United States, doctors, therapists and social workers' foremost goal when working with permanent disabilities is to optimize the person's quality of life. The personal well-being and subjective satisfaction of the individual are the primary areas of concern. A person with disabilities should have more than mere existence. He or she should be satisfied with oneself and with the life he or she leads. Quality of life means being able to exercise rights and participate in society. It means having a place to live, food to eat and clothes to wear. It means belonging to a group of people and having social relationships (Aznar and Castañón 785). In countries like the Dominican Republic, there are not laws or social workers insuring that people with disabilities have quality of life. At Hogar Luby, I am not sure I could honestly say that those children are doing more than merely existing. Nobody asks them if they are satisfied with their lives. They do have a clean facility, food and clothing and there are a few compassionate workers who show love, but there is not much that gives their lives purpose.

### Where We Go From Here

Despite the unyielding cycle of poverty that drives people with disabilities into inadequate health care, dreadful government facilities and low quality of life, there is hope for change. Fundación Cuidado Infantil Dominicano (FCID) (Foundation for Dominican Child Care) is one organization that works to promote health education, rehabilitation and opportunities for children with disabilities in the Dominican Republic.

Physical Therapist Trudy Bekker is one of the founders and national director of the program that has helped over 1,100 families since 1993. The philosophy of FCID is helping disabled children reach their maximum potential through community-based rehabilitation (Bekker). The goal is to help people help themselves. FCID trains community promoters that visit families of disabled children each week. They work with the mothers to educate the family about the disability and to develop activities that stimulate physical and mental growth. FCID has over 30 volunteer promoters that work with over 300 children. Disabilities range from cerebral palsy, mental retardation, deaf, blind and behavioral deficits. Most of the promoters are mothers of a disabled child. Training is provided in two-day sessions six times a year over a two year period. Promoters learn how to evaluate a disabled child in the areas of socialization, language, independence function, cognition and motor development (Greer). They are educated in the problems encountered by physical and mental disabilities in their communities. The promoters are trained how to exercise physical and occupational therapy, depending on the needs of the child. They learn how to do range of motion and stretch spastic muscles. They also learn the proper way to position a paralyzed child to prevent muscle spasms and pressure ulcers (Bekker; Greer). With the mother, the promoter works to develop weekly objectives for the disabled individual to accomplish. Once the objective is mastered, they set a new goal. The objective is made according to each individual's ability. For one boy it might be writing his name. For another it could be walking across the room or helping cook dinner. It could be reciting the alphabet or exercising a paralyzed limb. Objectives often involve the entire family to build understanding and

better relationships. The work FCID does is evaluated and approved by the Creighton University Physical Therapy program (Bekker).

FCID helps people help themselves by empowering families through educating and creating awareness that can break down the barriers of life with a disability. The program creates a community that offers social and emotional support. FCID helps families in such a way that they do not develop dependence on the promoter or the program (Bekker; Greer). They educate the family, specifically the mother, and open doors to opportunities for their child. With the primary caregiver administering rehab along with the promoter, treatment is consistent, which is “especially important in a country with an unstable health system” (Greer). The community-based rehabilitation allows treatment to be individualized to the needs of each child, eliminates transportation costs for the family, creates awareness of disability within the community and improves the child’s self-esteem. The program also prevents families from putting their child in a government facility (Bekker; Greer).

Many mothers in the community-based rehab program still struggle. One of the primary problems is that children often have more than one disability. Promoters are trained to work with physical or cognitive impairments, but not together, which is very typical of cerebral palsy. When a child does not have the ability to write or talk, therapy becomes more difficult. Also, promoters need to be educated in normal childhood development so that they can earlier identify disabilities in their communities. Often limitations of education come with a limited budget and a lack of neurological disorder specialists. In addition to improving the promoter education, there is a strong need for

community-based rehab throughout the country. FCID currently only serves the Santiago province. There are many more families in need of the assistance offered by this organization (Bekker; Greer).

FCID also helps people with disabilities find jobs within society. Currently, 30 women have been taught the skills necessary to work in a beauty salon. With these skills, the women can work and earn money anywhere, including within their own homes (Bekker). Beauty services are very popular in the Hispanic culture. The women with disabilities are helping to create public awareness by participating in the workforce. Job placements stimulate individual skills and help build relationships with the community. FCID teaches men how to sew or finds jobs for them in free zone factories. A few men with disabilities work in a Santiago factory assembling electronic parts. FCID is also working on sending some people to art school. This serves as a form of art therapy stimulating several areas of the brain and also gives individuals a way of earning money by selling their art (Bekker). Placing disabled people, especially women, into the workforce is helping overcome the barriers of life with disability.

FCID and other private organizations are making much progress through community-based rehabilitation and other outreach programs. These groups offer hope to many of the disabled throughout the world. Yet public health also must improve. Developing countries need to work to better their water and sanitation systems. They must promote preventative education and personal hygiene. Schools can begin with simply teaching children to wash their hands and seek medical attention when needed. They can offer child screening and immunizations. Governments need to put more money

toward public health as well. Bekker commented that if the Dominican public health system had medications for people, they would administer them without second thought. However, the fact is that they have nothing to offer their people (Bekker; Carman and Scott, 32; Greer; WHO “Disability”). Governments of developing countries must also start enforcing the laws that protect people with disabilities. They must improve their health care system and better the medical education. They must try to stop the preventable causes of disability. Answers to improving the life of people with disabilities involve more than medication and rehabilitation. Societies must develop positive attitudes toward disabled people and create more disability awareness (Bekker; WHO “Disability”). The cultural beliefs that limit people with disabilities need to be reversed. People have to believe that they have control over their own health. Disabled individuals must have quality of life. They must “be the owner of one’s life beyond the mechanical performance of it” (Aznar and Castañón 787). Still, the only way to overcome the struggle of people with disabilities in the third world is to break the cycle of poverty. Carman and Scott boldly claim, “The Caribbean region has been labeled the most inequitable in the world” (28). Until this changes, the Dominican Republic will continue to have nothing to offer its people. Disability is a harsh reality in our world. To live in the midst of poverty is to witness the pain that people with disabilities suffer everyday.

#### **IV. Justice for All**

We live in an unfair world. A man in a wheelchair must find his own way in an unfamiliar city in the cold bitterness of winter. An Iraqi soldier must sleep in a hospital infested with mice and cockroaches, slowly deteriorating from recent brain damage. A small child with untreated jaundice must live imprisoned in an orphanage without medication or therapy. This is not justice. Yet suffering and evil exist as part of life. According to Jesuit Dean Brackley, “we are all guilty bystanders in a cruel world...All that is needed for evil to triumph is that good people do nothing.” Some people are born with severely debilitating cerebral palsy. This is not evil; rather it is simply part of being finite beings. But when people with cerebral palsy suffer “terrible pain, alone, uncared for, without dignity—that is evil” (Himes 73). For the world to change, it is we who must change it. John Locke wrote that “every human being has a right to life, and therefore to those things necessary to preserve life.” We need to honor the life and dignity of every human person, whether lying on the hard floor of an orphanage or confined to a wheelchair and dependent upon a personal aid.

Yet why do so many lives fail to receive dignity? Why are people with disabilities so often neglected by their own cultures and societies? During the fourth century B.C. Aristotle wrote in *The Politics* that all societies work toward a common good and the political state is necessary to protect not only life itself but to protect a good life (54, 59). Humans reach this goodness through law and justice and through each citizen making his



or her contribution to the society (61, 177). Similarly, Jean-Jacques Rousseau wrote that humans naturally feel concern for other humans and organized civil society brings this forth (Nelson 235). Humans recognize the need to come together to overcome physical limitations.

However, societies such as the United States and Dominican Republic fail to achieve natural human goodness because despite the need to cooperate, we too often live to satisfy our own desires. Sociologist Gerhard Lenski's Ecological-Evolutionary Theory (2005) explains why societies come short of reaching justice for all. He writes that we are social beings obliged to cooperate in order to survive and to satisfy human needs and desires (109). Yet he also argues that humans are heavily influenced by self-interest (105). We often put our own needs and desires as top priority, which creates social conflict. This is not a new idea. In the seventeenth century, Thomas Hobbes similarly wrote that humans are "driven by selfish appetites and a desire for power over others" (Nelson 178). Lenski adds that society is imperfect. Not every aspect functions for the good of the whole; many parts aid the needs of individuals or certain groups. This leads to the presence of inequality in every human society (113). Goods and services are often distributed on the basis of power rather than need (114). People with disabilities are abandoned in poor public housing facilities and left homeless on the streets because resources that are already in short supply are not allocated to those who need them. Those with Down's syndrome or severed limbs are hit with the ramifications of inequality because humans so often act out of self-interest. Because societies resist change, we continue with our lives allowing people with disabilities to lose their insurance or to live

without much needed therapy and medication. This is not justice. We are not respecting others and their rights. We are not building relationships that promote equality and the common good (*Catechism of the Catholic Church* 1807).

### Where We Go From Here

There is no one answer to changing human society and solving the injustices that allow people with disabilities to suffer. And because the third world is in such a drastically different position than the first world, one simple solution cannot remove all obstacles that people with disabilities face. Yet there is hope in gradually easing the road for the disabled, in both the United States and in the Dominican Republic.

To see this hope, we can look at the progress through history. One hundred years ago our Congress passed the “ugly laws” banning people with disabilities from the public eye. Twenty years ago we passed a law protecting people with disabilities from discrimination in all aspects of society including employment, public accessibility, transportation and communication. Scientific progress has given us medical explanations for disability. Public policy has helped us understand disability in a social context, just as we view any other type of diversity. Understanding of disability will continue to grow as society continues to progress. Our response to disability, then, is a continuum on which the United States has made much progress but still has obstacles to overcome.

In the same way, the third world will eventually advance further on this continuum. As the Dominican Republic improves economically, scientifically and socially, understanding of disability will improve. Science and education will provide reason for causation rather than leading to disability blamed on divine punishment.

People will come to trust medical knowledge which shows genetics are uncontrollable rather than the result of cursed blood. This will end the cultural stigma of disability and bring people to be more open toward this type of diversity.

However, we cannot just sit and wait for this continuum to advance. If we continue to be guilty bystanders, we may have to wait another 80 years for a better law aiding people with disabilities. The most important thing we can do is create more awareness of life with disability. We need to eliminate fear and cultural stigmas. Society is strongly rooted in the environment, heavily influencing social structure and culture (Lenski 112). The individual is embedded in the heart of that environment. Improvement starts with creating awareness in each environmental factor that in turn directly affects the individual in Bronfenbrenner's bioecological model of development (Figure 2).

In the Dominican Republic, improvement will come with more community-based programs, like FCID, teaching the family and community about disability. This needs to happen in the cities as well as in rural areas. In both the United States and the Dominican Republic, there is much room for improvement in schools. American public school systems have good special education programs, but these programs segregate the disabled from the rest of the population. In the summer of 2007, I shadowed an occupational therapist in the special education department of a grade school in Fremont, Nebraska. While the education is very high-quality, these children never once throughout the day participate in activities with the rest of the children their age. Even at recess, children with disabilities go to the playground at a separate time in order to avoid conflict with the other children running around. Disabled children need to be integrated with other

children as much as possible while still getting the special attention they require. If we are going to create more awareness, then it needs to happen before humans develop the ability to judge. Children innocently fail to see diversity. The individual impacts his or her environment as much as he or she is impacted by the environment. If children are exposed to disability before they see it as something unfamiliar, something to be feared, then as they grow up, they will positively influence society and the way society views people with disabilities. Disability prejudice in the community, the workplace and the media will be reduced and will in turn stop negatively impacting the individual at the heart of the environment.

In both the United States and the Dominican Republic there are programs to get people with disabilities into the workforce. This creates awareness and change simply by others seeing the disabled out in the community and interacting with them. They are able to build relationships with each other. We need to encourage this even more. Depending on a person's disability, many can bag groceries, fold clothes in retail, do secretarial tasks, help in restaurants, or do janitorial work. I have a friend who is quadriplegic as a result of cerebral palsy but works as a recess monitor at a local grade school. The more the public interacts with disability, the more awareness we will have of life with disability, and thus the more obstacles will be overcome.

The media largely impacts social perspectives. We need more movies like *Finding Nemo* to teach that disability diversity is a normal part of life rather than movies like *Million Dollar Baby* teaching that death is a better choice than living a life of disability. We need public service campaigns addressing disability biases and eliminating

false assumptions. With globalization, much of the third world is largely impacted by the media of first world countries such as the United States. People in the Dominican Republic watch American-made movies, American television shows and even U.S. news reports. If we change how our media portrays people with disabilities, it will influence much of the world.

Cultural attitudes and laws are environmental factors with heavy influence on the individual. The laws exist; they just need to be enforced and interpreted to include all people with disabilities. Disabilities Cross Coalition is a group of organizations that have combined their efforts to lobby and get laws passed at the state and federal levels. We need to support this group and the legislation for which they fight. Cultural attitudes will change as societies become more aware with the life a disabled person lives.

We are not aiming for perfection. We simply need to achieve good. We belong to humanity and therefore have an obligation to speak out against oppression of the marginalized. We must take responsibility “beyond our own private lives” (Loeb 9). When we do nothing, when we remain silent, a part of us dies and a part of humanity is sacrificed (10, 12). Let us instead choose to live, defy the obstacles and relieve the suffering. Let us not be blindly obedient but actively hopeful. We can eliminate the quicksand, handcuffs and duct tape and give people with disabilities a quality life on that open highway, here in America, in the Dominican Republic, and throughout the world.

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